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William B. Carey, MD
Clinical Professor of Pediatrics
University of Pennsylvania
School of Medicine
Director of Behavioral Pediatrics
Division of General Pediatrics
Children’s Hospital of Philadelphia
Philadelphia, Pennsylvania

Allen C. Crocker, MD
Associate Professor of Pediatrics
Harvard Medical School
Associate Professor of Maternal and Child Health
Harvard School of Public Health
Program Director, Institute for Community Inclusion
Children’s Hospital
Boston, Massachusetts

William L. Coleman, MD
Professor of Pediatrics
The Clinical Center for the Study of Development
and Learning
University of North Carolina
Chapel Hill, North Carolina

Ellen Roy Elias, MD
Professor of Pediatrics
University of Colorado School of Medicine
Director, Special Care Clinic
The Children’s Hospital
Denver, Colorado

Heidi M. Feldman, MD, PhD
Ballinger-Swindells Professor of Developmental
and Behavioral Pediatrics
Stanford University School of Medicine
Stanford, California
Medical Director
Mary L. Johnson Developmental and Behavioral
Pediatric Programs
Lucile Packard Children’s Hospital
Palo Alto, California
EARLY INTERVENTION SERVICES
PENNY HAUSER-CRAM AND MARJI ERICKSON WARFIELD

WHAT ARE EARLY INTERVENTION SERVICES?
Early intervention (EI) services are designed to benefit the development from birth to the age of 3 years of children who have or are at risk of having disabilities or special needs that substantially delay development and to support the adaptation of their families. In general, the goals of EI are to facilitate service provision and coordination and, when necessary, to provide direct services. The services vary according to the nature of the child’s special needs. Direct services include speech and language therapy, occupational therapy, physical therapy, special instruction, and family education and counseling, although other services, such as assistive technology, nutrition instruction, and audiology services, may also be provided. Both the frequency and the intensity of EI direct services are low compared with other early education services, such as preschool or Head Start; the actual hours of EI service provided to families average less than 2 hours a week (Shonkoff et al, 1992; U.S. Department of Education, 2003). Therefore, EI services are designed to coordinate other services and to support parents and other caregivers in optimizing child development and family adaptation.

A BRIEF HISTORY OF EARLY INTERVENTION
The history of EI is embedded in a larger history of dual national commitments to serving young children at risk of poor developmental (including health) outcomes and their families and to providing services for individuals with disabilities within typical settings rather than in settings specialized only for those with disabilities. The federal responsibility for the well-being of children and their mothers was affirmed by the Social Security Act of 1935, Title V, which established the framework for Maternal and Child Health Services, Services for Crippled Children, and Child Welfare Services. Through Title V legislation, financial assistance to the states is provided to establish prenatal care, well-child clinics, and services to prevent infant mortality and disabilities that limit children’s health and development. In 1991, the Maternal and Child Health Bureau began supporting Healthy Start, an initiative to stimulate community-based services to reduce infant mortality and low birth weight and to eliminate racial disparities in perinatal outcomes.

In addition to public health services, federal support for children with disabilities emerged from educational services. Stimulated by the War on Poverty in the 1960s, Head Start was established as a means of providing early education experiences for children and support for their families. Related programs (e.g., the Abecedarian Project, the Brookline Early Education Project, and the High/Scope Education Perry Preschool Project) were initiated as randomized experiments or quasi-experiments to evaluate educational interventions in the early childhood years, largely for children living in poverty. Evaluations of such early childhood programs indicate that they have had positive effects on children, especially in the domain of cognitive development and long-term health and functional outcomes (Anderson et al, 2003; Palfrey et al, 2005).

Programs focusing on children with developmental disabilities were stimulated by the passage by Congress of the Handicapped Early Education Program in 1968, which provided federal funding for the development of a series of model programs. A more comprehensive federal role in supporting the development of programs and services for young children with disabilities took several decades. In 1975, the landmark legislation Education of All Handicapped Children Act (Public Law 94-142) was passed and guaranteed the right to free and appropriate education for school-age children with disabilities. Although this legislation also provided incentives for states to serve children aged 3 to 5 years with disabilities, it did not address the needs of infants and toddlers. In 1986, however, in amendments to the Education of the Handicapped Act (PL 99-457), states were required to provide services for children aged 3 to 5 years with disabilities in order to qualify for federal special education funding. That legislation also provided incentives to states to create programs to address the needs of infants and toddlers with disabilities. Reauthorized under a new title, the Individuals with Disabilities Education Act (IDEA) in 1991 (PL 101-476), the legislation determined specific activities required of the states (described in the

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next section) should they decide to set up a statewide system of EI services and thus participate in the federal program.

