

FEATURE ARTICLE

Family Supports and Services in Early Intervention: A Bold Vision

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This article utilizes four knowledge sources to characterize a current gap in policy and practice related to serving families in early intervention (birth to 5) programs. It argues that the field of early intervention has focused primarily on implementing family-centered practices by focusing on how families and professionals should interact. The field has not sufficiently addressed what supports and services should be offered to families to enhance the likelihood of positive outcomes for families themselves and for their children with disabilities. The paper concludes with recommendations for enhancing policy, research, and professional development related to family services and supports.

This paper converges four knowledge sources to distinguish and describe a current gap in policy and practice related to families:

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empirical, conceptual, statutory, and information obtained from a national summit. The gap is the absence of a clear conceptualization of *what* supports and services should be offered to families in early intervention (birth to 5) programs. We conclude that the field of early intervention (EI) has focused primarily on implementing family-centered practices by focusing on *how* families and professionals should interact. The field has not sufficiently addressed *what* supports and services should be offered to families to enhance the likelihood of positive outcomes for families themselves and for their children with disabilities.

It is critically important to distinguish between the *how* and *what* of approaches to working with families in EI programs. We use *how* to address the process of delivering

family-centered services, such as the way that professionals honor parents' choices, involve multiple family members, build on family strengths, establish partnerships, and collaborate with families in individualized and flexible ways. The common thread of *how* relates to the style of interaction and to interpersonal dynamics. Alternatively, we use *what* to refer to the specific types of family supports and services that are provided, such as respite care, provision of information (e.g., community resources, government benefits, legal rights, information about the nature of disability), and provision of emotional support (e.g., counseling, parent-to-parent match, participation in support groups).

We believe the field has not yet developed a conceptual framework for the types of supports and services (the *what*) that early childhood professionals should be competent to offer and early childhood programs should have the resources to provide; doing so is a necessary prerequisite for delineating family outcomes for which programs should assume responsibility. One reason for the lack of a family support and service framework is the current tenet of family-centered services that family choice should be honored and, therefore, families should not be "slotted" into particular supports and services. It is customary for many early childhood service providers to ask families what they want or what they need. Yet many families are likely to be so focused on their child's needs that they have not had the opportunity to reflect broadly on what would be helpful to them. Second, most families do not have access to information from other families of young children with special needs about what has been most helpful over the short run, information from families of older children about what has been most helpful over the long-run, or the practices that researchers have documented to be scientifically valid. Most early childhood professionals, including professional development providers, researchers, and service providers, do not have this information either. In short, people cannot exercise choice if they do not know

what their choices are. We want to be clear, however, that we are not suggesting professionals should be prescriptive in suggesting to parents which particular supports and services they should receive. Rather, the goal of having a conceptual framework of supports and services is to maximize rather than to limit choice.

The purpose of this article is to describe empirical, conceptual, and statutory analyses, as well as a National Summit on Early Childhood Family Supports and Services (referred to throughout paper as Summit), all carried out to assess whether our initial speculation was accurate about the field lacking an adequate conceptualization of the nature of family supports and services to be offered to families receiving EI services. By converging these four perspectives (empirical, conceptual, statutory, summit), we provide a unified case from multiple data sources that serves a function similar to triangulation in qualitative inquiry and presents corroborating evidence for our findings (Berg, 2006; Creswell, 1998).

First, we describe how such a large and diverse group of authors got together in writing this article. Figure 1 shows the process of constructing and co-constructing our thinking into its present form. Researchers at the Beach Center on Disability initiated conversations with many of the co-authors and other early childhood leaders in an effort to verify or refute initial working hypotheses about the current status of implementing family supports and services during the early childhood years. These initial conversations lead to a first phase (Phase I in Figure 1) that included preliminary analysis of the empirical literature, analysis of conceptualizations of family supports and services, and statutory analysis. This Phase I review appeared to verify initial hypotheses expressed by Beach Center researchers, other co-authors, and other leaders in the field. Based on this Phase I work, Beach Center researchers issued an invitation to attend a Summit held in January, 2006 to share perspectives, find common ground, and determine whether people would be interested in working within

professional development related to family-centered services and supports.

EMPIRICAL ANALYSIS: TRENDS IN THE DELIVERY OF FAMILY SUPPORTS AND SERVICES

Data from three sources were used to obtain a “snapshot” of the extent to which family supports and services are being provided to families in EI programs. We analyzed data compiled from (a) the Individuals with Disabilities Education Act (IDEA, 2004) implementation focusing on family-related supports and services; (b) the National Early Intervention Longitudinal Study (NEILS) on parent perceptions related to child-related supports and services and family-related supports and services; and (c) a study of family perspectives about service adequacy in one state.

IDEA Implementation and Family-Related Services and Supports

The National Early Childhood Technical Assistance Center (NECTAC) reported trends in the percentage of types of services listed on individualized family service plans (IFSPs) from 1994 through 2001, based on state reports (Danaher & Armijo, 2005). Of the 17 services identified in this report, three could generally be described as services to families: (a) family training, counseling, and home visits (a category of services listed in Part C of IDEA); (b) social work services; and (c) respite care (although respite care is not one of the IDEA-listed services, it was included in this IDEA-based report). All other services on IFSPs were services primarily to children. See Table 1 for a legislative definition of select service categories in IDEA.

