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Stakeholders' Perspectives on Community-Based Participatory Research to Enhance Mental Health Services

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Abstract

Historically, consumers of mental health services have not been given meaningful roles in research and change efforts related to the services they use. This is quickly changing as scholars and a growing number of funding bodies now call for greater consumer involvement in mental health services research and improvement. Amidst these calls, community-based participatory research (CBPR) has emerged as an approach which holds unique promise for capitalizing on consumer involvement in mental health services research and change. Yet, there have been few discussions of the value added by this approach above and beyond that of traditional means of inquiry and enhancement in adult mental health services. The purpose of this paper is to add to this discussion an understanding of potential multilevel and multifaceted benefits associated with consumer-involved CBPR. This is accomplished through presenting the first-person accounts of four stakeholder groups who were part of a consumer-involved CBPR project purposed to improve the services of a local community mental health center. We present these accounts with the hope that by illustrating the unique outcomes associated with CBPR, there will be invigorated interest in CBPR as a vehicle for consumer involvement in adult mental health services research and enhancement.

Keywords

Community-based participatory research; Mental health services; Consumer researcher; Organizational change

Globally, increased value is being placed on consumer involvement in the enhancement of health services (Boote et al. 2002; Crawford et al. 2002). In the United Kingdom and Australia, for example, funding bodies now mandate consumer involvement in research and development related to health services (Hancock et al. 2012; Oliver et al. 2001; Telford et al. 2002). Here, in the United States, a similar paradigm shift is underway. Consumers are increasingly being invited to have critical roles in policy formulation, service provision, support, evaluation and research (Campbell 1997; Chamberlin 2005; Pullman 2009).

Coinciding with calls for greater consumer involvement in the enhancement of health services, community-based participatory research (CBPR) has emerged as an approach which holds unique promise for capitalizing on consumer involvement in systems research and change (Craig 2008; Macaulay et al. 1999). As an orientation to research, CBPR emphasizes equitable partnership with community members in all facets of research (Jacquez et al. 2013) To date, a growing number of studies document CBPR being used in the areas of health services and health disparities, suggesting that this approach has utility for involving consumers in research and action that lead to the enhancement of health services (e.g. Krieger et al. 2002; Schulz et al. 2002a, b).

Within the mental health field CBPR has been gaining traction, especially in children and adolescent systems of care and service delivery (Jacquez et al. 2013). However, there have been few documented cases of CBPR being employed within publicly-funded organizations that deliver mental health services to adults (Craig 2008). The reasons for this are unclear, though some scholars have argued that because of the stigma still associated with persons with severe psychiatric diagnoses, there is a persistent question as to the capacity of members of this population to engage in research (Telford and Faulkner 2004).

As mental health services administrators and researchers consider the potential of CBPR for consumer involvement in service research and enhancement, what is needed is further discussion of the value added of this approach above and beyond traditional means of inquiry. This paper adds to that discussion. It interweaves the perspectives of various stakeholder groups on a consumer-involved CBPR project to improve the services of a local community mental health center. In so doing, this article highlights multilevel and multifaceted transformative benefits associated with consumer-involved CBPR.

The Case for Consumer Involvement in Mental Health Services Research

In their review of the consumer involvement literature, Hancock et al. (2012) identify three arguments commonly advanced for the inclusion of consumers in mental health services research. They are: (a) the ethical/moral argument; (b) the outcome quality argument; and (c) the consumer impact argument. We review these arguments and connect them to the larger recovery movement that has expanded the roles of consumers in mental health systems.

Historically, the mental health system’s relationship to consumers of its services is one that has been described as “paternalistic” (Chamberlin 2005; Craig 2008). Persons diagnosed with severe mental illness, as a result of their conditions, were believed to lack the capacity to truly appreciate the seriousness of their problems and the need for treatment (Chamberlin 2005). This led to a silencing of this population in the decisions that affected their lives and powerlessness within a system meant to address their needs (Ochocka et al. 2002). While vestiges of this perspective can still be observed today, consumers now experience greater agency within the mental health system. This is due, in large part, to the contributions of the recovery movement to the mental health field (Thompson 2012).

With foundations in civil and human rights, the recovery movement, also known as the consumer/survivor movement, emerged as a reaction to the perceived incapacity of the mental health system to support true social inclusion for persons diagnosed with psychiatric illnesses (Lammers and Happell 2003; Thompson 2012). In the aftermath of deinstitutionalization, a large number of persons with psychiatric diagnoses were in prison, homeless, jobless, and impoverished (Davidson et al. 2009). The medical model of mental health, with its exclusive focus on curing “illness” or reducing symptoms, was deemed inadequate for supporting persons with severe and persistent mental illness. What was needed and increasingly called for was a “social” model of mental health that emphasized restoring the individual to a meaningful life despite the presence of symptoms (Thompson 2012).

