

Family Outcomes of Early Intervention and Early Childhood Special Education: Issues and Considerations

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Demonstrating Results for
Infants, Toddlers and Preschoolers with Disabilities and Their Families



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For more information about the ECO Center, including other products, see www.the-eco-center.org.

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Special education and related services for infants, toddlers, and preschoolers with disabilities became a reality in the United States in 1986 with the passage of Public Law 99-457. Now known as Part C (early intervention for infants and toddlers ages birth to 36 months) and Part B-Section 619 (early childhood special education for preschoolers ages 3 through 5) of the Individuals with Disabilities Education Act (IDEA), this legislation requires states to make a free appropriate public education available to all preschoolers with identified disabilities. It also provides strong encouragement, incentives, and guidelines for serving infants and toddlers with identified developmental delays, established conditions likely to lead to a delay, and those at risk for developmental problems.

Most evaluations of the efficacy of early intervention (EI) and early childhood special education (ECSE) have focused on the extent to which these programs enhance developmental outcomes for children. Systematic reviews of research over the past 30 years indicate both short- and long-term benefits for children (Anderson et al., 2003; Gorey, 2001; Guralnick, 1998; Ramey & Ramey, 1998). Less attention has been paid to family outcomes, for at least three reasons: (1) an assumption that the primary goal of EI and ECSE is to help children; (2) lack of agreement about the nature of desired outcomes for families; and (3) both practical and measurement challenges inherent in assessing family outcomes.

The Office of Special Education Programs (OSEP), U.S. Department of Education, has funded the Early Childhood Outcomes (ECO) Center to promote the development and implementation of child and family outcome measures for infants, toddlers, and preschoolers with disabilities for use in local, state, and national accountability systems. The ECO Center is preparing a series of reports on key issues related to outcome measurement. This report focuses on outcomes for families and addresses four questions:

1. What is a family outcome?
2. What is the rationale for assessing family outcomes?
3. What challenges are inherent in defining and assessing family outcomes?
4. What frameworks have been suggested thus far for conceptualizing and measuring family outcomes?

This report provides background information to facilitate discussions among researchers, families, and professionals that can lead to recommendations for developing a set of family outcomes and procedures that can be used in state and national accountability systems.

What Is a Family Outcome?

For this report, we define “family outcome” as a *benefit experienced by families as a result of services received*. By “families” we mean “the people who think of themselves as part of the family, whether related by blood or marriage or not, and who support and care for each other on a regular basis” (Poston, Turnbull, Park, Mannan, Marquis, & Wang, 2003). In most early intervention and preschool programs “family” primarily refers to the parents of children with disabilities. However, benefit is possible for the nuclear or extended family unit or for other individuals within the family, including siblings or grandparents. A family outcome is not the receipt of services, but something that happens because services or supports are provided. For example, providing parents with information about their child’s condition is a service; if the parents understand that information and find it helpful in describing their child’s condition to others, advocating for services, or responding effectively when their child becomes upset, a benefit has been experienced and a family outcome has been achieved.

Satisfaction with services has been the dominant means of evaluating family effects of EI/ECSE over the past two decades. Virtually all studies, across many different program types, geographical locations, philosophical models, and age groups, reach a common conclusion: parents report very high levels of satisfaction with EI/ECSE programs. A number of concerns have been expressed, however, regarding the validity of parent satisfaction as an indicator of program quality or efficacy. These concerns are warranted, but do not undermine the basic premise that consumer satisfaction with services constitutes an indicator of program effectiveness (Roberts, Innocenti, & Goetze, 1999). Ideally, families should feel that the services they received are individualized, based on both child and family needs, effective in attaining desired outcomes, and delivered in a way that is respectful and empowering. New tools are needed to give families better options for rating the amount, type, and quality of services. Processes need to be put in place to make sure that parents can feel confident that when they do express dissatisfaction, it will not compromise the services their child receives or threaten the existence of the EI/ECSE program.

Despite the importance of satisfaction measures as a part of any program evaluation effort, this report suggests that satisfaction should not be considered an outcome of services. Satisfaction reflects whether consumers like and appreciate the services received, but does not necessarily mean that benefit has been received.

Families may also experience unintended negative consequences as a result of early intervention and preschool programs. Policies and procedures need to be in place to monitor whether such outcomes occur and to minimize them. For this paper, however, we limit the focus to the benefits of early intervention and preschool programs—what it is that families and professionals would like to see as a result of services and supports.

The Rationale for Assessing Family Outcomes

Early intervention and early childhood special education rarely reflect a single program or service, instead they involve many individuals, both those who receive and those who provide services. Figure 1 depicts some of the complex interactions among children, families, programs, and outcomes. The impetus for EI and preschool services stems initially from a child who has or is at-risk for having a disability. Each child has his or her own developmental abilities, functional skills, learning style, and type of disability or risk condition. Addressing the developmental and social challenges that accompany a disabling condition typically becomes the primary focus of EI, special education, and related services. However, young children are part of a family, which has its own set of needs, resources, priorities, and concerns. As described below, EI and preschool programs also have obligations to provide services to families, and often both child and family goals are established as part of intervention planning. Services are provided, some of which are child focused and some of which are family-focused. Both child and family outcomes can be achieved as a result of services or supports provided. However, the boundaries between family and child are usually less distinct: Helping a child learn a new skill could have a positive effect on family adaptation; helping a parent learn how to respond to a child's tantrums could have a positive effect on tantrums which, in turn, could improve the parents' confidence in parenting abilities as well as overall quality of life.

