Peer Respite Programs for Mental Health Crises: Research and Practice Initiatives in the United States

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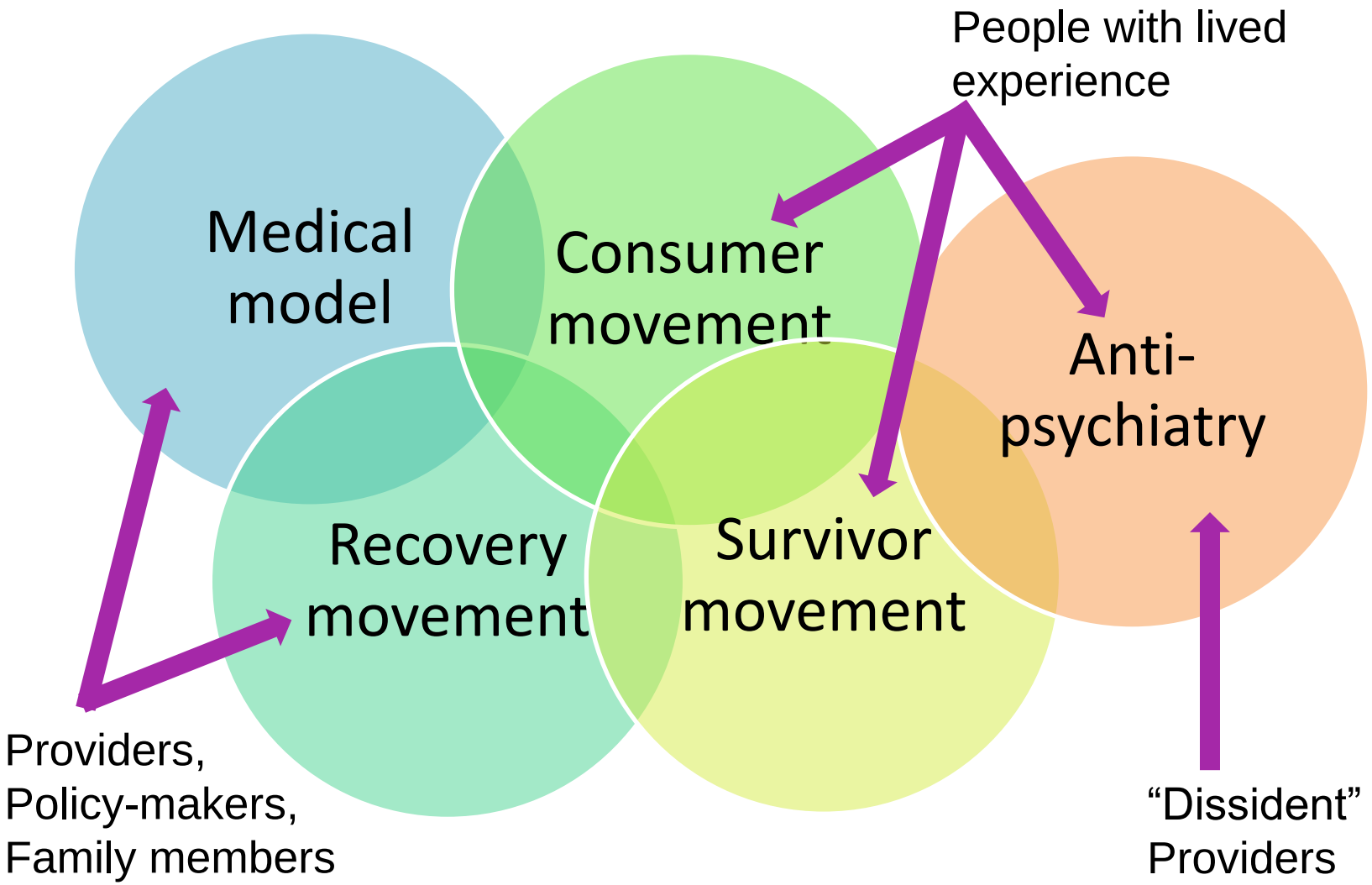
Lived Experience Research Network

Outline

- Background: context and review of the model
- Existing and planned respites
- Program design implications
- Suggestions for research & evaluation

Movements


People with lived experience
Medical model
Consumer movement
Anti-psychiatry
Recovery movement
Survivor movement
Providers, Policy-makers, Family members
"Dissident" Providers

BACKGROUND

Context

- Hospitalization for people experiencing a psychiatric crisis is often traumatic and costly
  - *"Hospitals are not an EBP"* – Dr. Dan Fisher
  - But neither are respites
- Alternatives to hospitalization are needed
- Mental health consumer/survivors have created alternatives to hospitalization, called peer-run crisis respites

What are peer-run respites?

