ARTICLE

Networks of Caring

A Qualitative Study of Social Support in Consumer-run Mental Health Agencies

Eric R. Hardiman
University at Albany, State University of New York, USA

ABSTRACT

This article examines consumer-run agency participation by adults with psychiatric disabilities. Using qualitative data from 10 intensive interviews, the purpose was to explore personal meanings attached to agency membership, and understand the lived experiences of participants. A grounded hermeneutic approach was utilized to analyse results. Findings reveal that individuals balance agency utilization and external peer network development. Organizational factors previously found related to social network enhancement (e.g. empowerment and emphasis on supportive services) were confirmed here. The emergent narratives captured in this study suggest that these agencies function as low-demand, accepting, safe, and sheltering environments while offering opportunities for human connection, shared agency ownership and community. Finally, access to otherwise unavailable peer-focused 'networks of caring' was of utmost importance to participants. Implications for the organization and delivery of services are addressed. Social workers and other mental health professionals seeking to maximize community integration and develop natural supports for clients should explore consumer-run agencies.

431

Although a growing number of reports in the literature have documented the proliferation of consumer-delivered services in the mental health sector (Davidson et al., 1999; Solomon and Draine, 2001), there remains a need to better understand the specific processes by which individuals with psychiatric disabilities construct meaning from participation in peer support services. Defined here as the exchange of mutual helping between individuals in consumer-run organizations, peer support (also referred to as self-help) has emerged as an innovative service delivery mechanism, particularly for those ill-served by traditional systems of care (Hardiman and Segal, 2003). Consumer-run services can also be viewed as an embodiment of client-centered principles such as those espoused by the social work profession (Solomon and Draine, 1996).

Consumer involvement in service delivery has been recognized in recent national reports as a promising new practice area in mental health (President's New Freedom Commission on Mental Health, 2003; US Department of Health and Human Services [USDHHS], 1999). The New Freedom Commission Report acknowledged the role consumers have to play in the transformation of the existing mental health system:

> Consumers and families with children with serious emotional disturbances have a key role in expanding the mental health care delivery workforce and creating a system that focuses on recovery. Consequently, consumers should be involved in a variety of appropriate service and support settings. In particular, consumer-operated services for which an evidence base is emerging should be promoted. (President's New Freedom Commission on Mental Health, 2003: 37)

Such national recognition suggests that after almost 30 years, consumer-operated services have reached a new level of prominence and are poised for increased research and development focus. However, despite growing attention, the evidence base for consumer-run services is still in a formative stage. Without further empirical examination, the survival of such services will face serious challenges in today's evidence-based funding environment (Mead et al., 2001).

Several core benefits of utilizing consumers as service providers have been identified in the literature (Davidson et al., 1999; Mowbray and Moxley, 1997; Mowbray and Tan, 1993; Salzer, 2002; Segal et al., 1995; Yanos et al., 2001). Solomon and Draine (1996) posit that consumer providers may be inclined toward a naturally empathic relationship with service recipients, and may be able to better advocate for their needs based on experience with the mental health system. Although the peer-to-peer helping relationship appears to be effective in the context of traditional agency settings (Besio and Mahler, 1993; Bichsel, 1997; Bledsoe Boykin, 1997; Felton et al., 1995; Klein et al., 1998), exponential benefits may be available to those in consumer-run organizations. Recent findings have delineated some of the benefits of participation in such agencies in both the individual and organizational realms (Hardiman and Segal,

2003; Hodges et al., 2004; Kaufmann, 1995; Nikkel et al., 1992; Van Tosh and del Vecchio, 2000). Access to peer role models, social network expansion, engagement in service provider roles, flexibility in services, client–centered focus, and increased empowerment are but a few of the theorized benefits for consumer–run agency participants.

To better understand the benefits of service use within a consumer–run service model, it is necessary to address the meanings recipients attach to their participation in such services. The primary goal of this article is to provide further insight into how and why individuals with psychiatric disabilities use services from a consumer–run organization, with a focus on self-constructed meaning.

The exploration within entails an implicit acknowledgement that to fully understand complex personal issues such as motivation, hope, help-seeking, and service utilization, it is necessary to go beyond quantitative measures and utilize qualitative methods addressing the constructed realities and meanings of participants. Narrative methods can give voice to stakeholder realities in evaluation research (Guba and Lincoln, 1989) and have been used to strengthen the understanding of participant narrative and discourse in program implementation for adults with psychiatric disabilities (Felton, 2003). Narrative methods are particularly appropriate for studying peer support in mental health (MacNeil and Mead, 2003). The purpose of the methodology used in this study was twofold: to augment previous quantitative findings through further exploration of a qualitative nature, and to allow for the emergence of participant narratives through a phenomenological process.

