

# The Research that Guides Us

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*National Federation of Families  
for Children's Mental Health*

**Parent Support  
Provider Institute**

November 16, 2011

# how family partners contribute to the phases and activities of the wraparound process





[www.ncecd.edu](http://www.ncecd.edu)

# Wraparound Implementation Guide:



# A Handbook For Administrators And Managers

In partnership with the National Center for Early Childhood Development  
Developed by the National Center for Early Childhood Development



# The Future!



## The Need

## The Theories

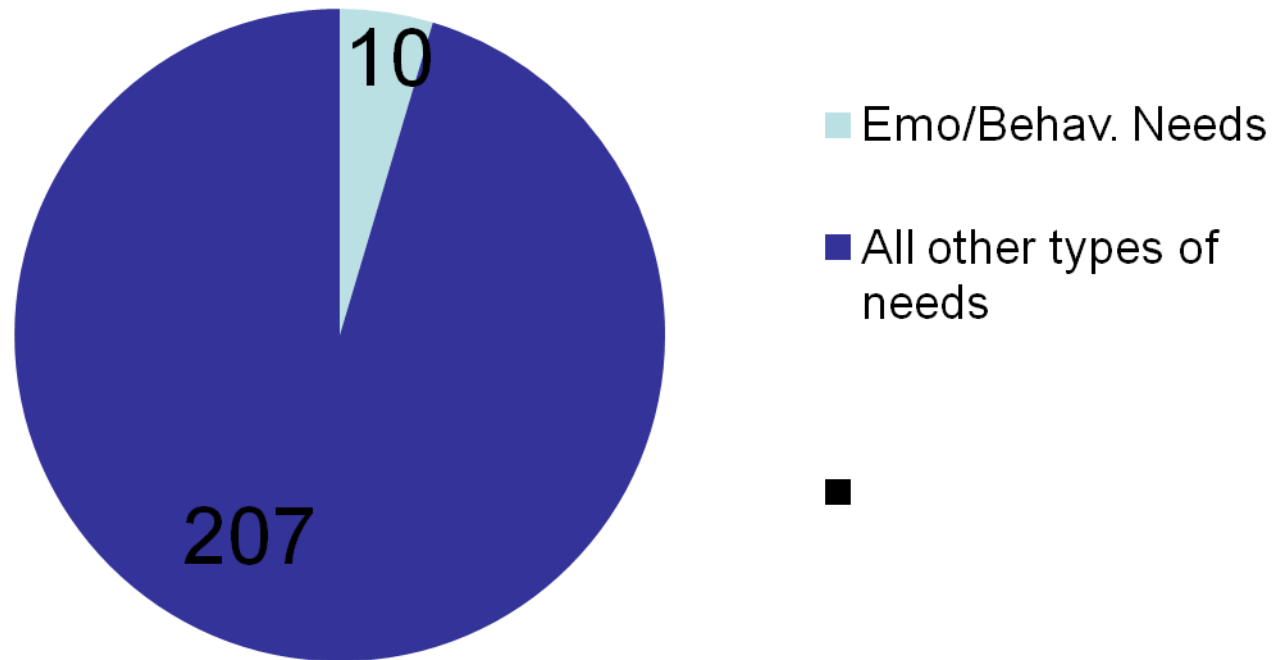
## The Research

# System of Care (Stroul & Friedman, 1986)

- “System of care values”
  - Family-driven
  - Community-based
  - Culturally competent
- Family support
  - One of the core necessary “operational” services in a system of care

# RTC on Family Support and Children's MH, Portland State

Number of parent organizations nationally



Friesen, 1986

# What do families need ... and what do they actually get?

	Needed	Received	Was it hard?
Special Ed svcs	86%	77%	48%
Psychologist	85%	81%	41%
Counselor	84%	74%	43%
Respite	85%	17%	74%
Parent Support	83%	53%	66%
Sibling Support	65%	15%	69%
Advocacy svcs	65%	31%	64%

# Groundbreaking study of “Family Associates”

- Randomized control trial
- Positive findings
  - Greater initiation of services – making and keeping a first appointment
  - Significantly higher scores on an empowerment measure (the Family Empowerment Scale)
  - Reduced barriers (transportation) and provided emotional and informational support
- Less effective at helping get needs met such as respite care and child care

Koroloff & Friesen, 1991; Elliott et al., 1998

# Albert Bandura

- *Social Foundations of Thought and Action* (1986)
- Self-Efficacy: The belief that one is capable of performing in a certain manner to attain a certain set of goals
- Having such a belief is *critical* to successful action toward goals... and a “happy productive life”



# Predictors of self-efficacy

- Prior successful experiences (Enactive mastery)
- Learning from others (Vicarious experiences)
- Understanding from peers (Verbal persuasion)
- Managing stress (physiological and affective state)



Bandura, 1997;  
Robbins et al., 2008

# Parent support builds self-efficacy

- Experienced parents help enrolled parents build on strengths and expand capacities (opportunities for **mastery**)
- An experienced parent with similar lived experiences is more likely to provide **vicarious learning experiences**
- A peer is also more likely to be able to be **persuasive** by providing a norm group against which a parent can compare herself
- Emotional support reduces stress – thus improving a parent's **physiological and affective state** and make them more effective
- All this leads to **greater self-efficacy** with the system, providers, and one's own family.

Robbins et al, 2008

# Promotoras de salud

- To engage and inform parents and adults about critical community health issues
  - Protecting sexually active youth by encouraging early and consistent use of contraceptives
  - The need to immunize babies
  - The need for cancer screening
- Reduce stigma
- Increase communication
- Support service use



Casey Foundation, 1997

# Why use *Promotoras*?

- Individuals with similar lived experiences, and who are community residents themselves, are effective health promoters:
  - There was less suspicion toward them;
  - They had access to more people in the community
  - Better able to make connections between community residents
  - More comfortable than professional health educators in discussing difficult aspects of teenage sex, cancer screening, etc
  - Led more direct and focused discussions than professional health educators
- As part of the community, *Promotoras* /Walkers & Talkers felt they had the responsibility and right to challenge other community residents with the message.

# The Results

- Community rates of pregnancy among sexually active youth declined from 33% to 27% in a 3 city initiative (Public/Private Ventures, 1999)
- Immunization rates rose from 37% to 50% in a San Diego barrio, compared to no change for control community (Waterman et al., 1996)
- Cancer screening 23% compared to 16% for a control group (Navarro, 1998)

# Caveats about *Promotoras*

- Usually combined “lay health workers” with many other things:
  - Media campaigns
  - Free walk-in clinics
  - Computerized reminder system
  - Continuing education of providers
- The model is “only as good as the health system it represents” (Waterman, 2004)



## Vets supporting vets

- Peer support from other vets has been found to be successful in helping vets manage chronic health conditions such as diabetes
  - Better than nurses (Heisler, 2011)
  - Better than financial incentives (Long, 2011)
- Helps them to overcome resistance to difficult med regimens
- Interestingly, no controlled research yet on peer support for PTSD



# Successful elements

- **Clearly Articulated Policies to Avoid Confusion**, especially around role boundaries and confidentiality.
- **Defined Selection Criteria for Peer Supporters:**
  - communication skills,
  - leadership ability,
  - character,
  - previous experience or training,
  - individuals who can serve as positive role models.
- **Leverage Benefits from “Peer” Status**, such as experiential learning, social support, leadership, and improved self-efficacy.
- **Enable Continued Learning through Structured Training**, by providing an atmosphere for peer supporters to support each other and improve peer support skills.

