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

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Outline

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

- Medical model
- Consumer movement
- Recovery movement
- Survivor movement
- Anti-psychiatry

People with lived experience

Providers, Policy-makers, Family members

“Dissident” Providers

Lived Experience Research Network
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 RESPITSES
# Existing Peer Respites

<table>
<thead>
<tr>
<th>Name</th>
<th>State</th>
<th>Model</th>
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<tbody>
<tr>
<td>Second Story</td>
<td>CA</td>
<td>Peer-operated</td>
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<tr>
<td>Peer Support Wellness &amp; Respite (Decatur)</td>
<td>GA</td>
<td>Peer-run</td>
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<tr>
<td>Peer Support Wellness &amp; Respite (White)</td>
<td>GA</td>
<td>Peer-run</td>
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<tr>
<td>Peer Support Wellness &amp; Respite (Bartow)</td>
<td>GA</td>
<td>Peer-run</td>
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<tr>
<td>Afiya</td>
<td>MA</td>
<td>Peer-run</td>
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<tr>
<td>Sweetser</td>
<td>ME</td>
<td>Peer-operated</td>
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<tr>
<td>Keya House</td>
<td>NE</td>
<td>Peer-run</td>
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<td>Stepping Stone</td>
<td>NH</td>
<td>Peer-run</td>
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<tr>
<td>Rose House (Milton)</td>
<td>NY</td>
<td>Peer-run</td>
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<tr>
<td>Rose House (Putnam)</td>
<td>NY</td>
<td>Peer-run</td>
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<tr>
<td>Foundations</td>
<td>OH</td>
<td>Peer-run</td>
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<tr>
<td>Alyssum</td>
<td>VT</td>
<td>Peer-run</td>
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<tr>
<td>WV Mental Health Consumer Association</td>
<td>WV</td>
<td>Peer-run</td>
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</tbody>
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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

  - 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
<table>
<thead>
<tr>
<th>Program evaluation component</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Organizational structure</td>
<td>Peer-run, Peer-operated, Mixed (and iterations thereof)</td>
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<tr>
<td>Processes of support</td>
<td>Commitment to mutuality</td>
</tr>
<tr>
<td>Interactions with other systems and stakeholders</td>
<td>Respites should be embedded in larger organization/system with other resources</td>
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<tr>
<td>Cost</td>
<td>Cost is NOT cost of a respite day vs. cost of a hospital day in a budget or billing statement</td>
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<tr>
<td>Outcomes</td>
<td>Individual for guests and staff</td>
</tr>
<tr>
<td>Building a peer-to-peer community resource</td>
<td>Making other mutual support/self-help resources available to increase access</td>
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<tr>
<td>Program evaluation component</td>
<td>Evaluation consideration</td>
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<tr>
<td>Organizational structure</td>
<td>Program environment facilitates autonomy &amp; equality</td>
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<tr>
<td>Processes of support</td>
<td>Coercion &amp; control over guests</td>
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<tr>
<td>Interactions with other systems and stakeholders</td>
<td>Referrals to and from providers; use of other mutual/social support resources</td>
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<tr>
<td>Cost</td>
<td>Other service utilization</td>
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<tr>
<td>Outcomes</td>
<td>Short-term “stabilization” and functioning; housing; “non-prosthetic” relationships</td>
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<tr>
<td>Building a peer-to-peer community resource</td>
<td>Long-term recovery, employment, community-engagement</td>
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<tr>
<td>Evaluation consideration</td>
<td>Measurement (Explanation/Examples)</td>
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<tr>
<td>Program environment facilitates autonomy &amp; equality</td>
<td>Community-Oriented Program Environment Scale (COPES)</td>
</tr>
<tr>
<td>Coercion &amp; control over guests</td>
<td>McArthur Coercion Scale</td>
</tr>
<tr>
<td>Referrals to and from providers; use of other mutual/social support resources</td>
<td>Counts from records are ideal; self-frequencies more reasonable often</td>
</tr>
<tr>
<td>Other service utilization</td>
<td>System-level data (county &amp; Medicaid) ideal; depends on program requirements</td>
</tr>
<tr>
<td>Short-term “stabilization” and functioning; housing; “non-prosthetic” relationships</td>
<td>More likely to be meaningful for people experiencing crisis after one-time stay</td>
</tr>
<tr>
<td>Long-term recovery, employment, community-engagement</td>
<td>Many recovery measures out there that address these domains</td>
</tr>
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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?
Contact

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