This study builds upon quantitative findings that both individual and organizational level factors impact the experiences of persons utilizing consumer–run agencies (Hardiman and Segal, 2003). The same study suggested that agency characteristics such as commitment to organizational empowerment, a non-judgmental agency environment, and the relative balance between concrete and affective services were among the strongest predictors of a peer-based network expansion. Although such findings appear to sufficiently illuminate some of the above distinctions for peer support users, important underlying meanings and narrative explanations have been left uncovered. The qualitative data collection and analytic techniques used here allow for both augmentation and clarification of such prior findings.

METHOD

Ten persons with psychiatric disabilities utilizing formal peer support services were recruited and interviewed for this study. The central objective was to give voice to the narratives of participants, while exploring the phenomenological construction of meaning around participation in a consumer–run agency

context. A secondary purpose was to augment existing findings and answer new questions posed after analysis of prior quantitative data. A qualitative exploratory approach was used, guided by a grounded hermeneutic framework (Addison, 1992). This approach involved the comparative and iterative analysis of textual data, in the form of interview transcriptions, as well as process notes taken by the researcher.

Participants

All interview participants were recruited from a consumer-run non-profit mental health agency located in northern California. The agency was utilized as a study site for two prior studies of peer-run services (Segal et al., 2002; Segal et al., 1995), and has been in operation since 1988. The agency provided a flexible mix of drop-in services, comprised of individual counseling, group counseling, socialization activities, concrete assistance obtaining benefits, housing, and advocacy opportunities. Estimated daily attendance was approximately 75 unique individuals. Agency members floated among programs and services without restriction. High priority was placed on anonymity, resulting in minimal agency record keeping. There were 5 paid staff and a rotating group of approximately 15 volunteers. All paid and volunteer staff were self-identified consumers of mental health services. A licensed community psychiatrist offered free consultation and/or counseling on a monthly basis on site. The agency was entirely funded by local government funding, although no formal affiliation existed with the public mental health system.

Six of the study participants were men, four women. African Americans were heavily represented ($n = 7$) in order to replicate their presence in the original study (Segal et al., 1995), and to address the paucity of research on minority utilization of peer support organizations. The mean age of participants was 49 years. Participants reported a range of times for length of agency attendance, from 2–10 years. All participants also reported lengthy experience as persons with psychiatric disabilities living in the community. All reported having utilized both traditional (i.e. professionally provided) services and consumer-provided services from numerous organizations.

Data Collection

Eligible study participants met two criteria: (1) the self-reported presence of a psychiatric diagnosis, and (2) a minimum of weekly agency attendance for at least three months. A modified form of targeted sampling (Watters and Biernacki, 1989) was used to achieve a sample demographically similar to those involved in the original agency studies (Segal et al., 1995). According to Watters and Biernacki (1989: 420), targeted sampling is a 'purposeful, systematic method' used to obtain specific numbers of participants within each of several groups, determined in advance by the researcher. In this case, participants were actively

sought who resembled the original sample in terms of ethnicity, gender, age, and length of agency experience.

The data collection strategy was semi-focused, iterative, and therefore flexible. This enabled the inclusion of targeted content areas, while honoring the need for interview participants to determine the course of their emergent stories. The semi-structured interview guide was developed in conjunction with colleagues having expertise in qualitative methodologies. Iterative modifications to the guide were made based on preliminary analysis of returning data from initial interviews. Basic domains of interest were created in part based on the results of prior quantitative analysis (Hardiman and Segal, 2003). The interview guide included questions that would expand upon earlier findings and help uncover social context and narrative meanings, while also allowing for exploration and a participant-directed focus.

All participants were recruited directly at the agency, during varied times of the day and week to address anticipated variation in times of attendance. Potential interviewees were identified through a key informant, a peer staff member at the site. Upon determining eligibility, informed consent procedures were followed, emphasizing that participants could withdraw at any time for any reason. Participants were given a stipend in appreciation of their completion of an interview. Interviews lasted 90 minutes to 2 hours, and took place either on site or in nearby community settings. All interviews were tape-recorded with permission of the participants and transcribed by a research assistant.

Analysis

Analysis using the grounded hermeneutic approach is conceptualized as a 'circular progression between parts and whole, foreground and background, understanding and interpretation, and researcher and narrative account' (Addison, 1992: 113). The fundamental goal of the analysis was to interpret the data, unlock its meanings, and develop a rich understanding of participants' lived experiences. In reaching this understanding, it was possible to address background contextual conditions and practices that ultimately affect how consumers participate in the agency, experience shared community, and construct personal meaning.