Thus working with families is sometimes difficult to differentiate from work with young children. But in addition to the interrelated nature of child and family goals and services, at least four arguments provide a strong rationale for considering families as recipients of EI and ECSE services and thus a target group for whom outcomes should be assessed:

Federal legislation is predicated on the assumption of benefit to families (Part C of IDEA) and family participation (Part B and Part C of IDEA). The purposes of EI for infants and toddlers were clearly stated in Part H of P.L. 99-457 (now Part C of IDEA):

The Congress finds that there is an urgent and substantial need (1) to enhance the development of handicapped infants and toddlers and to minimize their potential for developmental delay; (2) to reduce the educational costs to our society, including our nation's schools, by minimizing the need for special education and related services...; (3) to minimize the likelihood of institutionalization and ...maximize the potential for independent living in society; and (4) to enhance the capacity of families to meet the special needs of their infants and toddlers... (P.L. 99-457, 1986, Sec 671).

Purposes 3 and 4 reflect the intent for EI to provide sufficient supports so that families can care for their children at home and have both the skills and motivation needed to provide appropriate care and meet the developmental needs of their children.

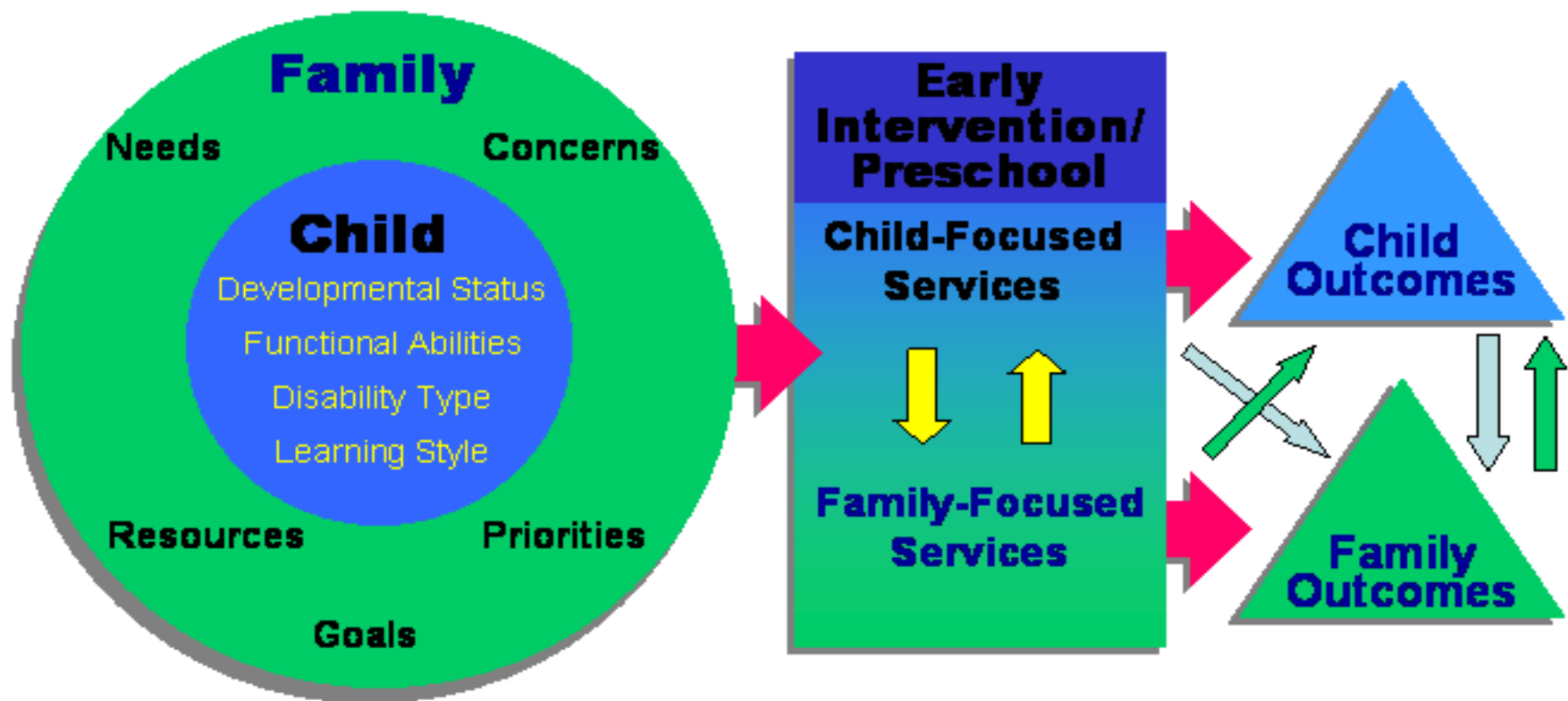


Figure 1. Interrelationships of Services and Outcomes for Children and Families

The regulations implementing Part B and Part C of IDEA also specify the nature of services to be provided for families. The obligations of states and local programs to families of infants and toddlers under 36 months of age (Part C) are different from those related to families of preschool-aged children (Part B), as indicated in Table 1. Both sets of regulations emphasize informed consent, parent participation in decision-making, access to records, and procedural safeguards. In addition, the infant-toddler regulations include an assessment of family resources, priorities, and concerns; procedures to address both child and family needs; and service coordination.

Table 1. Federal Requirements Related to Parents of Infants, Toddlers, and Preschoolers

Responsibilities for Part C Programs Serving Infants and Toddlers	Responsibilities of Part B Programs Serving 3- and 4-Year-Olds
<ul style="list-style-type: none"> • Include families as a part of each Individualized Family Service Plan (IFSP) team • Use a family-directed assessment of family resources, priorities, and concerns • If the family desires, include in the IFSP procedures to address both child and family needs • Fully explain the IFSP in the family's native language and obtain informed consent before providing EI services • Inform families of their right to accept or decline any EI service • Have established or adopted procedural safeguards • Provide a service coordinator for each family who is responsible for coordinating all services and serving as a single point of contact for parents • Review the IFSP with each family at least every 6 months • Provide written prior notice to parents before proposing, or refusing, to initiate or change any child's identification, evaluation, placement, or EI services 	<ul style="list-style-type: none"> • Attain informed parental consent before initially evaluating or reevaluating the child • Include parents as members of any group making decisions regarding the child's eligibility for special education and related services • Include parents as members of any group making decisions regarding placement of the child • Include parents as members of the Individualized Education Program (IEP) team • Have parents agree to and sign the IEP prior to the initiation of special education and related services • Use understandable terms in the family's native language to describe family's rights • Provide parents with access to any educational records relating to their children • Provide a copy of safeguard procedures for families, including due process and voluntary mediation • Provide written prior notice before proposing, or refusing, to initiate or change any child's identification, evaluation, educational placement, or the provision of a free appropriate public education