- Peer-run respites are crisis alternatives with the intended outcome of diverting hospitalization
- They are staffed and operated by peers who have professional training in providing crisis support to build mutual, trusting relationships
- Peer-run respites are usually located in a house in a residential neighborhood. They provide a safe, homelike environment for people to overcome crisis

Rationale

- The creation of alternatives to hospitals is because of consumer/survivors' experience with force/coercion/trauma in institutions
- Two sides of same coin: "Coming off drugs" & anti-psychiatry movement vs. unmet treatment need debate
  - Clearly, something isn't "working" with historical reliance on institutions and current reliance on psychiatric drugs

Overview of Operational Models

- **Peer-run** indicates that the board of directors is at least 51% peers
  - Peers staff, operate, and oversee the respite at all levels
- **Peer-operated** indicates that although the board is not a majority peers, the director and staff are peers
  - Often attached to a traditional provider
- **Mixed** are embedded in traditional provider but have peer staff
  - Peers do not have to be in leadership roles

Non-Peer-Run Models & Crisis Alternatives

- Soteria House
  - New program starting in VT
- Parachute
  - NYC has always clearly defined as not peer-run, despite basing some program decisions on peer-run respites
- First Episode Psychosis interventions
  - Low-dose medication alternatives + wraparound supports
  - NIMH RAISE
  - Open Dialogues

Why have these “models”?

- Traditional providers are trained in hierarchical power dynamics in treatment – this is what they know (whether they are aware or not)
  - Psychiatrists on staff or consultation for peer-operated respites should be selected carefully and offered training in peer support modalities and shared/supported decision-making

Why really have these "models"?

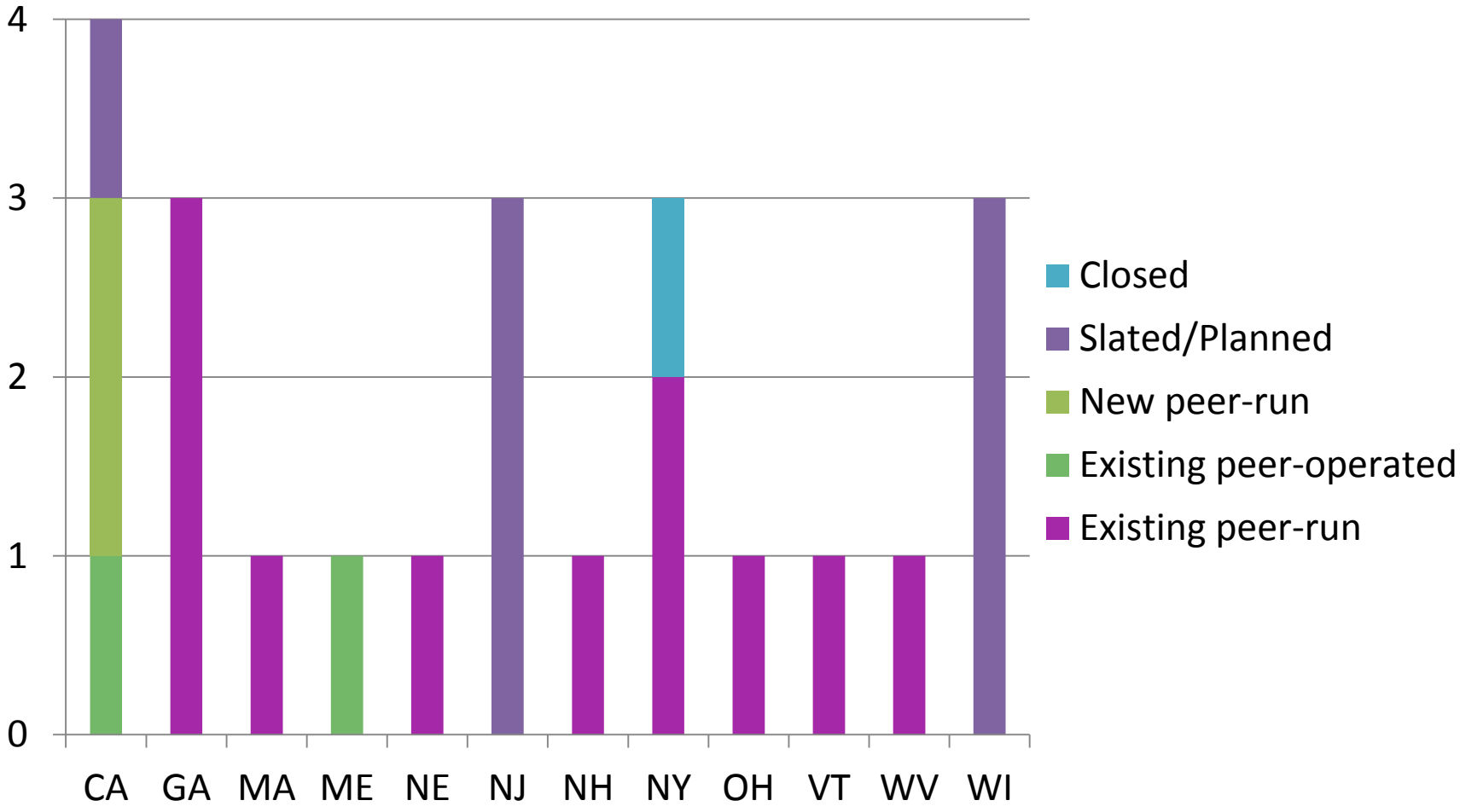
- Scarce resources and high competition for cost and quality
- Value-added of peer-run models
  - May have the added value of employing peers in positions of prestige/control in addition to front-line
  - Values of mutuality & equality in peer support may be even more important in crisis support
  - Yet to be studied in peer respites

