



Linking Family-Centered Principles with Practices and Outcomes

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RTI International



The Early Childhood Outcomes Center

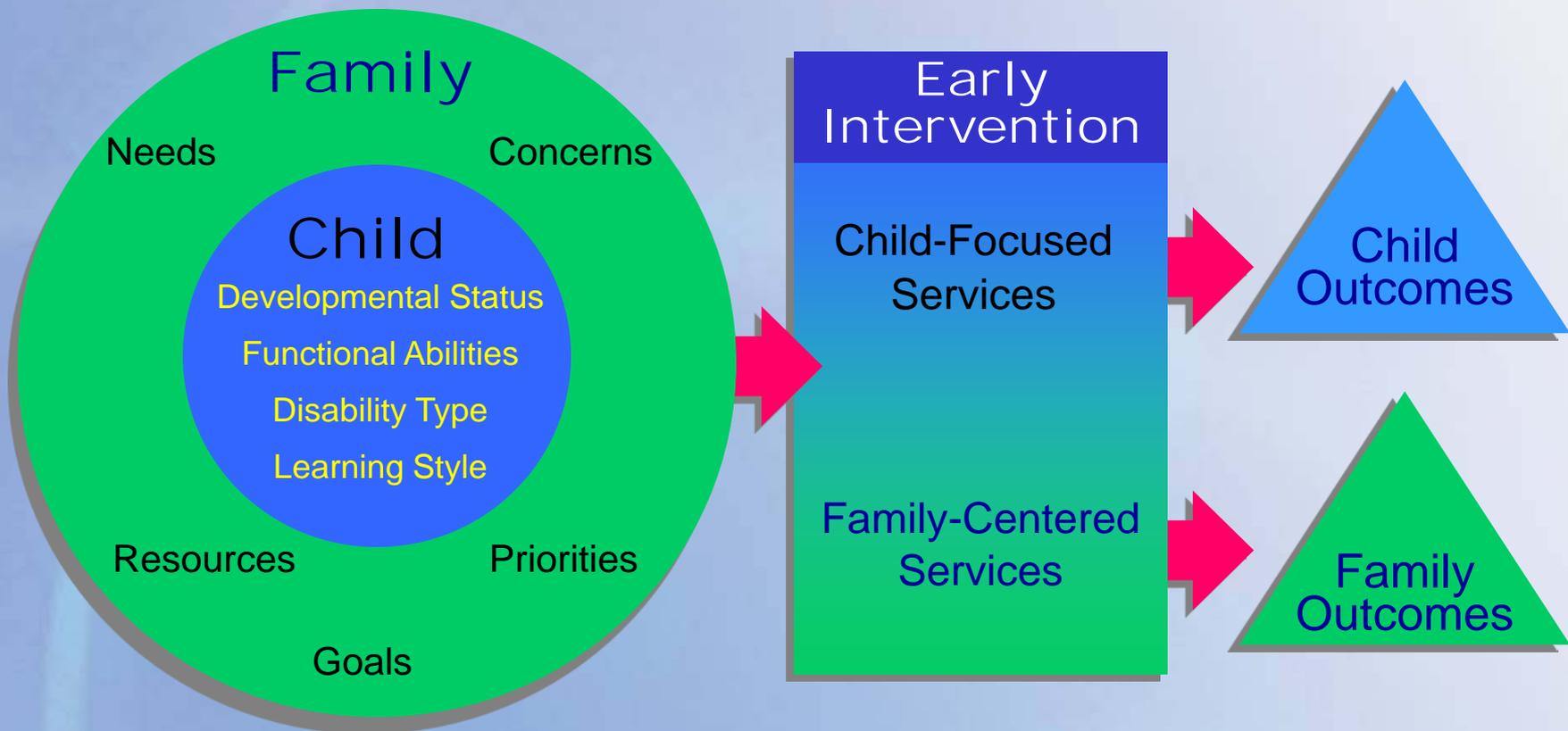


- Funded since 2003 by U.S. Department of Education
- Kathy Hebbeler (SRI International), Principal Investigator
- Partnership among multiple universities and research institutes
- I and my colleagues at RTI have been leading the work on family outcomes

