

Recovery Learning Community Outcomes Study

PROGRAM FOR RECOVERY RESEARCH
SYSTEMS AND PSYCHOSOCIAL ADVANCES RESEARCH CENTER (SPARC)
MA DMH RESEARCH CENTER OF EXCELLENCE
UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL, DEPT. OF PSYCHIATRY

Jonathan Delman, PhD, JD, MPH

Lorna Simon, MA

Karen Albert, MS

TABLE OF CONTENTS

I.	Executive Summary	3
II.	Introduction.....	4
III.	Methodology.....	6
IV.	Findings.....	9
V.	Discussion.....	20
VI.	References.....	22

I. EXECUTIVE SUMMARY

- Recovery Learning Communities (RLCs) are regional peer run and staffed organizations that offer a variety of peer supports and educational opportunities throughout a designated geographic area. They are funded primarily by the Massachusetts Department of Mental Health (DMH).
- This paper describes a study of the impact of RLC participation on respondents' subjective sense of recovery and on their health, social connectedness, and vocational status. A team of researchers, RLC representatives, and DMH staff developed a mixed-methods written survey. RLC participants completed the survey anonymously, in both paper and web-based formats. The study was approved by the DMH and UMass Medical School IRBs.
- Two-hundred and sixty-three (263) eligible people completed a survey between November 2013 and February 2014. The large majority were white/Caucasian and slightly more than half were female. Almost two-thirds had been participating in RLC activities for over one year, and a large majority were participating at least once per week. The most common activities reported by respondents were peer groups and meetings.
- Almost three-quarters of respondents felt that RLC participation contributed to their overall recovery. Among recorded demographic and RLC participation factors, only participation frequency and participation in most activities beyond groups/activities were associated with higher rates of overall recovery.
- With regard to specific aspects of recovery, respondents most commonly reported a meaningful improvement in their awareness of the right to be treated with dignity and respect and their feeling better about themselves. Respondents were least likely to report meaningful recovery improvements with regard to participation in activities outside the RLC and their taking on leadership roles inside and outside the RLC.
- A large majority of respondents reported positive life and health improvements since starting at an RLC, with many attributing those changes to RLC participation. Most respondents developed new friendships and became more comfortable in social settings. A large majority reported reduced use of emergency rooms and hospitals, the development of crisis action plans, and greater consideration toward looking for a job.
- When attributing life and health gains to RLC participation, respondents most frequently cited as very helpful the support and encouragement of RLC staff, friends they made there, having learned to successfully manage stress, improved self-confidence, and regular exercise.
- We recommend that RLCs consider quality improvement efforts to engage higher numbers of participants in developing wellness strategies and participating in community activities.
- We recommend further research to better understand how RLC participants make psychosocial gains and achieve recovery. This includes qualitative studies to learn how specific elements of RLCs impact key outcomes, and longitudinal studies to identify the steps and stages of recovery in relation to RLC participation.

II. INTRODUCTION

Mental health recovery for people diagnosed with serious mental illness (SMI) is a relatively new concept in the field. In the literature, recovery has been discussed as both a process and an outcome. The Substance Abuse and Mental Health Services Administration (SAMHSA) describes “recovery” as a non-linear “*process of change* through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential” (SAMHSA, 2011¹).

As an outcome, there are various interpretations of “recovery.” On a clinical level, recovery is seen as the reduction or remission of symptoms, and studies have demonstrated that this type of recovery takes place for people diagnosed with SMI (Harding, 1987; Harrow, 2012). Outcomes can also be assessed at a more personal level; as Deegan (1988, p. 1) notes, recovery is ‘to live, work, and love in a community in which one makes a significant contribution.’ It is now recognized that people diagnosed with SMI attain this type of recovery as well, in essence seeking and finding a valued social role for themselves. The research shows that this personal recovery is itself associated with symptom reduction, fewer psychiatric hospitalizations, and improved residential stability (SAMHSA, 2011).

Only recently has recovery become an overarching aim of mental health services systems (Slade et al., 2008). This new line of thinking challenges the conventional notions that SMI is a deteriorating disease and that the sole treatment aim should be symptom control. Thus, most types of mental health services do not focus on recovery outcomes, but instead are focused on stability or less frequently specific rehabilitation outcomes (e.g. education, employment).

Assessments of mental health program effectiveness have typically not used measures of personal recovery, even though there are several partially validated instruments (Salzer & Brusilovskiy, 2014; Shanks et al., 2013). Some programs do not use them because they do not see recovery as their aim and/or misunderstand the concept of recovery (Slade, 2014). Alternatively, many programs are not aware these measures exist or are unfamiliar with the process of outcomes measurement. Providers also face administrative burdens in assessing consumer perspectives on outcomes. For example, the above referenced instruments must be administered more than once longitudinally to the same group of consumers; data collection must be well-timed in order to obtain an equivalent assessment of a population’s outcomes (Slade, 2002).

