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Improving Capacity to Monitor and Support Sustainability of Mental Health Peer-Run Organizations

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Abstract

Peer-run mental health organizations are managed and staffed by people with lived experience of the mental health system. These understudied organizations are increasingly recognized as an important component of the behavioral health care and social support systems. This Open Forum describes the National Survey of Peer-Run Organizations, which was conducted in 2012 to gather information about peer-run organizations and programs, organizational operations, policy perspectives, and service systems. A total of 895 entities were identified and contacted as potential peer-run organizations. Information was obtained for 715 (80%) entities, and 380 of the 715 responding entities met the criteria for a peer-run organization. Implementation of the Affordable Care Act may entail benefits and unintended consequences for peer-run organizations. It is essential that we understand this population of organizations and continue to monitor changes associated with policies intended to provide better access to care that promotes wellness and recovery.

The National Survey of Peer-Run Organizations, which gathered information about peer-run organizations and programs, organizational operations, policy perspectives, and service systems, was conducted in 2012. It was the first national survey of peer-run mental health organizations since the 2002 Survey of Self-Help Organizations, which used different methods (1). This initial report describes the enumeration and survey methods and the importance of ongoing monitoring of these organizations.

Importance of peer-run organizations

The Substance Abuse and Mental Health Services Administration (SAMHSA) has identified consumer-operated service programs (referred to here as peer-run organizations) as an evidence-based practice (2). Mental health peer-controlled services comprise an important component of our nation's systems of care for persons with serious mental disorders (3–7). Mental health peer-support entities have existed for more than 40 years (8) but only within the past decade have trained peer support specialists and peer-run organizations been recognized as an integral part of our public mental health system (7). Peer-run organizations are defined as "programs, businesses, or services controlled and operated by people who

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have received mental health services," with the mission of using support, education, and advocacy to promote wellness, empowerment, and recovery for individuals with mental disorders (1).

Peers are in a unique position to promote recovery and wellness through support of persons with mental disorders that is based on empowerment, self-direction, and mutual relationships (9). Increasing the number of persons with mental disorders who are involved in the creation and implementation of high-quality services—and increasing their involvement in research processes related to these services—is an essential step toward improving the lives of persons with mental disorders by incorporating the unique insights of consumers.

To continue to measure real-world effectiveness and implementation and to promote fidelity, peer-run organizations need to be identified for participation in technical assistance and research. However, before this national survey, no comprehensive list of these organizations existed and no efforts had been made to categorize their characteristics and their connections with other mental health and health care providers. Such data are important for federal, state, and local efforts to sustain these programs as part of our nation's evolving health and mental health care systems.

Survey methods and results

The intent was to survey peer-run organizations that had a formal organizational structure (that is, director, board, and budget) either of their own or through a sponsoring organization. The survey focused on a group of organizations identified as peer controlled and staffed, which was based on the proportion of directors, staff, and board or advisory group members who self-identified as people with lived experience of the mental health system. The survey population excluded informal mutual-support groups, although organizations that sponsor mutual support groups were included.

The potential survey participants were identified by contacting statewide consumer networks (SCNs) and state offices of consumer affairs (OCAs) in every state from August 2010 to June 2012. Lists of peer-run organizations were obtained from all but two states, which did not maintain complete or up-to-date lists. In one of these states, organizations were identified through snowball searching with assistance from the state OCA. Contact with key informants in the two states suggested that we missed few, if any, potential participants.

In states that did not have an SCN identified by SAMHSA or the National Coalition for Mental Health Recovery (NCMHR), key local informants were contacted to provide missing information. Informants were told to include in their lists any organizations or programs they considered "peer-run" or "consumer-operated." Organizations in the Consumer Directed Services Directory of the National Mental Health Consumer/Survivor Self-Help Clearinghouse were also included. All organizations identified by the SCNs, OCAs, key informants, and national consumer-run organizations were contacted for participation in the survey.

The SCNs, OCAs, and key informants identified 948 organizations and programs, a wider population than was ultimately included in the survey. As data collection was conducted, we acquired information on new organizations. We also acquired information on those that had gone out of business. Organizations were considered out of business if there was confirmation from someone associated with the organization or a neighboring organization, SCN, or OCA that the organization was no longer in operation. Those for which the recruitment letter and e-mail were undeliverable and which also had a disconnected phone were considered out of business if there was no indication otherwise.

We sent the survey by mail and e-mail to 895 of the organizations and programs identified by the methods described above, and we achieved a response rate of 80%. On the basis of responses from these 715 organizations, we determined which met the definition of a peer-run organization. The definition was developed by a five-member panel of consumer advocates, technical assistance providers, program directors, and researchers. The final criteria were as follows: an incorporated, independent nonprofit organization or a nonincorporated organization that operates independently from a parent organization; at least 51% of the board of directors or advisory board are peers; the director is a peer; and most staff members or volunteers are peers. Additional classification methods included asking participants whether the organization provides “direct services,” defined in the survey as “when staff interacts with individual members or groups of members to provide peer support.” Data analysis included organizations that reported providing direct peer support services whether or not the organization was reported by the respondent as primarily a “direct service” organization.