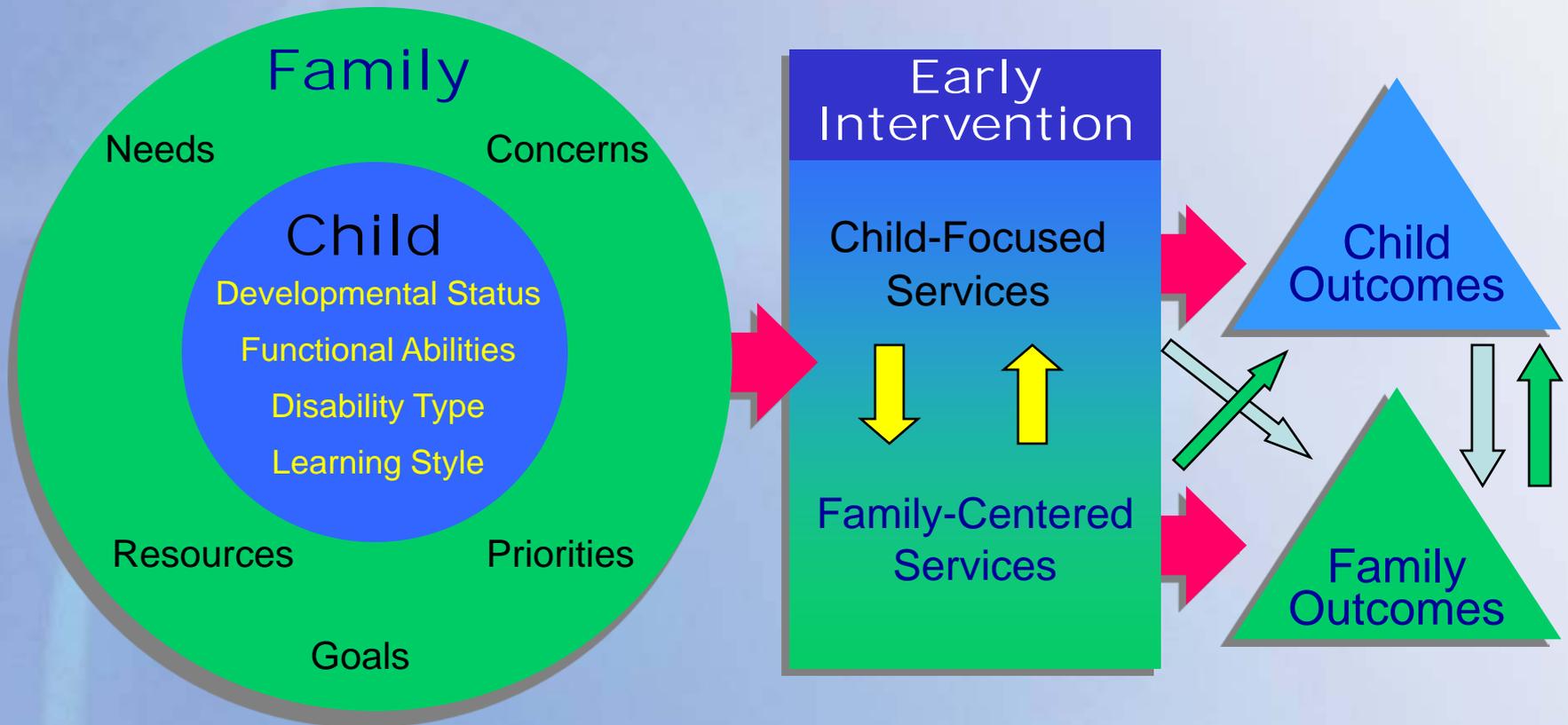
Goals

- Provide a rationale for assessing family outcomes in early intervention
- Discuss challenges in assessing family outcomes
- Describe the ECO family outcomes and how they differ from those being required by the federal government
- Describe the Family Outcomes Survey, including recent revisions to the scale
- Discuss future opportunities for research and improved practice with respect to family outcomes

Components of early intervention



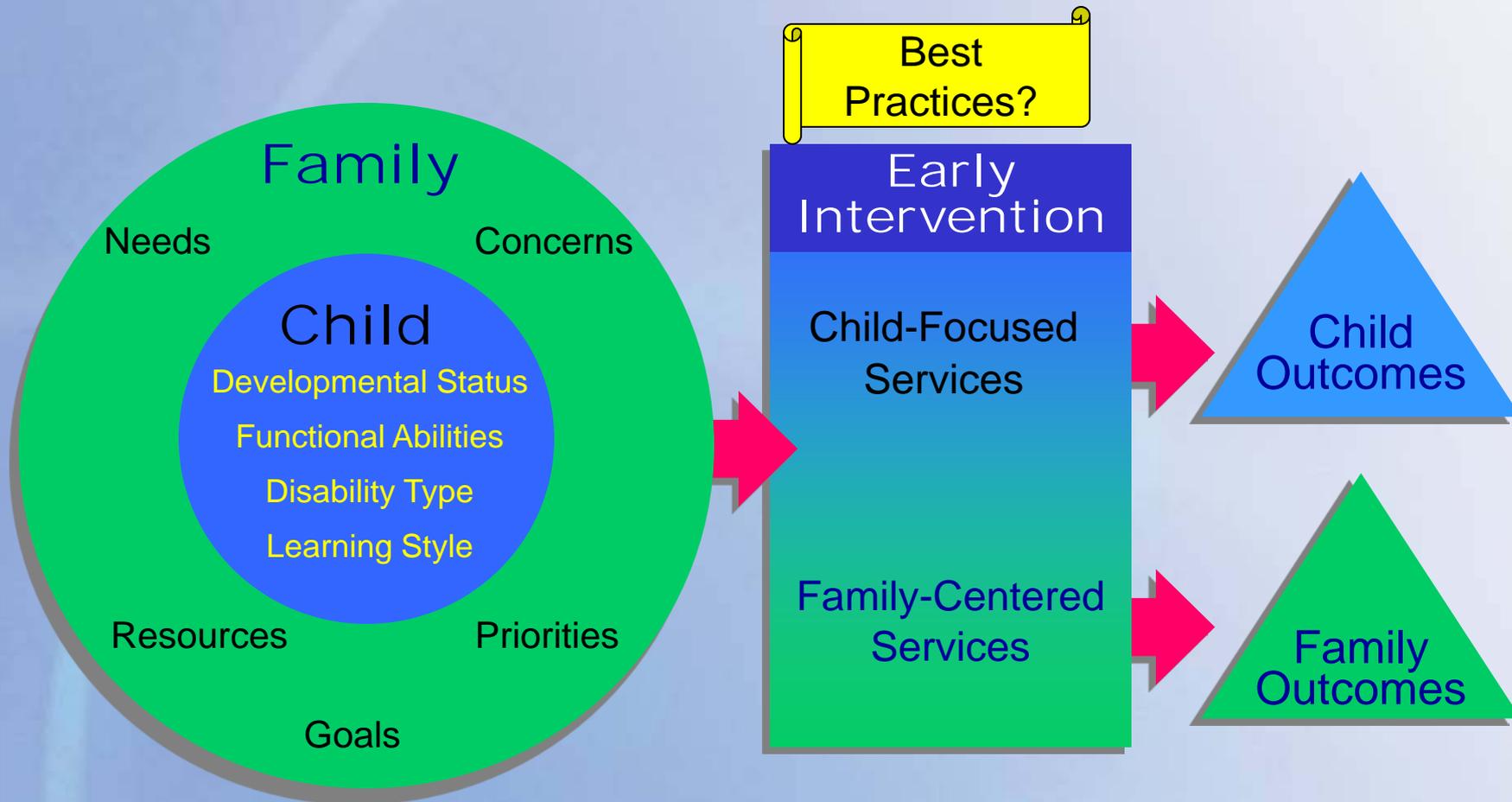
Child and family services and outcomes are often linked



