Engaging and Empowering Families: Research Findings on a Service Effectiveness Study of a Parent Empowerment Program

Chair: Kimberly Hoagwood, PhD
February 24, 2006

Panel
- Kimberly Eaton Hoagwood, PhD: Principal Investigator; OMH, Columbia University
- James Rodriguez, PhD: Co-I/Co-Project Director; OMH, Columbia University
- Geraldine Burton, FDC: Co-I/Co-Project Director, MHA of NYC, PEP
- Belinda Ramos, MA: Research and Training Coordinator, PEP
- Adam Stein, PhD: Co-I; MHA of NYC
- Jane Adams, Ph.D., Discussant

Manual Contributors
- Mental Health Association of New York
- New York State Office of Mental Health
- Columbia University’s Center for the Advancement of Children’s Mental Health
- New York University Child Study Center
- Contra Costa, California Mental Health Services
- The LINCS Program of Utah
- Maryland Center for Attention and Development Disorders
- Mount Sinai School of Medicine
- Vanderbilt University Center for Mental Health Policy

Funding Sources
- National Institute of Mental Health
- New York State Office of Mental Health
- Columbia University’s Center for the Advancement of Children’s Mental Health

Parent Advocates
- Enhance parent advocacy
  - Knowledge of children’s mental health needs and evidence-based treatments
  - Strengthen sense of self-efficiency
  - Improve parent management skills
  - Improve communication and assertiveness skills
- Ability to:
  - Engage parents
  - Teach parents new skills
  - Encourage parents to put new skills into action
  - Collaborate effectively with professionals
  - Enhance self-efficiency

Parents
- Increase knowledge of children’s mental health needs and evidence-based treatments
- Strengthen sense of self-efficiency
- Improve parent management skills
- Improve communication and assertiveness skills

Parent Empowerment Program Goals

PEP Manual Content

Parent Advocate Manual
- Introduction
- Getting Ready
- Building Engagement, Listening, and Boundary Setting Skills
- Developing Priority Setting Skills
- Building Your Teaching and Group Management Skills
- 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
- Teaching Tools for Parent Advocates

Parent Handbook
- Introduction
- Knowing Yourself
- Knowing Your Child
- Treatment Management Skills: How to be Your Child’s Care 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
Research Goals

- To test the effectiveness of a parent empowerment program on family advocates and caregivers using an experimental design
- To examine changes in knowledge, skills, and service self-efficacy on family advocates.
- To examine changes in service use, efficacy, strain & well-being among parents/caregivers.
- To generate effect size estimates and pilot a methodology for generating cost related data to be included in future larger studies of parent empowerment.

Design

- **Sample:**
  - 30 Family advocates recruited from NYC Family Support Programs
  - 5 parents/caregivers per family advocate followed prospectively
  - Random assignment of family advocates to PEP or wait-list
  - Pre/post and 1 year assessments of family advocates
- **Baseline, 3 and 6 month assessments of parents/caregivers**

Training Intervention

- Compare PEP training vs. Training as Usual
- 10 week core training program based on the PEP Manual
- Booster sessions
  - School services
  - Medications
  - Other childhood disorders (e.g. bipolar, depression, CD/ODD)
  - Driven by the needs of the group
- Ongoing technical support available

Training Family Advocates on the Foundations of Empowerment

Preliminary Findings: Family Advocates

Principal Investigator: Kimberly Hoagwood, Ph.D.

