



REPORT / PEERS IN RESEARCH

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Peers in Research:

A study of people with lived experience as collaborators in mental health research

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Contents

Plain English Summary	3
Introduction	3
Current Study	4
Methods.....	5
Peer Consultants	5
Focus Group / Data Collection	5
Design	5
Results.....	7
Benefits	7
Challenges.....	8
Challenges to peers being involved in research in general.....	8
Challenges to the peer workforce.....	8
Role Impact	8
Lessons Learned.....	9
Recommendations	9
Research process	9
Survey administration	10
Sharing results.....	10
Feedback on Focus Group Design	10
Discussion	11
Benefits	11
Challenges.....	11
Role Impact	11
Lessons Learned.....	12
Recommendations	12
Feedback on Focus Group Design	12
Recommendations	12
References	14
Appendix: Timeline of Study Activities	16

Plain English Summary

Mental health research has not traditionally considered or valued study participants' views. People who have lived experience should be involved in all aspects of research studies, from initial planning to sharing results. Working toward this purpose, from 2016 to 2017, people in recovery who were working as peer support providers at two mental health organizations in the Austin, Texas area were invited to work alongside researchers from the University of Texas at Austin on a study about recovery and peer support. Researchers wanted to know whether receiving peer support at these organizations helped people receiving mental health services recover. The peer consultants who worked on the study helped with planning research activities, study timeline, designing a survey instrument, choosing aspects of recovery to examine, asking people to complete surveys, and gathering data from electronic records systems related to services that people in mental health services received. The researchers then invited the peer consultants to a half-day focus group to ask for their experience working on the study. Additionally, peer consultants were asked how the process could be improved in the future.

Introduction

Recovery is “a process of change through which individuals improve their health and wellness, live a self-directed life and strive to reach their full potential” (Substance Abuse and Mental Health Services Administration [SAMHSA], 2015). The Surgeon General’s Report on Mental Health (U.S. Department of Health and Human Services [HHS], 1999) and the President’s New Freedom Commission on Mental Health (2003) named recovery the organizing principle for the transformation of mental health services and the expected outcome of mental health services.

Researchers have recommended including people with lived experience of mental health issues, including people in recovery, in the research process since the 1980s (Wallcraft, Schrank, & Amering, 2009). While the paradigm shift has been slow to occur, researchers in the late 20th and early 21st century have begun to recognize the value individuals in recovery bring to research processes and outcomes, given their expertise in defining recovery and what a recovery-oriented care system should include (Davidson, Tondora, O’Connell, Kirk, Rockholz, & Evans, 2007; Hancock, Bundy, Tamsett, & McMahon, 2012). Extensive research on the subject indicates that people in recovery (PIR)-driven research improves accessibility (readability, understandability, etc.) of research findings (Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2013). Other studies suggest that the involvement of PIR in research design enhances the reliability and validity of instruments and findings (Hancock et al., 2012; Linhorst & Eckert, 2002; Oades, Law, & Marshall, 2011; Rogers, Chamberlin, Ellison, & Crean, 1997). According to Barber and colleagues (2011) other potential benefits of collaboration with PIR in various stages of mental health research include:

- improving consent procedures and enhancing recruitment rates
- eliciting more candid interview responses
- questioning and correcting researcher misinterpretations in analyses
- highlighting findings most relevant to service users
- enhancing power and credibility of findings during dissemination
- facilitating wider and more accessible dissemination
- empowering and strengthening of the voice of people in recovery
- increased knowledge, skills, and confidence of people in recovery
- deepening researchers’ understanding of the issues people in recovery face

While a learning curve of involving people with lived experience in research has been noted, such as inexperience with data collection, such considerations can be anticipated and offset with appropriate training and support

(Bryant & Beckett, 2006). Differences in levels of understanding of research methodology, terminology, feasibility, and other challenges should be considered at the outset of a study collaboration (Barber et al., 2011).