From 1994 to 2001, the percentage of families in Part C receiving family training, counseling, and home visits dropped from 36% to 20%. These data might be confusing given that during 1999–2000 data collection, the U.S. Department of Education (2002) reported that 68% of all early intervention services were delivered in the home setting. Both the setting and service definitions under

Part C include reference to the home, which might need to be clarified. The provision of social work services also declined from 16% in 1994 to 10% in 2001, and respite care dropped from 7% in 1994 to 4% in 2001. The opposite trend was noted in the child-focused services of occupational therapy, speech/language therapy, and physical therapy. For example, speech and language therapy services increased from 34% to 52% of IFSPs between 1994 and 2001. Home visits by therapists in these disciplines might account for some of the confusion noted above if states counted these services as one of the therapies and not family training, counseling and home visiting. In general, these data suggest that child-focused therapies are utilized more frequently while family-oriented services are used less frequently.

How informative are these data? A possible interpretation is that current data-reporting protocols are inadequate. Reporting often might be driven by the funding stream for services. If local programs document direct services to children to fit Medicaid funding streams, supports and services to families might not be reported at all. The protocols might be poorly specified, allowing one state to count family training, counseling, and home visits as special instruction while another state reports special instruction separately from home visits.

Given these issues, is it possible that EI providers visiting the home with primarily child-oriented objectives might be simultaneously providing information and support to families? The limited evidence in the home-visiting literature suggests the answer might be “no.” McBride and Peterson (1997) reported that during home visits, 80% of the interventionist-parent discussions focused on the child’s skill development. They further reported that 49% of the early interventionist’s time was devoted to working directly with the child. While further research is needed to learn whether, how, and what kinds of supports and services families receive in the course of child-oriented service delivery, NECTAC data suggest a decline in emphasis on family supports and services.

Table 1
Parts B and C Services

Part B Related Services: (20 U.S.C. Sec. 1402(26) and Regulations)

- “Counseling services” includes rehabilitation counseling and services provided by qualified social workers, psychologists, guidance counselors, or other qualified personnel (34 C.F.R. Sec. 300.34(c)(2)).
- “Parent counseling and training” means assisting parents in understanding the special needs of their child, providing parents with information about child development, and helping parents acquire necessary skills that will allow them to support the implementation of their child’s IEP (or IFSP for Part C – see below under Part C Early Intervention Services) (Regulations 34 C.F.R. Sec. 300.34(c)(8)).
- “Social work services in schools” includes preparing a social or developmental history on a child with a disability; group and individual counseling with the child and family; working with those problems in a child’s living situation (home, school, and community) that affect the child’s adjustment in school ... (Regulations 34 C.F.R. Sec. 300.34(c)(14)).

Part C IFSP-Based Services (20 U.S.C. Secs. 1402 and 1432, and regulations at 34 C.F.R. Part 303.

- “Family training, counseling, and home visits” refers to services provided, as appropriate, by social workers, psychologists, and other qualified personnel to assist the child’s family to understand the child’s special needs and to enhance the child’s development (34 C.F.R. Sec. 303.12 (d)(3)).
- “Service coordination services” means assistance and services provided by a service coordinator (case manager) to a child and the child’s family (34 C.F.R. Sec. 303.12 (d)(11)).
- “Social work services” includes (1) making home visits to evaluate a child’s living conditions and patterns of parent-child interaction; (2) preparing a social or emotional developmental assessment of the child within the family context; (3) providing individual and family-group counseling with parents and other family members, and appropriate social skill-building activities with the child and parents; (4) working with those problems in a child’s and family’s living situation that affect the child’s maximum utilization of early intervention services; and (5) identifying, mobilizing, and coordinating community resources and services to enable the child and family to receive maximum benefit from early intervention services (34 C.F.R. Sec. 303.12 (d)(12)).
- “Special instruction” includes ... (3) providing families with information, skills, and support related to enhancing the skill development of the child (34 C.F.R. Sec. 303.12 (d)(13)).

Note. IEP = Individualized education plan; IFSP = Individualized family service plan; IDEA = Individuals with Disabilities Education Act.

NEILS Data

The National Early Intervention Longitudinal Study (NEILS) documented family perspectives on child and family services and outcomes (Bailey, Scarborough, Hebbeler, Spiker, & Mallik, 2004). Data were collected in telephone interviews with 2,600 primary caregivers at the approximate time of the child’s third birthday. Families were asked questions on nine dimensions of child services including the extent to which primary caregivers believed the services that their child received were appropriate, of high quality, effective, and of a sufficient amount. In general, almost three-fourths of families indicated that the amount of services to their child was about right, 91% rated the overall quality of services as excellent, and 75% reported early intervention had *a lot*

of impact on their child’s overall development.

With respect to family services, families were asked to (a) rate the help and information their family had received through early intervention and (b) evaluate the extent to which the help and information had affected their family (Bailey et al., 2004). Fifty-six percent reported the family-related help or information they received as excellent, as compared to the 91% excellence rating for child services. Furthermore, 59% reported their family was *much better off* because of the help or information received, compared to the 75% rating that early intervention had *a lot* of impact on their child’s development. Caucasian families reported higher satisfaction than families from diverse ethnic/racial backgrounds and fami-

lies at higher income levels were consistently more satisfied with services than families at lower income levels.

Families also were asked questions about specific outcomes. One outcome was the extent to which early intervention had enabled them to help their child grow, learn, and develop. Eighty-five percent reported they knew how to care for their child's basic needs, and 64% knew how to help their child learn and develop. More than one-third of the parents either agreed or strongly agreed they often have a difficult time figuring out what to do about their child's behavior. The cultural discrepancies related to race and income were even greater for questions pertaining to the achievement of outcomes as compared to questions pertaining to satisfaction with services.

