MENTAL HEALTH PEER-RUN ORGANIZATIONS NATIONWIDE:
CHARACTERISTICS AND ATTITUDES TOWARD THE AFFORDABLE CARE
ACT

by
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1. ABSTRACT

Background: Mental health peer-run organizations are operated by people who have received mental health services. This dissertation conducted the first nationally representative survey of peer-run organizations in a decade. It explored variations in activities and resources of peer-run organizations, and attitudes towards policy changes associated   with the Affordable Care Act (ACA) of 2010.

Aims: The aims of this study, following data collection, were: 1) Describe organizational characteristics and operations; 2) Examine the willingness of peer-run organizations to participate in Medicaid reimbursement and explore concerns; 3) Examine the willingness of peer-run organizations to participate in health homes and explore concerns.

Methods: The dissertation obtained data by conducting a nationwide web-based survey of peer-run organizations designed and implemented by the author, in collaboration with mentors and stakeholders. Almost 900 organizations/programs were identified through contacting statewide consumer networks and state offices of consumer affairs. Final inclusion criteria were related to management structure. Following exclusions, there were 380 organizations in the analyses. Analyses are primarily descriptive; multinomial logistic regression is used for the second two aims.

Results: The survey achieved a response rate of 80%. The study found that peer-run organizations are providing a range of community-based supports and activities, and that they vary in their resources. Analyses related to willingness to accept Medicaid show that many directors have concerns about how Medicaid reimbursement may affect the

values-orientation of the organization and staffing capacity to bill Medicaid. Analyses on health home participation demonstrate that existing patterns of encouraging members to use physical health services is associated with willingness to collaborate on these newer healthcare delivery designs—but that some peer-run organizations have concerns about working with medical professionals.

Conclusion: This study increases our understanding of the current operations of peer-run organizations nationwide, and provides baseline data for monitoring the impact of policy changes on these organizations. Results related to the ACA can inform system design and reimbursement changes. The study's design, data collection, and interpretation were directly informed by key stakeholders in order to ensure that the results would have immediate value to those invested in improving the lives of people with psychiatric disabilities.

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3. INTRODUCTION

"The history of mental health treatment is replete with examples of well-intentioned interventions, developed and perpetuated on the basis of nothing more than a potentially innovative concept, a desperate patient and provider population, a charismatic proponent, and little, if any, evidence….

In the face of budgetary pressures and outright cutbacks, states and local communities will inevitably seek additional funding for direct service support. Tempting as it is to respond with reprogramming of and reduction or elimination of knowledge enhancement efforts, there can be no more foolish and shortsighted a decision." (Arons, 2005, p. 1621)

The Affordable Care Act (ACA) is a major policy change that will impact service delivery and financing in ways we cannot fully anticipate (Mechanic, 2012). While the mental health system has become more recovery-oriented and person-centered (Goldman, Glied, & Alegria, 2008), there are ongoing internalized messages perceived by mental health service users about disability and impairment (Corrigan, Larson, & Ruesch, 2009; Ostrow & Adams, 2012). There is also a lack of data-driven policy-making and advocacy about many innovations in mental health services (Tanenbaum, 2005). Research that takes into consideration the perspectives of consumers/survivors on their programs, as well as the context of the external policy environment are an important advancement in data-driven policy-making about self-help initiatives (Nelson, Janzen, Ochocka, & Trainor, 2010).

This dissertation provides background, identification of the policy issues and potential impacts, and original data analyses that can be used by federal, state, and local agencies, service providers and advocates to understand how the ACA is viewed by peer-run organizations and to improve and integrate services for persons with mental disorders into the expanded health care system. The study provides baseline data that is necessary

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for monitoring future changes in peer-run organizations and the relationship of these changes to other changes associated with the ACA and the financing and organization of services for persons with mental disorders. The information gained from this study can aid healthcare planners, including the Social Security Administration (SSA), the Centers for Medicare and Medicaid (CMS), the Substance Abuse and Mental Health Services Administration's (SAMHSA), and local administrators, program directors and advocates as they attempt to maximize the gains made through community-based mental health peer-run organizations toward promoting recovery, empowerment, and community participation.

This study is important for explaining how the peer-run model is implemented nationwide, and educating the government, the organizations, and advocates about organizational development, reimbursement strategies, service planning, and potential for growth. It documents the policy environment, existing structures, operations, and funding of peer-run organizations as of 2012, and evaluates the preparedness of this population of organizations to participate with other providers and payers in transforming the system as the Affordable Care Act (ACA) is implemented.

Given ongoing research of the effectiveness of peer support as an intervention, the current study will provide essential data that will tie research outcomes to the characteristics of peer support. The ability to make these connections from clinical research to public health systems has implications for dissemination and successful implementation in real-world settings.

3.A. A NOTE ABOUT LANGUAGE

Throughout this document, the terms "consumer" and "survivor" are used to refer to people with lived experience of emotional and psychological states of distress that lead to being labeled with mental disorders, often called "serious mental illnesses" and treated by the psychiatric and social service systems as such (Deegan, 1988). Both "consumer" and "survivor" reflect terminology used in a social movement often referred to as the "consumer/survivor/ex-patient" movement (Morrison, 2013). In fact, this is not a single movement but movements having differing but overlapping goals of changing the mental health system, and are interdependent, diverse, and continue to change over time (Rissmiller & Rissmiller, 2006). The term "consumer" refers to anyone who currently uses or has used mental health services (Blyler, Fox, & Brown, 2010). This term is sometimes rejected by people with lived experience based on its analogy to the choice consumers have in the economic system (McGruder, 2001). "Survivor" commonly refers to people who have endured very negative experiences with either the service system and/or experiences of extreme distress (Chamberlin, 1990; Morrison, 2013). Whenever possible, in this document, the term "peer" is used to refer to the literal meaning of "peer-to-peer" interactions between people with shared experiences in the mental health system who support others in recovery (Chinman et al., 2014).

"Traditional mental health services" are those provided by non-peers – such as psychologists, psychiatrists, social workers, and front line staff. These services may be provided in individual practice settings, community mental health centers, assertive community treatment (ACT) teams, residential facilities, and emergency rooms. These settings are referred to as "traditional mental health service settings."

3.B. BACKGROUND AND SIGNIFICANCE

Peer support practices for people with psychiatric disabilities include activities in which individuals help themselves and others through supports, services, and advocacy, in order to empower people to participate in their communities and achieve independence (Blyler et al., 2010; Salzer, 1997). Peer-run organizations are consumer-operated services or self-help organizations that are staffed and operated by persons in recovery from mental illness with the mission of using peer support, recovery and illness education, and advocacy to promote wellness, empowerment, and recovery for individuals with psychiatric disabilities (Campbell et al., 2006). Mental health peer-operated organizations have been defined as "programs, businesses, or services controlled and operated by people who have received mental health services" (Goldstrom et al., 2006, p. 95).

Mental disorders are consistently found to be one of the leading causes of disability and burden of disease in developed countries (Kessler et al., 2009). Research has found that peer-operated organizations are providing essential community-based services (Goldstrom et al., 2004, 2006). Both the New Freedom Commission and the Surgeon General concluded that peer-operated mental health programs play an important role in the continuum of care for individuals with psychiatric disabilities (New Freedom Commission, 2003; Office of the Surgeon General, 1999).

Peer-run organizations promote advocacy and social inclusion through mentoring and support of persons with psychiatric disabilities by those who have faced and overcome similar challenges. This leads not only to connections within the community

of persons with psychiatric disabilities, but also promotes participation in the community by supporting people in accessing other community resources, wellness, and recovery.

3.B.i   *Importance of peer-run organizations*

Informal mental health peer support has existed since the 1970s (Chamberlin, 1978). However, only within the last two decades have trained peer support specialists and peer-run organizations become a more formalized part of our public mental health service system (Davidson & Guy, 2012). Peer support provided in traditional mental health service settings should be differentiated—both in terms of the evidence-base and implementation strategies—from that which is provided in independent peer-run organizations and their other operations. There is more evidence for peer support within traditional mental health service settings than within peer-run organizations (Davidson et al., 1999; Davidson & Guy, 2012; Repper & Carter, 2011). Nonetheless, peer-run organizations are important in that they provide an independent venue for support and empowerment separate from traditional mental health service settings (Chamberlin, 1978). As within other social movements, formal organizations provide infrastructural resources to facilitate change (McAdam & Scott, 2005; Smith & Fetner, 2010). Peer-run organizations are an important infrastructural component in the consumer/survivor movement (Chamberlin, 1990; Daniels et al., 2010). In particular, the organizational structure of peer-run organizations contributes to community-building and stigma-reduction (Segal, S. P., Silverman, C., & Temkin, T. L., 2013a).

Peer-run organizations support recovery as their primary mission (New Freedom Commission, 2003; Substance Abuse and Mental Health Services Administration, 2006). Recovery is defined as persons living in the community of their choosing with the

freedom to make choices about how they participate in that community (New Freedom Commission, 2003; SAMHSA, 2004). The goals of independence, empowerment, and equality are essential to recovery (Substance Abuse and Mental Health Services Administration, 2013b). These organizations build social support, which is protective factor of health. This is important because the social isolation facing many persons with mental disorders can increase morbidity and mortality (Institute of Medicine (IOM, 2012). Peer support is a process of mutual helping based on the principles of respect, shared responsibility, and mutual agreement of what the person being supported needs (MacNeil & Mead, 2003). Peer support interventions can include assistance in learning and overcoming the challenges of health/wellness and self-direction for many populations with a variety of health conditions (IOM, 2012).

Peer support has become increasingly recognized and attended to in the mental health system. For example, traditional providers have begun to include recovery values – such as shared decision-making and self-direction – in their care (Ostrow & Adams, 2012). Although a study in 2002 showed that providers rarely refer to mental health mutual support (Chinman, Kloos, O'Connell, & Davidson, 2002), peer-to-peer services can provide an alternative for individuals who prefer to use alternatives or supplements to traditional mental health services (Solomon, 2004). However, much of the evidence is based on peer-to-peer supports as adjuncts to traditional mental health services (Campbell et al., 2006; Solomon & Draine, 2001) rather than as standalone services.

Definition of a "peer supporter" for the purpose of peer support work: The work of advocacy organizations and government agencies to codify more nebulous uses of peer workers and peer support has led to recent developments to formalize what is

intended. The inter-National Association of Peer Specialists (iNAPS) has developed a definition of a "peer supporter." For the purposes of this report, a "peer supporter" is defined as:

> *someone who has experienced the healing process of recovery from psychiatric, traumatic and/or substance use challenges and, as a result, can offer assistance and support to promote another peer's own personal recovery journey […] people who have "lived experience" and have been trained to assist others in initiating and maintaining long-term recovery and enhancing the quality of life for individuals and their families (International Association of Peer Specialists, 2012, pp. 8-9).*

Peers working in peer-run organizations are "peer supporters." Their training was assessed in the survey in order to document current staff capacity, which can inform qualification for certification, and therefore Medicaid reimbursement of peer-run organizations.

Role of peer supporters: Peer support also has been referred to as "mutual support" or "self-help" (Fisher & Spiro, 2010). *Peer support* is inherently *mutual support* that encourages *self-help* and is naturally occurring in any group of people who view each other as peers (Blyler et al., 2010). "Peer" is a role, but it is not solely dependent on identity or lived experience. Within the mental health service system, a psychiatrist, psychologist, social worker, mental health counselor, or front-line staff person may have lived experience of mental health issues, services, or even have experienced significant disability or life disruption (Zerubavel & Wright, 2012). In general, the difference between a peer and a mental health professional is that peers occupy a role defined by the explicit use of their lived experience and recovery in the supports and services they provide, while the conventional roles of mental health

professionals are defined by professional knowledge and training, and personal disclosure is primarily unidirectional (Davidson, Chinman, Sells, & Rowe, 2006).

Newer developments in peer support may have complicated a naturally occurring human phenomenon of social support. Trainings for peers across the country have been developed (Katz & Salzer, 2006), and there are increasing opportunities for payment as a peer worker (Fine, 2012). Peers are working in traditional health and mental health settings, but the plurality work in independent peer-run organizations (Salzer, Schwenk, & Brusilovskiy, 2010). There is growing evidence for peer support contributing to positive outcomes (Chinman et al., 2014; Davidson et al., 2006) which has led to an increase in the peer support provided within the specialized sector of the mental health system. These developments in research and practice have provided opportunities for economic self-sufficiency of people with lived experience of the mental health system, formalized mechanisms for empowerment of this population, and social equality (in both society and with mental health professionals). However, those facilitating peer support efforts experience conflicts between the origins of peer support and its "grassroots" nature and the medical model (Daniels, A. et al., 2013).

Lack of attention to potential "unintended consequences" of the professionalization and financing of peer support could result in a mental health system that is more hierarchical than ever before—splitting "peer supporters" from their "peers" the way that "providers" have historically been split from "patients." Opposing those hierarchies that strip patients of self-direction has been the guiding vision of the consumer/survivor movement and recovery (Anthony, 1993), but much of the work on documenting the effectiveness of peer support and disseminating it has focused on

reinforcing hierarchies that are inconsistent with the original goals of peer support (Chinman et al., 2014; Morrison, 2013). While the intended processes of peer support in traditional mental health service settings may have shifted to reinforcing hierarchies between peer supporters and their clients, there is evidence to show that in independent peer-run organizations, "lateral" participant-democracy organization types are more empowering (Segal et al., 2013a). Therefore, reinforcing hierarchies through training or reimbursement could jeopardize what makes these organizations effective. Many of the issues related to reimbursement and organizational characteristics were addressed in this study through questions related to member input in decision-making, staff training, current financing, and attitudes toward aspects of health care reform including Medicaid reimbursement and participation in health homes.

3.B.ii Significance of the study

Peer-run organizations comprise an important component of our nation's systems of care for persons with psychiatric disabilities (Campbell, 2011; Campbell & Leaver, 2003; Clay, 2005; SAMHSA, 2011). Peer support has become increasingly important in the mental health system. Peer supporters are being integrated into traditional mental health service settings to facilitate mutual support groups, assist with access to other services and self-advocacy, and provide wellness mentoring (Davidson et al., 2006; Fine, 2012). The Medicaid managed care industry is increasingly interested in contracting with peer-run organizations to provide cost-effective models of care (Adler, Bergeson, Brown, & Fox, 2010; Association for Behavioral Health & Wellness, 2013; Daniels, A. et al., 2013; Sabin & Daniels, 2003). Peer-run organizations comprise a landscape of alternative

and supplementary services for individuals with psychiatric disabilities; however, this landscape is relatively neither measured nor quantified.

We are lacking in data to assist both providers and policy-makers in adapting practice and policy to support peer-driven and self-help interventions in a cost-effective and sustainable manner. Research is needed regarding the organizations' internal operations and qualifications such as staff training, their integration with other service providers, and ability to incorporate changes that are consistent with the evolving of the health care system.

The ACA may be the most significant restructuring of mental health services since deinstitutionalization, when the federal government became more involved in mental health service delivery and the system was rapidly transformed (Grob & Goldman, 2006). While the federal government may provide leadership on implementation of innovations, it is critical that local governments and organizations remain informed and be monitored so that adjustments to policies and practices can be made when necessary (Hayden, 1995). There is relatively little information concerning the population of current peer-run organizations and their reactions to how policy change may affect service delivery (Ostrow & Leaf, 2014).

This dissertation provides important and timely information not elsewhere available concerning the nature of this component of our service system and the role these peer-run organizations play in helping individuals achieve sustained recovery and community integration. Those who developed the ACA expect outcomes to be improved; however, many stakeholders are concerned that strengths of the existing mental health

system (such as understanding of the recovery process) may be intentionally or unintentionally weakened or eliminated because of adaptations by providers required by the Act (Mechanic, 2012).

3.B.iii Evidence for peer-run organizations

Peer-run mental health programs are an important component in the continuum of care for individuals with mental disorders (New Freedom Commission, 2003; Office of the Surgeon General, 1999). They have been shown to be effective in supporting recovery outcomes such as community tenure, reduced inpatient use, and gains in empowerment and self-efficacy (Klein, Cnaan, & Whitecraft, 1998; Mental Health Weekly, 2011b; Min, Whitecraft, Rothbard, & Salzer, 2007; Nelson et al., 2007; Rogers et al., 2007).

Many studies of peer-run initiatives are observational and have small or biased samples (Nelson, Ochocka, Janzen, & Trainor, 2006; Whitley, Strickler, & Drake, 2011). They may also have methodological flaws in measurement assumptions about what peer support should do (outcomes) and how (processes), sometimes attributed to lack of involvement of consumers in the research process (Nelson et al., 2010). Much of the research focuses on typical recovery and rehabilitation outcomes such as quality of life, functioning, and service utilization as well as satisfaction with services. These outcomes and processes have been contrasted in the literature to social integration frameworks that emphasize agency, social connectedness, and citizenship (Rowe et al., 2012; Ware, Hopper, Tugenberg, Dickey, & Fisher, 2007). Research that focuses on the unique processes and outcomes of peer support in terms of social integration may explain why some studies show significant changes for people receiving services (Bracke, Christiaens,

& Verhaeghe, 2008; Campbell, 2011; Hardiman & Segal, 2003; Segal et al., 2013a) and those that measure outcomes based on expectations of traditional mental health services do not show improvements (Pitt et al., 2013). It is also worthwhile to consider how a "peer support program" and its intended outcomes and processes are defined when conducting research and evaluation. This section will address some of the outcomes literature, studies on fidelity to the model, and implications of the origins of peer-run organizations and their connectedness with advocacy which can inform validity of research going forward, and has informed much of this study's methods.

Recovery outcomes and service utilization: Peer-run organizations provide a community-based setting for persons with psychiatric histories to be supported in recovery and rehabilitation in an environment that emphasizes shared power, self-direction, and social support networks (Brown & Lucksted, 2010; Nelson et al., 2006; Reinhart, Meissen, Wituk, & Shepherd, 2005). These organizations promote both personal empowerment (Segal & Silverman, 2002) and empowerment mediated by participation in the organization's services and programs (Rogers et al., 2007). Research on peer-to-peer support within groups and organizations has found positive effects of mutuality and social networks on self-efficacy both for those who provide and receive peer support (Bracke et al., 2008).

In addition to the benefits of peer-run organizations to their members, preliminary quantitative and qualitative studies on the impact of peer support roles on the workers have demonstrated the significant impact of employment and training on empowerment, hope and well-being, positive employment outcomes and job satisfaction (Hutchinson et al., 2006; Ratzlaff, McDiarmid, Marty, & Rapp, 2006; Salzer, Katz, Kidwell, Federici, &

Ward-Colasante, 2009). Peer supporters' experiences with recovery, respect from other community members, pursuit of education and training, and increased knowledge of recovery also have been documented (Moran, Russinova, Gidugu, Yim, & Sprague, 2012; Moran, Russinova, & Stepas, 2012), as well as impacts on professional networks and career development (Mowbray & Moxley, 1998; Salzer & Shear, 2002).

Reviews of peer support research have found positive impacts on self-efficacy, personal empowerment, reductions in crisis service utilization, and positive impacts on community integration outcomes such as employment (Davidson & Guy, 2012; Nelson et al., 2006). However, a recent Cochrane review of peer support (provided in traditional mental health service settings) found that outcomes such as quality of life, symptoms, satisfaction, and service utilization were not significantly different for people receiving services from a peer compared to traditional mental health services (Pitt et al., 2013). A limitation of this review and the studies reviewed is that peers were evaluated compared to professionals in providing the same services—not supports that may uniquely capitalize on what it is that makes peer supporters different than providers. The study authors recommended that future studies document the actual roles of peer supporters, as the process of peer support and the specific roles of peer supporters may affect the intended and actual outcomes.

Model fidelity: The Centers for Medicare and Medicaid Services (CMS) has designated peer support an evidence-based practice (Mann, 2010) and is providing guidance on the implementation of peer support by states using Medicaid waivers (Smith, 2007). SAMHSA has identified Consumer-Operated Service Programs (COSP) as an evidence-based practice (Campbell, 2009) and created an EBP toolkit including a fidelity

measure. The Fidelity Assessment/Common Ingredients Tool (FACIT) is a tool to evaluate fidelity to the consumer-operated/peer-run model that includes 46 items on the domains of Structure, Environment, Belief Systems, Peer Support, Education, and Advocacy (Johnsen, Teague, & Campbell, 2006).

While this dissertation research did not incorporate formal fidelity assessment, the survey questionnaire included questions about board composition, member involvement, and other aspects of fidelity to the model such as availability of peer support and advocacy. Some of these questions were adapted from the COSP FACIT to be consistent with the existing research on peer-run organizations.

Advocacy and community integration: Peer-run organizations focus on both supporting and empowering members as well as engaging in advocacy (Nelson et al., 2006). Consumer/survivor movement founders who also initiated and participated in some of the first independent mutual support groups and organizations for this population have written about the necessary relationship between mutual support, advocacy, self-advocacy, and "consciousness-raising" (Chamberlin, 1990). Peer support and peer-run programs are also important in informing systems advocacy to improve individuals' lives (Chamberlin, 1998; Johnsen et al., 2006; Zinman, Harp, & Budd, 1987).

Earlier national research has documented that most peer-run organizations engage in advocacy, provide a venue for mutual support groups, do community outreach, and offer opportunities for social and recreational activities (Goldstrom et al., 2004). These kinds of activities are essential for promoting community participation of individuals with psychiatric disabilities. Peer-run organizations promote advocacy by engaging in

advocacy activities within the organization (Goldstrom et al., 2006) and facilitate empowerment through organizational participation (Rogers et al., 2007). This encourages people with psychiatric disabilities who use or provide peer-delivered services to engage in both systems and individual advocacy.

Service system impact and development: Peer-run organizations contribute to system capacity and development. The Pillars of Peer Support conference attendees concluded that the peer workforce has more opportunities for training and professional development when there are peer-run organizations that involve and support consumers in service development and delivery (Daniels et al., 2010) because training of peers often occurs within the context of peer-run organizations (Katz & Salzer, 2006). The presence of these organizations can also provide additional capacity for mental health support in communities (Powell & Perron, 2010).

Research on the cost or potential cost-savings of peer-run organizations and programs considers both the program cost and the costs to the system of individuals using those services. This can produce very different results, and implications, depending on which perspective is taken. While program costs and cost per member may be lower in peer-run organizations than traditional mental health services, this may not translate into cost-savings for the system overall.

Program costs: The cost analysis for the Consumer Operated Services Program (COSP) multisite shows variability in costs between programs, which the authors explain as due to economies of scale: fixed costs for a peer support program (e.g. rent for a drop-in center) are the main driver, and there is little incremental cost for additional members

or service users once the program exists (Yates et al., 2011). Once a program is operational, more people can participate without increasing costs. Analyses such as these show relatively small program costs to serve large numbers of people in a peer-run organization—in one study the cost per member per day was a little over ten dollars (Brown, Shepherd, Wituk, & Meissen, 2007). A randomized controlled trial (RCT) of a peer-run crisis program showed the cost was $211 per day versus $665 per day for hospitalization (Greenfield, Stoneking, Humphreys, Sundby, & Bond, 2008).

System costs: Other studies take the payer perspective to understand the impact of peer supports on system cost. These cost studies are examining the *overall cost* to the system of individuals using peer support, not the program costs. These studies make different assumptions about the function of peer support and who uses it. The assumption is that people need support in greater access to traditional mental health services. A recent study of a Medicaid-funded peer support program showed that it did not reduce costs for Medicaid beneficiaries, and it increased prescription drug and professional services costs (Landers & Zhou, 2014). Although sub-group analyses for high utilizers was conducted, the authors did not critically assess whether the role of peer specialists in linking people with services and encouraging access to care is the intended purpose of peer support. The peer support program may have increased these costs because it was the role of the peer specialists to encourage service utilization. If peers are supporting people in increased access to care instead of system independence, this would logically drive up costs due to utilization (appropriate or inappropriate). This is a different perspective on peer support than looking at the program costs independent of service utilization.

This dissertation captures data related to program costs, but not the impact on system costs of peer-run organizations. It also documents other system capacity-building such as the training of staff, the services provided by the organizations to members, and activities related to community impact such as advocacy.

3.B.iv Significance in the context of the Affordable Care Act

The ACA has provided our health care system with the opportunity for significant reforms in quality of care, cost-containment, and models of service delivery. Key components of the ACA that may be especially important for peer-run organizations are health homes, integration of behavioral and physical health, and Medicaid expansion (Hyde, 2010). Although the implementation of these components is, as of yet, unclear, it is unquestionable that they will impact peer-run organizations because of these organizations current reliance on government funding, and the efforts of CMS and Medicaid managed care companies to involve them in these components (Adler et al., 2010; Daniels, A. et al., 2013; Daniels, A. S. et al., 2013).

The ACA and actions of many states to improve behavioral health systems will have critical implications for the services available to persons with mental disorders by promoting increased access to healthcare services. However, we need to pay attention to the early signs of unintended consequences of rapid and drastic health care policy changes, as these may impact the availability of supports provided by peer-run organizations if new financing mechanisms require change too rapidly and inflexibly for these organizations to adapt. For example, deinstitutionalization produced many negative outcomes due to poor planning about resource allocation, population need, and appropriate services (Grob & Goldman, 2006; Leff, Hughes, Chow, Noyes, & Ostrow,

2010). Thus we need to proactively monitor changes in access to services that will result from the ACA and changes in federal and state systems.

Medicaid expansion: The ACA intended to expand Medicaid coverage in all states to single, childless adults with incomes at or below 138% (effectively 133% because 5% of income is not to be considered) of the federal poverty level (FPL). The Supreme Court ruling in 2012 essentially made Medicaid expansion a state option, and not all states are expanding Medicaid at this time. Medicaid expansion as part of the ACA is afforded a 100% federal medical assistance percentage (FMAP) of the cost of providing Medicaid coverage for those who are newly qualified, and will decline to 90% after 2020, but the states need to agree to Medicaid expansion (Goldman, 2012). Some states are still resisting despite the financial and human benefit incentives (Kaiser Family Foundation, 2013). The Assistant Secretary for Planning and Evaluation (ASPE) estimated that 5.4 million individuals with a mental health or substance abuse disorder would gain insurance coverage through Medicaid expansion (Donohue, Garfield, & Lave, 2010) if all states implemented it. According to SAMHSA, Medicaid expansion could reach 2.7 million people who are currently uninsured and in need of mental health services (Substance Abuse and Mental Health Services Administration, 2013a). At the same time, restructured SAMHSA Mental Health Block Grants will focus on coordinating behavioral health prevention, treatment, and recovery support services with other health and social services (Department of Health and Human Services, 2011), and may be less available to support peer-run organizations.

Implications of Medicaid expansion for peer-run organizations: The first Medicaid-reimbursable peer support credential was implemented in Georgia in 2001, and

many other states have followed (Grant, Swink, Reinhart, & Wituk, 2010). The Centers for Medicare and Medicaid Services (CMS) supports the use of peer support in the states under state Medicaid plan waivers, and has issued guidance for the development and implementation of these services in recent years. CMS has identified peer support as:

> *an evidence-based mental health practice that States may use to expand opportunities for meaningful community inclusion* […] *CMS recognizes that the experiences of peer support providers can be an important part of effective treatment systems (Mann, 2010)*

Peer specialists are now Medicaid reimbursable in 31 states and the District of Columbia. It is unknown which exact mechanism (Rehabilitation Option and waivers) are being used in each state.

CMS provided guidance on the implementation of peer specialists as a Medicaid reimbursable service as follows: "Supervision must be provided by a competent mental health professional (as defined by the State)" (Smith, 2007).

"As defined by the State" refers to the federalist structure of the Medicaid program as a federal-state partnership. Because Medicaid is a federal-state partnership, states vary in what services are reimbursable in their Medicaid state plan and how they set standards for reimbursement. A "competent mental health professional" has been defined by most states as a non-peer provider, with the exception of Pennsylvania, which allows peer specialists to be supervised by other peer specialists. The nationwide standards for peer specialists which are being developed by iNAPS will likely enable the Pennsylvania model (peers supervised by peers), encourage Medicaid reimbursement in

all states, and increase workforce capacity and worker rights (e.g. unions) for peer specialists. If peers were allowed to supervise peers and can bill Medicaid, it would make it easier for peer-run organizations to receive Medicaid reimbursement without supervision by non-peer professionals. The exclusion of non-peers from positions of authority in peer-run organizations has been noted as an important tenet of their structure (Brown et al., 2007).

Initiatives such as joining a managed care company can provide that company with more diverse services to its clients, and also promote the ideas of recovery and resilience within the network. Already, many of the goals of managed care are those of peer support: increasing wellness and recovery, and reducing hospitalization. However, being "non-medical" is one of the essential features of peer support (Mead, Hilton, & Curtis, 2001). For the most part, peer support does not involve using mechanisms such as diagnoses, and certified peer specialists (CPS) are not trained to focus on or give diagnoses (Katz & Salzer, 2006). Medicaid reimbursement of peer support could mean having to adhere to standards such as using diagnoses.

Because of the shift in federal and state grants/contracts that these organizations have relied upon to Medicaid-reimbursable medical/mental health services, this dissertation research examines how these organizations view the new funding environment, as well as documenting their current funding sources. They were asked to note concerns related to many of the issues raised here—including medical necessity criteria, administrative capacity for billing, and values related to medical-model treatment.