# Peer support has been shown to improve a wide range of health outcomes

- Eating habits among women at risk for diabetes (Auslander et al. 2002)
- Decreased cocaine use (Egelko et al. 1998; Galanter et al. 1998)
- Improved health among persons with heart and lung disease or diabetes (Lorig and Holman 2003)
- Reduced smoking among cancer survivors (Emmons et al. 2005)
- Decreased high-risk behaviors associated with HIV exposure (Kegeles et al. 1996; Wright et al. 1998)
- Improved usage of HIV medications (Broadhead et al. 2002; Lyon et al. 03)

# NAMI Family to Family

- Designed to meet the needs of families of adults with mental illness
- Originally developed by families in 1991 and now taught by over 6000 trained family member volunteers
- Until very recently, no randomized studies
- New study of 133 F2F participants vs. 126 non-participants (Dixon et al., 2011)

# Study results

- Significantly better outcomes at 3 and 9 months for the F2F compared to comparison family members:
  - Empowerment on all 3 FES subscales (in family, service system, community)
  - Greater knowledge of mental illness
  - Better coping
  - Lower depression and anxiety
  - Better problem solving on family issues

# Tides are Changing!

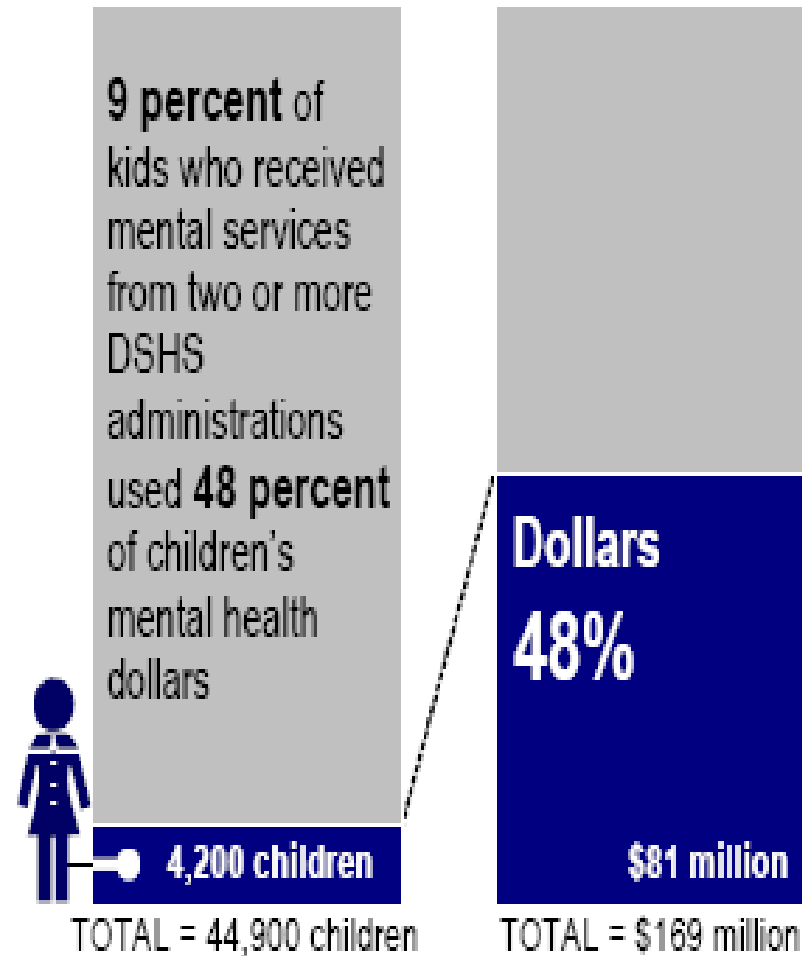


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# Peer support is coming of age in an era of health reform

- Practical importance:
  - Workforce shortages
  - Cost effective strategy
  - Targeting costly outcomes
    - Hospitalization, ER use, chronic health conditions
- Recent shifts in Institute of Medicine values:
  - Consumer driven
  - Choice based
  - Personalized

# Costs to the system of youth with the most complex needs



# Out of home placement rates of youths with the most complex needs



How many treated or placed away from home at some point in 2003?

Of those using mental health services from one DSHS program, **14 percent**.



Of those using mental health services from more than one DSHS program, **68 percent**





**What About Parent to  
Parent Peer Support?**

## Family-based services in children's mental health: a research review and synthesis

Kimberly Eaton Hoagwood

New York State Psychiatric Institute, Columbia University, New York, USA

A systematic review was undertaken of scientifically rigorous studies of family-based services in children's health and mental health. From a pool of over 4000 articles since 1980 in health and mental health that examined either specific family-based interventions for families of children or the processes of involvement, 41 studies were identified that met the methodological criteria for inclusion. These 41 studies encompassed 3 distinct categories: families as recipients of interventions (e.g., family education, support, engagement, empowerment); (b) families as co-therapists; and (c) studies of the processes of involvement (e.g., therapeutic alliance, engagement, empowerment, experiential, and choice). Too few experimental studies exist to conclude decisively that family-based services improve youth clinical outcomes. However, those studies that have been rigorously examined demonstrate unequivocal improvements in other types of outcomes, such as retention in services, knowledge about mental health issues, self-efficacy, and improved family interactions – all outcomes that are essential ingredients of quality care. Four implications are drawn from this review. (1) Effective family education and support interventions from studies of adults with mental illnesses and from studies of families of high-risk infants exist and can be imported into the field of children's mental health. (2) The range of outcomes that are typically assessed in clinical treatment studies is too narrow to afford an adequate view of the impact of family-based interventions. A broader view of outcomes is needed. (3) The absence of a robust literature on process variables other than therapeutic alliance limits conclusions about how and why interventions are effective. Attention to the processes by which families become involved in services will require a more robust and nuanced range of studies that attend simultaneously to processes of change and to outcome improvement. (4) Language of effective family-based interventions to delivery of evidence-based services is likely to amplify the impact of those services and improve outcomes for youth and families.