In an effort to promote recovery outcomes for individuals living with SMI, in 2005 mental health consumers in Massachusetts worked with the Department of Mental Health (DMH) to develop the Recovery Learning Community (RLC) model of peer service provision. RLCs are peer run recovery organizations, administratively and financially managed and staffed by people with a lived experience of emotional difficulties, and provide staff and participants with the experience of giving and receiving peer supports in empowering ways (Delman, Delman, Vezina & Piselli, 2014; Mead & MacNeil, 2006). RLCs are distinct from most other peer run programs because they provide peer support groups and classes in a variety of towns/cities as opposed to a single location. In Massachusetts, there are six RLCs that provide coverage across the Commonwealth. Anyone having

¹ <http://www.samhsa.gov/newsroom/advisories/1112223420.aspx>

mental health difficulties can participate in RLC activities, with a large majority of users being people diagnosed with a mental illness, including those with serious mental illnesses.

The RLCs are grounded in research demonstrating peer run organizations as evidence-based practices that promote health and wellness outcomes, including improvements in quality of life, social support, coping skills, and reductions in hospitalizations (SAMHSA, 2011). While peer led RLCs are promising practices, there is no research to date their effectiveness, and little information on how specific program elements impact recovery outcomes (Brown, 2009).

In this report we describe research and findings regarding the personal outcomes of people who participate in RLCs. Our focus is on people's subjective sense of recovery in relation to RLC participation, as well as their beliefs that the RLC helped them make positive changes in their work, health and social connectedness. The recovery outcomes survey instrument our team designed reflects the perspectives of RLC program directors, peer researchers, and the Massachusetts DMH.

This research is important to assess the effectiveness of the innovative RLC model. In addition, the survey asks respondents in this one-time assessment to consider directly how RLCs promoted specific personal and life changes. Currently there are no standardized measures that examine recovery outcomes in relation to service use (See Cavelti et al., 2012). The development of this survey is thus a significant contribution to the field of recovery research, and provides a launching point for programs to begin to measure their effect on personal recovery.

II. METHODOLOGY

This is a cross-sectional recovery outcomes study for people who have participated in Recovery Learning Community (RLC) activities. The data reported in this article were collected anonymously through a paper and web-based a survey. This project was approved by the UMass Medical School and DMH Internal Review Boards (IRBs).

Survey Development

The survey was developed in 2013 as collaborative effort of the six RLC Directors and designees, DMH leadership, and the UMass Systems and Psychosocial Advances Research Center's (SPARC) Program for Recovery Research. These stakeholders met multiple times over a six-month period to identify the primary staff outcomes the RLCs were designed to promote. A survey to assess those outcomes was drafted by SPARC and reviewed by the survey team. The survey was piloted with 20 RLC participants who provided feedback that was incorporated into the final version. The survey incorporates mixed methods, with mostly quantitative items. The survey was translated into Spanish and Portuguese by DMH staff.

Participants

RLCs are open to any community member living with a mental health issue, though most participants are people diagnosed with a mental illness. Participants were eligible for this study if they were 18 years of age and older and had participated in RLC activities in the previous six months. RLCs do not maintain a list of participants, and as a result a convenience sample was used for this study.

Survey

The survey we developed and administered contains four sections as described below: 1) Demographics, 2) RLC participation, 3) Recovery outcomes, and 4) Life and health outcomes.

Demographics

We collected information on eight demographic variables to describe our respondent group and to assess their impact on recovery outcomes. Demographics included gender, race/ethnicity, veteran status, homeless status, and vocational status.

RLC participation

We collected information on four RLC participation variables to assess their impact on recovery outcomes. Information was collected about the intensity of participation, length of participation, type(s) of participation, and the specific RLC the respondent was connected with.

Recovery Outcomes

Twelve items were developed to assess personal recovery outcomes. We used the FACT-G² anchor statement and scale to assessment reports of improvement. Thus, all items were prefaced with the statement "*As a result of my connection to the RLC...*" For example, item one is "*As a*

² FACT-G is an acronym for "Functional Assessment of Cancer Therapy, Global" This scale has been used and tested to detect retrospective change in quality of life for cancer patients. (Cella, Hahn, & Dineen, 2002).

result of my connection to the RLC, I am better able to handle stressful situations.” Respondents were asked to report “how true” each statement was using the following scale:

Not at all (1); A little bit (2); Somewhat (3); Quite a bit (4); Very much (5).

The team that developed the survey created items that were designed to fall into three domains representing the actual terminology used in the model’s title- Recovery/Learning/Community, as presented in Table 1.

