



**Peer led Recovery Learning Communities:
Expanding Social Integration Opportunities for People with the Lived Experience
of Psychiatric Disability and Emotional Distress**

Jonathan Delman, Deborah R. Delman, Brenda R. Vezina, and John Piselli

Author Notes:

Jonathan Delman is Assistant Research Professor and the Director of the Program for Recovery Research at the University of Massachusetts Medical School, Department of Psychiatry, in Worcester, Massachusetts, 01655, USA. Phone: 617-877-4148. Email: Jonathan.Delman@umassmed.edu.

Deborah R. Delman, CPS* is the Executive Director of the Transformation Center in Boston, Massachusetts 02119, USA, deborahd@transformation-center.org.

Brenda R. Vezina, MSW, CPS* is the Director of the Central Massachusetts Recovery Learning Community in Worcester, Massachusetts 01603, USA, Brenda.Vezina@centralmassrlc.org,

John Piselli, MA, CAGS, CRC is the Community Coordinator of the Metro-Suburban Recovery Learning Community in Quincy, Massachusetts 02169, USA, JPiselli@metrosubrlc.org.

*CPS - "Certified Peer Specialist"

Keywords: Psychiatric disability, Peer, Peer support, Peer-operated, Recovery, Social Integration, Social network, Social exclusion, Mental Health

Recommended Citation: Delman, J., Delman, D.R., Vezina, B.R., & Piselli, J. (2014). Peer led Recovery Learning Communities: Expanding Social Integration Opportunities for People with Lived Experience of Psychiatric Disability and Emotional Distress. *Global Journal of Community Psychology Practice*, 5(1), 1-11. Retrieved Day/Month/Year, from (<http://www.gjcpp.org/>).

Peer led Recovery Learning Communities: Expanding Social Integration Opportunities for People with the Lived Experience of Psychiatric Disability and Emotional Distress

Abstract

Social integration is the development of mutually supportive relationships with other community members. For people with psychiatric disabilities (PD) social integration is a critical aspect of mental wellness and recovery. While people with PD generally want supportive friends, their social networks tend to be weak, often limited to treatment staff and close family. The barriers to social integration of people with PD are often high, and include public discrimination, lack of confidence, and insufficient financial resources. In the United States, community mental health providers have focused primarily on illness management and have not successfully helped clients integrate socially. To fill that gap, people with lived experience of psychiatric disability have for many years established networks of peer support, including peer-facilitated groups.

With the aim of enhancing that approach, peers in Massachusetts developed the “Recovery Learning Community” model, a regional network of peer support and education operated and staffed by people with lived experience, are distinct from most other peer run programs in that they provide meetings and workshops in various community locations, not only in a single location. In this article, we describe conceptually and with examples the significant impact RLCs have on both the social integration of people with PD and the delivery of mental health services in United States and internationally.

Keywords: Psychiatric disability, Peer, Peer support, Peer-operated, Recovery, Social Integration, Social network, Social exclusion, Mental Health

Introduction

While people with psychiatric disabilities (PD) benefit greatly from the development of large and supportive social networks, mental health providers have generally been unable to meet their social support needs. People with lived experience of psychiatric disability and emotional distress in Massachusetts have tried to address these needs by developing and implementing regional networks of peer support, educational meetings, and recovery groups. In this article, we describe how the unique properties/characteristics of these regional “Recovery Learning Communities” (RLCs) provide participants with substantive opportunities for social integration.

Social integration is the development of mutually supportive relationships with other community members (Wong, Matejkowski, & Lee, 2010). Research has shown that social integration for people with PD results in reduced symptomology, reduced rates of hospitalization, and higher rates of recovery (Hendryx, Green, & Perrin, 2009). However, the weak social networks of people with PD are often limited to treatment staff and close family (Wong, Matejkowski, & Lee, 2010).

People with PD typically encounter high barriers to social integration (Perkins & Repper, 2013). These barriers include public stereotyping and discrimination, interpersonal social stigma, self-stigma, lack of confidence, and insufficient financial resources. Family members often take on the responsibility of providing their loved ones with socialization opportunities, but are most frequently left with feelings of failure and despair (Davidson et al., 2004). In addition, community mental health providers have not been effective in helping clients integrate socially (Schutt & Rogers, 2009). Their focus on illness management and community stability has taken precedence over the attainment of a valued and fulfilling role in society.