Clin Child Fam Psychol Rev (2010) 13:1–45  
DOI 10.1007/s10567-009-0060-5

## Family Support in Children's Mental Health: A Review and Synthesis

Kimberly E. Hoagwood · Mary A. Cavaleri ·  
S. Serene Olin · Barbara J. Burns · Elaine Slaton ·  
Darcy Gruttadaro · Ruth Hughes

Published online: 13 December 2009

# Parent to Parent



## A Synthesis of the Emerging Literature

July, 2008

Vestena Robbins, Janice Johnston,  
Kentucky Department for Mental Health,  
Developmental Disabilities, and Addiction Services

Holly Barnett,  
formerly with the Kentucky Department for Mental Health,  
Developmental Disabilities, and Addiction Services

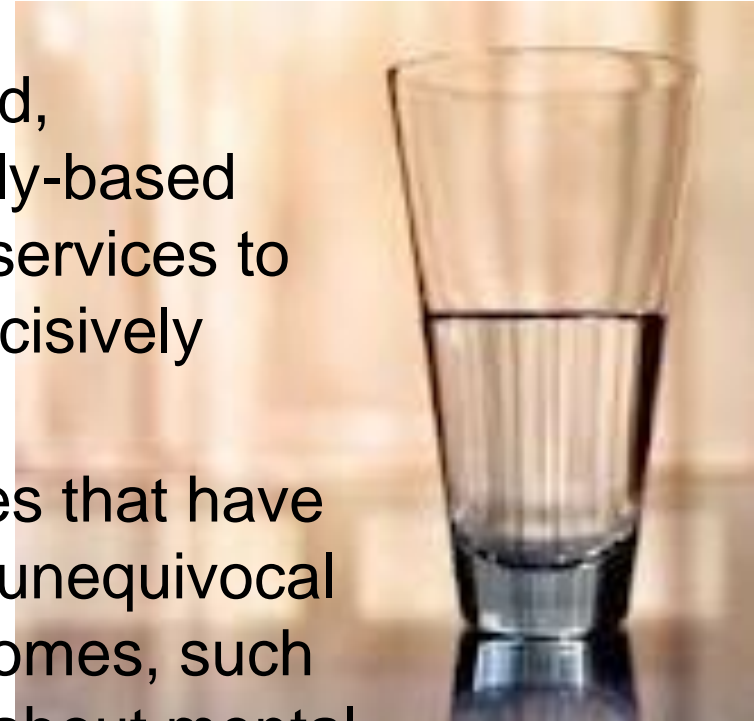
William Hobstetter,  
Kentucky Partnership for Families and Children, Inc.

Krista Kutash, Al Duchnowski, and Sasha Annis  
Research and Training Center for Children's Mental Health  
Louis de la Parte Florida Mental Health Institute  
University of South Florida



# Hoagwood, 2005

- “There are far too few well-conducted, scientifically rigorous studies of family-based services in children’s mental health services to conclude that these interventions decisively improve youth clinical outcomes.
- On the other hand, the careful studies that have been undertaken to date do identify unequivocal improvements in other types of outcomes, such as retention in services, knowledge about mental health issues, self-efficacy, and improved family interactions – all outcomes that are essential ingredients to quality care.”



## ...However...

- Studies that showed positive “intermediate” outcomes were not family peer to peer support. Mostly, they were:
  - Family psychoeducation
  - Classroom-based education
  - “Engagement interventions” such as telephone reminders and problem solving about attending treatment sessions

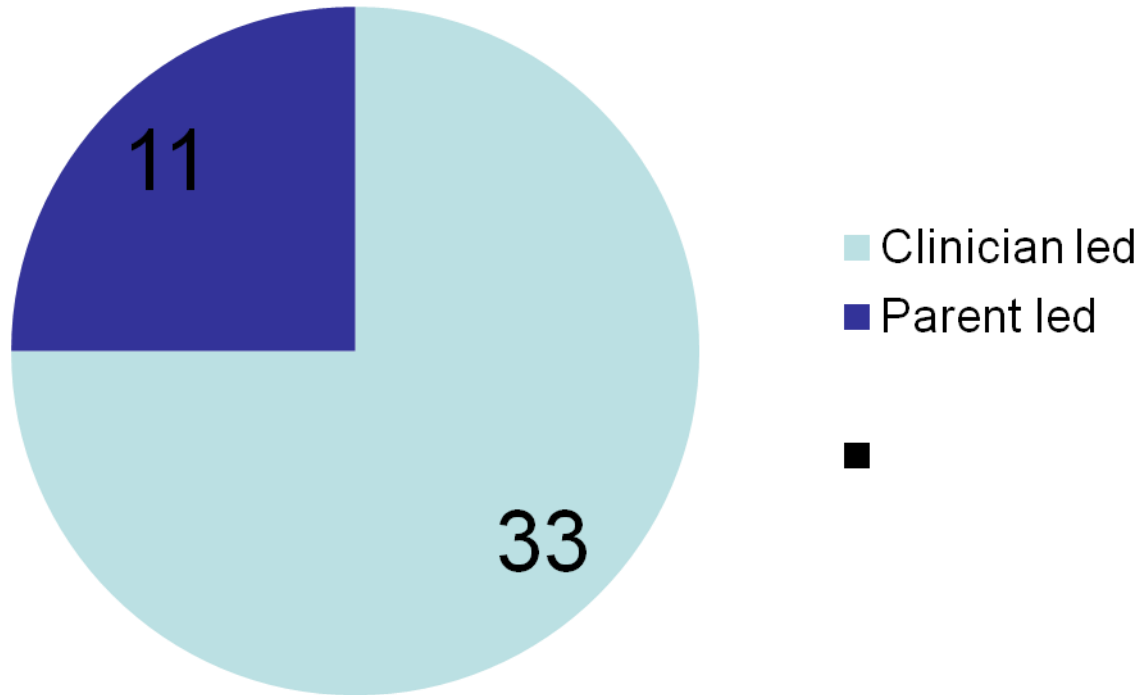
# Research on Family support (from Hoagwood 2005)

- “Family support has received the least amount of rigorous scientific attention.
- One might point out, however, that in contrast they have received the largest share of ‘thought pieces’ and pre-post evaluations.”