Current Study

The current Peers in Research (PIR) study is a follow-up to the **Peer Outcomes Pilot (POP)** study. Since Fiscal Year 2016, the researchers have been funded by Texas Health and Human Services Commission to conduct a pilot study of the recovery outcomes (e.g., crisis episodes, length of stay, engagement in services, acuity, etc.) of people receiving peer-provided mental health services. The researchers identified, and invited to participate in the pilot, two sites: provider organizations with well-established peer support programs. The POP study emphasized collaboration with peer support providers (PSP) in the conducting of research planning processes and activities. The PSPs participated in the following aspects of the research process:

- Peer providers collaborated with researchers on study design and planning
- Peer providers collaborated on survey development, testing, and feedback
- Peer providers were trained by researchers in survey administration
- Peer providers were paid for survey and other data collection

The purpose of the **Peers in Research (PIR)** study generally is involving people with lived experience in research to ensure that experiential knowledge informs the fundamental structure of investigations into the field of mental health recovery (e.g., study design, survey design, data collection processes and techniques, interpreting findings, etc.). This is rooted in empiricism: The tenet that knowledge comes primarily from sensory experience and that research hypotheses must be tested against these direct observations rather than relying on reasoning or intuition (Cozby, 2009). If we want to answer questions about recovery, we need to collaborate with people in recovery to ensure we are asking the right questions. This is accomplished through the PIR project by training peer specialists in evaluation strategies and collecting feedback to improve those processes.

Based on the existing literature and state of the evidence, authors of this report recognized the need for additional research that includes people in recovery in the research process. Authors collaborated with PSPs from two provider organizations who were participating in a pilot study focused on the outcomes of peer-provided services. PSPs are people who are in recovery from mental health issues, who are employed to assist others in earlier stages of recovery by sharing their lived experience. The decision to include people with lived experience who were also employed as PSPs fit the needs of the research team for peer consultants to 1) be consistently available throughout the duration of the study, 2) have access to organizational resources that would support planning insight and data collection, and 3) have a depth of experience with both recovery and the provision of peer-provided services. The PSPs worked with researchers across several study activities (research design, outcome measures, data collection, analysis, and dissemination), representing a range in levels of meaningful involvement: consultation, contribution, and collaboration (Wallcraft et al., 2009).

The purpose of the focus group that convened on May 24, 2017 was to reflect on and learn from PSPs' experiences of working with researchers in conducting the POP study, with the goal of identifying best/promising practices for the future. The focus of data collection during the focus group was 1) the research collaboration experience of the PSPs, 2) strategies used by the PSPs during collaboration in the research process, and 3) develop recommendations for improvements to future collaborations.

The purpose of this paper is 1) to describe the interactive data collection methods used during the focus group, 2) to describe the information collected as a result of that group, and 3) provide recommendations for future iterations of utilizing this unique, interactive method as a data collection tool.

Methods

Peer Consultants

The researchers collected the experiences of the PSPs who were involved in most phases of the POP study (page 4), from initial planning to dissemination. The PSPs were either full-time or contract employees of the two sites participating in the study, a community mental health center and a state psychiatric hospital. The PSPs had the support of their supervisors and organizations to take part in this work, in addition to maintaining their regular job duties. Over the course of the multi-year study (see Appendix 1 for timeline of the study), they worked with researchers in the following aspects of the research process:

- Study design and planning
- Outcome measures selection
- Instrument development, testing, and feedback
- Trained in survey administration via brief training conducted by researchers
- PSPs were paid for their work administering surveys and collecting other types of data
- A final focus group in which lessons learned regarding the study were reviewed

Of the 11 PSPs that were invited to participate in the PIR focus group, four people attended. Three of the participating collaborators were female, and one was male. All had worked at the same organization (inpatient hospital) during the course of the POP study (page 4), but at the time that the group was convened, one was working as a mental health project coordinator at a non-provider organization.