Family-Centered Practices

- Enjoy almost universal endorsement in the professional literature
- Are endorsed by almost all professional organizations representing professionals who work with young children with disabilities or special health care needs
- Are supported by research clearly documenting the relationship between FC-practices and a range of outcomes for children and families
- Are not consistently provided, because of factors such as leadership, training, attitudes, resources, and priorities
- Resources, training, and supervision will be critical
- In an accountability framework, documenting family outcomes can play a role in improving F-C practices

One approach to accountability focuses on practices



There is general agreement on the principles that underlie a family-centered approach

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

Family-centered principles should be embedded in all program activities

Family-Centered Principles

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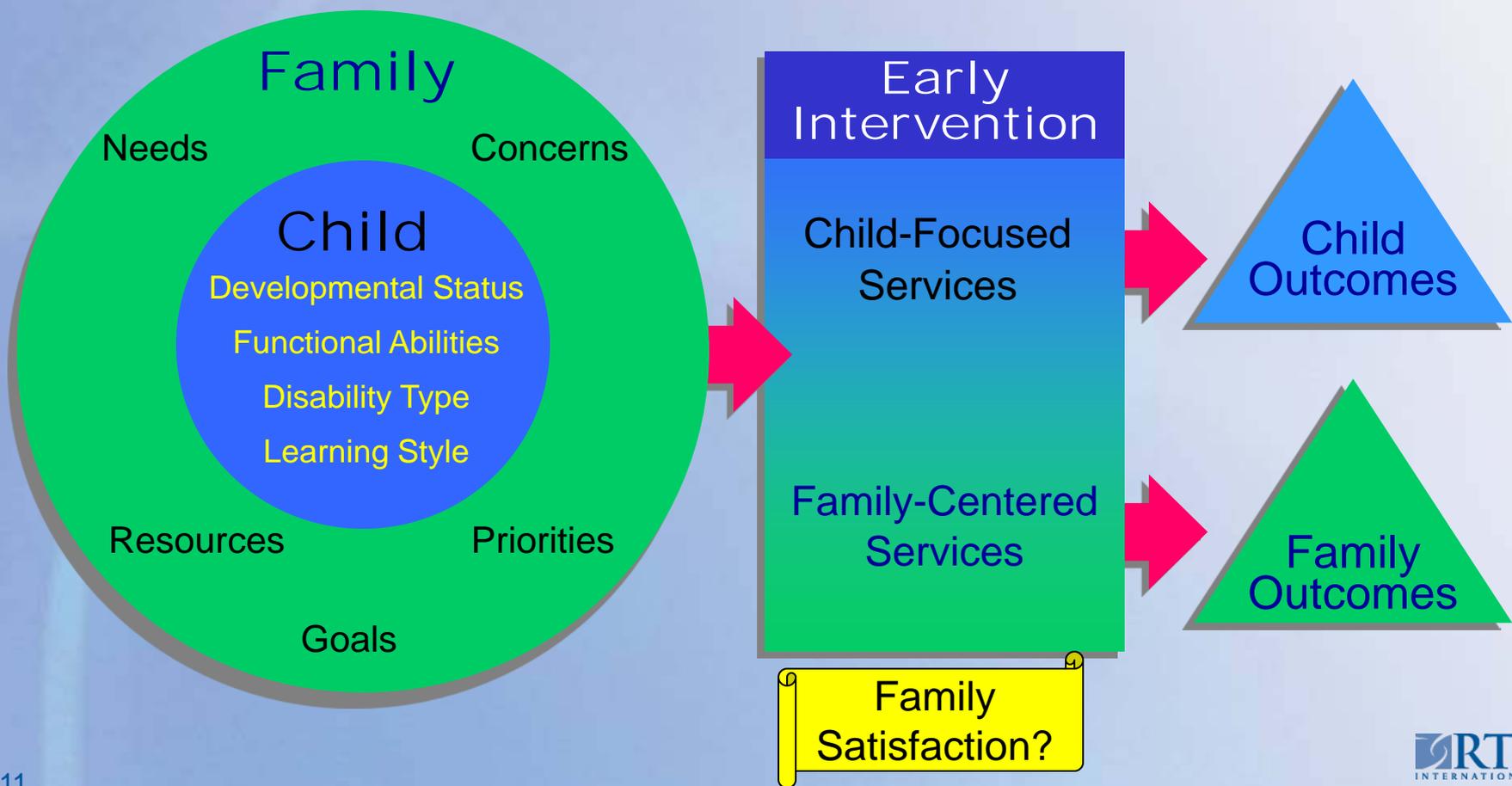
Program Activities