The data were analysed using a comparative, inductive method similar to that used in traditional grounded theory (Glaser and Strauss, 1967). After initial readings of transcripts, the data were open-coded, then analysed and revised through an ongoing iterative process. Coding continued until a saturation point was reached. During the later rounds of analysis, theoretical memos were written, analysed, and ultimately given their own coding schema (both in vivo and unique codes). The in vivo coding involved the use of particularly meaningful words or phrases from participants as codes. Such codes were grounded in the specific language and meaning systems of study participants themselves.

Unique codes were also created and refined in order to capture helpful concepts linking thematic materials. Themes emerged after several rounds of coding and analysis. Finally, textual data from the researcher's process notes were coded, analysed, and interpreted in a similar manner, in order to integrate context and the researcher's own insights through the circular process described.

Findings

A wide array of information was obtained about how and why the individuals in this study use consumer-run agencies. Participants' words were articulate and moving, and many described the interview process itself as empowering. For individuals with psychiatric disabilities, opportunities to share personal stories are difficult to find, and those interviewed here were thankful for the opportunity to speak and be heard.

Both similarities and differences between participants were explored, leading to a complex and multifaceted look at agency utilization. However, participants were clear and powerfully emphatic in their message about the importance of the agency to their lives. Five key themes emerged as most significant in the current analysis: (1) sanctuary, (2) recovery and survival, (3) respect and humanity, (4) shared 'ownership', and (5) networks of caring. These themes are explicated in the following subsections and connections drawn to the prior quantitative findings whenever possible.

It should be noted that the consistency of findings supporting each theme was remarkable, with data drawn from almost all participants, rather than an identifiable subset of individuals. No significant differences by gender or ethnicity were observed in the five themes reported on herein. In the few cases where meaningful disagreement and divergent views among participants were evidenced, such instances are delineated in the subsections following each theme, in order to clarify the findings. The uniformity of findings within the presented themes suggests both their depth and intensity among this sample, and suggests a degree of transferability to other similar sites.

Sanctuary
Participants eloquently described the multiple and formidable challenges faced as they struggle to live successfully in the community. For these persons, the world is often perceived as imposing and uncaring. Many described the challenges of social navigation in the community as overwhelming and without escape or relief. One gentleman reported feeling 'rootless and in need of a place to just be'. With its emphasis on unconditional acceptance and low interpersonal expectations, the consumer-run agency was a calming and centering influence. One participant's words portray the agency as a place of safety, refuge, and ultimately sanctuary:

> I've got someplace where I can go, feel comfortable, where I can hide out when I feel that it's not safe to be out there in the streets. Everybody knows my name here. I can actually relax, let my guard down.

Two dimensions of sanctuary were found in the data: (1) relief from the demands of the outside world, and (2) the safety and comfort associated with a low-demand environment where they are free to be themselves. The importance of relief was evident in the use of descriptive language to refer to the agency: 'a safe haven'; 'my home spot'; 'my place'; 'my home base'; a 'lifeline', and 'a sanctuary'. Members described it as being an important source of relief from harsh social realities and helping 'refuel' them to successfully meet a wide range of daily challenges. These challenges include, but are not limited to weather, police harassment, stigma and rejection, exhaustion, hunger, and poverty.

Compounding factors of homelessness, poverty, and substance abuse can add up to an existence in which there is little escape from hardship, little time for relaxation, and few places for meaningful social interaction. One individual described feeling like 'an outcast' everywhere except for the agency: 'To be an outcast! And I mean, this place doesn't make you feel like you're an outcast. And some of us *really* need each other.' Describing the feeling of safety and support from peers at the agency, another said, 'They're here to help. They make you feel that way. That they're here to help you and not persecute you or put you down.' Participants universally reported feelings of distress and mistreatment within society and valued the agency's ability to provide safety and to serve as a lifeline.

Survival and Recovery
Many view their attendance in consumer-run programs as a key resource essential to their very survival, a necessary component allowing them to work on the loftier goals associated with recovery. To the extent that recovery is paramount to individuals with psychiatric disabilities (Mancini et al., forthcoming), the peer-run agency is seen as an integral stepping stone to the restoration or creation of a meaningful life. Participants indicated that the agency was the one place where the nature and extent of their struggle for survival and recovery was truly recognized by others. One woman illuminated this vision perfectly:

> I think I'm a survivor. I keep saying I'm gonna call into one of those talk shows, you know how now it's cool to have mental health problems, all the stars have them. But *these* are the stars; these are the people who are surviving every day. With *severe* mental health issues. These are the heroes.

