



POETRY FOR PERSONAL POWER

what helps you through adversity?

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Recovery Movement Research Priorities

Prepared for: PCORI

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Artist Entrepreneurship | Peer Support | Mental Health Advocacy | Research | Healthcare Messaging





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Publication Development

This publication was developed as part of the work of the Patient-Centered Outcomes Research Institute's (PCORI) Eugene Washington Engagement Awards. Considering that this project is researching the needs of a group that is significantly undefined, relies on self-identification, and is often not asked for input, evidence-based Community Engagement Science methods were critical. Due to this necessity, a vital part of this project was also creating an advocacy toolkit and training advocates using the combined researched methodologies. Information for this Community Engagement Science is also included in this publication.

This project has been funded in whole with funds from the Patient-Centered Outcomes Research Institute's (PCORI) through the Eugene Washington Engagement Awards program.

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About the Developers

Poetry for Personal Power (P3) is a 501(c)(3) nationally recognized expert on trauma and resilience incorporated and headquartered in Wyandotte County, Kansas. This agency is patient-led and provides health and advocacy programming.

Programming includes:

- Peer support programs helping peers to learn to support themselves through adversity
- Health care messaging programs that use the energy of arts events to share concrete health-building tools
- Entrepreneurship training and promotion
- Systems-change advocacy, including CER and Community Engagement, aimed at improving the long-term wellbeing of people with mental health concerns.

P3 was formed in 2009 by founder Corinna West, an experienced Recovery Movement (ex)/patient advocate, as a stigma-reduction and social-inclusion program, funded by the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA). The mission of the organization is "Using art to show that emotional distress is temporary and transformative."

P3 is the first organization in the nation to receive two SAMHSA Bringing Recovery Supports to Scale (BRSS-TACS) grants in the same year. P3 was involved in the Creating Community Solutions national mental health dialogue project and managed one of the seven principal cities aiding in project completion and desired outcomes. The organization also created evidence-based evaluation tools for organizations as well as programs and has used its Wellbeing Impact Assessment process to train 19 community partners.

Currently, the organization is led by Sheri Hall, a Recovery Movement member, and advocate. The Principle Investigator on the project is Julianna Sellers, a Grief recovery specialist, Bachelor's Degree in Marriage and Family Studies from Brigham Young University – Idaho, advanced communications trainer, experienced health coalition advocate, and Peer Support Specialist.

Poetry for Personal Power has seven paid program managers working in the Kansas City, St. Louis, Kansas, and Colorado regions, and 74 sponsored artists and advocates. In 2016-2017 Poetry for Personal Power completed 263 events. Two thousand three hundred fifty-five artists shared stories about overcoming adversity, with 10,130 audience members. The following communities of diversity are represented by P3 staff and contractors: 54% of people with a mental health diagnosis, 61% African-American, 39% adults under age 25, 35% LGBTQ / Non-binary. All of P3's communities need more representation in CER research and Community Engagement.

For further information on Poetry for Personal Power, our research, and our programs, please visit poetryforpersonalpower.org.

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Patient-Centered Research Institute.





Abstract

Objective: To identify service user research priorities and preferences outside of traditional clinical treatments and promote best practice advocacy efforts for the continued communication of these priorities.

Setting Design: Descriptive research – Internet-based surveys deployed via email. The first study (Fall 2018) was hosted via Survey Monkey, the second (winter 2019) and hosted on LogicDepot systems. Surveys were both multi-punch and short response. Surveys were developed and distributed in collaboration with existing national networks that support peer specialists, provide technical assistance to consumer organizations, or advocate on behalf of mental health and addiction service users.

Participant eligibility criteria: Participants were able to self-identify as being a part of the recovery movement, being a person living with SMI/SUD/or Neuro Diversity.

Results: 8 studies were reviewed and 2 research studies conducted (study 1: fall 2018/37 respondents | study 2: winter 2019/212 respondents). Comparative analysis done on research results. First study was done with a limited amount of participants that were identified as professional advocates. This set of questions was formulated around funding/promotion / and balancing harms vs benefits. Second study included respondents from a wider population of service users, advocates, caretakers, and mental health workers that identify as members of the Recovery Movement. The initial study concluded that the top priority of advocates is that more research should be done to provide funding mechanisms to pay for peer support (77%) with more recent studies on peer support effectiveness coming in second (57%). Winter 2020 Study finds a majority of service users are interested in research on recovery support groups, effective therapies, and creative outlets as therapies.

Conclusions: This study showed the overall research priorities. It also allowed for comparative analysis between the groups of caretakers/advocates / and end-users. We found that advocates are not wholly in touch with what end users want and there is a need for better Community Engagement training for them to adequately represent the consumer voice. One of the main issues with this is that often advocates are often consumers so they rely on their own voice as if it was the voice of the entire movement. Distinction must be made between the story of the advocate and the story/needs/wants of the movement. The second study indicates that Advocates and Service Users may agree on the most important need however the two diverge across the rest with advocate responses showing little variance (all things are needed) and Service Users leaning towards prioritization.

Due to the nature of the Recovery Movement and the historical lack of patient/service user input into traditional medical practice, the responses that we received from the second study (85% service users) showed small differential between preferences and was almost even across the board proving the necessity for more research in all areas. To increase patient-centeredness in decisions involving research, further research and advocacy efforts with solid community engagement science for a larger sample, and for a larger number of conditions should be undertaken.





Executive Summary

Background/ Problem

There is not enough CER (comparative effectiveness research) that responds to the concerns of behavioral health system users (i.e., patients), especially with respect to the concerns of those who are dissatisfied with main-stream behavioral health care. It has been challenging to get the voice of people in recovery into research, but it is important. There haven't been many studies completed within the Recovery Movement done by other members of the Recovery Movement. This project was designed to help change that. This research identified the priorities that members of the Recovery Movement would like to see more research directed toward, which was then combined with the science of community engagement. This science is needed in order to overcome barriers to full inclusion and full patient-advocate participation in CER research.

Mental wellbeing is much more than just the lack of mental illness. Self-determination and being actively involved in determining the course of one's life is very important to mental wellbeing. As patients/service users are actively engaged in research, they are better able to influence and integrate the services and supports that are most helpful to them. Collecting and integrating both qualitative and quantitative data on a wider range of what service users find most helpful will increase the range of choices for others seeking support with mental wellness also. Mental wellness can mean the difference between life and death or even living a meaningful life versus barely surviving. Empirically based, research driven options help inform treatments and other support options that can increase mental wellness. Mental wellbeing is a need for everyone who has a mind. Those who are in recovery have had to work to develop and maintain this wellness, they have valuable knowledge that can benefit everyone.

Method

Poetry for Personal Power has worked with national experts on survey techniques to complete a national surveys of Recovery Movement priorities. An initial survey of members of the Recovery Movement was done at the beginning of this project which collected 37 responses from members of the Recovery Movement. Logic Depot partnered with us to create a platform to survey members of the Recovery Movement nation-wide. Strong advocates within the Recovery Movement helped to distribute this survey. 212 responses were collected from members of the Recovery Movement. This data was compiled considering how the people who were giving us information identified themselves in relation to recovery. The first survey was primarily research priorities in the categories of substance use addiction recovery, neurodiversity, and mental health addiction recovery were identified. We incorporated those research priorities into the researcher toolkit for distribution to those who are planning and creating future research and to inform funders. This research was also done to inform those who deliver services within peer and recovery spaces and the community at large.





The research and curriculum previously developed by Larry Davidson at Yale was synthesized with our advocacy practices and research to create a toolkit that is an easily replicable business system. 35 advocates with diverse demographics were trained. Of the 35 advocates, income range varied from 50% poverty to 250% poverty level, 19 were non-white advocates, 11 were young adults, 5 openly identified as LGBTQ advocates. Some advocates fell into multiple or even all of the above categories, 23 advocates were non-white, young adult, or identified as LGBTQ.

This publication is designed to describe the Recovery Movement CER priorities and preferences in detail. These advocates seek to help researchers learn how to lay out a compelling case for the involvement of patient stakeholders in behavioral health research. This four-pronged approach (service-user preference information, community engagement science, framing communication science, strong dissemination) was our approach to significantly increase the rates of engagement of patient advocates in the behavioral health research process.

Patient Engagement Plan

Primary engagement was done through a core project team of people with lived experience of recovery from behavioral health concerns. The team includes e-patients, Recovery Movement leaders, and researchers. The CER collaborator trainee team consisted of 35 individuals with lived experience of recovery. The team helped reach a national network of peers who gave input into Recovery Movement CER priorities, the community engagement science barriers to full inclusion, and the dissemination priorities for advocate and researcher training tools. Other stakeholders include researchers and funders with whom we are continuing communications.

Results

The key to understanding and interpreting this data is considering who the people are who participated in our research. The first survey that was done in Fall of 2018 involved leaders within the Recovery Movement, many of whom also identify as leaders within the movement.

In Fall 2018, the top research priorities identified were:

1. More about funding mechanisms to pay for peer support (I.E. studying Medicaid waivers)
2. More about peer support effectiveness
3. More about comparing wellness approaches to traditional approaches (I.E. yoga vs. Antidepressants)
4. More efforts on balancing harms vs. benefits
5. More about trauma neurobiology (tied for 5th)
5. City-wide resilience promotion research (tied for 5th)





In Winter 2020:

Top research priorities for substance or behavioral addiction recovery were:

1. Recovery support groups
2. Peer Support
3. The mind/body connection and occurrences of misdiagnosis for example a mental health diagnosis for a physical ailment
4. alternative/non-clinical models for mental health (tied for 4th)
4. wellness approaches versus tradition models, for example yoga versus medication (tied for 4th)

Top research priorities for Neurodiversity:

1. Effective therapies/sensory regulation techniques
2. Reducing stigma and educating more people about how to support people on the spectrum
3. Accommodations that help with functionality (tied for 3rd)
3. Medications that we are given and long term studies on their effects (tied for 3rd)
4. Wellness approaches versus traditional models, for example yoga versus medication (tied for 4th)
4. Adapting environments to support a wider variety of brain functionality (tied for 4th)

Top research priorities for Mental Health Recovery:

1. Art, music, writing, and other creative outlets as therapy
2. The mind/body connection and occurrences of misdiagnosis for example a mental health diagnosis for a physical ailment
3. Peer support
4. alternative/non-clinical models for mental health
5. wellness approaches versus traditional models, for example yoga versus medication

This publication will share their opinions on top topics that could use more Comparative Effectiveness Research (CER) It is a starting point for expanding more research into what can help most to build mental wellness. It is also a guide of best practices in community engagement science because connection and engagement go hand in hand with creating more wellness in our communities.





Nomenclature or Terminology Note

Multiple terms have been used through this Publication to mean "People with lived experience of recovery from behavioral health issues." At this time the "Recovery Movement" has not come to a consensus on what to call the community, how to define it, or what to call a person who has received or still does receive behavioral health services.