Family Perceptions of Service Adequacy

A third source of data derives from a survey of families in early childhood services in a single state (Summers et al., in press). A sample of 180 families from both Part C and Part B Section 619 preschool programs were asked if they needed various types of child and family services (as specified in Parts C and B). If families answered *yes*, they were asked if they were receiving adequate amounts of service using the response options *none at all*, *some but not enough*, or *enough*. Generally, families reported they were receiving enough of the child services (with exceptions of behavior support and self-care skills training). Overall, fewer families reported having a need for family-oriented services. The number of families who believed they were receiving enough of those services, however, was consistently low. For example, only 23% of families who needed information about services for their child were getting enough service; only 7% of the families who needed money to help pay bills were getting it.

Summary from Empirical Analyses

Data from federal reporting sources suggest a downward trend from 1994 to 2001 in the percentage of families who received family-

related supports and services in Part C programs. Furthermore, data from NEILS suggest families were more satisfied with the receipt of child-related supports and services than family-related supports and services. Approximately one-third of families reported not having adequate information to help their child learn and develop and to address their child's problem behavior. Based on data gathered from families in one state, families were more likely to be receiving enough services for their child as contrasted to their family. While additional research is needed to learn whether, how, and what kinds of supports families might be receiving in the context of the child-oriented services, these data do raise issues about the degree to which family needs for supports and services are being met.

CONCEPTUAL ANALYSIS: NATIONALLY SANCTIONED PRACTICES AND POLICY GOALS

For the conceptual analysis, we examined three sets of recommendations from national organizations and consortia, including the Early Childhood Outcomes Center (Bailey et al., 2006), the Division for Early Childhood (DEC) recommended family-based practices (Trivette & Dunst, 2005), and the policy goals pertaining to family support from the National Goals Conference (Lakin & Turnbull, 2005; Turnbull et al., 2005).

Early Childhood Outcomes Center (ECO) Consensus-Building Effort on Family Outcomes

The ECO Center, funded by the Office of Special Education Programs (OSEP), has focused over the last several years on conceptualizing child and family outcomes and developing a measurement system. This initiative associated with measuring child and family outcomes is a result of the Government Performance Results Act that requires government programs to demonstrate their effectiveness. Based on advisory board input, focus groups, and interviews, the ECO Center staff recommended measuring five

Table 2**ECO Center and OSEP Recommendations for Part C Family Outcomes**

ECO Recommendations	OSEP Recommendations
<ul style="list-style-type: none"> • Understand their child's strengths, abilities, and special needs • Know their rights and advocate effectively for their children • Help their children develop and learn • Have support systems • Access desired services, programs, and activities in their community 	<ul style="list-style-type: none"> • Percent of families participating in Part C who report that EI services have helped the family <ul style="list-style-type: none"> • Know their rights • Effectively communicate their children's needs • Help their children develop and learn

Note. ECO = Early Childhood Outcomes Center; OSEP = Office of Special Education Programs. From Bailey, D. B., Bruder, M. B., Hebbeler, K., Carta, J., deFosset, M., Greenwood, C., et al. (2006). Recommended outcomes for families of young children with disabilities. *Journal of Early Intervention, 28*, 227–251.

family outcomes for Parts C and B programs (see Table 2). OSEP partially accepted the ECO recommendations for Part C programs and recommended none of them for Part B 619 programs (see Table 2 for comparison). For Part B, OSEP recommended collecting data on the percent of parents with a child receiving special education services who report that schools facilitated parent involvement as a means of improving services and results for children with disabilities (Bailey et al., 2006).

Clearly, the recommended family outcomes, as displayed in Table 2, are not nearly as robust as the requirements for related services to families in the IDEA requirements for Parts C and B included in Table 1. Bailey and colleagues encountered differences of opinion from Part B Section 619 stakeholders on whether programs for children ages 3 to 5 years are required to provide family services. These opinion differences are described as follows:

Some stakeholders (typically individuals working in or responsible for Part B Section 619 programs) argued 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 currently are 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. (Bailey et al., 2006, p. 245–246)

The ECO Center's initial recommendations for five family outcomes provide a step forward in conceptualizing outcomes families might expect, but fall short of conceptualizing the *types* of family supports and services from which those outcomes derive. OSEP's response to the ECO Center's recommendations for Part B Section 619 outcomes is further evidence of a greater emphasis on the how of family-based practice (e.g., parent involvement) than on the what of family supports and services in ECSE services.

DEC Recommended Practices

The DEC recommended family-based practices and examples (Trivette & Dunst, 2005) are shown in Table 3. Three of the four practices (sharing responsibility and working collaboratively, using practices that are individualized and flexible, and being strengths- and assets-based) are focused primarily on the how or the process of developing relationships with families to serve them and their children. The fourth practice principle, practices strengthen family

Table 3

DEC Recommended Practices and Examples: Family-Based Practices

Families and professionals share responsibility and work collaboratively

- Family members and professionals jointly develop appropriate family-identified outcomes.
- Family members and professionals work together and share information routinely and collaboratively to achieve family-identified outcomes.
- Professionals fully and appropriately provide relevant information so parents can make informed choices and decisions.

Practices strengthen family functioning

- Practices, supports, and resources provide families with participatory experiences and opportunities promoting choice and decision-making.
- Practices, supports, and resources support family participation in obtaining desired resources and supports to strengthen parenting competence and confidence.
- Intrafamily, informal, community, and formal supports and resources (e.g., respite care) are used to achieve desired outcomes.
- Supports and resources provide families with information, competency-enhancing experiences, and participatory opportunities to strengthen family functioning and promote parenting knowledge and skills.
- Supports and resources are mobilized in ways that are supportive and do not disrupt family and community life.