People with PD have for many years engaged in mutual peer support, through which people with similar difficulties share knowledge and experiences and thus help each other emotionally, practically, and socially. Peer support can take place informally or in groups, which are often facilitated by an experienced member who works to facilitate an environment of empathy and non-judgment. In the 1970s and 1980s, peer led organizations, administratively and financially controlled and staffed by people with PD, emerged to develop and coordinate peer support programs and networks. (SAMHSA, 2011). These “peer run” organizations were uniquely capable of establishing a

recovery-oriented and psychologically safe culture in which peer support could thrive (Ostrow & Leaf, 2014).

We are members of a larger group of people with mental health conditions living in Massachusetts who have advocated that all services be recovery-oriented with a strong emphasis on peer support. We have all directed peer run organizations, seen the direct benefits they offer both staff and participants, and have had a significant role in the development of the Recovery Learning Community (RLC) model. RLCs are regional peer run and staffed education and training organizations that offer peer support, peer education and public education activities. RLC community members broadly describe themselves as people with “lived experience” of “mental illness”, “emotional distress”, a trauma history, and/or the iatrogenic effects of treatment. Thus, while we describe the population studied in the social integration research literature as the population studied- “people with physical disabilities”, we describe the population that participates in RLC activities more broadly as “people with lived experience”.

We discuss below the basis and potential for the RLC model to promote social integration and transformative change in community mental health at various ecological levels. To encourage innovation and research in this area, we also describe our conceptual framework on the impact of peer run RLCs on social integration and systems transformation.

The Social Networks of People with Psychiatric Disabilities

A social network is a construct with both structural and functional elements that describes a person’s relationships with others (Wong et al., 2010). The structural element is composed of the network’s size, density and the frequency and intensity of contact. For people with PD, research has documented that larger social networks generally improve their sense of support and well-being (Wong et al., 2010). The functional component of a social network includes social support, a person’s perception of and capacity for accessing emotional support, companionship, and direct assistance. People with PD appear to derive a sense of general satisfaction from regular contact with people, regardless of the solidity of those relationships. Research demonstrates that the social support component has direct positive effects on a person’s health and well-being. Social support acts as a counterbalance to stress, and for people with PD often results in symptom reduction, housing stability, and improved subjective quality of life and recovery (Wong et al., 2010). Social support is strongest when there is an interpersonal exchange of support and/or resources with others. When support is reciprocal in nature, the self-worth of a person with PD is enhanced by being a

helper and not consistently the “helped” (Kogstad, Mönness, & Sörensen, 2013).

Unfortunately, the social networks of people with PD tend to be weak. Friends tend to drop away shortly after someone is diagnosed with “mental illness”, acts oddly, and/or loses his/her social status. A significant subset of people with PD experience ongoing social isolation, which potentially contributes to higher rates of disordered cognition, paranoia, and suicidal ideation (Pevalin & Goldberg, 2003). Thus the social networks of people with PD are small and made up primarily of relatives and/or paid mental health workers (Davidson et al., 2004). These interpersonal relationships of people with PD can be prominently one sided. Clinicians are paid for interpersonal services that are not reciprocal, and parents often take on a primary caretaking and/or support role (Davidson et al., 2004).

Attending programs or living in group homes may enhance social networks of people with PD through ongoing contacts with their peers (Davidson et al., 2004). However, these limited social networks typically do not promote identity transformation beyond one’s psychiatric label, and can restrict opportunities for participation in broader community activities, such as gatherings not focused on mental health topics (Ware, Hopper, Tugenberg, Dickey, & Fisher, 2007).

People with Psychiatric Disabilities and the Process of Social Integration

Social integration is the process through which an individual uses intrapersonal and external resources to develop a satisfactory social network (Wong et al., 2010). To be socially integrated is to have an adequately sized social network that includes people without PD and contains supportive and reciprocal relationships. Socially isolated people with PD generally want that social support and a wider group of friends (Bradshaw, Armour, & Roseborough, 2007). The pathways to gaining social support may not always be obvious to people with PD, who may suffer from a loss of confidence due to living a life built around their diagnosis (Livingston & Boyd, 2010). Economic, social and health care structures that categorize citizens based on labels and social class have set a precedent that excludes people with PD from society at large.

People with PD struggle with developing social networks in part due to the societal and structural stigma associated with a “mental illness” label (Livingston & Boyd, 2010). People with PD are often stereotyped as irresponsible, disruptive, at fault for their adversity, and “lost causes” (Perkins & Repper, 2013). The unfounded belief that people with mental illness are inherently dangerous has been a causal element of social exclusion. For example, organizations offering volunteer opportunities (e.g., mentoring organizations) often screen out people with PD. Employers in

particular may be reluctant to hire people with PD, and even religious and spiritual communities have been known to discourage their participation in favor of people with other kinds of disabilities. As such, there is a strong affective component of social exclusion that includes personal shame and a sense of disenfranchisement.