Recovery emphasizes personhood rather than illness. As Davidson and Roe (2007) put it, recovery is “the process of living one’s life, pursuing one’s personal hopes and aspirations, with dignity and autonomy, in the face of the ongoing presence of an illness and/or vulnerability to relapse” (p. 464). At the core of the recovery perspective is seeing persons with psychiatric diagnoses as people—people with desires, aspirations, and needs just like everyone else (Davidson et al. 2009). Recovery calls for the mental health system to acknowledge personhood and consumers’ right to self-determination by placing consumers in the driver seat of their treatment and by supporting them in meeting restorative goals such as forging friendships and finding acceptance, hope, and meaning in their lives (Anthony 1993; Davidson and Roe 2007).

The arguments for the inclusion of consumers in mental health services research are consistent with the recovery movement and especially the following phrase which is often associated with the movement: “nothing about us without us.” From a moral/ethical standpoint, it can be argued that consumers are entitled to participate in research that will impact their lives (Telford et al. 2002). Research on but not involving consumers only reproduces the historical paternalistic relationship between the mental health system and consumers, thereby relegating consumers once more to a silenced and powerless position in that system. Additionally, it has been argued that consumers, as an important constituent of the general public who “owns” publicly funded research, should have a say regarding the particulars of mental health services research (Entwistle et al. 1998).

From a consumer impact perspective, there are benefits associated with persons with psychiatric diagnoses being involved in research. These individuals may gain valuable skills, a different view of themselves (i.e., as researchers and change agents), a sense of empowerment, and meaningful changes in the services they routinely access (van Draanen et al. 2013; Morrell-Bellai and Boydell 1994; Nelson et al. 2001). Some have even gone as far as to argue that engagement in research can be a part of these individuals’ recovery as it provides them an opportunity to contribute to their community and find meaning in their pursuits (Malins et al. 2011; Linhorst and Eckert 2002).

Last, consumer involvement in research stands to enhance the research product in terms of the validity and usability of research findings (Hancock et al. 2012; Linhorst and Eckert 2002; Happell and Roper 2007; Trivedi and Wykes 2002). Traditional mental health research has not afforded consumers influential roles in the research process (Koroloff and Friesen 1997). Given that consumers’ views and priorities related to their care often differ markedly from those of academic researchers and even mental health professionals, this has meant that the consumer perspective has not been preeminent in mental health research (Campbell 1997; Linhorst and Eckert 2002). Yet, recovery assumes that the consumer is best suited to speak about what is helpful, unhelpful, and needed in service delivery (Hancock et al. 2012), making the inclusion of consumers in research a means of enhancing the ecological and consequential validity of the research endeavor (Campbell 1997; Griffiths et al. 2004;

Entwistle et al. 1998). For this reason it is argued that consumers have an indispensable role to play in formulating research questions, developing appropriate methods, analyzing data, and making subsequent recommendations (Craig 2008; Happell and Roper 2007; Trivedi and Wykes 2002).

Community-Based Participatory Research as a Vehicle for Consumer Involvement and Mental Health Services Enhancement

As an approach to scientific inquiry and action, CBPR aims to involve academics and community persons as partners and co-researchers in generating knowledge and acting on that knowledge in ways that promote the health and wellness of communities (Hall 1992; Israel et al. 2001). This approach emerged within the field of international development as a strategy for addressing the social and economic conditions besetting disadvantaged communities (Macaulay et al. 1999). In the context of mental health services research it provides a vehicle for enhancing service delivery through involving consumers of those services in research and systems change.

The promise of CBPR for consumer involvement and health services improvement lies in what is distinct about the approach. First, CBPR has unique potential to involve consumers —as experts of their own experiences—in research in ways that extend beyond tokenism. The extent of consumer involvement in research can range from what Happell and Roper (2007) have referred to as “lip-service involvement” where consumers are simply consulted, to partnerships were consumers are involved in the research process. Similarly, the power consumers have compared to academics in any research endeavor varies as a function of the specific research approach (Trivedi and Wykes 2002). Israel et al. (2001) argue that participatory approaches aspire to be equitable, involving consumers as co-researchers in all facets of research and action. The assumption here is that to the extent that consumers are involved, the more valid and impactful the end product of CBPR will be.

In addition to promoting engagement in research among community members, CBPR places value on the perspectives of those previously silenced and historically marginalized (Israel et al. 2001; Macaulay et al. 1999). Often situated within a critical epistemology, CBPR privileges the perspectives of those lacking in power and attends to historical and contemporary social structures that adversely impact marginalized communities (Israel et al. 1998). In essence, CBPR facilitates a process of knowledge generation that incorporates the experiences and wisdom of community members in order to create structural changes that will impact the lives of these individuals (Israel et al. 1998, 2001; Wallerstein and Duran 2006).