Table 1. Recovery Outcomes Survey

Recovery	Learning	Community
I feel better about myself.	I am aware of my right to be treated with dignity and respect.	I have more supportive people in my life.
I have more hope for my future.	I have a better understanding of what recovery is for me.	I have a greater sense of connection and value to my community.
I take an active role in decisions about my life.	I am aware of new ways to improve my life.	I have taken on more leadership roles.
I am able to make positive changes in my life.	I am better able to handle stressful situations.	I am more involved in activities outside the RLC community

Life and Health Outcomes

We posed a series of questions to assess how RLC participation had affected more concrete changes in a respondent’s life. We first asked respondents to report whether specific aspects of their lives had changed since starting their participation in an RLC. The change items fell within three domains:

- School and Work life (7 items)
- Emotional and Physical health (5 items)
- School and Community Life (7 items)

The anchor statement for each item is “*Since being connected to the RLC, I...*” followed by a personal change statement, such as: “*have started to think about looking for job.*” Respondents had an option of responding “yes”, “no” or “not applicable.” (Unlike the above recovery-outcome items, we did not ask the respondent to directly tie the personal change to RLC use.)

If respondents answered “yes” to any item within a domain, they were asked whether their connection to the RLC had helped them to make any of the referenced changes, with the answer options being “yes”, “no” and “n/a.” If they answered “yes” to that question, they were asked to “*please describe or summarize*” how the RLC had helped them.

Data Collection

Our recruitment strategy provided for anonymity for interested RLC participants. Flyers were posted at all six RLC locations, and some RLCs posted the flyer on their website and/or

distributed them via email. At each RLC location there was a dedicated area where participants could pick up the survey, a stamped return addressed envelope, and a Fact Sheet describing the purpose of the survey, study procedures, and risks. Locked boxes were available at various RLC locations, away from staff sitting areas, where participants could return completed surveys. People who received an electronic weblink to the survey via email opened to the Fact Sheet and survey, which provided another link for them to submit the survey directly into the study data base. If respondents had a question or needed help filling out the survey, both the survey and Fact Sheet provided a toll free number and email through which they could reach a study staff for questions.

Data Analysis

Survey data were entered into a RedCap database, which is a secure web-based application for building and managing survey databases. Data were analyzed using SAS for Window 9.2 (SAS Institute, Cary, NC). We assessed the statistical significance of relationships among the key variables through correlation and regression analysis (i.e., *t*-tests, chi-square). P values were significant at below a 0.05 level. In addition, we developed outcome variables for two specific aspects of recovery:

Meaningful improvements in recovery

Published work has demonstrated that service users responding to the FACT-G scale are able to report changes in quality of life consistent with changes in observed health (Fallowfield et al. 2004). According to this line of research, responses of “quite a bit” or “very much” represent *meaningful* improvement, or changes likely associated with other health improvements for the respondent (Fallowfield et al., 2004). Thus, to detect the meaningfulness of respondents’ retrospective reports of change, we created a binary variable: 1) “meaningful improvement,” and 2) “minimal/no improvement.” Specifically, responses of “quite a bit” or “very much” were coded as “meaningful,” and responses of either “not at all,” “a little,” or “somewhat” were coded as minimal/no.

Overall recovery

To capture all measured aspects of recovery, we developed an overall recovery outcome score for each person by averaging their 12 response scores on the 1-5 Likert Scale; thus, each person received a single composite score between 1 and 5. Given the numeric values attached to each of these responses (see “Recovery outcomes,” page 5), we determined that an overall recovery score above 3.5 to be an indication of “meaningful” overall recovery.

Qualitative analysis

With regard to the open-ended questions in the Life and Health Outcomes portion of the survey, we conducted a content analysis for each of the three sections using an open coding method (Strauss & Corbin, 1990). Consistent with this methodological approach, a priori categories were not developed prior to analysis. Instead, the Principal Investigator (PI) and a research assistant separately coded the responses, identifying frequently referenced concepts and themes. They then met and reached agreement on the key themes for each section. The PI then clarified and refined the categories to eliminate those that were overlapping.

III. FINDINGS

Two-hundred and sixty-three (263) eligible individuals completed a survey between November 2013 and February 2014. Two-hundred and eighty one (281) people submitted a survey, but 18 of those surveys provided only a few demographic responses, and were thus not used.

Demographics

Slightly more than one-half of the participants were respectively female, middle-aged, and/or engaged in paid employment (see Table 2). A majority of respondents were white/Caucasian, with about 10% each identifying as Black or Hispanic/Latino. Almost all participants had some form of health insurance, with three quarters having MassHealth (i.e., Medicaid) and almost one-half having Medicare.