Health homes: A health home is a team of healthcare professionals that provide integrated health care, including behavioral and physical health; it is not necessarily a location or place but emphasizes a "health team" to provide and coordinate care for people with severe health conditions (Substance Abuse and Mental Health Services Administration, 2010). The Medicaid health home option was established by the ACA. Health home services may receive a 90% federal match for two years (Kaiser Family Foundation, 2014). The literature includes discussions of the "health home," or "person-centered medical home," and how these may improve patient-centered care and shift power dynamics in practice predate the passage of the ACA (Berwick, 2009). Various models of health homes for people with mental disorders have been proposed and developed over the past several years (National Council for Community Behavioral Healthcare, 2008), but all emphasize a focus on the person as a locus of care, in theory. The purpose of a health home for Medicaid beneficiaries with psychiatric disabilities is to integrate care for people with complex conditions; they will need to connect and coordinate services and supports, including primary and behavioral healthcare, and community-based services (Kaiser Family Foundation, 2014). Some states have already integrated mental health services administration into agencies that oversee other health care services and Medicaid in an effort to streamline state agencies and facilitate integration (Mental Health Weekly, 2011a).

Implications of health home implementation for peer-run organizations: Peer workers have been proposed as a potentially effective and cost-saving means of helping people navigate health systems and supporting wellness (Center for Integrated Health Solutions, 2012; Druss et al., 2010; Swarbrick, Murphy, Zechner, Spagnolo, & Gill,

2011). Peer-run organizations promote the idea of recovery and expand the capacity of the mental health system—both philosophically and in actual capacity—to deliver a wider array of services to more people (Campbell & Leaver, 2003); these concepts could also be influential in supporting person-centered care delivery systems in physical healthcare settings. Integrating peer supports could mean mainstreaming both the services and the values, which can influence the culture of the whole system (Daniels, A. et al., 2013).

One of the concerns of peer supporters is that if peers partner with traditional providers, there may always be a power imbalance. Another concern is that if peers partner with traditional organizations, they may have to assume or comply with a more medicalized approach. Peers feel that they have different values than most traditional providers, and that these values would be lost in a partnership (Campbell & Leaver, 2003). This dissertation examines the perspectives of peer-run organizations on participating in a health team within a health home. The organization directors were also asked about their concerns working in a health home, including those related to medicalization and power dynamics with other providers.

3.C. CONCLUSION

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, not substantially decreased in number or effectiveness. These changes could affect the sustainability of peer-run organizations, which may be resistant or have difficulty adhering to aspects of Medicaid participation. The aspects of Medicaid

reimbursement they may have difficulty with include billing and financial management, and complying with medical necessity criteria (Adler et al., 2010). These may be difficult for peer-run organizations because of their interest in focusing on strengths and not giving diagnoses (Holter, Mowbray, Bellamy, MacFarlane, & Dukarski, 2004). 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.

This dissertation addressed many of these issues in the current operations of peer-run organizations, including what services they provide and how they are currently funded. The research also addressed attitudes toward newly emerging mechanisms for financing and coordination of care—Medicaid reimbursement and health homes. The survey questions and analyses were built upon the existing literature on how peer-run organizations operate, and potential upcoming challenges for sustainability as a result of the ACA. This research addresses the intersection of peer support within peer-run organizations and changes happening in our healthcare system.

4. STUDY DESIGN AND METHODS

4.A. INNOVATION OF THE METHODS

This study is one of the first to survey a nationally representative sample of peer-run organizations. This study provides quantitative and uniform data to inform decisions about federal and state policies and policy priorities. This study also fills a gap in previous research, which has not explored program operations and resources, such as staff training, program policies, and attitudes of the organizations toward the Affordable Care Act (ACA).

There has not been a national survey of mental health peer-run organizations since the 2002 Survey of Organized Consumer Self-Help Entities conducted by the Substance Abuse and Mental Health Services Administration (SAMHSA). That study was limited in that the survey used a sampling frame based on per-person population estimates, and was not an attempt to capture the whole population of organizations (Goldstrom et al., 2004). Subsequent studies have been focused more locally, and used techniques such as snowball sampling and had relatively small sample sizes (Nelson et al., 2007; Whitley et al., 2011; Wituk, Vu, Brown, & Meissen, 2008).

The current project utilized a web-based survey, completed online by the executive directors of the peer-run organizations. This method is innovative in that it applied state-of-the-art survey techniques to study the population of a set of organizations that are difficult to monitor. They may be difficult to monitor because of peer-run organizations' foundation in the grassroots consumer/survivor advocacy movement and natural supports. Another innovation of this study is that it involved

peers/consumers/survivors in every stage of the project, consistent with guidelines on participatory disabilities research (Seekins & White, 2013). The study methods are described in greater detail below.

4.B.   TARGET POPULATION

The target population for this study is peer-run organizations in the United States in 2012, excluding independent mutual support groups that do not have a formal organizational structure (i.e., director, board, and budget). These organizations included in the study are formal organizations that are a majority controlled and staffed by peers: the majority of people on the board or advisory council, the executive director, and the majority of the staff/volunteers had to identify as people with lived experience of the mental health system ("peers/consumers/survivors/ex-patients") (Johnsen et al., 2006). These organizations are a subset of formal non-profit corporations (or independent subsidiaries of such) that are characterized by active involvement and leadership by people with lived experience of the mental health system and are involved in supporting recovery and empowerment through self-help initiatives and advocacy (Brown et al., 2007). Although informal mutual support groups were excluded, organizations that support or sponsor mutual support groups were included.   Independent mutual support groups were excluded because many of the aims of this research project would not apply, including current funding and organizational operations, as well as formal participation in aspects of the ACA such as Medicaid reimbursement or health homes.

4.C. INSTRUMENT DESIGN

The survey was designed to obtain current information on organizational operations, as well as attitudes towards upcoming changes associated with the ACA that

may affect peer-run organizations in order to be able to make recommendations to

advocates and policy-makers about adaptations to health care reform strategies.[1] It aimed

to acquire descriptors of organizational operations, including funding, staffing, and

services and activities. The subsequent survey sections captured knowledge and attitudes

about the ACA. The survey was designed with the input of experts on peer-run

organizations, including other researchers knowledgeable about consumer-operated

services and organizational studies (See Table 1).

Table 1: Individuals consulted in development of project and survey

Federal Government:	
Paolo Delvecchio	Consumer Affairs Specialist, HHS/SAMHSA/CMHS
Ingrid Goldstrom	Social Science Analyst, HHS/SAMHSA/CMHS
Wanda Finch	Project Officer, HHS/SAMHSA/CMHS
Ruth Katz	Acting Deputy Assistant Secretary, HHS/ASPE/DALTCP
Pam Doty	Senior Analyst, HHS/*ASPE*/DALTCP
Lisa Patton	Program Analyst, HHS/ASPE/DALTCP
Jean Close	Acting Technical Director, HHS/CMS/OA/CMCS
Marguerite Schervish	Health Policy Analyst, HHS/CMS/CMCS
Shawn Terrell	Health Insurance Specialist, HHS/OS/IOS
State and Local Government:	
Ron Manderscheid	Executive Director, National Association of County Behavioral Heallth & Developmental Disability Directors
Robert Glover	National Association of State Mental Health Program Directors
Advocacy Groups:	
Angela Kimball	Director of State Policy, National Alliance on Mental Illness (NAMI)
Ron Honberg	Director of Policy and Legal Affairs, National Alliance on Mental Illness (NAMI)
David Shern	CEO, Mental Health America (MHA)
Raymond Bridge	Writer, Public Education Department, Mental Health America (MHA)
Lauren Spiro	Executive Director, National Coalition for Mental Health Recovery (NCMHR)
Amanda Mays	Disability Advocacy Specialist, National Disability Rights Network (NDRN)
Consumer Technical Assistance Centers and Statewide Consumer Networks:	
Daniel Fisher	Executive Director, National Empowerment Center
Beckie Child	Executive Director, Peerlink
Susan Rogers	Director, National Mental Health Consumers' Self-Help Clearinghouse
Grace Sweet	Coordinator of Peer Support Coalition Initiative, California Consumer Self-Help Center
Kathy Muscari	Executive Director, West Virginia Mental Health Consumer Association
Jacob Bucher	Executive Director, Collaborative Support Programs of NJ Inc.
Elaine Carroll	State Network Coordinator, On Our Own of Maryland, Inc.
Managed Care Organizations:	

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[1] The survey instrument is in Appendix I.

Peter Ashenden	Director of Consumer Affairs, Optum Health Behavioral Solutions
	Research and Academia:
Philip Leaf	Professor, Department of Mental Health, Johns Hopkins Bloomberg School of Public Health
Elizabeth Stuart	Associate Professor, Department of Mental Health, Johns Hopkins Bloomberg School of Public Health
Mark Salzer	Professor and Chair, Department of Rehabilitation Sciences, Temple University
Chyrell Bellamy	Assistant Clinical Professor, Department of Psychiatry, Yale University School of Medicine
H. Stephen Leff	Associate Professor, Department of Psychiatry, Harvard Medical School
Richard Frank	Professor, Department of Health Care Policy, Harvard Medical School
Ramin Mojtabai	Associate Professor, Department of Mental Health, Johns Hopkins Bloomberg School of Public Health
Donald Steinwachs	Professor, Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health
Ann Skinner	Associate Professor, Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health
Saifuddin Ahmed	Associate Professor, Department of Population, Family, and Reproductive Health, Johns Hopkins Bloomberg School of Public Health
Jean Campbell	Associate Professor, Missouri Institute of Mental Health, University of Missouri
Larry Davidson	Professor, Yale University Medical School

The sections of the survey were adapted from the 2002 Survey of Self-Help Organizations conducted by SAMHSA. Many of the same questions and question formats for the sections that addressed funding and activities were modified by adding questions about more recent developments in peer-delivered services since 2002. Sections of the survey that asked about consumer involvement in management and decision-making were adapted from the COSP multi-site evaluation fidelity instrument. They were modified to be acceptable for a web-based survey, rather than a site-visit fidelity instrument. To help develop the interview for this study, key informants were interviewed either by phone or in person in an unstructured manner and were asked to identify the topics and questions most pertinent to ask of this population in the current policy context, and were consulted on design and format of the questions and answers.

An initial version of the instrument was designed by the candidate (Laysha Ostrow) in consultation with mentors at the Johns Hopkins School of Public Health. After that, the draft survey was reviewed by 5 mental health services researchers, who provided

feedback on question format, wording, and ordering. Pretesting was conducted by administering the survey over the web to representatives from five peer-run organizations that varied in organizational structure and geographic location. They were asked to provide feedback in writing in the survey instrument and were debriefed afterwards on their experience in an interview, and asked to clarify any comments they wrote in the survey. The survey was revised based on their feedback, and then pilot-tested with 10 different organizations. After the pilot test, the survey was not revised. The length of time was determined by the pilot testing, and was on average 20-30 minutes.

4.D. POPULATION ENUMERATION

At the start of the study, there was no comprehensive national list of peer-run organizations. Organizations such as the SAMHSA Consumer TA centers and the National Coalition for Mental Health Recovery (NCMHR) maintained partial nationwide lists. We identified 895 organizations/programs through our search. The primary strategy for identifying organizations was via contacting statewide consumer networks and state offices of consumer affairs from August 2010 to June 2012. The NCMHR and officials responsible for the SAMHSA Statewide Consumer Network grant program and the Center for Mental Health Services' Office of Consumer Affairs were consulted before and during the search. Statewide networks were contacted by email and phone to obtain lists of peer-run organizations in each state. In states that did not have a statewide network identified by SAMHSA or NCMHR, key local informants and organizations were contacted to provide missing information. This search method was supplemented with lists from the three National Consumer Technical Assistance Centers (National Empowerment Center, Peerlink, and National Mental Health Consumers' Self-Help

Clearinghouse). In some cases, local organizations identified others in their state to add to our list. Data obtained from the National Alliance on Mental Illness (NAMI) Grading the States 2009 survey demonstrate that the number of organizations in the project database exceeds the number of consumer-operated programs reported by the State Mental Health Authorities. This may indicate that in addition to organizations that are state-sponsored, additional organizations that obtain funding through other sources were captured.

As data collection was conducted, we gained further information that allowed us to make decisions about which organizations/programs to include, information on those that had gone out of business, and new organizations that had developed. Some organizations that were recruited contacted our research team and explained that they were community mental health centers who had a few peer supporters working there, but the peers were not in positions of management or control of the organization, and were excluded from the study. Other recruited respondents on occasion contacted us and said there was a new peer-run organization in their locality. We added these identified by other organizations to our recruitment list. Organizations/programs were determined to be out of business rather than a survey non-responder, if we had confirmation from someone formerly associated with the organization, a neighboring organization, statewide consumer network, or state office that they were no longer in operation. Organizations/programs for which we had a returned letter, a phone number that was disconnected, and a non-working email were also considered out of business.

4.E. DATA COLLECTION

4.E.i *Human subjects procedures*

This research study was determined "Not Human Subjects Research" by the Institutional Review Board at the Johns Hopkins School of Public Health, as defined by DHHS regulations 45 CFR 46.102, and did not require IRB review.

4.E.ii *Recruitment*

Funding for recruitment was provided by the Johns Hopkins Center for Mental Health Initiatives, with the assistance of the candidate's primary advisor, Dr. Philip Leaf. This funding was provided to pay research assistants for follow-up with non-responders, provide an incentive for participation, and conduct public dissemination. Research assistants were identified by the Statewide Consumer Network in Maryland (On Our Own of Maryland, Inc.), hired by the candidate, and trained by describing the study methods and purpose. They were trained in a protocol for follow-up with non-responders that included timing of follow-up contacts and a script.

For the purpose of conducting the survey we divided organizations into six cohorts. The recruitment of each cohort was determined by when we had complete information for all the organizations within a state. As soon as we had complete contact information within a state, letters and emails were sent to those organizations. The cohorts were grouped by state, but the rationale for recruiting a particular state was having complete contact information at that time, with a sufficient number of states or organizations to justify the resources for a mailing. The number of organizations in each cohort is shown in Table 1.

Table 2: Recruitment cohorts: Number of participants recruited and state

Cohort	Number of participants recruited	States
First	168	AR, AZ, CO, CT, DE, GA, HI, ID, IN, KS, MO, MT, NE, NC, NM, SC, SD, VT, WA, WI
Second	309	AL, DC, KY, MD, MI, MS, NH, RI, SD, TN, ME, IA, PA, OH
Third	89	IL, OR, MN, VA, WV
Fourth	101	AK, OK, FL, NJ
Fifth	170	CA, NY, MA, TX
Sixth	58	WY, UT, LA, and Youth-specific
Total	895	50 states and DC

Organizations were recruited by first sending a letter on Johns Hopkins Bloomberg School of Public Health letterhead[2] via the U.S. Postal Service introducing the study, its methods, and purpose. The invitational letter included a $5 cash incentive for each organization. The letter stated that participants should expect an email with a link to the survey, which should be completed by the executive director or designee. The invitational letter was endorsed by the SAMHSA consumer technical assistance centers and the NCMHR. This aimed to gain the trust of respondents, signal the importance of the study, and increase the response rate. Follow-up with non-responders included multiple email reminders and phone reminders by the candidate, Laysha Ostrow, and research assistants.

4.E.iii Data collection and response rate

Web-hosting of the survey was done by Qualtrics, Inc. The survey was entered into Qualtrics online survey software, which includes features for skip patterns, and multiple question formats used in this survey (e.g. multiple or single answer multiple choice, free text entry, and ranking) as well as data validation (e.g. not being able to enter certain characters or forced response). Data collection was conducted from April to

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[2] The invitation letter is in Appendix II

October 2012. The survey could be filled out anywhere with an internet connection, and could pause in the middle of the survey and come back to it later with their answers saved.

Figures 1 and 2 show the response rate – the final response rate was 80%. This is a higher response rate than obtained in many other studies of this size and scope and of similar types of organizations. Response rates for web-based surveys of organizations range from 68%-89%; and response rates for surveys of individuals average about 40% (Dillman, Smyth, & Christian, 2009; Schonlau, Fricker, & Elliott, 2002). We believe it was the multiple methods of contact, particularly repeated phone calls that resulted in the high response rate. There was also substantial interest expressed to the study team by peer-run organizations who wanted to participate in order to help produce a description of their operations and document their work and perspectives. The denominators for these response rates are in Table 2.

Figure 1: Cumulative Response rate
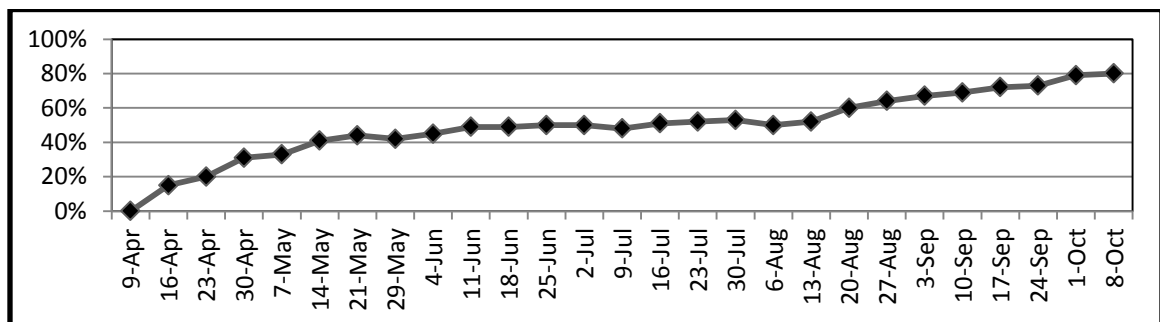
Figure 2: Response rate by cohort
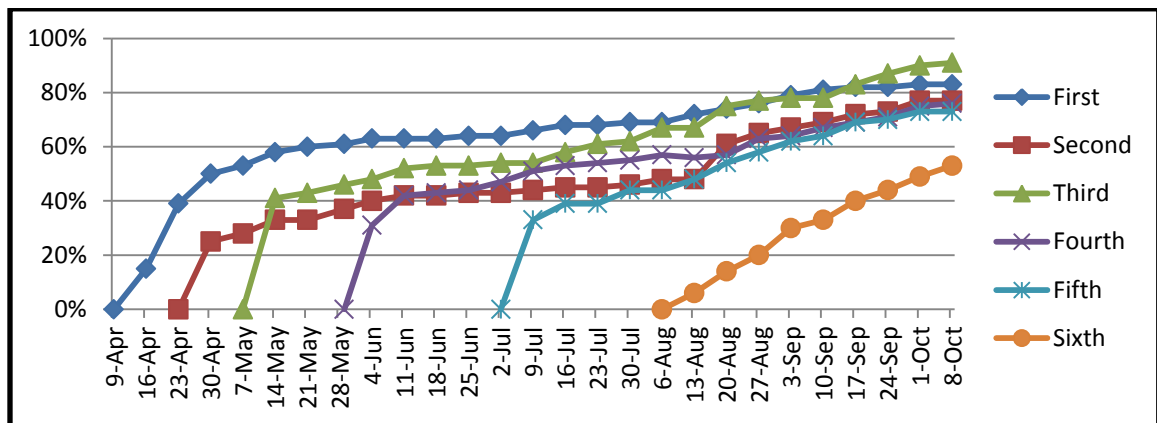
Table 3 shows the response rates – total and by cohort.

Table 3: Response rate: Total and by cohort

Date	Total	First	Second	Third	Fourth	Fifth	Sixth
9-Apr	0	0					
16-Apr	0.15	0.15					
23-Apr	0.2	0.39	0				
30-Apr	0.31	0.5	0.25				
7-May	0.33	0.53	0.28	0			
14-May	0.41	0.58	0.33	0.41			
21-May	0.44	0.6	0.33	0.43			
29-May	0.42	0.61	0.37	0.46	0		
4-Jun	0.45	0.63	0.4	0.48	0.31		
11-Jun	0.49	0.63	0.42	0.52	0.42		
18-Jun	0.49	0.63	0.42	0.53	0.43		
25-Jun	0.5	0.64	0.43	0.53	0.44		
2-Jul	0.5	0.64	0.43	0.54	0.47	0	
9-Jul	0.48	0.66	0.44	0.54	0.51	0.33	
16-Jul	0.51	0.68	0.45	0.58	0.53	0.39	
23-Jul	0.52	0.68	0.45	0.61	0.57	0.39	
30-Jul	0.53	0.68	0.46	0.62	0.57	0.44	
6-Aug	0.5	0.69	0.48	0.67	0.57	0.44	0
13-Aug	0.52	0.72	0.48	0.67	0.56	0.48	0.06
20-Aug	0.6	0.74	0.61	0.75	0.57	0.54	0.14
27-Aug	0.64	0.76	0.65	0.77	0.63	0.58	0.2
3-Sep	0.67	0.79	0.67	0.78	0.64	0.62	0.3
10-Sep	0.69	0.81	0.69	0.78	0.67	0.64	0.33
17-Sep	0.72	0.82	0.72	0.83	0.69	0.69	0.4
24-Sep	0.73	0.82	0.73	0.87	0.71	0.7	0.44
1-Oct	0.79	0.83	0.77	0.9	0.75	0.73	0.49
8-Oct	0.8	0.83	0.77	0.91	0.76	0.73	0.53

4.E.iv Qualification for study participation

Any organization identified by the statewide consumer network, office of consumer affairs, or national consumer-run organization was recruited into the study, although some did not meet the final study inclusion criteria. Final inclusion and exclusion criteria were related to management structure. The consensus panel agreed upon the following criteria for qualification as a peer-run organization or program:

For purposes of this research, a **peer-run organization** is defined as an organization that: 1) Is an incorporated, independent 501(c)(3) non-profit; 2) Has a board of directors that is a majority (at least 51%) peers/consumers/survivors/ex-patients; 3) Has a director who is a peer/consumer/survivor /ex-patient; and 4) Has a majority of staff members who are peers/consumers/survivors/ex-patients.

For purposes of this research, a **peer-operated program** is defined as a program that: 1) Is *not* an incorporated, independent non-profit; 2) Has an advisory board that is a majority (at least 51%) peers/consumers/survivors/ex-patients OR is under the umbrella of a parent organization that is a peer-run organization; 3) Has a director who is a peer/consumer/survivor/ex-patient; 4) Has a majority of staff members who are peers/consumers/survivors/ex-patients.

4.E.v *Data preparation*

Organizations/programs that did not qualify according to the criteria for being peer-run or peer-operated were excluded from the current sample. Because all organizations/programs that a statewide consumer network or other informant put on their list of peer-run organizations were recruited, we had to validate their qualification for study participation using the inclusion criteria described above empirically.

Of the 80% (n=715) of the 895 organizations that responded, 335 were dropped for analysis because they were primarily a substance use recovery-focused organization (n=31), did not fulfill any of the criteria for staff, director, or governing body (n=87), or did not meet any one or more of those criteria (n=217). Figure 3 shows the flow of

participants into recruitment, participation rates, and those who were dropped because they did not qualify.

