RECOVERY MOVEMENT RESEARCH PRIORITIES

by Poetry for Personal Power

WHO IS THE
RECOVERY MOVEMENT?

A group of people with lived experience of recovery from substance use or mental health issues who help support others on their recovery journey through arts, peer support, and more.

RECOVERY MOVEMENT'S PLACE IN COMPARATIVE EFFECTIVENESS RESEARCH

- People with lived experience know recovery tools, techniques, and treatments that have worked or not worked for them and those they have supported

- Recovery requires a multifaceted approach beyond medicalized mental health treatments

- Involving members of the Recovery Movement in Comparative Effectiveness Research (CER) can result in diverse methods of supporting wellness to be researched for efficacy

INCLUSION METHODS

- Poetry for Personal Power

- Break down of Recovery Movement Priorities

- Substance and Behavioral Addiction Recovery

- Neurodiversity

- Mental Health Recovery

- Community Engagement Science

A NEW APPROACH

- CER helps us understand most effective methods to create mental wellness at the individual and community level

- Research on mental health and substance use primarily focus on current providers services they provide

- Many members of the recovery movement have added additional supports outside of traditional services to sustain their recovery

- There's been a lack of research into how the Recovery Movement creates wellness

- Additional exploration into this community has the potential to
  - *expand treatment options,*
  - *increase access to more cost-effective options,*
  - *expand our view of how to support and sustain mental wellness*

THE POETRY FOR PERSONAL POWER PROJECT

The P3 Approach

- Survey of Recovery Movement Priorities

- Distributing Results

- Trained Advocates

- Teach Community Engagement Science

- Connecting through Conferences

RECOVERY MOVEMENT RESEARCH PRIORITIES

The initial Recovery Movement survey, in Fall 2018, identified top research priorities:

1. Funding mechanisms to pay for peer support *(i.e. studying Medicaid waivers)*

2. Peer support effectiveness

3. Comparing efficacy of wellness to traditional approaches *(i.e. yoga vs. Antidepressants)*

4. Efforts on balancing harms vs. benefits

5. *(Tied)* Trauma neurobiology and City-wide resilience promotion research

RECOVERY MOVEMENT RESEARCH PRIORITIES

TOP SURVEY RESEARCH PRIORITIES
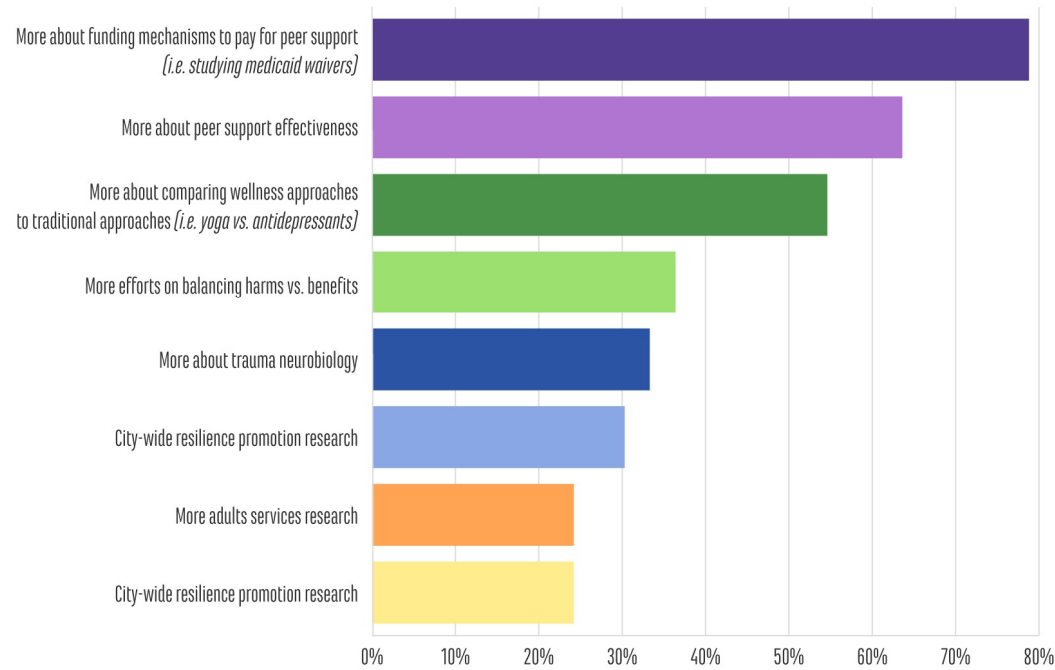
PEER ADVOCATES ROLE IN HEALTH

When asked "What is the most important action that Peer advocates can take to address health equity?" Respondents to the survey answered:

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

West, Corinna. Poetry For Personal Power.
"Recovery Movement Leaders priorities survey." Aug-Oct 2018

SUBSTANCE AND BEHAVIORAL ADDICTION RECOVERY PRIORITIES

1. Recovery support groups

2. Peer Support

3. The mind/body connection and misdiagnosing

4. *(Tie)* Alternative/non-clinical models for mental health

4. *(Tie)* Alternative/non-clinical models for mental health and wellness approaches versus traditional models, *i.e. yoga versus medication.*

Sellers, Julianna. Poetry For Personal Power.
"Recovery Movement Research Priorities." Survey. Jan-Mar 2020

SUBSTANCE AND BEHAVIORAL ADDICTION RECOVERY

Survey respondents included write-in suggestions to research priorities

- *"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 space to help people? Can we help families and people in treatment support each other?"*
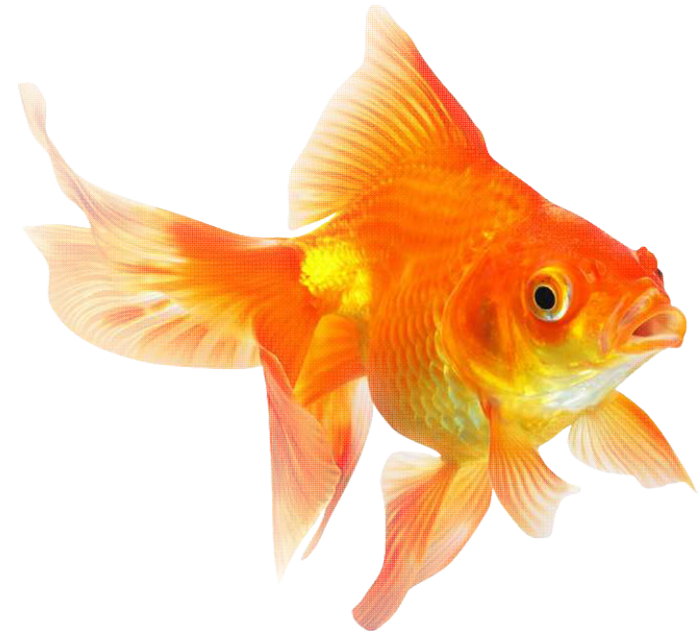
NEURODIVERSITY RESEARCH PRIORITIES

1. Effective therapies/sensory regulation techniques

2. Reducing stigma and education on supporting people on the spectrum

3. *(Tie)* Accommodations to help with functionality AND medications with focus on long-term studies on their effects

4. *(Tie)* Wellness approaches versus traditional models AND Adapting environments to support a wider variety of brain functionality

"EVERYONE IS A GENIUS. BUT IF YOU JUDGE A FISH BY ITS ABILITY TO CLIMB A TREE, IT WILL LIVE ITS WHOLE LIFE BELIEVING THAT IT IS STUPID."

- Albert Einstein

NEURODIVERSITY RESEARCH PRIORITIES

Write-in suggestions:

- *"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."*

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

- *"Open dialogue, hearing voices network, intentional communities"*

MENTAL HEALTH RECOVERY RESEARCH PRIORITIES

1. Art, music, writing, and other creative outlets as therapy

2. The mind/body connection and occurrences of misdiagnosing mental health 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

MENTAL HEALTH RECOVERY RESEARCH PRIORITIES

Write-in suggestions:

- *"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."*

WHAT DOES A SUCCESSFUL RECOVERY LIFE INCLUDE?

