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REGULAR ARTICLES

Recommended Outcomes for Families of Young Children with Disabilities

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The Early Childhood Outcomes (ECO) Center was funded by the Office of Special Education Programs to promote the development and implementation of child and family outcome measures for infants, toddlers, and preschoolers with disabilities. An evidence-based process with extensive stakeholder input led to the identification of five outcomes by which the effectiveness of services for families could be assessed: (a) families understand their child's strengths, abilities, and special needs; (b) families know their rights and advocate effectively for their child; (c) families help their child develop and learn; (d) families have support systems; and (e) families are able to gain access to desired services and activities in their community. These outcomes provide a framework by which states and the federal government could document whether early intervention and preschool programs are providing demonstrable benefits for families, and provide the basis for developing measurement systems to determine the extent to which such benefits have been attained.

Much has been written about the rationale for working with families of young children with disabilities (e.g., Diamond & Kontos, 2004; Kaiser & Hancock, 2003; Odom & Wolery, 2003) and the practices that constitute appropriate and effective family...
support (e.g., Barnett, Clements, Kaplan-Estrin, Fialka, 2003; Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004; Brady, Peters, Gamel-McCormick, & Venuto, 2004). Typical evaluations of family support efforts have focused either on documenting practices with families (e.g., Bailey, Buysse, Edmonson, & Smith, 1992; McWilliam, Tocci, & Harbin, 1998; Trivette, Dunst, Boyd, & Hamby, 1996) or assessing the extent to which parents are satisfied with services (e.g., Bailey, Hebbeler, Spiker, Scarborough, & Mallik, 2004; Iversen, Shimmel, Ciaceria, & Prabhakar, 2003; Lanners & Mombaerts, 2000).

Does documenting professional practice and family satisfaction constitute sufficient evidence of the effectiveness of family support efforts? This article is based on the assumption that although such data are important in evaluating program quality, the real test is whether a program promotes positive outcomes for families. A recent article based on the National Early Intervention Longitudinal Study (Bailey, Hebbeler, Spiker, Scarborough, Mallik, & Nelson, 2005) found that near the end of early intervention, around the child’s third birthday, families reported a high level of attainment of many family outcomes as a result of early intervention. Although this study provides important evidence of the benefits of early intervention for families, much work remains to be done in terms of identifying and documenting the full range of family benefits that might be expected from early intervention and preschool programs.

As a consequence, the Early Childhood Outcomes (ECO) Center was funded in 2003 by the Office of Special Education Programs, U.S. Department of Education to address accountability issues in early childhood special education. The ECO center is expected to work with parents, service providers, state agency directors, and federal program officers to develop and aid in the implementation of outcome measures that could be used by states and the federal government to evaluate infant and toddler programs operated under Part C and preschool programs under Part B, Section 619 of the Individuals with Disabilities Education Act (IDEA, 2004). A major part of this effort has focused on family outcomes: defining what is meant by family outcomes, developing a rationale for assessing family outcomes, reviewing existing frameworks, and meeting with numerous stakeholders. Using an evidence-based approach with extensive stakeholder input, five family outcomes have been identified. This article summarizes this process and provides a description and rationale for each of the proposed outcomes. We conclude with a discussion of both the opportunities and challenges inherent in using family outcomes in an accountability framework.

BACKGROUND AND LITERATURE REVIEW

What Is a Family Outcome?
We define “family outcome” as a benefit experienced by families as a result of services received. Although family often refers to the parents or primary caregivers of children with disabilities, benefit also is possible for siblings, grandparents, or other members of the extended family unit (Poston, Turnbull, Park, Mannan, Marquis, & Wang, 2003). A family outcome is not the receipt of services, but what happens as a consequence of providing services or supports. For example, sharing information with parents about their child’s condition is a service; if parents understand that information and use it to describe their child’s condition to others, advocate for services, or respond effectively to their child’s needs, a benefit has been experienced and a family outcome has been achieved. Evaluating service quality or satisfaction reflects whether consumers like and appreciate the services received, but does not necessarily mean that benefit has been received.

The Rationale for Assessing Family Outcomes
Most evaluations of the effectiveness of early intervention and preschool programs have focused on the extent to which they enhance child outcomes. Reviews of this research consistently indicate both short- and long-
term benefits for children (e.g., Anderson, Shinn, Fullilove et al., 2003; Gorey, 2001; Guralnick, 1998; Ramey & Ramey, 1998). Several arguments, however, suggest that families also are or should be recipients of early childhood services and thus a target group for whom outcomes should be assessed.

Federal legislation is predicated on the assumption of benefit to families and family participation. The purposes of early intervention 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 early intervention 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.