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

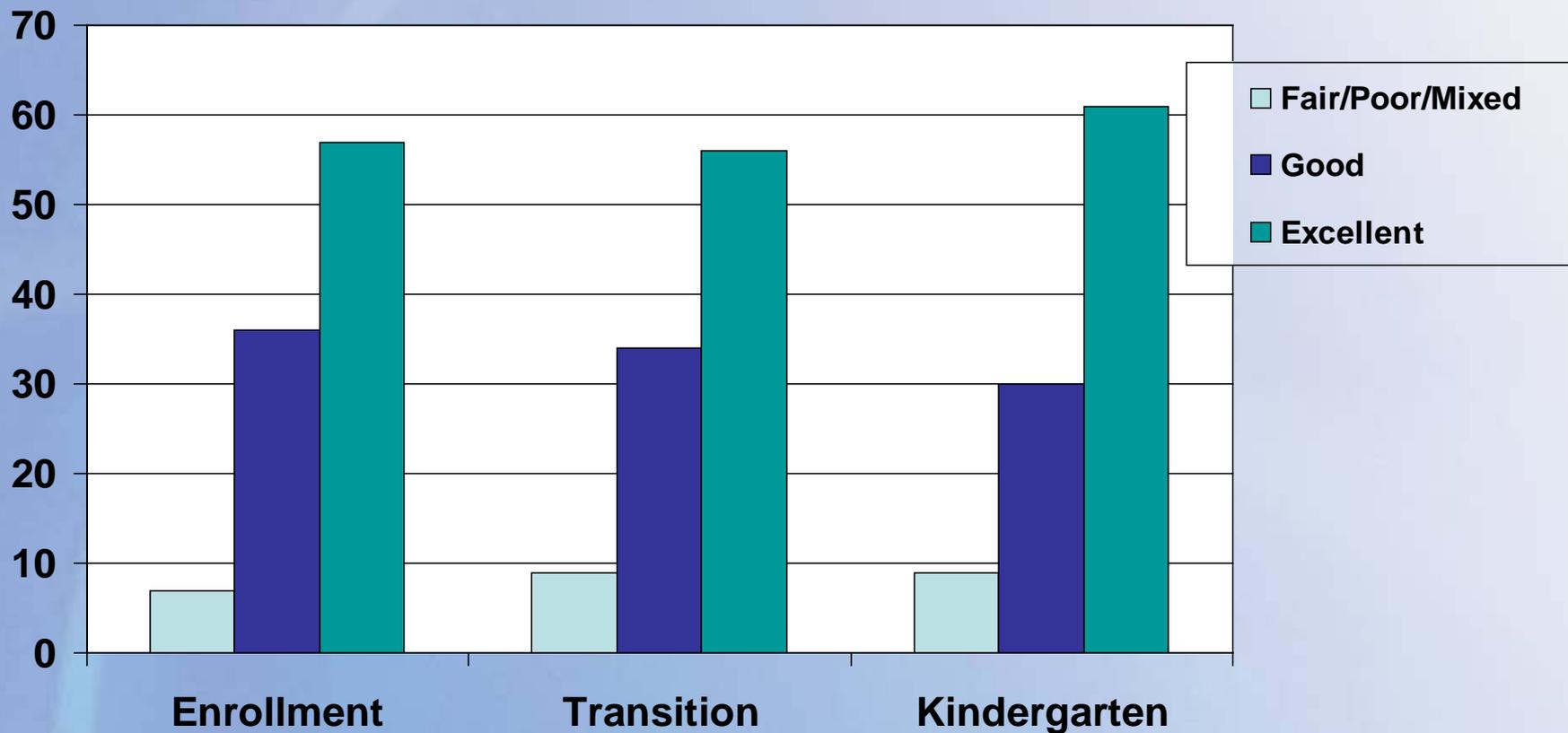
Example: Involving families in child assessments

- 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?

