Linking Family-Centered Principles with Practices and Outcomes

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Funded since 2003 by U.S. Department of Education
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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

**Family**
- Needs
- Concerns

**Child**
- Developmental Status
- Functional Abilities
- Disability Type
- Learning Style
- Resources
- Priorities
- Goals

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

**Outcomes**
- Child Outcomes
- Family Outcomes
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. 

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- Family-Centered Services

**Best Practices?**

**Outcomes**
- Child Outcomes
- Family Outcomes
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
- Shared philosophy
- Families as partners
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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

- **Enrollment**
  - Fair/Poor/Mixed: 5
  - Good: 35
  - Excellent: 30

- **Transition**
  - Fair/Poor/Mixed: 10
  - Good: 30
  - Excellent: 30

- **Kindergarten**
  - Fair/Poor/Mixed: 15
  - Good: 40
  - Excellent: 45
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

ECO Center Established
(2003)

Goal: Promote the development and implementation of child and family outcome measures that can be used in local, state, and national accountability systems

Activities:
- Consensus building
- Collaboration
- Technical assistance
- Research
- Recommendations
Using national consensus methods and ‘iterative social validation,” the ECO center recommended 5 family outcomes

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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

| Outcome 1: Understanding your child’s strengths, needs, and abilities |
|---|---|---|---|
| 1. We know the steps for our child’s growth and learning. | 0 | 0 | 0 | 0 | 0 |
| 2. We understand our child’s strengths and abilities. | 0 | 0 | 0 | 0 | 0 |
| 3. We understand our child’s delays and needs. | 0 | 0 | 0 | 0 | 0 |
| 4. We are able to talk when our child is making progress. | 0 | 0 | 0 | 0 | 0 |

| 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. | 0 | 0 | 0 | 0 | 0 |
| 6. We know our rights related to our child’s special needs. | 0 | 0 | 0 | 0 | 0 |
| 7. We know who to contact and what to do when we have questions or concerns. | 0 | 0 | 0 | 0 | 0 |
| 8. We know what options are available when our child leaves the program. | 0 | 0 | 0 | 0 | 0 |
| 9. We are comfortable asking for services & supports that our child and family need. | 0 | 0 | 0 | 0 | 0 |

| Outcome 3: Helping your child develop and learn |
|---|---|---|---|
| 10. We are able to help our child get along with others. | 0 | 0 | 0 | 0 | 0 |
| 11. We are able to help our child learn new skills. | 0 | 0 | 0 | 0 | 0 |
| 12. We are able to help our child take care of his/her needs. | 0 | 0 | 0 | 0 | 0 |
| 13. We are able to work on our child’s goals during everyday routines. | 0 | 0 | 0 | 0 | 0 |

| Outcome 4: Having support systems |
|---|---|---|---|
| 14. We are comfortable talking to family and friends about our child’s needs. | 0 | 0 | 0 | 0 | 0 |
| 15. We have friends or family members who listen and care. | 0 | 0 | 0 | 0 | 0 |
| 16. We are able to talk with other families who have a child with similar needs. | 0 | 0 | 0 | 0 | 0 |
| 17. We have friends or family members we can rely on when we need help. | 0 | 0 | 0 | 0 | 0 |
| 18. I am able to take care of my own needs and do things I enjoy. | 0 | 0 | 0 | 0 | 0 |

| Outcome 5: Accessing the community |
|---|---|---|---|
| 19. Our child participates in social, recreational, or religious activities that we want. | 0 | 0 | 0 | 0 | 0 |
| 20. We are able to do things we enjoy together as a family. | 0 | 0 | 0 | 0 | 0 |
| 21. Our medical and dental needs are met. | 0 | 0 | 0 | 0 | 0 |
| 22. Our child care needs are met. | 0 | 0 | 0 | 0 | 0 |
| 23. Our transportation needs are met. | 0 | 0 | 0 | 0 | 0 |
| 24. Our food, clothing, and housing needs are met. | 0 | 0 | 0 | 0 | 0 |
### Revised helpfulness items

**FAMILY OUTCOMES SURVEY**

**Section B: Helpfulness of Early Intervention**

**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.

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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.