HOW DOES FEDERAL LEGISLATION GUIDE CURRENT EARLY INTERVENTION SERVICES?

A national commitment to the provision of EI services is codified by Part C of the current reauthorization of the Individuals with Disabilities Education Act (IDEA 2004) (PL 108-446). All states have elected to participate in Part C. According to IDEA, the goal of such services is “to enhance the development of infants and toddlers with disabilities” and “to enhance the capacity of families to meet the special needs of their infants and toddlers” (20 USC 1431, as amended by the IDEA amendments of 2004). Several key components of EI services are required by IDEA. Among these are (1) the construction of an early identification and referral program (often referred to as child find activities), (2) the development of an individualized family service plan (IFSP), (3) the stipulation that EI services be provided in “natural environments” to the maximum extent possible, and (4) the construction of an interagency coordinating council. Each is described briefly.

Children and families may be referred to EI services by parents or by professionals, but current data indicate that in most states, the majority of referrals are made by pediatricians or other health care personnel. Although parents are often the source of referral in suburban communities, they rarely are in urban centers. States have indicated that their child find efforts have faced numerous obstacles. In general, public service campaigns including television, radio, and newspaper advertisements and distribution of information to health and medical settings are used, but these are often not produced in multiple languages or distributed sufficiently, especially in rural areas (U.S. Government Accountability Office, 2005). Therefore, a screening questionnaire completed by parents and reviewed by pediatricians or other health care providers can serve a critical function in locating children and families for whom EI services may be warranted.

Although participation in EI services is optional and services are subject to family approval, once a family decides to participate, the target child is provided with a comprehensive, multidisciplinary assessment. This assessment generally involves measurement of a child’s skills in all areas of development but also should focus on the child’s abilities within family-identified activities and routines. After the assessment, parents are asked to participate in the development of an IFSP, which includes the components listed in Table 92-1. Furthermore, mandates that families must be informed of their rights and must receive a review of the IFSP every 6 months.

A wide range of services can be specified on the IFSP (including, for example, speech and language therapy, occupational therapy, physical therapy, educational support, social services, audiology, assistive technology), but health services are included only to the extent that they are deemed “necessary for the infant or toddler to benefit from other early intervention services” (20 USC 1432). The service provided most frequently is speech and language therapy, followed by special instruction, physical therapy, and occupational therapy (U.S. Government Accountability Office, 2005).

Another requirement of Part C is that services be provided in natural environments. Natural environments are interpreted as those contexts in which children typically learn, play, and are nurtured. The child’s home, the childcare home or center, and the settings of other activities in which a family participates (e.g., religious services, community-based athletic activities) are considered natural environments. The most frequent setting in which services are provided is the home, followed by the childcare setting. Although a parent usually participates in EI services when they occur at home, a parent is less likely to do so when the services are provided in a childcare setting. Therefore, the Council for Exceptional Children recommends that EI service providers consult with teachers and childcare providers as well as with parents to maximize continuity in approaches to enhancing the child’s development.

Consideration of the transition from services provided through Part C to those provided by Part B of IDEA (i.e., preschool services) has also been placed in the legislation. Children can receive Part C EI services until they turn 3 years of age. Although a provision has been made for Part C funds to be used to continue to provide services from the age of 3 years to the beginning of the next school year, only 14 states have adopted this policy. In the most recent reauthorization, states have also been given the option of providing children and families with Part C services until the child is eligible for kindergarten (U.S. Government Accountability Office, 2005).

Finally, each state is required to develop an interagency coordinating council (ICC), which is a statewide, coordinated multidisciplinary and interagency system. In general, the ICC is composed of members from public health, mental health, education, and social services. The composition of the ICC differs by state, but all states are required to have parents on the ICC, which is consistent with the family focus of EI services.

STATE VARIATIONS IN EARLY INTERVENTION SERVICES

Much state discretion has been built into the federal legislation relating to EI services. In particular, states vary considerably in three dimensions of EI services: lead

Table 92-1. Components of the Individualized Family Service Plan

The individualized family service plan (IFSP) contains a description of the following:

- The child’s current functioning and skills
- The family’s strengths, resources, priorities, and concerns
- The major expected outcomes (including measures, criteria, and timeline)
- The specific services the child and family will receive, including their initiation and duration
- The natural environments in which EI services will be provided
- A named service coordinator
- Plans for a successful transition from EI to preschool services

EI, early intervention.
agency, service eligibility criteria, and service intensity. States are required to designate a lead agency, which will be responsible for ensuring public awareness about EI services as well as for defining eligibility criteria and establishing the process of service delivery. In 23 states, a combination of health and human service departments serves as the lead agency, whereas 16 states have designated health departments and 11 states have designated education departments as the lead agency (U.S. Government Accountability Office, 2005).