While CBPR may hold great promise for maximizing on consumer involvement in research, there are several well-documented challenges associated with CBPR that are worth reviewing (Blumenthal 2011; Minkler 2004; Horowitz et al. 2009; Israel et al. 1998; Shoultz et al. 2006; True 2001). First, academic researchers and consumers may have divergent interests and priorities for research. Negotiating these may not be easy, especially in instances where a project is funded by an entity that has its own priorities. Second, despite CBPR’s orientation around partnership and equity, researchers bring unique responsibilities (e.g., administration) and statuses (education, institutional affiliation) to the research endeavor that can undermine power-sharing and partnership. Last, compared to traditional research approaches, the successful execution of a CBPR project requires a great deal of time and energy on the part of community members and academic researchers. For example, consumers participating in research often require training and ongoing support to be effective in their new roles. Additionally, the research project may need to progress at a slower rate in order to accommodate the learning needs of consumers and to foster a true collaborative effort. Despite these challenges, CBPR practitioners have argued for the continued and unparalleled utility of this approach in bringing about sustainable and beneficial change in communities and systems.

Context of the Project

The CBPR project that is the focus of this paper emerged within discussions between an academic researcher and the new director of a large urban community mental health center. During an annual review of consumer satisfaction survey results the director, while pleased that the results demonstrated that 92 percent of consumers were: satisfied with care; would seek services at the center even if they had a choice; and would refer family and friends for care, expressed a desire to know more. He was interested in learning about the opinions of those who were not satisfied with the care they had been receiving at the Connecticut Mental Health Center (CMHC) and was interested in hearing from those who were satisfied how services could be improved. In collaboration with a colleague who has expertise in CBPR, it was decided that a group of consumers would be hired and trained to conduct focus groups to assess current perceptions of the care, the care environment, and make recommendations for improvement.

Given a desire to have the process be open to all who were interested, a forum was held to explain the project to consumers and the role of consumers (who would come to be known as consumer researchers) who would join the research team. Approximately 70 individuals attended this forum and 29 applied for a position as a consumer researcher. Of those who applied, 17 were interviewed by a peer leader[1] and two academic researchers. Four individuals were hired as consumer researchers. The research team, inclusive of the four consumer researchers and two academic researchers, met over the next 9 months with the purpose of enhancing the capacity of consumer team members to conduct all aspects of focus group research including: development of the focus group protocol; facilitation of focus groups; note taking; coding of transcripts; data analysis; report generation; and feeding information back to stakeholder groups. The research team conducted 14 focus groups comprised of 101 consumers who receive services at the center. All focus groups were facilitated by a consumer researcher. Another consumer researcher took notes and an academic researcher attended each group in a supportive role (e.g., brought refreshments, operated the tape recorder, distributed remuneration to participants). After the research team developed the coding scheme, each focus group transcript was coded separately by one consumer researcher and one academic researcher who then reviewed together any

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[1] In the context of CMHC, a peer leader is a current or former consumer of services who has made notable progress in their recovery and who is employed by the organization to design and deliver support services to consumers.

discrepancies and worked toward consensus. The research team collaboratively analyzed the data and developed a report and presentation. Consumer researchers presented findings to 12 stakeholder groups at CMHC including consumers who receive services, center leadership, and staff. While the entire process was initially envisioned to last a year, now 3 years later, the research team continues to collaborate on a number of projects at CMHC and is in the process of conducting a second round of focus groups.

Stakeholders' Perspectives

The narratives below represent the perspectives of various stakeholder groups on the aforementioned project. It highlights the hopes these groups had for the project and the perceived impacts of the project on CMHC and in some cases individuals. The stakeholder groups represented include: (a) the administrative leadership of CMHC; (b) directors and team leaders who oversee service delivery; (c) academic researchers; and (d) consumer researchers.

Connecticut Mental Health Center Leadership: Michael Sernyak, Jeanne Steiner and Robert Cole

In a number of ways the consumer researcher project was a natural progression for CMHC. Consumers, for some time, have been involved in various aspects of programming at CMHC and have even been part of a consumer advisory board that provided recommendations to the director on a monthly basis. The focus groups provided a vehicle for us to continue our movement toward more consumer involvement at CMHC. Specifically, we hoped for three things to come about as a result of this project. First, we wanted to pay more than lip-service to the idea of consumer involvement in the center. The consumer researcher-led focus groups represented an opportunity to employ consumers of our services and to involve them more directly in what happens at CMHC. For us, this was "recovery" in action. It was an answer to the question of how to put what can be a nebulous and vague concept into concrete practice.

