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

Kimberly Eaton Hoagwood
Columbia University

Geraldine Burton
Family Advocate, Family Advisor for NYCDMH
Project Director, Parent Empowerment Program
Columbia University

## Acknowledgements

The Family Advocacy and Research Board (FAR), Families Together in New York, Families on the Move, Mental Health Assn of NYC, NAMI of NYC, New York State Office of Mental Health, New York City Dept of Health and Mental Hygiene, National Institute of Mental Health, Robert Wood Johnson Foundation, MacArthur Foundation, Child and Adolescent Services Research Center in San Diego

Geraldine Burton, Nancy Craig, Wanda Green, Bernadine Meeks, Marlene Penn, Janine Lounsbury, Aurelia Mack, Deborah Miller, Nancy Parker, Paige Pierce, Euphemia Strauchn, Rue Zalia Watkins, Peter Jensen, Mary McKay, James Rodriguez, Serene Olin, Belinda Ramos, Mary Cavaleri, Anita Appel, Myla Harrison, Richard Hibbert, Marleen Radigan, Alissa Gleacher, Anthony Salerno, Tara Sher, Marleen Radigan, Hilary Hoagwood

## 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: CASSP, System of Care Principles
- 2001: IOM: Crossing the Quality Chasm: Consumers as True North
- 2005: IOM: Integrating Health, MH, Substance Abuse
- 2006: Kansas Group (Adams, T Osher, D Osher, Bruns, Menninger, Jensen, Hoagwood + Ks Keys Families): Ten Principles of Family Support
- 2006-present: Family to family programs disseminated by leading family associations (NAMI, Federation of Families, CHADD, CABF)
- 2006: National Wrap-Around Initiative: Role for parent partners
- 2008: Knitzer and Cooper's Unclaimed Children (revisited)
- 2008: MacArthur Fnd and RWJ National survey on Family Support Services (Hoagwood et al., 2008)
- 2008: Parent Partner Assessment Workgroup Guide (Slaton, Spencer, et al)
- 2008: Robbins et al. Parent-to-Parent Monograph
- 2009: MacArthur Fdn & RWJ Follow-up Survey
- 2009: Increasing professionalization of role of family advisors
- 2009: Certification process in some states
- 2009: Family support becoming a billable service in some states

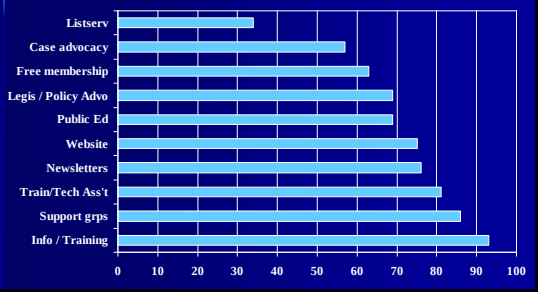
## The National Infrastructure for Family Support: RWJ & MacArthur Fdn National Survey on Family Advocacy, Support and Education Organizations (FASEO) (Hoagwood et al., 2008)

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

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

- Aims were to examine
  1. The size, structure, funding, and types of services offered by a national sample of family advocacy, support and educational 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

## Services offered by FASEOs (N=226)




## 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

## 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.

## 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

## 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 (Alegria et al., 2008)
- Family education improves self-efficacy and participation (Heflinger & Bickman, 1997; Bickman et al., 1998)
- 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.

## Key Elements

- Name of Program/Developers/ Program Definition/Purpose of program
- Organizational Affiliation/Stand alone or conjoined with child's treatment
- Format/Target audience/Target Disorder
- Family Support components
- Lead (family, clinician, team)
- Research Design
  - Published
  - In progress
- Primary Outcomes
  - Child
  - Caregiver
  - Other

## Five Categories of Support

1. Informational/Educational Support
   - Education about child behavior/development, treatment, services, system issues, resources
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/anxiety/stress 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

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

## Summary

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

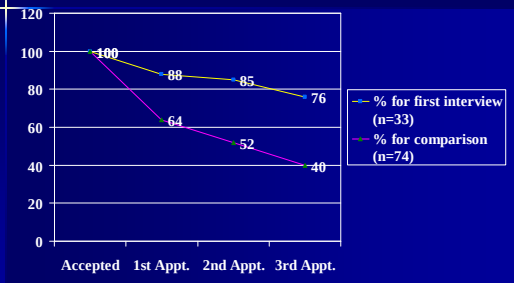
**New York State Initiatives to Improve Engagement and Empowerment of Families**