EI services are provided to children younger than 3 years who are developmentally delayed, but the definitions of such delay and how to measure it vary widely across states. These variations in turn influence eligibility. Some states (e.g., Georgia) base the definition of delay on standard deviation units, others (e.g., Arizona) on percent delay. Hawaii differs from other states by basing eligibility on the judgment of a multidisciplinary team. States also vary in whether they serve children who do not have a documented delay but who are at risk of having a substantial delay because of biologic or medical risk (e.g., low birth weight, chronic lung disease) or because of environmental risk associated with the caregiving and family situation (e.g., homelessness, parental developmental disability, parental age). In some states (e.g., Massachusetts), families of children with low birth weight are eligible for services; in others (e.g., Hawaii), families in which a parent is younger than 16 years may qualify. Other states (e.g., Florida) do not serve children who are "at risk" through Part C programs but monitor such children through other programs.

The most recent reauthorization indicates that states need to put in place policies and procedures of referral to EI services for children who have been victims of substantiated abuse or neglect or affected by illegal substance abuse (Danaher et al., 2006). The link between social service agencies and EI services optimally will be strengthened by this requirement, but so too should the relationship between physicians and EI. Once states embark on this new policy, an additional population will enter the EI service system regardless of a state's decision about including children "at risk."

Nationally, about 2.1% of the total population of children in the United States are served by EI (U.S. Department of Education, 2003), although it is estimated that EI currently serves less than the estimated 15% of children who will eventually be eligible for special education services (Bailey et al., 1999). States vary in terms of the percent of the 0-3 population served, from a low of 1.6% in Oregon to a high of 7.1% in Hawaii. Funding sources also seem to vary by state. Although all states receive funding under IDEA Part C, some use additional public or private funding sources. For example, Medicaid, Child Care and Development Block Grants, Temporary Assistance for Needy Families, Early Head Start, and Maternal and Child Health Title V are other sources of funds used in some states to support the provision of EI services. At least one state (New Jersey) charges a sliding monthly fee that depends on family size and income related to federal poverty guidelines (U.S. Government Accountability Office, 2003), although in most states, EI services are provided without charge to families regardless of their socioeconomic status.

**WHO PARTICIPATES IN EARLY INTERVENTION SERVICES?**

Although there is no one typical child or family who participates in EI services, data from the National Early Intervention Longitudinal Study (NEILS) (Searborough et al., 2004) yielded findings about important demographic trends in EI participation. The authors of this national survey reported that a higher proportion of African American and a lower proportion of white infants and toddlers were being served in EI in relation to the U.S. population for the 0-3 age group. Families also appeared to be disproportionately poor and mothers were less likely to be employed, although families of all employment and income groups are eligible to participate. Children were less likely to be living in a family with two parents and were more likely to have a sibling with special needs. About 40% of children had spent time in the neonatal intensive care unit. In addition, a relatively higher proportion of children in foster care (7%) were in EI services compared with those in foster care in the general population of infants and toddlers (0.8%). It is not clear if children in foster care represent a new demographic trend in participation in EI services or if they have been overlooked in prior investigations. Regardless, the reauthorization of IDEA Part C now includes an emphasis on locating infants and toddlers in foster care who meet the criteria for participating in EI. In summary, EI services are used by a large range of families, and trends indicate that future increases in EI enrollment will be composed of children in foster care and children who have been abused or neglected. Currently, EI services are reaching fewer young children with special needs than the number that is estimated to exist in the U.S. population (3.4%), and not all eligible children are being served (U.S. Government Accountability Office, 2005).

It has been noted that some children who could potentially benefit from EI services, such as those with socioemotional disorders, are not systematically tracked (U.S. Government Accountability Office, 2005) and therefore may not be receiving services. Children with socioemotional disorders appear to be a group that has been overlooked in referrals to EI services. Despite data indicating that 10% of kindergarteners arrive at school with problematic behavior (West et al., 2000), children with challenging behaviors are seldom identified in the infant and toddler years. This is a critical oversight as young children with severe behavior problems are likely to exhibit continuing difficulties with self-regulation, and their families are likely to experience increasing levels of stress (Fox et al., 2002). Some of these children may be referred to EI because of speech and language delays and consequent poor skills in verbal self-regulation. Others, however, may be overlooked because the “typical toddler” is often seen as having difficulties with self-regulation.