While we received many wonderful, unique responses we grouped them into like categories:

- Self-Determination and Recognition of Ability

- Community and Connection

- Meaning and Purpose

- Support and Use of Coping Tools

WHAT DOES A SUCCESSFUL RECOVERY LIFE INCLUDE?

Some 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, and Purpose."

WHAT DOES A SUCCESSFUL RECOVERY LIFE INCLUDE?

SELF-DETERMINATION AND RECOGNITION OF ABILITY
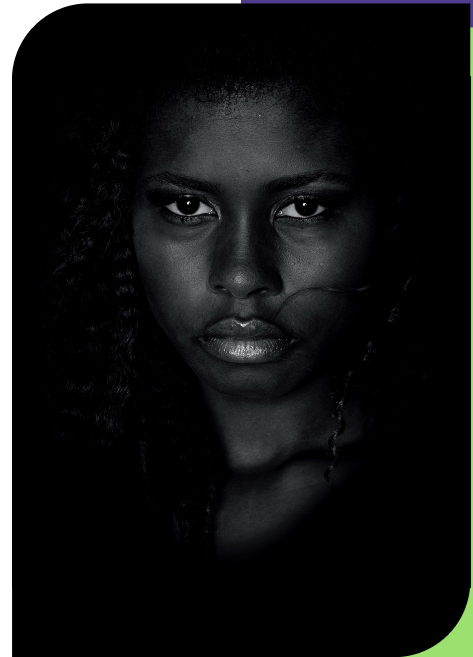
SELF-DETERMINATION AND RECOGNITION OF ABILITY

- *"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."*

WHAT DOES A SUCCESSFUL RECOVERY LIFE INCLUDE?

COMMUNITY AND CONNECTION

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- *"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."*

WHAT DOES A SUCCESSFUL RECOVERY LIFE INCLUDE?

MEANING AND PURPOSE
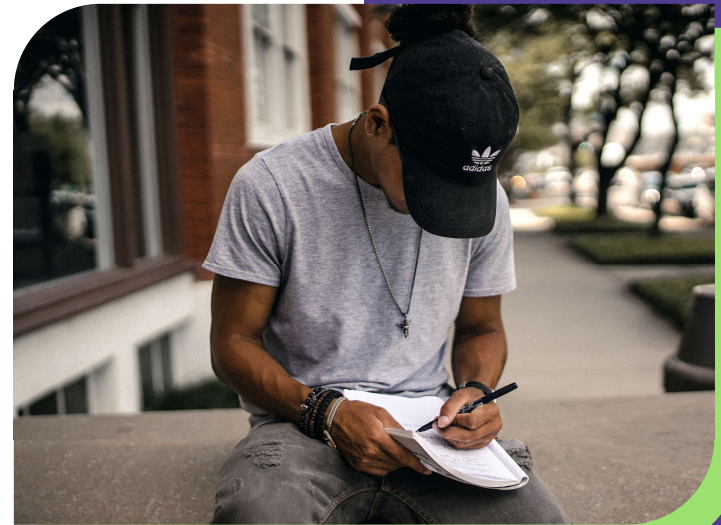
MEANING AND PURPOSE

- *"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."*

WHAT DOES A SUCCESSFUL RECOVERY LIFE INCLUDE?