The regulations accompanying IDEA also address working with families. Both Part C and Part B emphasize informed consent, parent participation in decision-making, access to records, and procedural safeguards. Part C regulations require assessment of family resources, priorities, and concerns; procedures to address family needs; and service coordination. Other entitlement services under Part C include family training, counseling, home visits, and social work services. Related services for families of preschoolers under Part B also include parent counseling and training, described as 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. Other Part B services for families are social work services, including group and individual counseling with the child or family, mobilizing community resources, and working with the family to address problems in the family’s living situation that might affect the child’s use of services. Thus, both Parts C and B include families as potential recipients and beneficiaries of services.

Child and family services and goals are integrally linked in early childhood programs. Early intervention and early childhood special education rarely reflect a single program or service, but rather involve many different individuals, both as recipients of services and as providers of services (Odom & Wolery, 2003). The initial impetus for services stems from a child who has or is at-risk for having a disability. Addressing the developmental and social challenges that accompany a disabling condition typically becomes the primary focus of services. A young child, however, is part of a family, which has its own needs, resources, priorities, and concerns. The child’s needs often cannot easily be isolated from his or her family context (Carpenter, 2001). As a result, the boundaries between family services and child services might be blurred. 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 by reducing tantrums which, in turn, could improve the parents’ confidence in parenting abilities as well as overall quality of life, exemplifying the transactional nature of both parenting and early intervention (Sameroff & Fiese, 2000).

Families play critical roles in their child’s development; helping families has direct implications for the extent to which children benefit from services. Research provides extensive evidence that parents and the family environment constitute powerful forces in shaping children’s development. Multiple dimensions of family life—the values and culture of the family, the physical environment of the home; the ways that
parents talk with, discipline, and teach their children; the models provided by parents and other family members; the overall tone of family interactions; the types of out-of-home experiences parents provide—all influence personality, social competence, self-concept, and development (Bruder, 2005; Dunst, 2001; Guralnick, 1999; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Landry, Smith, Swank, Assel, & Vellet, 2001; Osofsky & Thompson, 2000; Spiker, Boyce, & Boyce, 2002).

The special needs of children with disabilities, however, can challenge parents' confidence and competence (Trivette & Dunst, 2004). Challenging behavior, difficult-to-read communicative attempts, impaired learning, motor deficits, special health care needs, or difficulties in eating or sleeping often mean that parents must alter their home environments or parenting behaviors to accommodate their child's special needs (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993; Koegh, 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.

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. Children spend the largest amount of their time in everyday activities and routines with their families (Bruder, 2001). Support to families could be provided in any number of ways as suggested by research on both traditional parent education models (e.g., Girolametto, Pearce, & Weitzman, 1996; Kaiser & Hancock, 2003; Mahoney et al., 1999; McCollum & Hemmeter, 1997; Mobayed, Collins, Strangis, Schuster, & Hemmeter, 2000; Wendland-Carro, Piccinini, & Stuart Millar, 1999; Woods, Kashinath, & Goldstein, 2004) as well as in responsive models of family centered practice which include the provision of social support to families (Dunst, 2001; Dunst & Trivette, 1997). As an example of the latter, an analysis of the relationship between selected program variables and child outcomes using structural equation modeling found that the most powerful predictors of child outcomes were whether a program engaged in family-centered practices and whether those practices resulted in parents' appraisal of personal control and perceptions of informal supports (Dunst, 1999).

Family members themselves can be affected by having a child with a disability, and services ought to 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. For many family members, there are more personal ramifications of having a child with a significant disability. 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 quality of life. Some family members might experience pessimism, anger, anxiety, guilt, stress, despair, or even 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 might reduce their 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). 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 early childhood 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, which in turn could have a positive effect on a family’s perceived quality of life.

Documenting parent and family outcomes might be especially important for families whose children have serious health and developmental challenges and make relatively little progress. Despite our best, sometimes heroic efforts, some children have such serious disabilities that they make little progress in their health status, development, or behavioral competence. For some children, the fact that early intervention or preschool programs support stability, prevent the loss of skills, and help minimize the need for out-of-home placements can be a significant accomplishment. 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, services were ineffective or perhaps not warranted. Doing so ignores the possibility of important benefits for families who experience challenging, perhaps life-threatening, issues with their child.

**DERIVING RECOMMENDED OUTCOMES**

The ECO Center was charged with the task of “working directly with State educational agencies, local educational agencies, local agencies, technical assistance providers, parent organizations, parent trainers, other relevant organizations, and researchers to build consensus among stakeholders on what is important to measure, how the measurement should be conducted, the importance of using outcome indicators in early intervention and preschool special education, and the selection of child outcomes and indicators and family outcomes and indicators” (Federal Register, 2003, p. 44320).