Children with autism spectrum disorder (ASD) are another group with socioemotional difficulties. The
prevalence rate of children with ASD appears to have been underestimated according to a study funded by the Centers for Disease Control and Prevention (Yeargin-Allsop et al, 2003). As the ability to diagnose children with ASD during the infant and toddler years increases, it is likely that children with ASD will be a growing population in EI. Moreover, pediatricians will be asked to screen for ASD and refer young children who may show signs of this disorder.

**THE PRINCIPLES OF EARLY INTERVENTION**

The principles of EI emerge primarily from the scientific research base on child development, family systems, and human ecology. EI services have transformed from placing primary focus on providing therapeutic services to the child alone to a broader focus on providing services to the child as an integral part of a family, neighborhood, and community. This represents a move away from a deficit "fix the child" model to a relationship-based model in which the family with its social network is considered the main source of intervention and support for the young child’s development (Fig. 92-1). During the last 2 decades, the field of child development has increasingly recognized the importance of an ecologic perspective of the child as a part of the family, community, and culture (Bronfenbrenner, 1986), with a broader understanding that the child with disabilities, like all children, lives within multiple interacting systems (Guralnick, 2005b). EI is one of those systems, but it also has the concomitant responsibility of organizing other systems through service coordination.

One important principle of EI is that earlier provision of services is better for children and families. This is based on evidence that developmental trajectories can potentially be changed during the early years and that the development of secondary disabilities can be prevented by the provision of services when a child is very young. A comprehensive review of the science of development in early childhood suggests two critical findings about the role of experience in brain development (Shonkoff and Phillips, 2000). First, although few in number, some studies suggest that gene-environment interaction may explain differences in children’s reaction to patterns of parenting and child rearing events. Second, studies indicate that much brain development is experience dependent and that such development can change behavioral functioning. Although the early years are not the exclusive domain of such transformations, they often set the course of developmental trajectories.

Another critical principle is the importance of the family, especially of relationships within the family, as both a context and conduit for children’s optimal development. Parents and caregivers are central sources of support for the child’s learning and emotional well-being, but family relationships can also create the context in which parent-child and sibling interactions occur. The results of our research study on children and families who have participated in EI services, the Early Intervention Collaborative Study (EICS), indicate that children with disabilities have more positive developmental trajectories when they reside in cohesive families, regardless of the marital or socioeconomic status of the family (Hauser-Cram et al, 2001).

Families hold and pass on values and beliefs that are both distinct and culturally derived. Some values and beliefs are demonstrated through family rituals, such as family dinners and bedtime routines. Such rituals and routines require modification whenever a new individual joins the family, but when that individual is a child with disabilities, a larger number of accommodations are often required. These can include attending many appointments, gathering information from a range of sources, and changing employment schedules. Core values about parenting, the meaning of disability, and the appropriate role of service systems in assisting the family are situated within cultural belief systems that even in the absence of being fully articulated need to be acknowledged and respected by EI and other service providers. For example, parents are not the sole decision makers about a child’s well-being in some cultures in which grandparents’ views are given much weight (Garcia Coll and Magnuson, 2000). Moreover, the cause of a problem may be perceived differently across cultural groups. For example, Fadiman (1997) describes how the etiology of a child’s seizure disorders is viewed in distinctly different ways by her Hmong parents in comparison to her Western physicians. Such differences may result in cultural clashes about appropriate preventive and ongoing treatment. In addition, intervention that is meaningful to a family is bound to cultural theories of change. Such theories may be consonant with or differ significantly from those of Western service providers. The potential for cultural mismatch exists at many levels of belief systems, encompassing perspectives on how children best develop, the role of family members in supporting that development, and the ways in which services can effect developmental change.

EI often serves as a catalyst in helping the family build on the learning potential of the young child (Fig. 92-2). Through EI services, parents can be guided in ways to scaffold the child’s learning and can develop strategies to help the child participate in family and community activities. Parents in our study (i.e., EICS) have indicated that through EI, they have learned new routes to their
child’s learning by, for example, positioning the child appropriately, being patient by waiting for a child’s delayed response to a stimulus before responding, breaking down tasks into smaller and more manageable chunks, encouraging task persistence, and providing activities that are slightly but not overly advanced for the child. Through these accommodations, parents discover their child’s approach to learning and reaffirm their own role in the learning partnership.

Such a partnership, supported by EI services, can enhance the positive perceptions parents have of their child’s strengths and accomplishments. Although parents are often distressed at the time of their child’s diagnosis, EI services can help parents discover the unique ways their child with disabilities contributes to their life and the life of their family as a whole. In EICS, we found that mothers who had received more hours of EI service from entry to discharge reported positive changes in family cohesion (Warfield et al., 2000). In cohesive families, the child with disabilities is an integral and respected member of the overall family. For some families, the support and culture of EI can help them become more cohesive units.

