

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 Empowerment Program

<p>Parent Advocates</p> <ul style="list-style-type: none"> ▪ Enhance parent advocates' knowledge of: <ul style="list-style-type: none"> ▪ Children's mental health needs ▪ Evidence-based treatments and services ▪ Community and school services ▪ Ability to: <ul style="list-style-type: none"> ▪ Engage parents ▪ Teach parents new skills ▪ Encourage parents to put new skills into action ▪ Collaborate effectively with professionals ▪ Enhance self-efficacy 	<p>Goals</p>	<p>Parents</p> <ul style="list-style-type: none"> ▪ Increase knowledge of children's mental health needs and evidence-based treatments ▪ Strengthen sense of self-efficacy ▪ Improve parent management skills ▪ Improve communication and assertiveness skills ▪ Promote partnerships between parents and service providers
--	---------------------	---

PEP Manual Content

<p>Parent Advocate Manual</p> <ul style="list-style-type: none"> ■ 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 	<p>Parent Handbook</p> <ul style="list-style-type: none"> ■ 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
--	---

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.

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

Baseline Demographics Family Advocates

Total N	Total = 31	
	PEP Trained = 17	
	TAU = 14	
Gender	Female = 29	94%
	Male = 2	7%
Age	Average = 41	
	Range = 25-76	
Ethnicity	Caucasian = 1	3%
	African American = 15	48%
	Hispanic/Latino = 11	36%
	Asian = 1	3%
	Other = 3	9%
Education	Less than High School = 2	7%
	HS Diploma = 6	20%
	Some College = 15	52%
	Bachelors Degree = 7	24%
	Some Graduate = 1	3%
	Other Education = 3	
	Family Development Credential = 5	17%

Baseline Family Advocate Characteristics

Parents of Children with Special Needs	Total = 17 (55%)	
Scheduled Hours per Week	0-10 hrs = 3 (10%) 10-20 = 4 (13%)	20-30 = 4 (13%) 30-40 = 17 (55%)
Live in the community which they work	Total = 22 (71%)	
Number of years of Experience	Average = 5 yrs (Range = 0-25)	0 Yrs = 4 (17%) 1 - 3 Yrs = 6 (25%) 4 - 6 Yrs = 9 (38%) > 6 Yrs = 9 (20%)
Work Setting	Outpatient = 8 (26%) Inpatient = 4 (13%) In-home = 10 (32%) Schools = 9 (30%)	Partial Hosp = 4 (13%) Group/RT = 2 (7%) Other = 12 (39%)

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

Parent Participation 20%	<ul style="list-style-type: none"> Lack of attendance in group support meetings Transportation Language barriers
Lack of Resources/Support 24%	<ul style="list-style-type: none"> Lack of financial support to agencies High turnover rates with supervisor/administrators Poor sense of support from within the agency Misuse resources based on program needs "Red Tape"
Empowerment and Education 44%	<ul style="list-style-type: none"> Training parents to advocate for themselves Educating on diagnosis and medication
Systems 28%	<ul style="list-style-type: none"> Understanding the education system Advocating for parents in treatment disagreements Difficulties with the Foster Care System
Service Delivery 12%	<ul style="list-style-type: none"> Setting priorities with parents Matching services with the parents particular needs Assisting parents in achieving their goals

*Percentages are based on number of advocates that reported these challenges

NYC Family Advocates

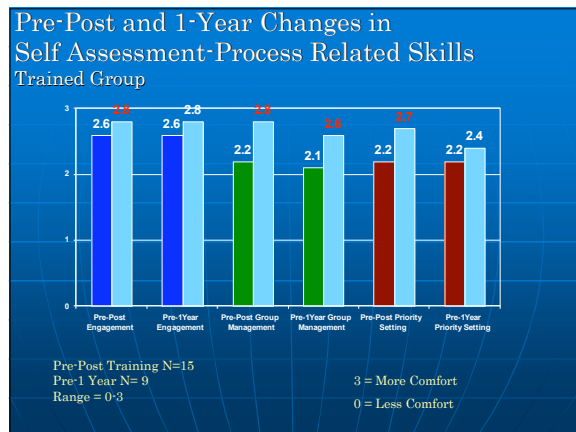
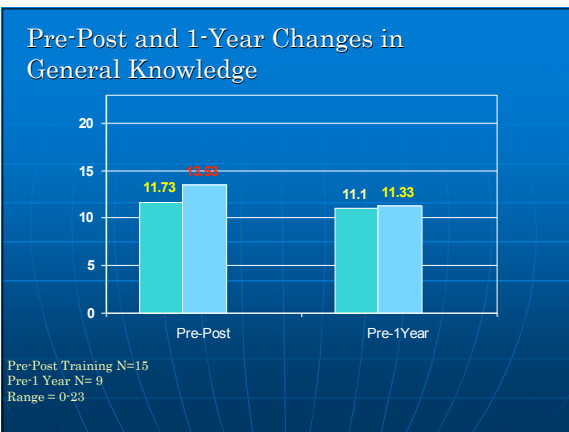
2. Key Points...
Family Advocates provide a wide range of services and supports