Figure 3: Organizations recruited, responded, and excluded

```
┌─────────────────────┐
│ Organizations on lists │
│   (n = 948 )        │────────┐
└─────────────────────┘        │    ┌──────────────────────────────┐
          │                    └───▶│ Confirmed out of business or  │
          ▼                         │ not peer-run                  │
┌─────────────────────┐             │   (n = 53)                    │
│    Recruited        │             └──────────────────────────────┘
│    (n = 895)        │
└─────────────────────┘
          │
          ▼
┌─────────────────────┐
│    Responded        │────────┐
│    (n = 715)        │        │    ┌──────────────────────────────┐
└─────────────────────┘        └───▶│ Excluded as a SU org          │
          │                         │   (n= 31)                     │
          ▼                         └──────────────────────────────┘
┌─────────────────────┐
│ Mental health orgs  │────────┐
│    (n = 684)        │        │    ┌──────────────────────────────┐
└─────────────────────┘        └───▶│ Excluded – not meeting any    │
          │                         │ criteria for staff, director, │
          ▼                         │ or governance  (n= 87)        │
┌─────────────────────┐             └──────────────────────────────┘
│ Some peer component │
│    (n= 597)         │────┐   ┌──────────────────────────────┐
└─────────────────────┘    ├──▶│ Excluded based on governance  │
          │                │   │   (n= 64)                     │
          │                │   └──────────────────────────────┘
          │                │   ┌──────────────────────────────┐
          │                ├──▶│ Excluded based on staff       │
          │                │   │   (n= 37)                     │
          │                │   └──────────────────────────────┘
          │                │   ┌──────────────────────────────┐
          │                ├──▶│ Excluded based on director    │
          │                │   │   (n= 90)                     │
          │                │   └──────────────────────────────┘
          ▼                │
┌─────────────────────┐    │   ┌──────────────────────────────┐
│ Meet all criteria   │    └──▶│ Excluded based on director &  │
│    (n= 380)         │        │ staff   (n= 26)               │
└─────────────────────┘        └──────────────────────────────┘
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Responses that met inclusion criteria are presented by region in Table 4 (as determined by the CDC) and by state in Table 5.

Table 4: Responses by region after cleaning for peer-run or peer-operated

Region	Number of respondents
West	75
Midwest	100
South	99
Northeast	106
Total	380

Table 5: Responses by state after cleaning for peer-run or peer-operated

State	Number of respondents	State	Number of respondents	State	Number of respondents
AK	8	KY	3	NV	1
AL	3	LA	1	NY	21
AR	2	MA	20	OH	20
AZ	5	MD	22	OR	14
CA	32	ME	11	PA	15
CO	4	MI	31	SC	1
CT	2	MN	5	SD	1
DC	3	MO	7	TN	10
DE	3	MT	1	TX	6
FL	6	NC	7	UT	1
GA	5	MT	1	VA	20
HI	1	NC	7	VT	4
IA	2	ND	1	WA	5
ID	1	NE	1	WI	9
IL	8	NH	9	WV	3
IN	1	NJ	24	WY	1
KS	14	NM	1	Total	380

4.F.   INVOLVEMENT OF PEOPLE WITH LIVED EXPERIENCE

The involvement of consumer/survivors in the project design and implementation highlight some of the important strategies that contributed to this study's success.

<u>Project team members:</u> The involvement of consumers and consumer-researchers at all levels of the project strengthened its design and implementation. The project director (the candidate) identified as a person with lived experience of the mental health system. All of the four research assistants who assisted with recruitment for data collection were also people who identified as consumer/survivors and had worked in peer-run programs and/or mental health activism. Although many other

consumer/survivors provided valuable input to the project, such as suggesting questions and topics for the survey instrument or participating in deciding exclusion criteria, they were not considered core team members.

Relationships in the community of peers and the use of project staff that identify as peers and work in peer-run programs were key to achieving a high response rate. Existing relationships of the project team members assisted in helping identify organizations in enumeration as well as encouraging responses to the survey. Follow-up with non-responders included multiple e-mail and phone contacts by research assistants who could be sensitive to the demands of organization directors and to their questions about the study and who could understand non-traditional organizational structures.

Input on design and analysis: Stakeholder interviews and consensus panel: 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 majority of individuals that gave input into the instrument design—regardless of affiliation or job description—were people with lived experience of the mental health system, in addition to their professional qualifications. The final inclusion criteria were decided upon by a consensus panel of five consumer/survivor advocates, technical assistance providers, program directors, and researchers. This improves the validity and real-world applicability of the definition for the community, because it emerged from that community itself.

5. AIM 1: NON-PROFIT DEVELOPMENT AND LEADERSHIP BY PEOPLE WITH LIVED EXPERIENCE: CHARACTERISTICS OF MENTAL HEALTH PEER-RUN ORGANIZATIONS NATIONWIDE

5.A. ABSTRACT

Objective: Mental health peer-run organizations[3] provide venues for mutual support among people diagnosed with mental disorders and also opportunities for community-building and systems change. This study reports on the characteristics of peer-run organizations in the U.S. and describes organizational features related to implementation and sustainability in the non-profit literature.

Methods: Data were obtained from the first national survey of peer-run mental health programs in a decade—the National Survey of Peer-Run Organizations. The study utilized a web-based survey, completed by the directors of organizations from April – October 2012. Final inclusion criteria were related to management structure with organizations not meeting the criteria eliminated from the data set. After the deletion of these organizations, the study included 380 peer-run organizations. We conducted descriptive analysis focusing on organizational operations and the percentage of consumer influence over the organization, as measured by board composition.

Results: Analyses indicated that peer-run organizations are providing a wide range of supports, educational and advocacy activities. These organizations vary widely in their capacity for providing support and engaging in activities, and human and financial resources. Some of this variation is related to the degree of consumer control.

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[3] Will be referred to as peer-run organizations for the remainder of this report

Most organizations seem to have implemented operations consistent with standards for peer-run organizations (Johnsen et al., 2006)

Conclusions: Peer-run organizations currently provide a variety of services and activities. They are diverse, which is in part associated with the degree of consumer control. The reach of peer-run services continues to grow nationwide, as does their need for more in-depth research. Future research should explore management and organizational dynamics that influence operations, implementation, and sustainability, in addition to continued research on outcomes.

5.B. INTRODUCTION

Peer-run organizations are organizations operated by a majority of people who have received mental health services, who are in positions of control in the organization. In this study, this refers to having a majority of peers on the board or advisory group, a director who identifies as a peer/consumer/survivor, and a majority of staff and volunteers who also identify as such (Ostrow & Leaf, 2014). Previous studies have also defined them as having a mission of using mutual support, education, and advocacy to promote wellness, empowerment, and recovery for people diagnosed with mental disorders (Goldstrom et al., 2006; New Freedom Commission, 2003; Substance Abuse and Mental Health Services Administration, 2006). Peer support occurs either within peer-run organizations or with peer specialists in other settings (Daniels, A. et al., 2013; IOM, 2012; Salzer et al., 2010; Substance Abuse and Mental Health Services Administration, 2011). There is lengthy and varied history of research on the effectiveness of mental health peer support with much of this research on peer support in traditional mental health service settings (Chinman et al., 2014). There is a smaller yet

growing literature on that which occurs in independent peer-run organizations (Campbell, 2009, 2011; Corrigan, 2006; Nelson et al., 2006; Nelson et al., 2007; Rogers et al., 2007). These organizations build social support, which is a protective factor for health; this is important because the social isolation facing many persons with serious mental illness can increase morbidity and mortality (IOM, 2012). The organizational structure itself contributes to community-building and stigma-reduction (Segal et al., 2013a).

Peer-run organizations have existed for many decades. These organizations emphasize involvement of people with lived experience of the mental health system to facilitate independence of the organizations and members (Chamberlin, 1978; Goldstrom et al., 2004; Ostrow & Leaf, 2014). While these are a particular type of non-profit, they are similar to many other non-profits in that they serve a role in society of empowering people, increasing community participation and social cohesion, and strengthening institutional development (De Vita, Fleming, & Twombly, 2001). Formal organizations provide infrastructural resources to facilitate social change (McAdam & Scott, 2005; Smith & Fetner, 2010). Peer-run organizations are an important infrastructural component in the consumer/survivor movement in terms of linking mutual support with systemic advocacy and promoting self-advocacy (Chamberlin, 1990; Daniels et al., 2010).

There has been both empirical research on peer-run organizations and how the model of organizations that are controlled and operated by people with lived experience affects outcomes, and consensus research on the key characteristics of the peer-run organization model (Campbell et al., 2006; Holter et al., 2004). Much of this research describes the characteristics of peer-run organizations such as control by persons with

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lived experience, member involvement, and voluntary supports—yet we do not know much about the organizations nationally because earlier studies did not sample from all organizations in the U.S.

The results reported here were analyzed according to representation of peers on the board of directors, and along domains consistent with other research on non-profits. Non-profit organizations have been defined in organizational studies in terms of five components: vision and mission, leadership, resources, outreach, and products and services (De Vita et al., 2001). The vision and mission of an organization are related to its purpose or goals. Leadership for nonprofit organizations includes professional staff, board members, and volunteers. Outreach includes marketing and public relations, community outreach, collaborations, and alliances. Financial resources include fundraising and sources of funding. Products and services are immediate program products resulting from the internal operations of the program, such as the delivery of planned services (De Vita et al., 2001).

This research reports on characteristics of peer-run organizations nationwide along these five components of non-profit organizations that can be considered when thinking about capacity-building for these organizations. This paper uses data obtained from the *2012 National Survey of Peer-Run Organizations*. The discussion includes the significance of these data for implementation, variation, and sustainability of peer-run organizations.

5.C. METHODS

The target population for the study is peer-run organizations, excluding independent mutual support groups. Exclusion of those without a formal organizational structure has been a criterion in other peer-run organization research (Brown et al., 2007). This project utilized a web-based survey, completed online by the directors of the organizations from April-October 2012, achieving an 80% response rate. An earlier paper presented in more detail the rationale for the study and the methods used (Ostrow & Leaf, 2014). It was developed and had two rounds of pre- and pilot-testing with the input of mental health services researchers, program directors, advocates, and government representatives. Final inclusion criteria were related to management structure operationalized by a consensus panel. Following cleaning according to these criteria, there were 380 organizations in the analyses. The survey contained 83 questions about governance, staffing, activities, and perspectives. Not all respondents had to answer all questions because of skip patterns based on earlier responses. The research project was deemed not human subjects research by the Johns Hopkins Bloomberg School of Public Health IRB.

The data analysis stratified the sample of peer-run organizations (n=380) into peer-controlled (n=190) and peer-directed organizations (n=190). Peer-controlled organizations are those whose board of directors is at least 91% people with lived experience. Peer-directed organizations are those whose board is 51%-90% people with lived experience. Data are stratified on this criterion in order to facilitate understanding of peer-run organizations within a common framework of non-profit organizations that promote social justice, with particular attention to what makes these organizations

unique. The data are reported along the domains of vision and mission, leadership, outreach, resources, and products and services in Tables 6-10. Analyses are descriptive and conducted with Stata 13 (StataCorp, 2013). Frequencies and means were compared between the two types of organizations—peer-controlled and peer-directed—using t-tests and chi-square statistics. Where cell sizes were smaller than five observations, Fisher's exact test was used with a χ^2 statistic.

5.D. RESULTS

5.D.i Vision and Mission

Directors provided information on members' input into organizational decision-making, and how they view their organizations and peer-delivered services as fitting in the mental health system in relation to traditional mental health services. They were also asked to comment on their experience obtaining funding. These characteristics and attitudes have been described as important to the vision and mission of the peer-run model in other research (Brown et al., 2007; Nelson et al., 2006)

Table 6: Vision and Mission

Variable	Total (N=380)		Peer-controlled (N=190)		Peer-directed N=(190)		χ^2	p
	N	%	N	%[a]	N	%[a]		
Majority of members involved in decision-making	261	69.1	146	77.3	115	60.9	11.9	<0.001
View of organization in system								
Addition	117	31.2	54	28.9	63	33.5	0.9	0.37
Alternative	22	5.9	17	19.1	5	2.7	7.0	<0.01
Some supports alternatives/Some additions	226	60.3	110	58.8	116	61.7	0.3	0.60
No opinion	10	2.7	8	2.3	2	6.7	0.4	0.52
How peer-operated services should be used								
Only use peer-operated	3	0.8	3	1.6	0	0.00	3.0	0.12
Mostly use peer-operated	83	22.3	47	25.3	36	19.3	1.9	0.16
Use peer-operated and traditional services equally	251	67.3	111	59.7	140	74.9	9.8	<0.01
Mostly use traditional services	6	1.6	4	2.2	2	1.1	0.7	0.45
Only use traditional services	0	0.0	0	0.0	0	0.0		
No opinion	30	8.0	21	11.3	9	4.8	5.3	<0.05
Report that funding sources ask to compromise values	70	18.5	41	21.7	29	15.3	2.6	0.1

[a] *Percents represent column percentage for each strata (peer-controlled and peer-directed)*

Program directors shared information about the role members have in decision-making processes. Overall, most organizations in the total sample (n=261; 69%) reported that decisions were based on the input of a majority of members. There was a significant difference between peer-controlled and peer-directed (χ^2=11.9, p<0.001) organizations, with peer-controlled reporting more consistent peer involvement than peer-directed (77% vs. 60%) organizations.

Directors were asked how they saw their organizations' activities and services fitting into the mental health system compared to services received from traditional mental health services and providers. Most directors in the total sample (n=226; 60%) saw some of their organizational activities as alternatives to traditional mental health services and other activities as complementary. Overall, over 30% (n=117) of directors in the total sample believed that their organizations' activities were best utilized as an

addition to traditional mental health services, but 19% (n=17) of peer-controlled organizations viewed their activities as purely alternatives compared to 3% (n=5) of peer-directed (χ^2=7.02, p<0.01).

Directors were also asked how they thought peer-delivered services should be prioritized by people seeking mental healthcare. The majority of the overall sample (n=251; 67%) believed that peer-delivered services should be utilized in equal measure with traditional mental health services, with 75% (n=140) of peer-directed organizations identifying with this more moderate view more frequently than peer-controlled (n=111; 60%; χ^2=9.77, p<0.01). No director reported that only traditional mental health services should be used.

5.D.ii Leadership

The results related to leadership include the status of the organization as a non-profit corporation or not (as this affects the independent decision-making of the director, board, and staff separate from a fiscal intermediary), the organization's age, characteristics of the director's lived and professional experience, and the number of staff and volunteers and their training. These attributes related to competence and ability of the leadership and staff can contribute to organizational capacity to be sustained and grow effectively (Kaplan, 2003).

Table 7: Leadership

Variable	Total (N=380)		Peer-controlled (N=190)[a]		Peer-directed (N=190)[a]			
	N	%	N	%	N	%	χ^2	p
Incorporated non-profit	313	82.4	147	77.4	166	87.4	6.5	<0.05
Leadership training offered	230	62.2	119	63.9	111	60.3	0.5	0.47
Director self-identification as a family member…								
Of an adult consumer	83	22.1	40	21.2	43	22.9	0.2	0.70
Of a child/youth	51	13.6	24	12.7	27	14.4	0.2	0.62
Director tenure at current organization								
Less than one year	37	9.9	19	10.1	18	9.7	0.0	0.89
One to five years	168	44.9	85	45.2	83	44.6	0.0	0.91
More than five years, but less than ten	70	18.7	34	18.1	36	19.4	0.1	0.75
Ten or more years	94	25.1	47	25.0	47	25.3	0.0	0.95
Director duration of being a peer support provider								
Less than one year	12	3.2	8	4.3	4	2.1	1.4	0.23
One to five years	109	29.3	49	26.5	60	32.1	1.4	0.23
More than five years, but less than ten	67	18.0	35	18.9	32	17.1	0.2	0.65
Ten or more years	176	47.3	87	47.0	89	47.6	0.0	0.91
	Mean	SD	Mean	SD	Mean	SD	t	p
Years in operation	15.09	11.5	13.52	9.3	16.72	13.2	2.7	<0.01
Mean number of paid staff	12.04	38.9	6.50	9.9	17.52	53.6	2.8	<0.001
Median number of paid staff	4		3		7		4.9	<0.001
Mean number of volunteers	15.35	51.9	18.22	70.0	12.49	22.6	-1.1	0.28
Median number of volunteers	5		6		5		-1.1	0.28
Difference in mean number of staff vs. volunteers	3.37	64.6	11.86	70.2	-4.99	57.6	2.3	<0.05
Trained staff and volunteers								
Peer group facilitator	5.02	8.2	4.25	7.1	5.78	9.2	1.8	0.07
Certified Peer Specialist	4.53	15.0	4.28	18.9	4.79	9.7	0.3	0.74
WRAP facilitator	2.66	5.3	1.86	3.0	3.47	6.8	2.9	<0.01
Recovery mentor	2.44	5.4	2.05	4.8	2.83	5.9	1.4	0.15
Warmline support	1.85	5.7	1.94	7.0	1.756	3.9	-0.3	0.76
Intentional Peer Support (IPS)	1.85	6.1	2.08	7.4	1.62	4.3	-0.8	0.45
Peer wellness coach	1.42	3.7	1.03	2.3	1.80	4.7	2.0	<0.05
Peer case manager	0.74	2.9	0.41	1.5	1.08	3.8	2.2	<0.05
Peer bridger	0.46	2.2	.35	1.1	.57	2.9	0.9	0.34

[a] *Percents represent column percentage for each strata (peer-controlled and peer-directed)*

Respondents reported the number of years the organization had been in operation.

The overall mean years in operation in the total sample was 15.1 (SD=11.45). Peer-

controlled organizations were significantly younger (13.5 years) than peer-directed

(16.7), an average difference of about three years (t=2.68, p<0.01). A high percentage of

all the organizations were incorporated non-profits (n=313; 82%), but incorporation status was more frequently associated with peer-directed organizations (n=166; 87%), with fewer peer-controlled being independently incorporated (n=147; 77%; χ^2=6.54, p<0.05).

Program directors were asked about their own professional experience. There was a bimodal distribution in the length of tenure of program directors in the overall sample, with 25% of directors in service for over ten years and 45% of directors in service for 1-5 years. The length of tenure as director was not significantly different between peer-controlled and peer-directed organizations. Directors also provided information about their history as peer support providers. A large proportion of program directors (n=176; 47%) have been peer support service providers for over ten years. This was not significantly different between peer-controlled and peer-directed organizations. Directors in the overall sample identified themselves as a family member of a child diagnosed with a mental illness 13.6% of the time, and as family members of a diagnosed adult 22% of the time—in addition to having their own personal lived experience. This did not differ between peer-controlled and peer-directed organizations.

In the total sample, the mean number of paid staff was 12 (SD=38.9) and the median was 4 paid staff. Peer-directed had a higher mean (17.5, SD=53.5 vs. 6.6, SD=9.9; t=2.78, p<0.01) and a higher median (7 vs. 3) number of paid staff than peer-controlled organizations. Overall, in the total sample, these organizations had a mean of 15.4 volunteers. The average number of volunteers did not significantly differ between the two types of organizations, with peer-directed having a mean of 12.5 volunteers and peer-controlled having a mean of 18.2. However, when looking at the difference within

each group, peer-controlled organizations had significantly more volunteers than paid staff (t=2.31, p<0.05). Therefore, there was a difference between these organization types in number of paid staff but not volunteers, but peer-controlled relied more on volunteers than their peer-directed counterparts.

Directors reported on the training of their organization's staff and volunteers in nine categories of peer support trainings. Peer group facilitators were the largest group of trained staff in the total sample, with a mean of 5 staff or volunteers within each organization trained in peer group facilitation. In several categories of training, peer-directed exceeded peer-controlled in the mean number of staff and volunteers. Peer-directed organizations had significantly more staff and volunteers trained in Wellness Recovery Action Planning (WRAP) (3.5, SD=6.8) than peer-controlled (1.9, SD=3.0). Peer-directed had more staff and volunteers trained in peer wellness coaching (1.8, SD=4.7) than peer-controlled (1.0, SD=2.3). Peer-directed also had more staff and volunteers trained in case management (1.1, SD=3.8) than peer-controlled (0.4, SD=1.5). In no training categories did peer-controlled organizations have a higher mean than peer-directed.

5.D.iii Outreach

The analyses for the outreach domain consisted of questions related to networking with other organizations, outreach to the public, number of members served, and the age categories of members served. Constituency and stakeholder relations—including relationships with similar organizations and with people served—are considered important in defining non-profit organizations (Balser & McClusky, 2005).

Table 8: Outreach

Variable	Total (N=380)		Peer-controlled (N=190)[a]		Peer-directed N=(190)[a]			
	N	%	N	%	N	%	χ^2	p
Affiliated with a statewide or national organization	223	58.8	110	57.9	113	59.8	0.1	0.71
Sufficiently connected to other peer supports	259	69.4	119	63.9	140	74.9	5.2	<0.05
Public outreach								
Website	265	69.7	121	63.7	144	75.8	6.6	<0.01
List-serve	74	19.5	41	21.6	33	17.4	1.1	0.30
Community outreach	349	93.1	170	90.4	179	95.7	4.1	<0.05
Mean unduplicated members (in last year)	1006	2968	1078	3484	934	2349	-0.5	0.63
Median unduplicated members (in last year)	300		250		400		2.4	<0.05
Populations served								
Adults	372	98.2	187	98.4	185	97.9	0.2	0.70
Older adults	249	65.7	124	65.3	125	66.1	0.0	0.86
Youth	247	65.2	125	65.8	122	64.6	0.1	0.80
Families of adult consumers	128	33.9	56	29.6	72	38.3	3.2	0.07
Families of children/youth	78	20.6	36	19.1	42	22.2	0.6	0.45
Children	43	11.4	16	8.5	27	14.4	3.2	1.07

[a] *Percents represent column percentage for each strata (peer-controlled and peer-directed)*

Directors were asked whether or not they believed their organization was sufficiently connected to other peer-provided services. In the total sample, 69% of respondents (n=259) reported that they did have a sufficient connection. Peer-directed organizations reported these connections more often (n=140; 75%) than peer-controlled (n=119; 64%; χ^2=5.21, p<0.05).

Directors reported communications-oriented activities. Operating a website was endorsed by close to 70% (n=265) of all of the organizations, but peer-directed reported operating a website (n=144; 76%) more than peer-controlled (n=121; 64%; χ^2=6.60, p<0.01). Overall, the majority of organizations (n=349; 93%) reported conducting community outreach, but peer-directed organizations reported these activities (n=179; 96%) more than peer-controlled organizations (n=170; 90%; χ^2=4.08, p<0.05). There

seems to be a small but statistically significant difference in the communications and outreach activities of peer-directed compared to peer-controlled organizations.

Organizations reported how many unduplicated members served in the previous fiscal year. It is important to note that the mean is inflated by several large-scale organizations with a relatively high numbers of members served and some much smaller ones. On average, organizations served 1,011 people, with a median of 276 members served. The smallest 25% overall had 100 members, and largest 25% had at least 771 members, with a range of zero to 33,125 members. The peer-directed organizations more frequently served a number of members in the top 25% (n=55; 29%) compared to peer-controlled, of which 21% (n=40) were in the top 25% of number of members served. Peer-directed organizations also had a higher median number (350) of people served than peer-controlled (225; z=2.37, p<0.05).

Nearly all (n= 372; 98%) of the total responding organizations served adults. Children up to age 17 (n=43; 11%) and their families (n=78; 21%) were the least common age-related demographic groups served overall. There were no significant differences in populations served between peer-controlled and peer-directed. Categories of age groups of members served were not mutually exclusive, so organizations could report on all the age groups they served.

5.D.iv Financial Resources

Even though many peer-run organizations have substantial volunteer commitments, the amount of funds available to an organization is important because it affects the ability to acquire other resources such as human resources (paid staff,

volunteers, and board members), physical resources (such as building space and equipment), as well as opportunities for outreach and services (De Vita et al., 2001), which can in turn increase financial resources. For non-profits in general, differences in the role and availability of government versus private funding sources from the perspectives of non-profit executives have been noted. Government resources are often seen as more stable and generous, but private funding can private a supplement to those (Alexander, 2000; Gazley & Brudney, 2007).

Table 9: Financial Resources

Variable	Total	(N=380)	Peer-controlled	(N=190)[a]	Peer-directed	N=(190)[a]		
	Mean	SD	Mean	SD	Mean	SD	t	p
Budget (mean)	$605,563	$2,150,052	$312,382	$641,348	$893,141	$2,935,077	2.4	<0.05
Budget (median)	$133,000		$85,369		$186,000		3.4	<0.001
	N	%	N	%	N	%	χ^2	p
Majority of funding from government sources	291	76.9	137	72.5	154	81.5	4.3	<0.05
Governmental funding sources								
State government	226	59.9	106	56.1	120	63.8	2.3	0.13
County/local government	159	42.01	74	39.2	85	44.9	1.3	0.25
Federal government	129	34.3	57	30.2	72	38.5	2.9	0.08
Medicaid/Medicare	29	7.7	12	6.4	17	9.1	0.9	0.32
No government funding	45	11.9	30	15.8	15	7.9	5.5	<0.05
Non-governmental funding sources								
Donations	256	68.1	130	69.2	126	67.0	0.2	0.66
Fundraising	215	57.0	106	56.1	109	57.9	0.1	0.71
Private grants	131	34.78	64	34.0	67	35.5	0.1	0.77
Affiliate	69	18.4	38	20.2	31	16.6	0.8	0.36
Payment for services/products	69	18.4	34	18.1	35	18.6	0.0	0.89
Member dues	54	14.4	27	14.4	27	14.4	0.0	0.98
No private funding	41	10.9	20	10.6	21	11.2	0.0	0.85

[a] *Percents represent column percentage for each strata (peer-controlled and peer-directed)*

Most organizations provided information about their budget and funding sources, although the response rate was lower for budget information than for other questions, with 18% of observations missing data on budget. There was no significant difference in the rate of missingness on budget questions between peer-controlled [19% missing] and peer-directed [17% missing]. The average operating budget for organizations was $608,563, but the median was $133,000. The smallest 25% had median budgets of $50,000 or less and largest 25% had median budgets of $405,000 or more. The ten largest had a median budget of $5,421,798 and a mean budget of $8,918,360. Peer-directed organizations more frequently had budgets in the top 25% percent (n=47; 30%) than peer-controlled (n=30; 19%; χ^2=9.9, p<0.05). Peer-directed organizations had a significantly higher mean budget ($893,141; SD=$2,935,077) than peer-controlled ($312,382; SD=$641,348; t=2.40, p<0.05). They also had a higher median budget ($186,000) than peer-controlled ($85,369; z=3.45, p<0.001) organizations.

Most organizations (n=291; 77%) received the majority of their funding from federal, state, or local governmental sources. Peer-directed organizations were more likely to receive the more of their funding from governments (n=154; 82%) than peer-controlled organizations (n=137; 73%; χ^2=4.32, p<0.05). More than half of the organizations that receive some funding overall (n=226; 60%) received some state government funding, 42% (n=159) received some county funding, and 34% (n=129) received some federal funding. About 16% (n=30) of peer-controlled organizations reported that they received no government funding, a significantly lower percentage than peer-directed (n=15; 8%; χ^2=5.50, p<0.05). Next to governmental sources, the most widely reported funding sources were donations (n=256; 68%) and fundraising (n=215;

57%). There were no differences between peer-controlled and peer-directed in private funding sources.

5.D.v   Products and Services

Non-profits often combine direct service programs and social advocacy (Grant & Crutchfield, 2007). This is also true of peer-run organizations, who support members through direct services and promote systems advocacy (Fisher & Spiro, 2010). We examined how many of the peer-run organizations primarily identify as a direct service provider, what supports they offer members, and what types of advocacy efforts they engage in. The organizations' involvement and interest in evaluation is also reported.

Table 10: Products and Services

Variable	Total (N=380)		Peer-controlled (N=190)		Peer-directed N=(190)		χ2	p
	N	%	N	%	N	%		
Direct support provider primarily	350	92.1	170	89.4	180	94.7	3.6	0.057
Supportive Services								
Self-care/wellness classes	317	84.5	155	82.4	162	86.6	1.2	0.26
WRAP	255	68.5	116	62.0	139	75.1	7.4	<0.01
Mutual support groups	304	81.9	146	78.4	158	85.4	2.9	0.08
Warmline/hotline	121	33.4	56	30.6	65	36.3	1.3	0.25
Case management	66	18.2	25	13.6	41	22.9	5.1	<0.05
Employment/Education counseling	182	44.9	79	42.4	103	55.3	6.2	<0.05
Housing	78	21.4	33	18.2	45	24.7	2.2	0.13
Legal assistance	119	32.3	56	30.2	63	34.4	0.7	0.39
Advocacy								
Any advocacy	350	92.1	177	93.1	173	91.1	0.5	0.45
Anti-stigma	313	83.9	156	83.4	157	84.4	0.1	0.80
Demonstrations/protests	150	40.6	80	43.0	70	38.2	0.8	0.35
Letter-writing	283	75.6	142	75.9	141	75.4	0.0	0.90
Participate on committees	281	74.9	132	70.2	149	79.6	4.4	<0.05
Evaluation activities								
Program has been evaluated	199	52.9	88	46.8	111	59.04	5.6	<0.05
Conduct research/evaluation/QI	139	36.9	62	32.8	77	40.9	2.7	0.10
Research ranked first priority	26	9.00	13	9.1	13	8.8	0.0	0.93

Supportive Services

About 92% (n=350) of the organizations described themselves as direct support providers. Non-direct support organizations (n=30) were often statewide consumer networks (n=17; 57%), education/advocacy centers (n=7; 23%) and technical assistance centers (n=5; 7%). The percentage of peer-directed organizations that reported primarily providing direct supports to people (n=180; 95%) was higher than peer-controlled (n=170; 90%), but the difference was not significant (χ^2=3.62, p=0.057).

The most frequently reported supports provided were self-care classes (n=317; 85%) and mutual support groups (n=304; 82%), which is to be expected given the overall missions of these organizations. There was no difference between peer-controlled and peer-directed in providing these specific supports. Most organizations (n=255; 69%) also

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offered WRAP groups, but a higher percentage of peer-directed organizations (n=139; 75%) did this than peer-controlled (n=116; 62%; χ^2=7.4, p<0.01). Case management (n=66; 18%) and employment counseling (n=182; 45%) were less frequently endorsed than other services, overall. Peer-directed organizations more frequently reported providing case management (n=41; 23%) than peer-controlled (n=25; 14%; χ^2=5.19, p<0.05). Peer-directed also more frequently (n=103; 55%) provide employment counseling than peer-controlled (n=79; 43%; χ^2=6.20, p<0.05).

Advocacy Activities