Although we had previously developed a framework for assessing family outcomes as a part of the National Early Intervention Longitudinal Study (Bailey et al., 1998), the need to recommend a set of national outcomes for use in program evaluation necessitated revisiting this framework. To develop a national set of family outcomes, we reviewed literature related to family outcomes and engaged in an iterative process involving multiple stakeholders to reach broad consensus.

**Method**

Ten general steps constituted the process by which outcomes were generated and agreed upon, as depicted in Figure 1. We initially met with our national advisory board to discuss plans for how we would identify family outcomes. The board consisted of a wide range of prominent stakeholders, including several parents of children with disabilities, researchers, and program administrators at different levels from around the nation. The board recommended that we start with a literature review and use that review plus our prior work to nominate an initial set of outcomes. At the end of the meeting the board agreed that our ultimate goal was to identify family outcomes that were (a) consistent with existing re-

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**Bailey et al.**
Figure 1.
Steps followed in generating family outcomes.

search literature and prevailing philosophical underpinnings of early childhood programs; (b) aligned with both the statutes and intent of the Individuals with Disabilities Education Act; (c) parsimonious and easily understood by professionals, policy makers, and the public; and (d) validated by diverse stakeholders as critical indicators of the effectiveness of early intervention and preschool programs. We then met with our two workgroups consisting of Part C early intervention coordinators and Part B, Section 619 preschool coordinators to get their reactions to how we were approaching these issues and solicit initial suggestions for considerations in developing a national set of guidelines.

Following those meetings we reviewed the literature on family outcomes, seeking reports that either used a comprehensive approach to determining family outcomes as a heuristic for research or that summarized the results of activities (e.g., focus groups, surveys) designed to identify appropriate outcomes for families. Using PsychInfo and searching on terms such as families and family outcomes we identified only a few relevant articles. We excluded from consideration those articles that examined only one aspect of working with families, such as an article evaluating the effectiveness of a parent training program. Our goal was to find work done by others to think more broadly about the full range of family outcomes. We drew on suggestions by our advisory board for other reports not in the empirical literature, and these suggestions proved fruitful, for example, leading us to several documents not published in traditional outlets yet reflective
of the goals for our search. Ten frameworks incorporating a broad continuum of methods were identified. Four were based on synthesis of best practices by the authors for the purposes of instrument development, evaluation recommendations, or literature reviews (Administration for Children, Youth, and Families, 1998; Bailey et al., 1998; Brooks-Gunn, Berlin, & Fuligni, 2000; Council on Quality Leadership, 2004); three were based on focus groups or discussions among stakeholders (OSEP Early Childhood Outcomes and Indicators Focus Group, 2003; Family Strand Participants, National Goals Conference, in press; Roberts, Innocenti, & Goetz, 1999); and three were based on systematic studies involving both quantitative and qualitative methodologies (Bruder, 2005; Early Childhood Research Institute on Measuring Growth and Development, 1998; Park, Hoffman, Marquis et al., 2003). A description of the context for each framework and the suggested family outcomes for each are displayed in Tables 1–3. We recognize that changes have been made in some of these frameworks (e.g., the Park et al., 2003 framework was modified in a more recent publication by Summers et al., 2005); however, the tables describe the frameworks as they were reviewed during the process of developing the recommended outcomes reported in this article.

We analyzed the 10 frameworks to determine overlapping recommendations. Although each framework approached family outcomes from slightly different perspectives, considerable overlap was evident. For example, most suggested that professionals ought to (a) help families learn about their child, his or her disability, and things that they can do to help maximize the child’s development; (b) support families in gaining advocacy skills and confidence in their ability to seek and access services; and (c) help families build strong support networks, both formal and informal. Because of our a priori definition of family outcome as a benefit occurring as a result of services, we eliminated from further consideration items regarding family satisfaction with services. A report describing the rationale and challenges associated with documenting family outcomes and summarizing the ten frameworks was prepared as background material and shared with subsequent stakeholder groups in order to facilitate decision-making (Bailey & Bruder, 2004).

We then convened a 2-day meeting of eight prominent family researchers, referred to as our Family Technical Work Group. Based on these discussions we generated an initial set of six family outcomes that could potentially be used in state and national evaluations of impact. We subsequently convened a two-day meeting of nine stakeholders (Family Work Group), including parents, directors of prominent parent organizations, and agency administrators, to review and provide feedback on the six outcomes. This discussion provided strong endorsement for five of the six outcomes, with some editing of the way they were stated and moderate endorsement of the sixth outcome, which focused on family quality of life. Quality of life was seen as an important outcome but was viewed by many as beyond the scope of early childhood programs. For example, this group, as well as other stakeholders, noted that many families face issues related to poverty which could seriously impact their quality of life in ways that are beyond the capacity of an infant, toddler, or preschool program to address.