Table 2: Respondent Demographics

Demographic	Category	N	%
Gender	Female	142	54
	Male	115	44
	Other	6	2
Race/Ethnicity	White	181	70
	Black	23	9
	American Indian/Alaska Native	3	1
	Asian	1	<1
	Hawaiian/Pacific Islander	1	<1
	Hispanic/Latino	30	12
	Other race	6	2
	Multi-racial	14	5
Age	18-22	10	4
	23-30	38	14
	31-44	54	21
	45-64	140	54
	65+	18	7
Veteran?		15	6
Homeless?		26	10
Employment	Employed full time	22	9
	Employed part time	69	28
	Stipend**	37	15
	Not employed	116	48

Demographic	Category	N	%
Paid by RLC for work	Yes- Salary	25	10
	Yes- Contractor	18	7
	Yes- Stipend**	38	15
	No	167	67
Insurance (check all that apply)	Mass Health	195	74
	Medicare	124	47
	Private insurance	37	14
	Other insurance	23	9
	Not insured	5	2
	Veterans Administration eligible	4	2
	Tricare/Military	1	<1

**A stipend is a sum of money paid to someone to support their participation in an activity or task; it is not considered a wage, i.e., payment for work.

Respondent participation in a RLC

Forty-one (41%) of respondents had participated in RLCs for over 2 years, and 65% over one year (see Table 3). Almost two-thirds (63%) participated in RLC activities at least twice a week, and 81% at least once per week. Most respondents (85%) participated in peer groups and meetings, and about one-half participated in social events, attended trainings and classes, and/or spent time at an RLC Resource Connection Center (RCC), a combination drop-in and informational support center.

Each RLC was represented by between 11% and 16% of the respondents, except for Western Mass, which represented 36% of the total respondents. There were no statically significant differences among responses based on RLC affiliation, except that Western Mass RLC participants were much more likely to participate in wellness-related activities (51% vs. 24% for all other RLCS), and spend more time at a RCC (71% vs. 42% for all other RLCs).

Table 3. Respondents' participation in RLC

		N	%
Length of time participating	Less than one month	17	7
	1 to 5 months	34	14
	6 to 12 months	35	14
	13-18 months	28	11
	19-24 months	32	13
	Over 2 years	103	41

		N	%
Frequency of participation	Almost every day	65	25
	2 or more times a week	98	38
	About once a week	47	18
	1 or 2 times a month	29	11
	A few times a year	18	7
		N	%
Geographic location	Western Mass	92	36
	Central Mass	28	11
	Metro Suburban	41	16
	Boston	39	15
	Northeast	27	11
	Southeast	29	11
Types of Participation <i>(in descending order)</i>	Groups/meetings	224	85
	Social events	139	53
	Spending time at resource centers	137	52
	Trainings/classes	126	48
	Volunteering/working with RLC	96	36
	Special events	91	34
	Wellness-related activities	89	34
	One-to-one peer support in community	78	30
	Project planning/advisory meetings	74	28
	Advocacy related	47	18
	Peer respite support	43	16
	By phone	40	15
	Other activities	31	12

Personal Recovery Outcomes

Table 4a below represents the descriptive findings for the 12-item Recovery Outcome survey. Respondents most commonly reported meaningful improvements regarding their greater awareness of the right to be treated with dignity and respect (80%), feeling better about oneself (77%), having more hope for the future (74%), and developing a better understanding of what recovery means for them (74%). Fewer respondents reported meaningful improvements with becoming more involved with activities outside the RLC (35%), taking on leadership roles (53%), and becoming better able to handle stressful situations (62%).

Table 4a. Recovery outcome item frequencies (in order of items presented to respondents)

Item	How True (as a percentage per item)					N
	Not at all	A little bit	Somewhat	Quite a bit	Very much	
<u>As a result of my connection to the RLC</u>						
Domain:	Learning					
I am better able to handle stressful situations.	5%	11%	22%	33%	29%	261
I am aware of new ways to improve my life.	2%	10%	17%	38%	33%	263
I am aware of my right to be treated with dignity and respect.	3%	5%	12%	27%	53%	261
I have a better understanding of what recovery is for me.	3%	7%	15%	32%	42%	262
Domain:	Community					
I have more supportive people in my life.	3%	10%	15%	26%	45%	260
I have taken on more leadership roles.	16%	13%	18%	22%	31%	260
I have a greater sense of connection and value to my community.	7%	10%	18%	29%	36%	261
I am more involved in activities outside the RLC community.	16%	18%	31%	19%	16%	258
Domain:	Recovery					
I take an active role in decisions about my life.	5%	10%	15%	34%	35%	260
I am able to make positive changes in my life.	3%	10%	20%	34%	33%	261
I have more hope for my future.	2%	10%	13%	29%	45%	263
I feel better about myself.	3%	8%	12%	34%	43%	261