Second, we wanted to elevate the status of consumers at CMHC. By staff and other consumers witnessing consumers play such a critical role in service improvement, we hoped for positive change in the ways both these constituents view the roles of consumers at CMHC. As it pertained to CMHC staff, we were interested in seeing more receptivity to input by consumers as indicators of how we as an organization are doing and where we needed to be headed with the focus of our services. For consumers, who often sit in the background of processes related to service improvement, we hoped that they would feel empowered to share with us not only their experiences and perceptions of the center, but perhaps more importantly their ideas of how to make things better. As the leadership of CMHC we recognize that there are a lot of great ideas out there about how to make the center better; however, the task has long been trying to connect with those ideas. We envisioned that the example provided through the focus groups—one in which consumers spoke freely about their experiences and ideas—would serve as a model for breaking down barriers to communication between consumers and the administration at CMHC.

Last, by having consumers assess the experience of other consumers, we hoped for some added validity, authenticity, and legitimacy to the results of the focus groups. The focus groups could have easily been facilitated by Dr. Kaufman or another academic researcher. However, there is something to be said about the level of comfort inherent in consumers talking to consumers about their experiences and perceptions and the quality of the information that is collected through such a process. Further, when consumers speak from and to their own experiences, it is hard to not sit up and pay attention. It is hard to remain in a state of inertia. So, in having consumer researcher-led focus groups, we were looking for: an avenue to further promote consumer involvement in the services they receive, which we saw as connected to the concept of recovery; an opportunity to challenge traditional ways of thinking about the roles consumers can play more generally at CMHC; and have data collected that would be seriously considered by virtue of who was doing the collecting.

Since the focus groups were conducted and their results fed back to the different constituent groups at CMHC, we have observed a number of positive organizational shifts. First, the results have given us a clear improvement target that has breathed new life into our performance improvement efforts and goals. Specifically, one of the key themes that came through in the results was respect. Consumers identified aspects of the care environment that felt disrespectful. Consequently, our center-wide performance improvement goal for the fiscal year has been promoting a culture of respect at CMHC. Additionally, our performance improvement committee, made up of administrators, clinical staff, and consumers has been tasked with developing and implementing policy, procedures and measures that will help promote a culture of respect by addressing specific concerns raised within the focus groups —thereby aligning our efforts directly with consumer preferences.

Second, there is a gradual shift underfoot around whose viewpoint we work from when delivering and evaluating services. It comes somewhat natural for administrators and clinical staff to believe that they understand what is best and what is needed for clients. However, the perspective of the consumer, which has always been there, is much more amplified as a result of the consumer researcher project. What we mean by this is that we now actively seek ways to involve consumers in decision-making. For example, when there is talk about new initiatives at the center, we are now more likely to wonder what consumers think about these initiatives and to invite consumers to provide feedback on our ideas. The importance of this cannot be overstated. Consumer involvement in decisions impacting the care they receive is, after all, the spirit of recovery. So, in this growing push for consumer involvement we find ourselves much more closely aligned with the ideals of recovery than we have ever been.

Third, we are directly addressing a number of concerns raised by consumers and implementing recommendations. For one, we are updating the physical environment of CMHC to make it more welcoming and comfortable for consumers. This includes, for example, renovating our lobby. Consumer feedback is also being incorporated into specific units of CMHC. After the results of the focus groups were fed back to different units at CMHC, a number of these units have been working independently to respond to feedback within the context of their staff. For example, on one unit we now have consultants working with staff to improve staff interactions. Also, team leaders, across various units, have been engaging their clinical staff in discussion around client and staff respect.

Continuous improvement in the services we provide is both a value and goal of the leadership of CMHC. We envision consumers, by right, playing an indispensable role in helping us honor that value and meet that goal. As we move forward as an organization, we eagerly anticipate new avenues for consumer involvement in helping us steer and shape the services provided through CMHC.

Connecticut Mental Health Center Service Directors and Team Leaders: Donna LaPaglia, Margaret Bailey, Candace Buchanan, Avon Johnson

There is something quite powerful in hearing consumers' experiences with the services we provide. That is what the consumer researcher project provided. It provided consumers a safe forum in which they could relay those experiences to us. To be clear, we had known about many of the concerns highlighted in the results, so we were not surprised by them. However, hearing the perspective of the consumers as it came through so strongly in the presentations forced us to ask ourselves, "Well, how are we going to address this? What are we going to do?"

There is something equally powerful in having consumers at the fore of the focus group project. Many of the unit leaders at CMHC have peer leaders on their staff. Consequently, we were quite convinced coming into the project that the consumer researchers would bring something unique to the work that could not be replicated. The evidence for this is everywhere. Take substance abuse treatment, for example. One has to be impressed when considering what peers have accomplished through peer-led initiatives such as Alcoholics Anonymous. So, there was certainly receptivity among unit leaders to the idea of consumer researcher-led focus groups. Further, given the value placed on recovery by CMHC and the Department of Mental Health and Addiction Services (DMHAS), the groups were a logical next step.