After revising the outcomes, conference calls were held with our Part C coordinators advisory group, our Section 619 preschool coordinators advisory group, and the Family Technical Work Group. These calls resulted in further editing of the outcomes and confirmed concerns about whether enhancing family quality of life should be a specific outcome for which early intervention and preschool programs should be held accountable. After reviewing all of the suggestions and comments, we decided not to include quality of life as a specific outcome, but rather include it in an introductory statement asserting that enhancing family quality of life is an ultimate goal of early childhood.
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<th>Source</th>
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| Bailey, McWilliam, Darkes, Hebbeler, Simeonsson, Spiker, Wagner (1998) | This article describes a conceptual framework for family outcomes in early intervention. 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 eight questions of interest. | **Family Perceptions of the Intervention Experience**  
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?  
**Family Perceptions of Impact**  
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? |
| Brooks-Gunn, Berlin, & Fuligni (2000) | This chapter summarizes research on the efficacy of early intervention programs for parents. The authors examined four different 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. |  
1. Parent education/employment/self-sufficiency  
2. Parent 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 |
Table 1  
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| Administration for Children, Youth, and Families (1998) | In 1995 Head Start began a process of identifying a set of Program Performance Measures and a major longitudinal study to determine outcomes. The Family and Child Experiences Survey (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). | Objective 2: Strengthen families as the primary nurturers of their children  
1. Head Start parents demonstrate improve 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  
Objective 4: Link children and families to needed community services  
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 |
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<td>Council on Quality and Leadership (2004)</td>
<td>The Council on Quality and Leadership 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.</td>
<td>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</td>
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Table 2
Frameworks for Conceptualizing Family Outcomes Based on Focus Groups and Limited Discussions with Stakeholders

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| Roberts, Innocenti, & Goetz (1999) | This article emerged from a series of discussions occurring among a consortium of professionals responsible for state-level early intervention 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. | 1. Service-related outcomes  
   a. types of services received  
   b. hassles perceived in obtaining services  
   c. level of parental control in interactions with service providers  
2. Satisfaction outcomes  
   a. general satisfaction with services provided  
   b. family sense of competence as a result of receiving services  
   c. the family's perceived relationship with the provider agency and staff  
3. Quality of life outcomes  
   a. family participation in everyday community activities  
   b. parent receipt of day care for the child  
   c. parent ability to return to work  
   d. parent engagement in activities that lead to better mental health  
   e. child demonstration of more appropriate behaviors  
   f. improved family medical outcomes, such as having a medical home |
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<td>Early Childhood Outcomes and Indicators Focus Group (2003)</td>
<td>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.</td>
<td>Family Outcomes and Indicators for Each</td>
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<td>1. Enhance family capacity to facilitate child development</td>
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<td>a. the family understands developmental milestones</td>
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<td></td>
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<td>b. the family knows how to incorporate instructional strategies into daily activities</td>
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<td>c. the family embeds adaptations, as needed, into everyday activities to allow the child to participate.</td>
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<td>2. Enhance family capacity to provide learning opportunities for their child</td>
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<td>a. the family identifies learning opportunities</td>
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<td>b. the family increases the number of opportunities for child participation</td>
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<td></td>
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<td>c. the family increases types of learning opportunities</td>
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<td>3. Families have a positive vision of child’s future</td>
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<td></td>
<td>a. families describe the type of future they want for their child</td>
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<td></td>
<td>b. families indicate that children will learn to be a contributing member within their community</td>
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<td>c. families indicate that their children participate in the traditions of their culture</td>
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<td>4. Families are confident in their ability to carry out parenting responsibilities and skills</td>
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<td></td>
<td>a. parents feel confident in their ability to access services</td>
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<td></td>
<td>5. Families view themselves as competent in parenting their child</td>
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<td></td>
<td></td>
<td>a. families indicate they are important change agents in their child’s development</td>
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<td>b. families indicate they are important change agents in the child’s system of services</td>
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<td>6. Families exercise options (control) within a framework of evidence-based practice</td>
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<td>a. families have options to receive services in family-identified settings and routines in the home and community</td>
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<td>7. Parents are effective advocates for their child</td>
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<td></td>
<td>a. parents advocate for services and supports for their child and family</td>
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| Turnbull, Turnbull, Agusta, Erwin, Fjuiura, Singer, Soodak (2006) | 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.” 12 topical areas were identified, subgroups convened, and reports produced from each. One subgroup focused on families, and produced a chapter in which they articulate an overarching goal for families and five associated goals. Not all fit the criteria for a family outcome statement, but may be informative in the development of family outcomes | 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.  
Goal A: 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.  
Goal B: To ensure that families full participate in communities of their choice through comprehensive, inclusive, neighborhood-based and culturally responsive supports and services.  
Goal C: To ensure that services and supports for all families are available, accessible, appropriate, affordable, and accountable.  
Goal D: 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.  
Goal E: 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. |
### Table 3

