Collaborating with Family Peer Advocates in Child Mental Health Research

Mary Acri & Priscilla Shorter
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Presenters

Mary Acri is a Research Associate Professor at NYU Grossman School of Medicine and oversees a portfolio of research focused on reducing mental health inequities among families disadvantaged by poverty.

Priscilla Shorter is an energetic and motivated peer professional with over 20 years of experience in the field of family support and advocacy in both education and hospital-research settings. She is currently a Parent Partner at the IDEAS Center, and in this capacity, provides training to clinicians and family support professional as well as having an active role in the research projects at the IDEAS Center.
Presentation Overview

1. Overview of peer-delivered family support services
2. Research initiatives involving peers
3. Research partnerships from the peer’s perspective
4. Q&A
Family Support Services

- Family support services (FSS) originated over 30 years ago:
  - Defined as services directed at caregivers of children with mental health problems to help them effectively address the needs of their families

- Peer-delivered family support services:
  - A subtype of family support wherein the provider is a family member who has the “shared experience” of caring a child with mental health difficulties.

- Peer delivered FSS in children’s mental health expanding nationally:
  - National Federation of Families credentialing more than 120 chapters.
  - 33 states offering either Family Support Services, Youth Support Services, or both
  - 31 states making Family Support Services a billable service.
  - 33 states allow Medicaid billing for peer services.
Objective of Peer-delivered Family Support Services

• Parent Empowerment:
  “A process of recognizing, promoting, and enhancing [parents’] abilities to meet their own needs, solve their own problems, and mobilize the necessary resources in order to feel in control of their own lives.”

• Four key components of empowerment
  1. Understanding and acceptance of their child’s diagnosis.
  3. Taking charge of their child’s care.
  4. Perseverance.
Theoretical Foundations

- **Social Support Theory**: emotional, instrumental, and informational support contribute to individual’s positive psychosocial adjustment and buffers against stress and adversity.

- **Social Learning Theory**: interacting with peers can lead to increased belief that behavioral changes can lead to positive results, enhanced self-efficacy, and increased hopefulness.

- **Social Comparison Theory**: Interacting with/perceiving peers favorably leads to increased optimism and motivation to take necessary actions to achieve change, while interacting with/perceiving peers as worse or inferior leads to greater perspective on how bad things can be.
Developing a Typology

- 2010: Review of services and programs that directly target parents and caregivers of children or adolescents with identified mental health needs
  - Key terms: Family or parent support, skill training, psychoeducation, parent management training, children’s mental health, supportive, adjunctive, health, education, mental health.

- Included all services and programs that are evaluated since 1990.
- No criteria on the design of the study; included any evaluated program.
- Resulted in 50 distinct programs; of them, 11 were delivered by a peer.
Typology

- Types of Family Support Services

1. **Informational/Educational Support**: education about child behavior/development, course of mental illness, treatment options, services.

2. **Instructional/Skills Development Support**: coaching on effective ways to address child’s illness or behaviors. Skill-building.

3. **Emotional and Affirmational Support**: promote experience of being affirmed, understood and appreciated

4. **Instrumental Support**: provide concrete services (e.g., respite, transportation).

5. **Advocacy Support**: provide specific information and leadership skill building to develop caregiver as an advocate at policy and system levels.
Peer-delivered Family Support Services

• Typically consisted of advocacy, instructional and informational support;
• Instructional support:
  – Self-care, communication, crisis management, problem-solving skills.
• Informational support:
  – Information about child mental health and the impact of mental health upon the family
  – Linkages to community resources
• Advocacy:
  – Empowering families with information about laws, entitlements, and strategies for advocacy
Peer-delivered Family Support Services

• Larger literature of peer-delivered family support services…

• Outcomes include…
  – Reduced stigma and distrust about mental health services\textsuperscript{6}
  – Improved activation in seeking care\textsuperscript{7}
  – Improved self-efficacy- i.e., active participation in decision-making\textsuperscript{8}
  – Improved knowledge with beliefs about children’s mental health and this is associated with use of higher quality services for children\textsuperscript{9}
Peer/Research Collaboration

• Community-based participatory approach
  – Community is a partner in the research team
  – Community participates in all aspects of the research project from start to finish

• An opportunity "for communities and science to work in tandem to ensure a more balanced set of political, social, economic, and cultural priorities, which satisfy the demands of both scientific research and communities at higher risk" - Hatch et al., 1993.

• Pillars
  – Responds to a history of exploitation and marginalization
  – Community empowerment
The Support, Teambuilding and Referral (STAR) Intervention

- STAR was developed to reduce caregiver stress.
- Families who engaged in Family Resource Centers across NYC
- Responded to a felt need by peers to support caregivers of children experiencing emotional, social or behavioral problems.
The Support, Teambuilding and Referral (STAR) Intervention

- Described project at staff meeting
- Peers who volunteered to participate joined the research team to build the intervention
- Research team provided outline of intervention; peers guided the session content
- Coupled education about the effects of stress with evidence-informed stress-reducing strategies (e.g., self-care activities)
- High satisfaction with intervention
The Screening, Education, and Empowerment Program

- Extension of STAR
- Peers felt that caregivers were experiencing depression, but did not have the tools to address the need
- Did not want to be perceived as mental health professional
- Within their roles to provide education, detection and outreach to services.
The SEE Intervention\textsuperscript{10}

- Theoretical/practice models: psychoeducation, patient activation model.\textsuperscript{11-13}
- Four sessions, $\frac{1}{2}$ hour in duration, added onto the regularly scheduled meetings between the peers and caregiver.
- SEE consists of the following components:
  - Screening caregivers for feelings of sadness,
  - Providing Education about mental health and treatment,
  - Fostering active linkages with mental health services,
  - Helping caregivers problem-solve barriers to treatment (e.g. transportation, insurance, childcare),
  - Empowering caregivers to become active participants in their care.
Results

• Feasibility
  • 22 intervention (fidelity) checklists completed; 96.4% of the content administered across sessions on average
  • All sessions were initiated and completed as planned.
• Acceptability:
  • Peers were highly satisfied with the manual content (M=4.52, SD=.86, range 4.13 to 4.74) and consultation (M=4.34, SD=.84, range 3.70 to 4.78)*
  • Minimal barriers to participation noted (M=1.96, SD=0.71)*

*Scores ranged from 1-5; higher scores indicate greater satisfaction and barriers respectively
## Benefits Peer Report

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<thead>
<tr>
<th>Benefits to Peers</th>
<th>n, %</th>
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<tbody>
<tr>
<td>Increases peer knowledge</td>
<td>n=7, 70%</td>
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<tr>
<td>Builds rapport with caregiver</td>
<td>n=5, 50%</td>
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<tr>
<td>Offers legitimacy to peer’s roles</td>
<td>n=1, 10%</td>
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<table>
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<tr>
<th>Benefits to Caregivers</th>
<th>n, %</th>
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<tr>
<td>Increases caregiver knowledge</td>
<td>n=6, 60%</td>
</tr>
<tr>
<td>Helps caregiver understand feelings</td>
<td>n=5, 50%</td>
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<tr>
<td>Empowers caregiver</td>
<td>n=4, 40%</td>
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Considerations from the Peer Perspective

• Why Family Advocates Exist
• Why I Exist
• People/families behind theories, hypothesis and numbers
Considerations from the Peer Perspective

- Family and Community Voice
- Partnership
- Sustainability
Take Home Points

• Seek Family/Peer/Community input from very beginning
• Sustainability ----build in system to transfer knowledge to community once you exist
Thank you!

Q&A
References


References