# Hoagwood et al. 2010

- Formal Family Support programs are increasing, as are family support organizations
  - 4 million members in at least 225 local organizations nationally.
- Identified 44 published descriptions of Family support programs with some type of evaluation data

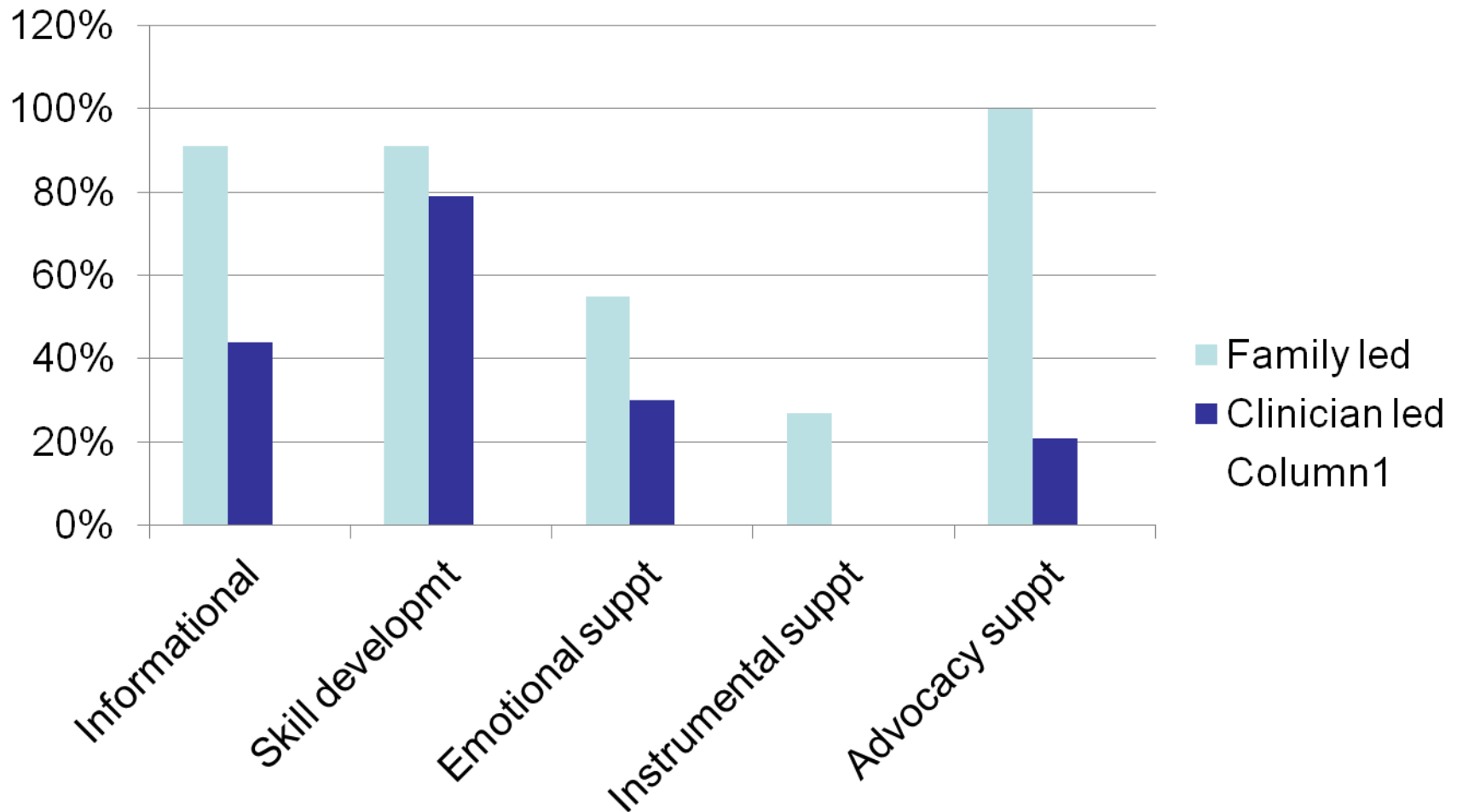
# Types of Family Support programs found



# Content of family support programs

1. Informational/educational
2. Instructional/skill development
  - Coaching on addressing child behaviors
  - Skill building (stress management, problem solving, etc.)
3. Emotional / affirmational support
4. Instrumental support
  - i.e., getting access to transportation or basic services
5. Advocacy support
  - Rights and resources
  - Leadership skill building to help parent be an advocate

# Family led programs attempt to do more



# The Controlled research

- 26 of the 33 clinician-led family support programs had controlled research studies
- As for the 11 family-led support programs, only 3 controlled studies were found.
- “Rigorous studies of family support programs in children’s mental health are exceptionally rare.”

# Robbins et al., 2008

- Eight rigorous studies found, generally quite positive
  - Six in disability and chronic illness
  - Only two for children with EBD
    - Ireys et al (2006) found reduced anxiety and increased social support in parents
    - The other was the original Koroloff & Friesen (1991) study of Family Associates!