Related findings have been reported by the researchers conducting NEILS (2007). They indicate that one benefit of EI is in helping families be hopeful about their child’s future. Optimism is likely to be an important ingredient in the parent-child partnership as well as in the relationships within the family. Indeed, the posited family strengths built into the culture of EI provide an attitude essential to the development of a strong parent-child relationship.

An additional aspect of parental and child benefits of EI is based on the importance of parents becoming advocates for their child. The difficulty of negotiating multiple systems of care has been highlighted in many studies of families with young children with special health care needs and developmental disabilities. Such negotiation is often a lifelong demand on families. The NEILS study found that a large majority of parents considered their sense of efficacy and skills related to child advocacy among the benefits they gained from EI services (Bailey et al., 2005). Parents also are an excellent source of assistance to other parents in becoming advocates. When we asked our EICS parents about advice they would give to families entering EI services, they provided a wide range of useful and practical suggestions but mainly focused on three themes: gather information, take care of yourself, and be patient with your child (Table 92-2).

A third critical principle of EI services is that systems need to work together on behalf of the child. This is accomplished through the ICC at the state level but requires effort on the part of service providers at the individual level. This principle is consistent with selected goals from Healthy People 2010 and recommendations from the Institute of Medicine (Anderson et al., 2003). Both entities indicate that multiple levels of influence (e.g., individual, interpersonal, institutional, community, and policy) need to be linked so that early childhood programs can best promote optimal child and family outcomes. All ICCs include parents and have a chairperson from an agency that is not the lead agency in the state. The goals of the ICCs are to collaboratively plan, implement, and evaluate EI services and to serve as a model for systems integration at all levels of service.

The need for such interagency collaboration exists at the program level as well, and some findings from an evaluation of Early Head Start indicate that links between that program and EI services can be made productively (Wall et al., 2005). Collaboration also needs to occur within the program as many types of service providers, with varying backgrounds and expertise in different domains of information and skills, need to function together on behalf of children and families. Such collaboration is rarely taught in university domain-specific programs yet is essential to service provision in EI.

Systems often become taxed during times of transition, and the federal law has some provisions to prevent gaps in services when families move from EI (Part C) to preschool services (Part B). Nevertheless, such gaps exist, and even when a smooth transition is enacted, families are likely to experience a difference between the family focus of EI and the child focus of preschool programs.

Table 92-2. Parents’ Advice to Families Entering Early Intervention Services

<table>
<thead>
<tr>
<th>Advice</th>
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<tr>
<td>Always ask questions. You are the one who knows your child the best.</td>
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<tr>
<td>Don’t wait for people to call you, call them.</td>
</tr>
<tr>
<td>Learn as much as you can about the ability and disability of your child.</td>
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<tr>
<td>Be an advocate and ask about what resources are available.</td>
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<tr>
<td>Link up early with other parents who have already gone through this experience.</td>
</tr>
<tr>
<td>No one really knows how your child will progress, so be patient.</td>
</tr>
<tr>
<td>Ask for documentation. The EI program had all this documentation that said “3 weeks ago he couldn’t do this” and now he’s doing it. They helped us see all the small milestones.</td>
</tr>
<tr>
<td>Professionals need to know that they are not just dealing with an illness or delay, they are dealing with the whole child and the whole family.</td>
</tr>
<tr>
<td>Understand that things don’t have to be cheerful all the time.</td>
</tr>
<tr>
<td>Don’t make too many exceptions for your child. At the same time, keep in mind her or his limitations and special needs.</td>
</tr>
<tr>
<td>Remember to take some breaks for your own well-being.</td>
</tr>
</tbody>
</table>

This is not the end of your life; it may even be the beginning.
Preparation for this transition requires collaboration at all levels of service from the state ICCs to the individual EI and preschool programs.

**EFFECTIVENESS OF EARLY INTERVENTION SERVICES**

Given the legislation that has pushed the development of state and local level EI systems and the general proliferation of programs and services under the EI umbrella, it is reasonable to ask what research evidence exists to support this national commitment. This section presents a brief review of past and current evaluations of EI, highlighting both the challenges and opportunities in conducting evaluation research in the EI field. An assessment is made of how the four key components of EI service systems operate and to what extent they have an impact on the children and families who are served. Directions for future EI evaluations are also discussed, with an emphasis on outlining opportunities for pediatricians to share their expertise in the continuing development and implementation of the EI service system.