The majority (n=350; 92%) of organizations overall reported engagement in some advocacy. The most common advocacy activities included anti-stigma efforts (84%) and letter-writing (76%). Least common activities were protests or demonstrations (41%). Policy committee participation was endorsed by 75% of organizations, but was more often associated with peer-directed organizations (n=149; 80%) than peer-controlled (n=132; 70%; χ^2=4.47, p<0.05). This was the only advocacy activity that was statistically significant different between the two groups.

Evaluation Activities

Altogether, 37% of organizations reported that they engaged in internal monitoring and quality control activities, while 53% reported that their programs have been evaluated internally or by an outside agency, with more peer-directed organizations (n=111; 59%) reporting having been evaluated than peer-controlled (n=88; 47%; χ^2=5.65, p<0.05). Research was ranked as a priority to improve organizational effectiveness by only 9% of organizations; the most frequently identified priority was collaboration with other peer support activities (23%).

5.E. DISCUSSION

This research reports the first national study of peer-run mental health programs in a decade. Peer-run organizations are providing a range of supports and advocacy activities. There were several differences between peer-controlled organizations and peer-directed. Overall, organizations with more control by people with lived experience were not significantly different from their counterparts who have a smaller, although still majority, involvement of peers on the board.

5.E.i   Vision and Mission

The member involvement data presented show that most peer-run organizations are involving members in decision-making, which is meaningful based on research on this being a critical ingredient in independent peer-run organizations (Holter et al., 2004). Peer-run organizations promote personal empowerment through participation in the organization's services and programs (Rogers et al., 2007). Organizations where people other than management participate in operational decision-making are referred to as "democratic organizations," where ideas of empowerment are embraced (Diefenbach & Sillince, 2011). However, it is notable that the pattern of involving a majority of members in decision-making was more often observed in peer-controlled organizations (77%) than peer-directed (61%). This may indicate that it is this particular subset of organizations that conform to the evidence on less hierarchical, more lateral peer support programs' effectiveness in decreasing stigma while increasing empowerment and inclusion (Segal & Silverman, 2002; Segal et al., 2013a). The data also suggest that it is these organizations that view themselves as alternatives to the traditional mental health system, since significantly more peer-controlled organizations endorsed this position than peer-directed

(19% vs. 3%). This is consistent with the vision of supporting leadership and independence of consumers (Morrison, 2013).

5.E.ii Leadership

Perhaps the most interesting finding in the data related to the "leadership" domain is that the peer-controlled organizations were more likely to be younger, not be incorporated, and had a smaller number of paid staff. This may be because they were, on average, younger than the peer-directed organizations because they may not be able to incorporate until they have had sufficient time to build capacity within the organization. The peer-controlled organizations had a significantly greater difference in the mean number of staff and volunteers in the organization than the peer-directed (+12 vs. -5), although the peer-controlled organizations did not show a difference from peer-directed organizations in average number of volunteers (18 vs. 13)—demonstrating that the peer-controlled are relying on a greater volunteer than paid workforce. They were also significantly less likely to have staff trained in what have become more institutionalized or "conformist" peer roles—such as WRAP, wellness coaching, and case management—which are popular with managed care companies for Medicaid reimbursement or are SAMHSA evidence-based practices (Daniels, A. S. et al., 2013; Federici, 2013). These data may indicate that these organizations are less stable at this time, having a shorter history, being less established (i.e. because of non-incorporation status), and having fewer human resources to rely on—and therefore may be more vulnerable in the immediate future to going out of business or being unable to sufficiently adapt to the environment.

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5.E.iii Outreach

A little over half of the organizations are affiliated with a statewide or national organizational—either operating as the Statewide Consumer Network or working with them. Most organizations felt they were sufficiently connected to other peer supports, although peer-directed organizations endorsed this more (75%) than peer-controlled (64%). These variables suggest that peer supports at the state and local levels operate in networks where they can collaborate with other peer-run organizations or peer supports to advance advocacy causes or improve service delivery through mutual learning.

The proportion of those who reported engaging in community outreach (93%) is consistent with the organizations' purported role in serving the population with serious mental disorders and educating communities (Clay, 2005). The annual number of members served was highly variable, with some organizations serving large numbers of people in their communities and skewing the distribution.

5.E.iv Financial Resources

Like the number of members served, the mean budget was much higher than the median—indicating that the distribution was skewed. The peer-directed organizations had larger budgets and less reliance on volunteers. They also report getting a majority of their funding from the government more than the peer-controlled ones (82% vs. 72%). Peer-controlled organizations also endorsed receiving "no government funding" more than peer-directed (16% vs. 8%). Given shifts in financing being undertaken in the behavioral health system (potential reductions in block grant and increasing Medicaid coverage), it will be important to recognize that peer-run organizations are relying on governmental sources more-so than private sources or insurance reimbursement. To some extent, it may

be the peer-directed ones, which more commonly rely on a majority government funding, that are more at risk with a shift to Medicaid funding; however, they also have more paid staff that are trained to provide Medicaid reimbursable services with more substantial evidence (Chinman et al., 2014; Daniels, A. S. et al., 2013), and therefore may be in a position to bring in organizational revenue through Medicaid.

5.E.v   *Products and Services*

A majority (92%) of organizations reported that they are direct service providers, providing a wide variety of supports—most frequently self-care classes, Wellness Recovery Action Planning (WRAP), and mutual support groups, and less frequently services like case management (18% of the overall sample), housing (22% of the overall sample), or legal assistance (32%). The peer-directed organizations are providing WRAP, case management, and employment counseling more, and in no service category are peer-controlled organizations providing more of any particular service. Although most organizations engage in various types of advocacy, the peer-directed ones report participating on policy committees significantly more (80% vs. 70%) than peer-controlled organizations.

There is a lack of emphasis on data monitoring or evaluation—either having been done or being a priority of the organizations. A little over half (53%) of the total sample reported having ever been evaluated, but only 37% reported conducting quality improvement activities or their own research. Only 9% ranked research as a first priority, although we might not expect that these organizations would endorse research as a priority because of attitudes of many mental health clinicians toward evidence-based practices (Tanenbaum, 2005). However, demonstrating effectiveness in health and mental

health services is become increasingly important for reimbursement and sustainability (Mechanic, 2012).

5.E.vi Strengths and Limitations

A strength of this study is the large number of peer-run organizations nationwide represented and the wealth of information, which we did not previously have. These data give us the ability to show on a national scale that these organizations are engaging in multiple forms of supportive services and advocating for systems change. The data should be of interest to the organizations, advocates, and those who plan and oversee health services. Data as such as these can be valuable in developing reimbursement and implementation policies that are consistent with the evidence for effectiveness of certain services.

A limitation of these preliminary analyses is that they are cross-sectional and are based at a survey conducted at a specific point in time. We have identified a number of factors that may affect the current operations of peer-run organizations, such as the attitudes of the staff, reimbursement rules, and capacity to participate in the increasingly data driven, and electronic data driven reporting requirements. Future analyses of these data could address relationships between these variables beyond their association with the peer-controlled/peer-directed governance structure. In addition, longitudinal data are needed to draw firmer conclusions about the sustainability of the organizations and whether factors affecting their productivity and viability change over time. Future research might also capture specific amounts of organizational resources (financial or human) going toward certain activities.

5.F. CONCLUSION

This research provides a description of peer-run organizations prior to the implementation of the Affordable Care Act. This constitutes data not available for the past ten years and data that will be important for monitoring changes in the health care system occurring after the implementation of the Affordable Care Act. All organizations included in this study meet the criteria of "peer-run" originally established in study guidelines (Ostrow & Leaf, 2014). These analyses examined organizations whose boards are almost exclusively comprised of people with lived experience ("peer-controlled") and those whose boards only have a simple majority ("peer-directed"). These two types differed in some important ways that are consistent with the writings of advocates based on their observations and experience of the role of consumer/survivor control of self-help initiatives in creating "alternatives" to the traditional mental health system (Chamberlin, 1990; Fisher & Spiro, 2010). The oft-quoted title of Judi Chamberlin's seminal work on the subject of mutual support and the consumer/survivor movement: *On Our Own* (Chamberlin, 1978), and later, the related title of Sally Clay's book on the Consumer-Operated Services Multisite Research Initiative: *On Our Own, Together* (Clay, 2005) indicate a long history of the importance to the consumer/survivor movement and their peer support initiatives of providing independent venues for support and advocacy (Morrison, 2013).

Based on the data showing that peer-controlled organizations more frequently involve a majority of members in decision-making and view their organizations as alternatives to traditional mental health services, they appear to be operating with more consistency with both the evidence and vision of peer-run organizations as places where

consumers can gain independence and empowerment (Morrison, 2013; Segal et al., 2013a). However, the peer-controlled organizations are more recently founded, not as well funded, have more volunteers than paid staff, fewer members, engage in fewer concrete activities identified as important in peer-run organizations, but involve their members in decision-making and identify as alternatives to traditional treatment more than their peer-directed counterparts.

With research emerging on these organizations' effectiveness in reducing stigma and promoting recovery, we need to be careful going forward that the organizations in local evaluations are consistent with the population for generalizability of results. If local programs are evaluated and shown to be effective, we cannot generalize results to the population if those organizations that are evaluated are different in their operations and services provided than the population. Organizations whose structure and operations do not conform to the best evidence should receive feedback and technical assistance on making improvements to be consistent with the evidence. The research community can aid organizations, payers, and advocates by providing data to support implementation of effective approaches and alternative approaches to common problems.

6. AIM 2: MEDICAID REIMBURSEMENT OF MENTAL HEALTH PEER-RUN ORGANIZATIONS: RESULTS OF A NATIONAL SURVEY

6.A. ABSTRACT

Objective: Changes in healthcare financing associated with the Affordable Care Act (ACA) may have significant implications for community-based mental health services in general. This study sought to understand whether knowledge of the ACA was associated with willingness of mental health peer-run organizations to become Medicaid providers.

Methods: Through the *National Survey of Peer-Run Organizations* conducted in April – October 2012, organization directors reported their organization's willingness to accept Medicaid reimbursement, knowledge of the ACA, knowledge of plans to expand Medicaid coverage, and whether people within the organization had discussed health care reform. Multinomial logistic regression was used to model the association between willingness and predictors. The specific concerns of those who said they were not willing, were willing but had concerns, or did not know if they were willing to be a Medicaid provider are described.

Results: Knowledge of the ACA, Medicaid expansion, and discussions with others about health care reform were not significantly associated with willingness to be a Medicaid provider. Having fewer paid staff was associated with not being willing to be a Medicaid provider, indicating that current staffing capacity influences both attitudes and practical concerns about capacity. Organizations had both ideological and practical concerns about Medicaid reimbursement.

Conclusions: Knowledge about the ACA does not appear to be related to attitudes about Medicaid reimbursement. Because of concerns reported, adapting specific requirements of Medicaid reimbursement will be important in sustaining peer-run organizations. Alternative and newly emerging financing mechanisms should be explored as means to maintain sustainability while recognizing the particular hesitation and limitations of organizations for participation in traditional Medicaid billing.

6.B. INTRODUCTION

Peer support interventions can include assistance in learning and overcoming challenges in health/wellness, and self-monitoring (IOM, 2012). There is lengthy and varied history of research on the effectiveness of mental health peer support initiatives. Much of this research is on peer support in mental health service settings (Chinman et al., 2014), but there is a smaller and growing literature on that which occurs in independent peer-run organizations (Campbell, 2009, 2011; Corrigan, 2006; Nelson et al., 2006; Nelson et al., 2007; Rogers et al., 2007).

6.B.i *Medicaid provisions and requirements*

Every state has some kind of behavioral health provision in their Medicaid plan. Medicaid billable services are based on documenting the medical need of beneficiaries for services that the state has agreed should be covered (Alakeson, 2008). Medicaid is an important payer nationwide for mental health services (NAMI, 2010) and Medicaid plans cover the cost of 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 specifics of coverage vary by state. Some state Medicaid programs have limited

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coverage for behavioral health. Others only cover services such as medication management and short-term psychiatric inpatient hospitalization, rather than a broader array of wraparound services, despite evidence for wraparound services (Mechanic, 2012). In some states, Medicaid covers peer support services (Landers & Zhou, 2014).

6.B.ii   Changes in Medicaid due to the ACA

One of the goals of the Affordable Care Act (ACA) is to provide health care systems with improvements in the quality of care, cost-containment, and increased focus on person-centered models of service delivery. Administered and funded through a federal/state partnership, Medicaid expansion under the ACA extends health coverage to adults with yearly income less than 133% of the federal poverty line.   An implication of the results showing the services that peer-run organizations provide is that Medicaid expansion could be an opportunity for peer-run organizations to implement evidence-based practices wraparound services that are not well disseminated or funded, such as supported employment (Isett et al., 2007; Marshall et al., 2014; Mechanic, 2012). Peer-run organizations can be targeted by funders to capitalize on their current activities and funding streams, help develop the organizations, and broaden community support programs for people with mental disorders.

The ACA has resulted in planned expansion to twenty-seven states' Medicaid programs (Kaiser Family Foundation, 2013). According to SAMHSA, if all states were proceeding with Medicaid expansion as initially suggested by the ACA, 2.7 million people who are currently uninsured and in need of mental health services would be covered by Medicaid (Substance Abuse and Mental Health Services Administration, 2013a). Although the implementation of all of the components is variable and in process,

the ACA is likely to have a significant impact on peer-run organizations as it will with other organizations providing behavioral health services.

6.B.iii Potential effects of Medicaid expansion on peer-run organizations

Some states cover a range of options through Medicaid that are or could be provided by peer-run organizations, such as supported employment or Wellness Recovery Action Planning (WRAP). However, because existing peer-run organizations often are funded by state and local revenues and by the SAMHSA Mental Health Block Grant, the expansion of Medicaid may be one of the greatest challenges for peer-run organizations. It is quite likely that funding for these organizations will change over the next few years with a shift from state or federal grants as federal funding outside of health insurance coverage is reduced or changed. Plans already are underway to reduce and substantially change the focus of these block grants (Department of Health and Human Services, 2011). The restructured block grants will focus more on coordinating behavioral health prevention, treatment, and recovery support services with other health and social services, filling gaps remaining when more individuals have health care coverage for their mental health needs. This could mean that these resources are shifted away from peer-run organizations. With changes in the availability of funding sources that do not require documentation of diagnoses or clinical/functional deficits, and the expansion of Medicaid coverage to many people who participate in the supports offered by peer-run organizations, these entities may reconsider funding options as the opportunities change along with changing governmental funding priorities.

6.B.iv Potential advantages of Medicaid reimbursement of peer support

The Centers for Medicare and Medicaid Services (CMS) supports the use of peer support services in the states under state Medicaid plan waivers. Medicaid expansion will make more resources available to peer-run organizations and allow for diversifying funding streams. Peer-run organizations that pursue Medicaid managed care contracts may have increased organizational revenue, sustainability, and ability to reach more people in distress. CMS has also issued guidance for the development and implementation of peer support services in recent years. Peer specialists are now Medicaid reimbursable in 31 states and the District of Columbia, as shown in Figure 1.

Medicaid managed care companies are interested in creating partnerships with peer-run organizations to enlist peer supporters to provide recovery-oriented supports to insurance plan members (Daniels, A. S. et al., 2013). If peer-run organizations join managed care company networks, the peer-run organizations can provide beneficiaries with a more diverse array of services, and also promote the ideas of recovery and resilience within the network. Many of the goals of managed care are aligned with those of peer support—increasing wellness and recovery, and reducing hospitalization—albeit for different reasons. Including peer-run organizations could mainstream both the services and the values, which can influence the culture of the whole system (Daniels, A. et al., 2013). Peer-run organizations reject conceptualizations of life problems as medical illnesses (Mead et al., 2001). This may hold the organizations back from joining managed care networks, but may broaden opportunities for recovery for managed care network beneficiaries and other providers (Davidson & Guy, 2012).

6.B.v Potential problems in Medicaid reimbursement of peer support

Peer-run organizations may be resistant to facets of Medicaid participation, such as the need for billing and financial management and complying with medical necessity criteria (Adler et al., 2010). Medical necessity criteria involve documenting diagnoses and functional deficits in clients. These criteria may be more difficult for peer-run organizations to document than other providers because of both ideological and practical reasons.

Ideological challenges: Peer-run organizations are not only unqualified to document diagnoses, but generally want to focus on non-medical approaches to members and the members' individual strengths (Holter et al., 2004). Some of the potential ideological challenges to Medicaid reimbursement that have been identified in the literature include compromising core values of peer support such as mutuality, equality in power between peers, non-coercion (Mead et al., 2001), and losing the ability to be advocates for a transformed mental health system, as a result of becoming embedded in that system (Adler et al., 2010; Campbell & Leaver, 2003).

Practical challenges: There are state standards for being certified as a peer specialist, although not all states require certification (Salzer, 2010). Certification for individual peer specialists is held by the peer community as positive because it allows peer specialists to work as professionals in traditional mental health settings (Daniels et al., 2010). Licensing and standards for peer-run organizations may be more complicated because of documenting medical necessity, and requirements for billing and supervision. For the most part, peer support does not involve giving diagnoses; peer specialists are not trained to focus on or give diagnoses, or document many of the current requirements of

medical necessity (Katz & Salzer, 2006). Financing for innovative mental health services is a challenge for many states and providers because of standardization and billing procedures (Magnabosco, 2006). The lack of adaptation of billing procedures and capacity for peer-run organizations to meet these requirements would be expected to be of concern. This study documented both ideological and practical concerns of peer-run organizations about billing Medicaid.

6.C. METHODS

This paper uses data obtained from the first national survey of peer-run mental health programs to be published in over a decade—the *2012 National Survey of Peer-Run Organizations*; more in-depth discussion of the study motivation and methods is presented in an earlier paper (Ostrow & Leaf, 2014). The target population for the study is peer-run organizations excluding independent mutual support groups that do not have a formal organizational structure. This has been a criterion in other peer-run organization research (Brown et al., 2007). Almost 900 organizations/programs were identified through contacting statewide consumer networks and state offices of consumer affairs from August 2010 to June 2012. As described in the previous chapter, organizations were asked several questions about their governance, staffing, activities, and perspectives. This project utilized a web-based survey, completed online by the directors of the organizations, achieving an 80% response rate. The survey contained about 83 questions although not all respondents were asked all questions, as they would "skip out" of sections if subsequent questions were not relevant. The survey was developed and had two rounds of pre- and pilot-testing with the input of mental health services researchers, program directors, advocates, and government representatives. Final inclusion criteria

were related to management structure operationalized by a consensus panel. Following

cleaning according to these criteria, there were 380 organizations in the analyses. The

research project was deemed not human subjects research by the Johns Hopkins

Bloomberg School of Public Health IRB.

6.C.i   Outcome

Directors were asked: "Are you willing to become a Medicaid provider? *A*

Medicaid provider is one that bills or submits claims for individuals served or services

provided." Response categories included: "Yes", "Yes, but we have some concerns",

"No", "Don't know", and "My organization/program is already a Medicaid provider."

Respondents who reported they were already a Medicaid provider (n = 30, 8.7%) were

excluded from analyses on willingness to become a Medicaid provider.

6.C.ii   Predictors

Directors were asked about their knowledge of the ACA: "How much do you

know about the Affordable Care Act (ACA)?" with possible response categories

"Nothing," "A little," "Some things", "A lot", "Everything", and "Don't know." The

question intentionally *did not* define the ACA; response categories "Don't know" and

"Nothing/A little" were collapsed because the question was not defined, and it was

assumed that those who don't know how much they know about a policy are likely

unaware of it and therefore more like those who said they knew "Nothing."

The directors also were asked if they knew of plans to expand Medicaid coverage

to more people. They were asked whether people within their organization had had

discussions amongst themselves, within the Statewide Consumer Network, and with a

government body about "health care reform." The term "health care reform" was used instead of "ACA" to identify discussions about policies that may be beyond the scope of the ACA, pre-date it, and to identify more general conversations about how the health system may be changing in ways that affect peer services.

Whether peer specialists are reimbursable through Medicaid was considered a predictor, because if organizations are in states where peer specialists are Medicaid reimbursable, it could affect how they perceive Medicaid reimbursement (positively or negatively). Information on Medicaid reimbursement of peer-delivered services was provided by SAMHSA (2011 NRI Profiles data and 2011 survey of NASMHPD's Medicaid and Financing division). Plans for Medicaid expansion, as of 2013, were obtained from the Kaiser Family Foundation (Kaiser Family Foundation, 2013). Organizational size was operationalized as the program director's report of the total number of paid staff (Jaskyte, 2011). Potential within-cluster correlation of responses by state in which participants were located was controlled for in the final statistical model using a robust variance estimate (Rogers, 1993). Multinomial logistic regression was used with reported willingness to become a Medicaid provider as the outcome.

A follow up question about specific concerns about Medicaid was asked of those who said they were willing to become a Medicaid provider but had concerns, those who said they were not willing, and those who said they were unsure. The concerns were constructed from existing guidance on adaptation of peer-run organizations for insurance reimbursement (Adler et al., 2010), and from key informant interviews with advocates, peer providers, government officials, and insurance company representatives (Ostrow &

Leaf, 2014). Frequencies of these concerns were reported. All analyses were conducted in Stata 13 (StataCorp, 2013).

6.D. RESULTS

First, the frequency of director responses to the outcome variable of willingness to accept Medicaid are presented in Table 11 with variables that were used in the regression model, including director knowledge of the ACA and activities related to health care reform, and state and organizational characteristics. Then the results of the regression model are presented in Table 12.

6.D.i   Characteristics related to the Affordable Care Act

As shown in Table 11, of the 316 direct service organizations who were included in the analysis, 52 (16.5%) said that they were willing to become a Medicaid provider without concerns. The remainder said they were willing but had concerns (n = 106, 33.5%), were not willing (n = 87, 27.5%), or did not know if they were willing (n = 71, 22.5%).

Table 11: Characteristics of exposure to the ACA by willingness to accept Medicaid

	Total (N=316)[a]		Yes (N=52)		Yes, concerns (N=106)		No (N=87)		Don't know (N=71)			
	N	%	N	%	N	%	N	%	N	%	χ^2	p
Knowledge of ACA												
Nothing/A little	164	51.9	21	40.4	46	43.4	45	51.7	52	73.2	18.79	<0.001
Some things	97	30.7	18	34.6	38	35.9	30	34.5	11	15.5	9.99	<0.05
A lot	55	17.4	13	25.0	22	20.8	12	13.8	8	11.3	5.56	0.14
Knowledge of Medicaid expansion	167	52.9	36	69.2	65	61.3	43	49.4	23	32.4	20.98	<0.001
Discussed healthcare reform with…												
Organization	167	53.2	30	58.8	65	61.9	43	49.4	29	40.9	8.69	<0.05
Statewide Consumer Network	135	43.1	29	56.9	55	52.4	30	34.45	21	30.0	15.16	<0.01
Government committee	86	27.5	22	43.1	36	34.3	18	20.7	10	14.3	16.84	<0.01
State Medicaid peer specialist reimbursement	217	68.7	37	71.2	66	62.3	58	66.7	56	78.9	5.77	0.12
State plans to expand Medicaid	201	63.6	32	61.5	73	68.9	52	59.8	44	62.0	1.99	0.57
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	F	p
Mean number of paid staff	7.9	11.1	11.2	12.2	10.3	14.1	6.2	7.5	5.8	9.7	4.4	<0.001
Mean number of members	1006.2	2968.8	948.9	1431.0	1098.3	3361.9	1127.7	3459.8	466.9	728.8	0.95	0.42

[a]*Those who were already Medicaid providers were excluded from this analysis.*

Approximately half (51.9%) of organization directors reported that they knew "nothing" or only "a little" about the ACA. This was reported most frequently (73%) by the organizations who did not know if they were willing to become a Medicaid provider. Only 17% of the sample overall reported that they knew "a lot", and of the ones who were willing without concerns, 25% reported that they knew "a lot" about the ACA.

About half (53%) of the sample knew of plans to expand Medicaid, but almost 70% of those who were willing to become a Medicaid provider without concerns reported that they knew of plans to expand Medicaid coverage to more people ($\chi^2 = 20.98$, p <0.001). Knowing of plans to expand Medicaid coverage was significantly associated with being in a state that is currently planning to expand Medicaid (70.9%, $\chi^2 = 14.58$, p <0.001). However, whether an organization was in a state that planned to expand Medicaid (64% overall) was not significantly associated with willingness to accept Medicaid reimbursement for the director's own program.

Most directors (53%) reported that people had discussed healthcare reform within the organization, but those who were willing to be a Medicaid provider but had concerns had these internal conversations more frequently (62%) than the overall sample ($\chi^2 = 8.69$, p <0.05). Fewer than half of directors (43%) reported discussions of health care reform within the Statewide Consumer Network, but 56.9% of those who were willing to be a Medicaid provider with no concerns said they had discussed with the Statewide Consumer Network ($\chi^2 = 15.16$, p <0.05). Slightly more than a quarter (28%) reported these discussions occurring directly between the organization and a government body, but 43% of those who were willing to be a Medicaid provider with no concerns said they had discussed with the government ($\chi^2 = 16.84$, p <0.05).

According to SAMHSA, 32 states included reimbursement of peer specialists in their state Medicaid plan (Hudock, 2013). The organizations surveyed in this study were located in 48 states and the District of Columbia (no organizations from Rhode Island and Mississippi were included in the data because no peer-run organizations that met the

study criteria could be identified). Close to 69% of the organizations in the study are in states where peer specialists are reimbursed by Medicaid.

Organizational size was measured by the number of paid staff. Paid staff is a common metric of organizational size when discussing innovations (Jaskyte, 2011); it is used here despite the number of volunteers many of these organizations have because the paid staff are the staff members who are currently using organizational financial resources that might be augmented or substituted by Medicaid reimbursement and would support this innovation in financing. On average, there were about 8 paid staff across organizations. The highest mean number of paid staff was in organizations that were willing without concerns to become Medicaid providers (mean = 11.22, SD = 12.20). The mean number of members served annually was 1006.2 (SD=2968.8) across all organizations, which did not differ by category of willingness to be a Medicaid provider.

6.D.ii *Medicaid expansion and peer specialist reimbursement*

Figure 4: Medicaid expansion and reimbursement of peer specialists, by state

■ Does reimburse / will expand
■ Does reimburse / no expansion
■ No reimbursement / will expand
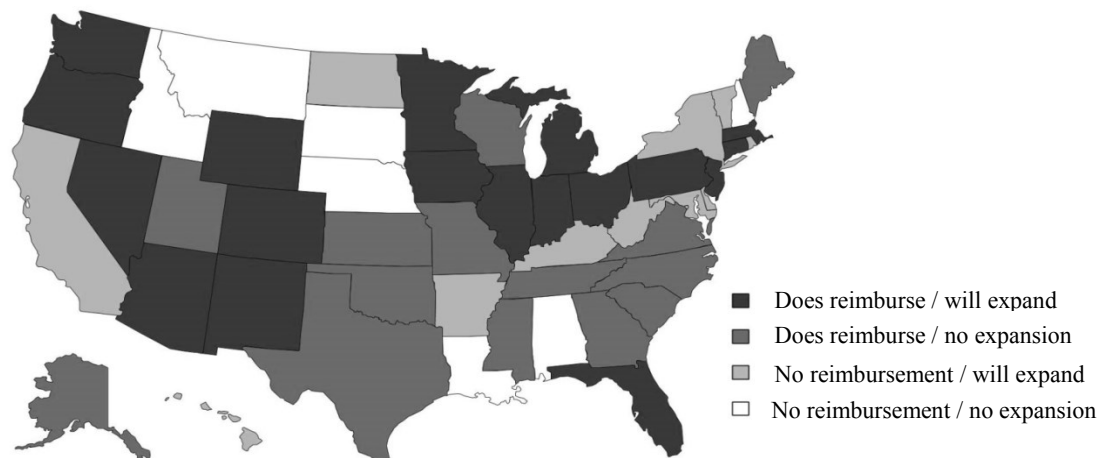□ No reimbursement / no expansion

Figure 1 reveals that most states 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 as planning for expansion. Shaded in dark grey are states that reimburse for peer-delivered services but do not plan for Medicaid expansion. States that plan for Medicaid expansion but have no provisions for reimbursement of peer-delivered services are shown in light grey. Finally, a minority of states (N=7) has neither plans for Medicaid expansion nor do they reimburse for peer-delivered services.