Practices are individualized and flexible

- Resources and supports are provided in ways that are flexible, individualized, and tailored to the child's and family's preferences and styles, and promote well-being.
- Resources and supports match each family member's identified priorities and preferences (e.g., mother's and father's priorities and preferences might be different).
- Practices, supports, and resources are responsive to the cultural, ethnic, racial, language, and socioeconomic characteristics and preferences of families and their communities.
- Practices, supports, and resources incorporate family beliefs and values into decisions, intervention plans, and resources and support mobilization.

Practices are strengths- and assets-based

- Family and child strengths and assets are used as a basis for engaging families in participatory experiences supporting parenting competence and confidence.
- Practices, supports, and resources build on existing parenting competence and confidence.
- Practices, supports, and resources promote the family's and professional's acquisition of new knowledge and skills to strengthen competence and confidence.

Note. From Trivette, C. M., & Dunst, C. J. (2005). DEC recommended practices: Child-focused practices. In S. Sandall, M. L. Hemmeter, B. J. Smith, & M. E. McLean (Eds.), *DEC recommended practices: A comprehensive guide for practical application* (pp. 107–126). Longmont, CO: Sopris West.

functioning, suggests, like the ECO Center, an outcome (e.g., parenting competence, new knowledge and skills) rather than a taxonomy of services or supports. The examples provided shed light on the settings and sources of supports (e.g., informal, community), but do not offer significant guidance on exactly what supports and services should be provided. Rather, the what of family supports and services ambiguously is referred to as practices, supports, and resources (see Table 3). The importance of how supports and services are delivered has been underscored

in research studies and other professional literature (Sandall, Hemmeter, Smith, & McLean, 2005; Smith et al., 2003). As stated earlier, we believe the intention is to provide as much family choice as possible which, on the one hand, is state-of-the-art practice. The lack of specificity might be the unintended consequence of emphasizing family choice. Practitioners might fear that developing a conceptualization of family supports and services offered to families as a menu of options might be too prescriptive. We believe that in seeking to promote greater choice,

Table 4

National Goals Conference: Overarching Goal and Five Associated Goals

- **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 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 families fully participate in communities of their choice through comprehensive, inclusive, neighborhood-based, and culturally responsive supports and services.
 - **Goal C:** To ensure services and supports for all families are available, accessible, appropriate, affordable, and accountable.
 - **Goal D:** To ensure sufficient public and private funding will be available to implement these goals and all families will participate in directing the use of public funds authorized and appropriated for their benefits.
 - **Goal E:** To ensure families and professionals have full access to state-of-art knowledge and best practices and they will collaborate in using knowledge and practices.
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perhaps the field has not been sufficiently clear about what supports and services programs should be prepared to offer and what information families should be provided.

National Goals Conference

The National Goals Conference was held in January 2003 under the primary sponsorship of The Arc of the U.S. and in partnership with over 40 organizations (mostly national), including nine federal agencies with the primary responsibility for implementing national legislation pertaining to people with disabilities. Its purpose was to explicate the “policy promises” that the United States has made to its citizens with developmental disabilities, to synthesize available research related to each promise, and to project a future research agenda to increase the likelihood of our nation keeping its promises. Twelve topical groups addressing key issues about developmental disabilities, one of which was family life, were involved in the conference. The participants represented a broad range of stakeholders including self-advocates with developmental disabilities, family members, researchers, service providers, and state/federal agency administrators (Turnbull et al., 2005).

The family life group was composed of 18 participants representing the broad range of stakeholder groups listed above. The charge

of the group was to review federal law and major court cases as the basis of identifying the policy promises made to families. Table 4 shows the overarching goal and five supporting goals related to policy promises to families, based on the comprehensive policy analysis conducted by the group. We highlight the 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” (Turnbull et al., 2005, p. 221). Translated into an emphasis particularly for early childhood programs, this would mean the overarching goal of serving families would be to support their caregiving efforts and enhance their quality of life. Particularly noteworthy is Goal C: “To ensure that services and supports for all families are available, accessible, appropriate, affordable, and accountable” (Turnbull et al., 2005, p. 221). This goal focuses on the characteristics of supports and services but is void of a conceptual framework for what specific services and supports should be provided.

Summary from the Conceptual Analysis

National consortia and organizations have authority for explicating state-of-the-art practices and policies through consensus-based methods involving their diverse and multiple stakeholders. The ECO Center, DEC, and the National Goals Conference

recommendations represent different constituencies within the disability field. DEC is the leading professional organization in the field of early intervention and early childhood special education (ECSE). Its members include researchers, administrators, faculty, providers, and parents, and its focus is on young children with disabilities aged birth to 8 years and their families. The ECO Center's work on outcomes also is focused on the ECSE field and has involved professionals, researchers, state and national policy makers, and family advocacy groups focused on early childhood. Alternatively, the National Goals Conference was sponsored by over 40 disability organizations and nine federal agencies, focused only on developmental disabilities, and had a lifespan focus. Its recommendations, although generally not well known within the early childhood field, are applicable to this analysis.

All of these sources of national guidance have much greater specificity on the how or the process of delivering supports to families. Additionally, all three efforts identify one or more family outcomes that are expected as the result of services delivered. None of the three, however, is specific about the types of supports and services that might be available to families to achieve those outcomes.

