

# Family and Youth Perspectives in Mental Health Services and Research

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Youth & Caregiver Involvement in Research:

- Grant proposal preparation (all phases - from brainstorming to reviewing final drafts);
- Review proposals for meetings and conferences (e.g., Building on Family Strengths Conference);
- Review questionnaires for clarity, acceptable language;
- Review other research documents, e.g., consent forms;
- Review pre-publication drafts;
- Hired as members of research teams
  - Variety of roles
  - All phases of research

# Shifts in perspectives

## FROM

- Psychological models
- Focus on pathology
- Child saving
- Families primarily as objects of intervention

## • TO

- Biopsychosocial models
- Strengths, empowerment
- Preserving, supporting families
- Families as partners in design, delivery, evaluation of services

# Premises:

- There is often a discrepancy between what youth and families need and want from services and what they get;
- Full participation of youth & parents in planning, implementing, and evaluating services will help reduce this gap.
- Levels: child & family; agency; community; policy.

# Questions about Youth & Family Participation

- Why should we? What's the rationale?
- What do we know about partnership/ collaboration, youth and family participation?
- What are we doing with what we know? What next?

# Rationale for participation

- It's the right thing to do
- Policy mandates:
  - U.S. Special Education (1975); federal mental health funding requirements (1980s & 90s);
  - England (1989) The Children Act
  - Australia?
- Improved outcomes

## Benefits of Family Participation Child and Family Level

- ☞ reduced need for inpatient treatment (Williams, 1988)
- ☞ shorter length of inpatient stay (Byalin, 1988, Williams, 1988)
- ☞ better service coordination (Koren, et al., 1997)
- ☞ increased likelihood that child will return home from out-of-home placement (Tam & Ho, 1996)
- ☞ increased caregiver satisfaction (Stein & Jessop, 1991)

## Benefits of Family Participation: Child and Family Level

- 📄 parents gain increased motivation and caseworkers offer more appropriate services (child welfare)(Rzepnicki, 1987);
- 📄 better classroom grades, school attendance, school retention - “chronically disruptive students”(Aeby, 1998);
- 📄 parents more likely to say that child’s service needs are met “very well” (Koren, et al., 1997)

# What do we know?

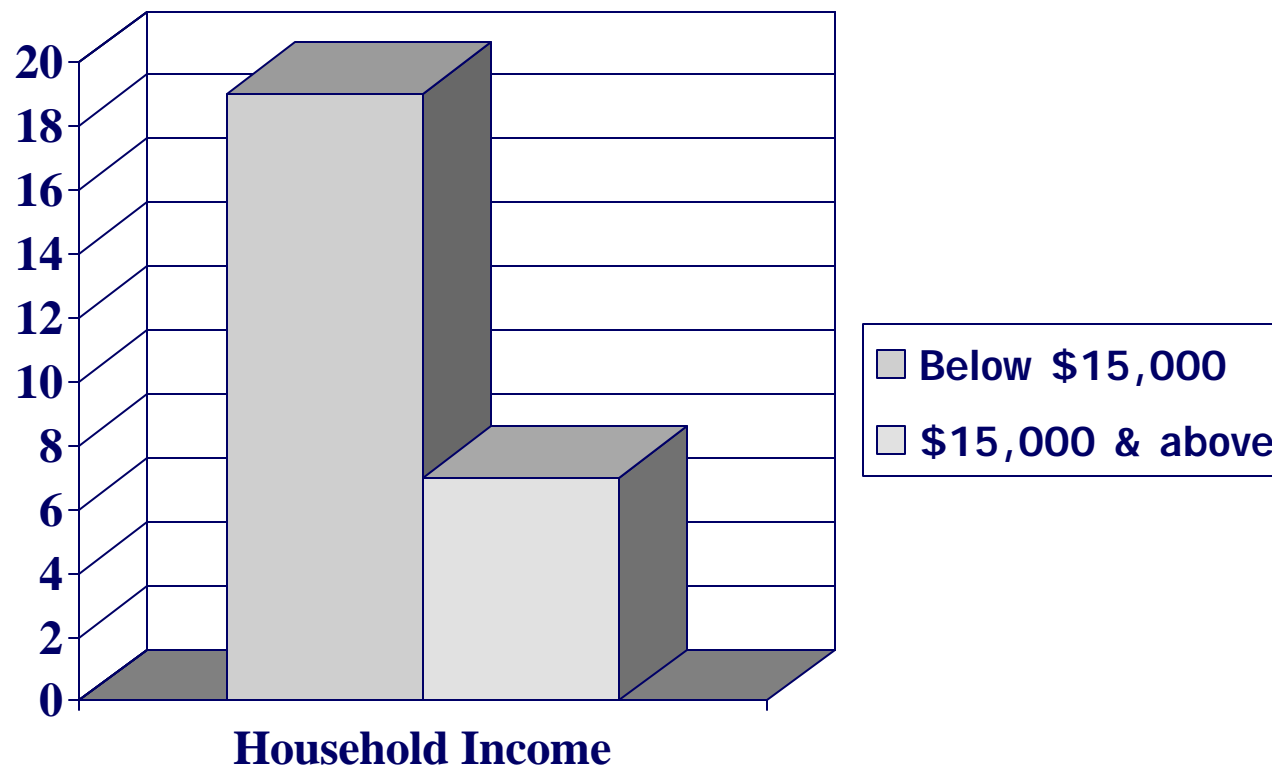
- What families say about service providers;
- What service providers say about families;
- Barriers and supports for collaboration;
- Barriers and supports to full participation in decision-making;