6.D.iii Analytic results of willingness to become a Medicaid provider

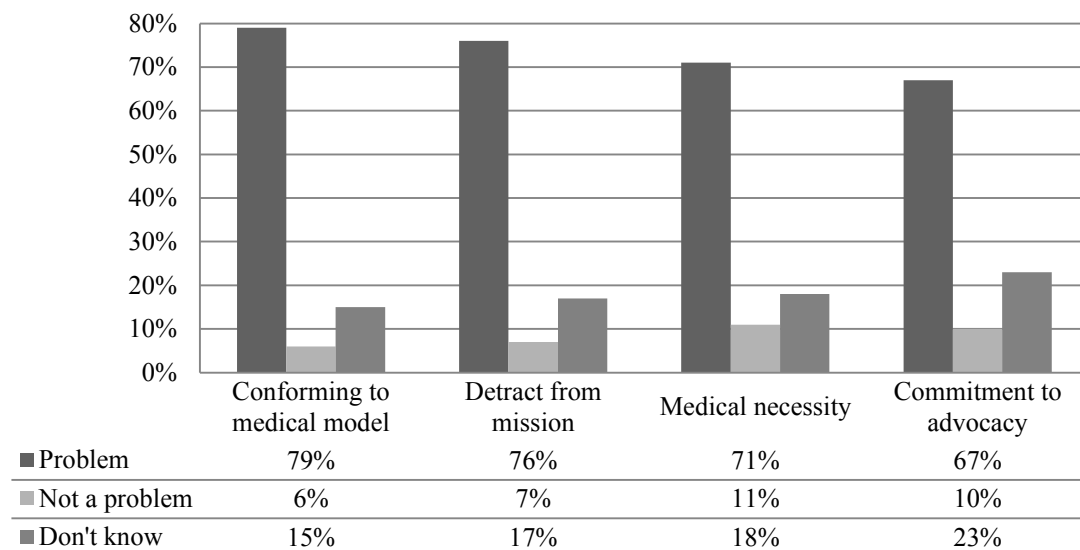**Table 12: Multinomial logistic regression of predictors of willingness to become a Medicaid provider**

Predictor variable	Not willing to be a Medicaid provider			Yes, willing to be a Medicaid provider but have concerns			Don't know if willing		
	(N=87)			(N=106)			(N=71)		
	OR	p	95% CI	OR	p	95% CI	OR	p	95% CI
Knowledge of the ACA									
Nothing/A little (reference)	--	--	--	--	--	--	--	--	--
Some things	1.12	0.78	0.49, 2.57	1.03	0.94	0.46, 2.31	0.48	0.11	0.19, 1.19
A lot	0.88	0.91	0.29, 2.57	0.92	0.86	0.36, 2.32	0.68	0.56	0.19, 2.45
Know of plans to expand Medicaid coverage	0.58	0.18	0.27, 1.28	0.74	0.40	0.36, 1.50	0.38	<0.01	0.18, 0.79
Discussed HCR within organization	1.05	0.93	0.39, 2.83	1.27	0.56	0.57, 2.81	0.89	0.78	0.38, 2.07
Discussed HCR within SCN	0.59	0.23	0.25, 1.41	0.92	0.82	0.46, 1.85	0.64	0.23	0.30, 1.34
Discussed HCR with a government agency or committee	0.49	0.18	0.18, 1.37	0.76	0.57	0.30, 1.94	0.43	0.054	0.19, 1.01
Peer specialists reimbursable in state	0.51	0.20	0.18, 1.41	0.54	0.20	0.21, 1.39	0.90	0.85	0.30, 2.71
State plans to expand Medicaid	0.92	0.86	0.35, 2.42	0.72	0.45	0.30, 1.70	0.70	0.50	0.25, 1.97
Number of paid staff	0.95	<0.01	0.93, 0.99	0.99	0.18	0.98, 1.00	0.97	0.14	0.92, 1.01

Base category is those who are willing without concerns, N=52

Knowledge of the ACA was not associated with willingness to become a Medicaid provider. Knowledge of plans to expand Medicaid was significantly associated with those who did not know if they were willing compared to those who were willing without concerns (OR = 0.38, p<0.01). If directors knew about Medicaid expansion, they were 60% less likely to report that they "didn't know" if they were willing to become a Medicaid provider. The only other significant predictor was the size of the organization. For every paid staff member, an organization was 5% less likely to say they were "not willing" to become a Medicaid provider.

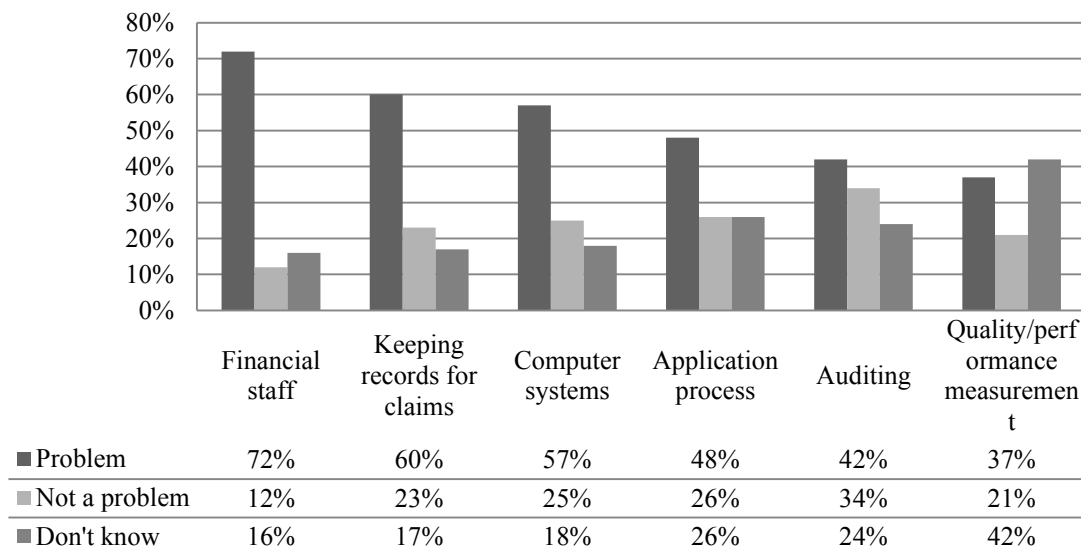### 6.D.iv Concerns about Medicaid reimbursement

Figure 5: Value-based concerns about Medicaid reimbursement by organizations that were not willing, had concerns, or did not know if they would be willing to bill Medicaid

	Conforming to medical model	Detract from mission	Medical necessity	Commitment to advocacy
■ Problem	79%	76%	71%	67%
▨ Not a problem	6%	7%	11%	10%
■ Don't know	15%	17%	18%	23%

Of the organizations that reported specific concerns about Medicaid reimbursement (those who answered to the willingness question: "Yes, but we have concerns," "No", or "Don't know"), 79% reported "conforming to the medical model" to

be a concern. Other common value-based concerns included: Medicaid reimbursement detracting from the mission (76%), medical necessity criteria (71%), and Medicaid reimbursement interfering with their commitment to advocacy (67%). Close to 80% of the respondents (n=152; 78%) reported all three of these concerns as problems.

Figure 6: Practical concerns about Medicaid reimbursement by organizations that were not willing, had concerns, or did not know if they would be willing to bill Medicaid

	Financial staff	Keeping records for claims	Computer systems	Application process	Auditing	Quality/performance measurement
■ Problem	72%	60%	57%	48%	42%	37%
■ Not a problem	12%	23%	25%	26%	34%	21%
■ Don't know	16%	17%	18%	26%	24%	42%

The most frequently reported practical concern was not having financial staff to manage billing (72%). Other practical concerns were related to keeping records for claims (60%) and sophistication of computer systems (57%). The application process (48%), auditing by an insurance company (42%), and quality and performance measurement (37%) were the least frequently reported concerns, although 42% of organizations said that they "didn't know" if quality and performance measurement would be a problem—indicating a potential lack of understanding of these requirements or their ramifications.

6.E. DISCUSSION

Although many organizations rely on governmental sources of funding, currently many of these streams (such as the block grant) do not have billing or financial reporting that would require knowledge of the ACA or Medicaid. Peer-run organizations may not have had the motivation to learn about the ACA or be in information networks that could provide this knowledge. The directors of most of the organizations in this study (83%) did not feel that they had a lot of knowledge about the ACA, although about half (53%) were aware of plans to expand Medicaid.

There was no relationship between peer-run organizations' willingness to bill Medicaid and state policies related to reimbursement of peer specialists or state plans to expand Medicaid. The peer specialist reimbursement policy of the state in which a peer-run organization is located did not have an effect on willingness of these organizations to bill Medicaid. Similarly, the policy of the state regarding Medicaid expansion had no effect on their willingness to bill Medicaid. We may see changes in attitudes that are related to the intersection of peer specialist reimbursement and Medicaid coverage expansion in the future.

The size of the organization was associated with willingness to become a Medicaid provider, and having staff to manage billing was a frequent concern. Those who have more paid staff were more likely to say they were willing to accept Medicaid reimbursement than those with fewer staff. The association between larger organizational size and willingness to bill Medicaid indicates the importance of capacity, at least in terms of influencing perceptions of the directors. Larger organizational size has been shown to influence the ability of non-profits to innovate (Jaskyte, 2011; Jaskyte &

Dressler, 2005). Adapting to new financing mechanisms such as Medicaid may be an important innovation for these organizations in the near future. It will be important to assure that appropriate procedures used for dissemination of knowledge and training are in place when more peer-run or other organizations are to be integrated into the system. Similar issues pertain for interfacing the significant number of alcohol and drug related peer-run institutions into the newly emerging behavioral health system.

At a time when more behavioral healthcare providers and state agencies see Medicaid reimbursement on the horizon as a sustainable source of revenue, this study demonstrated that understanding the ACA was not related to the willingness of a peer-run organization to participate as a Medicaid provider. We do not yet know whether these attitudes will predict how many peer-run organizations decide to accept Medicaid reimbursement. Educational endeavors about the ACA seem unlikely to address the organizations' unwillingness to bill Medicaid and their ideological and practical concerns. The current organizational structures were not created to manage the practical requirements that might accompany Medicaid. However, deciding to bill Medicaid may be more dependent on norms for maintaining the values of peer support as being mutual and non-professional, organizations' sense of control over the environment, and developing skills around billing Medicaid. There will also be a need to develop procedures that don't conflict with their values.

The concerns reported do reflect a degree of knowledge of the requirements of Medicaid reimbursement. The concerns reported by organizations about accepting Medicaid reimbursement are consistent with reports from the insurance industry about changes in operation that peer-run organizations may have to enact in order to be a

Medicaid provider (Adler et al., 2010). Directors may be knowledgeable about the specifics of Medicaid reimbursement without having enough information to know whether the organization could adapt.

The most frequent concerns were in the value-based categories. All of the ideologically-based concerns were reported by at least 70% of the participants except for the "commitment to advocacy." This may either be because these are the most significant barriers, or because the organizations see these as potential conflicts given that more concrete, practical concerns are further in the distance or not as well understood. For the practical concerns, the only one that exceeded more than 70% of respondents reporting it as a concern was the financial staff to manage billing. This is consistent with the finding that organizations with more staff were more willing to become a Medicaid provider. The perception that having staffing capacity would make Medicaid reimbursement more palatable is clear in both the analysis of willingness and the analysis of specific concerns. Going forward, we may see that as organizations explore Medicaid reimbursement, practical concerns other than staffing capacity become more salient. However, the first barrier may be overcoming significant concerns about the values on which these organizations were founded.

6.F. CONCLUSION

Policies such as the passage of the Mental Health Parity and Addiction Equity Act in 2008 and the Affordable Care Act in Congress in 2010 have provided many opportunities for financing of innovations in our mental health system (Glied & Frank, 2008; Mechanic, 2012). Peer-run organizations, while still small in number, provide essential services to communities (Chinman et al., 2014; Goldstrom et al., 2004). In

addition, the Pillars of Peer Support conference attendees believe that the peer workforce is strengthened when there are consumer-run organizations that serve to involve and support consumers in service development and delivery (Daniels et al., 2010). However, the existence and/or expansion of peer-run organizations is dependent upon the rapidly evolving federal, state, and local policies.

Peer-run organizations have several concerns, both practical and ideological, about receiving Medicaid funds. Reimbursing peer support through Medicaid risks compromising some of the core values of peer support, including mutuality, equality, non-coercion, and the lack of a power imbalance (Mead et al., 2001). Promoting empowerment and self-direction through non-hierarchical relationships has been the guiding vision of the consumer/survivor movement (Morrison, 2013). If peer-run organizations join managed care networks, there is a concern that they could lose the ability to be advocates for a transformed mental health system as a result of becoming embedded in that system (Adler et al., 2010). Our findings on specific concerns indicate that the population of peer-run organizations is considering values of self-direction and non-hierarchical relationships in relation to Medicaid reimbursement. They also had more practical concerns—such as not having financial staff to manage billing or keeping records for claims.

Addressing the very real concerns of peer-run organizations by providing more flexible billing mechanisms that use global payments or self-directed care funds to receive Medicaid reimbursement may be a potential solution. Emerging Medicaid financing options—such as self-directed care—address many of the peer-run organizations' concerns, since the organizations are concerned about documenting

medical necessity and having internal staffing capacity (Alakeson, 2008). These mechanisms are becoming more widely researched and developed (Alakeson, 2010) and are currently involving peer-run organizations in their implementation research (Cook et al., 2010). Self-directed care gives individuals direct control over service delivery dollars so that they can purchase goods, services, and supports—including peer support—and use the services of a financial broker, which would alleviate burden from smaller peer-run organizations of needing financial staff (Cook, Russell, Grey, & Jonikas, 2008). However, this model has not been widely implemented for people with psychiatric disabilities. More widely implementing financing mechanism like this one 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.

As demonstrated earlier in documenting the supports and activities of peer-run organizations, these programs are providing valuable resources to people with psychiatric disabilities to support social networks and community-building. 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 continued and expanded opportunities to support persons with mental disorders. Organizations could go out of business because of requirements for insurance reimbursement and simultaneous shrinking resources from their usual sources of funding. Statewide consumer networks, policy makers, providers, and other stakeholders should monitor whether this population is struggling to remain sustainable in the face of these changes in policies and procedures.

This study addressed some potential challenges, opportunities, and data to support concerns of peer-run organizations nationwide about Medicaid reimbursement. The ACA has provided our health care system with the opportunity for significant improvement in quality of care, cost-containment, and models of service delivery. Expansion of Medicaid and associated pressures to change funding from grants/contracts to reimbursement models may be some of the greatest challenges for peer-run organizations. If we anticipate and respond to their concerns with concrete and acceptable compromises and creative financing mechanisms, we could ensure the sustainability of both the peer-run model and the individual organizations.

7.   AIM 3: ATTITUDES OF MENTAL HEALTH PEER-RUN ORGANIZATIONS TOWARDS HEALTH HOMES

7.A.   ABSTRACT

Objective: The Affordable Care Act (ACA) includes specific provisions for the establishment of health homes as a Medicaid option for people with psychiatric disabilities. The health home will be inter-disciplinary, and will likely include peer supporters. They may need to enlist peer-run organizations to provide options for care coordination, social support, and wellness coaching. This study examined factors related to attitudes of mental health peer-run organizations nationwide towards joining a health home as part of the team.

Methods: The 2012 *National Survey of Peer-Run Organizations* collected data from organization directors on their organization's willingness to participate in a health home, knowledge of the ACA, patterns of linkages with physical healthcare providers, and organizational characteristics. Those who said they were not willing, were willing but had concerns, or didn't know if they were willing reported their specific concerns. Multinomial logistic regression was used to model the association between willingness to be part of a health home and predictors.

Results: Current and planned patterns of suggesting and encouraging physical healthcare to members was associated with willingness to be part of a health home. Larger organizations demonstrated more positive attitudes than smaller ones. Knowledge about the ACA was not associated with willingness. Organizations had concerns about

power dynamics between their organization and medical providers as part of the health home team.

Conclusions: Current organizational behavior concerning relationships to physical health providers and staffing capacity should be taken into account when proposing to include a peer-run organization as part of a health home team. Clearer explanations of financing mechanisms under the health home option and sensitivity to concerns related to control, coercion, and status should be attended to when including peers in health homes.

7.B. INTRODUCTION

Research has shown that there are significant associations between mental disorders and chronic conditions, and that the co-occurrence of mental disorders and chronic conditions increases role impairment (Kessler, Ormel, Demler, & Stang, 2003). Other studies have shown that people with mental disorders, compared to the general population, have worse health status on a number of indicators, including smoking, exercise, obesity, and co-occurring physical health conditions (Dickerson et al., 2006). Public mental health clients die 25 years earlier on average than the general population (Colton & Manderscheid, 2006). As the country moves toward expanding insurance coverage and integrating behavioral and physical healthcare, we are considering increased roles for peer supporters and peer-run organizations in innovative models such as the health home. Health homes have been proposed as one patient-centered option for people with mental disorders to integrate physical health and wellness with mental healthcare, coordinate access and wellness supports, and create financing mechanisms for integrated care (Center for Integrated Health Solutions, 2012).

7.B.i   Access to care and care coordination

The U.S. health care system relies on persons being able to navigate a complex system and evaluate treatment options (Levy & Royne, 2009). Studies have shown that people with mental disorders are about twice as likely to have been unable to obtain the medical care that they need (Druss & Rosenheck, 1998), and receive less preventive care (Druss, Rosenheck, Desai, & Perlin, 2002). Primary and specialty care doctors may resist treating those with a mental illness and a comorbid physical condition because there are often more complications when treating this population for physical conditions (Daumit et al., 2006; Khaykin, Ford, Pronovost, Dixon, & Daumit, 2010) and feel inadequately prepared to communicate with these patients (Maj, 2009; Mancini, 2008). Primary care doctors also may be unfamiliar with the role that self-management interventions play for persons with chronic conditions such as diabetes (Funnell et al., 2009).

7.B.ii   Role of peer-run organizations in access and coordination of care

Peer-run organizations could play an integral role in supporting members in accessing care, improving wellness strategies, and self-advocacy. Peer supporters are taking a lead in designing interventions and campaigns to focus on physical health and wellness, such as peer wellness coaching and illness self-management interventions (Swarbrick et al., 2011). Persons who lack empowerment have a more difficult time navigating the health care system (Weiss et al., 2010). This has been shown to be especially problematic among Medicaid beneficiaries (Weiss et al., 2010). Studies of people with chronic physical conditions show that they also perceive, experience, and anticipate stigma from health care providers, and that this affects access (Earnshaw & Quinn, 2011). Peer-run organizations have been shown to increase empowerment by

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members who use them (Corrigan, 2006; Rogers et al., 2007) and may reduce certain kinds of self-stigma through related processes (Corrigan, Patrick W et al., 2009).

7.B.iii Health homes

The Medicaid health home option was established by the ACA. Health home services may receive a 90% federal match for two years (Kaiser Family Foundation, 2014). Models of health homes for people with mental disorders have been under development and discussion for several years—with an emphasis on appropriate location and team membership as well as the person as the locus of care (Berwick, 2009; National Council for Community Behavioral Healthcare, 2008). CMS guidelines state that the Medicaid health home option for people with psychiatric disabilities should integrate medical treatment and community-based services (Kaiser Family Foundation, 2014).

One of the key mandates of the health home option is to coordinate and provide access to supports, including referral to community, social support, and recovery services (CMS, 2010). The Secretary of Health and Human Services is required to define a "health team" through regulations, and the legislation of the ACA indicates that the team should be interdisciplinary and inter-professional (CMS, 2010). Health homes should include a range of mental, physical, and behavioral health prevention, treatment, and recovery services, as well as person-centered planning, care coordination for integration, and referrals to other services and supports to promote recovery and resiliency (CMS, 2010).

7.B.iv Role of peer-run organizations in health homes

Peer specialists are increasingly included in Medicaid reimbursement and can be financed and included through this option (Daniels, A. S. et al., 2013). Peer workers have

been proposed as a potentially effective and cost-saving means of helping people navigate health systems and supporting wellness (Center for Integrated Health Solutions, 2012; Druss et al., 2010; Swarbrick et al., 2011). Peer wellness coaches have been proposed as a component of these health homes, as well a role for peers in peer-run organizations (Center for Integrated Health Solutions, 2012; Swarbrick et al., 2011).

Integrated care models where people can receive services and supports for mental health issues and physical health issues in either co-located or coordinated care settings was identified in legislation and implementation strategies for the Affordable Care Act, including the health home model. In some cases, peer-run organizations have joined managed care networks, and could provide an essential support to persons receiving services in health homes (Daniels, A. S. et al., 2013). However, as with many other aspects of the ACA, the implementation is still a work in progress. Whether or not peer-run organizations were willing to participate as part of a health home with providers was examined in this analysis to help policy-makers and health system administrators anticipate potential issues in including peers in health home implementation.

7.C. METHODS

This paper uses data obtained from first national survey of peer-run mental health programs to be published in over a decade—the *2012 National Survey of Peer-Run Organizations*; more in-depth discussion of the study motivation and methods is presented in earlier paper (Ostrow & Leaf, 2014).

The target population for the study is peer-run organizations, excluding independent mutual support groups. Exclusion of those without a formal organizational

structure has been a criterion in other peer-run organization research (Brown et al., 2007).

Almost 900 organizations/programs were identified through contacting statewide

consumer networks and state offices of consumer affairs from August 2010 to June 2012.

Organizations were asked several questions about their governance, staffing, activities,

and perspectives. This project utilized a web-based survey, completed online by the

directors of the organizations from April-October 2012, achieving an 80% response rate.

It was developed and had two rounds of pre- and pilot-testing with the input of mental

health services researchers, program directors, advocates, and government

representatives. Final inclusion criteria were related to management structure

operationalized by a consensus panel. Following cleaning according to these criteria,

there were 380 organizations in the analyses. The survey contained 83 questions about

governance, staffing, activities, and perspectives. Not all respondents had to answer all

questions because of skip patterns based on earlier responses. The research project was

deemed not human subjects research by the Johns Hopkins Bloomberg School of Public

Health IRB. Analyses were conducted in Stata 13.

7.C.i   Outcome

Directors were asked: "Would you be willing to work with other providers, such

as doctors, to be part of a health home for your members? *A health home is a type of*

provider organization where multiple providers (such as primary care doctors,

psychiatrists, and case managers) work together to coordinate health care." Response

categories included: "Yes," "Yes, but we have some concerns," "No," "Don't know," and

"My organization/program is already part of a health home." Respondents who reported

they were already part of a health home (n = 14, 4.1%) were excluded from analyses on willingness to become part of a health home.

7.C.ii Predictors

Directors were asked about their knowledge of the ACA: "How much do you know about the Affordable Care Act (ACA)?" with possible response categories "Nothing," "A little," "Some things," "A lot," "Everything," and "Don't know." The question intentionally *did not* define the ACA; response categories were collapsed and "Don't know" was included with "Nothing/A little" because the question was not defined, and it was assumed that those who don't know how much they know about a policy are likely unaware of it and therefore more like those who said they knew "Nothing."

Respondents reported whether people within the organization had "discussed health care reform with a government agency or committee appointed by the government." The term "Health care reform" was used instead of "ACA" to identify discussions about policies that may be beyond the scope of the ACA, pre-date it, and to identify more general conversations about how the health system may be changing in ways that affect peer services.

Directors were also asked what plans they had to incorporate integration of behavioral and physical health into the organization's programs—including encouraging members to use physical healthcare services. They were asked about the frequency of *suggesting* members use a variety of different "non-peer-delivered" services, including physical healthcare. Respondents were asked to *not count* times that they or their staff

had just given members informational materials. The possible answer categories were: Never, a few times per year, a few times per month, a few times per week, daily, and "don't know." They were not asked to report actual counts because referrals—as may be counted by the medical system—would likely not be tracked in any reliable data source in a peer-run organization, and even if they were, would increase respondent burden, and therefore potentially compromise response rate.

In addition to these questions, the number of paid staff and the number of unduplicated members served are included in the analysis. Number of staff is a typical measure of organizational size (Jaskyte, 2011). Members, as defined in the survey and in previous literature on peer-run organizations, are people who use the organizations services (Clay, 2005). The number of members was missing in 6% of reports. Because of missing data patterns in the analysis, the number of cases that would have been excluded was 13%. The number of members was imputed for missing observations using conditional mean imputation, with imputation conditional on the number of staff (Allison, 2007). Potential within-cluster correlation of responses by state in which participants were located was controlled for in the final statistical model using a robust variance estimate (Rogers, 1993). Multinomial logistic regression was used with willingness as the outcome.

A follow up question about specific concerns about participating in a health home was asked of those who said they were willing to become a Medicaid provider but had concerns, those who said they were not willing, and those who said they were unsure. The concerns were constructed from key informant interviews with advocates, peer providers, government officials, and insurance company representatives (Ostrow & Leaf,

2014). Frequencies of these concerns were reported. All analyses were conducted in Stata 13.

7.D. RESULTS

7.D.i   *Characteristics of peer-run organizations and health home participation*

Table 13 shows the characteristics of the organizations, the knowledge of the organization's director about the ACA, and other predictors used in the analysis. A total of 331 organizations reported that they provided direct support and were not already part of a health home. Of those, about 40% (n=131) said they would be willing to be part of a health home; 32% (n=106) said they were willing, but had concerns; 14% (n=45) were not willing to be part of a health home; 15% (n=49) responded "don't know."

Approximately half (n=168; 50.8%) of the organizations reported that they knew "nothing" or only "a little" about the ACA. Knowing "nothing" or "a little" was more frequently reported by those who said they did not want to be part of a health home (n=27; 60%) and those who didn't know if they were willing (n=34; 69.4%; χ^2=11.33; p<0.05). Less than one-fifth (n=63; 19%) of the overall sample reported knowing "a lot" about the ACA, but a high level of knowledge about the ACA was more frequently reported by those who were willing to be part of a health home and did not report concerns (n=34; 25.9%; χ^2=11.25; p<0.05).

Less than a third of the organizations (n=93; 28.4) reported that people from the organization (??) had had discussions about the impact of health care reform on peer services with a government body. This was more frequently endorsed by those who were willing but had concerns (n=37; 35.6%; χ^2=15.03; p<0.01). Most organization directors

said they had plans to encourage use of primary care services to incorporate integration of behavioral and physical health care (n=282; 87.9%). Those who were willing to be part of a health home without concerns almost unanimously endorsed these plans (n=117; 94.4%, χ^2=15.78; p<0.01).

Overall, only 8.4% (n=27) of organizations reported that they "never" suggest to members that members use physical healthcare services. This was reported by 20.5% (n=9) of those who said they were not willing to be part of a health home—significantly more than the other respondents who said they were willing to be part of a health home or didn't know if they were (χ^2=17.24; p<0.01). About a third of the sample (n=92; 28.6%) reported suggesting that members use physical health services a few times per month, but this was not significantly different across response categories. Suggesting the use of physical healthcare services a few times per week was more frequently reported by those who were willing to participate in health home but had concerns (n=33; 32%, χ^2=9.99; p<0.05) than the other responses to willingness to be part of a health home.

The mean number of members served annually by the organizations surveyed was 1,006 with considerable variation (SD=2,2968.8). The mean number of members did not differ across responses about health home participation. The mean number of paid staff was 12 (SD=38.95), which also did not vary significantly across response categories about health home participation.

Table 13: Characteristics of peer-run organizations by willingness to participate in health homes

	Total (N=331)		Yes (N=131)		Yes, concerns (N=106)		No (N=45)		Don't know (N=49)		χ^2	p
	N	%	N	%	N	%	N	%	N	%		
Knowledge of ACA												
Nothing/A little	168	50.8	59	45.0	48	45.3	27	60.0	34	69.4	11.33	<0.05
Some things	100	30.2	38	29.0	37	34.9	13	28.9	12	24.5	1.99	0.57
A lot	63	19.0	34	25.9	21	19.8	5	11.1	3	6.1	11.25	<0.05
Discussed healthcare reform with government agency	93	28.4	44	33.6	37	35.6	6	13.3	6	12.8	15.03	<0.01
Plan to encourage the use of primary care as part of integration	282	87.9	117	94.4	92	89.3	33	73.3	40	81.6	15.78	<0.01
Suggest physical healthcare to members…												
Never	27	8.4	6	4.8	4	3.9	9	20.5	8	16.3	17.24	<0.01
Few times/year	56	17.4	19	15.1	17	16.5	11	25.0	9	18.4	2.33	0.51
Few times/month	92	28.6	39	30.9	32	31.1	10	22.7	11	22.5	2.3	0.51
Few times/week	79	24.5	33	26.2	33	32.0	4	9.1	9	18.4	9.99	<0.05
Daily	44	13.7	22	17.5	12	11.7	6	13.7	4	8.2	3.15	0.37
Don't know	24	7.5	7	5.6	5	4.9	4	9.1	8	16.3	7.4	0.6
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	F	p
Mean number of members	1006.2	2968.8	1482.7	4688.9	758.4	1195.8	566.9	1556.2	910.7	1553.4	1.5	0.21
Mean number of paid staff	12.0	38.95	17	57.3	12.5	34.7	3.7	4.6	8.2	9.9	1.4	0.25

7.D.ii *Analytic results related to willingness to be part of a health home*

Regression results are presented in Table 14. The base category for the comparisons is those who were not willing to be part of a health home (n=45; 13.6%). Knowledge of the ACA was not related to attitudes towards participating in a health home. Having discussed health care reform was not significantly associated with being willing without concerns compared to not being willing (OR=3.04; p=0.08). Those who reported having plans to encourage the use of physical healthcare services as an effort toward integration were more than four times more likely to be willing to be part of a health home than to say they were not (OR=4.27; p<0.05), but the same was not true of those who were willing but had concerns (OR=1.87; p=0.33).

Organizations that suggested that members use physical healthcare services a few times per week were significantly more likely to say they were willing to participate in a health home (OR=5.05; p<0.05) or to say they were willing but had concerns (OR=11.20; p<0.05) than to say they were not willing. The number of members of the organization was controlled for in the analysis because the frequency of suggesting the use of services could be dependent on the opportunity to do so. In the analyses the number of members was not independently associated with frequency or willingness to be part of a health home. However, for every paid staff member, an organization was 9% more likely to say they were willing to be part of a health home or were willing but had concerns than to say that they were not willing (OR=1.09; p<0.05).

Table 14: Multinomial logistic regression of predictors of willingness to participate in a health home
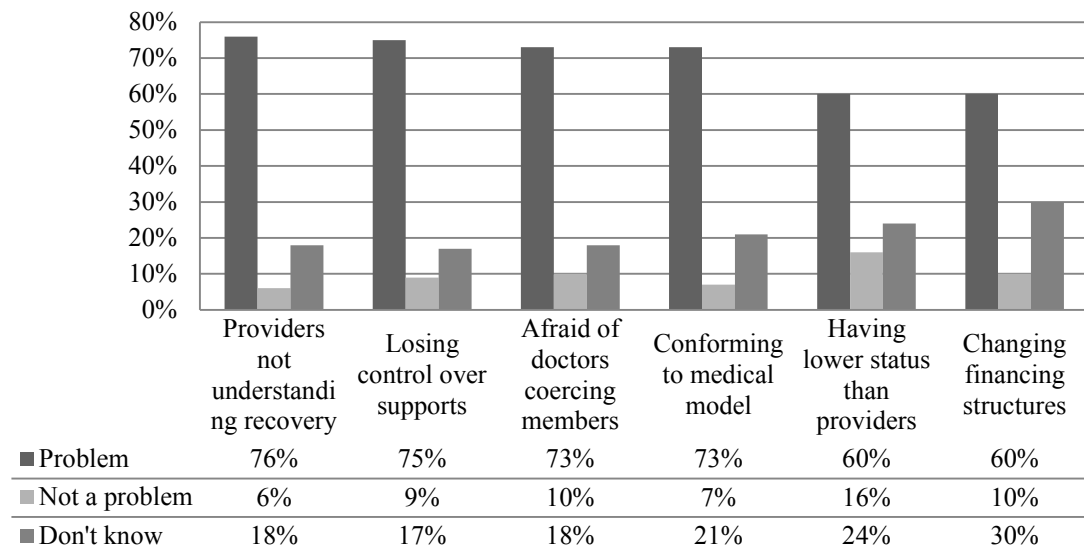
Predictor variable	Yes, willing to participate in health home			Yes, willing to participate in a health home but have concerns			Don't know if willing		
	(N=131)			(N=106)			(N=49)		
	OR	p	95% CI	OR	p	95% CI	OR	p	95% CI
Knowledge of the ACA									
Nothing/A little (reference)	--	--	--	--	--	--	--	--	--
Some things	0.86	0.72	0.39, 1.90	1.15	0.79	0.41, 3.22	0.64	0.41	0.23, 1.82
A lot	1.24	0.78	0.27, 5.73	1.24	0.76	0.32, 4.86	0.44	0.50	0.04, 4.72
Discussed HCR with a government agency or committee	3.04	0.08	0.89, 10.38	2.91	0.10	0.81, 10.49	1.38	0.70	0.27, 7.04
Plan to encourage the use of primary care as part of integration	4.27	<0.05	1.31, 13.91	1.87	0.33	0.52, 6.70	2.14	0.17	0.73, 6.27
Suggest physical healthcare to members…									
Never (reference)	--	--	--	--	--	--	--	--	--
Few times/year	1.94	0.38	0.44, 8.49	3.23	0.15	0.66, 15.81	0.67	0.57	0.17, 2.69
Few times/month	1.94	0.38	0.44, 8.49	3.23	0.15	0.66, 15.81	0.66	0.57	0.17, 2.69
Few times/week	5.05	<0.05	1.16, 21.89	11.20	<0.05	1.77, 70.71	1.45	0.59	0.38, 5.57
Daily	1.72	0.48	0.38, 7.79	6.22	0.32	0.39, 17.84	0.48	0.46	0.07, 3.37