STATUTORY ANALYSIS: FOUR FEDERAL STATUTES

We analyzed four federal statutes that most explicitly authorize services to children ages birth through 5 years with disabilities and their families. The statutes include the Individuals with Disabilities Education Act (IDEA; Parts C and B); Developmental Disabilities Assistance and Bill of Rights Act (DD Act); the Social Security Act – Children's Mental Health Act (CMHA); and Title V of the Social Security Act – Maternal and Child Health Services Block Grant (Title V), which we analyzed only as it applies to children with special health care needs and their families. We did not include Title XIX/Medicaid and its embedded Early Periodic Screening Diagnosis and Treatment

(EPSDT) program because each is a medical cost reimbursement program that is distinct from the other statutes that authorize programs and services. We identified the goals, supports and services, and the nature of partnerships between families and professionals that the four federal statutes require or authorize (see Table 5). We followed standard methods of statutory analysis (Hart & Sacks, 1994) identifying (a) the family-related goals that each statute declares and the intended beneficiaries of the statute; (b) the supports and services for families that each statute mandates or authorizes federal, state, or local agencies to undertake in pursuit of those goals; and (c) the nature of partnerships that service providers should seek to establish when working with families.

Only one of the statutes, IDEA Part B, creates an individual right to services and requires education agencies to provide certain services. The other statutes do not. They authorize state agencies to undertake certain activities. The distinction between required and authorized services derives from the different nature of the statutes. The individual rights (Part B) are enforceable by individual beneficiaries (children ages 3 to 21 years and their parents), and some of the services authorized by it are or may be required and thus be individually enforceable. The other statutes authorize state agencies to offer services; they do not require them to do so, and they do not require agencies to deliver particular services or create service rights that are individually enforceable. We address the distinction between require and authorize and between the nature of the rights-creating and services-authorizing statutes in the conclusion to this section.

Family-Related Goals

The family-related goals in these statutes are, generally speaking, to produce certain outcomes in children; to involve families in attaining those goals and, to a degree, to produce certain outcomes for the families; and to develop federal, state, and local agency capacities to implement the goals. At their

Table 5
Analysis of Goals, Supports and Services, and Nature of Partnerships in Four Federal Statutes

Statutes	Goals	Supports and Services	Nature of Partnerships
IDEA, Part C	Families' capacity to meet the special needs of their infants and toddlers with disabilities.	Services include assistive technology services; family training, counseling, home visits; psychological services; service coordination services; social work services; and special instruction. In addition, supports and services include public awareness programs to inform parents.	Notice; written consent; participation in developing the individualized family service plan, including family-directed assessment of resources, priorities, and concerns of the family and identification of supports and services necessary to enhance family capacity to meet the child's needs; state interagency council.
IDEA, Part B	Children's education can be made more effective by strengthening the role and responsibility of parents and ensuring that families have meaningful opportunities to participate in the education of their children at school and at home; to ensure that the rights of parents are protected; to ensure that parents have the necessary tools to improve educational results for children.	Related services include audiology, parent counseling and training, psychological services, school social work services, and speech pathology.	Participate in evaluation and IEP/ placement team decision-making; access to and control of records; receive and give various procedural due process notices and notices regarding remedies; resolve disputes by resolution session or mediation (before due process hearing).

Table 5
Continued

Statutes	Goals	Supports and Services	Nature of Partnerships
DD Act	<p>Strengthen the role of the family as primary caregiver; prevent inappropriate out-of-the-home placement; maintain family unity; reunite families. Assure that families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance; families have competencies, capabilities, personal goals that should be recognized, supported, and encouraged.</p> <p>Preserve, strengthen, and maintain the family.</p> <p>Provide support services necessary to support the family; enable families to nurture and enjoy their children at home and to make informed choices and decisions regarding the nature of supports, resources, services, and other assistance available; support family caregivers of adults with disabilities; strengthen State systems that are family-centered and family-directed, and that provide families with the greatest possible decision-making authority and control; promote leadership by families.</p>	<p>Training and technical assistance; respite care; parent training and counseling; support for families headed by aging caregivers; family-centered quality assurance; training in leadership, self-advocacy, and self-determination.</p>	<p>Coordinated, family-centered, family-directed, comprehensive system; right and opportunity to be the primary decision-makers and play decision-making roles in policies and programs.</p>

Table 5
Continued

Statutes	Goals	Supports and Services	Nature of Partnerships
Children's Mental Health Act	Comprehensive community mental health services to children.	Services in the cultural context that is most appropriate for the child and family; family counseling services; intensive home-based services; respite care; therapeutic foster care services; case management services; outreach services. Care coordination services; case management services; home visits; social support services; and, as listed in appendix to regulations, counseling services and home-based services.	An individualized plan of services developed and carried out with the participation of the family.
Maternal and Child Health Act	To improve the health of all mothers and children; promote family-centered, community-based, coordinated care and systems of services.		Family-centered, community-based, coordinated care.

Note. IDEA = Individuals with Disabilities Education Act; DD = Developmental Disabilities. Included are the Part C and Part B Services in which families are identified as potential beneficiaries by the respective part of the statute or its regulations.

core, all of the statutes except the DD Act seek goals related far more to child outcomes than family outcomes. These statutes must be understood, as they apply to individuals (including infants, toddlers, and young children) with disabilities, in light of the four goals that Congress sets out in the Americans with Disabilities Act (ADA) and IDEA, Part A. The first goal is to guarantee equal opportunity, which is the means for three other goals: economic self-sufficiency, independent living, and full participation. In some cases, the statutes regard the family as the means for achieving child outcomes; in other cases, such as therapeutic models of early intervention, the parent is much less relevant. Thus, the policies and authorized activities are primarily child-related; families (together with federal and state-local service-provider agencies) are the instruments for child-related outcomes. Under a family-systems approach, benefits to families are experienced but only as a consequence of, and as a means toward, benefits to the children. Thus, children are the primary beneficiaries, and families are the secondary beneficiaries.