In our roles related to the delivery of services, we have endeavored to address the issues raised and the recommendations made in a number of ways, some of which have been specific to units. One broad area of concern for consumers was medication and its side effects. Organizationally, trainings have been given to prescribers and clinicians. There have even been information sessions facilitated by our pharmacist for consumers and there are plans to have such sessions be a part of already existing therapeutic groups to increase their accessibility to consumers. On some units, specifically the inpatient units, consumers raised concerns around the timing of medication administration. They reported that because of the time of day they received their medication, they were not able to actively participate in many of the groups provided on the units. Prescribers on these units are now paying closer attention to whether the timing of medication administration is interfering with group engagement. Additionally, for those consumers for whom this might be an issue, there is now the possibility of receiving medication on a different schedule so as to maximize their ability to engage in desired services.

In addition to responding to consumers' concerns around medication, we also responded to consumers' need to be more informed of their rights as consumers of mental health services. The Connecticut Legal Rights Project (CLRP) visits CMHC on a regular basis to provide this information. We asked CLRP to put their visits on the schedule so that consumers will know when they can learn more about their rights or have specific questions about their rights answered. Related to this, while the patients' bill of rights is posted throughout CMHC some consumers noted that they did not know where they could access a copy of the document. As a result, there have been subsequent efforts to ensure the visibility of the bill to consumers.

We have also sought to increase the ease with which CMHC services can be navigated. In response to feedback given to one unit about its intake process, this unit is currently trying to enhance the experiences of consumers by making the intake process more efficient, streamlined, and ultimately consumer friendly. The plan, similar to a "secret shopper" process (without it actually being a secret), is to have peers present for a mock intake session and then provide feedback on the process. Specifically, they will highlight parts of the intake protocol that are redundant and challenging and provide recommendations to improve the protocol.

Last, each unit is working in an ongoing manner to enhance the interactions among staff and between staff and consumers. Specifically, we provide trainings and have discussions with our teams on how to ensure a climate of respect in the work and care environments. Some have even started to think about how staff and consumers can have reasonable and agreed-upon expectations for each other that ensure respect as well as good clinical care.

Throughout our account we have spoken about the impacts of the consumer researcher project on the care environment of CMHC. We also have observed another impact in the way providers are thinking about the relationship between providers and consumers. In a mental health setting it is easy to become siloed into provider and consumer roles. However, the more we see initiatives like the consumer researcher-run focus groups, the more we wonder about alternative possibilities. Specifically, we wonder about how providers and consumers can work together to bring about changes that will improve consumer outcomes. Perhaps this is what it means to be a "community" mental health center.

Academic Researchers: Joy Kaufman and Cindy Huang

We approached this project with a specific vision of the value to be added by having consumer involvement. One of us had prior experience facilitating focus groups as well as having community members facilitate focus groups to impact service systems and observed key distinctions between approaches. First, one's positionality (e.g., in terms of ethnicity, class, gender, etc.) can impact the data that is collected and what is learned from that data. For instance, there was a service system evaluation in which one of us facilitated the focus groups 1 year and trained and hired community members to facilitate them the following year. The target community was predominantly low income and Latino and African American in composition, and the community members who facilitated the focus groups matched these demographic characteristics. We found that the community members who facilitated the focus groups were able to solicit information from participants that an academic researcher (perhaps because of differences in ethnicity, socioeconomic status, relationship to the community, etc.) was not able to. Additionally, in the analysis of the data, community members often perceived themes that were not readily apparent to us, even though we are experienced qualitative researchers. These observations have led to a greater appreciation of how much is missed when community members are not involved as partners in the research that concerns their lives. Moreover, it has led to a commitment to use CBPR, when possible, in research related to communities.

In regards to the present project, we expected that the participation of consumer researchers would have some specific yields. First, we hoped that the consumer researchers would have the trust of their fellow consumers and that focus group participants would feel comfortable sharing their honest opinions and experiences related to CMHC. We also hoped that the consumer researchers' experiences as consumers would add some depth to our understanding of the data. Last, given that on an annual basis satisfaction surveys are administered to consumers, we hoped that the consumer-led focus group project—given the visibility and centrality of consumers in it—would have some added legitimacy that could help catalyze organizational change at CMHC.

In order to have the project meet the goals mentioned above it was important to recruit consumers who were a right fit for the project. We sought to select individuals who were committed to the project in a way that extended beyond the monetary incentive. Specifically, we looked for individuals who saw a higher purpose to their involvement with the project. As a result, those who were chosen were among those who perceived their participation as a way to help others or "give back" to a center that has played a substantial role in their recovery. Also of importance was selecting consumers who were at a point in their recovery where they could understand the project and effectively complete the tasks associated with their roles. Last, we wanted to ensure that our selected group of consumer researchers was representative of the CMHC consumer population in terms of gender, ethnicity, and age.

