

# CREATING CONDITIONS FOR SELF- AND CLIENT-EMPOWERMENT: MY EXPERIENCE WITH A CONSUMER ADVISORY BOARD

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*The following narrative describes the author's experience as a leadership consultant to the Places for People Consumer Advisory Board (CAB). As a social worker with a mental illness, she was expected to be both a mentor and a teacher. Though fundamental change has not occurred in agency processes as a result of this board's activities, the CAB members have a stronger voice and a more visible presence as leaders in the agency, through programs they have developed themselves.*

## Introduction

As a social worker who supports an empowerment approach to mental health service provision, I was excited when I was asked to serve as a leadership consultant to the Consumer Advisory Board (CAB) at Places for People, Inc., a psychosocial rehabilitation agency in St. Louis, Missouri. The psychiatric rehabilitation model supports consumer involvement in decision-making, and Places for People was attempting to make that involvement more of a reality (Linhorst, 2006). The CAB consisted of six Places for People clients who had been elected by participants in the Clubhouse—a psychosocial rehabilitation program—who were charged with serving as leaders in the program, and representing the concerns of their peers to agency leadership bodies.

The Clubhouse at Places for People was already a vibrant program, offering a safe, welcoming environment for adults with serious mental illness to come and participate in a variety of activities. Members were served a nutritious lunch each day; there was also a member-operated snack bar and thrift store. Computer facilities were available for members to use. Procovery-based groups (Crowley, 2000) as well as groups for individuals dually-diagnosed with substance use and mental illness were offered to members each day.

CAB members were active in the daily operation of the Clubhouse and, in their new roles, they were expected to offer their voices in agency decision-making processes.

My responsibility was to help members organize themselves, find their voices, and help ensure that CAB involvement in decision-making was more than just a token presence. I had been asked to assume this role because of my unique combination of identities: I am a professional social worker, and also a person living with serious mental illness. I was diagnosed with bipolar disorder in 1989, and have been working in the social work profession since earning my MSW in 1992. Although I've worked steadily since receiving my graduate degree, I've struggled with the symptoms of my disorder at the same time. I've had a number of inpatient hospitalizations in both public and private facilities, and I've participated in self-help activities in the St. Louis area. Because I have been able to advance my professional career despite my diagnosis, I was seen as a role model. I worked as a manager at Places for People from 1999 until I started doctoral studies in 2004, and had maintained positive relationships with many agency clients during my tenure there. The executive director at Places for People felt that I could connect in a trusting way with the members of the CAB, especially if they knew

that I was a mental health consumer in addition to being a social service professional. I was to serve not only as a consultant, but also as a mentor (Linhorst, 2006).

### **Initial Mistrust and Discouragement**

The relationship was not immediately trusting. I was working with the CAB in part because I was a consumer, but that was not my only role. Members were suspicious that I had been brought in to tell them what to do and think, so that there would not be any conflict with the organization. I needed to find a way to identify with the CAB's struggles and also be helpful. It took several meetings during which I, for the most part, kept my mouth shut, for the members to realize that I had no agenda other than to make sure they were taken seriously. I disclosed that I had been diagnosed with a mental illness, informed them that I took medicine appropriate for my illness on a daily basis, and that I was still actively involved in mental health services. This disclosure seemed to give me more credibility. However, they commented on my status as a doctoral student at a local university, indicating that they felt I had achieved a status that was far "above" what they would ever be able to attain. While I discouraged this viewpoint, I was not totally able to counteract it.

The pendulum swung a bit too far the other way, however, and the CAB members became dependent on me for the group's functioning. Often, they would not hold meetings unless I was going to be in attendance. Again, I tried to keep my mouth shut during the decision making process; when asked for my opinion I would share my thoughts, but often "kicked things back" to the group and stressed the importance of their own ideas and opinions. I did help the group with some facilitation skills, and attempted to serve as a role model of a consumer in a leadership capacity.

During that first year, the CAB assumed some new responsibilities in the Places for People Clubhouse. They met to share their observations with the Places for People Board of Directors and Program Committee. As members grew more comfortable in their roles, they became less dependent on me for

decision making. Because I held high expectations for them, I believe they raised their expectations of themselves (Crowley, 2000).

One troubling trend at meetings was that members did not believe the agency leaders would support them in the changes they wanted made. Typical CAB member comments included, "We can't ask them for that;" "They won't give us that;" "They won't pay for that." They needed to overcome a learned helplessness (Linhorst, 2006). Kathleen Crowley stated that "Overcoming fear is not done in a single action or a single moment; it is a continual process" (2000, p. 103). In facilitating communication between CAB members and agency leadership, I encouraged members to ask for what they wanted, and to ask for things that they viewed as high priorities for agency clients. Agency leaders could then take action to see that their concerns received attention and additional resources. Of course, not every suggestion would result in immediate change, but agency leaders had indicated to me that if the CAB identified a need, it would be taken seriously.