What families say about service providers

# Attitudes: Service Providers

“ My experience is that some providers make assumptions about the family based on a child’s behavior or illness without sufficient knowledge of the home life and history. This often puts parents (who are likely feeling responsible anyway) in the position of feeling like they caused the child’s problems. A real team approach is best when parents are respected and involved from the start. ”

## Lack of Respect is Related to Caregivers' Income:



Walker, J. (2000) Caregivers speak about the cultural appropriateness of services for children with emotional and behavioral disabilities.

## Parents' perceptions of professional behaviors (percent)

<u>Attribute</u>	<u>Very Important</u>	<u>Very Often</u>	<u>Individual Discrepancy</u>
Honesty	87	76	14
Non-blaming	83	72	15
Supports parent	78	60	21
Supports child	78	66	16
Includes in decisions	76	59	21
Accurate evaluation	68	48	26
Information - treatment	67	44	26
Follow-up	67	53	20

Friesen, Koren, & Koroloff (1992)

What service providers say  
about families

# Parent-Blaming Beliefs

- U.S.A.: “Evident for about half of a sample of social workers from the NASW Clinical Registry.” (Johnson, Renaud, Schmidt, & Stanek, 1998);
- Australia: “61.9 % of generic social workers displayed similar beliefs” (Ainsworth & Hansen, 2000).

# Parent-Blaming Beliefs: Questionnaire Items

- ✓ The most frequent cause of disturbed behavior in a child is poor parenting skills;
- ✓ Family dynamics are usually the major cause of children's emotional disorders;
- ✓ Psychiatric problems in children can usually be traced to psychopathological parenting;
- ✓ The most frequent cause of emotional problems in children is emotional dysfunction in parents;
- ✓ The most frequent cause of severe emotional disturbance in children is parenting behavior.

(Johnson, Renaud, Schmidt, & Stanek, 1998)

