

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

Don Bailey

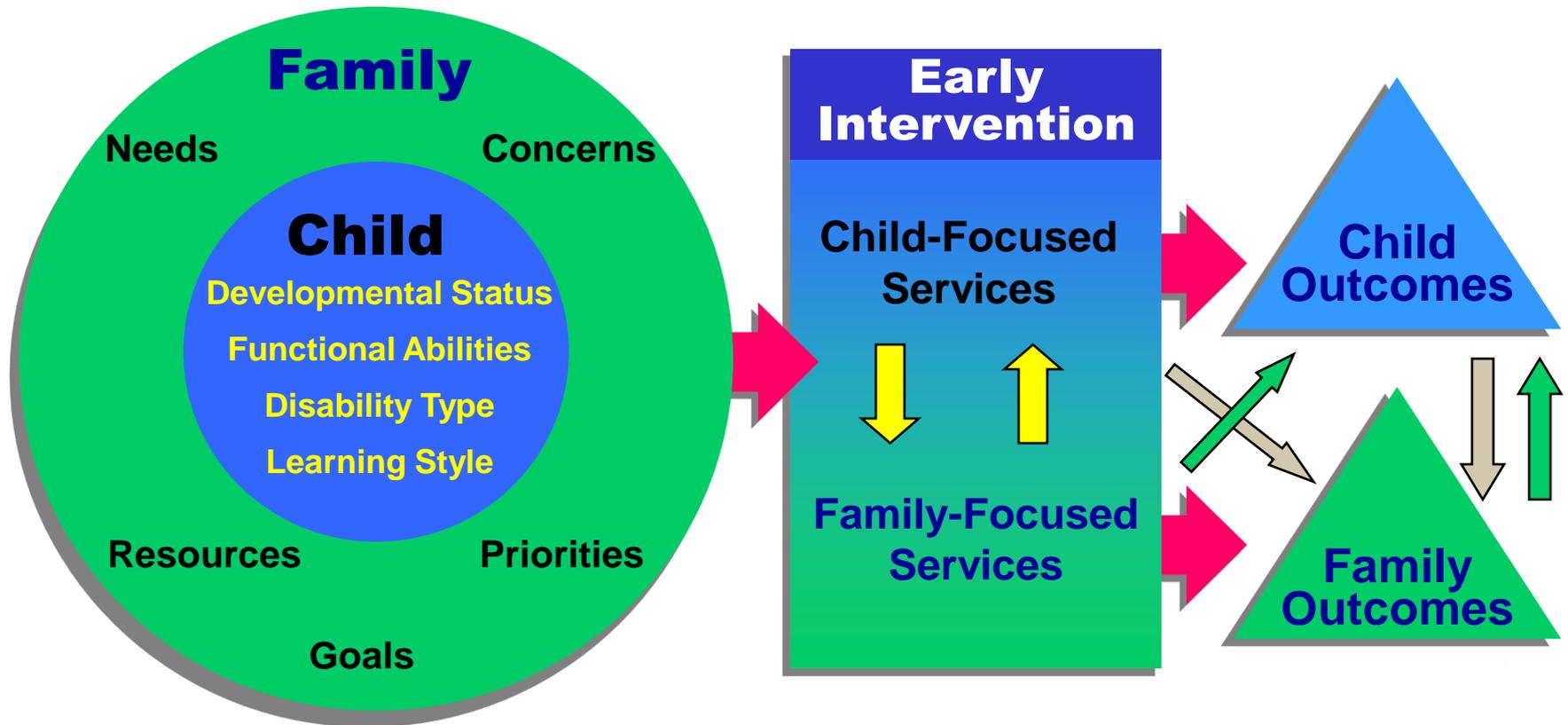
USDE and DHHS Listening and Learning Panel on Family Engagement