Focus Group / Data Collection

Data was collected via a 4-hour focus group. Consultant peer providers were solicited for feedback regarding experiences with their involvement in the POP study. Researchers in the study facilitated the focus group using Liberating Structures (see Design, page 5). The focus group was recorded and transcribed. Additionally, focus group participants submitted written responses to several of the scenarios and questions from the Liberating Structures sections of the focus group.

Design

Existing literature (Ghisoni et al., 2017), and prior experience in collaborations with PSPs influenced several elements of the focus group's design, including: information on the goals of the focus group sent prior to the focus group; mid-day focus group time (12 p.m. to 4 p.m.); refreshments provided; emphasis on experiential data collection (as opposed to interview/focus group question format); and follow up communication and feedback request sent following the focus group.

The primary tools used to evoke, elicit, and capture data were communication microstructures known as Liberating Structures (Lipmanowicz & McCandless, n.d.). These communication tools introduce small shifts in focus group protocols, exchange of ideas, and decision making. Facilitative power typically reserved for experts or leaders is shifted to everyone involved. These microstructures are designed to facilitate active participation and

communication of ideas from everyone. An online repository of Liberating Structures (Lipmanowicz & McCandless, n.d.) is free to use, and can be found at: <http://www.liberatingstructures.com/>.

Liberating Structures have only recently emerged as a data collection tool (A. Jackson & T. Levins, personal communication, June 19, 2017), though it's potential for shifting the dynamics of information sharing makes it a promising practice as a qualitative research method. See Table 1 for a design storyboard of the focus group.

