Families as Change Agents in Children’s Mental Health: Research Directions

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Why research matters to families

- Debunk myths (e.g., “bad” parenting); hs of family-blaming in psychiatry and psychology
- Improve knowledge about best practices for families and children—can’t understand what we don’t study
- Acknowledge and validate importance of family-centered services
- Improve measurement of outcomes relevant to families
- Improve policies supporting families
- Improve accountability for work performed by families

Why families matter to researchers

- Provide the most important context for understanding child development
- Child interventions are more effective when families are involved
- Ground research in real-world issues—keeps it real

Growth in Family Support Services

- 1986: CSSP, System of Care Principles
- 2001: IDQ: Crossing the Quality Chasm: Consumers as True North
- 2005: IDQ: Integrating Health, HIV, Substance Abuse
- 2006: National Wrap-Around Initiative: Role for parent partners
- 2008: Robbins et al. Parent-to-Parent Monograph
- 2008: MacArthur Fdn and RWJ National survey on Family Advocacy, Support and Education Organizations (FASEO)

The National Infrastructure for Family Support: RWJ & MacArthur Fdn National Survey on Family Advocacy, Support and Education Organizations (FASEO) (Hoagwood et al., 2008)

Linked to MacArthur Fdn’s Youth Research Network Director’s Survey (Schoenwald et al., 2008) of 200 MH clinics

228 interviews completed with Directors of Family-run organizations
- 82% response rate
- ¾ affiliated with national organizations: 32% NAMI; 15% PCORI; 15% MHA

Aims were to examine
1. The structure, funding, and types of services offered by a national sample of family advocacy, support and education organizations (FASEO) as reported by their Directors
2. The factors influencing decision-making within FASEOs
3. The types of partnerships between FASEOs and their local mental health providers

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FASEO (b) offer a wide range of support services.

Roles for families (N=226)

- 97% Educating other families
- 94% Advocating for MH service delivery
- 91% Peer-to-peer support
- 88% Leading support groups
- 88% Training families
- 81% Liaison with MH, other professionals
- 79% Direct advocacy on behalf of individual families
- 73% Outreach
- 61% Crisis Intervention
- 56% Respite
- 52% Case manager
- 50% Research collaborator
- 49% Consultation
- 43% Home visitation
- 39% Co-therapy
- 35% Conducting screening/assessments

Summary

- Variation in degree of connection with provider communities
- FASEO offer a wide range of support services
- Families provide a wide range of direct family-to-family (F2F) services

Working Alliances with MH Providers (N=226)

- 27% had no relationship with their local MH provider
- 19% had a very strong connection involving fiscal sharing of resources, formal representation on a board, sharing of outcomes information, and having a governance role.
- 54% had some connection
- Question: Implications of connections: how are they developed? When are they advantageous? When not?

2nd Wave Follow-Up Survey: Characterization of Working Alliances Between FASEO and MH Clinics

- Re-interview stratified random sample of FASEO respondents (N=120) (40 strong WA, 40 moderate WA, 40 no WA)
- (a) examine the sequence, process, and steps by which the working alliances were formed or if no relationships have been established to examine barriers to their formation;
- (b) identify the extent to which alliances are related to organizational context profiles of the clinics, using social-organizational data from Glisson et al (2008); and
- (c) identify FASEO structural or demographic factors (rural/urban; national or independent Status; populations served; % minority representation) that are related to the types of working alliances that have been formed.

Studies on Consumer Activation and Empowerment: Implications for Family Support Services

- Consumers who participate in the decision making process are more satisfied with services, have a greater sense of self-efficacy and confidence, an increased ability to cope with daily life, and more likely to achieve their treatment goals (Linhorst & Eckert, 2003)
- Consumer activation reduces stigma and distrust by improving communication (Linhorst & Eckert, 2003)
- Pathways: involvement (asking questions) increases activation/empowerment which increases decision-making which increases retention (Anger et al., 2000)
- Family education improves self-efficacy and participation (Helflinger & Bickman, 1977; Bickman et al., 1981)
- Family education improves knowledge and accurate beliefs about children's mental health; these are associated with utilization of higher quality services for children (Fristad et al., 2003, 2008)
State of the Evidence on Programs to Enhance Family Support, Education, Skills, Advocacy: A Review (Hoagwood, Olin, Cavaleri, Burns + NAMI, FFCMH, CHADD)

- Review of programs or interventions that provide direct support to parents/caregivers of children with mental health needs
- Inclusion criteria: formal curriculum, provide more than a didactic workshop, and have evaluation data
- Differentiate family-led vs. clinician-led vs. team-led
- Identify core components of programs (inside the black box), contrast the three groups, identify types of outcomes assessed
- Review covers 1990 to present
- Collaboration with NAMI, Federation of Families, CHADD
- Over 200 programs have been reviewed, and 46 currently meet criteria for inclusion.