Baseline Demographics Family Advocates

<table>
<thead>
<tr>
<th>Total N</th>
<th>Total</th>
<th>PEP Trained</th>
<th>TAU</th>
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<td>94%</td>
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<td>20-25</td>
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<td>20-25</td>
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<td>94%</td>
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<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Total</th>
<th>Caucasian</th>
<th>African American</th>
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<th>Education</th>
<th>Total</th>
<th>Less than High School</th>
<th>HS Diploma</th>
<th>Some College</th>
<th>Bachelors Degree</th>
<th>Some Graduate</th>
<th>Other Education</th>
<th>Family Development Credential</th>
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<td>2</td>
<td>11</td>
<td>15</td>
<td>7</td>
<td>7</td>
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Measures

**Family Advocates**
- Basic Demographics
- Work setting and environment
- Mental Health Services Efficacy
- Self-Assessment
- Objective Knowledge
- Working Alliance Inventory
- Community Participation Measure
- Focus Groups

**Parents/Caregivers**
- Demographics
- Mental Health Efficacy
- Caregiver Strain
- CES-D
- STAXI- Anger Expression Inventory
- Family Empowerment Scale
- Working Alliance Inventory

Principal Investigator: Kimberly Hoagwood, Ph.D.
Baseline Family Advocate Characteristics

<table>
<thead>
<tr>
<th>Parents of Children with Special Needs</th>
<th>Total = 17 (100%)</th>
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</thead>
<tbody>
<tr>
<td>% 10 hrs = 3 (18%)</td>
<td></td>
</tr>
<tr>
<td>20-30 hrs = 4 (24%)</td>
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<tr>
<td>30-40 hrs = 1 (6%)</td>
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</tr>
<tr>
<td>40-50 hrs = 1 (6%)</td>
<td></td>
</tr>
<tr>
<td>50-60 hrs = 2 (12%)</td>
<td></td>
</tr>
<tr>
<td>60-70 hrs = 1 (6%)</td>
<td></td>
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<tr>
<td>% 70-80 hrs = 1 (6%)</td>
<td></td>
</tr>
<tr>
<td>% 90-100 hrs = 3 (18%)</td>
<td></td>
</tr>
<tr>
<td>% 100 hrs = 1 (6%)</td>
<td></td>
</tr>
<tr>
<td>% 110 hrs = 1 (6%)</td>
<td></td>
</tr>
<tr>
<td>% 120 hrs = 1 (6%)</td>
<td></td>
</tr>
<tr>
<td>% 130 hrs = 1 (6%)</td>
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<table>
<thead>
<tr>
<th>Live-in the community in which they work</th>
<th>Total = 22 (100%)</th>
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<tbody>
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<tr>
<td>20-30 hrs = 4 (24%)</td>
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<tr>
<td>30-40 hrs = 2 (11%)</td>
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<tr>
<td>40-50 hrs = 1 (6%)</td>
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<td>% 70-80 hrs = 2 (11%)</td>
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<tr>
<td>% 100 hrs = 1 (6%)</td>
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<tr>
<td>% 110 hrs = 1 (6%)</td>
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<tr>
<td>% 130 hrs = 1 (6%)</td>
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<table>
<thead>
<tr>
<th>Number of years of experience</th>
<th>Average = 5 yrs (Range 0-20)</th>
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<tr>
<td>Pre-1 Year N= 9</td>
<td></td>
</tr>
<tr>
<td>% 1-5 yrs = 6 (66%)</td>
<td></td>
</tr>
<tr>
<td>% 6-10 yrs = 2 (22%)</td>
<td></td>
</tr>
<tr>
<td>% 11-15 yrs = 1 (11%)</td>
<td></td>
</tr>
<tr>
<td>% 16-20 yrs = 3 (33%)</td>
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<table>
<thead>
<tr>
<th>Work Setting</th>
<th>Output = 8 (26%)</th>
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<tr>
<td></td>
<td>Partial Hosp = 4 (13%)</td>
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<tr>
<td></td>
<td>Group/RT = 2 (7%)</td>
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<tr>
<td></td>
<td>Other = 12 (39%)</td>
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<table>
<thead>
<tr>
<th>Settings</th>
<th>In-home = 10 (32%)</th>
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<tbody>
<tr>
<td></td>
<td>Total School = 9 (30%)</td>
</tr>
<tr>
<td></td>
<td>School Opt = 3 Yrs = 6 (25%)</td>
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<td>Other = 12 (39%)</td>
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<table>
<thead>
<tr>
<th>Service Delivery</th>
<th>School Opt = 3 Yrs = 6 (25%)</th>
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<tbody>
<tr>
<td></td>
<td>Other = 12 (39%)</td>
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NYC Family Advocates

1. Key Points...
   Family Advocates are trying to fill in the gap between parents and services and are challenged in meeting the need.