Having a CBPR approach to the research was a complex endeavor that required us to manage dynamic and multifaceted roles related to the consumer researchers. At times, we functioned as "facilitators" whose task was to enhance the skills that were needed by the consumer researchers for their work. We operated from a belief that these skills were already present and it was just a matter of recognizing them and having the consumer researchers recognize them. Then, we worked to draw these skills out and hone them in a way that would be useful for project-related activities. At other times we were coaches. We provided support and encouragement as the consumer researchers completed tasks that in some ways felt very foreign to them. We also had to be managers. We coordinated the various activities the consumer researchers took part in. This included ensuring that they knew where and when they would be needed, and scheduling the focus groups. It was also being present for the focus groups to support the consumer researchers and provide continual feedback on their facilitation of the groups.

We would describe our relationships with the consumer researchers as one that was professional, but at the same time collaborative and authentic. Being collaborative and authentic was important given the power differential between us and the consumer researchers and given our goal to situate the project within a CBPR approach. To create a collaborative dynamic, we worked to ensure that the consumer researchers were comfortable with us and felt empowered in their roles. While we could not be completely disavowed of our power and status given our roles and responsibilities in the project, we wanted the consumer researchers to feel comfortable and safe enough to venture their own perspectives and to disagree with ours. Part of inviting consumers to give a counterpoint was acknowledging that even though we are "professionals" we may not know what is best and that they as consumer researchers bring unique strengths, experience, and expertise that we do not have. Collaboration occurred in a number of ways. For example, in formulating the questions for the focus group protocol, we would suggest a question and then ask the consumer researchers whether it made sense or should be changed in some way. Through a similar process we engaged them in writing the introduction that they would use before the start of each focus group. Over the course of four meetings we worked collaboratively with the consumer researchers until we had an introduction that they felt comfortable using. The consumer researchers providing their expertise in this way was crucial to ensuring that the interview questions and other written and spoken materials would be understandable to the consumer population of CMHC.

The expertise of the consumers was perhaps most apparent in the analysis of data and the representation of findings, especially as they pertained to challenging feedback that some focus groups participants provided. Given our positions as outsiders to the center, the consumer researchers provided useful context around the issues that were raised that we might not have been privy to without their involvement. Also, they connected and empathized with the perspectives of the consumers in a way that not only helped us understand the meaning of consumers' experiences and perceptions but also the significance of them. In so doing, the consumer researchers were able to bring the lived experiences and perspectives of the focus group participants to the fore of the data analytic process. In addition to the data analysis, the consumer researchers had a substantial hand in how the results were represented. For instance, one of the ways the findings of the focus groups were shared was through PowerPoint presentations. The consumer researchers provided input on the themes that were important to be highlighted and how these themes should be presented. This process took the form of our collaboratively creating the slides in meetings.

The contribution of the consumer researchers to this project was monumental. First, we believe they created a context in which other consumers felt comfortable sharing their opinions and experiences of CMHC. Second, their input in terms of how to word the focus group questions and the introduction likely made for a more efficient and effective focus group. Last, we believe that their role in helping us to clearly understand the lived experiences behind the data could not be replicated some other way. While conducting research in this manner was undoubtedly intensive in terms of time and effort, we believe that the usefulness of the end-product made it a worthwhile endeavor.

Consumer Researchers: Ronald Byrd, Eddrena Claggett, Sandra DeVeaux and Reno Perkins

One of the biggest challenges with having a mental illness is being invisible. When people look at you, they do not see you. They see your diagnosis. You are constantly overlooked because people think you have nothing to offer your community and society. Sometimes you even overlook yourself as you start to believe what others think of you. Taking part in this project has been a reminder to ourselves and others that we (persons diagnosed with a psychiatric illness) have something important to offer.

When we learned that we were selected for this project we were excited and honored. Each of us has felt “called” in one way or another to help people. Friends told Ronald that he should be a pastor because he was good at speaking and encouraging others. Sandra is a Certified Substance Abuse Counselor but because of her loss of her hearing and mental health difficulties has struggled to find work in her field. Eddrena, in her everyday life, has witnessed suffering and has always wondered how she could be of service. Reno dreams of one day working with youth who are troubled, but fears that his illness might get in the way of that dream. So, our excitement had to do with the fact that this project reignited dreams and hopes we had given up on. It reconnected us to our purpose in life. We felt honored because of all the people who applied we were being given an opportunity to help people and to improve a place that has been an important part of our recovery.

While we were excited about the project, we were also anxious. Could we really do this? Did we have what it takes? Would people take us seriously? This is where Joy and Cindy came in. They helped prepare us for the work we would be doing. Over several weeks we met with them for training. But the training was not what we expected. We were not expecting everyone to participate and be involved. Just as Joy and Cindy had some things they could teach us, we had things we could teach them and they were open to learning. For example, they would ask us what we thought about the interview questions and how we might word them so that people understand them. Also, Joy and Cindy kept it “real”; they never looked down at us. If they needed to slow down or go over something again they would, no questions asked. They also knew how to play to our strengths. Some of us were more comfortable with public speaking and facilitating groups, so we moderated more focus groups and presented the results more often. Some were better at coding the data and did more of the coding and analysis. We all worked, though, and felt that we were part of a team contributing something that would change the lives of a lot of people.

