Executive Summary

The following report is the result of the first national survey of peer-run mental health programs to be published in over a decade—the National Survey of Peer-Run Organizations. This report will briefly describe how directors from the participating 380 peer-run programs answered questions on their understanding of healthcare reform and their willingness to participate in Medicaid funding structures.

Highlights

- Over half of program directors reported they had little to no knowledge, or were unsure of their knowledge about the Affordable Care Act.
- Attitudes toward Medicaid reimbursement were unaffected by level of education about the Affordable Care Act.
- Directors had strong concerns, largely based on values, about accepting Medicaid reimbursement for the supports their organizations offer.
Introduction

Mental health peer-run organizations are managed and staffed by people with lived experience as users or survivors of mental health treatment. The services these organizations provide are increasingly recognized as important components of behavioral health and social support systems. It is essential that we better understand peer-run organizations on a national level, as well as useful methods for collecting data about them. In this way, we may continue to monitor changes associated with policies (e.g., the Affordable Care Act) which are intended to provide better access to care that promotes wellness and recovery.

The history of peer-run organizations dates back over 40 years (1), but public mental health systems have only begun to embrace such peer-delivered services in the last decade (2). Also referred to as Consumer-Operated Service Programs (COSP), the Substance Abuse and Mental Health Services Administration (SAMHSA) has deemed peer-run services an evidence-based practice (3).

Peer-run organizations use support, education, and advocacy to promote wellness, empowerment, and recovery for individuals diagnosed with mental disorders (4). Peer-controlled services are an important component of our nation’s systems of care for people seeking support for mental health challenges (2, 5-8). People with lived experience are in a unique position to promote recovery and wellness by emphasizing empowerment, self-direction, and mutual relationships (9). Furthermore, increasing peer involvement in the research and development of these valuable services ensures incorporation of the perspective of people with lived experience in every aspect of service delivery—an essential step toward improving the lives of those experiencing challenges to their mental health and wellbeing.

In order to measure peer-run programs’ service models and impact, peer-run organizations first need to be identified for participation in technical assistance and research. However, before this study, no comprehensive list of these organizations existed. We have also had no way to categorize these organizations’ characteristics and assess their connections with other mental health and healthcare providers. These data are important to promote fidelity, or continued adherence to evidence-based standards of service delivery. These data are also necessary for federal, state, and local efforts to support peer-run programs as part of our nation’s changing systems of health care.

Utilizing the input of peers at every stage of research, the three overarching goals of the National Survey were to:

1. Describe the present population of peer-run organizations in the United States,
2. Assess these organizations’ willingness to participate in Medicaid funding structures, and
3. Assess these organizations’ willingness to participate in health homes.

This report focuses on the second goal. The third will be discussed in an additional forthcoming report. The first report is available for download here.
Recruitment & Selection

This study focused on peer-run organizations with formal structures such as program directors, governing boards, and established budgets. From August, 2010, to June, 2012, researchers at Johns Hopkins University contacted statewide consumer networks (SCN) and state offices of consumer affairs (OCA) in every state and obtained lists of peer-run organizations. In states without a SCN, local informants provided missing information. Organizations in the National Mental Health Consumers’ Self-Help Clearinghouse Directory of Consumer-Driven Services (CDS) were also included. At times, local organizations identified others in their state to add to the list. This original search yielded 948 organizations or programs.

All organizations identified by SCNs, OCAs, or the national consumer-run organization were asked to participate in the National Survey. Researchers identified 895 potential peer-run organizations (or programs) that could contribute to the study’s aims, and 716 organizations (80%) responded. As data was collected, we gained information on organizations that had gone out of business, new organizations that had developed, and whether the organizations met the criteria of a peer-run organization or program.

An organization’s classification as peer-run was determined through consultation with five consumer/survivor advocates, technical assistance providers, program directors, and researchers. An organization met the final criteria for inclusion in the study if they:

- Had a board of directors or advisory board that was composed of at least 51% peers;
- Had a director who identified as a peer;
- Had a majority of staff members or volunteers who identified as peers; and
- Were either an incorporated, independent non-profit (i.e., a 501(c)3 organization), or were non-incorporated but operated independently from a parent organization.

A distinction was also made between organizations which provided primarily direct support services and those which provided non-direct support services. Direct support activities were face-to-face interactions between staff and members for the purposes of providing peer support or related services. Non-direct support organizations instead focused on advocacy and training-related activities.