Another barrier to social integration for people with PD is that many are surviving on subsistence levels of income (if that), while they rely on modest government income support and health benefits (Wong, et al., 2010). As a result, many people with PD do not have the resources necessary to obtain sustained access to many popular community based social activities, such as hobby clubs – if they can even afford the kind of attire that is necessary to be included socially within them (Bradshaw et al., 2007).

Despite these barriers, many people with PD have successfully become socially integrated by taking on established adult social roles such as employee, student, advocate, club member, parent, religious/spiritual member, and romantic partner (Bradshaw et al., 2007). The attainment of these roles is an ongoing process that often begins through interactions that involve not only reciprocity but also self-disclosure (Davidson et al., 2004). Reciprocity is more likely when people have shared interests and perspectives on life. Self-disclosure enhances the likelihood of friendship by providing a level of interpersonal intimacy. What's less clear is the capacity of community mental health services to promote meaningful social integration, and not only a support network but also friendship and bonding (Kogstad et al., 2013).

The Mediating Role of the United States Mental Health System

The United States mental health system is not designed to effectively promote social integration, and in some cases it acts as a barrier (Schutt & Rogers, 2009). Conventional approaches to mental health service delivery have often physically separated people with PD from others for extended periods of time. This includes multi-year stays in state hospitals, and housing in large residential programs and group homes. While these group settings can promote peer support and even camaraderie, this population reports high levels of loneliness and social isolation (Davidson et al., 2001).

Mental health clinics have typically not provided direct assistance to clients to help them socially integrate (Kogstad, et al., 2013). Providers generally are focused on clinical stability, symptom reduction, and/or the attainment of income and housing supports. Many such providers are concerned that social interactions outside the controlled mental health setting (i.e., with the general public) could be overly stressful and result in a “relapse”. A primary example

here is the practice of clinicians' discouraging people with PD from seeking and holding competitive jobs. This practice flies in the face of evidence supporting the capacity of people with PD to engage in and derive psychosocial benefits from competitive employment (Crowther, Marshall, Bond, & Huxley, 2001).

Some providers have promoted social integration for their clients through preparatory groups and classes on symptom management, improved self-esteem, and social skill development. Research has shown however that these indirect efforts do not enhance social networks (Davidson et al., 2001). Some psychiatric rehabilitation providers have aimed to create conditions for people to develop social skills, such as structured day programs, but the gains made within the program have not translated to more natural and unstructured community settings.

Because of the lack of social integration programming and success, the research on how people with PD successfully socially integrate is sparse (Wong et al., 2009). The research does suggest that it is important to look beyond the traditional mental health system to more natural settings for social integration to occur (Kogstad et al., 2013). Peer support and peer run programs are recognized as important to improving rates of social integration.

Peer support and Peer run organizations: Toward Mental Health Recovery and Social Integration

With peer support, people with PD share common concerns and provide emotional support and coping strategies to manage and promote personal well-being. Peer support presupposes that people with similar difficulties are more likely to relate to one another with empathy and validation. Peer support has typically been provided through grassroots get-togethers of people who found that the clinical system did not offer them sufficient support for their wellness and recovery (Brown, 2009).

During the 1960s and 1970s, people with PD in the United States began to develop their own peer support and advocacy organizations as an alternative to “mainstream services”, which were seen as unhelpful, paternalistic, and at times hurtful (Tannenbaum, 2012). These peer operated organizations were often incorporated as non-profits, with the majority of the board of directors being people with PD (SAMHSA, 2011). The most common peer-run programs early on were “drop in” centers, where people with PD could gather casually and socialize on a regular basis, without concerns about illness disclosure or employment status (Brown, 2009). Many peer operated organizations now offer education and advocacy training, specialized assistance for personal issues (e.g., personal finance, housing, medical care, etc.), warm lines (telephonic

peer support), and community connections (Ahmed et al., 2012). As of 2005, there were over two thousand consumer-operated organizations in the U.S. (Goldstrom, et al., 2005). Only in the past decade have peer run programs been considered an important component of the publicly funded mental health system (Ostrow & Leaf, 2014).