# “Parent Connectors”

**Kutash et al., 2011**

## **A program based on the premise that**

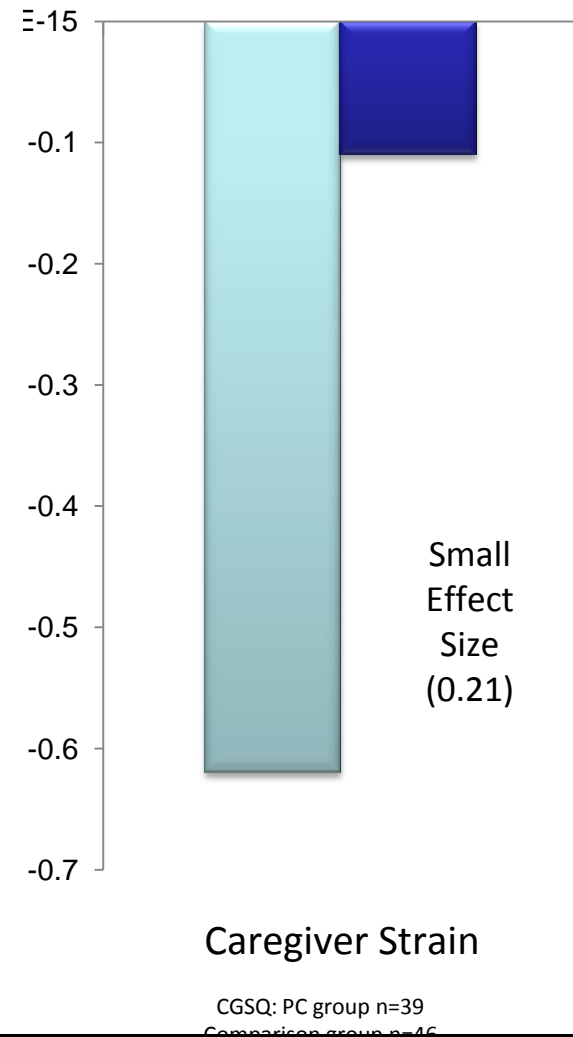
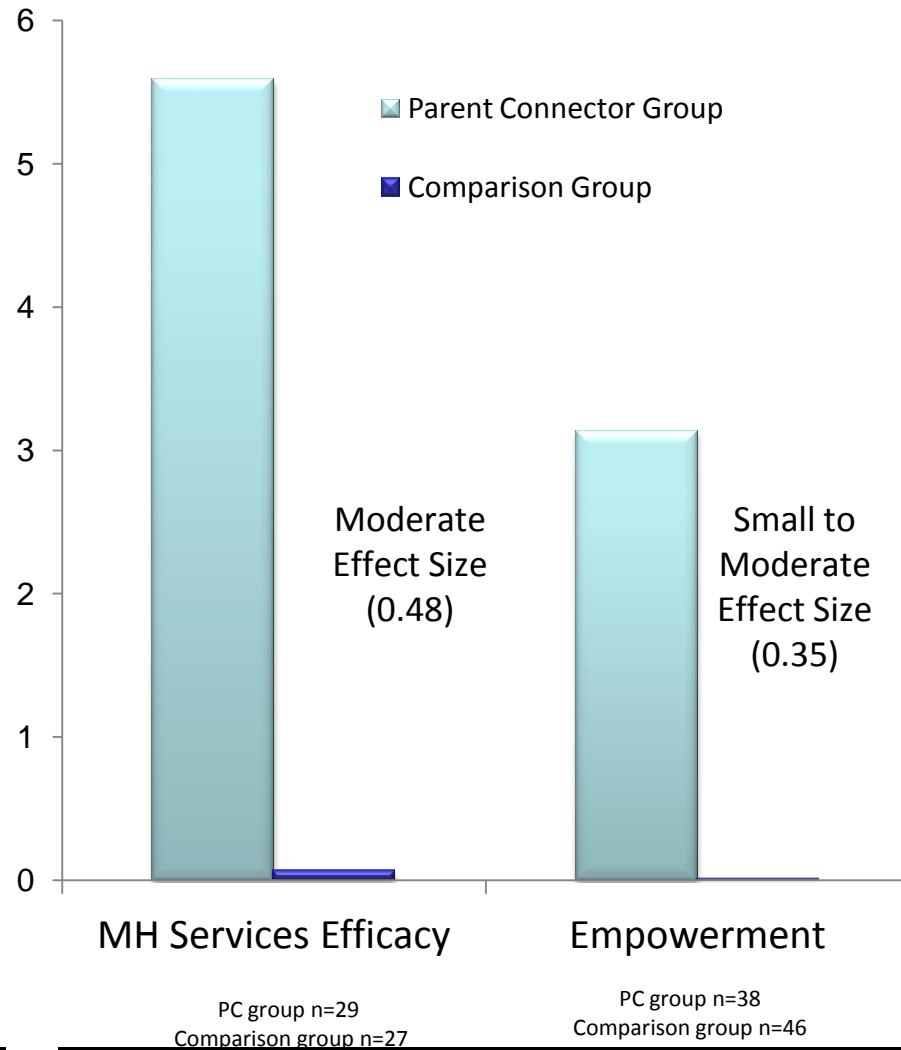
Parents of Youth served in special education classrooms due to emotional problems are not actively engaged in the education or mental health services provided to their children.

Schools are part of both the educational and mental health system and a good place to reach parent.

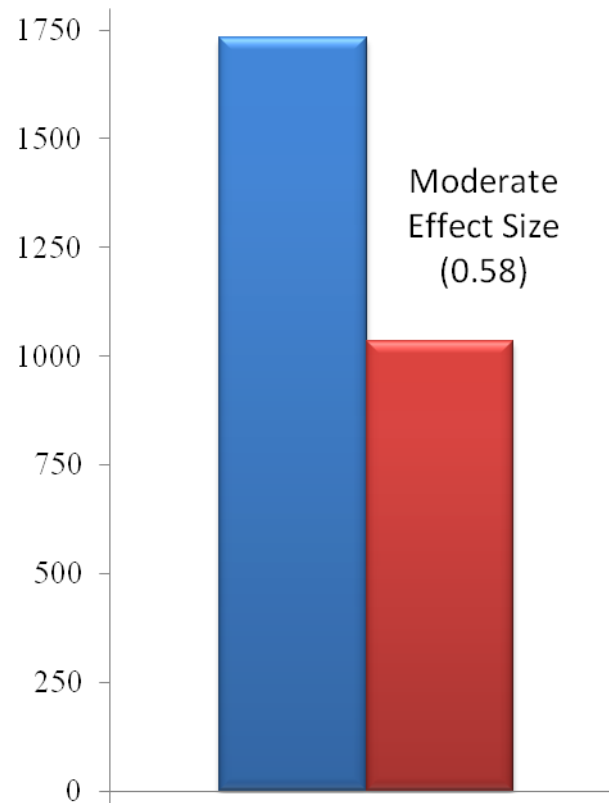
# “Parent Connectors”

- A peer to peer support program for parents of children of children with emotional disturbances (ED).
- Trained family members serve as Parent Connectors to deliver family support through weekly telephone contact.