Some peer-to-peer programs were excluded from the study. For example, informal mutual support groups (such as 12-step groups) were not included. Nevertheless, formal programs that sponsored or hosted such groups were still counted. Other organizations were considered out of business and excluded if researchers received confirmation of this status from someone knowledgeable about the organization, or if people at the organization could not be reached by phone, postal mail, or e-mail. In all, 380 respondents were included in the analysis. See Table 1 in the Appendix for regional representation of study participants.
Survey Results

As community mental health services may be particularly affected by the changing financial landscape associated with the Affordable Care Act (ACA), researchers included survey questions to assess program directors’ knowledge of the new legislation as well as willingness to become Medicaid providers—that is, accept reimbursement from this program for an assortment of services (such as case management or group support). Researchers suspected that an organization’s willingness to accept Medicaid funding would be associated with increased understanding of the ACA, knowledge of plans for their state’s Medicaid expansion, and discussion of health reform’s impact on peer-run services.

Why may the ACA be important for these organizations?

Because of the complexity of the policy and how drastically it may impact financing of health services, health care providers have to learn new standards and requirements. As discussed in the first report of this study, many peer-run organizations receive state, county, and federal funding. With changes in the availability of those funding sources and the expansion of Medicaid coverage to many people who participate in the supports offered by peer-run organizations, these entities may be forced to reconsider funding options. Although it is unclear at this time to what extent Medicaid reimbursement may become an important consideration for sustainability, managed care companies are interested in enlisting peer supporters and peer-run organizations to provide recovery-oriented supports to insurance plan members (10).

Discussion of Health Care Reform

Researchers investigated whether or not discussion of how health care reform may impact peer delivered supports—either within or external to the organization—would have any association with understanding of the ACA. Over half of the program directors surveyed reported that discussions about healthcare reform occurred within the organization. However, in a relatively large percentage of organizations—29%—it was unclear if members had discussed upcoming changes.

Analyses showed that discussions with others about health care reform were unrelated to an organization’s willingness to be a Medicaid provider. However, these discussions were significantly associated with reported knowledge of the ACA. Respondents who reported that they had discussed health care reform with others were more likely to report that they knew more about the ACA.
Understanding the ACA
Researchers wanted to understand if self-reported knowledge about the ACA made any difference in their willingness to accept Medicaid reimbursement for services.

In terms of self-reported knowledge of the ACA, potential responses were originally categorized as “none,” “a little,” “some,” and “a lot” of knowledge about the new legislation. Respondents could also report that they were unsure about their level of understanding (“don’t know”). Adhering to these original response options, we saw a relatively balanced representation of between the first four categories, ranging from 19-30% of the organizations for each option. A small fraction—less than 1% of directors—reported that they knew everything about the ACA.

It was interesting to see that when combining some categories, over half of the program directors reported that they had little to no knowledge of the ACA, or were unsure of their knowledge. Nearly a third of directors reported that they knew a lot, or everything there was to know about the ACA, and 19% reported “some knowledge.”

Understanding Medicaid Expansion
Administered through a federal/state partnership, Medicaid extends health coverage to adults and children with yearly income less than 133% of the federal poverty line. Every state has some kind of behavioral health provision in their Medicaid plan. In behavioral health settings, Medicaid plans cover a wide variety of supportive services, including counseling, recovery supports, and skills training. More intensive services, such as Assertive Community Treatment or inpatient hospitalizations, are also covered. For each of these services, the degree of coverage may vary by state. Some state Medicaid programs have limited coverage for behavioral health, and some offer a range of options that are or could be provided by peer-run organizations such as supported employment or Wellness Recovery Action Planning (WRAP).

Recent legislation has resulted in planned expansion to many states’ Medicaid programs. According to SAMHSA, if implemented nationwide, Medicaid expansion could reach 2.7 million people who are currently uninsured and in need of mental health services (11).

Of the organizations surveyed, about half (52%) were aware of initiatives to expand Medicaid coverage to more people.
**Attitudes toward Medicaid reimbursement**

While some (22%) were not sure about their willingness to become Medicaid providers, the largest group of program directors (34%) expressed that they had concerns of some kind, but were willing to do so.

Ultimately, researchers found that directors’ self-reported knowledge of the ACA was not related to an organization’s willingness to become a Medicaid provider.