Don't know	2.27	0.30	0.49, 10.54	3.17	0.21	0.53, 18.86	1.89	0.41	0.41, 8.53
Number of members	1.00	0.57	0.99	1.00	0.72	0.99, 1.00	1.00	0.80	0.99, 1.00
Number of paid staff	1.09	<0.05	1.01, 1.19	1.09	<0.05	1.01, 1.19	1.09	0.07	0.99, 1.18

Base category is those who are were not willing, N=45

7.D.iii Concerns about participating in a health home

Respondents who reported they were not willing to be part of a health home, were willing but had concerns, or didn't know if they would be willing were asked to report specific concerns about working with doctors and other providers in this type of arrangement.

Figure 7: Concerns about participation in health homes

	Providers not understanding recovery	Losing control over supports	Afraid of doctors coercing members	Conforming to medical model	Having lower status than providers	Changing financing structures
■ Problem	76%	75%	73%	73%	60%	60%
▪ Not a problem	6%	9%	10%	7%	16%	10%
■ Don't know	18%	17%	18%	21%	24%	30%

The most frequently reported concern was that "providers may not understand the recovery model" (76%) and "we are afraid we will lose control over the services and supports we can offer to our members" (75%). Other potential problems were that "we are afraid doctors will coerce or force our members into services, and our services are voluntary" (73%) and "working with doctors would force us to conform to a medical model" (73%). Less frequently reported concerns were "we will have lower status than other providers in the health home" (60%) and "we would have to change our financing structures" (60%). Respondents were also most frequently uncertain about the latter (30% responding "don't know").

7.E. DISCUSSION

The results of this study demonstrate some actionable implications for successful integration of peer-run organizations into health teams in health homes. Some of these implications are promising, and the others identify areas for attention that can help us prevent problems.

These results suggest that capacity in multiple ways—external relationships and existing patterns of coordination as well as organizational size—are most associated with more positive attitudes toward working with providers to integrate and coordinate care in a health home. Existing relationships with healthcare providers most strongly predicted willingness of peer-run organizations to participate in a health home, compared to knowledge of the ACA or discussions with a government body about healthcare reform. Those who reported active plans to encourage healthcare seeking behavior and are already suggesting to their members that they seek physical healthcare a few times per week were more likely than other groups to be willing to be part of a health home. A larger organizational staff also was associated with willingness to be part of a health home, which may indicate the importance of organizational capacity when implementing innovations in service delivery (Jaskyte, 2011; Jaskyte & Dressler, 2005). Smaller organizations with fewer relationships to primary care providers may struggle or resist partnering in a health home for their members at this time.

Implementation studies of health homes have shown that many decisions are made at the local level in collaborations between government officials and agencies and providers and other stakeholders (Takach, 2011). Only a minority of participants in this study (28%) reported participating in these kinds of discussions. Having participated in those discussions was not significantly associated with being willing to be part of a health home compared to not being willing.

The concerns reported reflect fears about behavioral and physical healthcare integration more generally (Croft & Parish, 2013). The mental health system and associated recovery movement have long perceived "exceptionalism" of this sector

because mental health services and policy have for so long been specialty sector serving people with serious mental disorders with different needs than the general population (Frank & Glied, 2006). This has also been reflected in healthcare financing policy until the relatively recent passage of the Mental Health Parity and Addiction Equity Act of 2008 (Glied & Frank, 2008) and may be waning with greater integration with other health services (Miranda, McGuire, Williams, & Wang, 2008). Peer-run organizations may also have concerns that their needs as organizations, and that of their members, will not be adequately addressed in an integrated healthcare system.

This population of peer support providers for people with mental disorders may be concerned not only about healthcare providers not understanding recovery or the medical model of psychiatric disorders, but also is concerned about "losing control" and having "lower status." Despite efforts to certify, credential, and legitimize peer supporters, there is still confusion among traditional mental health service providers about what qualifies peer supporters and what their role is (Davidson & Guy, 2012). Lack of clarity among providers about the role of peers in health homes could present problems in implementing peer supports as part of health homes. However, some components of health care (e.g. the Veterans Administration) have successfully integrated peers onto teams. Ensuring that roles and responsibilities were clearly defined was seen as being an important component leading to success (Chinman, Shoai, & Cohen, 2010). The concerns reported in this study are from the peer-run organization perspective, but can be useful in designing implementation and team-building approaches to address concerns about power dynamics between peers and providers.

Some concerns reflect the newness of the health home model. Concerns about changing financing structures were less frequently reported as a "big problem" but more frequently identified as confusing to respondents than any other concern. It may be unclear to peer-run organizations what is involved in financial arrangements in health homes. This may be because many of the organizations have not been involved with health homes nor have most of their members. The options for financing health homes include a monthly care management fee or network payments to connect to other behavioral and social services (Takach, 2011). If peer-run organization directors can receive skill-building education about the particulars of these mechanisms, they may be more agreeable as the financing structures become clear.

7.F. CONCLUSION

The health home model will build on states' past experience with medical homes for the Medicaid population. The health home model will also expand traditional medical home models by building linkages to other community and social supports to enhance coordination of medical and behavioral health care (CMS, 2010). As a legislative provision specifically for Medicaid beneficiaries, health homes have an emphasis on care coordination and involving community organizations (Bao, Casalino, & Pincus, 2013). This emphasis on care coordination is important in meeting the needs of Medicaid beneficiaries with complex health conditions. Because of the numerous wraparound supports that peer-run organizations are already providing, they are in a unique position to fill the role of supporting health home members.

Peer-run organizations could be valuable additions to health teams and health homes. Involvement of peer-run organizations can improve delivery of wellness

promotion coaching (Swarbrick, 2013) and self-advocacy interventions, and coordinate care and access to community-based supports (Croft & Parish, 2013). Peer support providers have first-hand experience and knowledge to assist others with similar conditions in managing their own health (Davidson & Guy, 2012) . In peer support, the focus is shifted from illness treatment to health promotion (IOM, 2012). Evidence has consistently found peer support valuable in addressing chronic illnesses; especially interventions related to self-management (IOM, 2012). Peer support and self-management are two intertwined vehicles for service delivery models that promote health, wellness, and empowerment. In many peer support interventions, peers provide the support to learn strategies for self-managing their life circumstances and distress (Copeland, 2009). Peer support interventions can include assistance in learning and overcoming the challenges of diet, exercise, medication effects, and self-monitoring illness control (IOM, 2012). Self-management promotes the person as a collaborator in the process of health and wellness improvement; peer support is a vehicle for building the skills and confidence to for persons with serious mental illness to do so (IOM, 2012).

However, as demonstrated by this study's results, peer-run organization directors had a number of concerns about their organizations participating in a health home. Directors were concerned that there may be unequal power dynamics between the peer providers and medical professionals, and that members may be subjected to coercive treatment. Concerns of these organizations about lack understanding of important constructs such as recovery and coercion should be anticipated and attended to. Challenging power dynamics within the treatment system and advocating for recovery-oriented approaches has been a central goal of consumer/survivor initiatives (Ostrow &

Adams, 2012). Because of historical disempowerment experienced by people with mental disorders (Meyer et al., 2011) and pervasive stigma and self-stigma that impacts self-efficacy (Corrigan, Larson, & Rusch, 2009), the effects of peer-run organizations on empowerment are particularly pertinent to health homes by adding additional supports and assisting clients.

The results of this study show that organizations that already regularly suggest physical healthcare services use and plan to do so more in the future were more willing to be part of a health home than those who did not engage in these patterns and plans. Planners of health home pilots and implementation may want to target peer-run organizations with existing relationships with primary care providers and patterns of encouraging members to attend to physical health and wellness. These organizations may be better suited to early implementation initiatives, and assist the system in learning strategies for engagement of other peer-run organizations in health homes in the future.

8.   DISCUSSION, CONCLUSION, IMPLICATIONS

8.A.   POLICY RECOMMENDATIONS

In the preceding three chapters describing the analytic aims, implications and recommendations for policy, practice, and research were discussed specifically in the context of the analytic aims, including: (1) organizational diversity, development, and management; (2) financing strategies under the ACA and Medicaid expansion; (3) integration of behavioral and physical healthcare in health homes. Here broader recommendations are synthesized and presented.

8.A.i   *Recommendation 1: Service/support array: Consistency with evidence and values*

This study provided data on the activities and operations of peer-run organizations providing services and advocacy that can form the baseline for tracking future changes. Peer-run organizations are an outcome of decades of consumer/survivor advocacy (Morrison, 2013; Ostrow & Adams, 2012). Their goals align with the movement's emphasis on self-determination and leadership within organizations and the community (Chamberlin, 1978; Chamberlin, 1998; Fisher & Spiro, 2010), as well as consumer/survivor leadership in research (Campbell, 2011). Because of this history and continuing interest of advocates in sustaining independent peer-run organizations, it is important that this type of organization remain sustainable within the changing external environment. Like other social movements of disadvantaged and minority groups, the infrastructure of formal organizations and paid positions of leadership provides an important linkage between invested stakeholders, allies, and comrades, and continue efforts towards reform. In particular for peer-run organizations, the values of non-

hierarchical relationships within the organizations has been documented by historical accounts (Morrison, 2013), theory (MacNeil & Mead, 2003), and empirical research (Segal et al., 2013a; Segal, S. P., Silverman, C. J., & Temkin, T. L., 2013b).

Peer-run organizations provide not only opportunities for members to participate in their communities (peers and non-peers), but also for those who work as staff and volunteers in the organizations to gain skills and training in support modalities, leadership, and financial management. There is research on the benefits of peers working in roles of support, as well as that on the benefits of employment more generally for people with psychiatric disabilities (Rosenheck, Kasprow, Frisman, & Liu-Mares, 2003). Therefore, it is important that these organizations be maintained in their current form to offer employment and leadership opportunities, as well as supplying communities with additional resources for people with psychiatric disabilities.

Statewide consumer networks, policy makers, providers, and other stakeholders should monitor whether implementation of the ACA is causing difficulties for the longer-term sustainability of this unique population of organizations in the face of unintended consequences of 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. Technical assistance and advocacy centers can provide a central hub in a state for providing skill-based education about Medicaid reimbursement or health home implementation, or assist in organizing local peer-run organizations to advocate for acceptable changes in policy.

8.A.ii Recommendation 2: Financing and sustainability of peer-run organizations in the era of the ACA

"Sustainability" of mental health peer-run organizations—as described here—indicates not just the continuing existence and financial solvency of these entities, but continued fidelity to their form and function. The concerns of the organizations expressed here regarding Medicaid reimbursement and related re-organization (either as independent providers or as part of networks such as health homes) need to be considered when designing, choosing, and implementing financing policies and best practices in service delivery. Although aspects of these policies are in conflict with this definition of sustainability at this time, it is important to recognize that interests of different stakeholders (including peer-run organizations, other providers, managed care companies, and policy-makers) intersect in the policy environment (Reich, 1990).

Policies and policy initiatives such as the President's New Freedom Commission in 2003, and the passage of the Mental Health Parity Act in 2008 and the Affordable Care Act in Congress in 2010 have provided many opportunities for innovations in our mental health system. Peer support is one of these promising innovations (IOM, 2012; Ramirez & Turner, 2010; Substance Abuse and Mental Health Services Administration ADS Center, 2012). As we increasingly recognize the value of independent peer-run organizations and patient-centered care (Green et al., 2014), we need to monitor if or how peer-run organizations may be negatively impacted in recent developments in policy and financing. As more people without health insurance or whose health insurance was provided through another mechanism get insurance coverage through the ACA and the associated increases in demand, peers are becoming an important addition to address

behavioral health workforce shortages (Hyde, 2013). Exploring innovative and alternative financing mechanisms and partnerships with the input of knowledgeable stakeholders can perhaps prevent unintended consequences on these organizations and their membership. This study addressed some potential challenges, opportunities, and data to support the use of creative financing mechanisms.

8.A.iii Recommendation 3: Future research

Although the number of peer-run organizations as defined here is rather small, these organizations provide an important service to communities. The data obtained by this survey can inform efforts to monitor the extent to which evolving federal, state, and local policies affect the services available to persons with mental disorders. Many researchers collect nationwide data, but local advocates and providers constitute the health care equivalent of the "canaries in the coal mine." As the ACA is implemented in each state, local advocates and providers can help ensure that the components of our service system that increase capacity, voice, and choice for people with lived experience of psychiatric disabilities and treatment remain sustainable. These efforts can be assisted by information gleaned from data collected in nationwide and local research projects.

One of the potentially significant findings of this study is that web-based surveys are feasible in research. The study demonstrates the feasibility of monitoring a population of peer-run organizations using a web-based survey, which facilitates nationwide assessment of important questions about organizational operations and attitudes.

It is important that these organizations continue to be enumerated and monitored for changes in organization and practice associated with the policy environment. In addition to actual data collection through a survey instrument, the updating of the

enumeration is valuable information in itself. The frequency of such updates and data collection waves will be important to establish and stagger appropriately to catch entries and exits, and reduce burden of ensuring correct contact information all at once.

8.B. IMPLICATIONS FOR PARTICIPATORY POLICY RESEARCH

The study's design, data collection, and interpretation were directly informed by key stakeholders—most of them, regardless of their professional role, identifying as people with lived experience—in order to ensure that the results would have value to those invested in improving the lives of people with psychiatric disabilities. These methods demonstrate broader implications not only on this specific topic, but for participatory research methods more generally. Many of the methods used in different stages of the project were consistent with the literature on social validity—*the extent to which those expected to use or benefit from research products judge them as useful and actually use them*—in disabilities research (Seekins & White, 2013, p. S20).

8.B.i *Role of people with lived experience of the mental health system in research*

It is important to recognize the difference between more inclusive participatory models of research as opposed to inclusion of people with lived experience in an advisory capacity. Participatory research includes not only the educated elite within a given minority group, but pursues research questions identified and developed by the target population (Minkler & Wallerstein, 2010). It should be done in a way that is collaborative and actionable, establishes structures for participation, and includes organizational representatives and trained researchers who identify with the community (Viswanathan et al., 2004). This kind of research can lead to greater participation rates in research by harder-to-reach populations, increased external validity, decreased loss to follow-up, and

increased individual and community capacity because community members begin to see the long-term gains associated with research, in comparison to participating in data collection or passive recipients of dissemination efforts (Viswanathan et al., 2004). With community member participation in all stages as well as research led by consumer-researchers, the researchers tend to be viewed not as disinterested outsiders but as allies actively working to meet the community's perceived needs (Meleis, 1996).

The involvement of consumers and consumer-researchers at all levels of this project strengthened its design and implementation through knowledge of the population and relationships within the community. It also contributed sensitivity and insight needed to design an appropriate instrument, enumerate the population, and implement successful recruitment techniques.

This research did not implement a full community-based participatory process because it was a dissertation. This presented difficulties in aspects of participation and project control such as the ability to have co-project leaders who were community members (despite the project director/candidate identifying as a peer), gaining more substantial involvement from the target population in analyses, and delaying dissemination longer than would ideally be done (Nelson et al., 2010; Seekins & White, 2013). Despite these challenges, substantial involvement and input in enumeration, instrument design, recruitment, decisions about analysis, and public dissemination were achieved. The additional funds provided by the Johns Hopkins Center for Mental Health Initiatives and the support of the candidate's primary advisor in obtaining and distributing these were instrumental in the project's success.

8.B.ii   Community buy-in

The invitational letter was co-signed by the SAMHSA consumer technical assistance centers and the National Coalition for Mental Health Recovery (NCMHR) to gain the trust of respondents and signal the importance of the study. Follow-up with non-responders included multiple e-mail and phone contacts by research assistants with lived experience of the mental health system. These research assistants could be sensitive to the demands of organization directors and to their questions about the study. The consensus panel that decided on final inclusion criteria consisted entirely of consumer/survivors; the definition was confirmed by these community members and was based on existing consumer-led research on fidelity to organizational structure (Campbell & Johnsen, 2001).

8.B.iii   Relevance to the consumer/survivor/ex-patient movement

This study provided data that is important in taking a more "democratic" approach for advocates seeking to represent the population of peer-run organizations nationally or in the states—attempting to fostering public discourse which is an essential role in policy-making (Majone, 1988). One of the essential purposes of this study was to provide nationally representative data to advocates and policy-makers to inform perspectives and make data-driven arguments when participating in public policy deliberations about the future of peer-run organizations—similar to these organizations being able to "vote" on their perspectives on policy dialogues held at the national and state levels. When discussing organizational operations and preferences for financing prominent advocates may not always represent constituents who are disadvantaged in program resources. More powerful voices are often given a platform in a democratic

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society. They also dominate in certain types of research commonly used in peer support, such as focus groups (Smithson, 2000).

9. APPENDIX I: SURVEY INSTRUMENT

National Survey of Peer-Run Organizations and Consumer Operated Services

Q1 Hello! Welcome the National Survey of Peer-Run Organizations and Consumer-Operated Services. By answering these questions, your views will be represented when we report the results. Please answer every question. In some cases you may have to make your BEST estimate, or select an answer that most closely fits what your program does or your opinion. If you really don't know the answer, then please select "Don't know", but do not leave any questions blank. In this survey, a "peer" or "consumer" refers to people who are receiving or have received mental health services, survivors/ex-patients, people with a psychiatric diagnosis/label, and people with mental health issues. A "member" is a person who uses your services. It will take you about 20-30 minutes to complete this survey. You may leave and come back to it. If you have any questions, please do not hesitate to contact Laysha Ostrow at (410) 929-2737 or email lostrow@jhsph.edu. Your time and dedication is appreciated!

Q2 Does your organization primarily serve people with substance use issues who do not have mental health issues?
- ○ Yes
- ○ No

Q3 Which of the following are members served by your organization? (please select all that apply)
- ❑ Children or teens, age 17 and younger
- ❑ Youth, ages 18-30
- ❑ Adults
- ❑ Older adults, ages 65 and older
- ❑ Family members of adult peers/consumers
- ❑ Family members of teens or young children
- ❑ Don't know

Q4 Which type of consumer-operated or peer-run organization best describes your organization?
- ○ Youth group or organization (including those that are internet-based)
- ○ Drop-in center (Sometimes called Wellness, Recovery, or Self-help centers)
- ○ Peer educator and advocacy program (where people are taught about recovery, services, or how to advocate)
- ○ Specialized peer support service (where a single problem, such as housing or unemployment, is addressed)
- ○ Peer support line or warmline
- ○ Organized self-help group (where the primary activity is to offer mutual support in a small group)
- ○ Statewide consumer network
- ○ Umbrella organization for smaller peer-support organizations (such as a parent organization, even if not statewide)
- ○ Technical assistance center or advocacy organization
- ○ Peer run crisis respite or peer run respite
- ○ Other type of organization

Q5 If you selected "Other type of organization", what best describes your organization?

Q6 Do you provide direct services to members or clients? Direct services are when you or your staff interact with individual members or groups of members to provide peer support.
- ○ Yes
- ○ No
- ○ Don't know

Q7 How many unduplicated people did you serve during the last fiscal year? Please enter the number of members or your best estimate if you do not know the exact number. If you are statewide or parent organization, only answer for the number of people that you served directly - not the number of people that your affiliated programs served. The

people you served may include those that participated in training or classes.DO NOT ENTER ANY WORDS OR LETTERS.

Q8   In what year was your organization/program started? Please enter a year in YYYY format (for example: 2012).   (Please answer for the organization/program which was identified in your invitation letter)   DO NOT ENTER ANY WORDS OR LETTERS.

Q9 Please select the days of the week that your program is open.
- ❑ Monday
- ❑ Tuesday
- ❑ Wednesday
- ❑ Thursday
- ❑ Friday
- ❑ Saturday
- ❑ Sunday
- ❑ Don't know

Q10 Are you a part of or affiliated with another group or organization (such as a statewide or parent organization)?
- ❍ Yes - We are AFFILIATED with the statewide or parent organization
- ❍ Yes - We ARE the statewide or parent organization
- ❍ No
- ❍ Don't know

Q11 If you are part of or affiliated with another group or organization, what is the name of the group or organization you are a part of or affiliated with?

Q12   Is your organization/program an independent non-profit corporation; in other words, a 501(c)3, 4, or 5?   If you are part of or affiliated with a parent organization or network, only answer for your program/organization. Do not answer for the parent organization.
- ❍ Yes
- ❍ No
- ❍ Don't know

Q13 If you are not an independent non-profit corporation, do you have your own advisory group that decides policies and procedures?
- ❍ Yes
- ❍ No
- ❍ Don't know

Q14 What percentage of the board or advisory group that decides policies and procedures are youth or persons who experienced the mental health system as a youth?
- ❍ No member of the board is a youth or an adult who experienced the mental health system as a youth
- ❍ Less than 51% of the board or advisory group members are youth or adults who experienced the mental health system as a youth (not a majority)
- ❍ 51-90% of the board or advisory group members are youth or adults who experienced the mental health system as a youth (a majority)
- ❍ 91-100%of the board are youth or adults who experienced the mental health system as a youth (a majority)
- ❍ Don't know

Q15   What is the composition of the board that decides policies and procedures?
- ❍ No member of the board is self-identified as a peer/consumer.
- ❍ Less than 51% of the board members self-identify as peers/consumers (not a majority).
- ❍ 51-90% of the board members self-identify as peers/consumers (a majority).
- ❍ 91-100% of the board members self-identify as peers/consumers (a majority).
- ❍ Don't know

Q16 What is the composition of the advisory group that decides policies and procedures?
- ❍ No member of the advisory group is self-identified as a peer/consumer.
- ❍ Less than 51% of the advisory group members self-identify as peers/consumers (not a majority)
- ❍ 51-90% of the advisory group members self-identify as peers/consumers (a majority)
- ❍ 91-100% of the advisory group members self-identify as peers/consumers (a majority)
- ❍ Don't know

Q17   What is the composition of the board of the parent organization or network (that you are a part of) that decides policies and procedures?
- ❍ No member of the board is self-identified as a peer/consumer.
- ❍ Less than 51% of the board members self-identify as peers/consumers (not a majority)
- ❍ 51-90% of the board members self-identify as peers/consumers (a majority)
- ❍ 91-100% of the board members self-identify as peers/consumers (a majority)
- ❍ Don't know

Q18 How influential are members or clients in the decision-making process of your organization?
- ❍ We make decision based on the input of a majority of members.
- ❍ We make decisions based on the input of a selected group of members.
- ❍ We make decisions based on the input of at least some members.
- ❍ We make decisions regardless of the input of members.

Q19   Is the executive director or program manager someone who identifies as a (select all that apply):. (Please answer for the organization or program that was identified in your invitation letter.)

❑ Peer/consumer/survivor/ex-patient
❑ Family member of an adult who has received mental health services
❑ Family member of a youth, teen, or young child with mental, emotional or behavioral health issues
❑ None of the above

Q20 How many years have you been in the position of director at this organization? (Please answer for the organization or program that was identified in your invitation letter or email. This should also be the organization for which you entered the year that the organization started)

❍ less than 6 months
❍ more than 6 months but less than 1 year
❍ 1 year
❍ 2 years
❍ 3 years
❍ 4 years
❍ 5 years
❍ 6 years
❍ 7 years
❍ 8 years
❍ 9 years
❍ 10 years
❍ more than 10 years
❍ Don't know

Q21 How many years have you been a peer support service provider?

❍ less than 6 months
❍ more than 6 months but less than 1 year
❍ 1 year
❍ 2 years
❍ 3 years
❍ 4 years
❍ 5 years
❍ 6 years
❍ 7 years
❍ 8 years
❍ 9 years
❍ 10 years
❍ more than 10 years
❍ Don't know

Q22 As the director, how skilled are you at financial management of an organization?
- ❍ Below Average
- ❍ Average
- ❍ Above Average
- ❍ Don't know

Q23 How effective is your organization at achieving its mission?
- ❍ Very Ineffective
- ❍ Ineffective
- ❍ Neither Effective nor Ineffective
- ❍ Effective
- ❍ Very Effective
- ❍ Don't know

Q24 Do you have a budget?
- ❍ Yes
- ❍ No

Q25 Please enter last fiscal year's budget in dollars. Please report for the same fiscal year that you reported the number of people served. Please make your best estimate. DO NOT ENTER A DOLLAR SIGN ($) OR WORDS.

Q26 From which of the following government sources does your organization or program get money to operate? Please select all of the government sources from which you get money.
- ❑ Federal grants or contracts
- ❑ State grants or contracts
- ❑ City/county/local government grants or contracts
- ❑ Unspecified government sources
- ❑ Medicaid or Medicare claims
- ❑ Other government sources
- ❑ None of the above
- ❑ Don't know

Q27   From which of the following other sources does your organization or program get money to operate?   Please select all of the private sources from which you get money.
- ❑ The group or organization you are part of or affiliated with
- ❑ Contributions, donations, bequests or memorials
- ❑ Membership fees or dues
- ❑ Fund raising activities
- ❑ Private grants or contracts
- ❑ Private insurance
- ❑ Payments for services or products you sell or provide
- ❑ Other sources
- ❑ None of the above
- ❑ Don't know

Q28 Is the majority of your funding (more than 50%) from the government or is it from private sources? Please make your best estimate.
- ○ More than 50% is from the government
- ○ More than 50% is from private sources
- ○ Our funding comes from the government and private sources equally (50% government funding and 50% private sources)
- ○ I do not know where the majority of the funding is from

Q29   Do you feel that funding sources have ever asked that you compromise your values in order to get funding?
- ○ Yes
- ○ No
- ○ Don't know

Q30 If you selected that you get money to operate from "Other government sources", please describe the government sources from which you get money.

Q31 If you selected that you get money to operate from "Other sources", please describe the other sources from which you get money.

Q32 How much do you know about the Affordable Care Act (ACA)?
- ○ Nothing
- ○ A little
- ○ Some things
- ○ A lot
- ○ Everything
- ○ Don't know

Q33 The next question is about discussing how health care reform may impact peer-run services. Have people within your organization…
- ❑ Discussed health care reform within the organization
- ❑ Discussed health care reform within the statewide consumer network
- ❑ Discussed health care reform with a government agency or committee appointed by the government
- ❑ I don't know if people have discussed health care reform

Q34 Do you know of plans to expand Medicaid coverage to more people?
- ❍ Yes
- ❍ No

Q35 Are you willing to become a Medicaid provider? A Medicaid provider is one that bills or submits claims for individuals served or services provided. If you are underneath a parent organization, please answer for your program only.
- ❍ Yes
- ❍ Yes - but we have some concerns
- ❍ No
- ❍ My organization/program is already a Medicaid provider
- ❍ Don't know

Q36 Please tell us all of the practical problems that make you concerned about becoming a Medicaid provider or why you would not be willing to become a Medicaid provider. We would like to know how much of a problem these things might be for your organization.

	Not a problem	A small problem	A big problem	Don't know