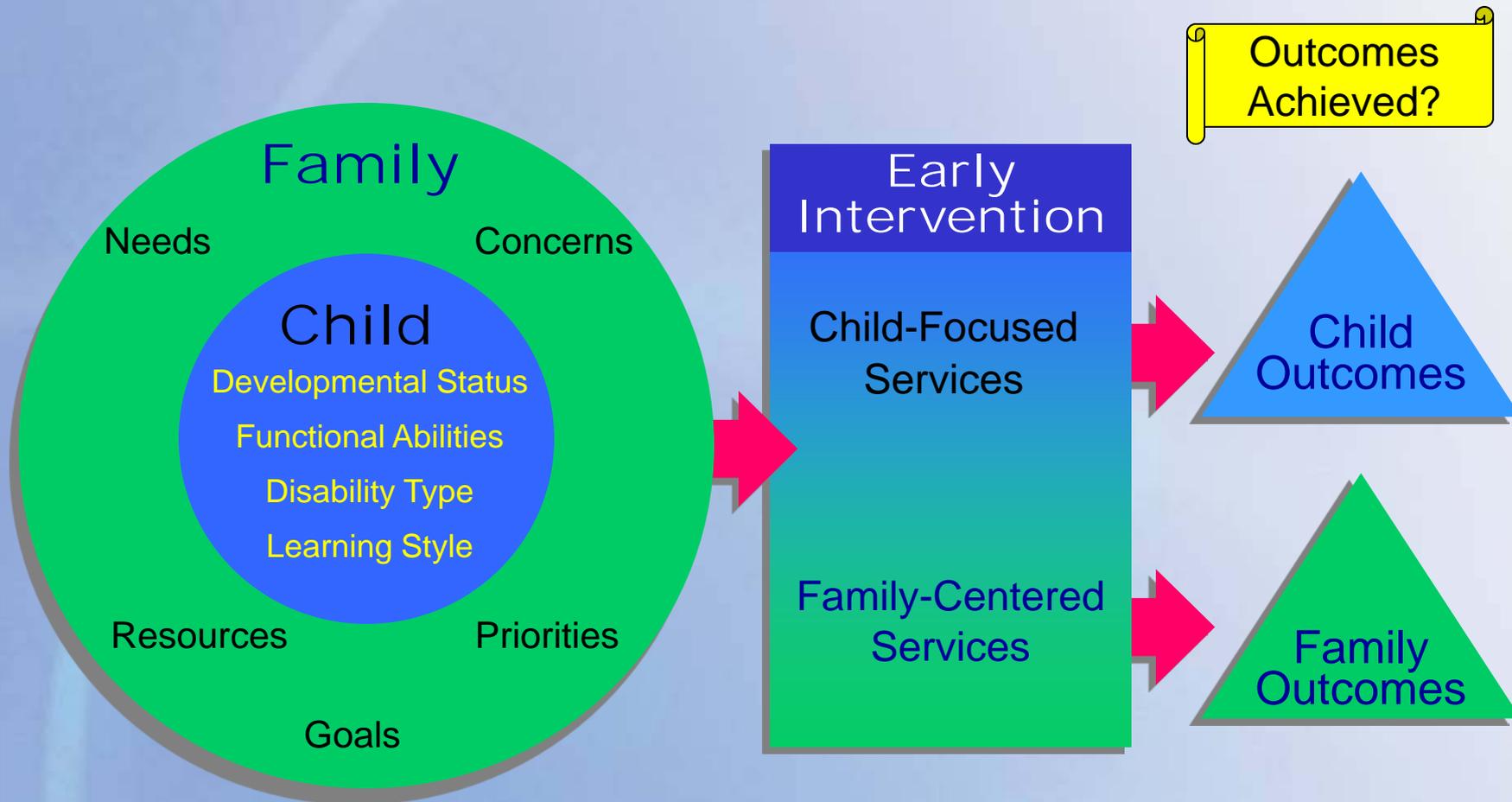
A second approach to accountability focuses on satisfaction



Perceived quality of help received by families



A third approach to accountability determines whether outcomes are achieved



A family outcome is different from a family's perceptions of services

- My family was given information about our rights in our native language
- The information we received about family rights was clear
- We are satisfied with the information we received about our rights
- **We know our rights and what to do if we are not satisfied.**

Documenting family outcomes has been stymied by lack of agreement on what and whether family outcomes should be assessed

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Family Outcomes



History of accountability and outcome assessment in U.S. EI programs

- When EI was first established in 1984, the federal government did not require states to report outcomes
- However, after 2000, all federal agencies were examined under a new law calling for “accountability for results.”
- Because EI had no long-term data about outcomes, it was rated as “Results Not Demonstrated.”