The pronounced emphasis on survival, coupled with the allusion to recovery, appears to be a common element of the consumer-run agency experience for many individuals. Although definitions of recovery varied, all

interview participants had in some way taken responsibility for management of their own situations. Many reported feeling a sense of freedom and power as a result. All participants viewed the agency as playing a predominant role in their pathways to recovery from mental illness. Recovery was defined most frequently by participants as effective illness management, avoidance of in-patient hospitalization, and some level of success in the search for personal meaning. Referring to the agency with a passionate sense of shared owner-ship, one individual said:

> I mean, it's *my* place. It would really really really be a big chunk missing out of my life if it was taken away. It would be sorta like one of my arms or one of my toes was gone. It's that important. That's what stands between me and that clinical stuff, and those doctors. OK? The ones that just want to medicate me all the time, have me come in there, look like a zombie, all this Thorazine in me, and then want to have a conversation. OK? This place is what keeps me away from all of that.

While not all of the participants shared this emphasis on avoiding the traditional mental health system, all agreed that without the consumer-run organization, they would feel adrift and lost in a labyrinthine system. On the verge of tears, one individual told me, 'If it weren't for this place . . . (long pause) . . . This is our security. This is where we gain our strength from. Because it takes a lot of strength. To go out there and endure.' Another indicated, 'We all need each other. We might disagree, but we need each other. We're not always gonna agree on something, but when it comes to actually needing some help, this is where we come.'

Respect and Humanity
Participants referred to a perceived sense of respect at the agency as critical in their decisions to continue attending. Rather than being patronized and treated as mental health 'cases', participants described being treated with basic decency and genuine respect. Many described this as the first time they had been so treated, enabling a changed outlook on possibility and hope for recovery. Particularly for those who reported dissatisfaction and prior negative experi-ences with the traditional mental health system, what they described as the 'humanity' of their treatment at the peer-run setting was significant. Addition-ally, they indicated that the negative social valuations of being labeled mentally ill or being homeless were rendered less powerful in the peer-run organization.

Participants reported that shared life experiences among members led to the creation of a non-judgmental environment characterized by comfort and genuine acceptance. One participant viewed the lack of judgment as fostering equality among members, 'When you come into the drop-in, basically everyone

is equal. Have you seen the commercial about the hair club? "I'm the president but I'm also a member." Well, that's kind of the situation here.' Describing the agency, another said, 'I think [self-help] is saying "you are here, you are not going to be ignored. You are a part of this community." We can have functional lives. This is nothing to be ashamed of, and we do accept what we are.' Participants also described this aspect of the organizational culture as a necessary philosophical foundation upon which other positive outcomes could be based. Further, the sharing of common experiences and concerns without fear of judgment allows participants members to move beyond labels and envision successful and supportive relationships in the community.

One participant noted, 'People at the drop-in really understand my needs more than family or other people. Because nobody really gives a shit. They're not judgmental. Life still goes on, and you get through it together, and you still go on.' Another gentleman said, 'When I worked here, clients would come in and they were scared and all of a sudden they would just change because of how I addressed them, how I talked to them, and how I respected them. Don't feel ashamed – this happens to different people too. You're not the only one.' A third said

> You know what really goes on here – everybody's human. Basically here, there's no line. There's no 'go behind the door and change when you cross over the line', you know 'I have to be professional now'. It's not really like that here. Everybody's pretty much straightforward so it makes it easier for communication, I think. It'd be easier to go to a staff member here, easier to communicate, you know.

There were also study participants who, while acknowledging the organization's non-judgmental and respectful environs, reported placing less emphasis upon that element in their decisions to attend. These individuals were less *personally* connected to the agency, but rather viewed it as a way to obtain concrete resources and services outside of a demand-based traditional setting. Accordingly with this shifted emphasis, these participants also reported less use of agency members for interpersonal support, and did not include them in their social networks. This reinforces and illustrates previous quantitative findings among consumer-run agency users (Hardiman and Segal, 2003). But for most of those interviewed, the acceptance, respect, and humanity of the non-judgmental environment was a central defining feature of their experience at the agency.

Shared Ownership
Through collective activity and organizational decision-making, participants reported a sense of shared ownership and increased agency commitment. Almost

all participants described the agency with terms connoting ownership: 'my place', 'our place', 'our home'. Many spoke using collective rather than individually oriented language as they shared their experiences. Feelings of ownership are intricately tied into the experience of a sense of belonging and self-defined *community* at the agency. They seem to approach agency participation not as a means to a singular end (e.g. to get housing or social security benefits), but rather as a commitment to sharing with others in the co-creation and ownership of a supportive peer community.

The intrinsically related issues of control and perceived power were forefront for many individuals interviewed. Control was most commonly defined as 'having a say in things', and was analysed here along both personal and organizational dimensions. Members seek to control their own lives through gaining a sense of personal efficacy and ability to influence their own futures, and to control the agency environment through engagement in shared organizational decision-making. The data here indicate a strong relationship between these two concepts. The experience of organizational control is an empowering process that bolsters self-confidence, is a source of pride, and often leads to increased mastery in other key life domains. Many reported that sharing in agency control allowed them to control at least one thing in their chaotic and seemingly uncontrollable lives. Having a say in agency matters thus provides a humanizing, affirming experience of control and power for persons otherwise disempowered.