SUPPORT AND USE OF COPING TOOLS

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- *"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 then 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."*

SUPPORT AND USE
OF COPING TOOLS

- *"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, etc)"*

- *"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."*

COMMUNITY SUPPORTED RECOVERY NEEDS

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

COMMUNITY SUPPORTED RECOVERY NEEDS

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

COMMUNITY SUPPORTED RECOVERY NEEDS

Community Ctd:

- *"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"*

- *"Understanding"*

COMMUNITY SUPPORTED RECOVERY NEEDS

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

Accessibility. Affordability:

- *"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"*

COMMUNITY SUPPORTED RECOVERY NEEDS

Accessibility. Affordability Ctd:

- *"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"*

COMMUNITY SUPPORTED RECOVERY NEEDS

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

Advocates, Training, and Funding:

- *"Advocates in rural communities."*

- *"Education and advocacy"*

- *"Funding for peer support"*

- *Knowledge of the option, and funding to serve those in need."*

COMMUNITY SUPPORTED RECOVERY NEEDS

Advocates, Training, and Funding Ctd:

- *"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."*

COMMUNITY SUPPORTED RECOVERY NEEDS

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

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."*

- *"Not to be labeled everybody can recover recovery is possible"*

- *"Reduce Stigma and a lack of acceptance"*

COMMUNITY SUPPORTED RECOVERY NEEDS

Racial Disparities and Other Stigmas Addressed Ctd:

- *"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."*

- *"Stopping the stigma. Stop the punishment and focus on treatment"*

- *"Tolerance"*

WISDOM THROUGH EXPERIENCE

Through sharing lived experiences we can provide greater impact in our communities.

"I feel the greatest skills is giving people their own voice and educating those people how to be their own advocate. Role playing with people to help them find their words and give honest feedback to help. Teaching and supporting others in how to be their own advocate help to foster independence. Again, they are their own expert in what they need, and advocacy is strongest when it is from the self."

- Open response to survey

HOW DO WE
USE THE SURVEY?

- Data can be used as a starting point for more research into creating mental wellbeing for everyone

- Researchers can use it as a baseline for inspiration and ideas starting new research projects

- Advocates can share this information with researchers

- Everyone can get ideas that may help increase their personal wellbeing

BEYOND THAT...

- How do we take this information and use it to impact our communities?

- How do we integrate it into research, funding, and service delivery?

- "Nothing about us without us!"

COMMUNITY ENGAGEMENT SCIENCE

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 no more than 50% professionals.*

   - *Peers are a source of innovation because they have been consumers of the systems in question.*

   - *Choose neutral funding resources and facilitators for coalition meetings.*

   - *Allow equal representation for parties present on the agenda.*

3. Allow Conflict with respectful dialogue

COMMUNITY ENGAGEMENT SCIENCE

4. Stick to the True Nature of Coalitions: raise money, distribute ideas, and advocate for policy change.

5. Input accessibility structure through online surveys, focus groups, street interviews, text, and phone calls.

6. Choose trained advocates

7. Pay Advocates for Their Time

8. Keep trying

WYCO ENGAGE

Core community outreach to address trauma in the Wyandotte County area of Kansas

Why WYCO?

- This county has more diversity and worse health outcomes than any other county in the state.

WYCO ENGAGE

How?

- We gathered a team of advocates from the community and had them ask the community what they wanted and needed.

- We reached out to businesses and organizations that provided services in multiple sectors of the community.

- We hosted a community meeting, offered free food, and invited people in off of the street to give us their input.

CREATIVE INFORMATION GATHERING

As part of our community input meeting, we asked people to draw their solution to trauma.

PIVOTING

- Through this process we built many ongoing relationships with advocates in our community.

- We also developed ongoing relationships with multiple organizations and are working on other projects with them.

STORY CIRCLES

- 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 deal with mental health and substance abuse challenges.

- Each member of each story circle brings their unique cultural and family heritage, individual beliefs and values, and lived experience to share.

- The story circle empowers them to participate in a collective learning community as well as to work on their personal self-care and recovery goals.

STORY CIRCLES

- Stories are powerful ways to build community and connection.

- Story circle is an opportunity to bring health care providers and service recipients together.

- Everyone is considered equal within the story circle.

- Facilitators introduce topics and keep things flowing smoothly.

- A talking stick is used to determine whose turn it is to share.

CONCLUSION

- We are excited to be able to help connect the Recovery Movement and Researchers in meaningful ways

- We hope you will take what you learned here and share with others.

- Follow up on any questions this sparks and do more research.

- Share with those in a position to do more research

- Support your mental wellbeing and stay well!

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