In addition, strong evidence for intended legislative benefit to families can be found in the Part B and Part C regulations regarding related services. For example, under Part B, one of the related services is “parent counseling and training,” including helping parents understand their child’s special needs and acquire skills that enable them to support the implementation of their child’s individualized program of services. Comparable language is found in Part C regulations which define “family training, counseling, and home visits” as a related service. Also, both Part B and Part C regulations describe “social work services” as a related service, including group and individual counseling with the child or family, mobilization of community resources, and work with the family to address problems in the family’s living situation that might affect the child’s use of services.

Current federal reporting requirements for the states reflect the legislative assumption that families have needs and rights with regard to service provision. For the most part, these requirements pertain to documenting the services provided. The one exception is in the Annual Performance Report for Part C—each state is required to respond to the following question: “Do family supports, services, and resources increase the family’s capacity to enhance outcomes for infants and toddlers and their families?” States are currently allowed considerable latitude in how they define family capacity and the ways in which such capacity is documented.

No information about family outcomes is currently reported for preschool programs. However, the procedural requirements conceivably could be extended to outcome statements. For example, the requirement to use simple, understandable terms in the parents’ native language to describe family rights could lead to an increase in the outcome: “parents of preschool children with disabilities fully understand their rights.”

Families play critical roles in their child’s development; thus, helping families has direct implications for the extent to which children benefit from EI and ECSE. A large body of research over the past half century provides extensive evidence that parents and the family environment are the most powerful forces in shaping children’s development. Multiple dimensions of family life—the values and culture of the family, the physical environment in the home; the ways that parents talk with, discipline, and teach their children; the models provided by parents, siblings, and other family members; the overall tone of family interactions; the types of out-of-home experiences that parents provide for their children—all represent powerful determinants of personality, social competence, self-concept, and skill development (Bruder, in press; Dunst, 2001; Guralnick, 1999; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Landry, Smith, Swank, Assel, & Vellet, 2001; Osofsky & Thompson, 2000; Spiker, Boyce, & Boyce, 2002). This research is true both for families of typically developing children and families of children with or at-risk for developmental disabilities.

However, it is also clear that the special needs of children with disabilities can tax parents’ confidence and competence (Trivette & Dunst, 2004). Such factors as challenging behavior, difficult-to-read communicative attempts, impaired learning, motor deficits, special health care needs, or difficulties in eating or sleeping mean that parents often must alter the home

environment and/or their parenting behaviors to accommodate their child's special needs (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993; Keogh, Garnier, Bernheimer, & Gallimore, 2000). Additionally, the necessity of interacting with medical, educational, and therapeutic systems of care and advocating for appropriate services pushes parents to gain new knowledge and skills as care coordinators and agents of change and support for their children.