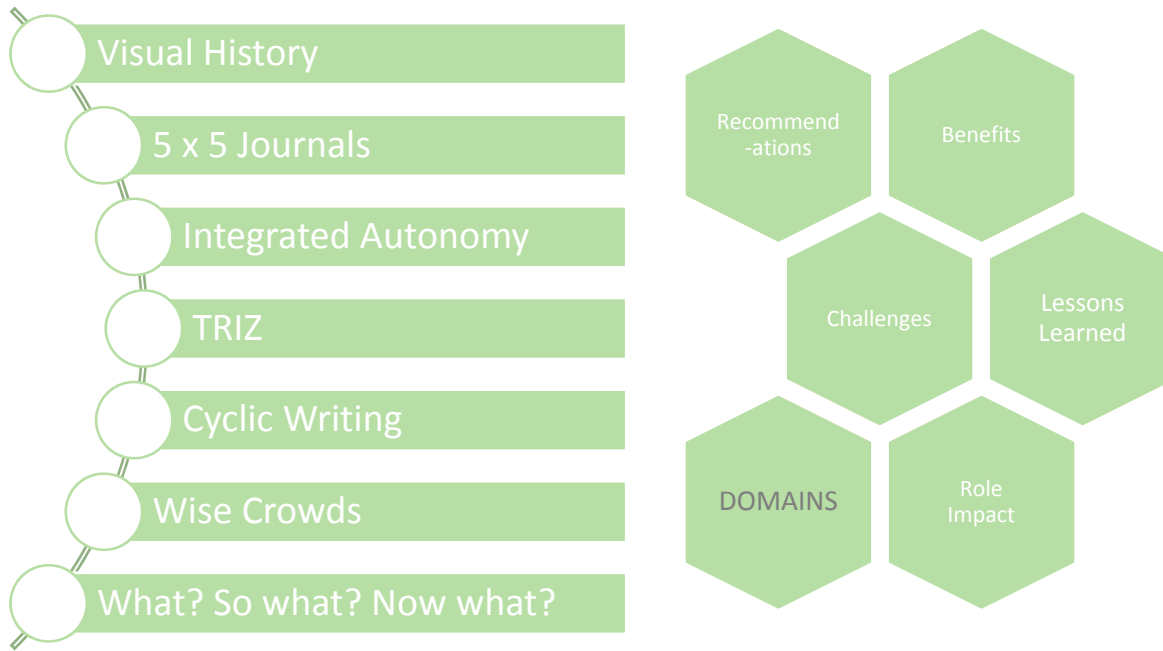
Table 1: Design storyboard

Agenda Item	Goal	Liberating Structures /Microstructure
Welcome, purpose, goals	Orient to the structure and goals of the day	Impromptu networking
What? Create context for working together	Reflect on what has happened so far; identify benefits, challenges, and questions	Visual history, 5x5 journals
So What? Distill lessons learned and develop solutions	Explore solutions without outside influence from "experts"	Integrated autonomy, TRIZ, Cyclic writing, Wise crowds
Now What? Identify future best practices and directions	Develop recommendations for future	What, So what, Now what?
Wrap-up	Next steps	--

In order to employ Liberating Structures as data collection tools, authors first developed more traditional focus group style questions in five domains: Benefits, challenges, role impact, lessons learned, and recommendations. These domains were then mapped to appropriate Liberating Structures and other *punctuation*¹ activities, with the consultation of a third-party expert on Liberating Structures (Figure 1).

¹ *Punctuation* are off-menu tools that augment the regular repertoire of Liberating Structures.

Figure 1: Liberating structures / punctuation activities, and the domains of interest of data collected



Following the focus group, a Qualtrics (2017) survey soliciting feedback on the focus group activities overall was e-mailed to the peer consultants. Additional resource materials requested during the focus group were also sent with the survey.

Results

Feedback from the peer consultants on collaborating in research processes revealed benefits of collaboration, challenges, and lessons learned through trial and error, as well as by sharing and distilling information among themselves. A number of recommendations resulted from consultant feedback including: boots-on-the-ground data collection; improvements that the researchers could make to the collaboration process; and ways to share results of the work. Summaries of the results from data collection in each domain are below.

Benefits

The peer consultants reported a number of **benefits to working as collaborators on the POP study** (page 4), and involving peers in research in general:

- Gives meaning to the work of peer providers
- Gives a voice to individuals receiving services
- Uncovering the truth [about how services affect outcomes], for better or worse
- Moving the [peer provider] profession forward
- Helpful to the Certified Peer Specialist community
- Helpful to staff in different settings
- Helpful to people in services
- Ground-breaking
- Making a difference
- Piquing curiosity
- Satisfying curiosity

- Helping to gather useful data

Challenges

Several individual-level and system-level **challenges related to collaborating in the POP study** (page 4) and peers collaborating in research emerged:

- Not being involved at the beginning of the project presented challenges to being involved in later phases of the study
- Administering the surveys on a busy unit
- Only being able to survey people on specific service areas (per eligibility criteria)
- Administering surveys took time away from being with people in a peer support capacity
- Uncomfortable to administer surveys sometimes; some reported feeling like an authority figure, not mutual
- Challenges foreseen with interpreting the data collected (e.g., participant biases when completing the surveys)
- Role confusion
- Time-consuming
- Sustaining interest in collaborating in the research independently over a long period of time
- Keeping track of materials on busy, chaotic units
- Onerous record-keeping
- Language barriers and inability to read deterring some people's responding to surveys
- Explaining/interpreting survey questions to people, without affecting their understanding or responses
- Infrequent check-ins make it easy to forget about the study
- Difficult to measure what peer support is/does and to measure subjective feelings
- People feared that survey responses would get back to treatment team and have negative consequences; they hoped that the "right answers" would help them to get out of the hospital more quickly
- Finding the appropriate process for locating people, contacting them, and framing participation in a meaningful way; maintaining a mutual, authentic, transparent process

Challenges to peers being involved in research in general

- Lack of awareness about research
- Emphasizing participation (i.e., completing surveys) rather than active involvement in research

Challenges to the peer workforce

- Calling peers "content experts" while underpaying them (e.g., being invited to speak at a conference as an unpaid volunteer)
- Few peer jobs available and jobs that are not well-compensated or valued; labor exploitation
- Peer support not seen as a "real" job: "You have potential, when are you going to get a 'real' job?"