For all items but one (“*I am more involved in activities outside the RLC*”) the majority of respondents believed “quite a bit” or “very much” that RLC participation led to “meaningful” improvement in that area.” (See Table 4b)

Table 4b. Rates of Meaningful recovery for each item

	Quite a bit & Very Much	N	Domain*
<u>As a result of my connection to the RLC</u>			
I am aware of my right to be treated with dignity and respect.	208 (80%)	261	L
I feel better about myself.	201 (77%)	261	R
I have more hope for my future.	195 (74%)	263	R
I have a better understanding of what recovery is for me.	195 (74%)	262	L
I have more supportive people in my life.	186 (72%)	260	C
I am aware of new ways to improve my life.	187 (71%)	263	L
I take an active role in decisions about my life.	180 (69%)	260	R
I am able to make positive changes in my life.	174 (67%)	261	R
I have a greater sense of connection and value to my community.	168 (65%)	261	C
I am better able to handle stressful situations.	161 (62%)	261	L
I have taken on more leadership roles.	137 (53%)	260	C
I am more involved in activities outside the RLC community.	91 (35%)	258	C

*R=Recovery, L=Learning, C=Community

Results according to domain: The last column in on the right in Table 4a shows each of the three domains items fall into. In general, meaningful change scores were higher in the Recovery and Learning domains than in the Community domain. Meaningful change rates in the Recovery domain ranged from 67% to 77%. The Learning domain has three items with meaningful change rates of between 71% and 80%, though only 62% reported meaningful change in their ability to handle stressful situations. The Community domain had the largest variation in meaningful change rates, ranging from 72% for having more supportive people in their lives to only 35% regarding involvement in activities outside the RLC.

Relationships to Overall Recovery: Of 263 respondents, 73% had a meaningful improvement in overall recovery (i.e., a change higher than 3.5 out of 5)³. Cross-tabulation analysis demonstrates that no demographic variable had a statistically significant relationship to overall recovery changes. With regard to the effect of RCL participation, both frequency and type of RLC use has a statistically significant association with higher rates of meaningful improvement in overall recovery ($p < .05$). Respondents who participated in RLC activities at least twice a week reported meaningful improvement scores at a rate of 80% (130 of 163 respondents), while those who participated once a week or less reported overall meaningful improvement at a rate of 54% (51 of 94 respondents); chi-square testing showed that difference was statistically significant ($p < 0.0001$).

As demonstrated in Table 5, participation in most of the RLC activities were significantly related to higher rates of meaningful changes in overall recovery.

³ See page 8 under "Overall Recovery" for a description of these scores.

Table 5. Association of type of RLC activity with Overall Recovery Outcome, T tests

Activity	Mean* for people participating in activity	Mean* for people not participating in activity	T** (statistical significance)
Groups/Meetings	3.87	3.51	-2.38
Trainings, classes	4.10	3.59	-4.41**
Planning/Advisory	4.22	3.66	-5.24**
Social Events	4.03	3.59	-4.00**
Wellness activities	4.10	3.70	-3.32**
Advocacy	4.36	3.70	-6.00**
Spending Time at Resource Center	4.00	3.64	-3.22**
Phone contact	4.20	3.76	-2.68
One to one	4.20	3.66	-5.70**
Volunteer or working @ RLC	4.22	3.59	-6.26**
Special events	4.12	3.66	-4.36**
Peer respite	4.10	3.77	-2.21

*Scale ranges between 1 (not at all) and 5 (very much).

** $p < .0038$ (adjusted for multiple comparisons)

Relationships to Participation in Activities Outside of the RLC Community: A Chi Square analysis showed that the length of participation in RLC activities had a statistically significant relationship to participation in activities outside of the RLC ($p < .05$). As demonstrated in Table 6, 74% of those participating for over one year believed at least somewhat that their involvement in activities outside of the RLC had increased, while that figure for respondents who had attended for one year or less was 52%.

Table 6. Cross Tabulation of Participation in Activities Outside of the RLC Community and Length of RLC participation ($p=.012$)

Length of participation:	One year or less	Over one year
% who believed “Somewhat,” “quite a bit” or “very much” that RLC participation resulted in greater involvement outside of RLC.	52%	74%
% who believed “Not at all” or “a little bit” that RLC participation resulted in greater involvement outside of RLC.	48%	26%
N	85	158

We used T tests to assess the impact of the type of RLC activity on participation in activities outside of the RLCs. As shown in Table 7, participation in most activities had a statistically

significant positive impact to participation in activities outside of the RLC (with the exception of groups/meetings, social events and special events).