# Outcomes for Parents



# Outcomes for Youth

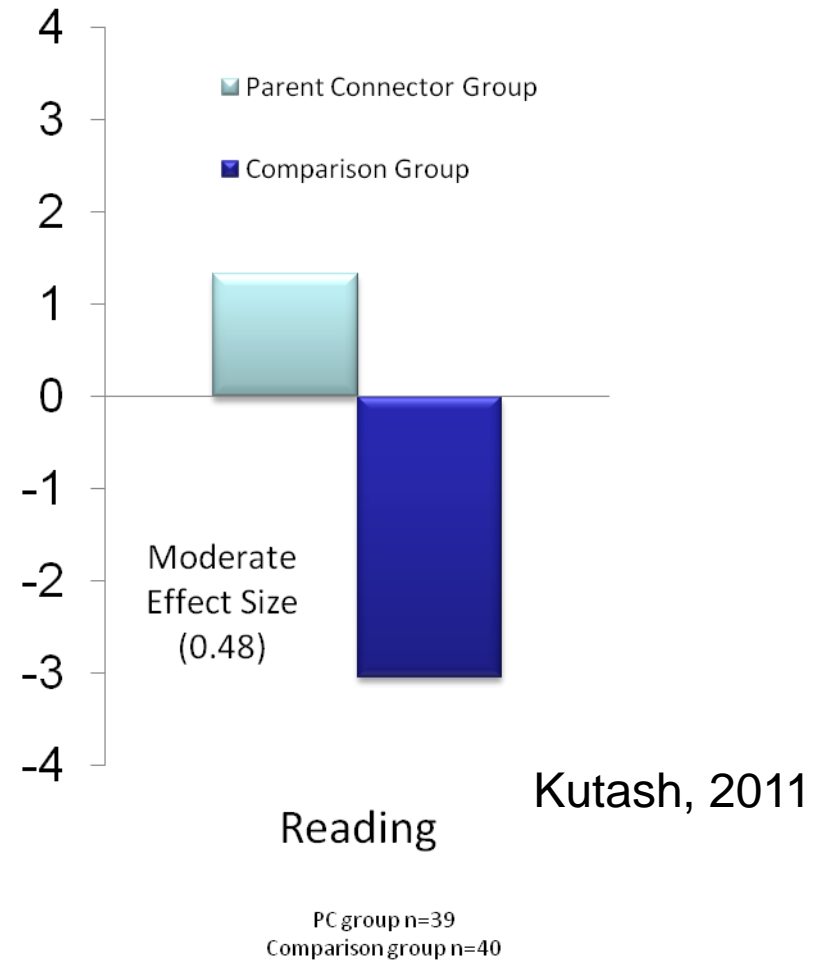
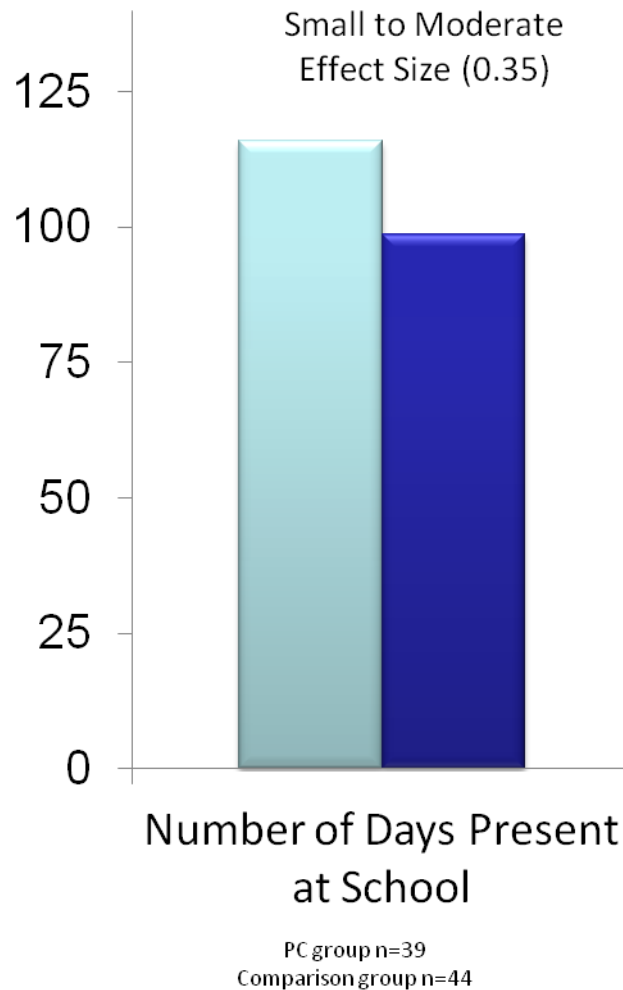


Minutes of MH Services  
Received

PC group n=31  
Comparison group n=34

Kutash, 2011

# Outcomes for youth





So... we have  
suitcases full  
of research  
studies.

What in the  
world have  
we learned?

# Peer to peer support is research based



**And increasingly accepted as  
a key health care option**

# Summary of the Research

- Peer support has been found to promote a wide range of health outcomes
  - Cancer screening among inner-city women
  - Diabetes management among veterans
  - Reproductive health choices among teens
  - Eating habits among women at risk for diabetes (Auslander et al. 2002)
  - Decreased cocaine use (Egelko et al. 1998; Galanter et al. 1998)
  - Improved health among persons with heart and lung disease or diabetes (Lorig and Holman 2003)
  - Reduced smoking among cancer survivors (Emmons et al. 2005)
  - Decreased high-risk behaviors associated with HIV exposure (Kegeles et al. 1996; Wright et al. 1998)
  - Improved usage of HIV medications (Broadhead et al. 2002; Lyon et al. 03)
- But... Peer support in Mental health is less well researched

# Summary of the Research

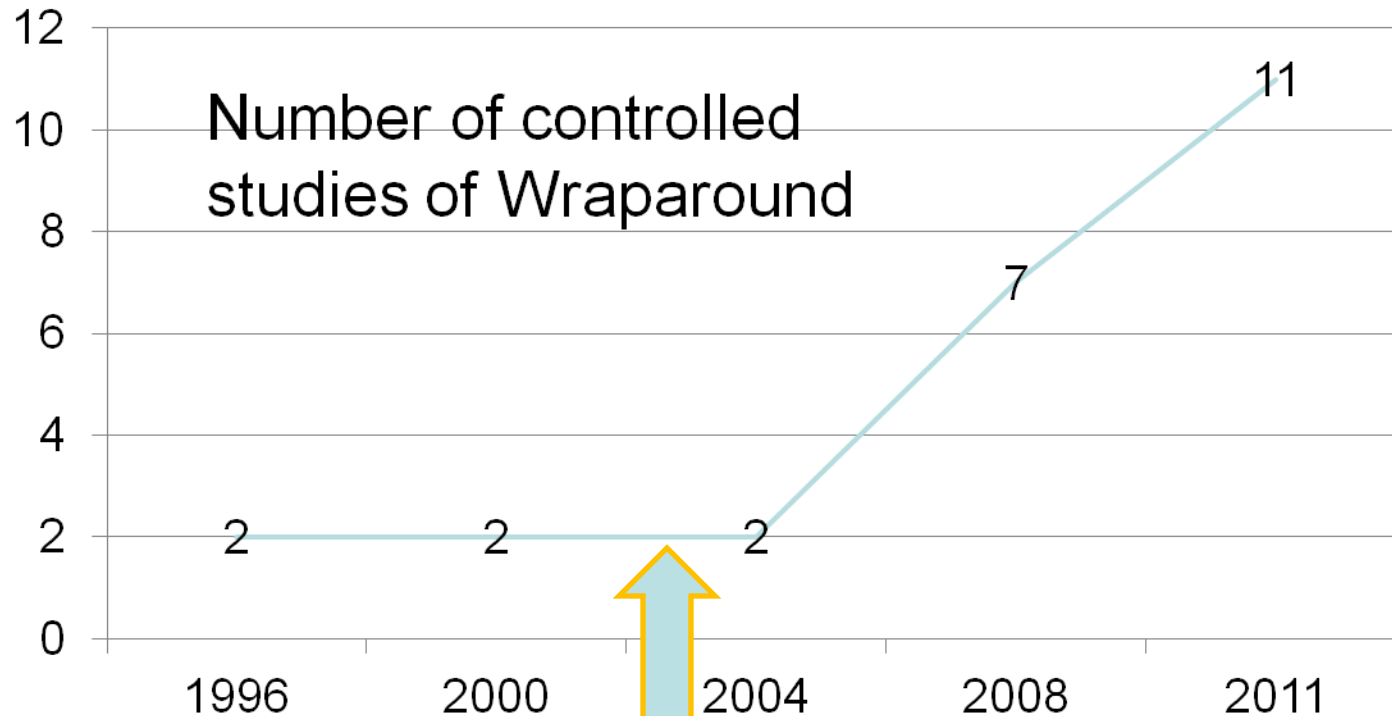
- Research on “Family support” interventions in MH is positive and growing rapidly
  - Parent training on managing behavioral problems
  - Engagement = Reminders and problem solving about treatment sessions
  - Psychoeducation
  - Clinician led multi-family groups
- But... only a few rigorous studies on parent to parent peer support