Role Impact

The peer consultants reported several ways which they hoped, or expected, that other people would perceive them in their roles as both peer and research contributor:

- Knowledgeable
- Informed
- Intentional
- Using sound practices
- Values-driven
- Kind

- A person-to go to for help, information, and to listen
- Pushing boundaries as a Certified Peer Specialist
- Well-meaning
- Forward thinking
- Hard working
- Contributing

In the course of working on the POP study (page 4), the peer consultants learned and refined ways to integrate scholarly and mutual aspects of their roles as peer provider and researcher. A few of those ways that they could remain mutual and connected while also carrying out research functions were named during the *Integrated Autonomy Liberating Structure*:

- Bringing in one's own lived experience to contributions toward survey development
- Remaining curious, in both roles
- Survey administration: Completing surveys together with people
- In the process of data collection, learning the stories of people receiving services
- Having follow-up conversations with people, after survey completion
- Developing the survey with people served through pilot testing
- The (future) sharing of results with persons served
- When needed, reading survey questions aloud to people, which is a type of engagement

Lessons Learned

When the peer consultants were asked to respond to the question, *"What do you see differently or more clearly as a result of your work on this study?"* they responded:

- One peer now sees the research process as more daunting, a long process with obscure rules.
- At first, one peer thought it would be as simple as asking the question: *Do you feel better after peer support?* Now s/he thinks differently.
- One peer reported that s/he was "glad it's not my job."
- One peer observed that survey administration is not fun (i.e., it is hard work), but that we need to gather this information to move the profession of PSPs forward. Interest, support, and funding follow the results of this type of work.

Recommendations

Researchers integrated the **experiences of, strategies used by, and recommendations given by the peer consultants who worked on the POP study** (page 4) to develop the following set of recommendations for improvements to future collaborations of people in recovery in mental health research:

Research process

- Focus groups could be conducted with people served at the site(s) to inform the study design, planning, and outcome selection processes.
- A peer support council on each service area within the site to be involved with data collection could be developed to better inform and implement all phases of the research process.
- More frequent check-ins or plug-ins between researchers and PSPs could help keep people up-to-date and motivated as some mentioned that it was easy to forget about the project.
- Offering a full/extended training (more comprehensive than the 1-hour brief training that was provided) for survey administration to PSPs could help to anticipate and reduce many of the issues or uncertainties that arose in the data collection process.

Survey administration

- Surveys could be administered in the *peer lounge*, rather than on units. The peer lounge is a private room with a comfortable library-like environment that welcomes people in services; it is a place to relax and also provides a setting for peer-provided groups to be conducted. This could accomplish both reaching more people to recruit (i.e., before a group is conducted) and/or improve confidentiality over the busy, chaotic unit environment.
- Nursing staff should not call people from across the room to come engage with the surveying peer; a message could be communicated to nursing staff from leadership at the outset of data collection, so that the PSPs are not having to explain themselves each time they arrive on a unit to administer surveys.
- Employing alternative survey administrators, whether persons who are currently receiving services (not PSPs) or people in recovery from outside the organization could reduce potential biases and role conflicts of PSPs.
- People receiving services could be included in survey development, as they offer a perspective unique from PSPs.
- One thing that worked well for the whole team of PSPs that were administering surveys was having one point person take over record keeping of anonymous survey identifiers as well as the survey “key,” containing information which could be used to link the survey data to administrative data in the future.
- Incentives could be offered for survey participation.
- Regarding describing the intention of the survey during recruitment without introducing bias, it was suggested that people could be told that the purpose of the survey is “to improve things at [this organization].” The statement is general enough so that it does not prime attitudes about peer support staff specifically, but it does accurately reflect an ultimate goal of the study.