**Frameworks for Conceptualizing Family Outcomes Based on More Extensive Research**

<table>
<thead>
<tr>
<th>Source</th>
<th>Context/Comments</th>
<th>Suggested Family Outcomes/Domains</th>
</tr>
</thead>
</table>
| Early Childhood Research Institute on Measuring Growth and Development (1998) | This monograph was generated by a group of researchers funded by the Office of Special Education Programs to study ways to measure growth and development in early intervention. 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 four that specifically related to family's involvement in their child's growth and development over time. Both sets of outcomes are described here. | **Family Outcomes Identified by Families**
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 the team.
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.  

**Family Outcomes Recommended by ECRI Team**
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.
<table>
<thead>
<tr>
<th>Source</th>
<th>Context/Comments</th>
<th>Suggested Family Outcomes/Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>Park, Hoffman, Marquis, Turnbull, Poston, Mannan, Wang, &amp; Nelson (2003)</td>
<td>This article is the second one in a research program to develop a measure of family quality of life outcomes. The first article was a qualitative study involving 34 focus groups and 20 interviews with non-English speaking families to establish a preliminary 10-domain structure. This article reports on the second study which involved approximately 1,200 respondents in a national field test to establish a factor structure. The 10 domains were reduced to 5 factors.</td>
<td>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.</td>
</tr>
<tr>
<td>Bruder (2005)</td>
<td>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.</td>
<td>1. Family Interaction 2. Parenting 3. General Resources 4. Health and Safety 5. Support for Persons with Disabilities</td>
</tr>
</tbody>
</table>

**Immediate Outcomes**

4. Children and families receive quality service.
5. Agencies and professionals are coordinated.
6. Transitions are successful.
7. Families are knowledgeable about the needs of their child.
8. Families make informed decisions about services, resources and opportunities for their child.
9. Families have the support, knowledge and tools to address their individual needs.

**Intermediate Outcomes**

6. Children and families receive appropriate supports and services that are coordinated, effective and individualized to their needs.

**Long-term Outcomes**

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.
services, and that the five proposed outcomes could serve as partial indicators of the extent to which that goal had been achieved. The five outcomes were then placed on the ECO Center web site and individuals around the nation were invited to review and comment on the outcomes. Nearly 100 comments were received, most of which commented positively on the overall framework. A few minor wording suggestions were made and a number of comments indicated concerns regarding whether the recommended outcomes should apply to both early intervention and preschool programs. A January 2005 meeting of the ECO Center National Advisory Board provided additional review and comment.

**Recommended Outcomes**

This iterative process of stakeholder input provided invaluable information. To illustrate some of the changes made and the issues that arose during this process, Table 4 lists the outcomes as proposed in September 2004, describes selected recommendations or concerns raised during the process of gathering stakeholder input. This table also shows the five family outcomes proposed as a result of this process.

**Outcome 1: Families understand their child’s strengths, abilities and special needs.** Although all parents must understand their child’s strengths, abilities, and special needs, parents of children with disabilities face unique challenges. As most children with or at-risk for a disability display atypical patterns of growth and development, it might be more difficult for their parents to achieve this outcome. Some parents might be concerned about delayed attainment of important developmental milestones or the failure to learn key skills. Others might have children who are difficult to parent, who exhibit unusual behaviors, or have behavior problems. Children with disabilities often have special risk factors, health problems, conditions, or diagnoses that force parents to learn new information about such topics as genetics, medications, surgeries, seizures, or adaptive technology. Research consistently indicates that information is the most commonly expressed need by parents of young children with disabilities (Bailey & Powell, 2005). Professionals can provide information for families and can help families learn new ways to access this information themselves. Information is empowering, helping parents understand their child’s abilities and special needs so that they can interact with their child in ways that maximize development and learning. Achieving this outcome also provides the foundation by which parents can advocate more effectively for their children (see proposed Outcome 2).