### **Empowerment Processes**

Fundamentally, however, empowerment was not something I could do *for* them. My objective was to empower CAB members to voice their experiences and opinions to agency leadership. I could have created conditions that made assumption of their personal power more likely (Linhorst, 2006), but they would have to find their own voices. Several activities contributed to the discovery and development of their own power.

The administration at Places for People asked the CAB to conduct a satisfaction survey of agency clients, which created a condition favorable to empowerment of the members. My doctoral training in research and measurement proved useful in a whole new way: they brainstormed questions to ask, and I helped them develop a workable questionnaire. Members then distributed and collected the surveys. Results were reported to the agency's staff and Board of Directors. It was determined that almost half of the respondents were involved in volunteer work,

and that many were attending self-help and support groups. Agency clients found psychiatric services, housing, and integrated dual-disorders services to be particularly helpful. Several clients mentioned that having more vocational opportunities might make them more likely to use the Places for People Clubhouse program. Clients rated the excellent food and the high morale and friendships at the Clubhouse as key reasons for their participation in the program. This knowledge was useful to CAB members in reporting the needs and priorities of agency clients to the Board of Directors and agency staff. It was good for the board and staff members to know that programs such as the integrated dual-disorders services were valued. The satisfaction survey a successful project for which CAB members could take credit, and about which they could feel a sense of accomplishment.

CAB members also empowered themselves through the introduction of a new "Buddy Program" within the Places for People Clubhouse. Members recommended a proposal whereby they would be responsible for orienting new clients to the clubhouse services. Community support teams would refer new clients to the CAB; members would then organize a Clubhouse tour and provide them with a support system as they became oriented to the Clubhouse environment. This proposal was enthusiastically received by Clubhouse and community support staff. The Buddy Program proved to be a way for CAB members to have an immediate positive impact on the workings of the Clubhouse.

### **Moving On**

As the CAB entered its second year, elections were held again to determine membership. Most members from the previous year were re-elected. They expressed a strong desire to be more "professional" in their operations, to learn new skills, and to articulate themselves more clearly. Linhorst (2006) discussed the importance of training for consumer advisory panels, not only to help consumers gain skills, but also to increase confidence, self-respect, and a sense of control. Offering leadership training to CAB

members would also help to create conditions facilitating empowerment. Using resources from the University of Pennsylvania Collaborative on Community Integration (Salzer & Baron, 2006), as well as the Boston University Center for Psychiatric Rehabilitation (Spaniol, McNamara, Gagne, & Forbess, 2009), I designed some training sessions for the CAB. We talked about principles of recovery and how they applied to leadership in their community, such as establishing priorities, communicating directly, and taking and expecting responsibility (O'Connor, 1997). We discussed effective group facilitation and participation skills, so that meetings would run more smoothly and members would feel more confident (Spaniol et al., 2009).

My CAB training was based on my own experiences as well. Developing the training had caused me to think about how I had experienced the process of empowerment in my own recovery. Some aspects of my recovery that had been most critical were: I had connected with other consumers who shared similar experiences; I had achieved stability with my symptoms (professionals had helped make this possible); and I discovered organized groups that were working for mental health advocacy. For several years, I had been involved with the NAMI chapter in St. Louis, participating in support groups and advocacy activities. These connections had helped me find the strength and courage to work toward my own recovery. In sharing my experiences of recovery with other people, I was able to strengthen my own self-confidence and reduce my sense of self-stigma. Additionally, I had developed a routine for treating my mental illness using self-help skills and the support of mental health professionals which enabled me to find stability with my symptoms. It seemed paramount to discuss with CAB members the importance of self-help and professional supports.

### **Sharing Stories of Recovery**

We also spent time talking about the best ways for CAB members to express their insights and opinions to the agency's staff and board of directors. I encouraged them to share

their own perspectives with agency leadership regarding which services had been most helpful to them when they first became clients of Places for People. They were surprised to learn that their particular experiences would be of interest to the board and staff, but as the members told their stories of recovery, I assured them that their individual narratives would be fascinating and important for agency administrators to hear (Nouwen, 1996). The CAB members told stories of desperation and hopelessness, describing how they had been homeless, addicted, in crisis, and suffering from poor physical health prior to getting involved with Places for People. They then related how the community support and the staff at Places for People had brought them hope, by connecting them with housing, mental health, and physical health services. Such services provided them not only with a roof over their heads and relief from symptoms, but also with a sense that life could be better.