Peer operated organizations were not designed only for people with PD to provide supports and services (Ahmed et al., 2012). People who invest their time to develop peer run programs have a shared and unconventional belief system, formed around the idea that recovery from mental illness is a reality and that it occurs through a community of staff/participant power sharing, self-determination, empowerment, and peer support. (Nelson, Ochocka, Janzen, & Trainor, 2006). This “radically” transformative programming requires that peers fully control program resources, unencumbered by conflicting agendas (Chamberlin, 2005). Thus, a peer run program operating within a larger organizational context may find it challenging to comply with organizational standards, such as job titles and pay rates that do not value the peer role. In addition, non-peer managers who oversee or share responsibility for “peer run” programs are usually risk averse, and may see peer innovators as “inexperienced” or irresponsible (Chamberlin, 2005). Even the possibility that management would veto a peer leadership programming decision or force a compromise in lieu of a new peer services approach (e.g., hearing voices support group) hampers peer driven innovation. Along with attaining full administrative control, challenges to implementation are often based on insufficient funding. Peer run programs have also consistently reported initial difficulties collaborating with providers who discount their value, and sometimes even their existence (Tannenbaum, 2012).

Research supports the effectiveness of peer run programs in improving people’s lives, including improvements in coping skills, social support, community tenure, vocational status, and quality of life (SAMHSA, 2011). Peer run services reduce the use of acute care service settings, such as hospitalizations and emergency rooms (Nelson et al., 2006). Brown (2009) posits that the positive atmosphere of a drop in center leads to members’ trying new activities, providing support to others, and developing friendships. Peers adopt leadership roles within these organization as employees, peer facilitators, and/or as board members, and most frequently by taking responsibility for a project. Peer programs provide an ideology of hope that serves as a basis for people to become active in their own recovery. Social role models exemplify “hope”, and can spark a full exploration of one’s potential. Peer programs offer a psychological sense of community for

a person to explore that potential (Nelson et al., 2006). Within such organizations, participants safely engage in non-clinical peer interactions and relationships, and thus develop identities that are independent of and stronger than a diagnostic category/label. And as peers gain control over resources and establish more balanced connections with providers and systems leaders, they are better able to effect systems policy advocacy for funding and policy restructuring (Ahmed et al., 2012).

With regard to social integration outcomes, studies report that active and sustained participation in peer run programs is strongly associated with larger social networks and increased social support, primarily within the peer community (Nelson et al., 2006; Schutt & Rogers, 2009). Some people taking part in the activities of peer run programs have reported developing the skills and confidence to join community groups, make friends, and re-connect with old friends (Brown, 2009). However, the research is inconclusive on the overall impact of peer run organization participation on the development of non-peer social networks.

The Recovery Learning Community Model

In Massachusetts, a new organizational model of peer-operated services and supports has emerged, in part to help people engage socially in a non-clinical setting. Recovery Learning Communities (RLCs) are staffed by people with PD who, in concert with many volunteers, run regional networks of peer support, peer education meetings, and public education. RLCs are distinct from most other peer run programs in that they provide peer support meetings, classes and workshops in various community locations (as opposed to a single location). Six RLCs, each spanning a different geographic region of Massachusetts, serve populations that range from close to a million in the more rural western and southeastern regions to over 2 million in the densely settled eastern and northeastern suburban regions of the state. Fundamentally, RLCs have five primary responsibilities:

- mental health recovery network development and coordination;
- peer support;
- regional continuing education and training for peer specialists and providers;
- enhanced information and referral including support for individual self-advocacy;
- regional systems advocacy.

RLCs are open to any community member who is struggling with a mental health concern. They are also open to community members who have an interest in learning about mental health issues. RLCs prioritize an organizational culture that extends a universal welcome to people in the general public as well as those who use mental health services or programs. Learning and

support opportunities are designed to be collaborative in all cases and are not “edited” in a particular way for a “mentally ill” population. This means that community members at large engage in activities just as they would through adult education programs, social clubs, or other groups that meet regularly.

The RLC program design was created through a process of community organizing and needs assessment that was led by the statewide peer advocacy organization M-POWER¹, along with other peer run entities in Massachusetts. The group’s leadership noted that (mental health) “recovery happens locally” and that a person in recovery benefits from continuity of relationships (CHANGE Planning Team Report, 2001, p. 3). Leaders realized that discreet program locations, even if numerous, would not engage people who did not attend mental health programs or who were in hospitals. This Recovery Learning Community Model, developed by people with PD, was then procured by the state mental health authority through a competitive bidding process in 2005.