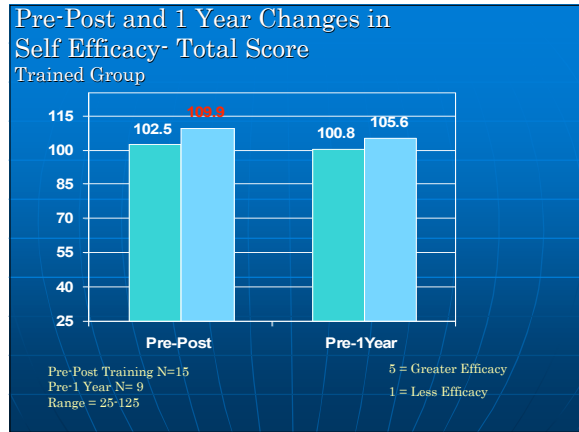
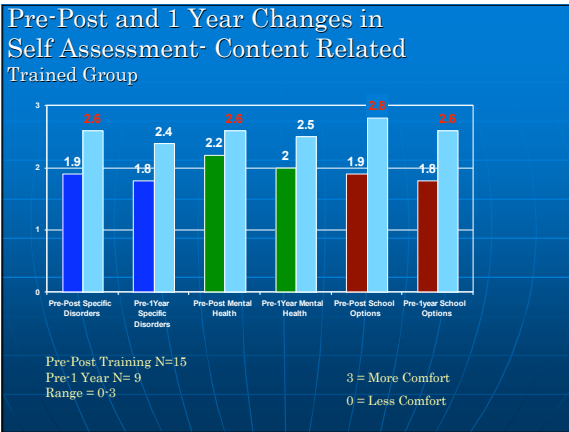
Support/Education 59%	<ul style="list-style-type: none"> Run parent support groups Provide information/educate on diagnosis and medication Skills teaching Parent education workshops
Liaison 53%	<ul style="list-style-type: none"> Court CSE/School Placement Communication between parent/school Mental health agencies
Service Coordination 53%	<ul style="list-style-type: none"> IEP/CSE Meetings Public Assistance SSI Psychological/Psychiatric Evaluations Mental Health Services Transportation Referrals
Direct Services to Children 45%	<ul style="list-style-type: none"> Homework assistance Peer programs Summer day camps After school programs Trips Arts/crafts
Other Duties 34%	<ul style="list-style-type: none"> Clerical/Office duties Progress/Quarterly reports Shopping with parents Filing/Chart maintenance
Program Coordination 14%	<ul style="list-style-type: none"> Supervise staff Coordinate parent support/peer programs Respite programs

*Percentages are based on number of advocates that reported these challenges

NYC Family Advocates

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





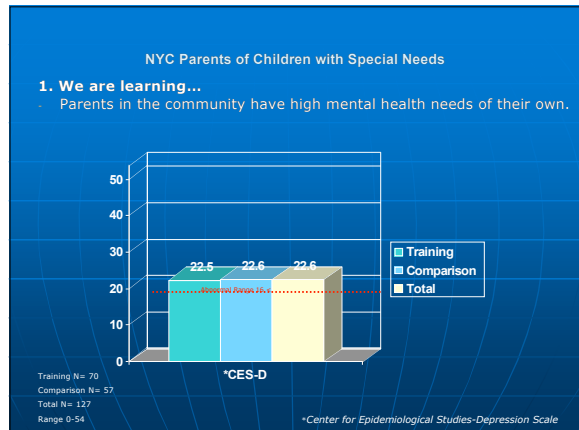
Empowering Caregivers of Children with Mental Healthcare Needs: Addressing Strains and Stresses of Inner-City Parents