- 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-Krispijin et al., 1999; Zawaanswijk et al., 2003).
- Has been divided into two specific steps: initial attendance and ongoing engagement (McKay et al., 1996; 1997; 1998). Rates of service engagement can differ at each and warrant specific consideration.
- Studies that focus on attendance at initial appointments found that rates of no-shows at intake range from 48%-62% (McKay et al., 1996; Harrison et al., 2005).
- Average length of care: 9% of youth and their families remain in care after a 3-month period (McKay et al., 2002).

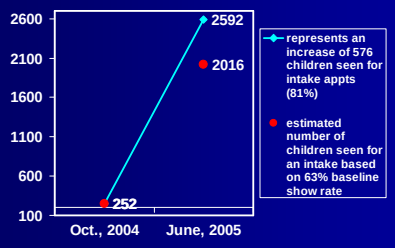
## Engagement strategies for intake and first appointments (McKay et al., 1999, 2005)

- 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.

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




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




## NYS Empowerment Studies: The Parent Empowerment Program (PEP)

- 40-hour training for family advisors/advocates working with parents/caregivers of youth with mental health needs (Jensen & Hoagwood, 2008)
- Followed by 6 month small group telephone consultation (12 hrs)
- Co-led by experienced parent advocate and MH professional to model collaboration
- Goals:
  - Enhance family advisors' knowledge of evidence-based practices in children's mental health
  - Enhance family advisors' skills and competencies in working with parents (engaging, boundary setting, priority setting, questioning, group management)
  - Improve parent activation and youth mental health
- Theory-based targeting principles of behavior change (Jaccard et al., 2002)
- Manualized

## Parent Empowerment Project (PEP) Manual Content

Parent Advisor Manual

- Introduction
- Getting Ready
- Building Engagement, Listening, and Boundary Setting Skills
- Building Your Teaching and Group Management Skills
- Developing Priority Setting 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

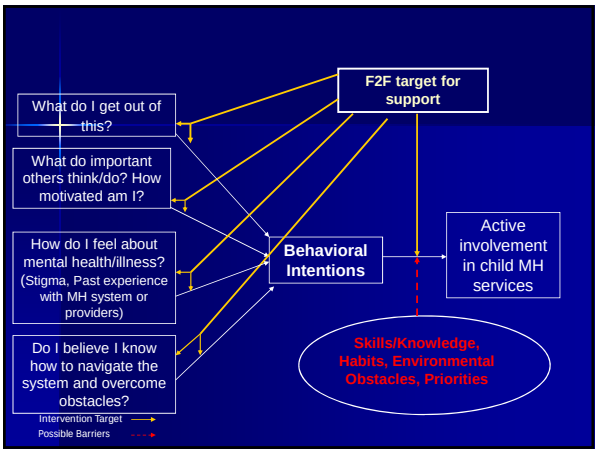
- Introduction
- Knowing Yourself
- Knowing Your Child
- Treatment Management Skills: How to be Your Child's Case Manager
- Specific Disorders and Their Treatments
- The Mental Health System of Care: What to Expect and How to Prepare
- Services and Options Through the School System
- Helpful Tools for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

## PEP Evaluation Findings

- Pilot study using experimental design
- N=32 family advisors and 124 parents in New York City (85% low income, minority) N=18 trained FA; N=14 comparison
- Examined impact of PEP training on
  - Family advisors' knowledge of MH services, collaborative skills, and self-efficacy
  - Parents' working alliance, self-efficacy, empowerment, strain
- Significant improvements pre/post in knowledge ($p<.001$), 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 6 months ($p<.05$) but not among parents in comparison group
- No differences in parents' service self-efficacy, empowerment, or strain
- Strongest predictor of parents' working alliance: working with advisor who provided home/school visits ($R2=.61$; $F=.0001$)
- High levels of depressive symptoms among parents (CES-D average 22.6 (cut off is 16); 2/3 above clinical cut-off)
- Heterogeneity of agency's social-organizational contexts and undervalued roles of family advisors

## 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
- Examine 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)