Some have suggested that programs should support families in their caregiving role of influencing their children's development. Children spend the largest amount of time experiencing everyday activities and routines in the context of their family (Bruder, 2001). Providing support to families as they face the challenges inherent in raising a child with special needs would seem to add obvious value to any services provided directly to children. Support could be provided under a traditional application of parent education, defined by Mahoney et al. (1999) as "systematic activities implemented by professionals to assist parents in accomplishing specific goals or outcomes with their children" (p. 131). Research suggests that a wide variety of models can be used to teach parents specific skills that enhance the interactions they have with their child with a disability (Girolametto, Pearce, & Weitzman, 1996; Kaiser, Hancock, Cai, Forster, & Hester, 2000; McCollum & Hemmeter, 1997; Mobayed, Collins, Strangis, Schuster, & Hemmeter, 2000; Wendland-Carro, Piccinini, & Stuart Millar, 1999; Woods, Kashinath, & Goldstein, 2004).

A broader model of family support could also be provided under the application of family centered practices, which include the provision of social support to families (Dunst, 2001; Dunst & Trivette, 1997). In a structural equations analysis of the relationships among a number of program variables and child outcomes, Dunst (1999) found that the most powerful predictors of child outcomes (as rated by parents) were whether a program engaged in family-centered practices and the extent to which those practices resulted in parents' appraisal of personal control and their perceptions of informal supports. And Bailey et al. (manuscript under review) found that parents' ratings of the amount and quality of services for the family were a more powerful predictor of perceived outcomes for children than were parents' ratings of the amount and quality of services for children. Furthermore, parents reported greater impact on children when they themselves experienced a greater level of family impact.

Family members themselves can be affected by having a child with a disability, and programs can promote positive adaptation and reduce potential negative impacts. Research provides ample evidence that the effects of having a child with special needs can extend well beyond caregiving, teaching, and the need to find services. Having a child with a significant disability can result in more personal ramifications for many family members. Sometimes these ramifications can be positive (Affleck & Tennan, 1993; Patterson & Leonard, 1994; Skinner, Bailey, Correa, & Rodriguez, 1999; Turnbull, Blue-Banning, Behr, & Kerns, 1986), as in cases of parents for whom having a child with a disability has provided new insights into what is important to them in their lives or helped provide or redefine a sense of purpose. Having a child with a disability can promote family cohesion as family members come together

to pursue a common cause; bring out strengths that were previously unrecognized; or open doors to neighbors, community organizations, or support groups.

In some families, however, having a family member with a disability can pose personal challenges to positive adaptation (Clare, Garnier, & Gallimore, 1998). The daily challenges and pressures of raising a child with a disability can negatively affect a person's quality of life. Some family members may experience pessimism, anger, anxiety, guilt, stress, despair, or depression. Although these are natural feelings experienced at one time or another by almost all families, for some their persistence and strength can compromise positive coping and the enjoyment of daily life. And, at the extreme, depression and feelings of hopelessness may reduce the ability to provide appropriate care and could result in negative outcomes for children (Goodman & Gottlieb, 2002; Hernandez-Reif, Field, Del-Pino, & Diego, 2000; Jones, Fields, & Davalos, 2000). However, research also provides considerable evidence that how family members define or appraise life events (McCubbin, Thompson, Thompson, & McCubbin, 1993; Patterson, 1993) and the extent to which they have adequate formal and informal support systems (Crnic & Stormshak, 1997; Dunst, Trivette, & Deal, 1994; Hauser-Cram et al., 2001) are highly associated with successful adaptation. Through positive and appropriate interactions with other families, the community, and EI and preschool programs, families can experience positive adaptation. Family members who feel "empowered" and confident in their ability to influence services and their child's development are less vulnerable to negative outcomes. In contrast, however, EI and preschool programs that are perceived as judgmental, inaccessible, unresponsive, or inadequate can also influence the extent to which families experience negative outcomes.

Documenting parent and family outcomes may be especially important for families whose children have serious health and developmental challenges and make relatively little progress. Despite EI/ECSE's best, sometimes heroic efforts, some children have such serious disabilities that they make little progress in their overall health status, development, or behavioral competence. Even with advanced measurement tools, the availability of assistive technology, and functional alternative goals and outcomes, a system that focuses exclusively on child progress could conclude that, for such children, EI/ECSE was ineffective or perhaps not warranted. Doing so, however, would ignore the possibility that EI/ECSE did provide important services and supports to families, as they experienced challenging, perhaps life-threatening, issues with their child. For some children, EI or preschool program support of stability, prevention of the loss of skills, and/or help in minimizing the need for out-of-home placements can be real accomplishments.