For example, Part C of IDEA declares that its purposes include these family-related ones: to enhance the development of infants and toddlers with disabilities, maximize individuals' potential to live independently, and enhance families' capacity to meet the special needs of their infants and toddlers with disabilities (20 U.S.C. Sec. 1431(a)(3)). The same end-means pattern repeats itself in the definitions of a statewide system. It is one that includes a family-directed identification of the needs of each family of such an infant or toddler to assist appropriately in the development of the infant or toddler to attain the Part C and Part A goals and the ADA goals (20 U.S.C. Sec. 1435(a)(3); see also 20 U.S.C. Sec. 1436(a)(2). The pattern is similar in Part B of IDEA, in CMHA, and in Title V.

By contrast, the DD Act explicitly identifies family goals under Titles I and II that include: enable families to nurture and enjoy their children at home; maintain

family unity; and preserve, strengthen, and maintain the family. Title II separately authorizes family support programs (access to child care services, respite care, training and leadership, self-advocacy, and self-determination) that implement the family goals.

Family-Related Supports and Services

When analyzing supports and services, it was important to return to the distinction between those that a statute authorizes and those that it requires, and to do so in light of the statute's purposes. IDEA Part B, 20 U.S.C. Sec. 1414(a)–(c), authorizes special education that will result in academic, behavioral, physical, and developmental outcomes for the student (ages 3 to 5 and 6 to 21 years). It then authorizes related services to be provided only if they are necessary to *enable the student to benefit from special education*, 20 U.S.C. Secs. 1414(a) and 1402 (26). This necessity-and-causality criterion makes it clear that the related services that are available to the student's family are available only because they primarily benefit the student to attain Part A and B goals. Because Part B is a rights-creating statute, the related services provisions are individually enforceable.

Part C requires the IFSP team to specify the services necessary to meet the child's unique needs so that the child might attain the Part C outcomes. These include enhancing the child's development, minimizing the potential for developmental delay, reducing educational costs, enhancing the family's capacities to meet their child's needs, and living independently. The ultimate goal – living independently – is one that drives all of IDEA; it is a general policy goal, applicable to Part B and C, Sec. 1400(c)(1). It also is an ADA goal. Arguably, the other Part C goals are subsidiary to it and are means for accomplishing it. Thus, only those IFSP services that benefit the child to attain that goal may be required. All other services are discretionary with the IFSP team; they are not required and a parent might not compel them to be provided.

As a general rule, all of the statutes except the DD Act and, to a lesser degree, Part C of

IDEA authorize services for children, not families. When the statutes authorize services that benefit families, they do so by general categories (see Table 1 for the identification of Parts B and C family-related services). Part C, 20 U.S.C. Sec. 1432(4) authorizes family training, counseling, and home visits. The field of early intervention generally views home visits as a service *setting*, not a particular *type* of service.

All statutes except IDEA Part B require case management and care coordination. Further, the services often include training, technical assistance, and counseling. Finally, two statutes include respite care for families. Of particular note, Title II of the DD Act authorizes family support, defines the term according to outcomes, and identifies family-support services. Title II of the DD Act (2002) incorporates the substance of the former Part I, family support, which was added to IDEA in 1994 and removed via expiration (sunset) in 1998.

Nature of Partnerships

The statutes uniformly advance family-professional partnerships by requiring agencies to give families notice of proposed actions and statutory rights, authorizing families to give or withhold consent to services, and authorizing families to participate in developing service-delivery plans and in policy. Several of the statutes (IDEA Part C, DD Act, and the MCH Act) use terms such as family-directed or family-centered. The DD Act states that families should be the primary decision-makers and play decision-making roles in policies and program development, requires some of the services to be based on family-centered and family-directed processes, requires the services to be culturally competent, and sometimes requires the services to be delivered in a family's home or community.

Summary from the Statutory Analysis

Only one statute, IDEA Part B, is individually enforceable with respect to family supports and services, and, even then, those supports and services are limited by the related standard involving necessity and

causality. The other statutes authorize state activities and are not individually enforceable. It is fair to conclude that, with respect to family supports and services, policy is more aspirational than individually enforceable. This is a major weakness that is only partially compensated for by the statutes' emphasis on how service providers and families should partner with each other. It is clear that how services and supports should be delivered in partnership is more entrenched in policy contrasted to what supports and services should be provided.

We conclude that family-related disability policies do not emphasize the needs of families who have members with disabilities, including those with young children.

- They focus primarily on the child or adult with a disability and on outcomes for that person, and they thereby diminish family outcomes.
- They lack clear and explicit requirements for family supports and services. They authorize but do not mandate those services.
- They contain no accountability provisions for any family outcomes. Goals exist, but mechanisms for enforcing them do not.
- They are strong on the how but weak on the what of family supports and services.