A few examples of evidence that this outcome has been achieved occur when families:

- Know expectations for typical development at different ages and stages
- Are aware of how their child is developing, and what might be the next developmental abilities that could be encouraged
- Are able to observe their child’s behavior and notice whether changes occur as a result of services, medication, changes in parenting, or alterations in the home environment
- Know about the special risk factors, conditions, or disability their child might have
- Know how to access information about child development or special needs through resources such as other parents, reading materials, professionals, or the Internet

**Outcome 2: Families know their rights and advocate effectively for their children.** Federal legislation makes it clear that parents have a set of rights with regard to access and services. For many parents, however, entry into early intervention or preschool programs coincides with the discovery that their child has or is at risk for a disabling condition. Most parents of very young children are not familiar with the programs offered under IDEA, have had little experience with specialists, and might not be aware of their rights and responsibilities. Services might be provided by many different providers and understanding the range of possibilities can be a daunting task. Parents will vary in their comfort and confidence in participating in team meetings,
### Table 4
Sample Changes to Outcomes as a Result of Stakeholder Input

<table>
<thead>
<tr>
<th>Proposed Outcome: September 2004</th>
<th>Sample Stakeholder Input</th>
<th>Final Proposed Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Families know their rights and advocate effectively for services</td>
<td>Some stakeholders felt that the ultimate goal is not advocating for services but on behalf of children.</td>
<td>Families know their rights and advocate effectively for their child</td>
</tr>
<tr>
<td>Families understand their child’s abilities and special needs</td>
<td>Some stakeholders felt that this goal was too narrowly limited to developmental status and special needs, and recommended that an understanding of strengths be included.</td>
<td>Families understand their child’s strengths, abilities, and special needs</td>
</tr>
<tr>
<td>Families help their child develop, learn, and behave appropriately</td>
<td>The phrase “behave appropriately” was bothersome to many stakeholders, implying discipline, manners, etc. Stakeholders recognized the importance of appropriate behavior and social skills, but felt that the phrase “develop and learn” captured those domains and was more acceptable.</td>
<td>Families help their child develop and learn</td>
</tr>
<tr>
<td>Families have the support they want from other family members, friends, neighbors, or others</td>
<td>Some professionals felt that the phrase “they want” opened up too many possibilities beyond the scope of what services could help facilitate. Other stakeholders felt that the examples given were too restrictive.</td>
<td>Families have support systems</td>
</tr>
<tr>
<td>Families access desired services, programs, and activities that are available to other families in their community</td>
<td>The phrase “that are available to other families” was initially included to account for cross-community variability in available services. But stakeholders felt that the outcome should not be contextualized in this way.</td>
<td>Families are able to gain access to desired services and activities in their community</td>
</tr>
<tr>
<td>Families are satisfied with their quality of life</td>
<td>Strong differences of opinion were expressed regarding this outcome. Many parents and some researchers felt that this was the most important of all outcomes. But service providers and administrators felt that it would be unfair to hold programs accountable for this outcome, and that it was much too broad.</td>
<td>Not included in the final recommendation, but acknowledged as an ultimate goal, one that could be enhanced if the other five outcomes were attained.</td>
</tr>
</tbody>
</table>
seeking out services, or advocating on behalf of their child.

A few examples of evidence that this outcome has been achieved occur when families:

- Know their rights and responsibilities related to service provision
- Know different service options and the types of services offered by different providers
- Feel comfortable talking with professionals or asking questions
- Know how to use the Internet or other sources to find out about rights and services
- Are able to participate effectively in team meetings to plan goals and services
- Advocate for services they feel are important
- Know what to do if they feel that needed services are not being provided

**Outcome 3: Families help their children develop and learn.** Having a child with special needs can challenge parents' confidence and competence. Such factors as challenging behavior, difficult-to-read communication attempts, impaired learning, motor deficits, sensory impairments, special health care needs, or difficulties in eating or sleeping mean that parents often must alter the home environment or parenting behaviors to accommodate their child's special needs. From its inception, one of the stated goals of Part C of IDEA has been to "enhance the capacity of families to meet the special needs of their infants and toddlers" (P.L. 99-457, 1986, Sec 671).