To bring a decentralized model to life, RLCs engage in purposeful networking activity to form many different relationships with people and organizations present in their geographic regions. In addition, each RLC has one or more office spaces which operate as hubs for networking, and are called “Resource Connection Centers” (RCCs). RCCs are locations where the general public can easily access RLC resources and often include computer access, drop-in support, resource libraries and volunteering opportunities. Business and governance functions also occur at these leased, donated or bartered-for spaces. Office hours may cover regular business hours or emphasize evening and weekend hours.

Using these RCC hubs as a base, the RLC develops weekly support meetings in libraries, shelters, coffee shops, state agency offices, church halls, community mental health program sites, hospital inpatient units, bookstores, food market community rooms, addiction recovery peer support centers, college student unions, and any other space where a collaboration is established. Events are organized for artistic displays, performances, educational presentations, and celebrations. These events occur at a variety of locations such as the local performance hall, college auditorium, city or town hall, library, religious organization hall, mental health or public service agency space, local movie theatre/café or RLC space. Meetings and events welcome the general public, and calendars for RCC-based and other activities are published monthly in print and on RLC websites.

RLC activities are varied and examples are provided in Table 1 below. The categories of activities, or types of participation, are drawn from the work of Brown (2009), who reported that social integration for drop-in center members was achieved through interpersonal interactions, work opportunities, a positive atmosphere, and recreational activities. For the community-based RLCs, we added two categories: “community connections” and “classes/trainings.”

¹ Massachusetts People/Patients Organized for Wellness, Empowerment and Rights

Table 1. *The Participation of People with PD in Recovery Learning Communities* (Adapted from: Brown (2009), p. 184)

Work activities	Recreation activities	Interpersonal interaction	Positive atmosphere	Community Connections	Classes/Trainings
Paid peer employment	Drum Circle Knitting circle	Attending peer support meetings	Role modeling	Outreach visits to other organizations	Wellness Recovery Action Plan (WRAP)
Group facilitation	Latin Karaoke	Attending education/training events	Social support, recovery stories, shared experiences	Public service event participation	Computer Class
Preparation for Peer Specialist work	Recovery through music Hiking	Assisting a person in self-advocacy	Shared leadership	Group trips	Financial Peace Addiction and Trauma
Office work (reception, email, fax)	Workouts at the local Gym Summer Cookout	Public Speaking Event coordination	Community-driven values and principles		Language classes (ASL, Spanish, English)

RLCs receive funding from the state mental health authority for core staff, who are required by both the model and the funding source to be people with PD. The RLC staff structure includes a Director who is responsible to community-wide governance and planning groups, and who supervises several coordinators who work twenty to forty hours per week. Staff coordinators support clerical/administrative functions, regional peer support activities, community outreach and networking, training, communications and/or anchor activity in a geographic subarea of the RLC region. Coordinators accomplish their responsibilities through a combination of personal task completion, coordination of volunteer activity, and supervision of people who may be engaged in just one to four hours per week to co-facilitate a support meeting or class.

RLC community participants are trained and often paid to facilitate support meetings or a variety of classes. RLCs economize on mileage costs by recruiting facilitators who live close to the meeting site, and may pay mileage only when the facilitator must travel beyond a specified distance. RLCs set clear training, ethical, and performance requirements for facilitators, whether they are paid or volunteer. The RLC staff and leaders regularly orient all participants - staff and volunteers - to values and principles that guide ethical relationships and community interactions. All RLC staff are trained to support a person in taking action to support him/herself, and to resist the temptation to act on behalf of another person.

To minimize the inevitable power imbalance between staff and participants, RLC staff and facilitators learn to present themselves holistically, inviting relationships of

mutuality with participants by sharing their own experiences, vulnerabilities and successes. In addition, RLCs create opportunities for participants to take on leadership roles. RLCs also plan network priorities through a dynamic process of assessing the community's need and passion for various initiatives, and then assessing available leadership and resources. RLCs gather input from participants, and hold open community planning meetings to set short- and long-term goals for the network.

RLC participation is completely voluntary. The voluntary nature of the RLC model is founded on the belief that the awakening, sustaining and refining of self-agency is essential to mental health recovery. Thus the respect for the choices a person makes (for example, toward or away from participation) is an essential and defining component of RLC organizational culture. Thus, RLCs orient mental health professionals to introduce people to the RLC staff rather than to simply refer clients to the RLC. RLCs do not expect or welcome introductions, which disclose a person's diagnosis or treatment goals, and instead expect to engage with a person around a mutual exchange of interests and ideas while orienting a newcomer to the options available through participation. RLCs do not document details of a participant's interactions as a condition of funding.