Challenges Inherent in Defining and Assessing Family Outcomes

Assuming the need to document family outcomes as a result of EI and preschool programs, several key questions must be answered in designing and implementing a system by which family outcomes are documented:

What family outcomes should be assessed? Decisions need to be made about what constitutes a reasonable and acceptable set of family outcomes to be documented. Several frameworks have been suggested in recent years and are described in detail in the next section. Although considerable overlap exists among the suggested frameworks, no work has been done to date to reach consensus about a common core of family outcomes. Factors to consider in determining family outcomes should include (1) parents' perspectives on desirable family outcomes; (2) the explicit and implicit rationale for EI and preschool program goals; (3) variations in models of service delivery, some of which focus on family outcomes more intentionally than do others; and (4) the validity and reliability of the measured process. Also important will be how federal and state regulations are interpreted. For example, the mandate to enhance the capacity of families to meet the special needs of their infants and toddlers can be interpreted in different ways. A strict interpretation might focus on parent education and parents' ability to provide an environment that fosters development. A broader interpretation could assume that enhancing family well-being and providing social support may also enhance family capacity. Ultimately, the process of identifying reasonable and acceptable family outcomes challenges families, agencies, and programs to be more explicit about the goals of EI and ECSE for families (Bailey, 2001).

Should a similar set of family outcomes be adopted for both EI and preschool programs? Federal legislation for infants and toddlers with disabilities differs from legislation concerning preschoolers, although both include services to families in several sections in which "related services" are defined. Nonetheless, a fundamental issue will be whether real or perceived legislative differences will determine the nature and extent of family outcomes to be assessed. Some will argue that preschool programs are not required to provide family services (despite the related service descriptions), and thus they are less accountable for attaining family outcomes. Others will argue not only that regulatory support for working with families of preschoolers does indeed exist, but also that regulations should not be the only factor in determining whether family outcomes are desirable. Many will make the case that family outcomes are important throughout the lifespan of individuals with disabilities.

How should family outcomes be documented? Once family outcomes are determined, measurement strategies will be needed to determine the extent to which outcomes are achieved. Unfortunately, the field suffers from a dearth of instruments or measurement tools to assess family outcomes. As a result, existing tools can sometimes determine which outcomes will be assessed, rather than the outcomes themselves becoming the focal point of measurement and decision-making.

Traditional concepts of reliability and validity suggest that the best way to document individual change entails repeated assessments using standardized procedures that accurately determine skill level or performance. Nonetheless, most family outcome assessments have relied heavily on parents' perceptions about the extent to which certain outcomes have occurred. A fundamental issue is how to provide objective, cost-effective evidence of family outcomes yet be sensitive to the perceptual nature of many outcomes. Research is needed to determine the

relative utility of assessment strategies from differing respondents, different perspectives, and varying measurement methods. Ultimately, the measurement strategies used will need to be acceptable to families, unobtrusive, and useful for the purposes intended (Henderson, Aydtlett, & Bailey, 1993). The process must also be acceptable to practitioners, if the resulting data are to be used for program improvement.

How can we establish a common set of outcomes that apply to all families?

Fundamental to the philosophy of EI is the need to individualize services. Doing so, however, poses challenges to evaluating outcomes for both children and families. How can a system designed to document family outcomes accommodate the wide range of individualized, situation-specific outcomes likely to be identified by families? Moreover, it is likely that, for some families, no family outcomes may be important; whereas for other families, family support may constitute the primary focus of the services in which they are interested. Ideally, an outcomes system would document both the extent to which common outcomes are attained, as well as the extent to which individualized goals are achieved.

What are the best ways to document changes in family outcomes over time? Child outcome assessment typically rests on an assumption of a developmental model of skill acquisition. Children learn new skills over time, and measurement strategies have been devised that reflect development in a relatively linear fashion. Normative data in the form of growth curves or standardized scores can be used to document change over time and to determine the extent to which the development of children with disabilities approximates “normal” development. However, many family outcomes may not be developmental in nature (i.e., the natural progression of change over time may not always move “forward”). In fact, some have described a cyclical nature for family challenges and adaptation at different points of child and family development. Accordingly, the timing of family assessment will be critical and could influence the extent to which outcomes are considered attained. Furthermore, few family measures have extensive normative data or growth curves that could be used as a reference point for evaluating change. In fact, concepts of what a “normal” family is or what constitutes appropriate adaptation are likely to be challenged both within and across cultural and ethnic boundaries, further complicating attempts to document change over time.

Frameworks for Conceptualizing Family Outcomes

Despite the challenges inherent in determining family outcomes, several frameworks have been conceptualized, nine of which are summarized in Appendix A. Four of the frameworks represent the results of focus groups, administrators’ surveys, or interviews designed to elicit desirable family outcomes from key stakeholders—families, service providers, program evaluators, and researchers (Early Childhood Research Institute on Measuring Growth and Development, 1998; Family Strand Participants, National Goals Conference, in press; Office of Special Education Programs, 2003; Research and Training Center in Service Coordination, 2004; Roberts et al., 1999). Teams of researchers developed the remaining five frameworks for use in the review of literature (Brooks-Gunn, Berlin, & Fuligni, 2000), development of research

instruments (Administration for Children, Youth, and Families, 1998; Bailey et al., 1998; Turnbull, Turbiville, & Turnbull, 2000), or as recommended guidelines for evaluating the effectiveness of human and social services organizations (Council on Quality Leadership, 2004).