Examples of evidence that this outcome has been achieved occur when families:

- Know and use styles of effective parenting
- Provide a nurturing and stimulating environment for their child
- Use effective techniques to enhance learning or manage special behavior problems
- Adapt the home environment or routines to reflect their child’s learning style or needs
- Know about and help their child use special adaptive equipment
- Know how to access and evaluate the validity of recommendations for dealing with particular learning or behavior challenges

**Outcome 4: Families have support systems.** Families sometimes might feel very alone in dealing with the fact that they have a child with a disability. They might not have anyone they feel comfortable talking to about their child. Their child's disability might preclude them from enjoying or participating in neighborhood activities, going out with friends, family reunions, or family holiday activities. For some, the daily challenges and pressures of raising a child with a disability can result in pessimism, anger, anxiety, guilt, stress, despair, or depression. Sometimes support is needed from professionals to get through these difficult periods, but research also shows the important role of informal support in positive coping (e.g., Thompson, Lobb, Elling, Herman, Jurkiewicz, & Hulleza, 1997). Using family-centered help-giving practices in early intervention programs can help families build and use informal support systems (Dunst, 1999).

A few examples of evidence that this outcome has been achieved occur when families:

- Feel supported in raising their children
- Maintain friendships and make new friends
- Are able to talk to friends and neighbors about disability-related issues
- Are able to participate in desired activities with family or friends
- Meet and get to know other families of children with disabilities
- Have neighbors, friends, or family who can serve as trusted babysitters

**Outcome 5: Families access desired services, programs, and activities in their community.** Most families need and choose to take advantage of a wide range of community resources, services, programs, and activities. These resources could include the medical community, child care, religious institutions, libraries, recreational centers, and, for older children, programs such as sports or scouting. The community resources that are used depend on the age of the child, the child’s needs, the family’s desire to
participate in those activities, and what is available in the community in which they live. Families vary considerably in their priorities and abilities to use community resources with their child.

Families of children with disabilities often experience challenges in accessing community resources, especially those that seem responsive to their needs and those of their children. For example, finding appropriate childcare or playgroup can be a problem for a parent whose child has seizures, is blind, has special feeding needs, takes medication, has behavior problems, or experiences any of the many other possible consequences of having a disability (Booth-LaForce & Kelly, 2004). Having a nursery that will provide appropriate care during religious services might be very important to a family in which attendance at religious services is a central part of their lives. Some doctors or dentists might not be as receptive to caring for children with disabilities as others.

A few examples of evidence that this outcome has been achieved occur when families:

- Have quality childcare so that parents can work or children can have opportunities for inclusive experiences with other children who do not have disabilities
- Have a physician and dentist who can provide care that is sensitive and responsive to their child’s special needs
- Have acceptable and trusted respite care services when informal care is not available
- Are able to participate in religious, recreational or educational groups that the family ordinarily would have participated in had their child not had a disability
- Participate in parent organizations or support groups relevant to their child’s disability and their family’s style and priorities

**SUBSEQUENT DEVELOPMENTS, ISSUES, AND CHALLENGES**

In February of 2005, the ECO Center submitted these recommendations to the Office of Special Education Programs (OSEP) at the United States Department of Education for consideration. OSEP is requiring Part C programs to report on the percent of families who report that early intervention programs have helped the family (a) know their rights; (b) effectively communicate their children’s needs; and (c) help their children develop and learn. OSEP is requiring Part B, 619 preschool programs to report the one family outcome, which is the same for all children participating in special education: the percent of families who report that schools facilitated parent involvement as a means of improving services and results for children with disabilities. The ECO center responded to these recommendations in May of 2005 with two major concerns: (a) the reporting requirements are satisfaction items, not statements of outcomes in the way we have defined outcomes (benefit experienced by families as a result of services provided); and (b) the reporting requirements only partially reflect the extensive input from the field regarding the range of desired family outcomes. OSEP acknowledges these concerns and has encouraged the ECO center to continue its work on the full range of family outcomes, shifting our focus to helping states identify ways to measure all of the recommended outcomes, not just those required by OSEP.

Agreeing on broad family outcomes is only the first step in determining whether those outcomes have indeed been achieved. Several key issues remain unresolved.

Should a similar set of family outcomes be expected for both early intervention and preschool special education programs? Federal legislation for infants and toddlers with disabilities differs from legislation concerning preschoolers, although both include several related services for families. 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 stakeholders (typically individuals working in or responsible for Part B Section 619 programs) argued

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2 The text of the ECO center response to OSEP can be found at www.the-eco-center.org
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. The way that services are currently structured for preschoolers often reduces the potential contacts professionals have with families and thus minimizes the likelihood of impact on families. Others, especially parents, argued 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. As a result of these differing perspectives, ECO recommended that the government request from Part C programs information on the extent to which Outcomes 1–5 have been attained, and that Part B 619 programs be expected to provide information on Outcomes 1–3.

In the future, however, it is likely that this debate will transcend the age parameters of Part C and Part B programs, as some Part C providers are concerned about expectations to achieve all five outcomes and some Part B providers readily endorse all. 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 measurement tools to assess family outcomes. As a result, existing tools can sometimes determine which outcomes will be assessed, rather than the outcomes themselves driving decisions about measurement.