Orlando, FL
May 4, 2010

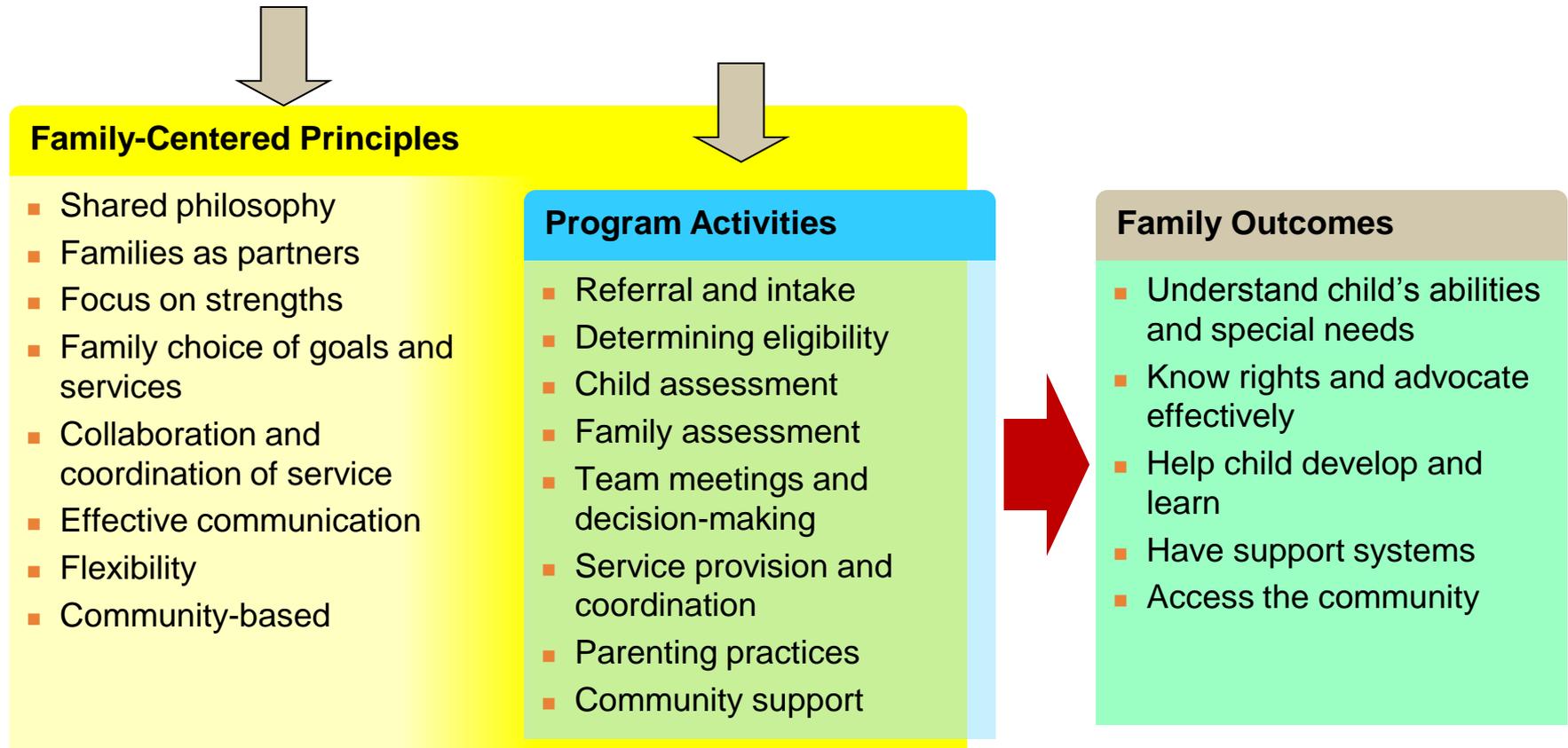
Family adaptation

- 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



Embedding family-centered principles in program activities can lead to improved family outcomes



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?

