Supporting and Engaging Families of Young Children with Disabilities: Eight Recommendations

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Family adaptation

• Having a child with a disability forces families to make alterations and accommodations in almost every aspect of life
• A primary goal of early learning programs ought to be helping parents successfully adapt
• We can help families adapt by
  – Using family-centered principles as the foundation for all that we do
  – Engaging in specific practices designed to promote desired family outcomes
  – Expecting programs to demonstrate benefit for families
Programs serving young children should lead to improved outcomes for both children and families.

**Family**
- Needs
- Concerns
- Resources
- Priorities
- Goals

**Child**
- Developmental Status
- Functional Abilities
- Disability Type
- Learning Style

**Early Intervention**
- Child-Focused Services
- Family-Focused Services

**Outcomes**
- Child Outcomes
- Family Outcomes
Embedding family-centered principles in program activities can lead to improved family outcomes

**Family-Centered Principles**
- Shared philosophy
- Families as partners
- Focus on strengths
- Family choice of goals and services
- Collaboration and coordination of service
- Effective communication
- Flexibility
- Community-based

**Program Activities**
- Referral and intake
- Determining eligibility
- Child assessment
- Family assessment
- Team meetings and decision-making
- Service provision and coordination
- Parenting practices
- Community support

**Family Outcomes**
- Understand child’s abilities and special needs
- Know rights and advocate effectively
- Help child develop and learn
- Have support systems
- Access the community
Example: Key questions about involving families in child assessments

- Do we try to determine family preferences about the purpose and format of child assessment, as well as their wish to be involved?
- Does the family’s perception of child needs and family routines determine the focus of assessment?
- Do we listen to family preferences in determining settings, times, and parent roles in child assessment?
- Do we address children’s strengths in the assessment process?
- Do we accept and use parents’ reports of their children’s abilities?
- Do we convey assessment information in a sensitive and jargon-free fashion?
RECOMMENDATION 1

Identify and implement strategies to support families who are wondering if their child’s development or behavior is progressing as expected.

- **Problem:** Families often experience delays and frustrations in validating concerns
- **Goal:** Enable earlier entry into early intervention
Patterns of early identification
(Bailey et al., *Pediatrics*, 2004)
Identifying children with fragile X
(Bailey et al., *Pediatrics*, 2009)
RECOMMENDATION 2

Ask state early intervention programs (0-3 years) to report outcomes experienced by families of children with disabilities

- **Problem**: Currently states are only expected to report on perceived helpfulness of EI
- **Goal**: Emphasize that benefit to families is as important as benefit to children.
A family outcome is different from a family’s perceptions of services

- My family was given information about our rights
- The information we received about family rights was understandable
- The information we received from Early Intervention helped us understand our rights
- We know our rights and what to do if we are not satisfied.
Recommended Family Outcomes
(ECO Center, Bailey et al., 2006)

• Families know their rights and advocate effectively for their child.
• Families understand their child's abilities and special needs
• Families help their child develop and learn.
• Families have the supports they want.
• Families participate in desired services and activities that are available to all families in their community.
ECO Family Outcomes and OSEP APR Requirements [Part C]

**ECO**
- Understand their child’s strengths, abilities, and special needs
- Know their rights and advocate effectively for their children
- Help their children develop and learn
- Have support systems
- Access desired services, programs, activities in their community

**OSEP**
- Percent of families participating in Part C who report that EI services have helped the family
  - Know their rights
  - Effectively communicate their children’s needs
  - Help their children develop and learn
RECOMMENDATION 3

Expand the vision of preschool programs to promote family outcomes.

• **Problem:** Preschool programs are less likely than infant-toddler programs to embrace family services, and outcomes are not required to be reported

• **Goal:** Assure continuity of family-centered principles, practices and results, birth through kindergarten (and hopefully beyond!)
APR Requirements for Part B, Section 619 Preschool Programs

• % of parents who report that schools facilitated parent involvement as a means of improving services and results for children with disabilities

• no specific indicator for preschool, nor the expectation for examining preschool family involvement separately from Part B (school-aged children)
Recommended Head Start (HS) Program Performance Measures (ACYF, 1998)

- **Objective 2**: Strengthen families as primary nurturers of their children
  - Demonstrate improve parenting skills
  - Improve their self-concept and emotional well-being
  - Make progress toward educational, literacy, and employment goals

- **Objective 4**: Link children and families to needed community services
  - With social service agencies to obtain needed services
  - With educational agencies to obtain needed services
  - With health care services to obtain needed care
  - Secure child care in order to work, go to school, or gain employment
RECOMMENDATION 4

Support the development and evaluation of personnel development and TA to improved capacity for engaging and supporting families.

• **Problem**: Professionals receive comparatively little training in how to work with families, and programs often segment family services rather than integrated across all activities.

• **Goal**: Professionals understand the importance of family-centered practices and implement them consistently.
RECOMMENDATION 5

Support research on families, especially for families of children with disabilities

- **Problem**: Almost all research programs in IES and Head Start emphasize or restrict funding to child-focused research.

- **Goal**: Identify evidence-based practices most likely to promote family engagement and adaptation.
RECOMMENDATION 6

Create a national data coordinating center on family outcomes and factors related to outcome attainment.

- **Problem**: States collect and report data, but no mechanism exists to integrate or use these data.

- **Goal**: Use national data and assist states to use their own data to answer important questions about factors associated with variability in family outcomes.
RECOMMENDATION 7

Conduct a national study of the status of parent involvement and family support programs

• **Problem**: Extraordinary variability exists in family support programs, and little is known about the relative costs and benefits of each

• **Goal**: Determine the cost, quality, and outcomes of parent involvement and family support programs.
RECOMMENDATION 8

Convene a national summit to reach cross-agency consensus on the goals and outcomes of programs serving families with young children.

• **Problem**: Agencies vary in nature and extent of expectations for family involvement and family outcomes

• **Goal**: A unified commitment to supporting family well-being and adaptation