In this document the words "patient-advocate," "ex/patient," "service-user," "patient," "person with a psychiatric disability," "psychiatric survivor," or "consumer" have been used interchangeably. Usage is typically based on usage in source material. All of these terms have strengths and weaknesses. Another term that applies is "Human Rights Advocate for people with behavioral health labels," although it has not been used in this document.

To describe service user participation, the terminology as written in the BMJ Journal "Exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety: a protocol for a systematic review of reviews" has been adopted for this publication. It is quoted in full below.

"There is considerable confusion about the use of terminology in this area. A number of different terms are often used synonymously with involvement, such as engagement or participation, while the terms patients and the public are also used interchangeably with 'citizen', 'consumer', 'layperson' or 'service user'. These conceptual differences have emerged from disparate traditions social movements, policies and practices to describe the involvement process.³⁰ They have also been used to imply a greater or lesser level of involvement, power or influence in decision-making processes within an organisation. However, this language does not always reflect the underlying ethos of these involvement activities.³¹ In the absence of a consensus on terminology, we define involvement as an activity that is done 'with' or 'by' patients or members of the public rather than 'to', 'about' or 'for' them.³² This definition reflects the fact that the involvement process has increasingly come to be seen as a process of partnership: '...the active participation of patients, carers, community representatives, community groups and the public in how services are planned, delivered and evaluated. It is broader and deeper than traditional consultation. It involves the ongoing process of developing and sustaining constructive relationships, building strong, active partnerships and holding a meaningful dialogue with stakeholders'."





Recovery Priorities Studies

Introduction

Mental Wellbeing is necessary for everyone who has a mind and is dependent on holistic wellbeing in the body and the mind. Mental health should be examined as much more than the lack of mental illness. Mental health and substance use recovery relies on holistic treatments that involve much more than medication and traditional treatment methods. Seeking overall mental health awareness and encouraging more service users to utilize methods that promote resilience, well-being, risk reduction, and prevention in addition to traditional mental health services could create better recovery outcomes. It is possible to study communities that are actively working to create and promote wellness, use their tools, and effect change overall. Studying the Recovery Movement and asking them directly about their needs, strengths, and challenges could lead to some of this knowledge.

Everyone will experience difficulties in life; those who have learned resilience tools and built strong support networks have an advantage. They know how to seek support, where support comes from, and what to do with support as it is received. The circle of learning can be expanded to include the voices of more people, thusly expanding the collective wisdom that helps the community build meaningful lives. This study is not comprehensive, but it is a starting point. It is an example of inclusion, collective wisdom, and a starting point for future research.

The Recovery Movement

The Recovery Movement is a movement spearheaded by people who have found that recovery from mental illness and substance use issues is not only possible but probable when the proper supports are in place. The Recovery Movement believes in the power of people to know their own bodies and minds, the power of the consumer's voice, and the power of people to help one another. A basic tenant of this movement is that systems should be built to sustain people and their wellbeing. It is also the belief of the Recovery Movement that behavior is not always an indicator of mental instability, even when the behavior has unintended damaging consequences. There is power in studying why people do what they do and how education may help them learn more helpful behaviors. Resilience, Post Traumatic-Growth, and studies of recovery are an important part of the research that has been launched.

The concept of the Recovery Movement dates as far back as John Percival, the son of the prime minister of England, documented his recovery from mental illness between 1830-1832 despite the treatment he was receiving. The modern version of the Recovery Movement began with patient advocacy back in the late 1980s and early 1990s, beginning with advocacy for more choice and humane treatments of those with severe mental health issues. This movement has expanded and includes people in recovery from substance use disorders as well as mental health. Included in the movement are also advocates for recognition and better treatment of people who have co-occurring physical and mental health challenges.





Traditional Mental Health is not solving the problems of the populations most in need as a standalone solution. Further research into alternative methods of treatment is necessary for systems and funding mechanisms to be built. The treatment focus for the Recovery Movement is the whole person as opposed to the concentrated sole focus of behavioral health with the recognition that larger societal systems, trauma, environmental factors, and physical factors also factor into a person's ability to sustain mental health? Suggested changes to the current system include many preventative measures.

- Providing community and professional supports for all as a preventative measure (aiding in the decrease of mental crisis)
- Supporting resilience and proactively teaching mental wellness tools at a base level and measuring the outcomes of effectiveness longitudinally.
- Providing additional services and supports to help consumers transition from treatment back into functional living situations

This publication will share their opinions on top topics that could use more Comparative Effectiveness Research (CER). It is a starting point for expanding more research into what can help most to build mental wellness. It is also a guide of best practices in community engagement science because connection and engagement go hand in hand with creating more wellness in our communities.

Background/ Problem

There is not enough CER (comparative effectiveness research) that responds to the concerns of behavioral health system users (i.e., patients), especially concerning the interests of those who are dissatisfied with mainstream behavioral health care. The project team's research priorities include wellness techniques, nonclinical supports, peer support, and fully informed consent about medication. Gathering the input of those in recovery for research has been challenging due to many factors. Prior to this project, no systematic surveys had been completed to define the Recovery Movement and to ask what the related CER research priorities are. Also, very few advocates, funders, or researchers understand the science on community engagement. This science is needed to truly overcome barriers to full inclusion and full patient-advocate participation in CER research.

Method

An initial multi-punch survey of Recovery Movement Leaders was completed in Fall 2018 with 37 respondents. The survey was distributed electronically via email and social media channels to potential participants that were previously identified as Recovery Movement leaders. Since the Recovery Movement remains largely undefined as a group, Recovery Movement Leaders are defined as people who serve as an advocate (with or without compensation) who believe in the principles of the movement. This survey was promoted by advocates who have access to followers as leaders within the Recovery Movement.





Winter 2019 Poetry for Personal Power partnered with Logic Depot to create a survey platform to collect data from Recovery Movement members who are primarily service-users nation-wide. The survey was distributed to 3579 potential participants via email list, CRO/RCO distribution network, and advocates. Distribution composition 96% Service Users (this number included those that do not have diagnoses and seek alternative forms of treatment to aid with recovery from mental health issues and/or trauma), 2% Advocate (non-related/paid/volunteer), 1% Service Delivery (works in behavioral health or with people that have substance abuse or addictive disorders), 1% Family/Caretaker. From that population a sample of 212 participants.

This data was compiled; the top 3 overall research priorities in the categories of substance use addiction recovery, neurodiversity, and mental health addiction recovery were identified. We incorporated those research priorities into the researcher toolkit for distribution to those who are planning and creating future research and to inform funders. We also analyzed the priorities between the groups of participants (advocates vs service users) to see if and where their interest aligned.

Study 1 Results - Fall 2018

The top priorities of Recovery Movement Leaders that have emerged include peer support access and funding mechanisms, mental vs physical treatment occurrences (appropriate treatment for physical symptoms when mental health is present), integration of mental and physical healthcare, advocacy for access to healthier food, housing, and basic need support. There is a shift within this movement away from accepting doctors as the final authority on health and wellbeing and moving towards the individual being the expert on what does and doesn't work well for their own body. Finding effective ways to help their voices be heard remains an ongoing concern.

Providing access to care is of significant importance to Recovery Movement Leaders. This access to care is essential since many advocates – Peer Support Specialist/Recovery Coaches /etc would not be able to perform these functions without making a living and supporting their families. However, the second result – peer support effectiveness is paramount. With greater care access, checks and balances must be implemented to ensure the desired outcomes.

Respondents were asked a follow-up to identify what specific needs were needing to be addressed by research. Two gave written responses that fell within the "wellness" threshold.

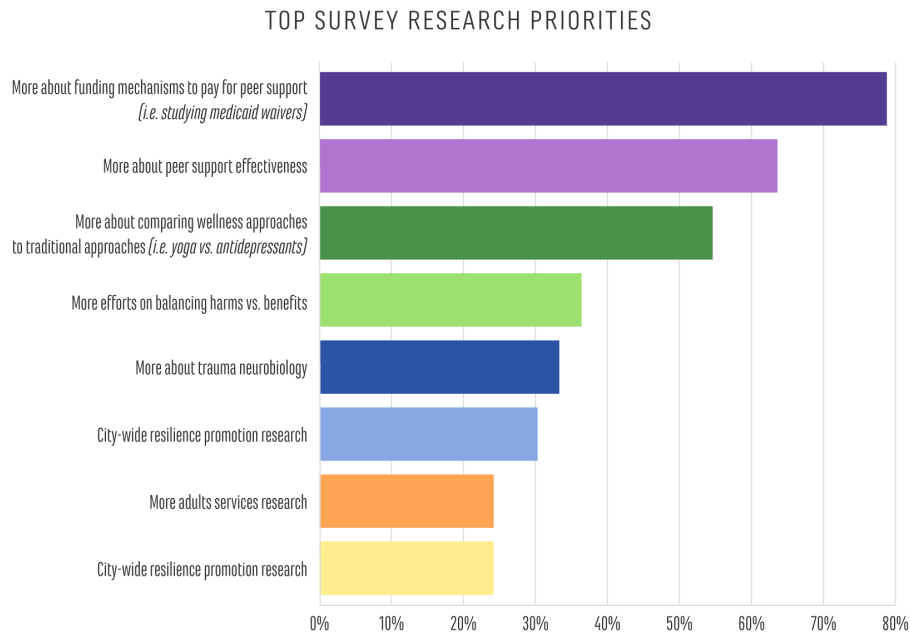
R1 *"Holistic mental wellness methods. Stop negatively labeling people. Nutrition. Physical care. Maslow's hierarchy of needs. Consumer driven task forces."*

R2 *"Connecting with nature (gardening, animal Care, conservation, hunting, camping, etc) to reduce symptoms and increase self reliance."*





What are your current research priorities for academic researchers?



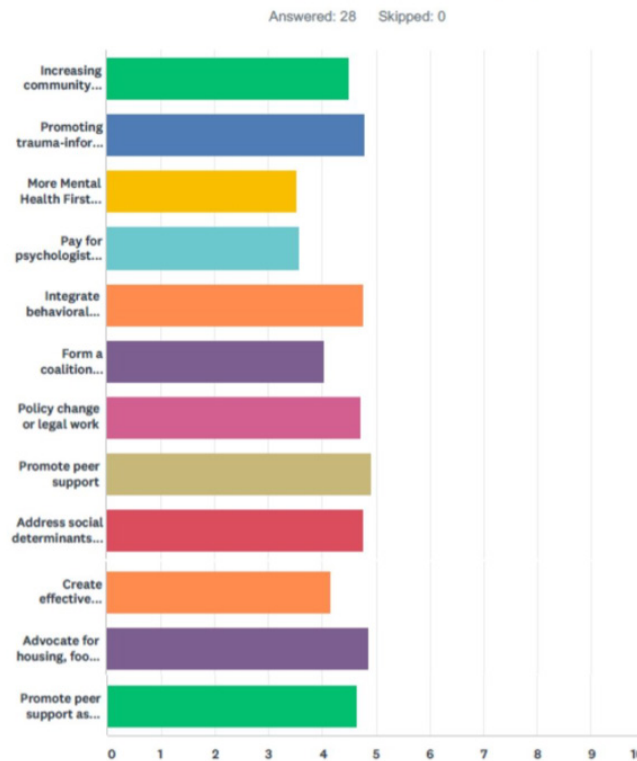
Top six responses:

1. *More about funding mechanisms to pay for peer support (ie studying Medicaid waivers)*
2. *More about peer support effectiveness*
3. *More about comparing wellness approaches to traditional approaches (ie yoga vs. Antidepressants)*
4. *More efforts on balancing harms vs. benefits*
5. *More about trauma neurobiology (tied for 5th)*
5. *City-wide resilience promotion research (tied for 5th)*





What do you think is the most important action that Peer advocates can take to address health equity?



