# Partners in Recovery: Social Support and Accountability in a Consumer-Run Mental Health Center

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**Objective:** Consumer-run mental health programs that include advocacy, peer counseling, and mentoring are somewhat commonplace in community mental health services, yet fully peer-operated mental health centers remain novel in the public mental health landscape. This ethnographic study of a consumer-run mental health center had two major aims: to learn what is distinctive about consumer-run services-for example, how they might strengthen personal capacity for social integration-and to explore how the development of these capacities might promote recovery. Methods: Data collection for this modified ethnographic study consisted of ten months of participant observation, coupled with semistructured interviews (N=25), a focus group (N=22), and dramatic skits (N=17), to identify and define the distinctive features of the program, both structurally and from the point of view of participants. Inquiry was framed theoretically by the capabilities approach. **Results:** Participants in this consumer-run mental health program experienced themselves as accountable for and to their peers in what amounts to a shared project of recovery. Conclusions: As part of a capacity-building approach in consumer-run services, programs should aim to not only provide social support for participants but also foster a culture in which service users are accountable for their peers. Such reciprocity may help to strengthen socialization skills, which could better prepare consumers for participation in the community at large. (Psychiatric Services 63:61-65, 2012)

Onsumer-operated mental health services have received increasing attention by recovery-oriented researchers. Such programs have been defined as service organizations in which the paid staff and most of the governing board are themselves users of mental health services (1). Studies have shown that consumer-run mental health services promote personal and organizational empowerment (2), increase hope (3), enhance independence and competence (4), counteract typical feelings of powerlessness (5), cocreate narratives that support recovery (6,7), and promote social support (4,8,9). However, the mechanisms by which these outcomes occur remain unclear. Despite increased interest in the public mental health arena, consumer-run services are often stigmatized and devalued in the professional marketplace (10,11) or do not have an interface with conventional existing services (12); in addition, the role of peer providers often remains ambiguous (13). Therefore, continued investigation is needed to establish how consumer-operated services function and the factors in any beneficial effects that might be observed.

Located in a suburb of New York City, Open Arms (a pseudonym) is a consumer-run mental health center, which is licensed by the New York State Office of Mental Health. Founded in 1988 by a group of mental health consumers interested in providing recovery alternatives, the organization has grown into a multiservice center. It offers assistance with employment, housing, and advocacy, in addition to clinical services that are delivered through personal recovery-oriented services, a service model developed by the New York State Office of Mental Health.

Our study had two major aims: to document what is distinctive about this version of consumer-run services—for example, how this model might orchestrate occasions that could strengthen capacity for social integration (14)—and to explore how the development of these capacities promotes recovery. This inquiry is theoretically driven by Amartya Sen's capabilities perspective (15–17). Re-

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cently extended into public mental health (14,17,18), the capabilities approach both links and recognizes a tension between two dimensions of quality of life: well-being and personal agency. The capabilities approach explicitly draws attention to the social determinants of disability (19).

Although the term "recovery" has become ubiquitous in mental health, its meaning remains vague and contested. Hopper (18) suggested that there are four key components of recovery: renewing a sense of possibility, regaining competencies, reconnecting and finding a place in society, and reconciliation work, or "the work of rebuilding a functional self-a person apart from the reality of illness" (18). Open Arms has developed particular expertise in providing a context for service users to reconnect with others and potentially "[reclaim] moral agency" (18). The capabilities approach may be one way to put the ideals of recovery into action. Rather than measuring successful outcomes in terms of treatment compliance or reduced rehospitalization, a capabilities approach asks to what extent individuals are able to lead the kinds of lives they consider worth living—lives of their own authorship. Ware and colleagues (14), for example, argued that successful outcomes should include consumers participating "as full citizens in the social world beyond treatment." Successful participants may take psychiatric medication, live in supportive housing, and continue to engage in services, but they are no longer defined by their illness.