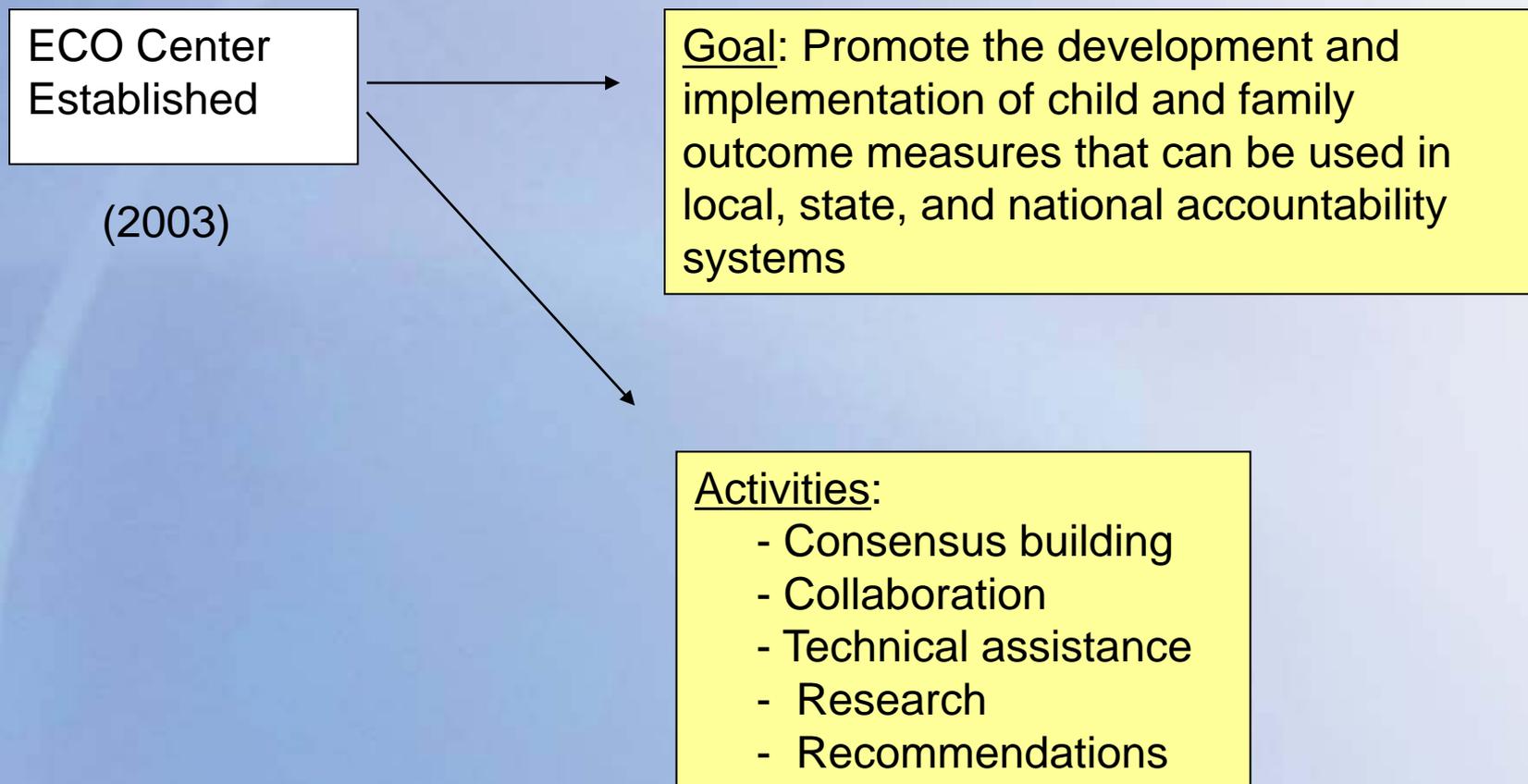
History of accountability (continued)

- All of a sudden, people began to worry that EI might lose its support and funding
- This forced the federal government to ask states to begin reporting data on outcomes for children and families
- Two general “indicators” were specified:
 - All infants and toddlers with disabilities will exhibit improved and sustained functional abilities
 - All families will report that EI services have increased their capacity to enhance their child’s development

Problems

- The indicators were just general statements and did not specify outcomes
- But, there was no national agreement on what outcomes are important
- The federal government had no authority to require states to use specific measurement tools, only to report certain types of data
- State and local programs were very worried about being accountable for outcomes
- Because EI is individualized, many questioned the ability to identify common outcomes for all children and families
- How can an outcome system be developed under these circumstances?

Early Childhood Outcomes (ECO) Center



Using national consensus methods and ‘iterative social validation,’ the ECO center recommended 5 family outcomes

Family-Centered Principles

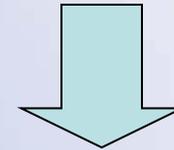
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Family Outcomes

- Understand child’s abilities and special needs
- Know rights and advocate effectively
- Help child develop and learn
- Have support systems
- Access the community



Characteristics of families who know their rights and can advocate for their child

- ❑ Know rights and responsibilities related to services
- ❑ Know where to go for services and other supports
- ❑ Know about different service options and providers
- ❑ Feel comfortable talking with professionals or asking questions
- ❑ Know how to use the Internet or other information sources
- ❑ Can participate effectively in team meetings
- ❑ Advocate for services they feel are important
- ❑ Know what to do if needed services are not being provided

Characteristics of families who understand their child's abilities and special needs

- ❑ Know expectations for typical development
- ❑ Are aware of the next developmental abilities that could be encouraged
- ❑ Understand their child's learning style and preferences
- ❑ Can observe their child's behavior and notice whether changes occur
- ❑ Know about their child's special risk factors, conditions, or disability
- ❑ Know about recommended interventions and practices
- ❑ Know how to access information about child development or their child's special needs

Characteristics of families who can help their child develop and learn

- ❑ Know and use styles of effective parenting
- ❑ Provide a nurturing and stimulating environment
- ❑ Help child participate in family routines and activities
- ❑ Use special techniques to enhance learning or manage behavior
- ❑ Modify the home environment or routines
- ❑ Help their child use special adaptive equipment

Characteristics of families who have the supports they want

- Feel supported in raising their children
- Maintain friendships and make new friends
- Have professionals providing the support the family wants
- Able to talk to friends and neighbors about disability
- Are able to participate in desired neighborhood activities, family functions, or going out with spouse or friends
- Meet and get to know other families of children with disabilities
- Have neighbors, friends, or family who can provide help