RLC leaders view of relationships and community in the context of the principle of "reciprocity." Thus, a business executive struggling with suicidal feelings receives warmth and wisdom from a person who is currently homeless but strong in internal safety. A local farmer drops by the RCC with baskets of vegetables that people take home and enjoy, and RLC participants

attend his mother’s funeral and sit with the man in his grief. A neighborhood Senior Center, concerned about depression in its community, invites RLC leaders to do a presentation, and a respected elder shares for the first time in public her institutionalization experience during the 1950s - which opens a deeply moving conversation. RLC participants join a local substance abuse taskforce to coordinate efforts with town officials and the public health agency. They find themselves as lead presenters in a conference on trauma and recovery, and find a new venue to showcase a film they created on the topic.

RLCs, Social Integration, and Systems Transformation

Our conceptual framework for how peer run organizations, particularly RLCs, can impact both participant social integration and mental health services transformation is described in Table 2. The first column is a distillation of Table 1’s categories of RLC participation, and the five columns flowing from that represent expected outcomes, from shorter to longer term. The descriptions of “Intrapersonal Outcomes” are

based on the work of Brown (2009). Thus, RLC activities create *opportunities for transformation* to an identity that is more outgoing, conscientious, independent, and group oriented. Through regular social interaction, members build *role (social, coping, job) skills*. Naturally people *reappraise* themselves in relation to their self-esteem and optimism. To Brown’s (2009) categories we have added “*self-agency*”, which is going beyond reappraisal to having the capacity to take action based on advancement in the other three intrapersonal domains.

The interpersonal outcome domains are derived from several sources. Brown (2009) uses the term “*resource exchange*” in reference to activities that permit a participant to take on role-related responsibilities, such as encouraging other people in attendance at peer centers to consider a paid position there or elsewhere. Ware and others (2007) describe “*active citizenship*” as exercising one’s skills and abilities to actively engage in and influence life and society as full citizens. “*Social network*” is the broadest description of an interpersonal domain and is discussed above.

Table 2. *Conceptual Framework: RLC participation and Social Integration and Community Impact Outcomes*

RLC Participation	Intrapersonal Outcomes	Interpersonal Outcomes	Community Outcomes	Systems Outcomes	National/ International Outcomes
Interpersonal interactions	Identity transformation	Social Network -Structural -Support	Educated public	People with PD in policy leadership	Meetings of community oriented organizations
Positive atmosphere	Self-appraisal	Active citizenship	Relationships change perceptions and judgments	Greater acceptance of provider disclosure	Research focus on community outcomes
Community connections	Self-agency	Resource Exchange	Normalization, Disclosure in safety	Less reliance on acute care	Manual/ toolkit
Work activities	Role skills		Improved public mental health	Greater reliance on social supports	Increased knowledge of social int. and correct supports
Recreation activities				Enhanced rates of recovery	
Classes/ Trainings					

The impact of participation is mediated by several variables. For the participant, social integration is less likely when the person is experiencing prejudice and discrimination, has a high degree of self-stigma, and has heightend levels of depression and anxiety. RLC participation as discussed above offers a person people, places and activities to lessen these burdens.

Inter and Intra Personal changes and Community Impact. Both intrapersonal and

interpersonal outcomes are established in the RLC through support and education that includes alternative healing opportunities (e.g. yoga), stress reduction, mindfulness, financial wellness, health self-advocacy, wellness and crisis prevention planning, and computer skills workshops. Visual arts and music naturally expand paths for connection and collaboration by de-emphasizing verbal communication and by involving both audience and participants. RLC drum circles,

“open mic” events, art gallery openings and shows, music theory and guitar lessons, to name a few examples, are offered to the community at large and often feature performances and exhibits for the greater community. For example:

Joseph had great difficulty in social situations. After participating in a RLC drum circle for a few weeks, he accompanied other RLC members to a public drum circle. He found it to be an enjoyable experience and was able to look people in the eye. He now calls himself a “fanatic” about drumming and attends “every circle (he) can find.” He also now facilitates two drum circles himself in a mental health agency and an alcohol and drug rehab center.

Practical skills and self-advocacy are part of learning about choices that lead to strengthened social networks and community connections. People experience success at job searches and learn about electronic social media to communicate with family and to connect with old friends. Financial Peace class members successfully achieved their financial goals, which included reducing the interest rate on credit card debt, securing a car loan at an affordable rate, setting up a bank account for savings, and saving for presents for family members.