The survey also asked what peer advocates can do to help with addressing inequalities and equity. The respondents felt overwhelming that peer support promotion was top priority. Peer Support teaches self-advocacy skills as well as the history and science behind mental health and substance abuse. Peers are also able to receive this treatment without a clinical diagnosis. This is critical to note because peer support can be used as a preventative measure for mental health outcomes instead of a reactionary after a mental health crisis or first-episode psychosis.

Q: "What is the most important action that Peer advocates can take to address health equity?"

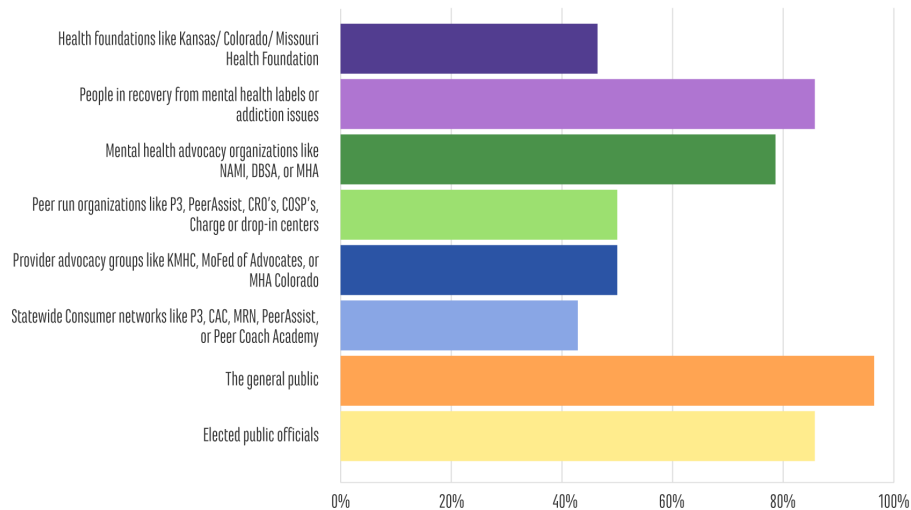
Top six responses:

- 1. Promote peer support**
- 2. Promote trauma-informed care**
- 3. Advocate for housing, food, income, and basic needs supports**
- 4. Integrate behavioral health and physical health**
- 5. Policy change or legal work**
- 6. Address social determinants of health**





Who needs to know more about the Recovery Movement and Health Equity in your state?



As previously mentioned, the Recovery Movement is largely undefined. Respondents were asked, "Who needs to know more about the Recovery Movement and Health Equity in your state?" The top three responses denote a lack of presence of the Recovery Movement within the general cultural context. Respondents also gave follow up written responses to this question to further elaborate on what they meant and why they needed these groups to know about the Recovery Movement.

R7 " I think that any kind of reform of this broken system is going to have to start with the people in recovery and the general public who don't know how or where to find the support that they need for emotional distress and mental wellness."

R9 "General Public - Most don't know that a Community Mental Health Center exists in their community and it provides Substance Use services Many don't know that there are so many people who utilize both in our community"

R20 "People in recovery, and consumer networks (including medical patient networks, ie MS and other chronic conditions), who can start banging on the foundations and the public officials to raise the profile of Recovery Movement and Health Equity actions with the general public. It's all connected"



Q: "Who needs to know more about the Recovery Movement and Health Equity in your state?"

Top 6 responses:

1. The general public
2. Elected Public Officials
2. People in Recovery from mental health labels or addiction issues
3. Mental Health advocacy organizations
4. Peer Run organizations
5. Provider Advocacy groups
6. Health Foundations

Study 2 Results – Winter 2019

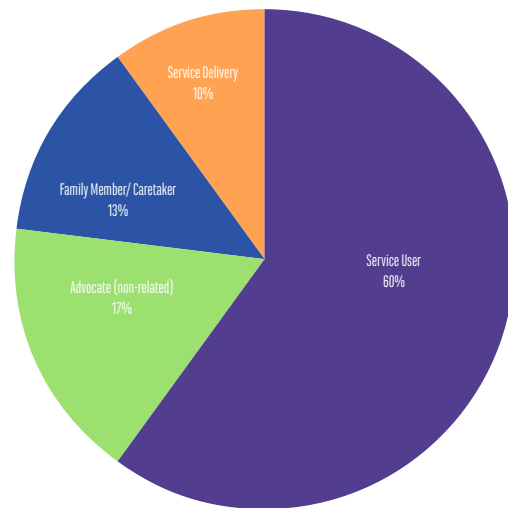
The second multi-punch survey was sent Winter of 2019 and collected additional data from 212 respondents. Logic Depot collaborated to host and distribute this survey. A team of peers reviewed and gave feedback on the survey before distribution.

The survey was distributed through a cultivated email list of participants derived from multiple events, workshops, and sessions held in the community and with service users from 2012 – 2019. Recovery Movement leaders Patty Schaeffer, Aja Owens, Paul Komarek , Ashley Grill, and Regina Holliday, Consumer Run Organizations, recovery agencies, and others helped to distribute the survey to their lists of other recovery movement members and service users. Onsite kiosks were also set up at consumer events. The survey was open for 2 months for data collection.





Respondent Self Identification - Code 1		Respondent Self Identification - Code 3	
Identified as having SMI	53%	Advocate (non-related/paid/volunteer)	40%
Identified as having SMI and SUD co-occurring condition	16%	Behavioral Health Worker SMI/SUD	40%
Service User/Consumer of behavioral health services/ did not disclose specific services or conditions.	10%	Caretaker of/Has family with SMI/SUD	20%
Behavioral Health Worker SMI/SUD	9%	Categorized (All Codes with intersection)	
Advocate (non-related/paid/volunteer)	3%	Service User	60%
Caretaker of/Has family with SMI/SUD	2%	Advocate (non-related)	17%
Neurodivergent (spectrum / aspbergers / etc)	2%	Family Member/ Caretaker	13%
Identified as having SUD	2%	Service Delivery	10%
Identified trauma effected/mental health undiagnosed	2%		
Behavioral Health Worker SUD	2%		
Respondent Self Identification - Code 2			
Advocate (non-related/paid/volunteer)	46%		
Caretaker of/Has family that is a service user (non-specified)	17%		
Caretaker of/Has family with SMI	13%		
Caretaker of/Has family with SMI/SUD	8%		
Identified trauma effected/mental health undiagnosed	8%		
Neurodivergent (spectrum / aspbergers / etc)	4%		
Behavioral Health Worker SMI/SUD	4%		





Advocate/Service User Comparison Analysis

Advocates and Service Users may agree on the most important need however the 2 diverge across the rest with advocate responses showing little variance (all things are needed) and Service Users leaning towards prioritization. These results emphasize the need for better advocate training and more community engagement in order to prioritize current service-user needs rather than overall systemic problem solving. All respondents agreed that there is a need for all things to be researched or have more palatable resolutions, however, service users are at the heart of understanding. They know, through experience, what the immediate need is from a lived experience perspective because more often than not, that need is not being met.

This prioritization also reveals areas where service delivery is making improvements. Advocates may still see a need because they feel "enough isn't being done" where service users will respond to actions taken and look of other areas for immediate action in order to push progress.





Advocate/ Service User Comparison		
Service User Ranking	What do you feel academic researchers should be researching with regards to addiction (substance or behaviors)? What do you feel we don't know enough about? What information do you feel would help people to better recover?	Advocate Ranking
1	I would like to see more research about wellness approaches vs traditional models (ex. Yoga vs Medication).	1
2	I would like more research on alternative/non-clinical models for mental health.	2
3	I would like to see more research about the Mind/Body connection and occurrences of misdiagnoses (ex. mental health diagnoses and treatment given for what is found to be a physical ailment or infection).	2
3	I would like more research on addiction recovery in Non-White families	2
4	I would like to see research on recovery support groups	2
5	I would like to see more research on addiction recovery in the LGBTQIA+ Community	1
6	I would like to see more research into peer support	1
7	I would like to see more research on the medications that we are given, more long term studies on their effects	2
8	Other (in a subsequent question)	4
9	Academic research is comprehensive in its current approach for my needs	3
Service User Ranking	What do you feel academic researchers should be researching with regards to neurodiversity and recovery? Neurodiversity the diversity of human brains and minds ? the infinite variation in neurocognitive functioning within our species, including the autism spectrum, ADHD, dyslexia, bipolar, and more. What do you feel we don't know enough about? What information do you feel would help people have better quality of life?	Advocate Ranking
1	I would like to see more research about wellness approaches vs traditional (ex. Yoga vs Medication).	1
2	I would like more research on effective therapies/sensory regulation techniques	2
2	I would like to see more research on reducing stigma and educating more people about how to support people on the spectrum	2
3	I would like more research on neuro-divergence for Non-White Families.	3
4	I would like to see more research about accommodations that help with functionality.	1
5	I would like to see more research on the medications that we are given, more long term studies on their effects.	1
5	I would like to see more research on adapting environments to support a wider variety of brain functionality	2
5	I would like to see more research on neurodiversity in LGBTQIA+ communities	3
6	Other (In a subsequent question)	4
7	Current practices related to neurodiversity are adequately addressing needs	4

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Service User Ranking	What do you feel academic researchers should be researching with regards to mental health recovery? What do you feel we don't know enough about? What information do you feel would help people to better recover?	Advocate Ranking
1	I would like to see more research about wellness approaches vs traditional (ex. Yoga vs Medication).	1
2	I would like to see more research about the Mind/Body connection and occurrences of misdiagnoses (ex. mental health diagnoses and treatment given for what is found to be a physical ailment or infection).	1
2	I would like to see more research into art, music, writing, and other creative outlets as therapy	2
3	I would like to see more research on peer support	1
4	I would like more research on alternative/non-clinical models for mental health.	2
5	I would like to see more research on the medications that we are given, more long term studies on their effects.	2
6	I would like more research on mental health in Non-White families.	1
7	I would like to see more research on mental health in LGBTQIA+ Communities	3
8	Other (in a subsequent question)	4
9	Current research efforts are adequately addressing needs	4
Service User Ranking	Of the following factors, which aspect(s) are the MOST key to your previous answer?	Advocate Ranking
1	Creation and adherence to a treatment plan	1
2	Restoration/Creation of quality relationships	1
3	Setting and achieving personal milestones	1
3	Physical well-being	1
3	Daily functionality	2
4	A standard quality of life	1
5	Sense of worth	1
5	Reduction/Elimination of negative life impacts	1
6	Reduction/Elimination of unintended impacts of treatment	1
7	Other (please explain)	3