# Our understanding of the theory and components of the model is improving

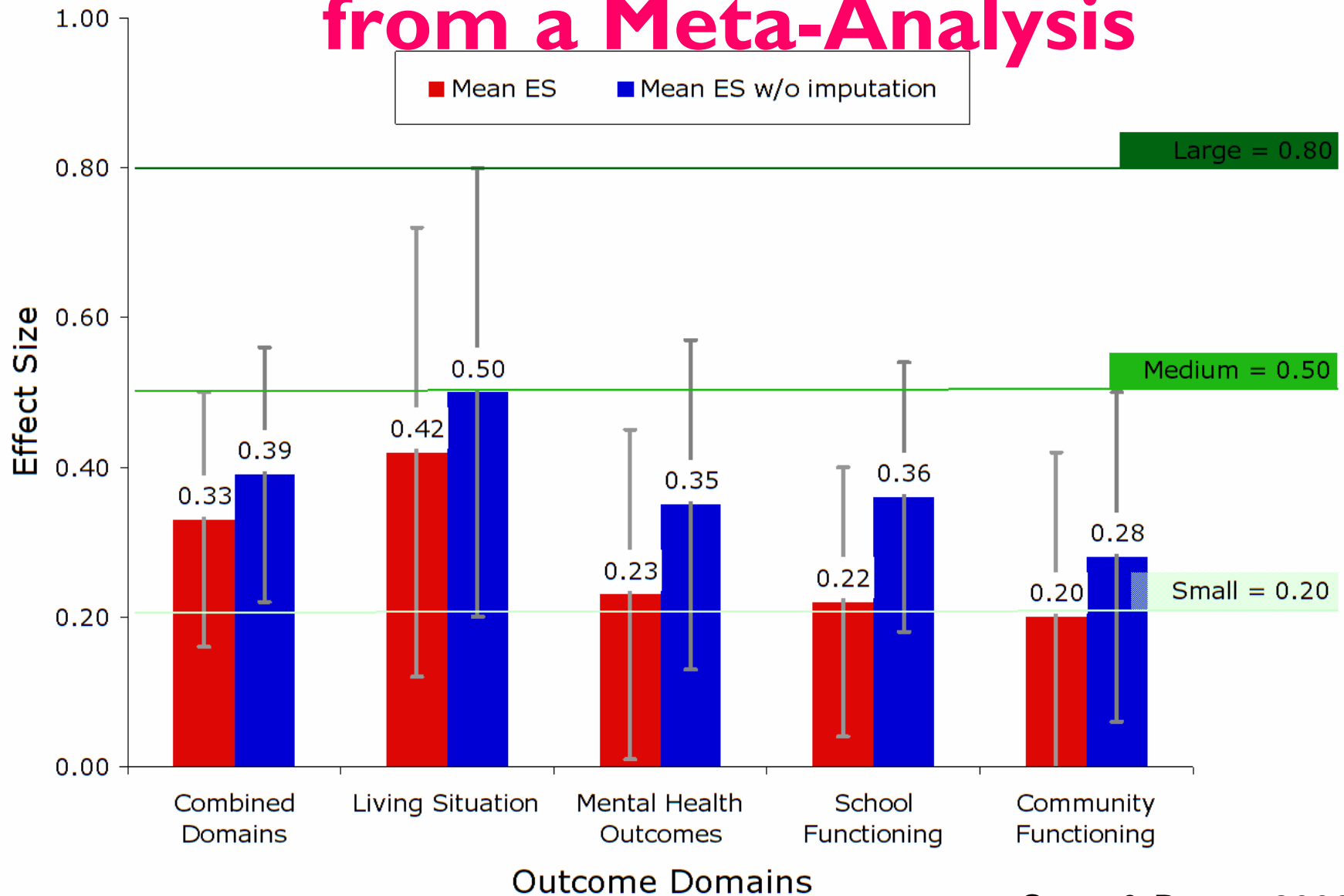
Informational/educational	Emotional support
Educational	Affirmation
Instructional	Hope
Skill development	Instrumental support
	Advocacy

...As is our understanding of what it requires to implement those components

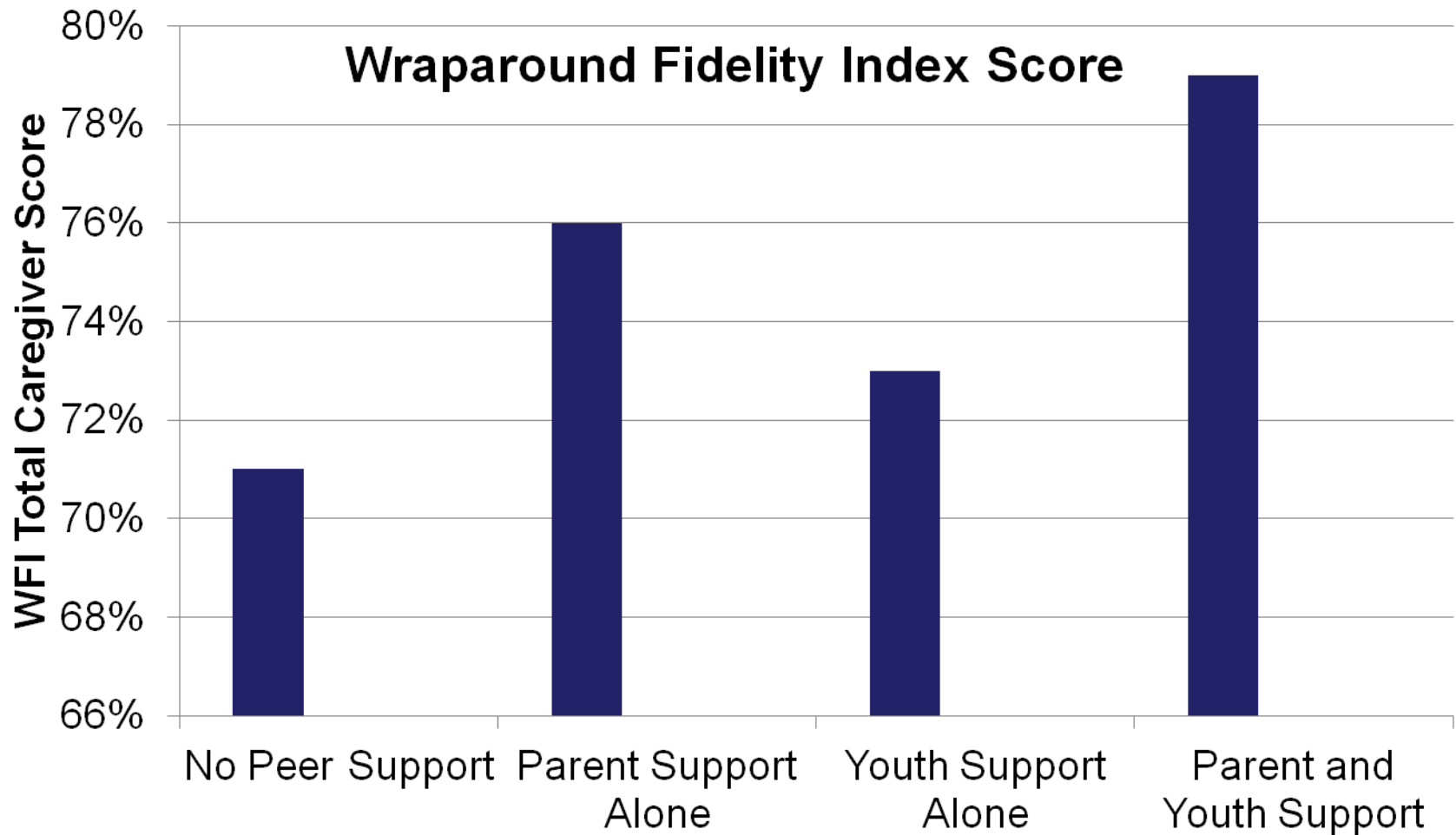
# When the model is defined, the research follows