NATIONAL SUMMIT LEADING TO COMMUNITY OF PRACTICE

The co-author team met with other family and professional leaders in a National Summit on Early Childhood Family Supports and Services. This Summit (a) was attended by 46 individuals in January 2006 and (b) provided an opportunity to review and highlight the analyses of Phase 1 (see Figure 1) and examine the contemporary practices and experiences of the diverse stakeholders in EI pertaining to family supports and services. Family and professional wisdom and values served as the major source of knowledge exchange (Buisse, Wesley, Snyder, & Winton, 2006). Summit participants included parents and other

family members of young children, youth, and adults with disabilities; leaders from national family and professional organizations; researchers and university faculty; graduate students; national technical assistance leaders; state policy leaders and coordinators; early intervention providers; and project officers from the Office of Special Education Programs (OSEP) and Maternal and Child Health (MCH)². Over a 2-day period, Summit participants discussed their past and present experiences and future expectations related to family supports and services. They generated a vision to guide the specification of *ideal* family supports and services in early childhood programs that might be possible in the next 5 years, assuming significant and sustainable progress. Using this vision as an overall guide, Summit participants attempted to reconcile the terminology, definitions, and frameworks currently used to refer to supports and services that families receive. Through open-ended discussions, it became obvious the participants used different definitions for such basic terms as family supports, family services, informal support, and formal support. Participants concluded that major work was needed to develop a nomenclature for these terms as a foundation for beginning the conversation to develop a conceptual framework of family supports and services. They also agreed that it would be beneficial for families to be informed about the broad array of family supports and services that have been documented to be effective through research or that are highly recommended by families and professionals.

The final discussion at the Summit focused on whether it would be desirable to develop and implement a Family Supports Community of Practice (CoP). A CoP consists of "groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis" (Wenger, McDermott, & Snyder, 2002, p. 4).

² Project officers attended through a teleconference connection.

The literature documents examples of successful CoPs that have worked together over time to address different purposes and achieve various outcomes (Cox, 2005; Dubé, Bourhis, & Jacob, 2005; Vaast, 2004). Whereas the purpose of some CoPs is to share knowledge about existing practices, CoPs also take a proactive stance of generating new practices and evaluating their effectiveness (Cox, 2005).

As the Summit participants considered the challenges related to actualizing their vision for 2011, they agreed a sustained effort involving many collaborators would be necessary to achieve the desired system enhancements. Participants wanted to avoid the scenario of “one more meeting” where problems are identified followed by a return to business as usual. Roberts (2005) succinctly expressed the frustration many others at the Summit affirmed:

As the convener of a meeting in 1996 on outcomes for early intervention sponsored in part by the Federal Interagency Coordinating Council (FICC)...I am struck by how little movement there has been in the field since that time. In the last decade, multiple research and practice institutes were funded and accomplished very good work. Yet, their effect on practice in the field is not as strong as it might have been. Perhaps it is because there has been no commonly accepted framework to insure that this information can be incorporated into the everyday activities of programs. (Roberts, 2005, p. 167)

Accordingly, Summit participants committed themselves to forming a CoP to generate knowledge collaboratively and to translate this knowledge into federal and state policy and into family supports and services that significantly enhance sustainable systems to benefit families of children with disabilities. Since the conclusion of the Summit, participants have continued to communicate through email exchanges and a subgroup of participants has collaborated on the writing of this article³.

³ At this writing, plans for two more meetings are underway.

Summary of the Summit

The Summit was organized strategically to bring together diverse groups, especially family leaders representing diverse constituencies in concert with early childhood professionals who had various roles within the field. Across the diversity reflected in these stakeholders, a consensus emerged that there is no agreed-upon nomenclature to talk about family supports and services much less to develop a comprehensive conceptualization of what supports and services should be used for professional development and service delivery. Permeating discussions throughout the Summit agenda was the perspective that too often problems are highlighted, but real change in implementing solutions does not occur systematically. Participants committed themselves to persistent and diligent work over a sustained period to conceptualize family supports and services, create the capacity in the field for professional competence and resources to provide these supports and services, enhance policy to create funding streams, and ultimately to connect services to family outcomes to ensure accountability.

RECOMMENDATIONS FOR FUTURE DIRECTIONS

As illustrated in Figure 1, this paper was drafted after the Summit and following additional in-depth empirical, conceptual, and statutory analyses as shown in Phase 2 of Figure 1. Beach Center researchers took the lead in drafting the recommendations based on input at the Summit and input that occurred through the process of sending the paper to all co-authors three times and soliciting their input, suggestions for changes, and confirmations. By getting input from diverse stakeholders represented on the co-author team (e.g., families, researchers, teacher educators, graduate students, technical assistance providers), it was possible to add, delete, and refine recommendations until this calibration reached the point of consensus. In addition, this paper underwent

a blind review process and revisions were made based on reviewer and action editor feedback.

Recommendations for Policy

Preserve and improve existing law. Two strategies can enhance the existing statutes. Each strategy requires incremental policy reform. Each should be attainable within the next 5 years, and each would need to be activated whenever Congress considers reauthorization or amendment of any of the four statutes.

The first strategy is to persuade Congress to preserve what already exists related to family support, particularly in the DD Act. The DD Act is up for reauthorization in 2007. The work of the CoP needs to be directed toward strengthening the DD Act in making its goals for families as primary beneficiaries more explicit, developing a life-span framework of supports and services to begin a “domino effect” for other federal statutes, and adding accountability provisions and individual rights provisions.

The second strategy is to persuade Congress to amend IDEA, Title V, and the Children’s Mental Health Act (as appropriate, given the purposes and language of each law) to incorporate explicitly family outcomes and to authorize supports and services for families. The law seeks consistency, as do those practitioners and families who are affected directly by one or more statutes. Consistency in policy and practice will result if Congress conforms those four laws to each other, using the continued advice, partnership, and participation of family organizations and the CoP for guidance in family policy in early intervention and early childhood special education.

Enhancing IDEA is particularly important because it is the primary statute on which early intervention and early childhood services rely. The family services in IDEA (as described in Tables 1 and 5) have not been expanded since Parts B and C were first enacted and have been limited in their actual implementation. The CoP might focus its effort to build the knowledge base and establish the momentum for significant and

comprehensive enhancements of family goals, supports and services, and partnerships in the next reauthorization of IDEA, which can be expected around 2009.