Service User Ranking	Please rank your key success factors.	Advocate Ranking
1	Creation and adherence to a treatment plan	1
2	Restoration/Creation of quality relationships	1
3	Setting and achieving personal milestones	1
3	Physical well-being	1
3	Daily functionality	1
4	A standard quality of life	1
4	Reduction/Elimination of unintended impacts of treatment	1
5	Sense of worth	1
5	Reduction/Elimination of negative life impacts	1
6	Other (please explain)	2
Service User Ranking	How would you define the Recovery Movement (choose as many as apply)?	Advocate Ranking
1	A group of people with lived experience of recovery from substance use or mental health issues who advocate to help others find recovery.	1
2	Specific organizations or groups of individuals engaged in advocacy work aimed towards recovery.	2
2	Anyone who believes recovery from substance use or mental health issues is fully possible.	3
3	Please provide your definition in a subsequent screen.	3





Survey 2 Winter 2019 - Overall Results

Question	Rank	Response	%	Count
What do you feel academic researchers should be researching with regards to addiction (substance or behaviors)? What do you feel we don't know enough about? What information do you feel would help people to better recover?	1	I would like to see research on recovery support groups	13%	40.72
	2	I would like to see more research about wellness approaches vs traditional models (ex. Yoga vs Medication).	12%	37.76
	3	I would like to see more research about the Mind/Body connection and occurrences of misdiagnoses (ex. mental health diagnoses and treatment given for what is found to be a physical ailment or infection).	12%	36.82
What do you feel academic researchers should be researching with regards to neurodiversity and recovery? Neurodiversity the diversity of human brains and minds? the infinite variation in neurocognitive functioning within our species, including the autism spectrum, ADHD, dyslexia, bipolar, and more. What do you feel we don't know enough about? What information do you feel would help people have better quality of life?	1	I would like more research on effective therapies/sensory regulation techniques	14%	43
	2	I would like to see more research on reducing stigma and educating more people about how to support people on the spectrum	13%	39.1
	3	I would like to see more research on adapting environments to support a wider variety of brain functionality	12%	36.62
What do you feel academic researchers should be researching with regards to mental health recovery? What do you feel we don't know enough about? What information do you feel would help people to better recover?	1	I would like to see more research into art, music, writing, and other creative outlets as therapy	15%	43.56
	2	I would like to see more research about the Mind/Body connection and occurrences of misdiagnoses (ex. mental health diagnoses and treatment given for what is found to be a physical ailment or infection).	14%	42.42
	3	I would like to see more research on peer support	13%	37.88
Please rank your key success factors.	1	Sense of worth	14%	39.68
	2	Restoration/Creation of quality relationships	13%	35.1
	3	Physical well-being	11%	31.32
How would you define the Recovery Movement (choose as many as apply?)	1	A group of people with lived experience of recovery from substance use or mental health issues who advocate to help others find recovery.	34%	38.06
	2	Anyone who believes recovery from substance use or mental health issues is fully possible.	29%	34.06

Artist Entrepreneurship | Peer Support | Mental Health Advocacy | Research | Healthcare Messaging



Top research priorities for substance or behavioral addiction recovery were:

1. *Recovery support groups*
2. *Peer Support*
3. *The mind/body connection and occurrences of misdiagnosis for example a mental health diagnosis for a physical ailment*
4. *Alternative/non-clinical models for mental health (tied for 4th)*
4. *Wellness approaches versus tradition models, for example yoga versus medication (tied for 4th)*

Written in suggestions included:

"I would like to see research on veterans recovery from addiction and subscription in the military."

"Prevention efforts that help people identify what life events can lead to the need for protection of their mental health status."

"What helps people stabilize and get their life back? How many people feel they are being listened to and supported by clinicians? What can we do outside of clinical spaces to help people? Can we help families and people in treatment support one another?"

Top research priorities for Neurodiversity:

1. *Effective therapies/sensory regulation techniques*
2. *Reducing stigma and educating more people about how to support people on the spectrum*
3. *Accommodations that help with functionality (tied for 3rd)*
3. *Medications that we are given and long term studies on their effects (tied for 3rd)*
4. *Wellness approaches versus traditional models, for example yoga versus medication (tied for 4th)*
4. *Adapting environments to support a wider variety of brain functionality (tied for 4th)*





Written in suggestions included:

"I want to know more about disability accommodations, getting support in school, extending the terms of college classes, finding ways to live with what is happening."

"Open dialogue, hearing voices network, intentional communities."

"PRIORITIZE these. Additionally, neurodiversity is much more than autism. Start asking about stigma in growing up with disability. It's ignored in ACEs."

Top research priorities for Mental Health Recovery:

1. *Art, music, writing, and other creative outlets as therapy*
2. *The mind/body connection and occurrences of misdiagnosis for example a mental health diagnosis for a physical ailment*
3. *Peer support*
4. *Alternative/non-clinical models for mental health*
5. *Wellness approaches versus traditional models, for example yoga versus medication*

Written in suggestions included:

"I prefer to focus support on people with health concerns as well as families. Too much of today's recovery group communications are too focused on being strange sick ideosyncratic or weird, or anti medicine, or whatnot. Health is health, success in life and happiness are universal. What is really important to people needing help or receiving care today? This is research focused on the whole population not just activists or people with lots of symptom burden."

"Not that mental illness experiences are normalized, but the feelings the individual experiences are part of the human experience, and the individual can become a part of society as their own individual."

"The momentum that comes from realizing people can and do get better, The knowledge that the end product of treatment (both good and bad) rests with the insights gained from those who were "treated". It's people, not pills, not "treatment", "not training, not degrees... It's PEOPLE that matter."





This survey also gathered qualitative data from this survey by asking open ended questions. Here are some of those questions and some highlights taken from among the open ended responses:

In your own words, what does a successful recovery life include?

The responses seemed to have some common themes including self-determination and recognition of ability; community and connection; meaning and purpose; support and use of coping tools; and more. Some of these responses fit in multiple categories and have additional insights, like this one: "Sounds cliché but the truth is that for me, successful recovery is progress and comfort-ability in the 4 domains that have been identified: Health, Home, Community, Purpose." The responses were categorized and the categories flowed well together to create a model of what is needed to create mental wellness.

What Does a Successful Recovery Life Include?





Self-determination and recognition of ability:

"A recovery life should include addressing change in the stigma related to acknowledging your mental health status with or without a diagnosis"

"Being able to make your own decisions."

"Living one's own life."

"living the life you want to achieve."

"self-determination, customized support, job, respect, good place to live, peer support"

"Successful Recovery Life includes strong consistency and transparency when difficulties may arise."

"Whatever the person themselves defines it."

"The person involved to be able to genuinely say I am where I want to be with life."

Community and connection:

"Community, acceptance of self and by community, self-love."

"Life that includes Faith, Family, Community, Good Health and tools to address stress and space for those who struggle to get well without victim blaming."

"Not feeling alone. Not feeling like you are a burden. Not wishing the paramedics had been slower. Feeling that there are people who understand. Being able to talk openly, not hiding."

"Successful recovery includes a person living the life that they want, being active and healthy in the community."

"Writing, Music, Exercise, Friends, Family, Self-Partnership"





Meaning and purpose:

"Daily practice of something that one loves or is learning to do, multiple methods of support i.e. friends, family and colleagues Healthy food and lots of clean pure water."

"Doing something I enjoy and purposeful. Meaningful."

"Having joy back in my life. Having the energy and desire to participate in life. Feeling physically and emotionally well."

"It would include: a sense of purpose, contentment, gratitude, joyfulness, fulfillment."

"Meaningful relationships, meaning in life regarding spirituality, a meaningful job and/or volunteer work."

Support and use of coping tools:

"A successful recovery life includes support and healthy coping tools. It is extremely essential that someone in recovery has consistent support to ensure they do not relapse. In addition, when someone in recovery cannot access their support system right away, they need healthy coping tools that reminds them to push through and overcome the desire to revert back to old bad habits."

"I feel recovery is an individual journey. For myself, I work to keep my independence but if I need more support them I will advocate for what I need. I feel voice is very powerful and we are all experts in what we believe would be helpful to us. We should have options because options and choice are empowerment. I feel it helps people to be understood so Peer work is very valid in the process of recovery for all individuals."

"The person feels they are on a good track in life. They have a sense of belonging and competence. They feel supported and challenged (by things they want to challenge themselves with). They have support that makes sense to them and helps them achieve access to opportunities, people, places, and things that matter to them. They are welcome and included in social situations that they value. (Dating, working, being family, parenting, ect.)"

"Peace within oneself. Feeling accomplishment. Ability to give and receive love. Understanding that each day may still be a challenge but having the tools to get through it."

What is the largest need, as it relates to recovery, that is present, to the best of your knowledge, in your community?

Here again, there were some basic themes that emerged about what the largest unmet needs were. As these needs are addressed with teamwork and support, community wellness can be created.





Largest Needs in the Recovery Community



Community:

"A social group or groups to participate in."

"Connection. There is a huge need for people with lived experiences to find ways to connect and support one another. They also need to be connected to the larger community. There also needs to be access to integrated medical care that takes into account both physical and mental health."

"Good Relationship Skills."

"I am guessing but I think it's likely the church. I am in Mobile, AL and after that I would think its family."

"Kindness and respect in every care setting and throughout the community."

"Need to know the positive impact support networks have in the recovery process."

"Needing community-based supports."

"The ability of people with stories of recovery to know how to share stories and feel safe, welcome doing so.. There is NO recovery community here. None. The NAMI affiliate is a sad joke. We are rural, and I'm new here. As a direct result, STIGMA grows and thrives. And people are more interested in doing battle at city council meetings than addressing stigma in the community via education."

"Understanding."





"Accessibility. Affordably."

"Affordable/accessible housing (housing first-without required sobriety), employment support and fair wages for people of working age."

"Insurance reimbursed services."

"Lack of health justice and financial security."

"Lack of support for basic living and health, lack of peer support, lack of respect for peer advocacy."

"Mental Health seems to be going undiagnosed frequently in the community."

"Opportunities for broader services that is not tied to financial availability and available services outside of business hours."

"Safe housing and food for all, well trained open recovery guides."

"Testing for nutritional deficiencies, through health insurance."

"The largest need is access to recovery assistance for those in recovery looking to recover. It is not that there is not enough resources, however, more individuals who need the services need to know it's out there. It is also a need to create more innovative and creative programming or opportunities for those in the recovery moment to engage in."

"There needs to be adequate therapy med management and people that actually care perhaps those in the field should get an incentive, but sometimes money causes people to focus more on the monetary and neglect the true reason why we need such advocates in the first place. There are more people out in the world struggling with needing recovery and there is not enough advocates, therapists to support the influx of people."