   - Lack of attendance (31%)
   - Lack of support to agencies (24%)
   - Lack of financial support to agencies (20%)
   - Meager resources based on program needs (12%)
   - Inefficiencies with the Foster Care System (12%)

2. Key Points...
   Family Advocates provide a wide range of services and supports

   - Support/Education 59%
   - Direct services to children 56%
   - Advocates 45%
   - CSE/School Placement 45%
   - Parent education workshops 45%
   - School/Program placement 45%
   - Communication between CSE and School 45%
   - Mental health assessment 45%
   - Service coordination 33%
   - Other duties 34%

3. Key Points...
   When provided with the opportunity for ongoing training and support, Family Advocates are highly satisfied:

   - Overall Training Appraisal
   - 10-week Training Attendance
   - Training Evaluation Rating

Pre-Post and 1-Year Changes in General Knowledge

<table>
<thead>
<tr>
<th>Pre-Post</th>
<th>Pre-Year</th>
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<tbody>
<tr>
<td>11.73</td>
<td>11.33</td>
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Pre-Post and 1-Year Changes in Self Assessment-Process Related Skills

<table>
<thead>
<tr>
<th>Trained Group</th>
<th>Spec Dis Pt. 1</th>
<th>Spec Dis Pt. 2</th>
<th>MH Systems</th>
<th>School Opt</th>
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<td>2.7</td>
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</table>

NYC Family Advocates

- When providing training, Family Advocates are highly satisfied.
- Family Advocates are challenged in meeting the need.
- Family Advocates are highly satisfied.
19th Annual RTC Conference
Presented in Tampa, February 2006

Pre-Post and 1 Year Changes in Self Assessment: Content Related
Trained Group

Pre-Post and 1 Year Changes in Self Efficacy: Total Score
Trained Group

Empowering Caregivers of Children with Mental Healthcare Needs:
Addressing Strains and Stresses of Inner-City Parents

NYC Parents of Children of Special Needs Descriptors

NYC Parents of Children with Special Needs

1. We are learning...
Parents in the community have high mental health needs of their own.
2. **We are learning...**
Parents are caring for youth with high mental health needs.

3. **We are learning...**
Parents believe that they are only moderately included in their children’s treatment and educational planning.

**Service Use**

**Family Advocate Perspectives on the Parent Empowerment Process: Turning Points**

Focus Groups: Parent Advocates
Defining Empowerment

- Education/Knowledge
- Resources
- Personal Attributes
  - Being in Control
  - Make Change
  - Self-confidence
  - The ability to speak up (assertiveness)
- **It’s A Process!!**

Mechanisms of Empowerment

- Identification → Unanimity
- Focusing on Strengths → Validation
- Open-mindedness → Acceptance
- Modeling

Qualities of an Effective PA

- Good Listener
- Personal Experience
- Persistence
- Knowledgeable
- Caring

Ingredients of Family Support

- Family-friendly environment
  - Engaging staff
  - Training for agency personnel
  - Parent input
  - Multilingual and multicultural
- Concrete needs
  - location,
  - child care,
  - flexible time,
  - $$ for necessities

Implications of our findings thus far...

- Family advocates are in need of ongoing training and support/supervision to negotiate obstacles to fulfilling their current role – providing support, information and facilitating access to appropriate services
- Family advocates could be an untapped resource in the service delivery process to youth and families
- Family advocates could potentially meet some of the unmet needs of parents by being more effectively integrated into the child mental health system
Parent empowerment training can produce changes in the short run, but ongoing support and training are crucial for long term effectiveness.

- Parent empowerment needs to be a part of an overall family driven program/philosophy.