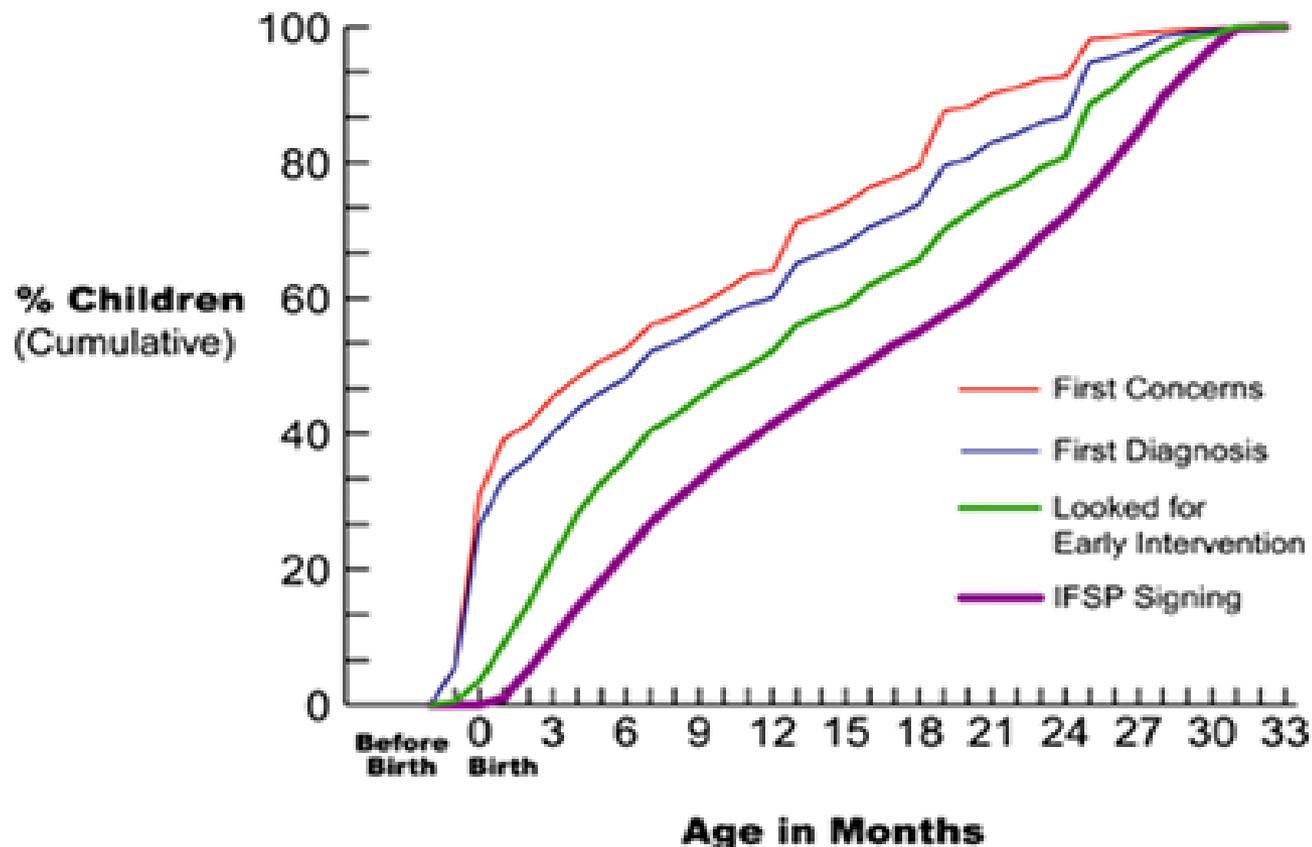
RECOMMENDATION 1

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

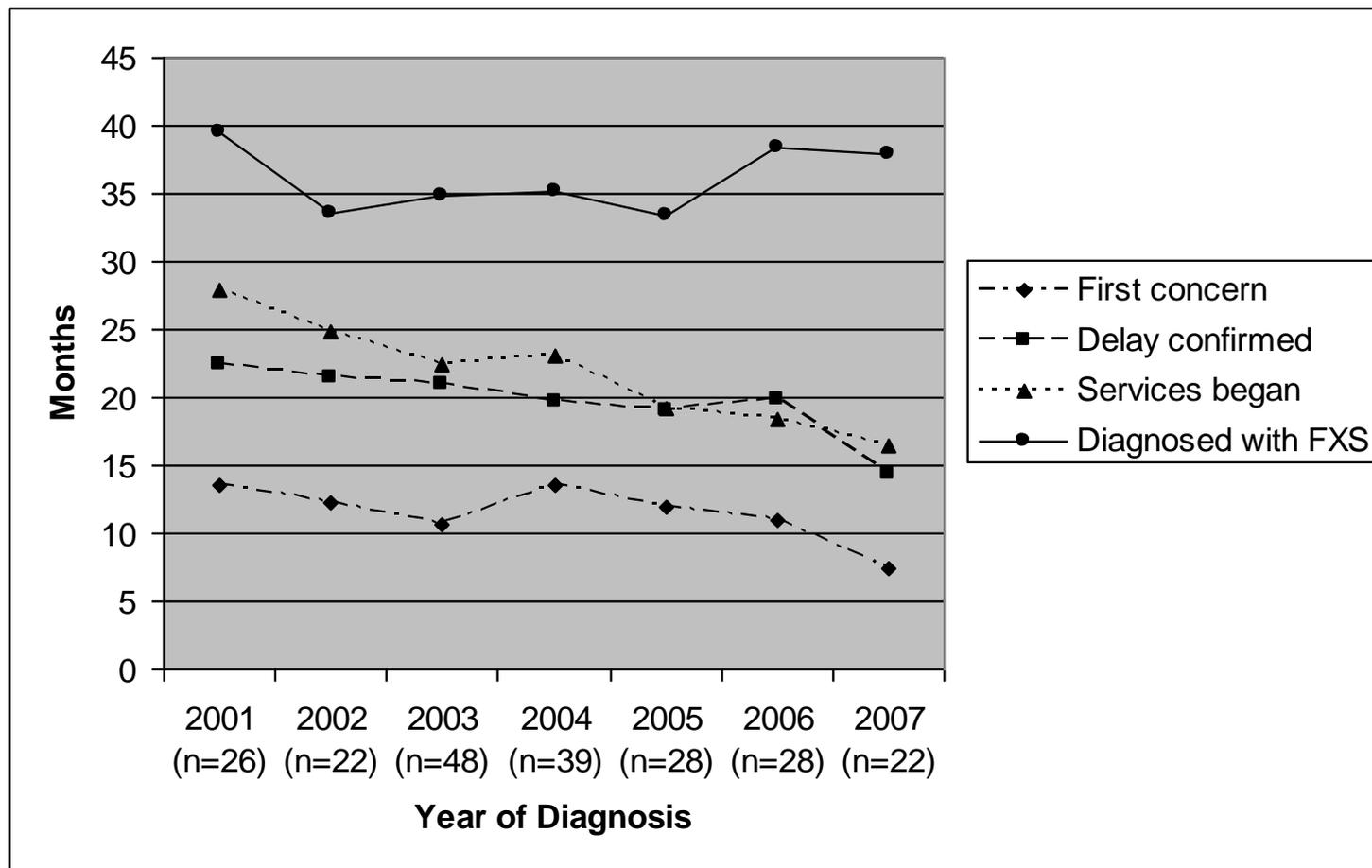
- Problem: Families often experience delays and frustrations in validating concerns
- Goal: Enable earlier entry into early intervention

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