Advocates, Training, and Funding:

"Advocates In Rural Communities."

"Education And Advocacy."

"Funding For Peer Support."

"I Feel We Can Do More With Individuals Trained At Peer Specialists And The Support Of Self Disclosure Is Valid In Building An Understanding. Peer Specialists Are Non Judgmental And Support Any Recovery Path A Person Is Wanting To Try. Some On Going Connection And Support Helps For Peer Specialist And Individual To Learn Of The Individuals Experiences And Possibly Exploring Other Options If The Past Taken Isn't Helpful For The Individual. It Helps To Have A Mutual Relationship."

"Knowledge Of The Option, And Funding To Serve Those In Need."

"Lack Of Education."

"Peer Support And Other Tools That Help Build Connection And Community Support..."

"Research Re Peer Efficacy In Providing Recovery Supports."

"Someone To Care, Coach, Listen, Be A Companion, Be A Facilitator And Leader."

"The Mental Health Center Is Always Looking For, Recruiting, New Clients. Those Who Recover, Do Well And Don't Need Services Disappear. Their Stories Of Wellness And Recovery Are Not Told. Their Recovery Stories Don't Support The System Of Care."





Racial Disparities and Other Stigmas Addressed:

"Decriminalization And De-Stigmatization Of Drugs And Their Use Must Be First. No One Gets Better In A Jail Cell. Cops Do Not Help Anyone. The Last 50 Years Of The Racist Right Wing Drug War Has Been Successful In Destroying This Country And Created The Violent Police State We Have Now With 2 Million People Locked Up And Millions More Imprisoned By The Overt Violent Racist Oppression."

"I Don't Want To Presume That I Know The Answer To This Question. But I Would Say The Effects Of White Supremacy And Need For Minority Lead Mental Health Initiatives Are Of Paramount Importance. Not Because Minorities Should Be The Ones To Teach Us About These Issues But Because There Is A Need For Safe Spaces For Them To Be Seen And Heard And Valued For The Wisdom, Knowledge, And Truth Of Their Lived Experiences. I Live In Charlottesville, Virginia And Over The Past Few Years There Has Been Major Efforts To Do This But There Will Always Be A Need For More. Also Income Equality And Affordable Housing."

"Not To Be Labeled Everybody Can Recover Recovery Is Possible."

"Reduce Stigma And A Lack Of Acceptance."

"Stopping The Stigma. Stop The Punishment And Focus On Treatment."

"The Absence Of African Americans Represented Within Support Within Organizations. And The Assumption That Churches/Pastors Are A Viable Resource."

"Tolerance"

Overall Peers Felt Like They Needed A Way To Connect And Belong In Communities To The Extent That They Desired That Connection, They Wanted Access To The Care And Support They Need In A Way That They Were Able To Afford, They Wanted Education, Advocate Training, And Access To Participate In Peer Support, And They Wanted To See Racial Disparities And Other Stigmas Addressed. They Need Many Of The Same Things As The Rest Of The Population. They Have Just Struggled A Bit More Getting Access To These Ideals Than Many Others Have. With Greater Awareness, These Things Can Be Addressed Much More Effectively Going Forward.





Community Engagement Science

Introduction

A core piece of mental wellbeing is the recognition that it inherently can't be separated from physical and emotional well-being. Part of why there is no simple one size fits all solution to maintaining mental well-being in a community is because there are diverse needs that must be understood and met. There are basic principles that are useful in helping provide context around what will be most helpful. Still, ultimately it is most beneficial to directly involve affected populations in defining and resolving their own challenges.

The phrase "Nothing about us without us," originated (in its English form) within the disability rights movement but is also the rallying cry of the Recovery Movement and relevant within mental health and overall human rights. The concept of inclusion and representation for marginalized people groups is not new. This phrase can be traced back as far as the 16th century and has emerged within different societies for various movements. In short, this is not a new concept. However, attempting to act on the idea frequently disrupts systemic norms. The ability of each human, regardless of their respective impairments or differences, to be involved and influential in the shaping of their own lives is paramount to recovery. Building healthy communities requires inequalities in addressing the social determinants of health to be eradicated.

Community Engagement Science involves learning how and when to include the members of the population being studied. An essential part of conducting any research is building a research team and involving various groups of stakeholders. Coalitions seem to be a popular way for groups of people to gather to try to influence the way that services are provided. Poetry for Personal Power has trained advocates to participate in coalitions, conferences, and completed multiple Community Engagement practices.

Why Improve Community Engagement?

According to the initial survey completed Fall 2018, respondents cited various issues with being involved in advocacy equity work. The top among these issues was having problems with the dominant paradigm in the room. Advocates and advocacy organizations are often invited to meetings, coalitions, and activities for input where a pre-determined solution has been presented. This results in tokenizing of the representative, having them there for appearances or to appease funding requirements. This type of environment also results in rejection of advocate solutions, silencing, and erasure that causes trauma and will deter further participation. Respondents also cited not knowing who else was working on advocacy and not getting invited to decision making circles. Research has determined that many smaller organizations work in silos and are unaware of the activities of other organizations. Well-rounded community engagement would help in this area as well.





Q: What are the barriers that make health equity advocacy work harder for your organization?

Top 6 responses:

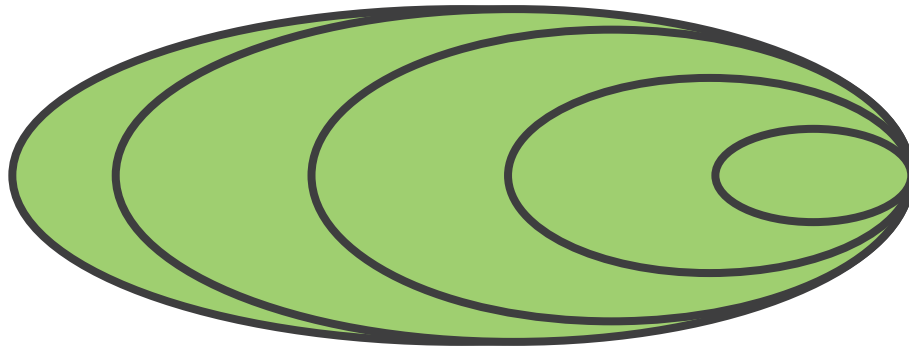
- 1. We have problems with the dominant paradigm in the room**
- 2. We need input processes to happen outside the meeting format**
- 2. I don't know who else is working on health advocacy**
- 3. Feeling "tokenized" (tie)**
- 3. Coalitions make all the decisions before inviting us (tie)**
- 4. My agency cannot work for free (tie)**
- 4. We don't get invited to the health equity coalitions (tie)**
- 5. We have trauma issues related to "rejection," "not being heard," or "denying my story"**
- 6. Physical Health challenges make meeting attendance hard**

The mental health research community still holds biases that prevent more meaningful and robust engagement with stakeholders as genuine research partners. Examining such implicit and explicit biases can be a first and integral step towards changing and opening up the scientific process for the benefit of the surrounding community. Stakeholder involvement can come in multiple forms and levels, spanning everything from advising and consultation on one end, all the way to stakeholder owned and operated research endeavors. Researchers and community partners are encouraged to explore these diverse possibilities and consider what makes the most sense to their particular project. Stakeholder partners, and researchers themselves, often report positive transformations, not only concerning research but their personal journey, with less alienation and more connection as a result. Though challenges may await such partnerships, these challenges are often the source and site of the work itself. That is, challenges present opportunities for researchers and community partners to learn more about each other, thereby strengthening the scientific process for all.

Each individual of a community or people group is interdependent. Creating real prosperity means including everyone. Future success requires the contributions of all citizens, including the ones that often go unheard. Allowing the inclusion of multiple forms of expertise expands innovation. The breakthrough idea or brilliant issue resolution could be held by the community member that never gets included in dialogues due to low or irregular engagement. Community members and people with direct, lived experience of mental health and other conditions know vital information and have direct access to knowledge about life and recovery, but are rarely included as research partners.

Improving community engagement also expands the sphere of influence. Promoting proliferation of peers into higher levels of influence within advocacy efforts is proven to increase outcome satisfaction, aid in continued progress, and help with dissemination efforts of new information across all levels.





Spheres of Influence



<p>Global</p> <p>Examples:</p> <ul style="list-style-type: none"> • <i>UN Universal Declaration on Human Rights.</i> • <i>WHO Consultative Group on Equity and Universal Health Coverage.</i> • <i>Multinational Corporate Marketing</i> 	<p>Society</p> <ul style="list-style-type: none"> • <i>Cultural Values</i> • <i>Political Priorities</i> • <i>Public Policies</i> • <i>Laws & Regulations</i> • <i>Economic Capacity</i> • <i>Science & Tech</i> • <i>Absorptive Capacity</i> • <i>Resource Allocations</i> 	<p>Community</p> <ul style="list-style-type: none"> • <i>Neighborhood</i> • <i>Workplace</i> • <i>Schools</i> • <i>Place of Worship</i> • <i>Community</i> • <i>Organizations</i> • <i>Health Literacy</i> 	<p>Interpersonal & Social</p> <ul style="list-style-type: none"> • <i>Family Support</i> • <i>Friendships & Networks</i> • <i>Social Interactions</i> • <i>Group Membership</i> 	<p>Individual</p> <ul style="list-style-type: none"> • <i>Personal Beliefs</i> • <i>Attitudes</i> • <i>Behaviors/ Habits</i> • <i>Knowledge Base</i> • <i>Circumstances</i> • <i>Other Life Course Influences</i>
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White, pg5

When looking for authentic representation and community building, the most useful question is, “who still isn’t here?” Lack of representation is an important thing to address. It is the job of the advocate to advocate for permissive inclusion where there is a lack of representation. If the advocate enacts their voice as the voice for the absent without permission and the input of the under-represented parties, the advocate would then be participating in one of the things that Community Engagement Science seeks to correct - erasure. The job of the advocate is to create space for inclusion and ensure that all parties are represented in appropriate proportion.

When engaging the community, depending on the level of engagement, many members will happily offer the information requested. They are excited that they are being asked and willing to be involved. Some could express anger, suspicion, apathy, discontentment, or not want to be involved (no matter how much “good” is intended). Community members from both sides of the spectrum will have plenty of questions.





Questions:

Who are you? (your org/who you represent/who is paying you/how much)

What are you doing? (What are your intentions, and have you calculated your unintended effects?)

Why are we being included? (Why now? We have never been included before.)

Why we not being paid for our input?

How will my information/input be used?

Will my face/name be included with the input?

Will you claim our ideas as your own?

What are your processes for including others?

Will you be here to see this action through?

Questioning and feelings of mistrust and discontent are not uncommon and can cause discomfort or potentially ruin an engagement strategy if not appropriately handled. Following productive Community Engagement Science will build the necessary trust to help ease the impact of these initial reactions and mitigate potential disruptions to progress. Functional community engagement has many different advocates with varying personalities and skillsets that help transform unease from both sides into robust dialogue into productive energy. Processes must be put in place to allow for this. Well planned and intentional community engagement comes in the form of trained facilitators, room on the agenda for all, stipends for advocates (experienced advocates as well as novices), input methods outside of meetings, training for community advocates, and community action as a result. These quality processes help protect the people that are hosting the community engagement as well as stakeholders.