Dramatic examples of social integration occur among people who have been locked in a cycle of frequent hospitalizations. For example, at one RLC five people had been hospitalized from 60 to 120 days in a single year. Each had accepted this cycle of hospitalizations as an inevitable part of dealing with an illness. Hearing that recovery was possible at the RLC was new knowledge for them. Support meetings facilitated from a stance of mutuality between facilitators and participants provided an opportunity to reappraise their ability to manage difficulties without hospitalization. Engaging in RLC activities resulted in each person establishing or re-establishing social roles including “supporter,” “facilitator” and “leader.” As a result, transformational identity shifts became possible from “mental patient” to “grandmother,” “friend,” “cable producer,” “musician” and/or “poet.” Each of these people was able to find and use a new way of thinking about her difficulties, use her expanded social network, and demonstrate agency in self-care so that going to the hospital was not necessary for long periods of time. For example,

In 2011 Marilee was hospitalized for over 80 days. In 2012 she began coming to the RLC and has been hospitalized once since that time. She wanted other people in her city to become aware of the hope for mental health recovery. With another RLC member she took a cable TV access course and is now producing cable access shows on mental health and wellness. In addition, she displayed her flute talents

at RLC events, and was asked to perform at a city hall for over 140 people as part of a mental health awareness program. Her interest in music revitalized, she tried out for and was accepted into a music collective that arranges performances at various community events.

Although there is a relatively high prevalence of serious mental illness within the United States, few disclose their conditions to others and many do not seek treatment. The stigma and prejudice accompanying mental illness often results in a loss of self-esteem (“internalized oppression”) and self-agency. The peer network model aims to stimulate conversations and relationships that break down this barrier of silence, ease the path to more conversations about mental health struggles, and break down the artificial barrier between those who are “identified mental patients” in the community and those who “can pass as normal.” Peer network planners believe in the experience of mental health recovery that with greater self-acceptance there are new realistic pathways for increased quality of life and self-agency. At the same time, this networking model is expected to enrich the community at large by de-cloaking the experience of extreme emotional states, and by initiating broader community conversations where resourceful strategies, role modeling and support become increasingly available. By engaging with people who are suffering, other community members, mental health providers and policy makers collectively, RLCs are establishing a broader sense of community based competence to discuss and respond to mental health issues that occur regularly in community life.

Perhaps the most crosscutting theme in the prevalence of mental health issues in our society is not that the experiences are abnormal, but that people are generally uncomfortable and feel disempowered to discuss them and learn about healing. Thus, the experience of hearing voices is more prevalent than one would believe because few discuss it in general public conversation. The experience of suicidal thinking and self-inflicted violence is rarely discussed, yet it is known to be fairly common, especially at specific ages within a variety of cultural groups. RLC conversations address all these topics, sharing tools and strategies, and the empathy that is needed for developing self-agency and connection.

System, National and International Impacts. The goal of system restructuring is to make a positive impact on the quality of life of people with lived experience and the community as a whole. The RLC model is designed to promote “radical” notions of recovery, peer support, and social integration of people with PD. One key method was identifying allies—within the existing service structure and within the broader community—where the network would be cooperatively involved with community groups,

professions and agencies to increase the areas where there is consensus around mental health issues.

RLCs are at the forefront of understanding the prevalence and impact of trauma on high service use and early mortality. RLCs have been moving systems to a greater understanding that hope and personal relationships provide the foundation for mental health recovery. RLCs advocated to successfully initiate a peer operated respite center where alternative personal support is offered to people who stay overnight rather than be admitted to a hospital.

While the Massachusetts mental health authority currently promotes “person centered planning” and “recovery oriented programs,” many individuals who work within it remain unclear of exactly what that means and how to achieve it. RLC staff and participants provide experiential guidance through advisory boards and workgroups that focus on eliminating vestiges of a system that expected lifelong dependence. They also participate in a statewide policy committee called The Transformation Committee, which is charged with advising the state on integrating peer support roles and certified peer specialists in traditional services. RLC members meet with legislators to inspire them with the understanding of concrete positive outcomes when a program focuses on recovery and activates the person’s own energy for self-care.

The RLC model itself works to break down barriers between services for addiction recovery, criminal justice, adults with physical disabilities, elders and youth. These divides, generated by funding silos and by negative societal stereotypes, are bridged by the relational community connections and system advocacy of RLCs. A unifying factor among these groups is the experience of trauma and marginalization, which can be addressed by personal empowerment and access strategies.