Although many studies on consumer-run mental health programs have focused on the empirical measurement of social support and empowerment (2,4,8,20), researchers lack good conceptual tools for describing how such benefits are orchestrated and implemented and what role they may play in recovery. Ware and colleagues (14) have argued that growth and development-particularly in the interpersonal realmshould be privileged aspects of outcome assessment; in their view, recovery is distinctively a process of reclaiming social agency. They identified a class of contrived challenges (what they call "occasions") that offer

protected opportunities for service users to develop and exercise "moral and social competencies." Such practices go beyond the provision of social support. They stressed the reciprocal nature of such exchanges, emphasizing that full social participation and the regard of others hang on one's capacity for reliably "being there" for someone, for giving in return, and for taking responsibility for one's conduct in the microexchanges of everyday life.

# Methods

Using modified ethnographic methods, we conducted ten months of fieldwork, from November 2008 to August 2009. Generally, this meant the first author spent roughly ten hours on site each week, participating in daily activities with the community. Such embeddedness allowed us to capitalize on the informality of unscheduled encounters and unscripted interchange (21). Over an extended course of fieldwork, she interacted with virtually all active members of Open Arms and gained an informed sense of prevailing norms. In addition to participant observation, we used semistructured interviews (25 participants), a focus group (22 participants), and dramatic skits (17 participants) to identify and define the distinctive features of the program, both structurally and from the point of view of participants. After giving a complete description of the study to interview and group recruits, we obtained their written informed consent. The methods used in this study were approved by the institutional review board of the Nathan S. Kline Institute for Psychiatric Research. The impetus to conduct this study arose from the Open Arms community; research aims and study design were developed collaboratively.

The study community included Open Arms members—adults with axis I mental disorders (generally psychotic and bipolar disorders), many with histories of multiple hospitalizations and co-occurring substance use disorders—as well as Open Arms peer staff, clinicians, administrators, and on-site workers. Approximately 98% of Open Arms' clinical staff, facilitators, and support staff also use mental health services. Open Arms is a diverse community in terms of age, race-ethnicity, and sexual orientation. All members were invited to participate in interviews, focus groups, and skits; although there was no systematic recruitment, our sample contained a cross-section of members in terms of duration of membership with Open Arms, age, gender, race-ethnicity, and psychiatric diagnosis.

The dialectical nature of ethnographic inquiry (22) adds depth and texture that would be difficult to capture through other methods. Fieldwork takes place in real time, unfolding in natural environments. Ethnography involves a continuous process of taking part in and interpreting a broad range of events, interpersonal encounters, group activities, and the usual customs of everyday life. Critical to the method is the premise that the most effective way to learn what is significant or important for community members is not to ask them directly in interviews, but to document how they construct meaning through interactions in ordinary life (22). Ethnography puts a large premium on validity (23,24); with a tool kit of practices, ethnographers create innumerable opportunities to formulate, refine, and, if need be, reconstruct interpretive accounts of how life is lived in a given venue.

Participant observation in this project meant engaging with people in the small transactions of everyday life—having coffee; participating in classes; accompanying consumers to advocacy, employment, and housing offices; and relaxing in lounge areas. The only excluded on-site venue was individual therapy sites, which are private and confidential spaces. Field notes and analytic memos developed throughout the study informed the development of the interview and focus group guides.

Semistructured interviews were conducted with 25 participants, facilitators (nonclinicians who ran therapeutic groups), clinicians, and staff. The range of participants who volunteered for interviews was roughly representative of ages, genders, and number of years of membership in Open Arms. Interviews explored peer-run services, social support, and recovery, asking questions such as, "Are there things about Open Arms that seem different from other services or mental health centers?" "How does Open Arms help you in your own recovery process?" "What do you think when you notice another participant hasn't been around for a while?" Interview schedules were developed with an eye toward learning about not only individual experiences but also the customary practices of this community.