**Past Evaluations of Early Intervention**

Guralnick (2005b) has divided evaluations of EI programs and services into two phases based roughly on whether they assessed EI before or after the passage of the original legislation, PL 99-457, in 1986. First-generation studies, defined as those conducted primarily before PL 99-457, assessed whether EI was effective in terms of whether child functioning improved as a result of the intervention. Consistent evidence has been found for the positive although modest impact of EI on children with disabilities, including those at environmental risk, those at biologic risk, children with autism, and children with Down syndrome (Guralnick, 2003a).

In addition to addressing the question of the overall effectiveness of EI, one prominent analysis selected the 31 highest quality evaluations of EI for children with biologic concerns to assess whether effectiveness varied for children with different characteristics and which selected program characteristics had a greater impact on child outcomes (Shonkoff and Hauser-Cram, 1987). Greater cognitive gains were found for children characterized as developmentally delayed in comparison to children with intellectual disabilities. Children with orthopedic disabilities experienced the smallest gains in cognition. In terms of severity, infants identified as mildly impaired experienced better outcomes if they entered an EI program before they were 6 months of age versus after 6 months of age, whereas age at entry had no influence on the outcomes for children with more severe disabilities. Two program characteristics were also found to be associated with greater child effects. Programs with well-defined curricula versus those with less well defined curricula and programs that had high levels of parent involvement versus those with little parent involvement were more effective. Although the studies selected for this analysis were the best available for children with biologic disabilities, there was not enough data to assess effectiveness in terms of outcomes other than child cognition, such as social competence, behavior, or motivation. Further, even fewer data were available to evaluate effectiveness relative to family functioning.

Despite these overall positive findings, the first-generation studies were based primarily on model EI programs with considerable resources and highly trained staff. EI programs operating under Part C legislation, however, are more varied and serve a more diverse population. To help guide the development and implementation of effective EI service systems under Part C, therefore, evaluations must address a greater number of more specific questions.

**Current Evaluations of Early Intervention**

Second-generation evaluations of EI have focused on assessing what types of interventions work best for whom, under what conditions, and toward what ends. Thus, second-generation evaluations are seen as a potential source for development of evidence-based practices (i.e., practices that have been identified by empirical research as influencing desired outcomes for children, families, professionals, and systems) (Odom and Wolery, 2003).

**Evaluation Challenges and Opportunities**

Two key methodologic challenges face researchers who want to conduct second-generation evaluations. First, traditional experimental designs, using random assignment to create a treatment group that gets the intervention and a control group that does not, have been promoted as the best way to attribute the benefits participants get from an intervention to the treatment itself (Weiss, 1998). Now that EI services are mandated for all eligible children and families who want to participate, however, denying services to a child and family for the purposes of placing them in a control group is unethical and illegal. Second, services under Part C are to be individualized to fit the needs and goals of each child and family. The treatment can no longer be a “one size fits all” intervention with predefined types of services provided at a set level of intensity for a selected time aimed at one common set of outcomes.

Fortunately, evaluation science has moved away from a strict focus on experimental designs, random assignment, predetermined interventions, and impact studies and has embraced the use of a broader set of evaluation questions and methods (Warfield and Hauser-Cram, 2003). No one standard evaluation strategy is considered appropriate for all programs, services, or interventions. Rather, individualized plans need to be developed for each situation to maximize the fit between the program’s or system’s capacity for evaluation and the goals of the evaluation. Evaluation plans should encourage input from all stakeholders (i.e., not only EI administrators and staff but also current collaborators and potential collaborators such as pediatricians and social workers).

Three main foci of evaluations can produce data needed by EI administrators and providers seeking to institute evidence-based practices. First, EI evaluations must address questions of accountability. Evaluations can document accountability by presenting data on the
extent to which the program is identifying and serving those who are entitled to services, providing the range of services it is mandated to provide, and establishing some reasonable match between participant need and service receipt. In addition, evaluations that measure participant satisfaction can show how a program is being accountable to its constituents. Second, EI evaluations need to address questions of system and service quality. These studies must seek to develop ways to assess the quality of the services delivered (i.e., to what extent services go beyond the minimum standards required by law) and measure the perceived (as opposed to the objective) effects of the intervention. These analyses are useful for providing feedback that can be used to reform or to improve the system, program, or service being evaluated. Third, EI evaluations must still address impact questions, particularly to understand the nature of the relation between the mandated components of EI services (i.e., child find and referral activities, individualized services, the provision of services in the natural environment, and service coordination) and a series of appropriate outcomes, which depending on the nature of the evaluation could be focused on child development, family adaptation and empowerment, or system operation and efficiency.