The third strategy is to embed family support within Medicaid (Title XIX, Social Security Act). First, Congress could amend the Act to provide explicitly that family support is a Medicaid reimbursable service. Second, The Center for Medicare and Medicaid Services (CMS) could provide in its “New Freedom” or system change-grant templates that family support is a Medicaid reimbursable service. Either choice faces obstacles: (a) the need to define family support (such as the DD Act defines it, by outcomes and nature of services); (b) the cost-containment requirements that the Deficit Reduction Act of 2005 placed on Medicaid; and (c) the fact that medical costs are the ever-enlarging sector of the domestic gross national product and consequently diminish available funds for other discretionary domestic expenditures, such as education. Nevertheless, it seems that states include Medicaid expenditures as family support expenditures when reporting data on that element of their federal-state budgets (Braddock, 2002). Given items (b) and (c), above, preserving the states’ use of Medicaid funds for family support, however, might require explicit action by Congress or CMS.

Enactment of new legislation. In addition to preserving policy that already exists, a second recommendation for enhancing policy related to family supports and services would be for Congress to enact a new law, American Families of Individuals with Disabilities Act (AFIDA). The AFIDA would adopt the overarching goal declared in the National Goals Conference: to support family caregiving efforts and enhance families’ quality of life (citing the provisions of the DD Act about families having a claim to “enjoy” their child). It would authorize federal, state, and local activities, funded by joint federal-state appropriations, to carry out the five National Goal Conference’s subgoals (see Table 4). The AFIDA also

would establish program evaluation criteria consistent with the research literature that defines family quality of life (Hoffman et al., in press; Summers et al., 2005; Turnbull et al., 2005).

Recommendations for Research

Much work is needed to guide the development, implementation, and monitoring of family supports and services within EI. Specific directions for research include the following:

- Develop an initial conceptualization of family supports and services based on three sources of knowledge – best-available research evidence, family and professional wisdom, and family and professional values (Winton, 2006).
- Synthesize research to document the relationship between specific types of family supports and services and family outcomes at the early childhood, elementary, secondary, and young adult lifespan stages.
- Document the sample demographics in the research synthesis to ascertain the extent to which families from culturally and linguistically diverse backgrounds have been adequately included in research.
- Partner with DEC and other organizations to recruit success stories (told from the perspectives of both families and service providers) linked to the domains/topics/subtopics of the family supports and services framework and evidence-based practice; organize the success stories for easy, quick, and free Internet access. Conduct a qualitative analysis of the success stories to discern grounded theory related to what is working for families and service providers.
- Conduct a line of studies (including longitudinal research) to document the effectiveness of various types of family supports and services and how effectiveness relates to various child and family demographics.
- Conduct research on knowledge utilization related to family supports and services to document the types of knowledge generation, knowledge organization and translation, and knowledge mediation and

application (Winton, 2006) approaches that work best for families who have varying demographic characteristics including income, native language, ethnic/racial background, geographic location, and nature and extent of child's disability.

- Conduct research with young adults with disabilities who are experiencing a self-determined and inclusive lifestyle and with their family members on what priorities they believe are most important in providing supports and services to young children with disabilities and their families to experience individual and family quality of life across the lifespan.
- Conduct a line of studies to document the impact of the enhancement of family outcomes on child outcomes and explore interventions to strengthen child outcomes through the enhancement of family outcomes.

A broad agenda such as the one proposed here will require a consortium of investigators and family advocates focusing on aspects of the framework but coordinated to enable eventual synthesis of an evidence base to guide practices and policies. A coherent research agenda targeted on family supports and services might be organized around a logic model based on the framework and outlining hypothesized short-term, immediate, and long-term outcomes for various services and supports within the framework. Members of the research consortium would investigate aspects of the supports and services framework but all would agree to use common measures of family and child outcomes, including longer-term measures of child achievement and family quality-of-life outcomes. The involvement of families, family advocates, and practitioners within a participatory action research paradigm would be a necessary component of the research consortium's efforts. Participation by families in the design, conduct, and interpretation of research to validate a framework of family supports and services is not only compatible with a program of research that is rigorous and leads to a strong evidence base; it also is

a necessary element in the long-term utility and acceptability of the results (Lamb-Parker, Greenfield, Fantuzzo, Clark, & Coyle Coolahan, 2002; Santelli, Singer, DiVenere, Ginsberg, & Powers, 1998; Turnbull, Friesen, & Ramirez, 1998).

Recommendations for Professional Development Directions

An effective professional development curriculum is critical to achieve long-term change and implement evidence-based practices identified through a program of research. At every step along the way, participatory research teams would need to identify critical learning competencies and program structures necessary to implement the family supports and services framework and achieve the desired outcomes. Both aspiring students and professionals in the field need competencies and program structures to instill needed knowledge, skills, and attitudes to serve families. Faculty and trainers will need professional development so they can adequately prepare and support practitioners. Along with providing effective training, it is equally important to recruit future professionals from among diverse ethnic and socio-economic groups to foster greater understanding and support to families from culturally and linguistically diverse backgrounds.

FINAL CHALLENGE

The challenges are great. So is the need. The recommendations presented will not be achieved quickly. Nor the needs met easily. To advance the agenda outlined here, the advice offered by legendary basketball coach, John Wooden, from the University of California at Los Angeles (UCLA), is pertinent:

When you improve a little each day, eventually big things occur...Not tomorrow, not the next day, but eventually a big gain is made. Don't look for the big, quick improvement. Seek the small improvement one day at a time. That's the only way it happens – and when it happens, it lasts. (Wooden, 1997, p. 143)

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