There is great potential for the RLC model to have national and international impact through effective dissemination and research. Beyond attending and presenting at conferences, we hope to conduct research on the effectiveness of RLCs, first by developing a manual and toolkit and then working with partners to collect and analyze data. Ultimately, we aim to develop new knowledge for systems and policy leaders to establish effective methods of peer driven social integration and services transformation.

Acknowledgements

We would like to thank the Massachusetts Department of Mental Health for its continued funding for RLC operations and development. In addition, we’d like to thank the University of Massachusetts, Department of Psychiatry’s Program for Recovery Research for

supporting our initial research development on RLC operations and effectiveness.

References

- Ahmed, A. O., Doane, N. J., Mabe, P. A., Buckley, P. F., Birgenheir, D., & Goodrum, N. M. (2012). Peers and peer-led interventions for people with schizophrenia. *Psychiatric Clinics of North America*, 35(3), 699.
- Bradshaw, W., Armour, M. P., & Roseborough, D. (2007). Finding a place in the world: The experience of recovery from severe mental illness. *Qualitative Social Work*, 6(1), 27-47.
- Brown, L. D. (2009). How people can benefit from mental health consumer-run organizations. *American Journal of Community Psychology*, 43(3-4), 177-188.
- Chamberlin, J. (2005). User/consumer involvement in mental health service delivery. *Epidemiologia e Psichiatria Sociale*, 14(1), 10-14.
- Crowther, R., Marshall, M., Bond, G., & Huxley, P. (2001). Vocational rehabilitation for people with severe mental illness. *Cochrane Database of Systematic Reviews*, 2.
- Davidson, L., Haglund, K. E., Stayner, D. A., Rakfeldt, J., Chinman, M. J., & Tebes, J. K. (2001). “It was just realizing . . . that life isn’t one big horror”: A qualitative study of supported socialization. *Psychiatric Rehabilitation Journal*, 24, 275–292.
- Davidson, L., Shahar, G., Stayner, D. A., Chinman, M. J., Rakfeldt, J., & Tebes, J. K. (2004). Supported socialization for people with psychiatric disabilities: Lessons from a randomized controlled trial. *Journal of Community Psychology*, 32(4), 453-477.
- Goldstrom, I., Campbell, J., Rogers, J., Placklow, B., Henderson, M., & Manderscheid, R. W. (2005). 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.
- Hendryx, M., Green, C. A., & Perrin, N. A. (2009). Social support, activities, and recovery from serious mental illness. *Journal of Behavioral Health Services and Research*, 36, 320-329.
- Kogstad, R. E., Mönness, E., & Sörensen, T. (2013). Social networks for mental health clients: Resources and solution. *Community Mental Health Journal*, 49(1), 95-100.
- Livingston, J. D., & Boyd, J. E. (2010). Correlates and consequences of internalized stigma for people

- living with mental illness: a systematic review and meta-analysis. *Social Science & Medicine*, 71(12), 2150-2161.
- Massachusetts People/Patients Organized for Wellness, Empowerment and Rights (2001). *CHANGE Planning Team Report*. Boston, MA
- 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, 247–260.
- 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.
- Perkins, R., & Repper, J. (2013). Prejudice, discrimination and social exclusion: reducing the barriers to recovery for people diagnosed with mental health problems in the UK. *Neuropsychiatry*, 3(4), 377-384
- Pevalin, D. J., & Goldberg, D. P. (2003). Social precursors to onset and recovery from episodes of common mental illness. *Psychological Medicine*, 2, 299-306.
- Schutt, R. K., & Rogers, E. S. (2009). Empowerment and peer support: Structure and process of self-help in a consumer-run center for individuals with mental illness. *Journal of Community Psychology*, 37(6), 697- 710.
- Substance Abuse and Mental Health Services Administration (SAMHSA) (2011). The Evidence: Consumer Operated Services. <http://store.samhsa.gov/shin/content//SMA11-4633CD-DVD/TheEvidence-COSP.pdf>, Rockville, MD.
- Tanenbaum, S. J. (2012). Consumer-operated service organizations: organizational characteristics, community relationships, and the potential for citizenship. *Community Mental Health Journal*, 48(4), 397-406.
- Ware, N., Hopper, K., Tugenberg, T., Dickey, B., & Fisher, D. (2008). A theory of social integration as quality of life. *Psychiatric Services*, 59(1), 27-33.
- Wong, Y. I., Matejkowski, J., & Lee, S. (2010). Social integration of people with serious mental illness: Network transactions and satisfaction. *The Journal of Behavioral Health Services & Research*, 38(1), 54-71.