Facilitating focus groups was something that we had never done. However, for some of us who had been peer leaders in other settings or who had participated in groups like Narcotics Anonymous, it felt familiar. Facilitating the focus groups gave us a sense of fulfillment because we were talking to people who were going through the same things we had been through. We also felt we were giving them an opportunity to say how they really felt without fear that someone might get back at them and with the knowledge that what they had to say was going to be heard by the people in charge. In fact, we had participants thank us for allowing them the opportunity to share their opinions about the mental health center. They were grateful that we were telling their stories and using their stories to bring about change in the mental health center. Perhaps the best part of the focus groups was having other people with mental health issues see what we were doing. We not only wanted to bring about change in services but in people. We wanted consumers to know that you can have mental health challenges and still make a difference in the world.

Presenting the results of the focus groups and our recommendations was terrifying at times. We had to present before providers, administrators and even consumers. It got easier, though, as people seemed really interested in what we had to say and tended to agree with our results and recommendations. Their comments made us feel like they valued what we had done and were taking what we said to heart. In fact, we saw change taking place even within the presentations. For example, some of the physicians agreed with what we found out about consumers' experiences with medication and began talking about what they could do differently to have better medication outcomes. We felt hopeful that what we learned through the focus groups would be used to help bring about more improvement in services.

We would say that overall we felt honored to be a part of this project. We were even surprised at what we were able to do and how well we did it. The greatest satisfaction, however, came from being part of something again. We felt like we were contributing once more by speaking up for people like ourselves who are invisible and who are not always heard. We also benefitted from learning more about CMHC and about mental illness from talking to consumers. We liked the money, too, and having a place to go and something to do. When you have a mental illness, not having something do and somewhere to go make it worse. We look forward to doing this again and seeing our work bring change to people's lives.

Discussion

Historically, consumers of mental health services have not been given key roles in research and change efforts related to the services they use (Craig 2008; van Draanen et al. 2013). One likely reason for this is the pervasive stigma around mental illness which tacitly assumes members of this population do not possess the capacity to meaningfully engage in such endeavors (Telford and Faulkner 2004). The first-person accounts we presented challenge this assumption. Not only are individuals with psychiatric diagnoses able to meaningfully participate in research and service enhancement, they bring something unique and irreplicable to these efforts. Additionally, these accounts suggest that CBPR can be a useful vehicle for maximizing the unique contributions consumers can make to mental health services research and enhancement.

Community-Based Participatory Research and Consumer Involvement

The combined accounts of stakeholder groups suggest that the research approach employed by the consumer researcher project (i.e., CBPR) has utility in facilitating certain outcomes. Moreover, these outcomes are in keeping with common arguments advanced for consumer involvement in mental health services research. First, it has been argued that consumer involvement in research that impacts their lives should be a moral and ethical imperative, especially in light of the paternalistic stance the mental health system has taken toward consumers historically (Entwistle et al. 1998; Telford et al. 2002). While there is little doubt that the participatory approach of the project promoted consumer involvement in research, it is the extent of involvement facilitated by this approach that is worth considering. What CBPR seems to offer above and beyond traditional modes of research are avenues for consumers to be involved in research as partners and collaborators with academicians as opposed to simply "consultants" or "advisors" (Craig 2008; van Draanen et al. 2013). Indeed, in this project consumers were actively involved in all aspects of research and action. They took a leadership role in the framing of the focus group questions, facilitated focus groups, analyzed data, shaped the ways results and recommendations were presented, and presented the findings and recommendations to stakeholder groups. Thus, CBPR holds promise—perhaps more than any research approach—to honor the moral and ethical imperative to meaningfully involve consumers in research and change efforts.

The second argument made for consumer involvement in mental health services research is that the products of such research are enhanced by simple virtue of the inclusion of consumers in the research process (Hancock et al. 2012; Linhorst and Eckert 2002; Happell and Roper 2007; Trivedi and Wykes 2002). The academic researchers, in their account, agreed with the premise of this argument. They maintained that consumer researchers brought a contextualized perspective to the analysis of the data that resulted in a fuller and more nuanced understanding and representation of the experiences of consumers. Additionally, the involvement of consumers seemed to enhance the action component of the research. Both the leadership and service director and team leader stakeholder groups mentioned an added legitimacy and authenticity to the project because of the involvement of consumers. This legitimacy and authenticity helped catalyze change within the organization as both groups felt compelled to concretely address the findings and recommendations of the study. These observations suggest that CBPR may represent a means to effectively harness the perspectives and energies of consumers in service to high quality research and impactful actions to enhance services (Macaulay et al. 1999).