Complementing these expanded evaluation questions are a broader array of qualitative and quantitative methods available to address them. A wide range of qualitative methodologies are now encouraged because of their ability to ask questions and to probe for answers not easily obtained by quantitative strategies. These approaches include focus groups, case studies, and observation studies (Patton, 1987) as well as mixed method approaches that integrate quantitative and qualitative methods (Hauser-Cram et al., 2000). Further, sophisticated multilevel data analysis techniques are now widely available that allow evaluators to assess the influence of community-level characteristics on individual children and families as well as to track changes in measures of child development and family adaptation over time and test whether child, family, or program characteristics are significant predictors of those changes (e.g., Hauser-Cram et al., 2001).

The following sections review selected evaluation studies that have sought to assess accountability, quality, and impact questions relative to the implementation of each of the four key components of EI outlined in the legislation.

**Child Find and Referral Services**

Three main strategies have been identified as useful in making states and localities more accountable for identification and referral. First, five types of risk registers have been identified as useful for child find purposes (Dunst et al., 2004). These include birth defects surveillance programs, newborn medical screening programs, newborn hearing programs, child protective services registries, and population-based registries. Second, pilot studies have been conducted to understand the processes and relationships that must be built between systems to use these information sources not only to increase identification but to set up procedures for the consistent referral of children to EI. For example, a pilot program in Massachusetts built linkages between the Department of Social Services that handles cases of child abuse and neglect and the Department of Public Health that is the lead agency for Part C EI. These linkages increased the number of children in substantiated cases of abuse and neglect who were referred to and assessed by EI. More than two thirds of these children were found eligible for EI and subsequently received services (Lippitt, 2003). Third, physician training and pediatric resident training programs that promote an understanding of the value and benefit of EI have facilitated referrals by physicians (Shapiro et al., 2003).

**Individualized, Family-Centered Services**

Many barriers to implementation of individualized family-centered EI services have been identified. These often involve dilemmas around matching resources and needs. For example, although ideally families are to list their needs and goals and the types of services they require to meet those needs and to reach their goals, providers may emphasize the use of those services that are reimbursable under Part C (Shannon, 2004). The match between resources and needs also must consider the number and duration of visits that insurance companies will cover. One model for better equalizing the involvement of families and professionals in developing and implementing family-centered services has been to use parents of young children with disabilities as parent educators in the Part C system (Gallagher et al., 2004). In Georgia, parent educators work with families new to EI to help identify family needs, inform families about parent resources, help train EI providers, and serve on local and state ICCs. During the years, families have consistently rated the parent educators as most helpful in terms of disseminating information, encouraging families to become involved in EI, and helping families feel like an important member of the EI team (Shannon, 2004).

**Services in the Natural Environment**

The requirement to provide early interventions in natural learning environments is a tremendous test for providers because the traditional service delivery models do not fit easily into this new approach. One indicator of the challenge in making this shift was demonstrated by a study in which the content of IFSPs from EI programs in eight states was examined in relation to how they referenced activities in natural environments (Dunst et al., 1998). More than 3000 IFSP outcome statements were evaluated and only 1.3% of the outcome statements were described in terms of everyday family activities; even fewer (0.4%) were described with reference to everyday community activities. Despite these findings, some limited evidence exists on the effectiveness of natural learning environments to improve child functioning. Dunst, Bruder, and Trivette (2001) described how parents can identify goals for their child to achieve and activities that their child enjoys. In consultation with an EI provider, a match between a favorite activity (e.g., playing in the sandbox at a local playground) and a desired outcome (e.g., improved
social interactions with other children) can be achieved by encouraging parents to increase the frequency with which their children participate in their favorite activity over time and giving them strategies for reducing negative behaviors (e.g., throwing sand) and increasing positive behaviors (e.g., sharing sand shovels). The use of these natural learning opportunities has been associated with reductions in behavior problems.

Service Coordination

In a review of studies assessing the benefits of service coordination in EI, the impact was found to vary by the type of outcome evaluated (Dunst and Bruder, 2002). In these studies, the implementation of service coordination was demonstrated by an improved flow of resources, supports, and services. Although increased coordination was not associated with improved parenting and child functioning, it was consistently associated with higher levels of parent satisfaction and reports of greater parental well-being and quality of life. The status of implementing service coordination policies and procedures at the state level has been examined in a national survey of state Part C coordinators. Harbin and colleagues (2004) found that in general, most states do not yet have a sufficient policy infrastructure (e.g., specific interagency agreements) to support the implementation of effective service coordination. However, some progress has been made. For example, although only about one quarter of states specify the authority of the service coordinator to integrate services across agencies, when authority is specified in detailed interagency agreements, service coordinators have authority to direct personnel in multiple agencies and thereby increase integration.