These narratives also included potent descriptions of the CAB members' resilience and perseverance, even when their life circumstances were the most difficult. These stories moved me, and I told the members that their descriptions of services that had worked well would help the board and staff make decisions about what was truly important in the agency's repertoire of mental health services (O'Connor, 1997). I was reminded that community-based mental health services are often a life-or-death matter for those who participate in them. Not only had the CAB members in some cases struggled with suicidal feelings, but they had also experienced homelessness, substance use disorders, and physical health crises which had placed their lives at risk.

However, I wondered whether it was fair to ask the CAB to share these stories with people they barely knew. Was asking the members to share stories of the most vulnerable times in their lives with people who had authority over them empowerment or exploitation? Because CAB members were under no obligation to talk to the Program Committee or the Board of Directors unless they wanted to share their stories, I felt at peace with my decision to encourage them to

talk about their experiences. The CAB members also seemed to feel good about telling their stories when they realized that this information would help the Board and Program Committee in their decision-making. The following month, several CAB members met with the agency's Program Committee to share their narratives of change. Committee members were indeed deeply affected by the stories that were told. The CAB members' descriptions of programs and services that had saved their lives helped the Program Committee make decisions regarding service priorities and definitions of quality and "success" in Places for People's programming. Services for clients who have both mental illness and substance use disorders continue to be an important aspect of the offerings at Places for People. Additionally, effective integration of physical and mental health services has become an increasing priority for agency administrators.

#### **Advocacy Skills and Self-Empowerment**

This past month, representatives from the local National Alliance on Mental Illness (NAMI) chapter came to a CAB meeting to share information on mental health advocacy at the state level. CAB members were eager to hear about those issues. NAMI representatives also emphasized the importance of personal stories to mental health advocacy efforts. Many state legislators have not had experience with mental health services—nor with mental illness—so they do not understand how critical mental health services can be to service users (O'Connor, 1997).

CAB members interacted enthusiastically with the staff from NAMI as they strategized ways that Places for People clients could best advocate for mental health issues. They expressed interest in sharing what they learned about state-level advocacy with other members of the Places for People Clubhouse. They were pleased to hear from NAMI staff that effective advocacy could take place in their home community, as well as at the state capitol. They discussed ways to communicate with state representatives in the neighborhoods surrounding the Clubhouse, and they learned

about local mental health advocacy groups where they could share their opinions and observations.

My interactions with CAB members at Places for People also motivated me to participate in my own advocacy efforts. If CAB members had the courage to talk about their experiences with publicly-funded mental health services, why was I not willing to share my own story? Yes, I had a professional boundary to maintain, but who was being protected by that boundary? I did not share intimate details of my own experiences, but was motivated to send letters to my state representative and senator, disclosing that I had previously been a client of public mental health services, and that these services had saved my life more than once. In particular, I shared about my stay in a public psychiatric hospital for three weeks during the summer of 1996, when I was unemployed and in crisis. That hospitalization had kept me alive and had given me hope for the future.

This disclosure was a small effort to try to protect mental health funding in the 2010 state budget, but it felt good to inform my representatives that mental health was a priority for me as a taxpayer. I felt connected. As Henri Nouwen has stated, "Once you have discovered that you are called to live in solidarity with the hungry, the homeless, the prisoners, the refugees, the sick, and the dying, your very personal pain begins to be converted into *the* pain, and you find new strength to live it" (p. 104). Hearing the stories of CAB members helped me understand how blessed I was with my own safety net of services, and how important speaking out was in reducing self-stigma.

#### Plans for the Future

For the future, we are planning a "Meet-Your-Board-Members" event for CAB members to get to know the Places for People Board of Directors. All CAB members have been asked to brainstorm questions that they would like to ask members of the Board, and to bring those questions to this meeting. My hope is for CAB members to believe more and more that other advocates and agency leaders are their peers, and that communication

will become open and ongoing. Sharing personal stories should become more comfortable as CAB and board members get to know each other.

The participation of the CAB in the agency governance process has not—at least not yet—led to changes in the operations of the organization. Bringing consumers' voices to the decision-making process is a new occurrence, not only for Places for People, but for many mental health agencies, and change is slow (Linhorst, 2006). However, I do feel that the CAB has given a voice to consumers at Places for People that they did not previously have, I feel that the CAB is taken seriously by agency administrators. This can be seen in the CAB's development of the Buddy Program for new agency clients, and in this program's enthusiastic adoption by agency staff. It is also evident in the energetic response to the CAB's consumer satisfaction survey.

It is gratifying that I have been able to assist this group of six very motivated agency leaders to become more confident in their activities and communications. Being of assistance to CAB members has helped me to hear my own voice, to share my story more readily, and to view myself as a "peer-helper" with these amazingly resilient individuals.

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