# Wraparound Effect Sizes from a Meta-Analysis



# Wraparound is Enhanced by Family Support



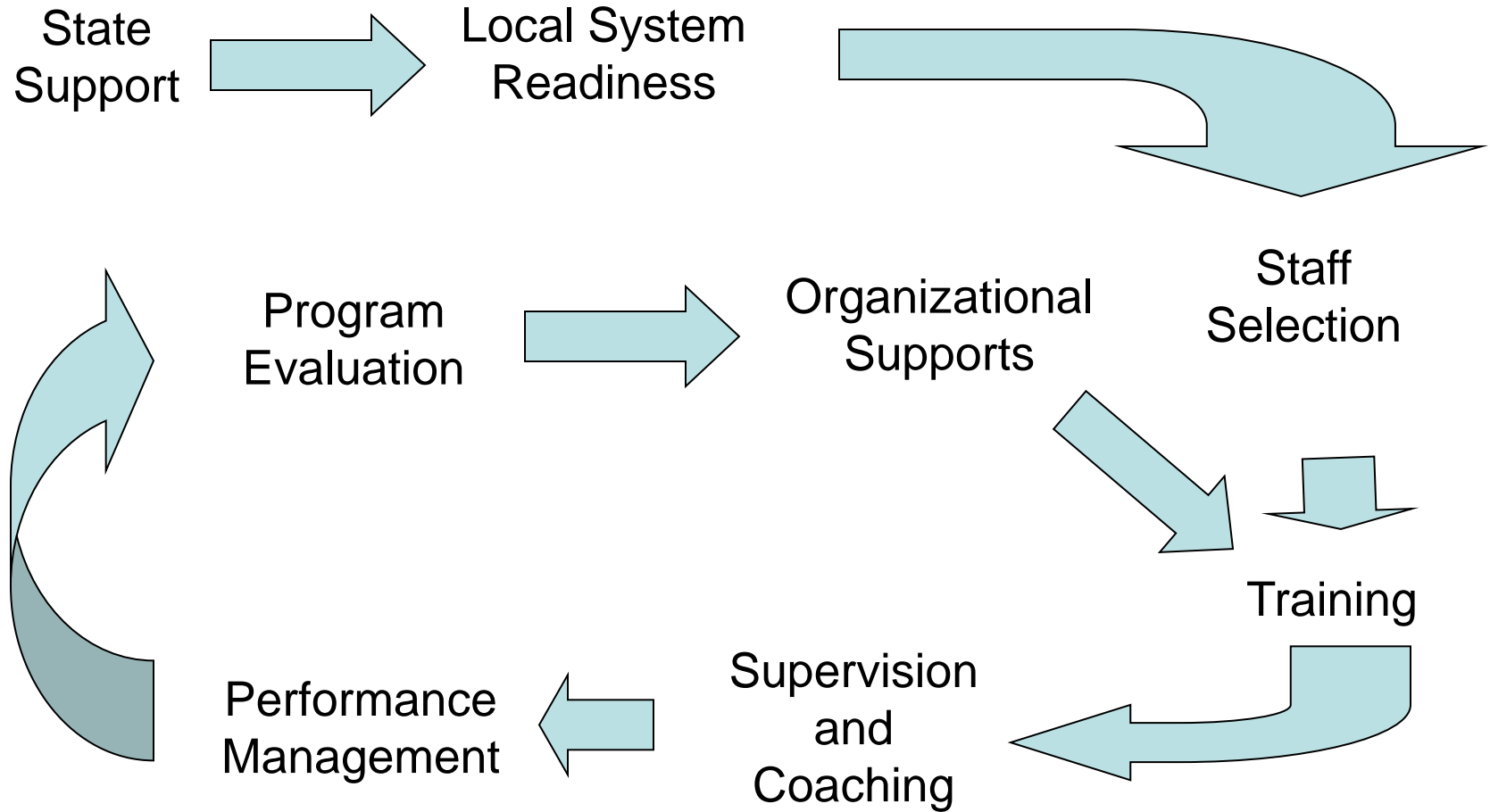
# Manage the Discussion on Outcomes

- There are a lot of ideas about what Parent to Parent peer support is supposed to accomplish:
  - Parent empowerment, education?
  - Parent stress, anxiety, depression?
  - Engagement and attendance in treatment?
  - Child behavior and clinical outcomes?
- This is an empirical question but also a values question!

**It takes  
implementation  
support to  
ensure good  
parent support**



# Implementation Drivers



From Fixsen et al (2005)

# Measure what Matters

- Family Needs (See, for example, Family Assessment of Needs and Strengths, CANS)
- Parent progress through their journey (Targeted Parent Assistance, Jane Adams)
- Measures of adherence, dose, and quality

# Adherence

Concept	Measurement System
Determine whether PCs are providing participants with each of the 14 critical elements of the program.	Weekly rating by PC of critical element delivery using the Family Contact Log
	Beginning of program, PC rating of family's needs in regards to each critical program element using the Perceived Family Needs Assessment.
	At the mid-Point of the program, participants rate whether PCs delivered critical elements using the PC Adherence Scale.

Example from *Parent Connectors* Program; Kutash et al., 2011

# **It takes a village to support positive mental health outcomes for families**



# Is there research to lead us?



## Or is it time for us to lead the research?