Participants help create a social reality in which they report they are all equals, share in control, and ultimately are treated as valuable human beings regardless of fault or limitation. Individuals realize they can interact with others, help peers in need, and co-create supportive environments of their design. Participants described the experience of shared control and environmental co-creation as nothing short of life changing. As an example, agency rules are created by members during 'community meetings' and are enforced by all members and staff alike. One participant said with visible pride, 'Clients made the rules. Clients made every last one of them rules up there.'

Although control emerged as a particularly resonant theme, it must be noted that for several participants, their experience of organizational control has decreased to varying degrees in recent years. As a consequence, they described feeling less involved, less committed to, and less in tune with the agency itself. It is likely that such diminished control is linked with other organizational shifts. Those interviewed who expressed the greatest dissatisfaction with the lack of organizational control were also less likely to include agency peers in their personal social networks, perhaps due to the adoption of a disinvested stance at the agency.

While the ideals of mutual support and collective empowerment that undergird consumer-run organizations stress shared control, organizational

reality is often quite different. Maintaining allegiance to a fully democratic model of agency control is wrought with challenges and can fail without proper supports. Yet consumers voice a strong emphasis on involvement and shared control as essential to an effective peer-run environment. One participant passionately noted:

> A facility cannot be run like it should unless the clients are involved, and heard. I don't care what facility you have. Because that's what makes a facility, and that's where you get your respect. You have to be involved too, otherwise they're not going to be involved. When you see like this is happening, you'll get more involved, and then you'll get other people to get involved. It's like a team.

Network of Caring

One of the most useful in vivo themes that emerged was the concept of the peer-run agency as a 'network of caring' for members. Related to the existence of a shared community, the network of caring implies an extension of the egocentrically focused social network concept to a communal or organizational setting. It provides a framework with which to view supportive interactions at the agency. As part of this network, individuals enter into reciprocal relationships with agency-involved peers. A common network feature emphasized by study participants was stability: the agency is dependable and always available. For persons without stability in other life areas, the agency represents a rock upon which they can stand.

The experience of community through participation in a network of caring is a tangible benefit for agency members. One participant used the following words:

> When I come here, I'm around people who are in the same status as I am. We all seem to understand what we're going through. A lot of us are able to help each other. We pass information to each other, like on where the best benefits are. We also, you know, it's like a network of caring.

Regardless of status, perceived relative importance of services versus affective support, or level of satisfaction with organizational issues, participants reported acceptance as part of a community of like-minded and caring individuals. The resulting network was described in ways suggestive of mutual interdependence. One woman with several years of agency participation said, 'We sit and talk. I can confide in them and they can confide in me. That's the beautiful thing.' Another said, 'You see what you can do for another person. It's not all about what you can do for yourself. It's all about what you can do for others and that's what the staff is there for.' For many, having access to others with shared life experiences, facing similar challenges, and who can effectively provide

support adds up to a novel experience of *community* and in some cases *family* replacement without which they would be isolated. One gentleman provided a poignant description of his experience:

> It's an emotional community, cause we're all in the same basis . . . We all under-
> stand where we're coming from, we all out here and we try to give each other
> as much support, you know, as they possible can within their means. And some-
> times it's really heartening to hear someone say, you know what, I saw a place
> over here and I got the number for you . . . somebody's thinking about you in
> a positive way, it helps with your inside.

For those individuals who are organizationally empowered, the inter-dependent nature of community at the agency carries added importance. Additionally, participants indicated that involvement in this network leads to a greater likelihood of making strong peer connections at the agency who can then serve as sources of interpersonal support via inclusion in one's personal social network. One woman echoed this sentiment, noting, 'People can com-municate with each other and hold onto each other. Because having friends is very important to people.' Another said:

> I think I'm more of a special person for them because at least I will listen. Even
> though I have the same problems they have, I will listen to them. I will still listen
> to their problems and see where they come from, and maybe I can help them,
> or maybe if I listen to them maybe they can tell me something that will save
> me, you know what I'm saying?

DISCUSSION

The central focus of this study was to illuminate personal narratives, lived experi-ences, and meaning attached to participation in a consumer-run mental health agency. As a uniquely grassroots phenomenon, such agencies are often closed to the involvement of traditional providers and remain something of a mystery to those on the outside. Support for peer-run organizations has emerged primarily from advocates and through descriptive studies. There is reason to strengthen our empirical understandings of this unique service modality and to work toward developing fidelity standards and criteria to ensure maximum utility for indi-viduals in need (Holter et al., 2004; Mead et al., 2001). This exploratory study adds to the body of knowledge by honoring the importance of actual consumer voices in clarifying user-identified benefits within peer-run settings.