EXISTING RESPITES

Existing Peer Respites

Name	State	Model
Second Story	CA	Peer-operated
Peer Support Wellness & Respite (Decatur)	GA	Peer-run
Peer Support Wellness & Respite (White)	GA	Peer-run
Peer Support Wellness & Respite (Bartow)	GA	Peer-run
Afiya	MA	Peer-run
Sweetser	ME	Peer-operated
Keya House	NE	Peer-run
Stepping Stone	NH	Peer-run
Rose House (Milton)	NY	Peer-run
Rose House (Putnam)	NY	Peer-run
Foundations	OH	Peer-run
Alyssum	VT	Peer-run
WV Mental Health Consumer Association	WV	Peer-run

Population flux



Population flux

- Now approximates more of a “normal” population with entries and exits
- Los Angeles County: 2 new respites
- New Jersey: 3 new respites slated to open
- San Francisco: 1 planned
- New York: 1 closed

PROGRAM DESIGN CONSIDERATIONS

Does the organizational "model" at the structural level mean anything?

- Even purely peer-run and peer-staffed organizations may be entrenched in hierarchical and bureaucratic organizational structures
- When people are in crisis, these power dynamics may be even easier to succumb to
- This basic criterion may mean little without actual measurement at the organizational level

Local Context

- Local context must be taken into account
  - Financial resources
  - Other peer-run/mutual support resources
  - Mental health providers
  - Treatment utilization and involuntary commitment policies

Relationships to Other Supports

- In a 2012 survey, all respites reported that other providers either occasionally or frequently refer people to their services. None reported that providers never refer to them
- They most frequently referred to housing and employment supports
- Perhaps, to be maximally effective, respites should be in an organization/network of ongoing peer and wraparound supports

Respites and other policy/practice initiatives

- Assisted outpatient treatment (AOT; “Laura’s Law” in CA)
  - Respites could provide a place for people in the continuum of “assisted” treatment
  - Contrary to mission of voluntary/non-coercive nature of mutual support; considerations of legal status in CA
- Early Intervention/First Episode
  - Targeting young people to prevent “survivorhood”

SUGGESTIONS FOR RESEARCH

Why is research needed?

- Evaluating peer-run respites is an important next step in their development and implementation
- They must be evaluated for cost, outcomes, and cost-effectiveness if they are to succeed
  - Given equal outcomes, the lower cost alternative is the better choice
- What do we mean by “alternative” if the processes, outcomes, and costs are not different?

Deductive Evidence Base?

- Peer support is considered an EBP by SAMHSA and CMS
- Non-peer crisis interventions have a substantial evidence base
  - Soteria House
  - First Episode Psychosis interventions
    - Low-dose medication alternatives + wraparound supports
  - Crisis residential/respite (non-peer-operated)
- Peer-run respites = peer support + crisis alternatives

Community-Based & Participatory Research Design

- Involve people working in the program and community members who may use the program or have insight into it in evaluation design and all stages of data collection
  - Adds social validity to evaluation results (i.e. will be more useful for dissemination & implementation of findings)
  - Creates informed design tailored to program
  - Builds trust with researchers/research team
- Concerns of “ethics” of randomization in COSP study because inconsistent with values