We do not want to go through the application process	○	○	○	○
We do not have enough financial staff to manage the billing	○	○	○	○
We do not have computer systems to handle the requirements	○	○	○	○
We do not want to be audited by an insurance company	○	○	○	○
We do not want to keep records for billing and claims	○	○	○	○
We are not able to participate in Medicaid's requirements for quality and performance measurement	○	○	○	○

Q37 Please tell us all of the philosophical or value-based problems that make you concerned about becoming a Medicaid provider or why you would not be willing to become a Medicaid provider. We would like to know how much of a problem these things might be for your organization.

	Not a problem	A small problem	A big problem	Don't know
We do not want to have to justify medical necessity in order to provide our services	○	○	○	○
We are afraid we would have to conform to a medical model	○	○	○	○
We feel that becoming a Medicaid provider organization would detract from our mission of focusing on recovery	○	○	○	○
We are afraid we cannot commit to remaining advocates if we are part of an insurance company network	○	○	○	○

Q38 Are there any other problems that makes you concerned about becoming a Medicaid provider or would not be willing to become a Medicaid provider?

Q39 Do you think there may be problems with peer-run organizations or consumer-operated services accepting Medicaid reimbursement through billing and claims?
- ○ Yes
- ○ No
- ○ Don't know

Q40 What practical problems do you think there may be with peer-run organizations or consumer-operated services accepting Medicaid? We would like to know how much of a problem you think these things are.

	Not a problem	A small problem	A big problem	Don't know
Not wanting to go through the application process	○	○	○	○
Having enough financial staff to manage the billing	○	○	○	○
Having computer systems to handle the requirements	○	○	○	○
Not wanting to be audited by an insurance company	○	○	○	○
Not wanting to keep records for billing and claims	○	○	○	○
Not being able to participate in Medicaid's requirements for quality and performance measurement	○	○	○	○

Q41 What philosophical or value-based problems do you think there may be with peer-run organizations or consumer-operated services accepting Medicaid? We would like to know how much of a problem you think these things are.

	Not a problem	A small problem	A big problem	Don't know
Not wanting to have to justify medical necessity in order to provide our services	○	○	○	○
Being afraid of having to conform to a medical model	○	○	○	○
Feeling that becoming a Medicaid provider organization would detract from the mission of focusing on recovery	○	○	○	○
Being afraid that they cannot commit to remaining advocates if they are part of an insurance company network	○	○	○	○

Q42 Do you think there are any other problems with peer-run organizations or consumer-operated services accepting Medicaid?

Q43 What plans do you have to incorporate integration of behavioral and physical health into your organization's programs?

	Yes	No	Don't know
Hire or train more peer wellness coaches	○	○	○
Offer more wellness classes, such as meditation, smoking cessation, or exercise groups	○	○	○
Encourage members to use physical health services, such as visiting a doctor or nurse	○	○	○
Help members create personalized wellness plans	○	○	○
Other	○	○	○

Q44 How important do you believe physical health and wellness is for your members?
- ○ Not at all Important
- ○ Very Unimportant
- ○ Neither Important nor Unimportant
- ○ Very Important
- ○ Extremely Important
- ○ Don't know

Q45 If selected that you have other plans to incorporate integration of behavioral and physical health care into your organization's programs, please describe those plans.

Q46 Would you be willing to work with other providers, such as doctors, to be part of a health home for your members? A health home is a type of provider organization where multiple providers (such as primary care doctors, psychiatrists, and case managers) work together to coordinate health care.
- ○ Yes
- ○ Yes - but we have some concerns
- ○ No
- ○ We are already part of a health home
- ○ Don't know

Q47   Please tell us all of problems that make you concerned about being part of a health home or why you would not be willing to be part of a health home. We would like to know how much of a concern these things are for you.

	Not a problem	A small problem	A big problem	Don't know
Working with doctors would force us to conform to a medical model	○	○	○	○
Other providers may not understand the recovery model	○	○	○	○
We are afraid we will lose control over our services and supports we can offer to our members	○	○	○	○
We are afraid doctors will coerce or force our members into services, and our services are voluntary	○	○	○	○
We will have lower status than other providers in the health home	○	○	○	○
We would have to change our financing structures	○	○	○	○

Q48 Are there any other reasons that you are concerned about being part of a health home or are not willing to be part of a health home?

Q49 Do you think there may be problems with peer-run organizations or consumer-operated services working with other providers, such as doctors, to be part of a health home for their members? A health home is a type of provider organization where multiple providers (such as primary care doctors, psychiatrists, and case managers) work together to coordinate health care.
   ○ Yes
   ○ No
   ○ Don't know

Q50 Please tell us all of problems there might be with peer-run organizations and consumer-operated services being part of a health home. We would like to know how much of a concern these things are for you.

	Not a problem	A small problem	A big problem	Don't know
Working with doctors would force them to conform to a medical model	○	○	○	○
Other providers may not understand the recovery model	○	○	○	○
They might lose control over the services and supports they offer to their members	○	○	○	○
Doctors might coerce or force their members into services, and their services are voluntary	○	○	○	○
They might have lower status than other providers in the health home	○	○	○	○
They might have to change their financing structures	○	○	○	○

Q51 Are there any other reasons that you are concerned about peer-run organizations or consumer-operated services being part of a health home ?

Q52 Does your organization maintain centralized records or a filing system of members and services provided?
- ○ Yes
- ○ No
- ○ Don't know

Q53 Are these records kept on a computer-based system?
- ○ Yes
- ○ No
- ○ Don't know

Q54   What do you see as the biggest barriers to computer-based systems to keep records of members and services in consumer-operated services or peer-run organizations?

	Not a barrier	A small barrier	A large barrier	Don't know
Computer-based record systems are not adapted specifically for peer-run organizations	○	○	○	○
Computer-based records violate the anonymity of members	○	○	○	○
Staff members are not proficient with computers	○	○	○	○
Computer-based record systems are too expensive	○	○	○	○

Q55   The previous questions asked about Medicaid reimbursement, wellness, health homes, and electronic records. These are aspects of health care reform.   Do you feel that your organization is adequately prepared for health care reform?
   ○ Yes
   ○ No
   ○ Don't know

Q56 How often does your organization suggest to members that they use the following non-peer-operated service providers or help them access these services: Please DO NOT include times that you have only given members information about these services.

	Never	A few times a Year	A few times a Month	A few times a Week	Daily	Don't know
Psychotherapy	❍	❍	❍	❍	❍	❍
Medication management/Psychiatry	❍	❍	❍	❍	❍	❍
Inpatient hospitalization or residential crisis care	❍	❍	❍	❍	❍	❍
Emergency room	❍	❍	❍	❍	❍	❍
Case management or ACT	❍	❍	❍	❍	❍	❍
Disability benefits	❍	❍	❍	❍	❍	❍
Physical health care services	❍	❍	❍	❍	❍	❍
Employment/Job assistance	❍	❍	❍	❍	❍	❍
Housing assistance	❍	❍	❍	❍	❍	❍
Legal assistance	❍	❍	❍	❍	❍	❍

Q57 How often do traditional mental health service providers refer consumers to your organization?
- ❍ Never
- ❍ A few time a year
- ❍ A few times a month
- ❍ A few times a week
- ❍ Daily
- ❍ Don't know

Q58 How often do you suggest to members that they use other peer-provided services?
- ❍ Never
- ❍ A few time a year
- ❍ A few times a month
- ❍ A few times a week
- ❍ Daily
- ❍ Don't know

Q59 Do you think that your organization is sufficiently connected to other peer-provided services in your area?

❍ Yes
❍ No
❍ Don't know

Q60 Please tell us how strongly you agree with the following statements about MOST of the traditional mental health service providers in your area.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Don't know or No opinion
Traditional mental health providers in our area support recovery values.	❍	❍	❍	❍	❍	❍
Traditional mental health providers in our area provide recovery-oriented services to our members.	❍	❍	❍	❍	❍	❍
Traditional mental health providers in our area are supportive of peer-run services.	❍	❍	❍	❍	❍	❍
There is a conflicted relationship between peer-provided services and traditional mental health providers in our area.	❍	❍	❍	❍	❍	❍
Traditional mental health service providers in our area emphasize medication too much.	❍	❍	❍	❍	❍	❍

Q61   Which statement best describes your organization's views about how you fit into the mental health system?

○ We tend to see our organization's activities as an ALTERNATIVE to services received from traditional mental health services and providers.

○ We tend to see our organization's activities as ADDITIONS to services received from traditional mental health services and providers.

○ We tend to see some of our activities as ALTERNATIVES and some of our activities as ADDITIONS to services received from traditional mental health services and providers.

○ No opinion

Q62 In your opinion, which if the following best describes how consumer operated service programs versus traditional mental health services should be used? Would you say people should:

○ Only use consumer-operated service programs

○ Mostly use consumer-operated service programs

○ Use both equally

○ Mostly use traditional mental health services

○ Only use traditional mental health services

○ No opinion

Q63 How many paid part-time and full-time staff do you have?

_____ Part-time

_____ Full-time

Q64   Currently, how many volunteers do you have? Volunteers are people who do work for your organization but do not get paid.

_____ Volunteers

Q65   How many staff or volunteers are trained as...   Please enter the number of staff members trained in each of the following.

_____ Certified peer specialists

_____ Recovery mentors

_____ Peer wellness coaches

_____ WRAP facilitators

_____ Peer group facilitators

_____ Intentional Peer Support (IPS)

_____ Peer bridgers

_____ Peer case managers

_____ Warmline support staff

Q66   Does your organization offer the following trainings?
- ❑ Certified peer specialist
- ❑ Recovery mentoring
- ❑ Peer wellness coaching
- ❑ WRAP facilitation
- ❑ Peer group facilitation
- ❑ Intentional Peer Support (IPS)
- ❑ Peer bridgers
- ❑ Peer case management
- ❑ Warmline support training
- ❑ None of the above
- ❑ Don't know

Q67   How many staff and volunteers are peers/consumers/ex-patients/survivors?
- ❍ None of the staff or volunteers
- ❍ Up to half of the staff and volunteers
- ❍ Most of the staff and volunteers (more than half)
- ❍ All of the staff and volunteers
- ❍ Don't know.

Q68 This section asks about your organization's activities and programs. If you are a statewide or parent organization, please answer for the activities or programs you provide - not those provided by your affiliate programs.

Q69 Is there an adult who provides oversight for the program?
- ❍ Yes
- ❍ No
- ❍ Don't know

Q70 Do you operate a list-serve or website?
- ❍ List-serve
- ❍ Website
- ❍ Both a list-serve and a website
- ❍ Neither
- ❍ Don't know

Q71 Do you provide any of the following for people?

	Yes	No	Don't know
Leadership training such as how to serve on boards, public speaking and advocacy training	○	○	○
Self-care or wellness classes or activities	○	○	○
Wellness Recovery Action Planning (WRAP) courses	○	○	○
Mutual support groups	○	○	○
Warmline or hotline	○	○	○
Crisis respite care	○	○	○

Q72 Do you directly provide any of the following:

	Yes	No	Don't know
Case management	○	○	○
Employment or Education counseling	○	○	○
Housing (such as Supported Housing)	○	○	○
Assistance with the legal system	○	○	○

Q73 Do you run a Drop-in center (sometimes called a Wellness, Recovery, or Self-Help center)
- ○ Yes
- ○ No
- ○ Don't know

Q74 Does your organization coordinate conferences for youth, or tracks/sessions for youth at local or national conferences?
- ○ Yes
- ○ No
- ○ Don't know

Q75 Does your organization do any of the following advocacy activities?

	Yes	No	Don't know
Anti-stigma activities	○	○	○
Demonstrations or protests	○	○	○
Letter writing or testifying for legislatures	○	○	○
Participate on committees that make recommendations to policy-makers	○	○	○
Outreach into the community	○	○	○

Q76 Do you do any other types of advocacy? If so, please explain.

Q77 Does your organization conduct research (either on your activities or other subjects related to mental health)?
- ○ Yes
- ○ No
- ○ Don't know

Q78 Has your program ever been evaluated? Please check Yes if your program is currently in the process of being evaluated.
- ○ Yes
- ○ No
- ○ Don't know

Q79 What do you think your organization needs in order to be more effective? Please rank the choices, with 1 being the most important and 7 being the least important.
_____ Collaboration with other peer support activities
_____ Collaboration with traditional mental health services and providers
_____ Outreach into the community (such as neighbors)
_____ Representation of your organization to other stakeholders by consumer advocates
_____ More technical assistance
_____ More research on consumer-operated services/peer-run organizations
_____ More opportunities for staff training

Q80 Please tell us any other thoughts or comments you have about operating a peer-run organization.

Q81 As the executive director of the organization or program manager, would you like more education about managing an organization?
- ❑ Yes, I would like education on financial management
- ❑ Yes, I would like education on leadership and other management issues
- ❑ Yes, I would like education about both leadership and financial management
- ❑ No, I would not like education on managing an organization
- ❑ Don't know or No opinion

Q82 Please check if you would like to receive a progress report on this survey in 6 months.
- ❑ Yes, please keep me updated!

Q83 Would you like to see the results of this survey presented at state or national meetings?
- ❑ State
- ❑ National
- ❑ I don't care if the results are presented at meetings

Q84 This is the last page of the survey. When you hit the Next button YOUR ANSWERS WILL BE SUBMITTED and you cannot go back.

10. APPENDIX II: INVITATION LETTER TO PARTICIPANTS

Dear Name

Johns Hopkins Bloomberg School of Public Health is conducting a nationwide survey of peer-run organizations and consumer-operated services. ***Organization* is invited to participate in this study.**

Peer-run services are an essential part of promoting mental health. Your participation in the survey will help other stakeholders understand the contribution you are making to communities. It will also allow us to understand the challenges faced by peer-run organizations as the system changes and reforms are implemented. Your responses will contribute important information for planning, funding, and sustainability.

The survey should be completed by the Executive Director or Program Director, or a designee that is equally knowledgeable about the organization. We would like to know your perspective. The survey was created by people with lived experience of mental health services and recovery. We also got input from other peer providers and advocates. Nothing about us without us!

Results will be shared with peers, advocates, and government agencies that support mental health. These reports will be widely disseminated. We intend to make your voice heard. The reports will inform policies that affect you. The results reported on the survey cannot be traced back to your individual organization. Your responses will be combined with others' from your state and nationally.

You will receive an email with a link to the survey shortly. The email will come from *Laysha Ostrow (Johns Hopkins University)*. Please check your junk mail if you do not see the email. Contact us if you do not have an internet connection: We can find another way for you to participate. **Please contact us with any questions.**

Many thanks and best wishes,

Laysha Ostrow and the National Survey Team
Johns Hopkins Bloomberg School of Public Health, Department of Mental Health
Baltimore, Maryland
www.jhsph.edu

We have enclosed $5 as a token of our gratitude for your participation. It is important to get responses from all organizations in order to make the results really have an impact!

THIS STUDY IS ENDORSED BY THE NATIONAL CONSUMER TECHNICAL ASSISTANCE & ADVOCACY CENTERS:

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11. APPENDIX III: RECOMMENDATIONS FOR REPLICATION OF THE PROJECT

The purpose of this section is to highlight some of the challenges in data collection and analysis to inform future projects. Research similar to that reported here that captures the current status of peer-run organizations and can monitor changes over time 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.

11.A.i Enumeration of the population

Enumerating is fundamental to further measurement, knowledge acquisition, and dissemination. The method of using stakeholder input to enumerate the population was used in this study.

The 2002 SAMHSA Survey of Self-Help Organizations reported an estimated 7,500 mutual support, consumer-operated, and self-help organizations programs in the U.S., but targeted a broader population than this study (Goldstrom et al., 2006). We were unable to access the list used by SAMSA in 2002.   About 5,500 of those in the SAMHSA study were mutual support groups and family-run organizations, so would not be eligible for this study. The SAMHSA study team used a screening instrument that asked potential participants "is your organization a consumer or client-operated service or business?" and whether "people who identify as having received mental health services work as staff or administrators, serve on the board, or in some other way run or operated this organization." We used empirically-based methods for exclusion by asking about the

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self-identification of directors, proportion of staff, and proportion of board or advisory group members as people with lived experience of the mental health system.

Statewide consumer networks should attempt to collaborate with organizations/programs in their states and counties to maintain updated lists, and clarify organizational/program boundaries. Our research found that the composition of "statewide consumer networks" and the extent to which they engaged with all peer-run/operated organizations in their states varied considerably. Many statewide consumer networks considered smaller drop-in centers as separate organizations. They have their own budgets and their own directors and in some cases they have their own advisory boards. In other states these drop-in centers were considered subsidiaries of the statewide or other organization because they had entwined fiscal and administrative structures.

11.A.ii Generating the instrument

Many individuals were interviewed to generate the survey instrument. These individuals represented diverse points of view on peer support, the mental health system, the ACA, and survey research methods. The discussions with these key informants were not formal interviews—although questions were developed ahead of each consultation for the particular stakeholder. The conversations were not audio-recorded nor verbatim notes taken; after each key informant interview notes and potential questions were written in a field notebook. In the future, when developing questionnaires such as this one, researchers may want to record interviews, and transcribe and code them.

Members of the consensus panel on inclusion criteria were concerned that the "values" of independent peer support organizations were not adequately measured. This

is because of social desirability bias in self-report—where there can be significant difficulty constructing closed-ended questions where the respondents may choose the "right" answer even if it does not reflect actual practices or beliefs. In the future, a social desirability scale could be integrated to address this potential bias if questions on "values" were included (DeVellis, 2011).

11.A.iii   Variable type and definition in web-based surveys

While continuous variables (when appropriate to the construct under measurement) provide more information for analysis, they may not be most efficient for data collection. In particular, in this web-based survey, the variables that were collected in a free-text entry format were annual budget, year the organization started, and number of unduplicated members in the past year. Consequently, there was missing data or unusable answers more frequently than any other variables because they required the respondent to type an answer rather than check a box. Some respondents typed "don't know"; in rare cases for budget, some respondents wrote-in responses such as "this information is private" or even "none of your business." This is similar to study participants' hesitation to share financial or income information, despite sharing many other personal details such as patterns of substance use—but was not expected of organizational representatives. For members, respondents sometimes wrote out the number (e.g. two hundred) or listed number of members for individual programs instead of the total for the organization; consequently, these had to be hand-recoded into usable number formats. Future surveys of this nature should use categorical variables for these to avoid missing or uninterpretable data. Given the wide variability in these variables that is present in the current dataset, it is likely that recommendations on appropriate

categories could be made—since it does not appear that very high or very low numbers were missing, but rather missing or unusable in some other "random" pattern.

Reviewers of the results, including committee members, wanted to know how much funding was incurred from each of the ten funding sources participants were given as an option to say their organization either did or did not get money from. The variable was created dichotomously in this way to reduce participant burden and inaccurate or missing data. The question could be asked in terms of dollar amounts or percentages to increase precision. Additional funding categories in future surveys might include the criminal justice system and pharmaceutical companies—given current resource availability and interest from the population in these.

Because the questions on Medicaid reimbursement and health home participation needed to be worded differently for direct and non-direct support organizations (based on potential eligibility for participation in these aspects of the ACA), participants were asked to report whether their organization was or was not a direct support provider to design appropriate survey branching. Another way to ask this question could be to ask for the percentage of time or resources that an organization dedicates to direct support—given the results showing that most engage in some kind of "direct support", such as sponsoring mutual support groups.

11.A.iv Inter-rater reliability and member input

Given more resources, including time and project staff, future survey re-designs may want to consider both establishing inter-rater reliability and seeking member input on some questions. If an assistant director is part of the organization, this person could

conceivably answer the survey as well; in the absence of this but the presence of a board of directors, the board president could fill this role in testing. The potential for this depends very much on the structure, size, and capacity of the organization, and may vary widely.

For questions addressing how the supports and activities are viewed (i.e. an "alternative" or not) as well as the degree of member input in decision-making, researchers may consider seeking member and staff input. However, this would take significantly more resources to achieve consistently across so many organizations, and may be infeasible or even unnecessary, depending on the goals of the project. In this project, the objective was not to solicit member or staff input directly.

11.A.v General recommendations for the future

While valuable data is available in this data set these data would become infinitely more valuable with longitudinal follow-up. This would allow us to track changes—including those in financing and organizational sustainability. SAMHSA's National Survey of Substance Abuse Treatment Services (N-SSATS) collects data annually on the number and characteristics of substance abuse treatment facilities. The Agency for Health Care Research and Quality (AHRQ) collects data annually on health care providers, including community mental health centers, through their Area Resource File (ARF). No state or federal agency does this for mental health peer-run organizations. As reported here, we have enumerated this population, but we had to make decisions with little precedent. The primary problem begins with the definition of an organization. Corporations are registered with the IRS, but not all peer-run organizations are independent corporations nor would this categorization be reflected in any IRS

database. Traditional mental health and substance use providers are easier to count than peer-run organizations because they generally have a Medicaid or Medicare provider ID or are registered in their state or county. Many peer-run organizations/programs do not maintain traditional organizational boundaries because of instability of funding and financial management, and because of the grassroots nature of peer support.

12. REFERENCES

2011 NRI Profiles data and 2011 survey of NASMHPD's Medicaid and Financing division.

Adler, D., Bergeson, S., Brown, M., & Fox, P. (2010). The Next Step to Sustainability: Expanding Our Family/Consumer Run Organization's Impact By Joining A Managed Care Organization Network: OptumHealth Public Sector & Child, Adolescent and Family Branch, CMHS/SAMHSA.

Alakeson, V. (2008). Self-directed care for adults with serious mental illness: the barriers to progress. *Psychiatric Services, 59*(7), 792-794.

Alakeson, V. (2010). International development in self-directed care. *Issue brief (Commonwealth Fund), 78*, 1-11.

Alexander, J. (2000). Adaptive strategies of nonprofit human service organizations in an era of devolution and new public management. *Nonprofit Management and Leadership, 10*(3), 287-303.

Allison, P. D. (2007). Missing Data, Quantitative application in social sciences No. 07-136: Sage university press.

Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal, 16*(4), 11.

Arons, B. S. (2005). Recovering the momentum for federal support of multisite demonstrations. *Psychiatric Services, 56*(12), 1621-1621.

Association for Behavioral Health & Wellness. (2013). Peer Support Services: A Valuable Component of Behavioral Healthcare. Washington, DC: Association for Behavioral Health and Wellness.

Balser, D., & McClusky, J. (2005). Managing stakeholder relationships and nonprofit organization effectiveness. *Nonprofit Management and Leadership, 15*(3), 295-315.

Bao, Y., Casalino, L. P., & Pincus, H. A. (2013). Behavioral health and health care reform models: patient-centered medical home, health home, and accountable care organization. *The Journal of Behavioral Health Services & Research, 40*(1), 121-132.

Berwick, D. M. (2009). What 'patient-centered'should mean: confessions of an extremist. *Health Affairs, 28*(4), w555-w565.

Blyler, C. R., Fox, R., & Brown, N. B. (2010). How Governments and Other Funding Sources Can Facilitate Self-Help Research and Services *Mental Health Self-Help* (pp. 235-262): Springer.

Bracke, P., Christiaens, W., & Verhaeghe, M. (2008). Self-Esteem, Self-Efficacy, and the Balance of Peer Support Among Persons With Chronic Mental Health Problems. *Journal of Applied Social Psychology, 38*(2), 436-459.

Brown, L. D., & Lucksted, A. (2010). Theoretical foundations of mental health self-help *Mental health self-help* (pp. 19-38): Springer.

Brown, L. D., Shepherd, M. D., Wituk, S. A., & Meissen, G. (2007). Goal achievement and the accountability of consumer-run organizations. *The Journal of Behavioral Health Services & Research, 34*, 73-82.

Campbell, J. (2009). Federal Multi-Site Study Finds Consumer-Operated Service Programs are Evidence-Based Practices: Missouri Institute of Mental Health.

Campbell, J. (2011). Outcomes measurement and the mental health movement: Research, recovery and recognition in the human services. In J. Magnabosco & R. Manderscheid (Eds.), *Outcomes measurement in the human services: Cross-cutting issues and methods: Second Edition*. Washington DC: National Association of Social Workers Press.

Campbell, J., & Johnsen, M. (2001). Fidelity Assessment/Common Ingredients Tool (FACIT) Protocol. St. Louis, MO: Missouri Institute of Mental Health.

Campbell, J., & Leaver, J. (2003). *Emerging new practices in organized peer support.* Paper presented at the Report from NTAC's National Experts Meeting on Emerging New Practices in Organized Peer Support March.

Campbell, J., Lichtenstein, C., Teague, G., Johnsen, M., Yates, B., & Sonnefeld, J. (2006). The Consumer Operated Service Programs (COSP) Multi-site Research Initiative: Final Report. Saint Louis, MO: Coordinating Center at the Missouri Institute of Mental Health.

Center for Integrated Health Solutions. (2012). Behavioral Health Homes for People with Mental Health & Substance Use Conditions: The Core Clinical Features. Washington, DC: National Council for Community Behavioral Healthcare, Substance Abuse and Mental Health Services Administration and Health

Resources and Services Administration (SAMHSA-HRSA) Center for Integrated Health Solutions (CIHS).

Chamberlin, J. (1978). *On Our Own: Patient-Controlled Alternatives to the Mental Health System*. New York: Hawthorn Books, Inc.

Chamberlin, J. (1990). The Ex-Patients' Movement: Where We've Been and Where We're Going. *Journal of Mind and Behavior, 11*(3), 323-336.

Chamberlin, J. (1998). Citizenship rights and psychiatric disability. *Psychiatric Rehabilitation Journal, 21*, 405.

Chinman, M., George, P., Dougherty, R. H., Daniels, A. S., Ghose, S. S., Swift, A., & Delphin-Rittmon, M. E. (2014). Peer Support Services for Individuals With Serious Mental Illnesses: Assessing the Evidence. *Psychiatric Services*.

Chinman, M., Kloos, B., O'Connell, M., & Davidson, L. (2002). Service providers' views of psychiatric mutual support groups. *Journal of Community Psychology, 30*(4), 349-366.

Chinman, M., Shoai, R., & Cohen, A. (2010). Using organizational change strategies to guide peer support technician implementation in the Veterans Administration. *Psychiatric Rehabilitation Journal, 33*(4), 269.

Clay, S. (2005). *On our own, together: Peer programs for people with mental illness*: Vanderbilt University Press.

CMS. (2010). Letter to State Medicaid Directors. Re: Health Homes for Enrollees with Chronic Conditions: Centers for Medicare and Medicaid Services, Department of Health and Human Services.

Colton, C., & Manderscheid, R. (2006). Congruencies in increased mortality rates, years of potential life lost, and causes of death among public mental health clients in eight states. *Preventing Chronic Disease, 3*(2), A42. http://www.cdc.gov/pcd/issues/2006/apr/05_0180.htm

Cook, J. A., Russell, C., Grey, D. D., & Jonikas, J. A. (2008). Economic Grand Rounds: A Self-Directed Care Model for Mental Health Recovery. *Psychiatr Serv, 59*(6), 600-602. doi: 10.1176/appi.ps.59.6.600

Cook, J. A., Shore, S. E., Burke-Miller, J. K., Jonikas, J. A., Ferrara, M., Colegrove, S., . . . Ohrtman, M. (2010). Participatory action research to establish self-directed care

for mental health recovery in Texas. *Psychiatric Rehabilitation Journal, 34*(2), 137.

Copeland, M. E. (2009). Mental Health Recovery Including Wellness Recovery Action Planning Program Description. West Dummerston, VT: Mary Ellen Copeland: Mental Health Recovery and WRAP.

Corrigan, P. (2006). Impact of consumer-operated services on empowerment and recovery of people with psychiatric disabilities. *Psychiatric Services, 57*(10), 1493-1496.

Corrigan, P. W., Larson, J. E., & Ruesch, N. (2009). Self-stigma and the "why try" effect: impact on life goals and evidence-based practices. *World Psychiatry, 8*(2), 75-81.

Corrigan, P. W., Larson, J. E., & Rusch, N. (2009). Self-stigma and the "why try" effect: impact on life goals and evidence-based practices. *World Psychiatry, 8*(2), 75-81.

Croft, B., & Parish, S. L. (2013). Care integration in the patient protection and affordable care act: Implications for behavioral health. *Administration and Policy in Mental Health and Mental Health Services Research, 40*(4), 258-263.

Daniels, A., Grant, E., Filson, B., Powell, I., Fricks, L., & Goodale, L. (2010). Pillars of Peer Support: Transforming Mental Health Systems of Care Through Peer Support Services. Atlanta Georgia: The Carter Center.

Daniels, A., Tunner, T. P., Bergeson, S., Ashenden, P., Fricks, L., & Powell, I. (2013). Pillars of Peer Support Summit IV: Establishing Standards of Excellence. Atlanta, GA: Pillars of Peer Support.

Daniels, A. S., Cate, R., Bergeson, S., Forquer, S., Niewenhous, G., & Epps, B. (2013). Best Practices: Level-of-Care Criteria for Peer Support Services: A Best-Practice Guide. *Psychiatric Services, 64*(12), 1190-1192.

Daumit, G. L., Pronovost, P. J., Anthony, C. B., Guallar, E., Steinwachs, D. M., & Ford, D. E. (2006). Adverse events during medical and surgical hospitalizations for persons with schizophrenia. *Archives of General Psychiatry, 63*(3), 267.

Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J. K. (1999). Peer support among individuals with severe mental illness: A review of the evidence. *Clinical Psychology: Science and Practice, 6*(2), 165-187.