Traditional concepts of reliability and validity of scores suggest that the best way to document individual change is through repeated assessments using standardized procedures to determine accurately skill level or performance. Nonetheless, most family outcome assessments have relied heavily on parent perspectives of the extent to which certain outcomes have occurred. A fundamental issue is how to provide objective, cost-effective evidence of the attainment 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 using varying measurement methodologies. Ultimately, the measurement strategies used will need to be acceptable to families, unobtrusive, and useful for the purposes intended (Henderson, Aydlett, & Bailey, 1993). It also must be a process that is acceptable to practitioners and those who will request and use the data.

How can we establish a common set of outcomes that apply to all families? Fundamental to special education philosophy is the need to individualize services. A system based on the premise of individualization 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 might be identified; whereas for other families, family support might constitute the primary focus of the services in which they are interested. Our work has proceeded under the assumption that it is possible to develop a core set of outcomes that apply to all families. Ideally, an accountability system would document both the extent to which common outcomes are attained, as well as the extent to which individualized goals are achieved. The identification of a common set of outcomes does not diminish the importance of developing and documenting the achievement of individualized goals.

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 (e.g., Bailey, Hatton, & Skinner, 1998). Many family outcomes, however, might not be developmental in nature (i.e., there might not be a natural progression of change over time that always moves “forward”). In fact, some have described the cyclical nature of family challenges and adaptation at different points of child and family development. This means that the timing of family assessment will be critical and could influence the extent to which outcomes are considered attained. For example, families might feel less confident when they transition from Part C to Part B services than when they are firmly connected to either program. 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.

CONCLUSION

Drawing on the best available research literature, federal legislation, and the input of numerous stakeholders, we propose five family outcomes for early childhood programs, derived from an extensive review of the literature and a set of interactions with researchers, parents, program administrators, and policy makers. We argue that family outcomes should be documented as a measure of program effectiveness because of (a) the integral linkages between children and families, especially during the early years; (b) federal legislative requirements, both direct and implicit; and (c) research showing the potential of interventions to help parents support their child’s development and promote positive adaptation among family members. But despite these arguments and general consensus in the field regarding the importance of working with families, we anticipate initially limited acceptance of the premise that documenting family outcomes constitutes a necessary component of evaluations of early intervention and preschool programs, for two primary reasons.

First is the belief held by many practitioners, program administrators, and policymakers that the primary purpose of services is to support children’s development and learning. According to this argument, work with families must be done with appropriate sensitivity and attention to family rights and diversity, but is justified primarily on the extent to which it helps further children’s learning. The limited focus of Part C on family outcomes that enhance child development and the failure of Part B to explicitly address family outcomes for preschool programs reinforce these beliefs and make broadening support for accountability for family outcomes a difficult task.

Second, is the perception held by many researchers and policy makers that no matter how you approach it, family outcomes inherently represent “soft” data. According to this argument, family outcomes are impossible to measure objectively; thus any assessment that asks families to report outcomes attained is hopelessly constrained by high levels of family satisfaction with services for young children and a tendency to rate outcomes positively due to lack of experience with alternative forms of services, tremendous appreciation that any services have been provided, and in some cases a fear that reporting less-than-optimal outcomes might threaten future support for early intervention and preschool programs.

Despite these concerns, we assert that documenting benefit to children constitutes a necessary but insufficient assessment of the accomplishments of early intervention and preschool programs. In an era of evidence-based practices in special education (Odom, Brantlinger, Gersten, Horner, Thompson, & Harris, 2005), we argue that families should be both beneficiaries and consumers of services. Accountability thus must go beyond providing required services and documenting quality practices with families, ultimately to ask whether those services result in measur-
able outcomes for families (Bailey, 2001). The outcomes proposed here reflect the potential of high quality early childhood programs to benefit families. They will provide a basis for instrument development, research, and program evaluation as the ECO Center moves into the next stages of its work. Hopefully they will stimulate further reflections on the nature and substance of services provided, and the critical role of families vis-à-vis the ultimate intent of early childhood programs.

REFERENCES


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The outcomes presented in this paper were developed through a year-long consensus-building process that involved the input and review from numerous stakeholders including federal, state, and local policy makers and administrators, local providers, family members of children with disabilities, and researchers. We would like to acknowledge the critical contribution of those who provided input to the development of these outcomes. We especially acknowledge the contribution of our ECO work group members including those from our family technical work group, family member work group, Part C work group, and 619 work group who contributed so generously of their time in the development of these outcomes.

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