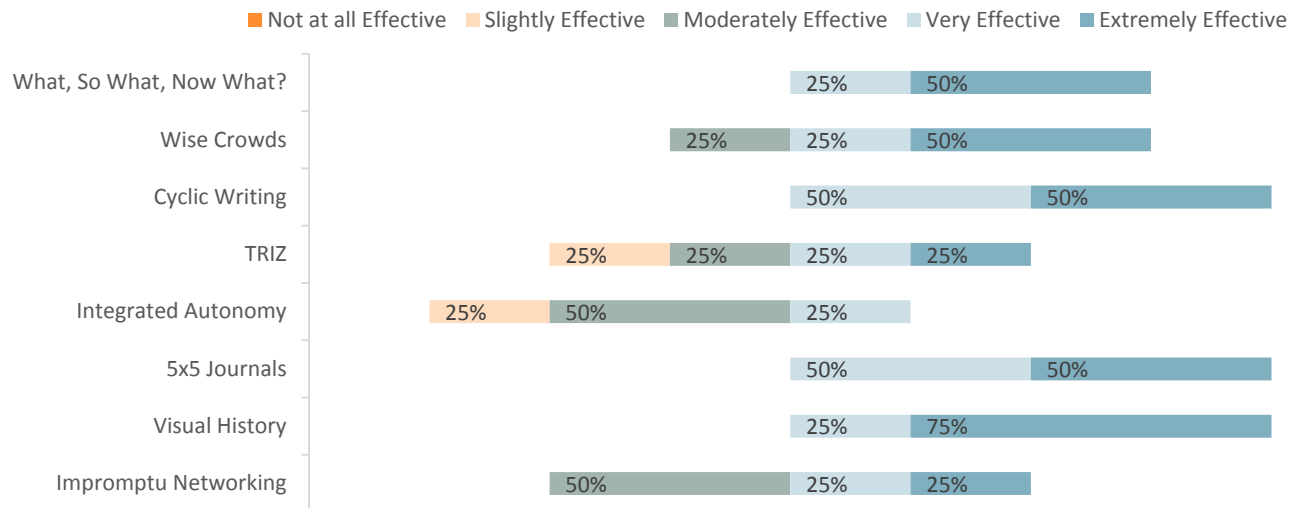
Sharing results

- A trauma-informed follow-through with participants to check-in and to share results could assist people in reducing any negative thoughts primed by completing surveys or other data collection activities.
- An online follow-up to share results (e.g., through a link provided to participants) could doubly serve as a way for people to sign up to participate in future research (possibly longitudinal).
- More creative follow-up to share results could result in broader and more meaningful dissemination.
- Emphasize helping all stakeholders to see the “big picture.”

Feedback on Focus Group Design

During and immediately following the focus group, feedback was provided that the Liberating Structures format was well-received, and that the 4-hour focus group was highly engaging. Results of the follow-up survey which solicited feedback on the focus group activities overall, and each of the Liberating Structures specifically, revealed that the peer consultants thought the purpose of the focus group was clearly defined and they were satisfied with the time of day of the focus group, length of the focus group, and the information sent prior to and following the focus group. Feedback on each specific Liberating Structure revealed that some achieved purpose better than others. For example, the Visual History activity was the most highly rated in terms of effectiveness. The purpose of that activity was to orient the peer consultants to the varying levels of involvement of one another, as well as to serve as a reminder of what each consultant had been involved in over the course of the POP study (page 4), creating context and a mental framework for the activities that followed throughout the remainder of the focus group. See Figure 2 for ratings of the effectiveness of each individual Liberating Structure.

Figure 2: Effectiveness Ratings of Liberating Structures Activities



Discussion

Benefits

Overall, the main reported benefits of PSPs collaborating in the research process were: giving meaning to the work of peer providers, advancing the peer provider profession, and providing useful information to people in services, mental health providers, and the peer provider community. These types of benefits might be expected to impact, at the very least, both job retention and provider knowledge.