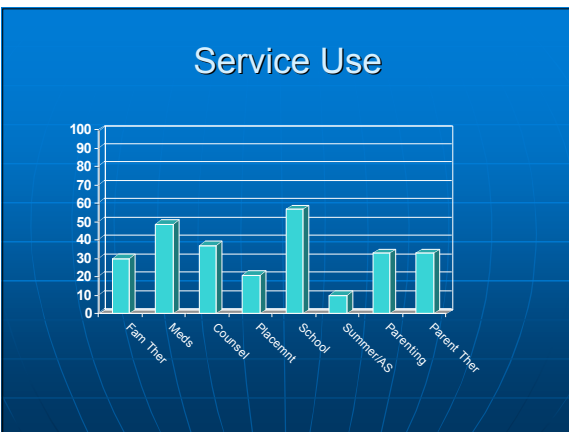
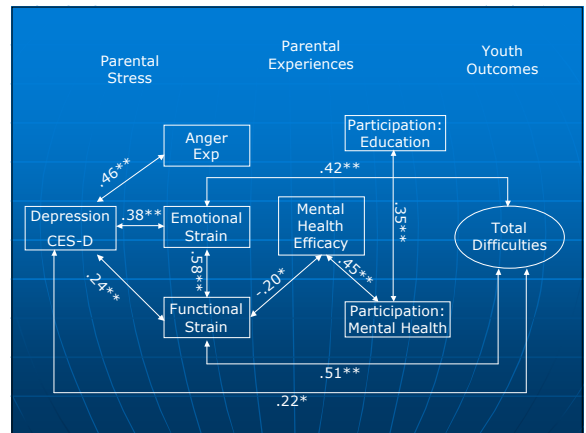
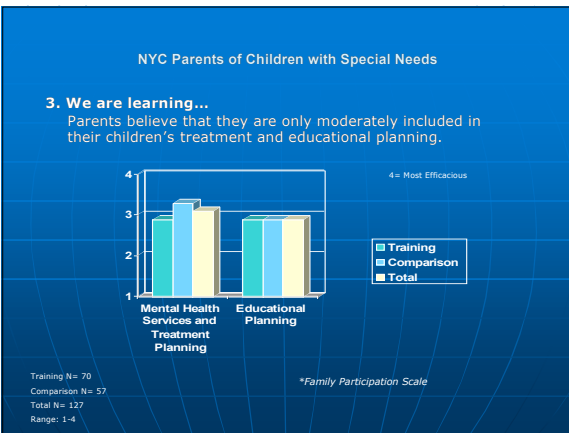
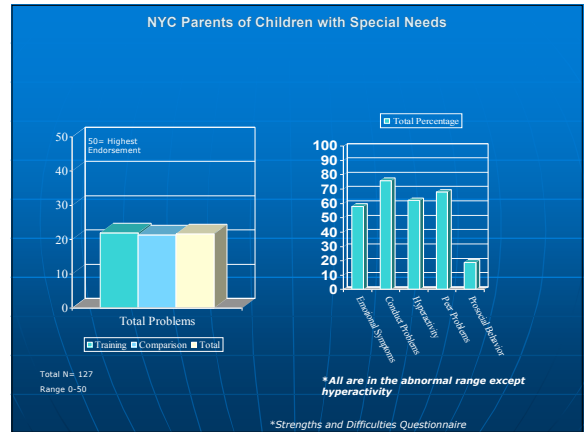
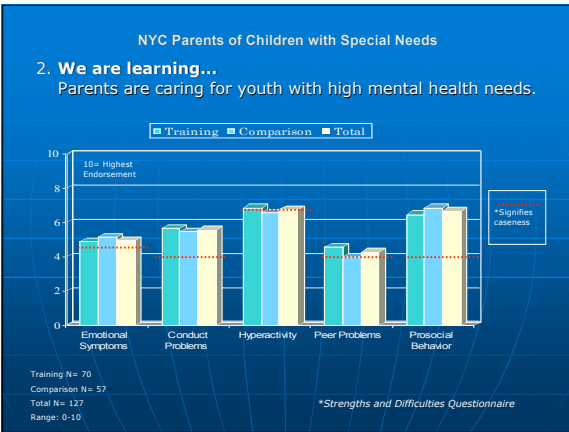
Preliminary Findings: Caregivers

NYC Parents of Children of Special Needs Descriptors

Total N	Total = 127 Training = 70 TAU = 57
Ethnicity	Caucasian = 6 % African American = 46 % Hispanic/Latino = 26 % Other = 13.1
Education	Less than High School = 8 % Some HS = 28 % HS Diploma = 28 % Some College = 21 % Bachelors Degree = 9 % Some Graduate = 3 % Unreported = 3 %
Marital Status	Single, never married= 41% Married= 21% Separated= 13% Divorced= 13% Widowed= 6% Unreported= 5%

Income Range (yearly)	< \$6,999 = 33% \$7,000-14,999= 23% \$15,000-29,999= 19% \$30,000-44,999= 8% \$45,000-\$59,999= 6% >\$60,000= 4% Unreported= 6%
Parenting Status	Biological = 82% Adoptive= 6% Grandparents= 5% Aunts/Uncles= 2% Step Parents= 2% Foster Parents= 2% Guardian= <1%
Number of Children Receiving Services Per Household	One= 62 % Two= 10 % Three= 2 % >Four= 2% Unreported= 23% (Not receiving/in process)
Target Child Age	Training Mean = 10 Comparison Mean = 13 Total Mean = 11.5





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...

Implications

- 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

Implications (continued)

- 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