Characteristics of families who participate in desired community activities and services

- Have quality childcare and babysitting
- Satisfactory medical and dental care
- Have acceptable and trustworthy respite care
- Are able to participate in religious, recreational or educational activities
- Participate in parent organizations or support groups relevant to their child's disability and their family's style and priorities

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

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)

ECO Scale: *Family Outcomes Survey*

- A self-report instrument completed by families
- Items developed through extensive lit review and feedback from parents and professionals
- Revised version recently published (2011)
 - New nominations, Q-sorts, consensus building, pilot testing
 - Validation with 265 families in Illinois and Texas
 - Confirmatory Factor Analysis (CFA) and Item Response Theory (IRT) used to finalize items and validate clusters
- Posted on website (www.the-eco-center.org)
- 11 translations available so far

The revised FOS

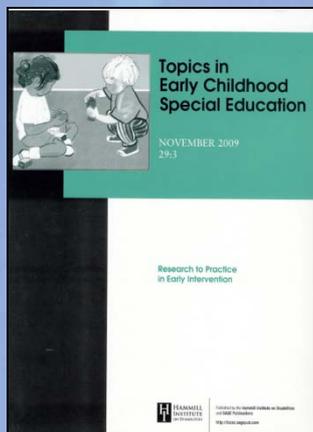
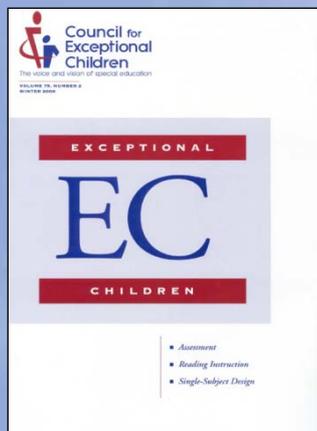
FAMILY OUTCOMES SURVEY		Section B: Helpfulness of Early Intervention				
Instructions: Section A of the Family Outcomes Survey focuses on the ways in which you support your child's needs. For each statement below, please select which option best describes your family right now: not at all, a little, somewhat, almost, or completely.		Not at all	A little	Somewhat	Almost	Completely
Outcome 1: Understanding your child's strengths, needs, and abilities						
1.	We know the next steps for our child's growth and learning.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2.	We understand our child's strengths and abilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.	We understand our child's delays and/or needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4.	We are able to tell when our child is making progress.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outcome 2: Knowing your rights and advocating for your child						
5.	We are able to find and use the services and programs available to us.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6.	We know our rights related to our child's special needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.	We know who to contact and what to do when we have questions or concerns.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8.	We know what options are available when our child leaves the program.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9.	We are comfortable asking for services & supports that our child and family need.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outcome 3: Helping your child develop and learn						
10.	We are able to help our child get along with others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11.	We are able to help our child learn new skills.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12.	We are able to help our child take care of his/her needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13.	We are able to work on our child's goals during everyday routines.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outcome 4: Having support systems						
14.	We are comfortable talking to family and friends about our child's needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15.	We have friends or family members who listen and care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16.	We are able to talk with other families who have a child with similar needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17.	We have friends or family members we can rely on when we need help.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18.	I am able to take care of my own needs and do things I enjoy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outcome 5: Accessing the community						
19.	Our child participates in social, recreational, or religious activities that we want.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20.	We are able to do things we enjoy together as a family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21.	Our medical and dental needs are met.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22.	Our child care needs are met.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23.	Our transportation needs are met.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24.	Our food, clothing, and housing needs are met.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Revised helpfulness items