Although each author or group has approached family outcomes from slightly different perspectives, considerable overlap is evident. For example, most agree that programs ought to (1) help families learn about their child, his or her disability, and things that they can do to help maximize the child's development; (2) support families in gaining advocacy skills and confidence in their ability to seek and access services; and (3) help families build strong support networks, both formal and informal. However, more work needs to be done to synthesize these frameworks and obtain feedback from additional groups in order to create a recommended set of outcomes for use in state and national accountability systems.

Next Steps

This document has articulated a beginning rationale for assessing family outcomes, identified some of the major challenges to doing so, and described systems or frameworks for family outcomes that have been suggested in the literature. The document will now be used for two primary purposes:

1. **Soliciting feedback from the field.** We hope that many individuals will read this report and provide feedback about its content. We are especially interested in your reactions to the rationale for, and any reflections on, anticipated challenges (including your suggestions for addressing those challenges). If you are aware of other frameworks or would like to nominate outcomes not reflected in the existing frameworks, please do so. We would also be interested in other suggestions you may have for specific outcomes that you believe should be included in a national accountability system. Please email any reactions or suggestions to Don Bailey at don_bailey@unc.edu or Mary Beth Bruder at bruder@nso1.uchc.edu.
2. **Facilitating the work of targeted workgroups.** In the next few months we plan to hold several meetings of workgroups for various constituencies (researchers, parents, service providers, and state agency personnel). These groups will be asked to address many of the issues raised in this document, including:
 - a. For purposes of reporting to the federal government, what should be the major family outcomes for which states generate data?
 - b. How should those outcomes be assessed?
 - c. To what extent and how could an accountability system for family outcomes reflect unique individual family outcomes (e.g., by documenting the extent to which "family goals" on the IFSP are achieved), versus more global outcome statements that would be applicable to all families?

- d. How broadly should family outcomes be construed? Do outcomes that are desirable differ from those for which programs should be held accountable?
- e. Should different levels of accountability for family outcomes be expected for EI and preschool programs?
- f. Who should be responsible for collecting family outcome data?
- g. To what extent will outcome data be based on family report?
- h. What are the intended purposes of EI and preschool programs for young children with disabilities and their families?

We hope that through a systematic and inclusive process we can generate a set of family outcomes that are acceptable to families and service providers; that can be measured efficiently and in a valid fashion; and that reflect the potential of EI, when appropriately implemented, to benefit families as well as children.

Appendix A. Frameworks for Conceptualizing Family Outcomes

Source	Context/Comments	Suggested Family Outcomes/Domains	
Bailey et al. (1998)	This article describes a conceptual framework for family outcomes in EI. The framework was created to guide the development of family outcome questions used in the National Early Intervention Longitudinal Study (NEILS). The NEILS interview included 27 items designed to address the 8 questions of interest.	<u>Family Perceptions of the Intervention Experience</u> <ol style="list-style-type: none"> 1. Does the family see EI as appropriate in making a difference in their child's life? 2. Does the family see EI as appropriate in making a difference in their family's life? 3. Does the family have a positive view of professionals and the special service system? 	<u>Family Perceptions of Impact</u> <ol style="list-style-type: none"> 1. Did EI enable the family to help their child grow, learn, and develop? 2. Did EI enhance the family's perceived ability to work with professionals and advocate for services? 3. Did EI assist the family in building a strong support system? 4. Did EI help enhance an optimistic view of the future? 5. Did EI enhance the family's perceived quality of life?
Early Childhood Research Institute (ECRI) on Measuring Growth and Development (1998)	This monograph was generated by a group of researchers funded by OSEP to study ways to measure growth and development in EI. Through a subcontract with PACER, Inc., a series of interviews was conducted with parents of children with disabilities. Families identified 11 outcomes for families of young children with disabilities. From these 11 outcomes, the research team and its advisory board selected 4 that specifically related to the family's involvement in the child's growth and development over time. Both sets of outcomes are described here.	<u>Family Outcomes Identified by Families</u> <ol style="list-style-type: none"> 1. Families will understand the law as it pertains to the IFSP/IEP process. 2. Families will understand basic child development and be able to assess how their child's development is progressing. 3. Families will understand their child's disability and know how to access supports within the community related to that disability. 4. Families will be able to identify their needs, including those related to cultural, linguistic, or disability specific issues. 5. Families will be made aware of the IFSP/IEP system as soon as a need is identified and will have information on how to access those services if desired. 6. Families and children will receive services they have identified as being necessary in a timely manner. 7. Families will perceive themselves as equal and integral members of 	<u>Family Outcomes Recommended by the ECRI Team</u> <ol style="list-style-type: none"> 1. Families will have a basic understanding of child development and will be able to identify needs for their child, including those related to cultural, linguistic, or disability-specific issues. 2. Families will be able to assess how their child's development is progressing related to general outcomes identified on the IEP/IFSP. 3. Families will be confident in their abilities to make choices about interventions for their child and will be able to implement those interventions effectively. 4. Families will feel that their beliefs and values are respected by other members of their child's team, and will see themselves as equal and integral members.