We must note – the inclusion of people with lived experience is not a “favor,” it is an expectation and burgeoning standard. Community members often call for greater relevance and connection of science to their everyday lives and neighborhoods. Participatory research represents a direct way to foster both, through greater incorporation of community input, cultural diversity, and local ingenuity.

There is a rich yet often forgotten history of meaningful, permissive stakeholder and service user involvement in research, spanning the whole breadth of health and mental health sciences. This movement is global, with several funders now requiring the participation of stakeholders and the public community in research projects. Persons with lived-experience and community members are doing researchers a favor by providing input, and in turn, all are doing the community a service. Research demonstrates the value and effectiveness of stakeholder involvement in research, both for stakeholders and for the research community.





P3 Experience with Community Engagement and Advocacy:

P3 Advocacy Strategy Development

Poetry for Personal Power Advocacy Strategy Development Framework trains advocates to add behavioral health and advocacy into their daily lives, which naturally helps with trauma reduction. Our advocacy strategy is built to help communities become more involved and included in decision making and problem-solving processes. After priorities are identified and synthesized with national priorities, our messaging is refined by experienced advocates, and further refined by our technical support team. The level of impact on policy can be increased depending on the skill, training, and sphere of influence of the advocate. Most laypeople do not recognize their spheres of influence or how much impact they could have. We train advocates to make use of their immediate spheres, expand them, and increase their impact by utilizing evidence-based approaches drawn from businesses and social issue advocacy organizations (Unilever, Nesta, and the Frameworks Institute).

Levels of Outcome Impact on Policy	
Access	The voices of previously excluded stakeholders are now heard
Agenda	Desired policy change is supported by powerful decision makers
Policy	Desired change is translated into new legislation or regulations
Output	New policy is implemented as proposed
Impact	New policy has intended consequence
Structural	New policy is now widely accepted as the new norm
<i>(Casey, 15)</i>	

Poetry for Personal Power has a multi-layer approach with Community Engagement that includes Advocacy plus Peer Support. We offer Peer Support externally as a service within communities, and internally for advocates to help mitigate burn-out. Providing Peer Support within the community is a double-duty strategy. It implements the methodology of David Gershon outlined in his book Social Change 2.0. This work improves the functionality of current systems while introducing new practices that have transformational effects. Peer Support allows advocates to build one-on-one relationships with peers in the community, build trust, complete needs assessments, and find resources for them. They are dually able to advocate for social change at the Community and Interpersonal levels, ensuring advocates do not lose touch with the needs of the people of the community. Involvement at this level also aids in the empowerment of community members outside of regulated structures. Advocacy is not about waiting for big changes, but about enabling small changes that pile up.





Our communications and messaging were developed by service users of behavioral health services, refined by experienced advocates, and further refined by our technical support team. We work with poets by using their creative expertise as people whose life work involves communicating meaning and emotions. Our work with poets and artists multiplies the practical value of our messaging. Each of our advocates translates the messaging by building their own unique approach and tailoring our messaging to their own community. African-American advocates have more impact in their own communities as do LGBTQ, Farmers, Asians, Hispanics, etc. Advocates more effectively speak to the needs of their own people because they can speak from the experiences of their people and work with their people to accurately inform decision-makers. The multi-voice approach accords with social movement theory, which posits that multiple voices delivering a variety of compatible messages are more effective at delivering social change than many people repeating one slogan.

The P3 advocacy strategy is developed by holding 100+ public input sessions per year via healthcare messaging events. We also collect input via Facebook, blogging, emails, and surveys related to advocacy priorities. This data collection also includes our staff and board. Collection outreach includes other advocacy organizations, community organizations, partnership efforts, relationship building with funders. All must recognize the focus of each organization that is involved in each interaction. There is a difference between organizations whose focus is on clinical priorities and groups of advocates who focus on recovery and social determinants of health. The advocate should know what type of organization they are speaking to and share the information that matters to that particular group.





Most Notable Advocacy Successes:

Policy change:

- Poetry for Personal Power wrote 3 of the 7 position papers being presented at the Kansas Mental Health Coalition Advocacy Day 2019.
- June 2018 the Missouri Federation of Behavioral Health Advocates, the leading policy change group in Missouri whose mission is "works to ensure consumers have a voice in the development and implementation of behavioral health policy," voted to add "consumer input" to their monthly agenda. February 2019 – 1st month that the "consumer voice" appeared on their agenda.

Resilience

- 2016 -2017 P3 teams hosted over 80 Resilience Poetry slams, 40 Social Inclusion Events, and 50 Substance Use Prevention Events. Audiences said our most important behavioral health concepts were resilience info 38%, overcoming adversity 28%, trauma information 12%, recovery 11%, mental health resources 8%, and toxic stress info 4%.

Peer Input

- 2016-2019 P3 supported "consumer input", 129 Advocates have given peer input into 22 projects, with 1747 hours of total peer input provided.

Conferences

- P3 helped 48 advocates make 98 conference appearance at 28 conferences.

Community Needs Surveys

- 74 advocates have gathered 1010 Community Needs Surveys in 9 projects.

Wellbeing Impact Assessment

- 5 advocates have helped 31 nonprofits and 58 nonprofit staffers make 60 programmatic change ideas related to increasing resilience or mental wellbeing impact.

Art As Advocacy

- 15 advocates completed Infographics, Walking Gallery Jackets, Graphic Novel for ACA education, Movie Edits, PSA creation, and Workshops / Presentations / Seminars / Classes.

Recruiting Lobbying Advocates

- 25 advocates recruited to statewide Policy teams.

WyCo Engage

- P3 met with over 70 organizations/businesses to discuss community needs, services offered, service disconnects (why they are not able to connect to service users), what needs they see in the community and what they are doing to address them. WyCo Engage street team talked to members of the collecting qualitative research regarding needs and wishes. 142 surveys collected from lay community members (homeless / service users / from low income). Hosted a community engagement event at the KCK Public Library infused with an art contest. Art contest consisted of participants drawing their solutions to trauma and offering ideas for increased resilience. 90 people attended, 10 participated in the visual art contest and explained their solutions to the group.





Rubric, Tools, and Best Practices:

This rubric should be used and shared with participants at all advocacy levels. It is designed to aid with the examination of current processes, solution creation, and change management. Please take note of the first item on the list – timing. Timing is one of the most crucial elements of this entire process. If all interested parties are not able to participate before RFPs are created, proposals for services will be released to the community, possibly requesting services and projects that the community does need or that will not reach the community as a whole.

The rubric was compiled with various resources of information from Poetry for Personal Power Community Engagement Work, surveys/evaluations collected, and a literature review of David Chavis' Promises and Paradoxes of Community Coalitions (Chavis, 2001) and the Seven Partner Values taught by the Center for Learning and Leadership. An advocate brain trust was formed, and a list of 13 initial points were drafted. These 13 points were used within the WyCo engage project and tested for verity. After review, the 13 points were reworded then further paired down to 8. These 8 points plus the Best Practices have been used for advocate training starting Winter 2019.





Rubric:

1. **Timing:** Invite stakeholders and interested parties to contribute ideas before RFPs (Requests for Proposals) are released.
2. **Stakeholder Team Composition:** Teams should be comprised of at least 30% grassroots advocates and not more than 50% professionals. The rest of the team should include service users. Choose neutral funding resources and facilitators for coalition meetings. Allow equal representation for parties present on the agenda.
3. **Allow Conflict:** The most productive coalitions have a process to allow conflict. Remember to follow trauma care principles within respectful dialogue.
4. **Stick to the True Nature of Coalitions:** Coalitions do these things well: raise money, distribute ideas, and advocate for policy change. It has been proven that coalitions do not manage programs, innovate, or gather grassroots input well.
5. **Input Accessibility Structure:** Options include: online surveys, focus groups, street interviews, text, and phone calls. Be culturally competent - meetings don't work for many due to their limitations.
6. **Choose Trained Advocates:** Passion is great, but community advocates should be trained for advocacy and equipped with information regarding community-specific history and needs.
7. **Pay Advocates for Their Time:** Advocacy is a skill-set and when done properly very demanding. Advocates are valuable.
8. **Keep Trying:** Provide a variety of invitational opportunities to community members and stakeholders with consistent accountability. Even if most people do not come to the first meeting, keep inviting, keep pushing, keep pursuing. It is common that with a new effort trust and knowledge must be built. It may take upwards of 3 invitations before some respond. Keep trying.

Community Member Voice:

Don't come into my community and tell me what you are going to do, ask me what I want, then be willing to work with me towards a solution.





Story Circles Tool Overview

Story Circles is a tool that P3 has used within communities to bring researchers, peers, professional, elected officials, and laymembers of the community together in an informal forum allowing them to speak in a relaxed atmosphere. This creates a “human” experience where participants are able to share a space and speak with equal weight as members of the community. Spaces like these are an important and innovative part of community engagement because they work differently than “Town Halls” where the community comes together to speak specifically about systemic problems. These spaces are more organic and speak to mental health, well being, and societal issues, then possible solutions can be drawn from these interactions.

Systemic processes that have led to the dehumanization of participants and power differentials between participants and providers. P3 partnered with Dr. Deborah Wilcox in developing Story Circles and the program was fully piloted in Colorado.

People are designed to learn and to pass information between generations through stories. Stories help us connect and see each other as humans, individuals. Story circles are designed to create a place where providers, researchers, consumers, and advocates can all come together as human beings and really hear one another. It is a process for creating an environment that helps offset the power differentials that often exist in other interactions. This format can be used to bring together a variety of people to share experiences, learn from each other, and have important conversations in a way that feels safe to all involved. It provides a solid foundation for more research that includes the voice of a wider range of people.

The purpose of the “P3 Wellness and Resilience Story Circles” are to promote sustained mental health wellness, recovery and resilience within community with both peers and providers who are involved in mental health Recovery Movement and services. The Story Circle engages peers and providers in awareness and skills that empower persons who suffer with mental illness, and or substance abuse challenges to become involved in sustained self-care and resiliency. In addition, Story Circles provide opportunities for peer leadership development, and for service providers to join the Story Circles with the intent to of being in community with peers, and to have the opportunity to listen in a different way, and learn about the varied aspects of the recovery journey from persons with lived experience.