**Concerns**

Many direct support organizations surveyed had several concerns about accepting Medicaid funding. Among those organizations which were unwilling to accept it, had concerns, or did not know if they would be willing, most believed that the following would be big philosophical or value-based problems: Conforming to medical models of service delivery (72%), departure from their recovery-oriented organizational mission (62%), a new need to justify medical necessity (59%), and reduced feasibility of advocacy activities when part of an insurance network (54%). A large practical concern shared by most organizations (60%) was not having enough financial staff to handle billing.
A relatively high number of organizations, 42% in the subset, reported that they did not know how Medicaid would affect assessment of quality performance. The same proportion of organizations believed that record-keeping in accordance with Medicaid standards would be a big problem for them. Organizations had an even mix of responses regarding any problems with the application process. Organizations seemed the least concerned about auditing in terms of their acceptance of Medicaid.

Overall, knowledge of Medicaid expansion was not associated with an organization’s willingness to be a Medicaid provider.

**Synthesis**

Researchers were interested in seeing how knowledge of ACA and Medicaid willingness would blend in participating organizations. Organizations were divided into categories according to their willingness to accept Medicaid reimbursement. Then, within those groups, all possible responses to questions regarding their understanding of the ACA were tallied.

Organizations which reported willingness to accept Medicaid, or that they already accepted it, had
more balanced proportions of responses. Medicaid providers reported at a much higher rate that they knew “a lot” about the ACA.

As might be expected, organizations that were unsure of their willingness to accept Medicaid funding reported at the highest rate (73%) that they knew little to nothing about the ACA. Although many organizations rely on governmental sources of funding, currently many of these streams (such as the block grant) do not have reporting requirements that require knowledge of the ACA or Medicaid. As discussed in our last report, most organizations—particularly those providing direct services—do secure funding from governmental sources (see chart below).

The “state” of expansion

To provide more contextual information in this analysis, researchers also considered whether peer specialists were reimbursable through Medicaid in their state, which could affect how the influence of the ACA is perceived. Researchers “controlled” for state’s influence in statistical modeling; that is, they could see a clearer picture of Medicaid willingness regardless of organizations’ locations.

Researchers obtained information on Medicaid reimbursement of peer-delivered services from data gathered by SAMHSA (12), while plans for Medicaid expansion, as of 2013, were obtained from the Kaiser Family Foundation (13). The map displayed below reveals that most states, shaded in dark blue, currently reimburse for peer-provided services and plan for Medicaid expansion in 2014. Note that Indiana and Pennsylvania plan for Medicaid expansion after 2014 and were counted in this group of states. Shaded in medium blue are states which reimburse for peer-delivered services but do not plan for Medicaid expansion. States which plan for Medicaid expansion but have no provisions for reimbursement of peer-delivered services are shown in light blue. Finally, a minority of states has neither plans for Medicaid expansion nor do they reimburse for peer-delivered services.
While neither the state in which a peer-run organization is located nor the state's policies regarding reimbursement of peer specialists have an effect on willingness of these organizations to bill Medicaid, there is a lot of variability between states in terms of the intersection of peer specialist reimbursement and Medicaid coverage expansion to more of the population. We may see changes in attitudes that are related to these intersecting policies in the future. At the time of this study, these policies did not significantly affect attitudes—but it will be important to track changes in financing policies and the response of peer-run organizations as the ACA is further implemented.

**Conclusion**

Peer-run organizations, while still small in number, provide essential services to communities and continue to grow. However, their existence is in a state of flux, dependent upon the rapidly evolving federal, state, and local policies which impact the services available to people diagnosed with mental illness. Peer-run organizations have several concerns, both practical and philosophical, about receiving Medicaid funds. Of the organizations surveyed, attitudes toward Medicaid reimbursement were unaffected by level of knowledge about the Affordable Care Act. It may be that the changing aspects of Medicaid reimbursement most pertinent to peer-run organizations are more important to their survival than education on the ACA. Emerging Medicaid financing options, such as self-directed care and 1915(i) waivers, could be important to maintaining the sustainability of peer-run organizations while preserving the values and unique supports that these organizations offer their communities and members.

*This report is the second in a multi-part series. Future reports will discuss these organizations’ willingness to be a part of health homes as well as their efforts to enhance physical health and wellness in peers seeking services.*
Appendix

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