Table 7. Association of type of RLC activity with Activities outside the RLC

Activity	Mean* for people participating in activity	Mean* for people not participating in activity	T**
Groups/Meetings	3.0	2.9	-0.66
Trainings, classes	3.3	2.8	-2.97**
Planning/Advisory	3.4	2.9	-3.11**
Social Events	3.1	2.9	-0.95
Wellness activities	3.3	2.9	-2.17**
Advocacy	3.7	2.9	-4.17**
Spending Time at Resource Center	3.2	2.8	-2.14**
Phone contact	3.5	2.9	-2.33**
One to one	3.5	2.8	-4.44**
Volunteer or working @ RLC	3.3	2.8	-3.05**
Special events	3.3	2.9	-2.78
Peer respite	3.4	2.9	-2.12**

*Scale ranges between 1 (not at all) and 5 (very much).

**p<.0038 (adjusted for multiple comparisons)

Life and Health Outcomes

Tables 8, 9 & 10 present the percentage of respondents who felt that aspects of life and health had improved since starting their participation in RLC activities.

Work and School

In this domain, the most commonly reported changes since starting RLC participation (where the item was applicable to respondents) were thinking about looking for a job, starting to look for a job, and having improved computer skills.

Table 8. Work and school changes for participants

Since being connected to the RLC, I have	% Responding yes	Number of respondents
Started to think about looking for job	76	183
Started to look for a new job	59	185
Improved computer skills	56	190
Started a new job	37	198
Enrolled in school or GED program	23	149
Received promotion at work	22	170
Completed school or GED program	9	127

Following the completion of the seven yes/no items, people were asked: *“Has your connection to the RLC, helped you to make any of these school and work life changes?”* Three-quarters of respondents believed that the RLC had helped them make at least one such change, and they were asked to “describe or summarize” how the RLC had helped.

Many of these respondents described how RLCs offered **support and encouragement** to help them develop a desire to seek employment. For example, one person stated:

“Support with career exploration, motivation, belief in myself, resourcing in regards to school and work are some of the positive outcomes as a result of my connection with the community. Because of the RLC I got on a PASS Plan with social security, finished my undergraduate education and (am) now beginning the graduate school process. I now work at the RLC as an advocate while also working a 2nd job. The resources, empowerment and support I’ve discovered through the RLC have made the most significant contribution to my health, well-being and future prospects in all facets of my life.”

Respondents also described the **confidence** gained through RLC participation to seek and find employment or education/training. As one person noted:

“Taking on the task of job searching after an unplanned health crisis (which influenced my ability to keep the job), peer support workers helped me gain the confidence needed to motivate myself in restarting the process.”

The RLCs also provided more concrete support for people trying to make work/education changes, most commonly through 1) providing general support, 2) enhancing skills and 3) direct job preparation and search support.

One person reported on the **general support** he received:

“I had reached finally rock-bottom existential despair. I cannot say that has been discharged, but I no longer desire non-existence, and it is much more clear that I benefited from many, many people in my life and continue to do so. This has nothing to do with feeling obligation or a changed morality. I just plain met people for the first time in my life I felt affinity with. A lot of them. Really, everyone affiliated with the RLC. No

exaggeration. There is a common thread I have found in no other affinity group, intentional community or therapeutic networking. It is uncanny.”

A variety of respondents gained **skills**, with the most common being computer training and facilitation training: *“I have learned how to do more on the computer when I was helping with the calendar and had to problem-solve other things.”*

Direct **job preparation and search support** was common, most frequently through resume development:

“Help editing my writing of resume, resources for trainings, new friends, skills needed to get work, advocacy skills for personal and political work, email alerts to events and trainings as well as job possibilities and the respect and validation that boost my confidence to go for my dream of working again.”

Physical and Emotional Health

In this domain, changes since starting at the RLC (where applicable) occurred for over three-quarters of the respondents with regard to all items except for starting to exercise regularly.

Table 9. Physical and emotional changes for participants

<u>Since being connected to the RLC, I have:</u>	% Responding yes	Number of Respondents
Had fewer hospitalizations	82	184
Had fewer emergency room visits	79	180
Developed plan for what to do when extremely stressed	79	242
Taken steps to work on my substance abuse issues	74	94
Started exercising regularly	52	214

The majority of respondents reported that changes in their physical and emotional health occurred because of their RLC participation. In describing how the RLC had helped them make these changes, the most frequent theme was learning to manage stress in order to avoid the use acute care settings. They also noted that participating in Wellness Recovery Action Plan⁴ ® (WRAP) groups had helped them, whether or not they had come up with a formal plan. Mentioned as frequently was “exercise,” such as yoga and walking. Many mentioned the importance of peer support in staying well and decreasing their use of acute services. Several discussed how they had become more self-aware, often no longer seeing themselves as “an illness,” but as a whole person. Below are some representative quotes:

“I have an outlet for stress management and haven't tried to kill myself since I've come here.”