Davidson, L., Chinman, M., Sells, D., & Rowe, M. (2006). Peer support among adults with serious mental illness: a report from the field. *Schizophr Bull, 32*(3), 443-450. doi: 10.1093/schbul/sbj043

Davidson, L., & Guy, K. (2012). Peer support among persons with severe mental illnesses: a review of evidence and experience. *World Psychiatry, 11*(2), 123-128.

De Vita, C. J., Fleming, C., & Twombly, E. C. (2001). Building Nonprofit Capacity. *Building capacity in nonprofit organizations*, 5.

Deegan, P. E. (1988). Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal, 11*(4), 11-19.

Department of Health and Human Services. (2011). April 11. *Federal Register, Volume 76*(Issue 69).

DeVellis, R. F. (2011). *Scale development: Theory and applications* (Vol. 26): Sage Publications.

Dickerson, F. B., Brown, C. H., Daumit, G. L., LiJuan, F., Goldberg, R. W., Wohlheiter, K., & Dixon, L. B. (2006). Health Status of Individuals With Serious Mental Illness. *Schizophr Bull, 32*(3), 584-589. doi: 10.1093/schbul/sbj048

Diefenbach, T., & Sillince, J. A. (2011). Formal and informal hierarchy in different types of organization. *Organization Studies, 32*(11), 1515-1537.

Dillman, D. A., Smyth, J. D., & Christian, L. M. (2009). Internet, mail, and mixed-mode surveys: The tailored design method.

Donohue, J., Garfield, R., & Lave, J. (2010). The Impact of Expanded Health Insurance Coverage on Individuals with Mental Illnesses and Substance Abuse Disorders. Washington, DC: Assistant Secretary for Planning and Evaluation, Department of Health and Human Services.

Druss, B. G., & Rosenheck, R. A. (1998). Mental disorders and access to medical care in the United States. *The American journal of psychiatry*.

Druss, B. G., Rosenheck, R. A., Desai, M. M., & Perlin, J. B. (2002). Quality of preventive medical care for patients with mental disorders. *Medical Care, 40*(2), 129.

Druss, B. G., Zhao, L., von Esenwein, S. A., Bona, J. R., Fricks, L., Jenkins-Tucker, S., . . . Lorig, K. (2010). The Health and Recovery Peer (HARP) Program: A peer-led

intervention to improve medical self-management for persons with serious mental illness. *Schizophrenia Research, 118*(1), 264-270.

Earnshaw, V. A., & Quinn, D. M. (2011). The Impact of Stigma in Healthcare on People Living With Chronic Illnesses. *Journal of Health Psychology*.

Federici, M. R. (2013). The importance of fidelity in peer-based programs: The case of the Wellness Recovery Action Plan. *Psychiatric Rehabilitation Journal, 36*(4), 314.

Fine, T. (2012). Under the microscope. Peer support: A valued part of recovery, wellness and health reform. Washington, DC: National Association of County Behavioral Health and Developmental Disability Director.

Fisher, D., & Spiro, L. (2010). Finding and Using Our Voice: How Consumer/Survivor Advocacy is Transforming Mental Health Care. *Mental Health Self-Help*, 213-233.

Frank, R., & Glied, S. (2006). *Better But Not Well: Mental Health Policy in the United States since 1950*. Baltimore, M.D.: Johns Hopkins University Press.

Gazley, B., & Brudney, J. L. (2007). The purpose (and perils) of government-nonprofit partnership. *Nonprofit and Voluntary Sector Quarterly, 36*(3), 389-415.

Glied, S., & Frank, R. (2008). Shuffling toward parity--bringing mental health care under the umbrella. *New England Journal of Medicine, 359*(2), 113-115.

Goldman, H. H., Glied, S. A., & Alegria, M. (2008). Mental Health in the Mainstream of Public Policy: Research Issues and Opportunities. *Am J Psychiatry, 165*(9), 1099-1101. doi: 10.1176/appi.ajp.2008.08040584

Goldman, T. (2012). Health reform gets its day in court—the Supreme one. *Health Affairs, 31*(1), 8-11.

Goldstrom, I., Campbell, J., Rogers, J., Lambert, D., Blacklow, B., Henderson, M., & Manderscheid, R. (2004). Mental health consumer organizations: A national picture. *Mental health, United States*, 247-255.

Goldstrom, I., Campbell, J., Rogers, J., Lambert, D., Blacklow, B., Henderson, M., & Manderscheid, R. (2006). National estimates for mental health mutual support groups, self-help organizations, and consumer-operated services. *Administration and Policy in Mental Health and Mental Health Services Research, 33*(1), 92-103.

Grant, E. A., Swink, N., Reinhart, C., & Wituk, S. (2010). The development and implementation of a statewide certified peer specialist program *Mental Health Self-Help* (pp. 193-209): Springer.

Grant, H. M., & Crutchfield, L. R. (2007). Creating high-impact nonprofits. *Stanford Social Innovation Review Fall, 2007*, 32-41.

Green, C. A., Estroff, S. E., Yarborough, B. J. H., Spofford, M., Solloway, M. R., Kitson, R. S., & Perrin, N. A. (2014). Directions for Future Patient-Centered and Comparative Effectiveness Research for People With Serious Mental Illness in a Learning Mental Health Care System. *Schizophr Bull, 40*, S1-+.

Greenfield, T. K., Stoneking, B. C., Humphreys, K., Sundby, E., & Bond, J. (2008). A randomized trial of a mental health consumer-managed alternative to civil commitment for acute psychiatric crisis. *American Journal of Community Psychology, 42*(1), 135-144.

Grob, G., & Goldman, H. H. (2006). *The Dilemma of Federal Mental Health Policy: Radical Reform or Incremental Change?* New Brunswick, N.J.: Rutgers University Press.

Hardiman, E. R., & Segal, S. P. (2003). Community membership and social networks in mental health self-help agencies. *Psychiatric Rehabilitation Journal, 27*(1), 25-33.

Hayden, F. G. (1995). Instrumentalist policymaking: policy criteria in a transactional context. *Economics Department Faculty Publications*, 16.

Holter, M. C., Mowbray, C. T., Bellamy, C. D., MacFarlane, P., & Dukarski, J. (2004). Critical ingredients of consumer run services: Results of a national survey. *Community Mental Health Journal, 40*(1), 47-63.

Hudock, W. (2013). [Peer specialist reimbursement cite at CMHS meeting (email communication)].

Hutchinson, D. S., Anthony, W. A., Ashcraft, L., Johnson, E., Dunn, E. C., Lyass, A., & Rogers, E. S. (2006). The personal and vocational impact of training and employing people with psychiatric disabilities as providers. *Psychiatric rehabilitation journal, 29*(3), 205.

Hyde, P. (2010). Behavioral health 2010: Challenges and opportunities. *Retrieved March, 25*, 2011.

Hyde, P. S. (2013). Report to Congress on the Nation's Substance Abuse and Mental Health Workforce Issues.

International Association of Peer Specialists. (2012). National Practice Guidelines for Peer Supporters. Sparta, MI: International Association of Peer Specialists.

IOM. (2012). Living Well with Chronic Illness: A Call for Public Health Action. Washington, DC: Institute of Medicine, Committee on Living Well with Chronic Disease.

Isett, K. R., Burnam, M. A., Coleman-Beattie, B., Hyde, P. S., Morrissey, J. P., Magnabosco, J., . . . Goldman, H. H. (2007). The State Policy Context of Implementation Issues for Evidence-Based Practices in Mental Health. *Psychiatr Serv, 58*(7), 914-921. doi: 10.1176/appi.ps.58.7.914

Jaskyte, K. (2011). Predictors of administrative and technological innovations in nonprofit organizations. *Public Administration Review, 71*(1), 77-86.

Jaskyte, K., & Dressler, W. W. (2005). Organizational culture and innovation in nonprofit human service organizations. *Administration in social work, 29*(2), 23-41.

Johnsen, M., Teague, G., & Campbell, J. (2006). Assessing Consumer-Operated Services: Development and Characteristics of the Consumer-Operated Service Program Fidelity Assessment Common Ingredients Tool (COSP-FACIT) *Final Report of the COSP Multisite Research Initiative*. St. Louis, MO: Missouri Institute of Mental Health.

Kaiser Family Foundation. (2013). Status of State Action on the Medicaid Expansion Decision, as of December 11, 2013. from http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/

Kaiser Family Foundation. (2014). Integrating Physical and Behavioral Health Care: Promising Medicaid Models. Menlo Park, CA: Kaiser Commission on Medicaid and and Uninsured.

Kaplan, H. B. (2003). *Organizational innovation: Studies of program change in community agencies*: Springer.

Katz, J., & Salzer, M. (2006). Certified Peer Specialist Training Program Descriptions. Philidelphia, PA: UPenn Collaborative on Community Integration of Individuals with Psychiatric Disabilities.

Kessler, R. C., Aguilar-Gaxiola, S., Alonso, J., Chatterji, S., Lee, S., Ormel, J., . . . Wang, P. S. (2009). The global burden of mental disorders: an update from the WHO World Mental Health (WMH) surveys. *Epidemiologia e psichiatria sociale, 18*(1), 23.

Kessler, R. C., Ormel, J., Demler, O., & Stang, P. E. (2003). Comorbid mental disorders account for the role impairment of commonly occurring chronic physical disorders: results from the National Comorbidity Survey. *Journal of Occupational and Environmental Medicine, 45*(12), 1257.

Khaykin, E., Ford, D. E., Pronovost, P. J., Dixon, L., & Daumit, G. L. (2010). National estimates of adverse events during nonpsychiatric hospitalizations for persons with schizophrenia. *General hospital psychiatry, 32*(4), 419-425.

Klein, A. R., Cnaan, R. A., & Whitecraft, J. (1998). Significance of Peer Social Support With Dually Diagnosed Clients: Findings From a Pilot Study. *Research on Social Work Practice, 8*(5), 529-551. doi: 10.1177/104973159800800503

Landers, G. M., & Zhou, M. (2014). The Impact of Medicaid Peer Support Utilization on Cost. *Medicare & Medicaid Research Review, 4*(1), E1-E17.

Leff, H. S., Hughes, D. R., Chow, C. M., Noyes, S., & Ostrow, L. (2010). A Mental Health Allocation and Planning Simulation Model: A Mental Health Planner's Perspective. In Y. Yih (Ed.), *Handbook of Healthcare Delivery Systems*. New York, NY: Taylor & Francis Group.

Levy, M., & Royne, M. B. (2009). The impact of consumers' health literacy on public health. *Journal of Consumer Affairs, 43*(2), 367-372.

MacNeil, C., & Mead, S. (2003). Discovering the Fidelity Standards of Peer Support in an Ethnographic Evaluation. *Journal of Communtiy Psychology*.

Magnabosco, J. L. (2006). Innovations in mental health services implementation: a report on state-level data from the US Evidence-Based Practices Project. *Implementation Science, 1*(13), 13.

Maj, M. (2009). Physical health care in persons with severe mental illness: a public health and ethical priority. *World Psychiatry, 8*(1), 1.

Majone, G. (1988). Policy analysis and public deliberation. *The power of public ideas, 157*, 158.

Mancini, A. D. (2008). Self-determination theory: a framework for the recovery paradigm. *Adv Psychiatr Treat, 14*(5), 358-365. doi: 10.1192/apt.bp.107.004036

Mann, C. (2010). Dear State Medicaid Director, Re: Community Living Initiative. Baltimore, MD: U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services.

Marshall, T., Goldberg, R. W., Braude, L., Dougherty, R. H., Daniels, A. S., Ghose, S. S., . . . Delphin-Rittmon, M. E. (2014). Supported employment: Assessing the evidence. *Psychiatric Services, 65*(1), 16-23.

McAdam, D., & Scott, W. R. (2005). Organizations and movements. *Social movements and organization theory*, 4-40.

McGruder, J. (2001). PART TWO: PHILOSOPHICAL PERSPECTIVES. *Recovery and Wellness: Models of Hope and Empowerment for People with Mental Illness, 17*(3-4), 59.

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

Mechanic, D. (2012). Seizing Opportunities Under The Affordable Care Act For Transforming The Mental And Behavioral Health System. *Health Affairs, 31*(2), 376-382. doi: 10.1377/hlthaff.2011.0623

Meleis, A. I. (1996). Culturally competent scholarship: Substance and rigor. *Advances in nursing science, 19*(2), 1-16.

Mental Health Weekly. (2011a). Calif. Reorganizes MH to Create New State Hospital Department. *Mental Health Weekly, 21*(48), 1-3. doi: 10.1002/mhw.20310

Mental Health Weekly. (2011b). Peer support services help reduce hospitalizations, curb costs. *Mental Health Weekly, 21,* 5.

Meyer, P. S., Mueser, K. T., Southwick, S., Litz, B., Charney, D., & Friedman, M. (2011). Resiliency in individuals with serious mental illness. *Resilience and mental health: Challenges across the lifespan*, 276-288.

Min, S. Y., Whitecraft, J., Rothbard, A. B., & Salzer, M. S. (2007). Peer support for persons with co-occurring disorders and community tenure: A survival analysis. *Psychiatric Rehabilitation Journal, 30*(3), 207-213.

Minkler, M., & Wallerstein, N. (2010). *Community-based participatory research for health: From process to outcomes*: John Wiley & Sons.

Miranda, J., McGuire, T., Williams, D., & Wang, P. (2008). Mental health in the context of health disparities. *American Journal of Psychiatry, 165*(9), 1102-1108.

Moran, G. S., Russinova, Z., Gidugu, V., Yim, J. Y., & Sprague, C. (2012). Benefits and mechanisms of recovery among peer providers with psychiatric illnesses. *Qualitative health research, 22*(3), 304-319.

Moran, G. S., Russinova, Z., & Stepas, K. (2012). Toward understanding the impact of occupational characteristics on the recovery and growth processes of peer providers. *Psychiatric rehabilitation journal, 35*(5), 376.

Morrison, L. J. (2013). *Talking Back to Psychiatry: The Psychiatric Consumer/Survivor/Ex-Patient Movement*: Routledge.

Mowbray, C. T., & Moxley, D. P. (1998). Consumers as mental health providers: First-person account of benefits and limitations. *Journal of Behavioral Health Services & Research, 25*(4), 397.

NAMI. (2010). Public Mental Health Service Funding: An Overview. Arlington, VA: National Alliance on Mental Illness.

National Council for Community Behavioral Healthcare. (2008). Medical homes and people with mental illness: A National Council issue brief.   Retrieved November 25, 2008, from http://www.thenationalcouncil.org/cs/public_policy/medical_homes_issue_brief

Nelson, G., Janzen, R., Ochocka, J., & Trainor, J. (2010). Participatory action research and evaluation with mental health self-help initiatives: A theoretical framework *Mental Health Self-Help* (pp. 39-58): Springer.

Nelson, G., Ochocka, J., Janzen, R., & Trainor, J. (2006). A longitudinal study of mental health consumer/survivor initiatives: Part 1—Literature review and overview of the study. *Journal of Community Psychology, 34*(3), 247-260.

Nelson, G., Ochocka, J., Janzen, R., Trainor, J., Goering, P., & Lomotey, J. (2007). A longitudinal study of mental health consumer/survivor initiatives: Part V– Outcomes at 3-year follow-up. *Journal of Community Psychology, 35*(5), 655-665.

New Freedom Commission. (2003). Achieving the Promise: Transforming Mental Health Care in America. Rockville, M.D.: Department of Health and Human Services.

Office of the Surgeon General. (1999). Mental Health: A Report of the Surgeon General. Rockville, MD: Department of Health and Human Services, U.S. Public Health Services.

Ostrow, L., & Adams, N. (2012). Recovery in the USA: From politics to peer support. *International Review of Psychiatry*(1).

Ostrow, L., & Leaf, P. J. (2014). Improving capacity to monitor and support sustainability of mental health peer-run organizations. *Psychiatr Serv, 65*(2), 239-241. doi: 10.1176/appi.ps.201300187

Pitt, V., Lowe, D., Hill, S., Prictor, M., Hetrick, S. E., Ryan, R., & Berends, L. (2013). Consumer-providers of care for adult clients of statutory mental health services. *Cochrane Database of Systematic Reviews, 3*.

Powell, T., & Perron, B. E. (2010). Self-help groups and mental health/substance use agencies: the benefits of organizational exchange. *Substance use & misuse, 45*(3), 315-329.

Ramirez, A. G., & Turner, B. J. (2010). The role of peer patients in chronic disease management. *Annals of internal medicine, 153*(8), 544-545.

Ratzlaff, S., McDiarmid, D., Marty, D., & Rapp, C. (2006). The Kansas Consumer as Provider program: Measuring the effects of a supported education initiative. *Psychiatric rehabilitation journal, 29*(3), 174.

Reich, R. B. (1990). *The power of public ideas*: Harvard University Press.

Reinhart, C., Meissen, G., Wituk, S., & Shepherd, M. (2005). Setting level characteristics in consumer-run organizations that enhance member outcomes. *International Journal of Self Help and Self Care, 4*(1), 137-147.

Repper, J., & Carter, T. (2011). A review of the literature on peer support in mental health services. *Journal of Mental Health, 20*(4), 392-411.

Rissmiller, D. J., & Rissmiller, J. H. (2006). Evolution of the Antipsychiatry Movement Into Mental Health Consumerism. *Psychiatr Serv, 57*(6), 863-866. doi: 10.1176/appi.ps.57.6.863

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Rogers, E. S., Teague, G. B., Lichenstein, C., Campbell, J., Lyass, A., Chen, R., & Banks, S. (2007). Effects of participation in consumer-operated service programs on both personal and organizationally mediated empowerment: Results of multisite study. *population, 11*, 12.

Rogers, W. H. (1993). Regression standard errors in clustered samples. *Stata Technical Bulletin, 13*, 19-23.

Rosenheck, R., Kasprow, W., Frisman, L., & Liu-Mares, W. (2003). Cost-effectiveness of supported housing for homeless persons with mental illness. *Archives of General Psychiatry, 60*(9), 940.

Rowe, M., Clayton, A., Benedict, P., Bellamy, C., Antunes, K., Miller, R., . . . O'Connell, M. J. (2012). Going to the source: creating a citizenship outcome measure by community-based participatory research methods. *Psychiatric Services, 63*(5), 445-450.

Sabin, J. E., & Daniels, N. (2003). Managed Care: Strengthening the Consumer Voice in Managed Care: VII. The Georgia Peer Specialist Program. *Psychiatr Serv, 54*(4), 497-498. doi: 10.1176/appi.ps.54.4.497

Salzer, M. S. (1997). Consumer empowerment in mental health organizations: Concept, benefits, and impediments. *Administration and Policy in Mental Health and Mental Health Services Research, 24*(5), 425-434.

Salzer, M. S. (2010). Certified peer specialists in the United States behavioral health system: an emerging workforce. *Mental Health Self-Help*, 169-191.

Salzer, M. S., Katz, J., Kidwell, B., Federici, M., & Ward-Colasante, C. (2009). Pennsylvania certified peer specialist initiative: Training, employment and work satisfaction outcomes. *Psychiatric rehabilitation journal, 32*(4), 301-305.

Salzer, M. S., Schwenk, E., & Brusilovskiy, E. (2010). Certified peer specialist roles and activities: Results from a national survey. *Psychiatric Services, 61*(5), 520.

Salzer, M. S., & Shear, S. L. (2002). Identifying consumer-provider benefits in evaluations of consumer-delivered services. *Psychiatric rehabilitation journal, 25*(3), 281-288.

SAMHSA. (2004). National Consensus Statement on Mental Health Recovery. Rockville, M.D.: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.

SAMHSA. (2011). Recovery Support Services: Peer-Operated Recovery Community Center. Rockville, MD: Substance Abuse and Mental Health Services Administration, Financing Center of Excellence.

Schonlau, M., Fricker, R. D., & Elliott, M. N. (2002). *Conducting research surveys via e-mail and the web*: Rand Corp.

Seekins, T., & White, G. W. (2013). Participatory action research designs in applied disability and rehabilitation science: Protecting against threats to social validity. *Archives of physical medicine and rehabilitation, 94*(1), S20-S29.

Segal, S. P., & Silverman, C. (2002). Determinants of client outcomes in self-help agencies. *Psychiatric Services, 53*(3), 304-309.

Segal, S. P., Silverman, C., & Temkin, T. L. (2013a). Are All Consumer-Operated Programs Empowering Self-Help Agencies? *Social Work in Mental Health, 11*(1), 1-15.

Segal, S. P., Silverman, C. J., & Temkin, T. L. (2013b). Self-Stigma and Empowerment in Combined-CMHA and Consumer-Run Services: Two Controlled Trials. *Psychiatric Services, 64*(10), 990-996.

Smith, D. G. (2007). Dear State Medicaid Director, SMDL #07-011: U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services.

Smith, J., & Fetner, T. (2010). Structural approaches in the sociology of social movements. In B. Klandermans & C. Roggeband (Eds.), *Handbook of Social Movements Across Disciplines*. New York: Springer.

Smithson, J. (2000). Using and analysing focus groups: limitations and possibilities. *International Journal of Social Research Methodology, 3*(2), 103-119.

Solomon, P. (2004). Peer Support/Peer Provided Services: Underlying Processes, Benefits, and Critical Ingredients. *Psychiatric Rehabilitation Journal, 27*(4), 392-401.

Solomon, P., & Draine, J. (2001). The state of knowledge of the effectiveness of consumer provided services. *Psychiatric Rehabilitation Journal, 25*(1), 20-27.

Substance Abuse and Mental Health Services Administration. (2006). National Consensus Statement on Mental Health Recovery. Rockville, M.D.: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.

Substance Abuse and Mental Health Services Administration. (2010). What is a Health Home? Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.

Substance Abuse and Mental Health Services Administration. (2011). Leading Change: A Plan for. SAMHSA's Roles and Actions. 2011–2014. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA).

Substance Abuse and Mental Health Services Administration. (2013a). Enrollment under the Medicaid Expansion and Health Insurance Exchanges. A Focus on Those with Behavioral Health Conditions in each State. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.

Substance Abuse and Mental Health Services Administration. (2013b). SAMHSA's Working Definition of Recovery. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.

Substance Abuse and Mental Health Services Administration ADS Center. (2012). Peer-Driven Innovations: Changing Systems, Changing Lives. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.

Swarbrick, M. (2013). *Introduction to Wellness Coaching*. Freehod, NJ: Collaborative Support Programs of New Jersey, Institute for Wellness and Recovery Initiatives.

Swarbrick, M., Murphy, A. A., Zechner, M., Spagnolo, A. B., & Gill, K. J. (2011). Wellness Coaching: A New Role for Peers. *Psychiatric Rehabilitation Journal, 34*(4), 328-331.

Takach, M. (2011). Reinventing Medicaid: state innovations to qualify and pay for patient-centered medical homes show promising results. *Health Affairs, 30*(7), 1325-1334.

Tanenbaum, S. J. (2005). Evidence-based practice as mental health policy: Three controversies and a caveat. *Health Affairs, 24*(1), 163-173.

Viswanathan, M., Ammerman, A., Eng, E., Garlehner, G., Lohr, K. N., Griffith, D., . . . Lux, L. (2004). Community-Based Participatory Research: Assessing the Evidence: Summary.

Ware, N. C., Hopper, K., Tugenberg, T., Dickey, B., & Fisher, D. (2007). Connectedness and citizenship: redefining social integration. *Psychiatric Services, 58*(4), 469-474.

Weiss, B. D., Blanchard, J. S., McGee, D. L., Hart, G., Warren, B., Burgoon, M., & Smith, K. J. (2010). Illiteracy among Medicaid recipients and its relationship to health care costs. *Journal of Health Care for the Poor and Underserved, 5*(2), 99-111.

Whitley, R., Strickler, D., & Drake, R. E. (2011). Recovery centers for people with severe mental illness: a survey of programs. *Community Mental Health Journal*, 1-10.

Wituk, S., Vu, C. C., Brown, L. D., & Meissen, G. (2008). Organizational capacity needs of consumer-run organizations. *Administration and Policy in Mental Health and Mental Health Services Research, 35*(3), 212-219.

Yates, B. T., Mannix, D., Freed, M. C., Campbell, J., Johnsen, M., Jones, K., & Blyler, C. R. (2011). Consumer-operated service programs: Monetary and donated costs and cost-effectiveness. *Psychiatric Rehabilitation Journal, 35*(2), 91-99.

Zerubavel, N., & Wright, M. O. D. (2012). The dilemma of the wounded healer. *Psychotherapy, 49*(4), 482.

Zinman, S., Harp, H., & Budd, S. (1987). Reaching across: Mental health clients helping each other. *Riverside, Calif, California Network of Mental Health Clients*.

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Human Services Research Institute, Cambridge, MA   2010-2012
Mental Health Client Action Network (MHCAN), Santa Cruz, CA   2013
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Committee Memberships

National Institute of Mental Health Alliance for Research Progress, Bethesda, MD 2013-
Mental Health America-San Francisco Advisory Council, San Francisco, CA   2013-
National Coalition for Mental Health Recovery Research Committee, Washington, DC
2013
On Our Own of Frederick Advisory Council, Frederick, MD   2013-2014
SAMHSA Wellness Research and Evaluation Subcommittee   2011-2013
Protection & Advocacy for Individuals with Mental Illness, Boston, MA 2009-2010
Human Rights Committee, Cascap, Inc. Cambridge, MA   2008-2009
SAMHSA/CMHS Innovations in Recovery Crisis Alternatives Workgroup, Rockville,
MD   2009

Professional Affiliations

American Public Health Association, Mental Health section   2012-
ACMHA: The College for Behavioral Health Leadership   2009-

Peer-Reviewed Publications and Book Chapters

Ostrow, L., Manderscheid, R., & Mojtabai, R. (2014). Stigma and difficulty accessing
      medical care in a sample of adults with serious mental illness. *Journal of Health
      Care for the Poor and Underserved.*

Ostrow, L. & Leaf, P.J. (2014). Improving capacity to monitor and support sustainability
      of mental health peer-run organizations. *Psychiatric Services,65*(2), 239-241.

Leaf, P.J, **Ostrow, L.** Manderscheid, R., Shern, D. & Eaton, W.W. (2012). *Progress
      made but much more to be done.* In W.W. Eaton (Ed.) *Public Mental Health.* New
      York: Oxford University Press.

Ostrow, L. & Adams, N. (2012). Recovery in the USA: From Politics to Peer Support. *International Review of Psychiatry, 24*(1), 70-78.

Ostrow, L. & Manderscheid, R. (2010). Medicare Mental Health Parity: A High Potential Change that is Long Overdue. *Journal of Behavioral Health Services & Research*, 37(3), 285-290.

Leff, H.S., Hughes, D.R., Chow, C.M., Noyes, S., & **Ostrow, L.** (2010). A Mental Health Allocation and Planning Simulation Model: A Mental Health Planner's Perspective. In Y. Yih (Ed.) *Handbook of Healthcare Delivery Systems*. New York, NY: Taylor & Francis Group.

Ostrow, L. & Manderscheid, R. (2009). Medicare and Mental Health Parity. *Health Affairs, 28*(3), 922.

Non-peer Reviewed Publications

Ostrow, L. (2013) Civil rights, dangerousness, and mental illness: Beyond the 2[nd] Amendment. *American Public Health Association Student Assembly News & Views, Spring 2013 Edition.* URL: http://www.apha.org/NR/rdonlyres/E586B4E4-40C1-4966-9824-11DA29E0FEFE/0/SpringEdition2013.pdf

Ostrow, L. & Fisher, D.F. (2011) Peer-Run Crisis Respite: A Consumer-Operated Alternative to Psychiatric Hospitalization. Lawrence, MA: National Empowerment Center. URL: http://www.power2u.org/downloads/Ostrow-Fisher-PRCR-12.20.2011.pdf

Ostrow, L. (2010) A Case Study of the Peer-Run Crisis Respite Organizing Process in Massachusetts. Washington, DC: National Coalition for Mental Health Recovery. URL: http://ncmhr.org/downloads/Ostrow_Groundhogs-case-study.pdf

Leff, H.S., Chow, C., Pepin, R., **Ostrow, L**., Conley, J., Jameson, M., & Cichocki, B. (2007). *"A New Hope": The Evidence on Housing for Persons with Severe Mental Illness and Its Implications*. Cambridge, MA: Human Services Research Institute.

Publications Under-Review

Ostrow, L. & Hayes, S. (in review). Non-profit development and leadership by people with lived experience: Characteristics of mental health peer-run organizations nationwide. *Psychiatric Services.*

Conference Presentations and Posters

Ostrow, L., Fisher, D., Frank, R., Davidow, S., Leaf, P. (2013, November*). Peer-Run Organizations and the Affordable Care Act: Research, Policy and Practice Perspectives*. Panel presentation at the American Public Health Association 141[st] Meeting and Exhibition, Boston, MA.

Campbell, J., **Ostrow, L.**, Child, B., Dech, E. (2013, December). *Advocacy and Research Hand-in-Hand.* Workshop at the SAMHSA Alternatives 2013 Conference, Austin, TX.

Ostrow, L. (2012, October). *Bringing the Voice of Peer-Run Programs to the Policy Dialogue: Results of a National Survey.* Workshop at the SAMHSA Alternatives 2012 Conference, Portland, OR.

Ostrow, L. (2012, October). *Peer-Run Respites in the Continuum of Care.* Poster presented at the American Public Health Association 140th Meeting and Exhibition, San Francisco, CA.

Blyler, C., Lupton, C., Leff, H.S., Chow, C., Gonzalez, G., Cichocki, B., Wieman, D., Camacho-Gonsalves, T., **Ostrow, L.** (2011, March). *Before We Disrupt, Have We Transformed?* Poster presented at the ACMHA Summit, New Orleans, LA.

Leff, H.S., Wieman, D., **Ostrow, L.**, Chow, C., Cortes, D., Desrosiers, A., Hermann, R.C. (2010, March). *The Effects of Perceived Cultural Responsiveness and Technical Quality of Care on Perceived Overall Quality of Behavioral Healthcare.* Poster presented at the 2010 Harvard Psychiatry Research Day Poster Session, Boston, MA.

Invited Presentations and Panels

Jacobs, Y., Myrick, K., **Ostrow, L.,** Vega, E. (2013, November). *Peer Respite Centers.* Roundtable Discussion at the Mental Health Services Oversight and Accountability Commission (MHSOAC), Sacramento, CA.

Ostrow, L. (2013, November). *Peer Respite Programs and Peer-driven Crisis Supports for Mental Health: Programs and Findings in innovative support services.* Featured presentation at Community Forum Presented by the Mental Health Association of San Francisco, San Francisco, CA.

Dykens, E., Hyman, S., Insel, T., **Ostrow, L.**, & Volkow, N. (2013, October). *Pushing Back the Frontiers of Knowledge: Research into Mental Illness, Substance Use Disorders, and Intellectual and Developmental Disabilities.* Panel discussion at the Kennedy Forum, Boston, MA.

Ostrow, L. (2013, May). *Peer support for people labeled with mental illness.* Guest lecture in Introduction to Mental Health Services, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD.

Ostrow, L. (2012, June). *Using Peers as the Path to Crisis Care.* Presentation at the On Our Own of Maryland 2012 Annual Conference, Rocky Gap, Maryland.

Ostrow, L. (2010, February). *Peer-Run and Delivered Mental Health Services.* Presentation at 2011 ISCTM National Mental Health Research-to-Policy Forum, Washington, DC.

Research Support

Ongoing Support

Principal Investigator: Philip Leaf   2010 – present
Project: Child Mental Health Services and Service Systems Training Grant
Funder: National Institute of Mental Health (NIMH)

This grant supports both research time for dissertation study and coursework and related requirements for attendance and completion of a doctoral degree.
Role: Pre-doctoral Fellow

Completed Support

Principal Investigator: Laysha Ostrow   2012-2014
Project: National Survey of Peer-Run Organizations and Consumer-Operated Services
Funder: Center for Mental Health Initiatives, Johns Hopkins Bloomberg School of Mental Health
This study is being conducted by John Hopkins School of Public Health. The overall goal of the study is to conduct a survey of peer-run organization and consumer-operated service programs. The study will contribute to information on the role peer-run organizations are playing in the mental health system. The study will provide data for planning, reimbursement, and sustainability, and will be important for diffusing the peer-run model, and educating the government, the organizations, and the advocates.
Role: PI

Principal Investigators: Nev Jones and Laysha Ostrow   2013-2014
Project: Lived Experience Research Network
Funder: Foundation for Excellence in Mental Health Care
The Lived Experience Research Network (LERN) was awarded a matching grant from the Foundation for Excellence in Mental Health Care (FEMHC). The FEMHC grant will match funds up to $50,000 from other sources for projects and initiatives carried out by LERN consistent with its mission of conducting research that informs advocacy and fully involves community members and stakeholders.
Role: Co-PI

Principal Investigator: Amy Colesante   2013
Project: Promoting Engagement Practices in Peer Evaluation/Research
Funder: Substance Abuse and Mental Health Services Administration (SAMHSA)
The Mental Health Empowerment Project (MHEP) was awarded a Bringing Recovery Supports to Scale Technical Assistance Center (BRSS TACS) award for peer-run organizations for the project Promoting Engagement Practices in Peer Evaluation/Research (PEPPER). MHEP has partnered with LERN to design and implement the project, which will be evaluating strategies by researchers in the U.S., U.K., and Canada to engage consumer/survivors of the mental health system in research and evaluation projects. PEPPER will compare strategies, stakeholder perspectives, and evidence and disseminate results to the peer and research communities to advance meaningful participation of people with lived experience in research projects.
Role: Research Co-Director

Principal Investigator: David Stapleton   2013
Project: Disability Research Consortium, Mathematica Policy Research
Funder: Social Security Administration (SSA)
The Disability Research Consortium (DRC) is dedicated to building the evidence base needed for policy changes to the disability support system. The fellowship award was

made under the DRC to conduct data analyses and dissemination of results of data collected from April-October 2012 as part of the National Survey of Peer-Run Organizations and Consumer-Operated Services.
Role: Dissertation Fellow

Principal Investigator: Laysha Ostrow   2010
Project: Case Study of the Peer-Run Crisis Respite Organizing Process in Massachusetts
Funder: Heller Master of Public Policy Scholarship
This was a case study on in Massachusetts of a group of consumer/survivor advocates, called Groundhogs, who organized themselves in early 2009 to design, lobby for, and implement peer-run crisis respites in the state. This case study focused on Groundhogs' organizing strategies, intended to inform advocacy groups in other states and counties that are interested in peer-run crisis respites.
Role: PI

Principal Investigator: H. Stephen Leff   2008-2010
Project: The Effects of Perceived Cultural Responsiveness and Technical Quality of Care on Perceived Overall Quality of Care
Funder: Robert Wood Johnson Foundation
This study, funded by the Robert Wood Johnson Foundation, included four sample populations -Haitians, Portuguese-speakers (mostly Brazilian), Hispanics/Latinos, and African-Americans. Perceived Overall Quality of Care (POQC) was measured using the Experience of Care and Health Outcomes (ECHO) survey instrument, which asks mental health consumers about their experience of and satisfaction with their mental health care. Technical Quality of Care (TQC) was measured through electronic medical record reviews, using established clinical guidelines for quality of care for depression and other major mental illnesses.
Role: Project Coordinator