Qualitative Research

- Mixed methods approaches where qualitative research is part of formative research design process & informs interpretation of results
- Qualitative interviews for constructs that can only be addressed that way
  - Closed-ended/quantitative questionnaires may pick up latent or observed constructs that allow participant “self-expression”
- Qualitative data for constructs that have no validated quantitative measurement

Research to-date: “Gold standard” RCT

- One RCT of a peer-run respite
  - The average improvement in symptom ratings was greater in the peer-run alternative
  - The peer-run alternative group had much greater service satisfaction
  - The study authors concluded that this alternative was “at least as effective as standard care” and a “promising and viable alternative”

Research to-date: Qualitative evaluation

- Qualitative evaluation of the Sweetser program in Maine
  - Guests reported learning new ways to deal with and thrive in the critical domains of self-definition, crisis, rituals/patterns of care, and relationships
- Evaluation of Rose House in NY
  - Guests reported peer-run respite supports were more client-centered and less restrictive, staff were more respectful, and that the respite felt less stigmatizing
  - Survey of 10 Rose House guests found that 7 had not used psychiatric inpatient hospitals since becoming involved with the respite

Research to-date: Self-evaluation

- Mixed methods self-evaluation at Afiya in Mass.
  - Developed own survey to understand guests experience/perspective and "Hopes for Stay" form
  - Had Afiya not been available…?
    - 56% would have gone to the hospital had Afiya not been available
    - 18% would have ended up at a traditional respite
    - 9% would have stayed with a family member/friend
    - 14% would have just stayed home
    - 9% would have had no other options
  - 100% reported that compared to hospital/ traditional respite, Afiya was welcoming, offered clear information, used respectful language and offered opportunities to connect with others

Research to-date: Propensity score matching methods

- Second Story Santa Cruz evaluation is one of the first to use a rigorous design that captures system, program, and individual level processes and outcomes
  - Preliminary results indicate that people who used the respite were 78% less likely than similar non-respite users to use inpatient and emergency services

Program evaluation component	Definition
Organizational structure	Peer-run, Peer-operated, Mixed (and iterations thereof)
Processes of support	Commitment to mutuality
Interactions with other systems and stakeholders	Respites should be embedded in larger organization/system with other resources
Cost	Cost is NOT cost of a respite day vs. cost of a hospital day in a budget or billing statement
Outcomes	Individual for guests and staff
Building a peer-to-peer community resource	Making other mutual support/self-help resources available to increase access

Program evaluation component	Evaluation consideration
Organizational structure	Program environment facilitates autonomy & equality
Processes of support	Coercion & control over guests
Interactions with other systems and stakeholders	Referrals to and from providers; use of other mutual/social support resources
Cost	Other service utilization
Outcomes	Short-term “stabilization” and functioning; housing; “non-prosthetic” relationships
Building a peer-to-peer community resource	Long-term recovery, employment, community-engagement

Evaluation consideration	Measurement (Explanation/Examples)
Program environment facilitates autonomy & equality	Community-Oriented Program Environment Scale (COPES)
Coercion & control over guests	McArthur Coercion Scale
Referrals to and from providers; use of other mutual/social support resources	Counts from records are ideal; self-frequencies more reasonable often
Other service utilization	System-level data (county & Medicaid) ideal; depends on program requirements
Short-term “stabilization” and functioning; housing; “non-prosthetic” relationships	More likely to be meaningful for people experiencing crisis after one-time stay
Long-term recovery, employment, community-engagement	Many recovery measures out there that address these domains

Things to consider not measuring

- Satisfaction measures are easy to administer, but have become a folly of mental health services research
  - Satisfaction measurement is positively biased
- Recovery measures not relevant
  - The goal of crisis care is addressing immediate issues. Recovery is a life-long process and would not expect valid changes in scores; especially issue of regression to the mean and crisis being “rock bottom”

Future research

- To date, there has not been large scale, multi-site, quantitative evaluation of organizational processes, utilization, outcomes, or costs
- Eventually there will be enough respites with enough in common to do large scale evaluation
  - Will need fidelity measurement, but programs are all different!
- Issues in sample size for individual respites; tradeoff with small, “homelike” environment

Toolkit for Evaluating Peer-Run Respites

- Partnership between LERN, HSRI, and NEC
- Collecting information from all existing respites about what measurement and designs they have used, challenges faced
- Will provide resource for other programs and evaluators about how to design peer-run respites evaluation
- Both supports programs & funders in their evaluation efforts and helps promote consistent measurement

COMMENTS!
&
QUESTIONS?

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