“Regular contact w/ people - a place to go to not be lonely and isolated.”

⁴ “WRAP® is a wellness and recovery approach that helps people to: 1) decrease and prevent intrusive or troubling feelings and behaviors; 2) increase personal empowerment; 3) improve quality of life; and 4) achieve their own life goals and dreams.” <http://copelandcenter.com/wellness-recovery-action-plan-wrap>

“WRAP plan, I have enough support to have not gone back to hospital for almost 5 years after 30+ years of hospital and other mental Health treatment, I have valued myself and have better health and whole wellness.”

Social and Community Life

Most respondents reported improvements since starting RLC participation in staying out of legal trouble, making new friendships, and being more comfortable in social situations. However, less than 50% of respondents reported improvements (where applicable) in leaving abusive relationships and improving their housing situation.

Table 10. Social and community changes for participants

<u>Since being connected to the RLC, I have:</u>	% Responding yes	Number of Respondents
Stayed out of legal trouble	93	103
New friendships	92	246
More comfortable in social situations	85	231
Better family relationships	64	198
Left an abusive relationship	45	76
Moved to better housing	40	116
Found housing after being homeless	30	70

Most (86%) respondents felt that the RLC had helped them make at least one school or community life change. Many talked about the “friends” they had met at the RLC. Also mentioned were changes in self-worth and positive self-image and a decrease in anxiety in social settings:

“I have made a lot of new friends and that is not easy for me.”

“I have met people like me since working with the RLC & now they are some of the most supportive friends that I have in my life.”

“My new friends from groups and trainings are dear and valuable supports, my family life is improved as I became more me through sharing with peers this also helped ease my social stress.”

Perception of RLC

Overall, about two-thirds of the respondents were very or completely satisfied with the RLC, and 90% were at least somewhat satisfied.

Table 11. Satisfaction with RLC

% satisfied with supports and trainings that RLC makes available.	Completely satisfied	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied	Completely dissatisfied	N
	25	43	22	4	4	1	256

Overall Life Satisfaction:

Table 12. Satisfaction with life overall

% satisfied with life overall:	Completely satisfied	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied	Completely dissatisfied	N
	14	32	34	9	10	2	257

Forty-two percent (42%) were very or completely satisfied with their life overall, and 82% were at least somewhat satisfied. Satisfaction with life overall was moderately associated with overall recovery and strongly associated with participation in activities outside of the RLC ($P < .0001$ for both items).

IV. DISCUSSION

This report summarizes survey data collected from 263 respondents who participated in RLC activities over four months. Approximately two-thirds of the respondents had been RLC participants for over one year, and almost two thirds of respondents participated on a weekly basis.

The large majority of respondents (73%) reported meaningful gains in their overall recovery because of their participation in RLC activities. More frequent participation in RLC activities were tied to rates of meaningful improvement in overall recovery.

Aspects of recovery with the highest rates of meaningful gains because of RLC participation were: 1) feeling better about oneself, 2) having more hope for the future, 3) learning what recovery means for oneself, and 4) becoming aware of one's rights to be treated with dignity and respect. Higher rates of meaningful gains for these outcomes are representative of a respondent group just beginning to lay the foundation for additional recovery-oriented gains, such as becoming more active in making life decisions and having a greater sense of connection to one's community.

Aspects of recovery with the lowest percentage of respondents with meaningful gains were: 1) taking on more leadership roles in and outside of the RLC (53%), and 2) greater involvement in activities outside the RLC community (35%). There are several possible explanations for these low percentages. First, respondents may have been relatively less interested in leadership roles or in activities outside their RLC. For example, respondents may have perceived higher obstacles to the attainment of these outcomes. Second, it may be that many participants wanted or needed to make gains in areas within the Recovery and Learning domains before venturing into "leadership" and/or developing relationships outside the RLC. Third, RLCs may not be emphasizing activities that promote these kinds of outcomes. Finally, the sample may be excluding some people who have become more involved in activities outside the RLC because they have reduced their RLC participation and would be less likely to complete the survey.

The data demonstrate the many positive life and health benefits that individuals attribute to RLC participation. Most respondents cited the importance of RLC participation in helping them develop new friendships and becoming more comfortable in social settings. A majority of respondents reported that RLC participation resulted in their reduced use of emergency rooms and hospitals. A majority also related RLC participation to developing a crisis action plan, addressing substance abuse issues, and considering a job search. (On the other hand, RLCs tended to not provide significant support for respondents' school or GED attainment or for improved housing.) Respondents made these gains most commonly through the support and encouragement of RLC staff, friends they made there, and by learning how to successfully manage stress. Their confidence improved and they were more likely to manage their own health, by for example starting to exercise.