Building on what we learned in interviews, we planned to conduct multiple focus groups, anticipating that this would prompt an exchange of views among participants. In practice, the focus group dutifully reinforced prevailing positive views about consumer-run mental health care but did so in a somewhat scripted and formulaic manner. Rather than conduct a second focus group as planned, we invited the next group to improvise dramatic skits as a way of potentially gleaning more authentic responses. Adapted from theater games used in quasi-therapeutic undertakings (25, 26), this technique asks participants to draw a slip of paper from a hat and then act out with their peers the scenario specified on the slip. Drawing upon field notes, we worked up descriptions of likely everyday predicaments that Open Arms members might confront: "You come into Open Arms and notice a fellow member seems intoxicated. What do you do?" Or "Your neighbor asks you for advice about her teenage daughter who has been cutting herself and may be suicidal. How do you respond?" This exercise provided participants an opportunity to think out loud and on the fly; Open Arms peers were invited to comment, allowing us to observe how members took stock of morally freighted moments and made decisions in contrived versions of real-life situations.

Using modified grounded-theory methods (27), the first author took the lead in data analysis, with substantive input from her coauthors. An open coding approach was used to facilitate identification of latent themes across field notes and transcripts from interviews, the focus group, and skits. From this initial coding, theoretical memos were developed, which shaped our interpretive process. Our analysis also included procedures for triangulating data to expose discrepancies or divergent findings. The research process was iterative, forcing us to formulate, refine, and revamp our findings throughout the extended period of data collection.

#### Results

At Open Arms, supporting one another's recovery, often in intimate ways, has become part of the local culture of the community, a crucial element of what it means to belong there. Many members share apartments, spend holidays with one another, and converse on the phone daily. If someone was missing, it was often another member who checked on the individual, making it nearly impossible for someone to drop out or relapse unnoticed. This reciprocal sense of accountability that members haveboth to and for one another-was the most striking finding with respect to our study objectives.

The question of social integration has always been a fundamental one for psychiatric researchers. Most mental health services strive to foster community and social connectedness among participants. But the artificiality of many such efforts is concerning. In a recent ethnography of a psychiatric unit in England, mental health consumers tended to define "real friends" as "people you know from the outside." Or as one informant poignantly stated, "these [fellow patients] aren't real friends; they're just people I hang around with" (28). These sentiments clash notably with those of members of consumer-run services.

What seems to matter most at Open Arms is that relationships among peers are authentic. Open Arms member "Rich" (all names mentioned herein are pseudonyms) praised a class on relationship issues of importance to members of the Queer community: "This is the first time in my life I've really felt connected. I have a boyfriend, I have friends." He explained that romantic relationships at Open Arms are viewed positively, something not widely addressed in the literature. Many members consider Open Arms their primary social nexus. As Kelly remarked, "I'm not usually here on Fridays. I came today because I'm having an 'off day.' There is just something about being here that makes me feel better." Rather than pointing to specific services within the walls of the center, what members describe is how the culture of Open Arms seems to help them in the recovery process.

Michelle, who has been a member for over ten years, warned (with evident affection), "You better call ahead if you are going to miss days at Open Arms. Otherwise you are going to have a bunch of people calling and asking where you are." Similarly, Angelica described how "people call each other all the time to see what is going on, just to check in. Open Arms is a family, and that is how I want to keep it." The term "family" surfaces repeatedly when participants and staff describe Open Arms. It serves to index not only how close members are but also the degree of mutual accountability they feel and the extent to which they feel called upon to speak honestly with one another.

Especially with respect to staying sober or adhering to medication regimens, participants mentioned not letting down their peers. As James put it, "I've been with Open Arms for a long time. I've got a lot of years of recovery under my belt, so the last thing I want to do is disappoint anyone, most of all everyone at Open Arms." Or as Matthew explained, "Sometimes people are brutally honest, which can be hard. But there is that trust—I know they have my best interest at heart. Otherwise I probably couldn't really hear what they are saying. But it's like a family."

This "brutal honesty" often comes in the form of openly discussing one another's symptoms. Take, for example, Pablo, who exhibited manic symptoms. Pablo's peers openly monitored his behavior, serving notice when it threatened the bounds of propriety in classes with "Pablo, slow down!" Pablo acknowledged, "I would interrupt people, and the group would remind me not to do this. Sometimes I will get really angry, but then I remember we have an understanding. They are looking out for me. Outside of Open Arms you can't say nothing to people because you gotta be polite. But here . . . you can just come out and say it as long as you are respectful. This is a peer-run program, so this is how it works. . . . I am equally as responsible for my peers as I am for myself. So I actually owe it to them to tell someone if they are using, or not taking their medication or just having a rough time."