The final argument for consumer involvement in mental health services research is that such involvement can be beneficial to consumers and can even be a part of their recovery process (Malins et al. 2011; Linhorst and Eckert 2002). A small but growing literature adds credence to this argument, demonstrating that consumers' involvement in research provides opportunities for skill acquisition, empowerment, and social connection among other benefits (Craig 2008; Schneider et al. 2004). The consumer researchers whose work is the focus of this paper mentioned that taking part in research reconnected them with dreams and a sense of purpose they had come to give up on because of their illnesses. Related, their positions as consumer researchers provided them a role in which they could be seen that did not implicate their psychiatric diagnoses. Last, the project afforded the consumer researchers the opportunity to give back, to contribute something of themselves that is of value and that would improve the lives of others. These reported benefits of research involvement are noteworthy given their alignment with the concept of recovery. Scholars and activists have argued that recovery from severe and persistent mental illness is fundamentally about being able to pursue one's life in the face of illness (Davidson and Roe 2007). The consumer research project seemed to have afforded the consumer researchers such an opportunity. They noted that ultimately the project gave them "a place to go and something to do."

Implications

In addition to the tangible organizational changes that came about as a result of the project (e.g., updating physical setting, modifying medication administration schedule, etc.), there were intangible shifts in CMHC that should not be overlooked. As previously mentioned, the leadership group envisioned the consumer researcher project, in part, as a vehicle of change related to the perspectives staff and consumers held about the role of consumers in the organization. In the aftermath of the project, some stakeholder groups observed shifts in organizational culture such as staff re-thinking the roles of consumers in the organization and having interest in learning more about consumers' perspectives on the organization and its various initiatives. This suggests that consumer-involved CBPR projects can have ripple effects that extend beyond implemented changes to an organization. The impacts of such projects may permeate the culture of an organization in positive ways. Thus, in considering the impact of consumer-involved CBPR on mental health organizations, it is important to not only attend to immediate structural changes, but also changes in the beliefs, perspectives, and attitudes of stakeholders over time.

CMHC as a mental health organization is unique in that it has been on a trajectory toward more consumer involvement in various aspects of the organization's functioning for quite some time. Evidence for this is in the already expanding roles of consumers in the organization (e.g., advisory committee, peer leaders). The fact that CMHC had been moving along a trajectory toward greater consumer involvement prior to the initiation of the consumer researcher project may suggest an important implication for the use of consumer-involved CBPR within mental health organizations. That is, the successful implementation of CBPR projects within a mental health organization likely hinges on the organization's "readiness" to have consumers take on greater roles within the organization. Findings from the literature on organizational change support this assertion, concluding that readiness for change is a critical precursor for the successful implementation of any innovation (Amatayakul 2005; Armenakis et al. 1993). Thus, if an organization is not ready for increased consumer participation, CBPR could be subject to some degree of skepticism, uncertainty, or resistance on the part of an organization's membership. Not surprisingly, findings from the literature on consumer involvement suggest that mental health and medical professionals not valuing consumer involvement is a persistent barrier to consumer-involved research (Entwistle et al. 1998; Griffiths et al. 2004; Ochocka et al. 2002; Telford and Faulkner 2004). Thus, in maximizing on the benefits of consumer-involved CPBR within a mental health setting, researchers and administrators should carefully consider the extent to which the organization is ready for increased consumer involvement. Indications of organizational readiness for increased consumer involvement might include efforts on the part of an organization's leadership to create employment opportunities for consumers and advisory roles whereby consumers can influence organizational change. Another indication might include a desire by staff for more peer support services, which might suggest a growing recognition of the expanded roles consumers can play in mental health organizations. Last, an organization possessing a recovery orientation to services (Anthony 2000) might be a good indicator of openness to expanded roles for consumers. In the event that an organization is not ready for this type of research, systematic steps may need to be taken to prepare the organization's staff for consumer-involved research. One step might include a "change message" (Armenakis et al. 1993; Armenakis and Harris 2002) as part of a social marketing campaign that highlights the need for and extols the virtues of consumer involvement in research and action.

Conclusion

We are in the midst of an exciting movement toward increased involvement of consumers in research and enhancement efforts related to the mental health services they access (Boote et al. 2002; Crawford et al. 2002). Not only is this an ethically sound position, it is a position that has scholarly and action-oriented merit (van Draanen et al. 2013; Hancock et al. 2012; Linhorst and Eckert 2002; Morrell-Bellai and Boydell 1994; Nelson et al. 2001). The accounts presented in this paper provide some evidence to suggest that consumers bring something unique and valuable to mental health services research and enhancement efforts. They also suggest that CBPR is primly situated to maximize on the unique contributions of consumers to research and action with mental health systems. Consequently, we assert that consumer-involved CBPR can be a valuable tool in service of the community mental health agenda and eagerly anticipate the day when this approach is the rule rather than the exception.

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