For many participants, the mere existence of consumer-run organiz-ations is symbolic of meaningful choice and alternatives to traditional mental healthcare. Only two of the individuals reported having no current contact with professional mental health providers. These two individuals also described

themselves as further along in their recovery from mental illness than most agency users, suggesting lower levels of actual service need. For the remaining persons, the agency was a critical corollary to their overall service configuration in the mental health system. Such findings imply that consumer–run organizations need not be viewed as competitive with traditional community mental health agencies. Successful co–existence at the least, and coalition and collaboration at higher levels, appear to be feasible goals for both types of organizations.

Perhaps the most compelling findings in this study relate to shared 'ownership', survival and recovery, and the creation of 'networks of caring'. These themes resonate clearly with many of the essential structure and process-related features of consumer–provided services as identified by national experts (Holter et al., 2004). Traditional community mental health agencies, often over-burdened, understaffed, and struggling to meet regulatory mandates, simply cannot emphasize these same features in addition to their primary focal areas. This should not be viewed as a critique of traditional service delivery models, rather a recognition that their strength lies in the provision of concrete services such as case management, medication, group modalities, and referral.

As supported by the participant narratives here, consumer–run agencies have the flexibility to emphasize different goals: the provision of sanctuary, shelter from the challenges of daily community survival, shared organizational 'ownership', opportunities to engage in meaningful helping roles, role modeling of successful community integration and recovery, and finally access to peer-based networks of individuals who play a caring and supportive role often missing from the lives of persons with psychiatric disabilities.

The desire to share in collective organizational control can be viewed in terms of the organizational empowerment concept developed by Segal et al. (1997). Using this framework, individuals are organizationally empowered when they have meaningful input into agency decision–making and feel they are a controlling part of a functioning whole. Agency members in this study who participate in organizational control and feel that they have a say in what goes on at the agency also reported feeling more satisfaction and increased invest-ment in agency success.

Maintaining commitment to the unique values and principles central to consumer–run agencies can be challenging. Study participants, particularly those with long-term agency involvement, alluded to these challenges. Some expressed concern about future agency direction and the need to maintain a course con-sistent with the values of peer support and mutual aid. Interestingly, none of the participants expressing such concerns had considered leaving, and most indi-cated they would be actively working toward agency change. These findings suggest the need for future study of organizational maintenance needs for peer-run agencies.

The most striking differences among participant narratives centered on the relative balance consumers strike between utilizing the organization as a source of concrete services and resources versus emotionally supportive services. Though not mutually exclusive, these positions represent the ways in which individuals often make sense of agency participation, particularly early in their involvement with the agency. Several participants reporting greater emphasis on concrete resources were newer to the organization and also expressed higher ambivalence. This suggests they were still exploring and building trust in the consumer-run model itself. From long-term participants, two distinct utilization patterns emerged: (1) initially seeking affective support services, personal connections, and community but 'weaning' themselves eventually to an increased focus on concrete resources targeted in specific categories, and (2) initially seeking concrete services and resource assistance but eventually shifting to an unexpected focus on mutual support, relationships, and community. These opposing pathways through the peer–run agency experience suggest fluid and shifting patterns of need. There may indeed be two distinct groups of potential agency users, each with a unique set of challenges for recruitment and maintenance of support within the agency environment.

For the minority of participants who reported avoiding emotional connection with peers, it may be that ambivalence toward the agency was fueled by a desire to form a self-identity characterized by success, independence, and movement away from peer/consumer communities. To view oneself as part of a peer community defined by disability may represent failure and stagnation to some, whereas to others it signifies meaning, connection, and support. For the former group, participation in peer-run organizations may be a step away from dependence on the mental health system, with its emphasis on illness, treatment, and compliance. By construing continued participation as related only to the receipt of concrete services, they may indeed be allowing for the maintenance of a personal identity dominated by independence, success, and distance from others with psychiatric disabilities. One participant's words beautifully capture this possibility: 'I come here for things I need, and sure I interact with people here. But I wouldn't be friends with them on the outside. I don't need that – I need a place to live, help with benefits. The *real* things.'

CONCLUSIONS

The challenges associated with successful community living for adults with serious psychiatric disabilities are profound. The individuals interviewed for this study have reported a critically under-explored and frequently devalued service modality. The emergent narratives suggest that participants experience their interactions with the consumer-run agency as highly meaningful and integrated with their daily lives. Ultimately, the most useful aspect of the

organization appears to be its ability to function as a low-demand, accepting, safe, and sheltering environment while offering opportunities for genuine human connection, shared ownership, and community. Finally, access to and having the chance to develop otherwise unavailable peer-focused 'networks of caring' was paramount to most participants. Such networks may provide the critical links between formal service utilization and supported socialization (Davidson et al., 2001) or friendship (Boydell et al., 2002).