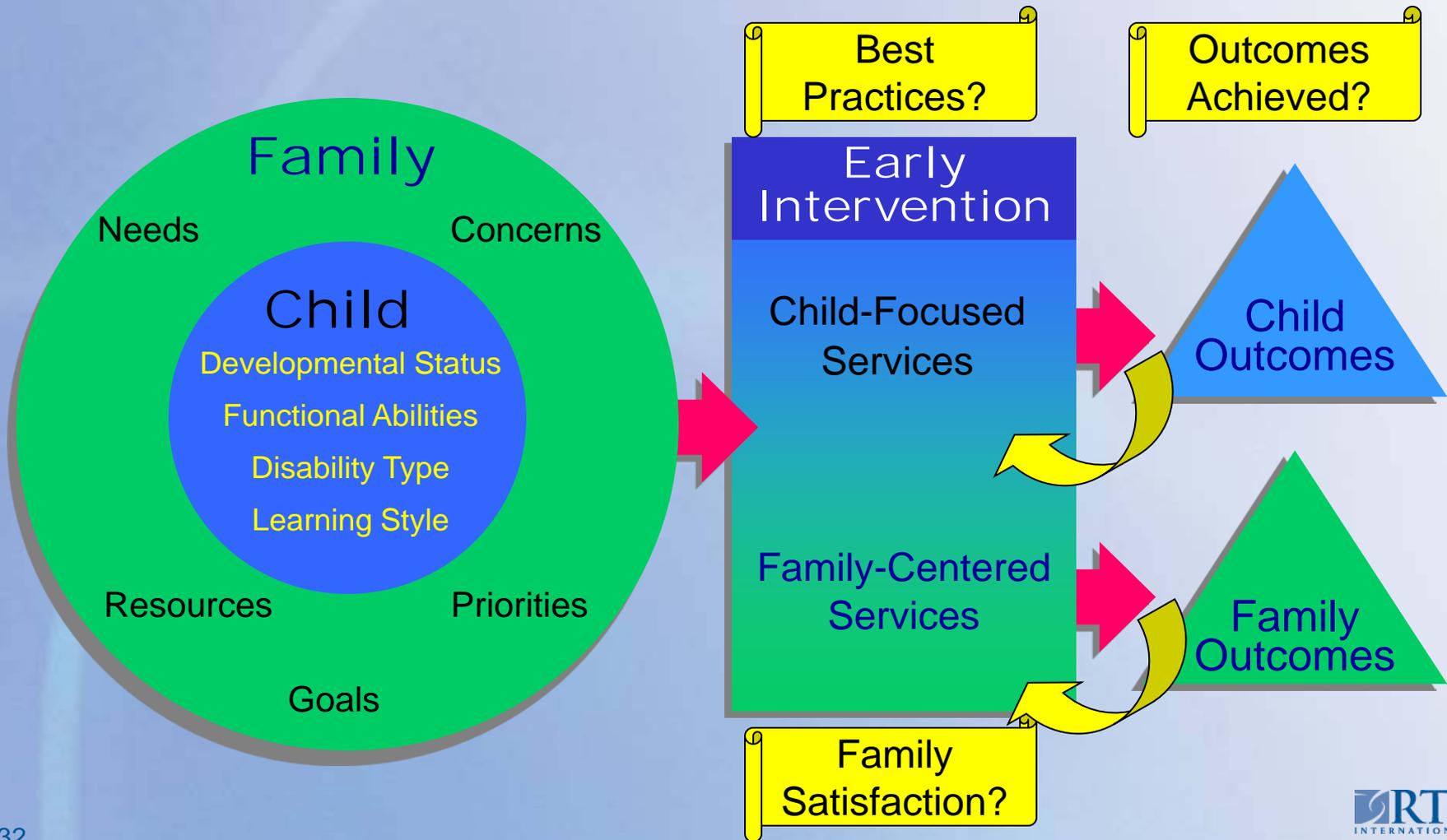
FAMILY OUTCOMES SURVEY Section B: Helpfulness of Early Intervention		Not at all helpful	A little helpful	Somewhat helpful	Very helpful	Extremely helpful
Instructions: Section B of the Family Outcomes Survey focuses on the helpfulness of early intervention. For each question below, please select how helpful early intervention has been to you and your family over the past year: Not at all helpful, a little helpful, somewhat helpful, very helpful, or extremely helpful.						
Knowing your rights						
How helpful has early intervention been in...						
1.	giving you useful information about services and supports for you and your child?	<input type="radio"/>				
2.	giving you useful information about your rights related to your child's special needs?	<input type="radio"/>				
3.	giving you useful information about who to contact when you have questions or concerns?	<input type="radio"/>				
4.	giving you useful information about available options when your child leaves the program?	<input type="radio"/>				
5.	explaining your rights in ways that are easy for you to understand?	<input type="radio"/>				
Communicating your child's needs						
How helpful has early intervention been in...						
6.	giving you useful information about your child's delays or needs?	<input type="radio"/>				
7.	listening to you and respecting your choices?	<input type="radio"/>				
8.	connecting you with other services or people who can help your child and family?	<input type="radio"/>				
9.	talking with you about your child and family's strengths and needs?	<input type="radio"/>				
10.	talking with you about what you think is important for your child and family?	<input type="radio"/>				
11.	developing a good relationship with you and your family?	<input type="radio"/>				
Helping your child develop and learn						
How helpful has early intervention been in...						
12.	giving you useful information about how to help your child get along with others?	<input type="radio"/>				
13.	giving you useful information about how to help your child learn new skills?	<input type="radio"/>				
14.	giving you useful information about how to help your child take care of his/her needs?	<input type="radio"/>				
15.	identifying things you do that help your child learn and grow?	<input type="radio"/>				
16.	sharing ideas on how to include your child in daily activities?	<input type="radio"/>				
17.	showing you how to work with your child when the service providers aren't there?	<input type="radio"/>				
18.	giving you chances to practice skills and learn from a service provider?	<input type="radio"/>				
19.	working with you to know when your child is making progress?	<input type="radio"/>				

What have we learned from our research using the FOS?

- Robust psychometric properties
- Wide acceptance among states
- Families generally reported positive outcomes
- Family-centered practices are associated with outcomes
- Race/ethnicity and language continue to be associated with outcomes
- International interest



Outcome data should be fed back into the program to improve practices, ultimately to improve outcomes



Conclusions

- Family-centered care is not a fleeting phenomenon, but an enduring set of guiding principles for all professionals working with young children with disabilities
- The factors associated with variable implementation of FC practices need to be identified and addressed
- The mechanisms or pathways by which FC practices lead to improved outcomes need to be modeled and understood
- Whether and how programs should be held accountable for family benefit stands as a formidable challenge for our field, but one that must be addressed if we are to fulfill the implicit and explicit expectations of services provided prior to kindergarten.