Source	Context/Comments	Suggested Family Outcomes/Domains	
		<p>the team.</p> <ol style="list-style-type: none"> 8. Families will be confident in their abilities to make choices about services for their child. 9. Families will be self-advocates. 10. Families will understand the differences between the IFSP and the IEP processes, and the resulting implications for service provision. 11. Families will feel that their beliefs and values are respected by other members of the team. 	
Roberts et al. (1999)	<p>This article emerged from a series of discussions occurring among members of a consortium of professionals responsible for state-level EI evaluations. The consortium was part of the Federal Interagency Coordinating Council's Subcommittee on Service Integration and Continuity of Services. The group identified three outcome domains: system outcomes, family outcomes, and child outcomes. Three categories of family outcomes were identified.</p>	<ol style="list-style-type: none"> 1. Service-related outcomes: <ol style="list-style-type: none"> a. Types of services received b. Hassles perceived in obtaining services c. Level of parental control in interactions with service providers 2. Satisfaction outcomes: <ol style="list-style-type: none"> a. General satisfaction with services provided b. Family's sense of competence as a result of receiving services c. Family's perceived relationship with the provider agency and staff 3. Quality of life outcomes: <ol style="list-style-type: none"> a. Family's participation in everyday community activities b. Parent's receipt of day care for the child c. Parent's ability to return to work d. Parent's engagement in activities that lead to better mental health e. Child's demonstration of more appropriate behaviors f. Improved family medical outcomes, such as having a medical home. 	
<p>Turnbull, Turbiville, & Turnbull (2000)</p> <p>Park et al. (2003)</p>	<p>The first reference summarizes the authors' perspectives on the evolution of family-professional partnerships. They argue for "collective empowerment" as the model for the 21st century, and they articulate three types of outcomes for families, all under the general rubric of empowerment. In subsequent publications, including the second reference, this research team has addressed a wider range of potential family outcomes (with special focus on family quality of life) and developed measures to assess each</p>	<p><u>Family outcomes from the "Collective Empowerment" chapter</u></p> <ol style="list-style-type: none"> 1. Synergy: an enhanced nature of interactions among individuals that occurs through a combination of empowerment and collaboration 2. Creation of renewable and expandable resources 3. Increased satisfaction by all participants. 	<p><u>Other family outcomes identified by the research team</u></p> <ol style="list-style-type: none"> 1. Motivation outcomes (perceived self-efficacy, perceived control, hope, energy, persistence) 2. Knowledge/skill outcomes (information, problem-solving, coping skills, communication skills) 3. Quality of life (10 domains identified: advocacy, emotional well-being, health, environmental well-being, productivity, social well-being, daily family life, family interaction, financial well-being, parenting) 4. Empowerment

Source	Context/Comments	Suggested Family Outcomes/Domains	
			5. Community Integration.
Brooks-Gunn, Berlin, & Fuligni (2000)	This chapter summarizes research on the efficacy of EI programs for parents. The authors examined four types of services (parent-focused home-visiting programs, parent-focused combination center- and home-based programs, intergenerational literacy programs, and parent-focused literacy programs). Six domains of parent outcomes were determined, and research related to how successful each model is in promoting family outcomes was summarized.	<ol style="list-style-type: none"> 1. Parents' education/employment/self-sufficiency 2. Parents' mental and physical health 3. Observed parent-child interaction/relationship quality 4. Use of child-related services 5. Parenting attitudes, knowledge, and quality of the home environment 6. Child maltreatment indicators. 	
OSEP (2003)	In January 2003 OSEP convened a group of 22 key stakeholders to "discuss and identify child and family outcomes, performance indicators, and assessment methodologies to measure progress of children birth through five years of age served under IDEA Part C and Part B." Seven family outcomes and a set of accompanying indicators were developed.	<p><u>Family Outcomes and Indicators for Each</u></p> <ol style="list-style-type: none"> 1. Enhance family capacity to facilitate child development <ol style="list-style-type: none"> a. The family understands developmental milestones. b. The family knows how to incorporate instructional strategies into daily activities. c. The family embeds adaptations, as needed, into everyday activities to allow the child to participate. 2. Enhance family capacity to provide learning opportunities for their child <ol style="list-style-type: none"> a. The family identifies learning opportunities b. The family increases the number of opportunities for child participation. c. The family increases types of learning opportunities. d. Families have a positive vision of child's future e. Families describe the type of future they want for their child f. Families indicate that children will learn to be a contributing member within their community g. Families indicate that their children participate in the traditions of their culture 3. Families are confident in their ability to carry out parenting responsibilities and skills <ol style="list-style-type: none"> a. Parents feel confident in their ability to access services b. Families view themselves as competent in parenting their child c. Families indicate they are important change agents in their child's development d. Families indicate they are important change agents in the child's system of services 4. Families exercise options (control) within a framework of evidence-based practice <ol style="list-style-type: none"> a. Families have options to receive services in family-identified settings and routines in the home and community 5. Parents are effective advocates for their child 	