There is a homespun elegance to such accounts and a moral dimension to their importance. Pablo and others described how this accountability for their peers gives them a sense of worthiness, in that they feel trusted, capable, and needed by others.

Open Arms is structured on an educational rather than on a clinical model. Classes are aimed at supporting a variety of psychosocial goals that members develop when they are admitted. One of the more popular classes is called Learning About Your Diagnosis, conducted by a psychiatrist who regularly discusses recent research findings with participants. One student was Angelica: "As a teenager I started getting racing thoughts. I always thought that was normal until I [required hospitalization]. Now not only do I know all about bipolar, but we learn what is happening down to the level of neurotransmitters....[T]his helps me explain more to my family." Members are encouraged to learn about mental illness and addiction as a way of gaining mastery. As Matthew put it, "I've learned a lot about my mental health, coming to Open Arms. . . . [Before,] I just felt bad. Now I can say exactly what the symptoms are and whether or not I'm in a relapse mode. It's not as scary when you have the book knowledge. At other places, it was just, like, the counselors had all the knowledge. But here we all can tell you every little scientific thing about mental illness." Learning what typically only clinicians know tips the balance of power by democratizing expert knowledge.

Many members claim that having peers as providers gives them role models. For Mike, "Hiring people who are also in recovery is key.... It's inspiring. They are productive; they want to be part of society. It makes me feel like I can do it, too." Peer providers not only lead through example; they also teach classes throughout the day on topics such as independent-living skills, intimate relationships, and communication. Rather than focusing primarily on problems, members are coached in strengthening their resources, talents, and capacities. Although members participate enthusiastically in their classes, when asked open-ended questions about how Open Arms helps with recovery, the most salient responses were connected to relationships with peers and staff alike.

#### Discussion

Our study suggests that a local culture of reciprocal support-where one is just as responsible for providing support as for receiving it-promotes an ethic of accountability, a factor we argue may enhance recovery. Unlike more conventional service settings in which users are asked to remain militantly compliant (indeed, to "consume" services), Open Arms community members are expected to contribute. Specifically, reciprocal accountability both for and to fellow members amounts to a programmatic commitment to a shared process of recovery and encourages what Ware and colleagues (29) called "local citizenship."

But like other contrived oases in a mental health system not widely known for them, Open Arms has its metes and bounds. Members sometimes referred to community life as "on the outside." Such descriptions often emerged when illustrating positive traits associated with the Open Arms program and its members (for example, "My friends here get what I'm going through, unlike my friends on the outside"), and this language may reveal something important about the transferability of such capabilities. An important area of further research may be to determine the extent to which consumer-run services prepare members to establish relationships with nonconsumers outside treatment centers. Further research is also needed on mental health outcomes to establish the demonstrable effects of accountability and reciprocal support.

This study had a number of limitations. Open, inclusive recruitment has obvious benefits, but the convenience sample that results may introduce selection bias. Our on-site research time was also limited to only ten hours per week for ten months, which is brief for ethnographic research.

# Conclusions

Successful recovery or rehabilitation is often linked to obtaining gainful employment, housing, and psychiatric stability. We argue that the mutual accountability garnered through stable and authentic relationships may act as capacity building toward these broader goals. Enhancing the capacity to support and relate to others may have positive synergistic effects. Although social support that merely moves in one direction (mental health care consumers receiving support) likely benefits mental health care consumers, service models that can occasion reciprocal relationships that promote enhanced accountability may indeed prove therapeutic beyond treatment as usual.