Among the survey respondents, 380 met the criteria for a peer-run organization (Table 1).

Potential impact of the Affordable Care Act

The Affordable Care Act (ACA) and actions of many states to improve behavioral health systems will have critical implications for the services available to persons with mental disorders. The intention of these policy changes is to promote more positive outcomes for persons with mental disorders (10). Although the ACA promotes increased access to valuable services, the essential values and methods of support provided by peer-run organizations could be inadvertently disrupted if we do not collaboratively pay attention to the early signs of unintended consequences of rapid and drastic health care policy changes. For example, deinstitutionalization, an earlier policy reform, produced many negative outcomes (11). Thus we need to proactively monitor changes in access to services that will result from the ACA and changes in federal and state systems.

Given the substantial financing and organizational changes that are under way, it will be important to monitor the participation of peer-run organizations in evolving systems of care to ensure that opportunities to support persons with mental disorders are continued and expanded. Organizations may be forced out of business because of the challenges they may face in complying with requirements for insurance reimbursement and because of shrinking resources from their usual sources of financing. SCNs, policy makers, providers, and other stakeholders should monitor whether this unique population is struggling to remain

sustainable in the face of unintended consequences of these changes in policies and procedures. Organizations that are primarily technical assistance and advocacy centers will be increasingly important to assist local organizations in adapting to a new policy environment.

Lessons learned

The consumer movement is a grass-roots civil rights movement begun in the 1970s by people who had been subjected to poor treatment in state mental institutions. They started their own support network, informally made up of mutual support and advocacy. Peer support has its roots in the consumer movement, which has made peer support a priority (12).

This foundation in grassroots organizing and natural support highlights some of the important strategies used in this project, as well as its difficulties. This study applied state-of-the-art survey techniques to a population that is difficult to monitor. The involvement of consumers and consumer-researchers at all levels of the project strengthened its design and implementation. Relationships in the community of peers and the use of project staff who identify as peers and who work in peer-run programs were key to achieving a high response rate. Peers working in research, government, managed care, advocacy, and program development provided insights needed to design an appropriate instrument, enumerate the population, and implement recruitment techniques. The invitational letter was endorsed by the SAMHSA consumer technical assistance centers and the NCMHR to gain the trust of respondents and signal the importance of the study. Follow-up with nonresponders included multiple e-mail and phone contacts by research assistants with lived experience of the mental health system who could be sensitive to the demands of organization directors and to their questions about the study and who could understand organizational structures. Because the panel that decided on final inclusion criteria consisted entirely of consumers, the validity of the definition for the community is more robust—because it emerged from that community itself.

Some difficulties were encountered obtaining lists of these organizations. Many peer-run organizations do not maintain a traditional organizational structure, because of the grassroots nature of peer support. Our research found that the composition of SCNs and the extent to which they engaged with all of the peer-run organizations in their states varied considerably. We found that many SCNs considered smaller drop-in centers to be separate organizations. They have their own budgets, directors, and in some cases their own advisory boards; however, they are not necessarily independent nonprofit organizations. We made decisions about whether to include these drop-in centers by consulting with the parent organization or SCN that acts as a sponsor to them.

Next steps

Although the number of peer-run organizations is rather small, these organizations provide an important service to communities. The data obtained by this survey will inform efforts to monitor the extent to which evolving federal, state, and local policies affect the services available to persons with mental illnesses. Many researchers collect nationwide data, but

local advocates and providers constitute the “canaries in the mine.” As the ACA is implemented in each state, local advocates and providers will help ensure that the components of our service system that increase capacity, voice, and choice for people with lived experience of mental illness and treatment remain sustainable. These efforts can be assisted by information gleaned from data collected in nationwide and local research projects. Future analyses of the survey data will provide additional information about the organizations’ operations, activities, current financing mechanisms, concerns about changes associated with the ACA (including participation in Medicaid reimbursement and health homes), and connections to other non-peer providers.

Peer-run organizations are an ephemeral yet essential part of the mental health system. They are difficult to track, but their progress, processes, and challenges must be continuously and carefully monitored. Research similar to that reported here should be conducted on a regular basis. It must meaningfully involve consumers in research design and implementation and ensure that changes in policy have positive outcomes.

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Table 1

Survey respondents that met criteria for a peer-run mental health organization, by region

Region	Direct service (N=350)[a]	Not direct service (N=30)	Total (N=380)
Northeast	95	11	106
West	68	7	75
Midwest	94	6	100
South	93	6	99

[a] "When staff interacts with individual members or groups of members to provide peer support"