Source	Context/Comments	Suggested Family Outcomes/Domains	
		a. Parents advocate for services and supports for their child and family	
Administration for Children, Youth, and Families (1998)	In 1995, Head Start began identifying Program Performance Measures, along with a major longitudinal study, the Family and Child Experiences Survey (FACES), to determine outcomes. The FACES study selected and has been following a national random sample of children in Head Start programs. Data have been collected on family outcomes as part of the interview process, but the primary focus of the reports has been on child outcomes. The Program Performance Measures system has five broad objectives with accompanying indicators. One objective directly addresses family outcomes (Strengthen families as the primary nurturers of their children) and another indirectly (Link children and families to needed community services).	<u>Objective 2: Strengthen families as the primary nurturers of their children</u> <ol style="list-style-type: none"> 1. Head Start parents demonstrate improved parenting skills. 2. Head Start parents improve their self-concept and emotional well-being. 3. Head Start parents make progress toward their educational, literacy, and employment goals. 	<u>Objective 4: Link children and families to needed community services</u> <ol style="list-style-type: none"> 1. Head Start parents link with social service agencies to obtain needed services. 2. Head Start parents link with educational agencies to obtain needed services. 3. Head Start parents link with health care services to obtain needed care. 4. Head Start parents secure child care in order to work, go to school, or gain employment training.

Source	Context/Comments	Suggested Family Outcomes/Domains
<p>Family Strand Participants, National Goals Conference (in press)</p>	<p>In January 2003, the Arc of the United States, in cooperation with a number of federal agencies, organizations, and universities, sponsored a 3-day meeting entitled, "National Goals, the State-of-Knowledge and an Agenda for Research on Intellectual and Developmental Disability." Twelve topical areas were identified, subgroups convened, and reports produced from each. One subgroup focused on families and produced a chapter that articulated an overarching goal for families and five associated goals. Not all fit the criteria for a family outcome statement, but they may be informative in the development of family outcomes</p>	<p>Overarching Goal: To support the caregiving efforts and enhance the quality of life of all families so that families will remain the core unit of American society.</p> <p><u>Goal A:</u> To ensure family-professional partnerships in research, policy-making, and the planning and delivery of supports and services so that families will control their own destinies with due regard to the autonomy of adult family members with disabilities to control their own lives.</p> <p><u>Goal B:</u> To ensure that families full participate in communities of their choice through comprehensive, inclusive, neighborhood-based, and culturally responsive supports and services.</p> <p><u>Goal C:</u> To ensure that services and supports for all families are available, accessible, appropriate, affordable, and accountable.</p> <p><u>Goal D:</u> To ensure that sufficient public and private funding will be available to implement these goals and that all families will participate in directing the use of public funds authorized and appropriated for their benefits.</p> <p><u>Goal E:</u> To ensure that families and professionals have full access to state-of-the-art knowledge and best practices and that they will collaborate in using knowledge and practices.</p>
<p>Council on Quality and Leadership (2004)</p>	<p>The Council on Quality and Leadership (CQL) is a membership organization providing services and resources to increase the effectiveness of human and social service organizations and systems. This document, prepared by CQL staff, articulates a set of values and organizing principles for programs working with families of young children with disabilities and suggests an individualized approach to assessing family outcomes in 20 areas. Some of these are not explicit family outcomes, but all are listed here.</p>	<ol style="list-style-type: none"> 1. Families are informed. 2. Families choose child development goals. 3. Families choose their goals. 4. Families are satisfied with their services. 5. Families are satisfied with their life situations. 6. Families choose services and supports. 7. Families have economic resources. 8. Families remain together. 9. Children spend time in inclusive environments. 10. Children develop relationships. 11. Families are a part of their communities. 12. Families attain their goals. 13. Children attain developmental milestones. 14. Families remain connected to natural supports. 15. Children are safe. 16. Families exercise rights. 17. Families are respected. 18. Children have the best possible health. 19. Children are free from abuse and neglect. 20. Families experience continuity and security.

Source	Context/Comments	Suggested Family Outcomes/Domains
Bruder (in press)	This chapter describes the studies conducted on service coordination practices and outcomes as part of the OSEP-funded Research and Training Center on Service Coordination.	<p data-bbox="982 232 1241 256"><u>Immediate Outcomes</u></p> <ol data-bbox="999 277 1885 548" style="list-style-type: none"> 1. Children and families receive quality service. 2. Agencies and professionals are coordinated. 3. Transitions are successful. 4. Families are knowledgeable about the needs of their child. 5. Families make informed decisions about services, resources, and opportunities for their child. 6. Families have the support, knowledge, and tools to address their individual needs. 7. Children and families receive appropriate supports and services that are coordinated, effective, and individualized to their needs. <p data-bbox="982 589 1234 613"><u>Long-term Outcomes</u></p> <ol data-bbox="999 634 1850 711" style="list-style-type: none"> 1. Families acquire and/or maintain a quality of life to enhance their well-being. 2. Families are able to meet the special needs of their child. 3. Children's health and development is enhanced.

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