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#### References

- Mowbray CT, Holter MC, Stark L, et al: A fidelity rating instrument for consumerrun drop-in centers (FRI-CRDI). Research on Social Work Practice 15:278– 290, 2005
- Segal SP, Silverman C, Temkin T: Measuring empowerment in client-run self-help agencies. Community Mental Health Journal 31:215–227, 1995
- 3. Hodges JQ, Hardiman ER, Segal SP: Hope among members of mental health self-help agencies: a descriptive analysis. Social Work in Mental Health 2:1–16, 2004
- Chamberlin J: Speaking for ourselves: an overview of the ex-psychiatric movement. Psychosocial Rehabilitation Journal 8:56– 63, 1984
- Chamberlin J, Rogers JA: Planning a community-based mental health system: perspective of service recipients. American Psychologist 45:33–41, 1990
- Brown LD: Making it sane: using narrative to explore theory in a mental health consumer-run organization. Qualitative Health Research 19:243–257, 2009

- 7. Felton B: Defining location in the mental health system: a case study of a consumerrun agency. American Journal of Community Psychology 36:373–386, 2005
- Nelson G, Lomotey J: Quantity and quality of participation and outcomes of participation in mental health consumer-run organizations. Journal of Mental Health 15:63–74, 2006
- Mowbray CT, Tan C: Consumer-operated drop-in centers run by and for psychiatric consumers: evaluation of operations and impact. Journal of Mental Health Administration 20:8–19, 1993
- Chinman M, Kloos B, O'Connell M, et al: Service providers' views of psychiatric mutual support groups. Journal of Community Psychology 30:349–366, 2002
- Hardiman ER: Referral to consumer-run programs by mental health providers: a national survey. Community Mental Health Journal 43:197–210, 2007
- Goering P, Durbin J, Sheldon CT, et al: Who uses consumer-run self-help organizations? American Journal of Orthopsychiatry 70:367–373, 2006
- 13. Mowbray CT: Benefits and issues created by consumer role innovation in psychiatric rehabilitation; in Consumers as Providers in Psychiatric Rehabilitation. Edited by Mowbray CT, Moxley DP, Jasper C, et al. Columbia, Md, International Association

for Psychosocial Rehabilitation Services, 1997

- Ware NC, Hopper K, Tugenberg T, et al: A theory of social integration as quality of life. Psychiatric Services 59:27–33, 2008
- Sen A: Commodities and Capabilities. Oxford, United Kingdom, North-Holland, 1985
- 16. Sen A: Development as Freedom. New York, Knopf, 1999
- Nussbaum MC: Women and Human Development: The Capabilities Approach. Cambridge, United Kingdom, Oxford University Press, 2000
- Hopper K: Rethinking social recovery in schizophrenia: a capabilities approach. Social Science and Medicine 65:868–879, 2007
- Mitra S: The capability approach and disability. Journal of Disability Policy Studies 16:236–247, 2006
- Hardiman ER, Segal SP: Community membership and social networks in mental health self-help agencies. Psychiatric Rehabilitation Journal 27:25–33, 2003
- Lederman R: The perils of working at home: IRB "mission creep" as context and content for an ethnography of disciplinary knowledges. American Ethnologist 33: 482–491, 2006

- 22. Wollcott HF: The Art of Fieldwork. Walnut Creek, Calif, Alta Mira Press, 2001
- Emerson RM, Fretz RI, Shaw LL: Writing Ethnographic Fieldnotes. Chicago, University of Chicago Press, 1995
- 24. Sanjek R: Fieldnotes: The Making of Anthropology. Ithaca, NY, Cornell University Press, 1990
- 25. Kamo N, Carlson M, Brennan RT, et al: Young citizens as health agents: use of drama in promoting community efficacy for HIV/AIDS. American Journal of Public Health 98:201–204, 2008
- Middelkoop K, Landon M, Smit J, et al: Design and evaluation of a drama-based intervention to promote voluntary counseling and HIV testing in a South African community. Sexually Transmitted Diseases 33:524–526, 2006
- Charmaz K: Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis. Thousand Oaks, Calif, Sage, 2006
- Parrott FR: "Real relationships": sociable interaction, material culture and imprisonment in a secure psychiatric unit. Culture, Medicine and Psychiatry 34:555–570, 2010
- Ware NC, Hopper K, Tugenberg T, et al: Connectedness and citizenship: redefining social integration. Psychiatric Services 58: 469–474, 2007

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