Although organizational context appears to be an important factor affecting individual experience within programs, the data described here offer transferability to other consumer-run settings. With drop-in centers among the most common consumer-operated configurations in mental health, it is reasonable to conclude that this study offers relevant knowledge for those seeking to understand similar drop-in settings. Although less directly, it is also appropriate to draw links with other consumer-run organizations providing a larger scope of services, due to common factors such as choice, flexibility, and shared governance.

It can be argued that the development and utilization of natural supports within community settings is among the most critical needs for adults with psychiatric disabilities. Without social support, independent living is often a misnomer, more accurately characterized by social isolation and dependence on an outpatient mental health system. Community mental health agencies, social workers, and other providers seeking to assist consumers in genuine community transition should take note of these findings. While traditional providers have a wealth of expertise in clinical treatment and intervention modalities, encouraging natural support is a far more complex and often ignored challenge.

Consumer-run agencies are but one example of the increasing use of peer support services in mental health. Although existing within the social service sector, these agencies represent for many individuals a more fluid integration of the community, social, and professional realms. Viewed as such, their potential benefits should be explored vigorously by mental health professionals seeking to maximize community integration for consumers. As an emerging practice modality that delivers on social work's commitment to client-centered principles, consumer-run services should also be accorded increased research attention and focus.

Acknowledgements

References

Addison, R. (1992) 'Grounded Hermeneutic Research', in B. F. Crabtree and W. L. Miller (eds) *Doing Qualitative Research*, pp. 11–124. Newbury Park, CA: Sage.

Besio, S. and Mahler, J. (1993) 'Benefits and Challenges of Using Consumer Staff in Supported Housing Services', *Hospital and Community Psychiatry* 44(5): 490–1.

Bichsel, S. L. (1997) 'Consumers as Case Management Assistants: Making Consumer Employment a Viable Part of Psychiatric and Support Services', in C. T. Mowbray, D. P. Moxley, C. A. Jasper and L. L. Howell (eds) *Consumers as Providers in Psychiatric Rehabilitation*, pp. 264–75. Columbia, MD: International Association of Psychosocial Rehabilitation Services.

Bledsoe Boykin, C. D. (1997) 'The Consumer Provider as Role Model', in C. T. Mowbray, D. P. Moxley, C. A. Jasper and L. L. Howell (eds) *Consumers as Providers in Psychiatric Rehabilitation*, pp. 375–86. Columbia, MD: International Association of Psychosocial Rehabilitation Services.

Boydell, K. M., Gladstone, B. M. and Crawford, E. S. (2002) 'The Dialectic of Friendship for People with Psychiatric Disabilities', *Psychiatric Rehabilitation Journal* 26(2): 123–31.

Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D. and Tebes, J. (1999) 'Peer Support among Individuals with Severe Mental Illness: A Review of the Evidence', *Clinical Psychology: Science and Practice* 9(2): 165–87.

Davidson, L., Haglund, K. E., Stayner, D., Rakfeldt, J., Chinman, M. and Tebes, J. K. (2001) 'It Was Just Realizing . . . that Life Isn't One Big Horror': A Qualitative Study of Supported Socialization', *Psychiatric Rehabilitation Journal* 24(3): 275–92.

Felton, B. J. (2003) 'Innovation and Implementation in Mental Health Services for Homeless Adults: A Case Study', *Community Mental Health Journal* 39(4): 309–22.

Felton, C., Stastny, P., Shern, D., Blanch, A., Donahue, S., Knight, E. and Brown, C. (1995) 'Consumer as Peer Specialists on Intensive Case Management Teams: Impact on Client Outcomes', *Psychiatric Services* 46(10): 1037–44.

Glaser, B. G. and Strauss, A. L. (1967) *Discovery of Grounded Theory: Strategies for Qualitative Research.* Chicago: Aldine DeGruyter.

Guba, E. G. and Lincoln, Y. S. (1989) *Fourth Generation Evaluation.* Newbury Park, CA: Sage.

Hardiman, E. R. and Segal, S. P. (2003) 'Community Membership and Social Networks in Mental Health Self-help Agencies', *Psychiatric Rehabilitation Journal* 26(4): 25–33.

Hodges, J. Q., Hardiman, E. R. and Segal, S. P. (2004) 'Hope among Members of Mental Health Self-help Agencies: A Descriptive Analysis', *Social Work in Mental Health* 2(1): 1–16.