Five Categories of Support

1. Informational/Educational Support
   - Education about child and behavior, development, treatment, and illness issues
2. Instructional (Skill development)
   - Skill building to coach caregiver on effective ways to address child’s needs
   - Skill building to address parents’ well-being, e.g., communication skills, problem solving, anger management
3. Emotional
   - Shared communication among families to promote caregiver affirmation, lack of blame
4. Instrumental
   - Provision of concrete services—respite care, transportation
5. Advocacy
   - Provision of specific information about parental rights and resources
   - Leadership skill building

Comparison by Type of Program

<table>
<thead>
<tr>
<th>Type of Support</th>
<th>Family Led (n=11)</th>
<th>Clinician Led (n=29)</th>
<th>Team Led (n=6)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information/Education</td>
<td>n=10, 91%</td>
<td>n=21, 72%</td>
<td>n=5, 83%</td>
<td>36 programs</td>
</tr>
<tr>
<td>Instruction/Skill dev</td>
<td>n=10, 91%</td>
<td>n=24, 83%</td>
<td>n=5, 83%</td>
<td>39 programs</td>
</tr>
<tr>
<td>Emotional</td>
<td>n=6, 55%</td>
<td>n=9, 31%</td>
<td>n=6, 100%</td>
<td>21 programs</td>
</tr>
<tr>
<td>Advocacy</td>
<td>n=11, 100%</td>
<td>n=6, 21%</td>
<td>n=5, 83%</td>
<td>6 programs</td>
</tr>
<tr>
<td>Instrumental</td>
<td>n=1, 27%</td>
<td>0</td>
<td>n=3, 50%</td>
<td>22 programs</td>
</tr>
</tbody>
</table>

Summary

- Types of outcomes assessed and differences across groups
- Measurement gaps
- Research agenda

New York State Initiatives to Improve Engagement and Empowerment of Families

- Engagement: A process that begins with a child being identified as experiencing mental health difficulties and ending with a child receiving mental health care (Laitinen-Krispijn et al., 1999; Zwaanswijk et al., 2003).
- Has been divided into two specific steps: initial attendance and ongoing engagement (Weiss et al., 1996; 2000).
- Rates of service engagement can differ at each intake range from 48%-62% (Hickey et al., 1996; Starman et al., 2002).
- Average length of care: 9% of youth and their families remain in care after a 3-month period (Hickey et al., 2002).
Engagement strategies for intake and first appointments (McKay et al., 1999, 2005)

- Protocol for intake and first visit engagement interviews
  - 1) setting a comfortable tone;
  - 2) prioritizing collaboration with parents;
  - 3) focusing on practical concerns;
  - 4) problem solving barriers to next appointment.

NY Performance Indicator #2: # completing an intake assessment over time (using unweighted endpoint rate of change across 14 agencies) Cavaleri et al., 2006

![NY Performance Indicator #2: # completing an intake assessment over time](image)

NY Performance Indicator #2: # completing an intake assessment over time (using unweighted endpoint rate of change across 14 agencies) Cavaleri et al., 2006

- Represents an increase of 274 children seen for intake visits (8%)
- Estimated number of children seen for an intake based on 63% baseline show rate

PEP Evaluation Findings

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Engagement studies (McKay et al., 1998; 2001; 2005)

- N=32 family advisors; N=14 comparison
- Self-efficacy (p<.02) among FA
- Significant difference pre/post among parents working with PEPSignificant difference pre/post among parents working with PEP
  - Improving parent activation and youth mental health
  - Enhance family advisors’ knowledge of MH services, collaborative skills, and self-efficacy

Parent Empowerment Project (PEP) Manual Content

- Introduction
- Knowing Yourself
- Knowing Your Child
- Treatment Management Skills: How to be Your Child’s Case Manager
- Specific Disorders and Their Treatments
- The Mental Health System of Care: What to Expect and How to Prepare
- Services and Options Through the School System
- Helpful Tools for Parents

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PEP Evaluation Findings

- N=32 family advisors and 124 parents in New York City (85% low income, minority)
- No differences in parents’ service self-efficacy, empowerment, or strain
- Significant improvements pre/post in knowledge (p<.003), skills (p<.003) and service self-efficacy (p<.02) among FA
- Significant difference pre/post among parents working with PEP-trained advisors in working alliance at 4 months (p<.05) but not among parents in comparison group
- No differences in parents’ service self-efficacy, empowerment, or strain
- Stronger effects for parents working alliance. Working with advisor who provided home/school visits (OR=4.6; p<.003)
- High levels of activation among parents (CES-D average 22.8; cut off is 16) showed mental outlook
- Relationship of agency’s social-organizational contexts and undervalued roles of family advisor
New Model of PEP

- Added structured 6 month consultation + activation model based on behavioral science theory (TRA/TBP, Jaccard's Unified Theory (2002)
- Restructured training to focus more on engagement, motivational interviewing, and boundary setting skills
- Published guidebook to support curriculum (Jensen & Hoagwood, 2008)
- Add cross-training for advisors working in clinical settings to target clinician attitudes, beliefs, expectations

Concluding Remarks: Building a Science on Family Activation and Support Programs

- Nothing about us without us: Ongoing and continuous collaboration
- Serious attention to relevant measurement development needed
- EXAMPLE: Family-driven outcomes engineering: Nancy Craig and NY Western Region Family Advisors FANS system
- Strengths-based measurement systems needed
- YET for policy planning purposes, child outcomes cannot be ignored
- Need clinician cross-training and curriculum development: Not enough to focus solely on empowering families without simultaneously changing clinical systems
- Need strong theoretical models: Social-organizational and behavioral science offers promise
- Examining mediators and moderators of engagement and empowerment
- Recognize the journey, turning points, individual preferences and choice: Apply alternative design models (West, Duan et al., 2008)