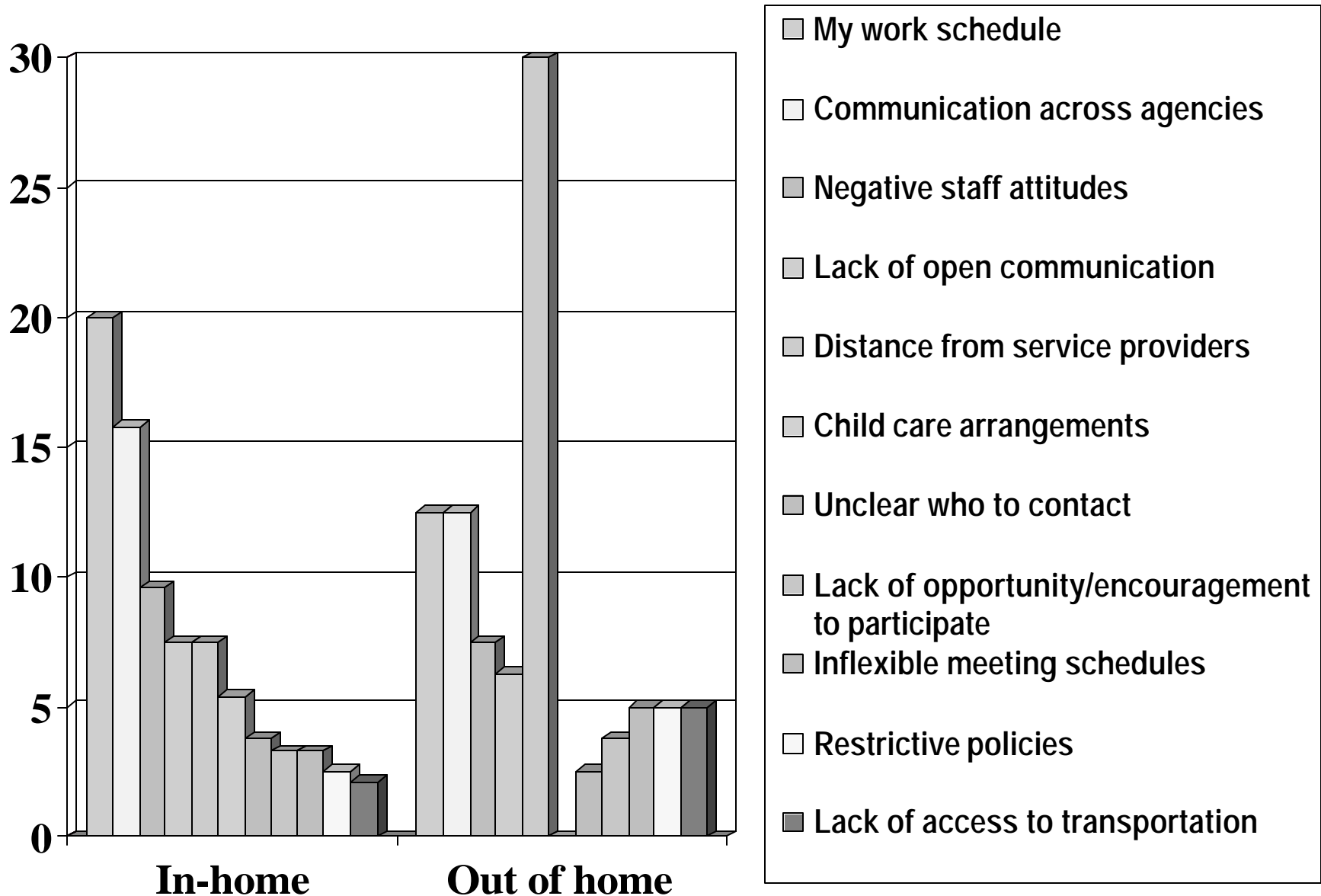
# Components of Collaboration

Factors related to easiest/most difficult professional:

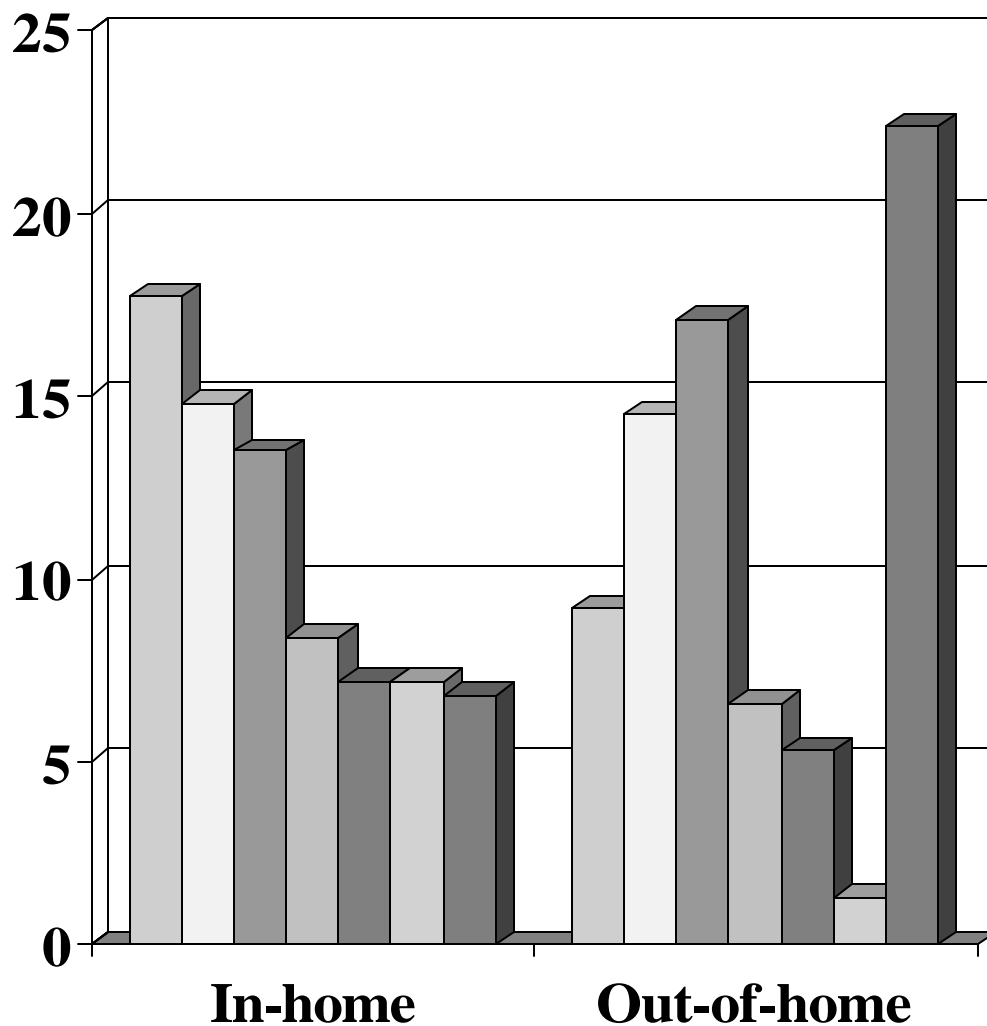
- Supportive understanding
- Accessing services
- Sharing information
- Utilizing feedback

(DeChillo, Koren, & Schultze, 1994)

# Most Difficult Barriers to Participation



# Most Important Supports for Participation



- Treated me with dignity and respect
- Made me feel my participation was important
- Provided a contact person
- Communicated with all relevant family members
- Encouraged all family members to participate
- Supported transitions in/out of services/programs
- Notified me of concerns

# What are we doing? \*

- Helping families organize at local, state, national levels;
- Expanding roles of youth, families, youth & family organizations;
- Identifying examples of good practice;
- Training, dissemination (Building on Family Strengths Conference);
- Policy stimulus, policy implementation research.

\* National network of researchers, advocates, policy-makers, service providers

# Family Organizing

- Supported formation of Federation of Families for Children's Mental Health, Alexandria Virginia ([www.ffcmmh.org](http://www.ffcmmh.org));
- Collaborate with National Alliance for the Mentally III
- Provide opportunities for organizing at national conference (e.g., Native American families, youth);
- Use web page and bulletin to promote networking.

## Expanded Roles: Youth & Family Agency Level

Family members serve in a variety of outreach and support roles, as:

- first point of contact for new children and families;
- information giver and supporter in intake, treatment/educational planning meetings;
- “system guide” and navigator in complex service system;
- member of program evaluation team.

## Expanded Roles: Youth & Family Organizations

- Provide information and support to family members and youth;
- Service delivery (hire, supervise case managers, family advocates);
- Participation in planning bodies, service and system-level evaluations;
- Stimulate needed policy change.

## Find & Disseminate Examples of Good Practice

- “Promising Practices” series
  - Family-Provider Collaboration
  - Early Childhood Mental Health
  - Family-friendly Respite services
- “The most useful thing a service provider ever said to me was ...”
- *Focal Point* (collaboration, “enrichment”, families as policy-makers, work-family issues)

## The most useful thing a provider ever said:

- “It’s not your fault! You are not powerful enough to have caused the kinds of problems your child has”
- “Believe in your instincts. You’re the expert on your child.”
- “I value your input.”
- “What do you need for yourself?”
- “I don’t know.”
- “I don’t know what caused this problem, but I’m willing to work with you to make things better for your son and family.”

## Advocacy Focus: Youth & Family Participation

- ✓ Hire, train, and support family members in outreach & support roles (with evaluation);
- ✓ Acknowledge and support (\$) family organizations as key to improving access and acceptability of services.
- ✓ Full participation in evaluation, review of services at all levels; includes training in evaluation principles, research methods.
- ✓ Listen to youth and families.