Multicultural Competency:

Story Circles bring people together in community across cultural differences, to share life experiences about what matters to them and their communities. Story Circles also help people to listen deeply to one another, build trust, discover common ground, and to identify shared values. The Talking Stick, which is often used in the story circle ritual, is an Age-Old cultural tradition that was utilized by many native cultural groups and tribes to promote voice and choice, and democracy within their villages. The Talking Stick is passed around the circle to ensure that everyone has an equal opportunity to share his or her stories within the group. Story Circles support mental health wellness and recovery in multiple ways:





- Participants establish personal wellness goals for themselves
- Promotes personal and group reflection
- Build personal relationships and community across cultural and human differences
- Gain support healing through sharing
- Generates personal growth
- People gather together to share collective experiences
- Engage in talk focused on healing from stigma and oppression
- Build relationships across cultural differences
- Learn how one's cultural awareness promotes healing, holistic health, wellness and mental health wellness and recovery.



The Talking Stick, which is often used in the story circle ritual, is an Age-Old cultural tradition that was utilized by many native cultural groups and tribes to promote voice and democracy within their villages. The Talking Stick is passed around the circle to ensure that everyone has equal opportunity to share his or her stories within the group. The story circle opens a space for peers and providers to share lived experiences and to hear one another differently.

Multicultural Competency is Evidenced within the Story Circle Process:

Each member of the story circle has a unique cultural and family heritage, and has an individual set of beliefs and values that are influenced by their ethnicity, class, education, gender, sexual orientation, spiritual beliefs, ability, -and age (along with other cultural identities and life experiences. The Story Circle involves participants in a collective learning community, primarily to work on their personal "self-care" and recovery goals.





Multicultural Competency is Evidenced within the Story Circle Process:

Each member of the story circle has a unique cultural and family heritage, and has an individual set of beliefs and values that are influenced by their ethnicity, class, education, gender, sexual orientation, spiritual beliefs, ability, -and age (along with other cultural identities and life experiences. The Story Circle involves participants in a collective learning community, primarily to work on their personal "self-care" and recovery goals.

Story Circles are designed to collaborate with providers, agencies, researchers, peer advocates, and community stakeholders, to promote systemic change within the mental health and the broader healthcare community, to improve the recovery of persons who suffer with mental health and substance abuse challenges.

Story Circle Group Process Approach

Theme-centered Interaction (TCI), (1994):

Is a concept and a method for working with groups, goal is social learning and development of the person, and to assist in creating humane environments which make possible personal growth and living learning as a key to improving society purpose was to "enable a healthy person to remain healthy".

Improvisation:

Create and perform (poetry, music, drama, or verse) spontaneously or without preparation, not practiced and invented by the performers. Improvisation is also the activity of making or doing something that you have not planned.

Experiential Engagement:

The process of learning through experience, and is more specifically defined as learning through reflection on doing.

Co-construct with peer participants the curriculum (story circle themes). Below are some suggested themes:

- Holistic Health and Self-Care
- Mental Health Recovery
- Wellness Circle - personal assessment and goal setting
- An Understanding of Mental Health
- The Role of Medication in Recovery and Wellness
- Learning to Manage Symptoms and Side Effects
- Effective Communication
- Communicating with Your Providers
- Coordinating Your Care
- Building Social Supports and Involving Others
- Planning for Wellness: Incorporating the arts: poetry, music/song, visual art





At the conclusion of each Story Circle Evaluations are given regarding the circle and research thus making each Story Circle a gathering point for qualitative and quantitative data. These story circles have been successfully implemented in Colorado for most of the duration of this project. Some of them have been hosted in Kansas City in both Kansas and Missouri. In light of recent social distancing changes due to Covid-19, story circles have moved online using zoom rooms to facilitate the gathering. The online platform has increased accessibility allowing more participants from more locations to join.

Best Practices

1. Funding – Service user input is important in community engagement and research. However, there are barriers to this input. The average peer in the community is employed. If they are not employed, travel (even inner-city) may pose an economic hardship. Service users may also have small children to tend to, family members that they are care-takers of etc. Funding stakeholder involvement will afford them the opportunity to participate.
2. Give advocacy structure and tools with intentionality. Some of these should include:
 - comprehensive information debrief with the priorities of the advocacy
 - accessible tools for information gathering
 - one point of contact
 - a defined reporting structure
 - multiple access points for input (online/in-person/etc.)
3. Schedule training with accessibility. Everyone is not able to attend training Monday through Friday 8-5. Training may have to be broken up over nights and weekends or even scheduled online. Be flexible.
4. Learn what is already there instead of trying to create a new program – work through existing channels and create ways for these channels to work together.
5. Promote empowerment. Empowerment cannot be taught, but individuals can share them; they have been empowered and provide a space for others to figure out what is needed for self-empowerment.
6. Never say “I am going to teach you_____” That statement automatically denotes a power structure where the facilitator’s words carry more weight than that of everyone else’ in the room. Instead, frame the work that is being done with more cooperative language.
7. When attempting to gather answers to severe problems from the community, try to point participants back into themselves with well-placed questions. The objective here is not to release accountability from responsible parties but instead to generate focus on immediate solutions. We know what THEY won’t/haven’t done for us, what can WE do for ourselves while holding them accountable. (The “we” here is inclusive and indicates that the advocate is also there to help in the solution.)

Remember - this is engagement, so be engaging! Go where the people are and get them excited!





WyCo Engage Case Study

The largest city in Wyandotte County is Kansas City, Kansas. It was a fascinating microcosm for many of the inequities and social determinants of health that need to be addressed within our larger society. Wyandotte County has the worst rank in Kansas when it comes to premature deaths, access to care, and other social determinants of health. According to the Wyandotte Economic Development Council, "Wyandotte County has more than 165,288 people and ranks as the 4th most populated county within the state. The largest Wyandotte County racial/ethnic groups are White (42.9%), followed by Hispanic (26.8%) and Black (24.5%)." Data USA stated that: "As of 2017, 15.7% of Wyandotte County, KS residents (25.7k people) were born outside of the United States, which is higher than the national average of 13.7%." This information includes many immigrant refugees who have resettled in the area from parts of Africa and Asia. Community Engagement in this area began by learning more about the local community to be served.

The Community Health Council of Wyandotte County recently completed its H.E.A.T. Report (Health Equity Action Transformation) that took a solid look at the social determinants of health in various parts of Wyandotte County. They had used the Kirwan Opportunity Index and input from members of the community to compile the report. Mental Wellness doesn't exist in a bubble; it is dependent on physical wellness and many other factors. The places where people live and the opportunities they have contribute to their physical and mental wellbeing. The Kirwan Opportunity Index measures social factors like poverty, unemployment, housing, education, the food system, and more. (Reese, et al. 2013) Studying these factors can help make sense of health inequities within a community. In Wyandotte County, opportunities were lowest, and health inequities were highest in the Black/African American neighborhoods located in the Northeastern part of the county, followed by the predominantly Hispanic communities. One of the starkest measures of these health inequities was the Infant Mortality Rate. In 2014 infant death mortality for Kansas was 6.3 infant deaths per 1000 births. In Wyandotte County, the infant death mortality rate was 11 for Blacks/AA, 6.5 for Hispanics, and 5.2 for White (non-Hispanic) per 1000 births. The average age at death was between 59-62 in Black/AA neighborhoods, but in predominantly white neighborhoods just a few miles west, the average age of death range was 71-81. (Norris)

Before applying for funding, we recruited artists and advocates who are interested in behavioral health advocacy to assist with program design. One of the qualifications for joining the team was that artists must already be connected with at least two groups in their own community. By specifically looking for people and organizations who are already a part of the community, we ensure that each artist brings in their own social networking. Advocates were trained to administer community surveys, reaching into various areas of the community. They spoke with people on the street, door to door, and in public places throughout the community. Grocery stores are specifically important here, especially when attempting to reach specialized segments of the population. Wyandotte county is ethnically diverse with a large immigrant population. One of the best ways to reach these community members is to be present where they shop, and they would not typically shop at a "big box" grocery store, but the neighborhood, family-owned store that has the selection of foods that is specific to their culture. One of our advocates frequently spoke to people on the bus during his usual commutes. Our advocates reached homeless people, immigrant communities, and many people who expressed surprise at being asked for their input and involvement.





It is also known that many Wyandotte County residents travel to Kansas City, MO for entertainment, and some students even go there for school (attending private/low-cost / Catholic Schools). Efforts were made to reach these residents as well as surveys distributed online. Along with being present in the community, P3 also held its own outreach events and community input sessions. One of the more notable input sessions was in the downtown library in Kansas City, Kansas. That library location attracts a large amount of homeless foot traffic, low-income residents, people of varying ages and demographics, and is also located across the street from S.I.D.E. (a mental health drop-in center). Our advocates stood outside of the library to invite participants in off of the street. We fed those who came pizza and asked them for their input in various ways (voting by beans on their input about the location of a new grocery store, community needs surveys, artistic expression regarding their solution to trauma). The most important thing about having variety and advocates on-hand to assist those that needed it was that we encountered some participants that wanted their opinions noted, but were illiterate. Some did not speak fluent English. There were others that, due to disability, did not have the fine motor skills required to fill out their own surveys. More community input was gathered by assisting and feeding than any other method.

Partnership development through the community was widespread and organic. Strategically, these partners were to also fall in line with the key sectors as identified by Scattergood in their Collaboration and Cross-Sector networks (child welfare, health care, behavioral health, housing, environment, arts and culture, business and workforce, government, parks and recreation, education and early childhood, public health, faith, social services, community development, law enforcement and criminal justice, and philanthropy). Many small groups and organizations are doing work in Wyandotte County; however, they often operate in silos and are unaware of what others are doing in the community. The objective of overall partnerships was to bring all of these organizations together to work together, learn from each other, and create more sustainable sources of revenue going forward.

The active ingredients/social messages of this engagement were designed around resilience and social capital research, particularly in the African-American community. Well-being breaks down into two categories: "happiness and satisfaction," and "meaning and purpose." This was important in the African-American community, where resilience is a slightly different process. Immigrant communities showed the need for additional supports.

Different types of trauma were prevalent in immigrant communities. This trauma was not just from refugee camps or their countries of origin. Some participants expressed that they were struggling with language barriers, and social determinants (ability to make a living, access to health care, living conditions etc.). Many of them expressed that their greatest need is to have a space to gather where they can feel like they truly belong. There was a need for English classes among these Asian refugee immigrants that also needed to be extended to Latino immigrants and African refugees. The Bhutanese also expressed a need for classes to teach their history and traditional language to a generation that is growing up not fully fluent in either language. The ability to have these classes and mental health help would come from access to funding that these communities were not aware of or equipped to access.





Through this engagement, Poetry for Personal Power was able to aid in the creation of connections, strong relationships, and ongoing collaborations. P3 met with over 70 organizations/businesses to discuss community needs, services offered, service disconnects (why they are not able to connect to service users), what needs they see in the community and what they are doing to address them. WyCo Engage street team talked to members of the collecting qualitative research regarding needs and wishes. One hundred forty-two surveys collected from lay community members (homeless / service users / from low income). Hosted a community engagement event at the KCK Public Library infused with an art contest. Art contest consisted of participants drawing their solutions to trauma and offering ideas for increased resilience. Ninety people attended, ten participated in the visual art contest and explained their solutions to the group.