Holter, M. C., Mowbray, C. T., Bellamy, C. D., MacFarlane, P. and Dukarski, J. (2004) 'Critical Ingredients of Consumer-run Services: Results of a National Survey', *Community Mental Health Journal* 40(1): 47–63.

Kaufmann, C. L. (1995) 'The Self-help Employment Center: Some Outcomes from the First Year', *Psychosocial Rehabilitation Journal* 18(4): 145–62.

Klein, A. R., Cnaan, R. A. and Whitecraft, J. (1998) 'Significance of Peer Social Support for Dually-diagnosed Clients: Findings from a Pilot Study', *Research on Social Work Practice* 8(5): 529–51.

MacNeil, C. and Mead, S. (2003) 'Honoring Narrative Evidence in the Research and Evaluation of Peer Support', unpublished manuscript.

Mancini, M. M., Hardiman, E. R. and Lawson, H. (forthcoming) 'Making Sense of it

All: Consumer Providers' Theories about Factors Facilitating and Impeding Recovery from Psychiatric Disabilities', *Psychiatric Rehabilitation Journal*.

Mead, S., Hilton, D. and Curtis, L. (2001) 'Peer Support: A Theoretical Perspective', *Psychiatric Rehabilitation Journal* 25(2): 134–41.

Mowbray, C. T. and Moxley, D. P. (1997) 'Consumers as Providers: Themes and Success Factors', in C.T. Mowbray, D. P. Moxley, C. A. Jasper and L. L. Howell (eds) *Consumers as Providers in Psychiatric Rehabilitation*, pp. 504–17. Columbia, MD: International Association of Psychosocial Rehabilitation Services.

Mowbray, C. T. and Tan, C. (1993) 'Consumer-operated Drop-in Centers Run by and for Psychiatric Consumers: Evaluation of Operations and Impact', *Journal of Mental Health Administration* 20(1): 8–19.

Nikkel, R. E., Smith, G. and Edwards, D. (1992) 'A Consumer-operated Case Management Project', *Hospital and Community Psychiatry* 43(6): 577–9.

President's New Freedom Commission on Mental Health (2003) *Final Report: Achieving the Promise: Transforming Mental Health Care in America*, July 22. Washington, DC: Office of the President, http://www.mentalhealthcommission.gov (consulted Mar. 2004).

Salzer, M. S. (2002) 'Best Practice Guidelines for Consumer-delivered Services', paper prepared for Behavioral Health Recovery Management Project: an Initiative of Fayette Companies, Peoria, IL; Chestnut Health Systems, Bloomington, IL; and the University of Chicago Center for Psychiatric Rehabilitation, http://www.bhrm.org/guidelines/salzer.pdf (consulted Mar. 2004).

Segal, S. P., Hardiman, E. R. and Hodges, J. Q. (2002) 'Characteristics of New Clients at Self-help and Community Mental Health Agencies Located in Geographic Proximity', *Psychiatric Services* 53(9): 1145–52.

Segal, S. P., Silverman, C. and Temkin, T. (1995) 'Characteristics and Service Use of Long-term Members of Self-help Agencies for Mental Health Clients', *Psychiatric Services* 46(3): 269–74.

Segal, S. P., Silverman, C. and Temkin, T. (1997) 'Program Environments of Self-help Agencies for Persons with Mental Disabilities', *The Journal of Mental Health Administration* 24(4): 456–64.

Solomon, P. and Draine, J. (1996) 'Service Delivery Differences between Consumer and Nonconsumer Case Managers in Mental Health', *Research on Social Work Practice* 6(2): 193–207.

Solomon, P. and Draine, J. (2001) 'The State of Knowledge of the Effectiveness of Consumer Provided Services', *Psychiatric Rehabilitation Journal* 25(1): 20–7.

US Department of Health and Human Services (1999) *Mental Health: A Report of the Surgeon General*. Rockville, MD: US Department of Health and Human Services.

Van Tosh, L. and del Vecchio, P. (2000) *Consumer-operated Self-help Programs: A Technical Report*. Rockville, MD: Center for Mental Health Services.

Watters, J. K. and Biernacki, P. (1989) 'Targeted Sampling: Options for the Study of Hidden Populations', *Social Problems* 36(4): 416–30.

Yanos, P. T., Primavera, L. H. and Knight, E. L. (2001) 'Consumer-run Service Participation, Recovery of Social Functioning, and the Mediating Role of Psychological Factors', *Psychiatric Services* 52(4): 493–500.

Eric R. Hardiman, PhD, is Assistant Professor, School of Social Welfare, University at Albany, SUNY. He conducts research in peer support, consumer-delivered services, psychiatric recovery and housing. He is currently finishing a qualitative study of peer-delivered disaster relief/support services in New York City following September 11, 2001. He received his PhD from the University of California, Berkeley.