This research has some limitations. First, a cross-sectional survey of this nature captures

only a snapshot of information about the respondents. Second, while we can identify significant correlations among variables, we are unable to identify cause/effect relationships. Third, our sample is one of convenience, so the generalizability of our results may be limited. In fact, most of our respondents were satisfied with RLC supports and trainings overall; to the degree that participants participated less frequently or stopped participating, their perspectives were not well represented.

Many people have benefited from their contact with RLCs, in ways that have had major impacts on their lives. Other relatively common individualized gains translate to major societal benefits, such as the reduced use of hospitals and emergency rooms saving health care costs. In addition, RLC participants make positive psychosocial gains in areas that clinical programs do not directly address, such as learning about “recovery” and expanding social networks. The RLC model has a unique approach to facilitating personal self-efficacy, wellness and recovery. The RLC model helps people with useful non-clinical wellness options not commonly offered within clinical health systems.

We suggest that the RLCs focus quality improvement efforts on two areas:

- Participant engagement in community life, including enhanced social networks;
- Further assistance in developing strategies for participants develop wellness strategies, such as regular engagement in routine exercise.

Future research should focus on understanding how RLC participants make psychosocial gains and achieve recovery. First, we recommend doing qualitative studies to better understand how specific elements of RLCs impact key outcomes. For example, SPARC has a collaborative grant with the Central Massachusetts RLC that includes interviewing participants and staff about how participants enhance their social networks. And given the RLC role in helping participants reduce acute health care use, we recommend organizational studies on bringing key elements of RLCs into developing integrated models of health care. Second, we would recommend a longitudinal study to follow participants over time to better understand the stages of recovery facilitated by RLCs. .

V. REFERENCES

Brown, L. D. (2009). How people can benefit from mental health consumer-run organizations. *American Journal of Community Psychology, 43*(3-4), 177-188.

Cavelti M., Kvrjic S., Beck E. M., et al (2012). Assessing recovery from schizophrenia as an individual process: a review of self-report instruments. *European Psychiatry 27*:19–32,
Deegan, P. E. (1988). Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal*.

Cella, D., Hahn, E. A., & Dineen, K. (2002). Meaningful change in cancer-specific quality of life scores: differences between improvement and worsening. *Quality of Life Research, 11*(3), 207-221.

Corbin, J., & Strauss, A. (Eds.). (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Sage.

Delman, J., Delman, D. R., Vezina, B. R., & Piselli, J. (2014). Peer led Recovery Learning Communities: Expanding Social Integration Opportunities for People with the Lived Experience of Psychiatric Disability and Emotional Distress. *Global Journal of Community Psychology Practice, 5*(1).

Fallowfield, L., Cella, D., Cuzick, J., Francis, S., Locker, G., & Howell, A. (2004). Quality of life of postmenopausal women in the Arimidex, Tamoxifen, Alone or in Combination (ATAC) Adjuvant Breast Cancer Trial. *Journal of Clinical Oncology, 22*(21), 4261-4271.

Harding, C. et al. (1987). The Vermont Longitudinal Study of Persons with Severe Mental Illness, I. Methodology, study sample, and overall status 32 years later. *American Journal of Psychiatry, 144*, 718-728.

Harrow, M. (2012). Do all schizophrenia patients need antipsychotic treatment continuously throughout their lifetime? A 20-year longitudinal study. *Psychological Medicine, 1-11*.

Mead, S. & MacNeil, C. (2006). Peer support: What makes it unique? *International Journal of Psychosocial Rehabilitation, 10*(2), 29-37.

Salzer, M. S., & Brusilovskiy, E. (2014). Advancing Recovery Science: Reliability and Validity Properties of the Recovery Assessment Scale. *Psychiatric Services*.

Shanks, V., Williams, J., Leamy, M., Bird, V. J., Le Boutillier, C., & Slade, M. (2013). Measures of personal recovery: a systematic review. *Psychiatric Services, 64*(10), 974-980.

Slade, M. (2002). What outcomes to measure in routine mental health services, and how to

assess them: a systematic review. *Australian and New Zealand Journal of Psychiatry*, 36(6), 743-753.

Slade, M., Amering, M., Farkas, M., Hamilton, B., O'Hagan, M., Panther, G., et al. (2014). Uses and abuses of recovery: implementing recovery-oriented practices in mental health systems. *World Psychiatry*, 13(1), 12-20.

Substance Abuse and Mental Health Services Administration (SAMHSA) (2011). *The Evidence: Consumer Operated Services* p. 32 <http://store.samhsa.gov/shin/content//SMA11-4633CD-DVD/TheEvidence-COSP.pdf>, Rockville, MD.