Challenges

Challenges reported can be classified as both individual-level and system-level. Individual level challenges generally revolved around environmental and time constraints, and tensions between the “research” role and the “peer” role. System level challenges included lack of awareness about research generally and the dearth of jobs available to peers offering adequate salaries. Where peer providers are underemployed, in menial roles with exploitative salaries, the opportunities for involvement in research projects are generally non-existent.

Role Impact

Regarding the potential impact of collaboration in research may have on a PSPs perceived role, they reported hoping, or expecting, that others would see them as informed, hardworking, and deliberate in their roles, while also preserving peer values and pushing the boundaries of what it means to be a peer.

The PSPs also described new or refined ways that they had learned to integrate the seemingly exclusive scholarly and mutual aspects of their roles as peer provider and researcher. Generally, the PSPs described ways in which they could bring their lived experience and mutual connection skills to different phases of the research process:

engaging with people during survey pilot testing and the survey administration process, bringing lived experience to the study planning process, including the development of survey constructs and items and methods of administration, and (in the future) engaging with people to share study findings.

Lessons Learned

While the researchers learned a number of invaluable lessons from the peers collaborating on the POP study, the PSPs also described some things that they saw differently as a result of their collaboration. Mainly that they understood more of the complexity of the various moving parts of the research process, something that appeared more simplistic from afar. The PSPs also noted that it is precisely the type of hard work which they undertook on this study that is needed to advance the profession as funding follows data.

Recommendations

The recommendations made by the peer consultants regarding the research process and sharing results will be considered by researchers for future activities of the POP study (page 4). Generalizable recommendations for involving people in recovery in research should be considered in future research:

- Additional study planning activities that involve people with lived experience are needed, for example, focus groups conducted with people served at the site(s) to inform the study design, planning, and outcome-selection processes
- More extensive training and ongoing support from researchers are needed to maximize the contributions of people with lived experience working collaboratively in research roles
- An effective dissemination of study findings should require people with lived experience in order to share meaningful information more broadly, through creative and trauma-informed approaches

Feedback on Focus Group Design

The use of Liberating Structures activities that were intended to support more meaningful data collection, as an alternative to more traditional and rigid focus-group style questioning, was well-received. While different Liberating Structures were reported to have varying degrees of effectiveness in eliciting information (see Figure 2), overall the activities were perceived to improve group flow and engagement. Considering that a major underlying purpose of Liberating Structures is to fundamentally change the way that groups of people work together, it is not surprising that the most highly rated activity was the Visual History, the purpose of which was to create context and a mental framework for the group's work together. These activities, combined with refreshments served, sustained engagement over the 4-hour length of the focus group.

Recommendations

The following recommendations should be considered to support future studies involving Peers in Research:

- ❖ Peer providers as a workforce are themselves a “disruptive innovation;” they are change agents toward the goal of shifting a medical-model mental health system to a recovery-oriented one. Further, including peers or people with lived experience as collaborators in research activities typically reserved for academics is a “disruptive innovation.” Such innovations call for a departure from the status quo, requiring the use of

alternative communication and data collection methods. The use of Liberating Structures as a “disruptive innovation” (Lipmanowicz & McCandless, n.d.), or tools to plan, conduct, and reflect on mental health research, should be considered as an alternative to more rigid and traditional methods used by research teams.

- ❖ Whether peer provider employees or current or former service recipients, people credentialed with lived experience should be appropriately compensated for their collaboration in and contribution to research. Telling people that you value what they have to offer, but not paying them for their offering, is just lip service.
- ❖ Research studies that involve people with lived experience of mental health services (e.g., POP study, page 4) should be incentivized by funders. Additional funds would be needed to compensate collaborators appropriately and to support the training and administrative infrastructure behind the teams, including budgeting for innovative dissemination strategies.

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Appendix: Timeline of Study Activities

Peer Outcomes Pilot Study Timeline of Activities FY 2015 – FY 2017