We are participating in the Alive and Thrive community engagement program for this area, which has formed its own coalition with funding from the Wyandotte Health Foundation to pull together 16 sectors that will help to make Wyandotte a more resilient, trauma aware city. Currently, this project has over 50 participating organizations (not including governmental entities). We also partnered with the Kansas Bhutanese Community Foundation offering them Technical and Grant Writing Assistance to help receive funding to increase the services to their community. The Bhutanese Community was in severe lack of medical services, organization, few community members have access to English classes, legal assistance, and other community supports that should be readily available. SAMHSA awarded them \$600,000 to build infrastructure within their community. We are continuing to partner and work with them on the implementation of this project.



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Conclusion

While this project gathered many responses, it is in no way exhaustive and more continuous research should be done to gather the feelings and objectives of the service user. Recovery models should be service oriented and focused on the service user not just on the end result.

More study is required and as more study is completed, one challenge will be bridging the gap between study results, and meaningful long-term change. It is the desire of the organization that by using the research and materials presented from this project, more organizations, researchers and advocate will engage stakeholders in meaningful ways and at appropriate times within projects and research. We also hope that more funding for these types of studies will become available and greatly thank PCORI for taking an interest in such progressive studies.

In behavioral health there is little funding for prevention, recovery, services, or other patient priorities, and thus even explaining these priorities does little good. During the course of this project we have spoken with several researchers who agree with patient priorities, however there are no grants to change the current course of research so there is little they can do. Studies such as these that work to define recovery groups, gather a collective voice and amplify it will aid in such measures.

A major success of this project is the innovation of Story Circles. Kein Lee and Community Engagement science worked with us as consultants on this project. They recommended necessary actions that would likely to produce changes in the power structure, and our Colorado Team in conjunction with Metro State Denver agreed to produce a series of Wellness and Recovery groups for funders and researchers to help people in power produce a different power structure. These groups were shown in Ohio to have strong system change potential, and we are using these groups in Denver to invite researchers to make shared production with people with lived experience of recovery.

Several different engagement methods were piloted during this grant, using survey monkey process, Facebook discussion polls, different types of video chats and conference calls, and work with more than one type of gathering service. The importance of allowing service users and advocates to provide input in multiple ways is paramount. We learned, if you make a way for them, they will comply. Electronic methods also helped combat other forms of accessibility issues that people with sight or auditory limitations may have. Issuing information electronically allows end users to use other delivery systems that will mitigate those limitations allowing their voices to be heard as well.





We encourage all forms of new research that seek to explore unanswered questions and particularly to involve those areas that have been traditionally less studied in the field of Mental Health. We would encourage a reframing of the question shifting the focus from effective mental health treatment to what is most effective at creating and sustaining mental wellbeing. To the degree that we can take a holistic viewpoint of what mental wellbeing looks like, we can greatly increase the ways that we address and sustain greater individual and community wellness. The broader the field of research becomes, the more it benefits all. There are more than enough unanswered questions to provide great topics for exploration. Yet it can be helpful to have a starting point. Our research finds that the starting point is talking to people in recovery, listening to what is and is not working for them, and learning what is important to them. We are excited to continue to partner with those who are committed to discovering and gathering evidence to support the methods that will help all of us build and maintain mental wellbeing. Please don't hesitate to reach out if you would like to involve our community and increase collaborative research into the priorities identified by members of the Recovery Movement.

Acknowledgements

Thank you to all those who have made this project possible. To the members of the Recovery Movement who have been so open in sharing their experiences and incite. Thank you to Corinna West, the founder of Poetry For Personal Power, who initiated this project and secured its funding. Thank you to Sheri Hall for her current and ongoing leadership of Poetry For Personal Power which helped bring this project to its completion. Thank you to Dr. Deborah Wilcox, Brian Be, and Andre Carbonell, and other sponsored artists who have been so instrumental in getting our Story Circles up and running, for attending conferences, spreading community engagement work, and their continued advocacy work. Thank you to Richard Boles who helped us with citation work.

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Notes

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Respondent Self Identification - Code1	
Identified as having SMI	53%
Identified as having SMI and SUD co-occurring condition	16%
Service User/Consumer of behavioral health services/ did not disclose specific services or conditions.	10%
Behavioral Health Worker SMI/SUD	9%
Advocate (non-related/paid/volunteer)	3%
Caretaker of/Has family with SMI/SUD	2%
Neurodivergent (spectrum / aspbergers / etc)	2%
Identified as having SUD	2%
Identified trauma effected/mental health undiagnosed	2%
Behavioral Health Worker SUD	2%

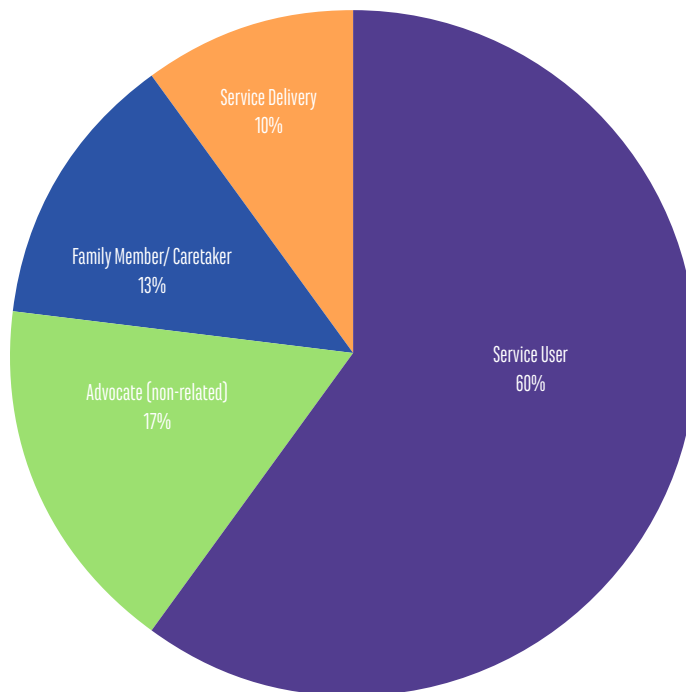
Respondent Self Identification - Code 2	
Advocate (non-related/paid/volunteer)	46%
Caretaker of/Has family that is a service user (non-spec- ified)	17%
Caretaker of/Has family with SMI	13%
Caretaker of/Has family with SMI/SUD	8%
Identified trauma effected/mental health undiagnosed	8%
Neurodivergent (spectrum / aspbergers / etc)	4%
Behavioral Health Worker SMI/SUD	4%





Respondent Self Identification - Code 3	
Advocate (non-related/paid/volunteer)	40%
Behavioral Health Worker SMI/SUD	40%
Caretaker of/Has family with SMI/SUD	20%

Categorized (All Codes with intersection)	
Service User	60%
Advocate (non-related)	17%
Family Member/ Caretaker	13%
Service Delivery	10%





Advocate/ Service User Comparison		
Advocate Ranking	What do you feel academic researchers should be researching with regards to addiction (substance or behaviors)? What do you feel we don't know enough about? What information do you feel would help people to better recover?	Service User Ranking
1	I would like to see more research about wellness approaches vs traditional models (ex. Yoga vs Medication).	1
1	I would like to see more research on addiction recovery in the LGBTQIA+ Community	5
1	I would like to see more research into peer support	6
2	I would like more research on alternative/non-clinical models for mental health.	2
2	I would like to see more research about the Mind/Body connection and occurrences of misdiagnoses (ex. mental health diagnoses and treatment given for what is found to be a physical ailment or infection).	3
2	I would like more research on addiction recovery in Non-White families	3
2	I would like to see research on recovery support groups	4
2	I would like to see more research on the medications that we are given, more long term studies on their effects	7
3	Academic research is comprehensive in its current approach for my needs	9
4	Other (in a subsequent question)	8
Advocate Ranking	What do you feel academic researchers should be researching with regards to neurodiversity and recovery? Neurodiversity the diversity of human brains and minds ? the infinite variation in neurocognitive functioning within our species, including the autism spectrum, ADHD, dyslexia, bipolar, and more. What do you feel we don't know enough about? What information do you feel would help people have better quality of life?	Service User Ranking
1	I would like to see more research about wellness approaches vs traditional models (ex. Yoga vs Medication).	1
1	I would like to see more research on addiction recovery in the LGBTQIA+ Community	5
1	I would like to see more research into peer support	6
2	I would like more research on alternative/non-clinical models for mental health.	2
2	I would like to see more research about the Mind/Body connection and occurrences of misdiagnoses (ex. mental health diagnoses and treatment given for what is found to be a physical ailment or infection).	3
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2	I would like to see research on recovery support groups	4
2	I would like to see more research on the medications that we are given, more long term studies on their effects	7
3	Academic research is comprehensive in its current approach for my needs	9
4	Other (in a subsequent question)	8

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Advocate Ranking	What do you feel academic researchers should be researching with regards to mental health recovery? What do you feel we don't know enough about? What information do you feel would help people to better recover?	Service User Ranking
1	I would like to see more research about wellness approaches vs traditional (ex. Yoga vs Medication).	1
1	I would like to see more research about the Mind/Body connection and occurrences of misdiagnoses (ex. mental health diagnoses and treatment given for what is found to be a physical ailment or infection).	2
1	I would like to see more research on peer support	3
1	I would like more research on mental health in Non-White families.	6
2	I would like to see more research into art, music, writing, and other creative outlets as therapy	2
2	I would like more research on alternative/non-clinical models for mental health.	4
2	I would like to see more research on the medications that we are given, more long term studies on their effects.	5
3	I would like to see more research on mental health in LGBTQIA+ Communities	7
4	Other (In a subsequent question)	8
4	Current research efforts are adequately addressing needs	9
Advocate Ranking	Of the following factors, which aspect(s) are the MOST key to your previous answer?	Service User Ranking
1	Creation and adherence to a treatment plan	1
1	Restoration/Creation of quality relationships	2
1	Setting and achieving personal milestones	3
1	Physical well-being	3
1	A standard quality of life	4
1	Sense of worth	5
1	Reduction/Elimination of negative life impacts	5
1	Reduction/Elimination of unintended impacts of treatment	6
2	Daily functionality	3
3	Other (please explain)	7

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Advocate Ranking	Please rank your key success factors.	Service User Ranking
1	Creation and adherence to a treatment plan	1
1	Restoration/Creation of quality relationships	2
1	Setting and achieving personal milestones	3
1	Physical well-being	3
1	Daily functionality	3
1	A standard quality of life	4
1	Reduction/Elimination of unintended impacts of treatment	4
1	Sense of worth	5
1	Reduction/Elimination of negative life impacts	5
2	Other (please explain)	6
Advocate Ranking	How would you define the Recovery Movement (choose as many as apply)?	Service User Ranking
1	A group of people with lived experience of recovery from substance use or mental health issues who advocate to help others find recovery.	1
2	Specific organizations or groups of individuals engaged in advocacy work aimed towards recovery.	2
3	Anyone who believes recovery from substance use or mental health issues is fully possible.	2
3	Please provide your definition in a subsequent screen.	3