Future Evaluations of Early Intervention

Guralnick (2005a) outlines three key areas for future evaluation studies in EI. First, greater specificity is required that matches intervention strategies, child and family needs, and improved outcomes. This requires well-defined subgroups of children and families as well as better defined interventions. Second, given that 25% to 30% of children with disabilities experience behavioral difficulties, evaluation studies need to incorporate mental health issues in part by including socioemotional development as an outcome. Third, more evaluations focused at the system level are needed to assess and better understand the variation in program quality across community-based EI programs.

Pediatricians can facilitate the future development of EI services and systems by developing closer ties with the EI programs in their area and lending their clinical expertise in the creation of IFSPs. Pediatricians can also consider ways to more closely screen and monitor their young patients for socioemotional difficulties that may warrant an EI referral. Finally, pediatricians have some experience referring their patients to specialists and setting up associated mechanisms for coordinating care. This expertise could be very helpful to local and state ICCs, where much work is needed to implement the service coordination envisioned in the IDEA legislation.

PEDIATRICIANS AND EARLY INTERVENTION SERVICES

The role that pediatricians take in relation to EI services is variable and still evolving, but pediatricians are a central part of the multidisciplinary team serving the child and family and often act as the gateway for referrals to other services like EI. Pediatricians also provide continuity for the family across the span from early childhood through adolescence, when children and families are entering and exiting other services including EI and various school settings. The American Academy of Pediatrics Committee on Children with Disabilities (1999) has identified nine services that have direct relevance for the EI experience of children and families. By ensuring that children with disabilities in their practices have access to these services, pediatricians can fulfill the roles outlined for them by IDEA. These services are listed in Table 92-3.

Across these services, pediatricians must perform three critical tasks: identification, collaboration, and management. These tasks make it possible for infants and toddlers with disabilities and delays to benefit fully from EI services. Identification supports child find activities by using medical expertise to indicate at an early age whether a child might benefit from EI. Making a diagnosis or supplying information relevant to an eligibility determination can enhance the ability of EI providers to serve children with a variety of needs. The results of one study indicate that pediatricians are likely to refer a child with an established diagnosis but disinclined to refer children to EI because of speech and language delays or because of parental concerns about a child's inappropriate behavior (Silverstein et al, 2006). Thus, children and families who might benefit from EI are not consistently referred.

Collaboration involves building relationships with EI providers so that the pediatric office and EI agency are able to create an intervention plan best suited for each individual child and family. Although such collaboration would be useful for all children, it is essential for children with special health care needs. Research has identified practices that facilitate building of collaboration among physicians and EI providers (Buck et al, 2001). For example, the Richmond Infant Council, one of 40 ICCs in Virginia, established working relationships with key personnel in physician offices, such as

| Table 92-3. Pediatric Services Relevant to Children and Families in Early Intervention |
|--------------------------------------|--------------------------------------|
| Establish a medical home.            | Establish a medical home.            |
| Be knowledgeable of criteria for referral to EI. | Be knowledgeable of criteria for referral to EI. |
| Provide screening, surveillance, and diagnosis. | Provide screening, surveillance, and diagnosis. |
| Make referrals.                      | Make referrals.                      |
| Participate in assessments.          | Participate in assessments.          |
| Provide counsel and advice to parents. | Provide counsel and advice to parents. |
| Assist in the creation of the IFSP.   | Assist in the creation of the IFSP.   |
| Provide coordinated medical services. | Provide coordinated medical services. |
| Advocate for the child and family.   | Advocate for the child and family.   |

EI, early intervention; IFSP, individualized family service plan.
Summarized from the American Academy of Pediatrics, Committee on Children with Disabilities.
referral coordinators and nurses. From this work came the development and posting of a Web site designed for use by physicians that includes eligibility information, referral forms, and links to other related Web sites. Training in use of the Web site was provided to physicians and nurse practitioners. As a result, referrals from physicians for infants and toddlers in need of EI services in Richmond have grown (Buck et al., 2001).

Finally, management refers to coordination of services across systems for individual children and families but also to identification of areas where changes in policy could facilitate EI service delivery for all children and families. One way in which this could occur is by having pediatricians participate in local and state early intervention ICCs. At the individual level, pediatricians need to routinely ask parents about their experiences in EI and to educate service providers as well as parents about a child's health concerns and needs.

**SUMMARY**

EI services, authorized under IDEA, are now part of the service network in every state. These services, although modest in intensity, are designed to help coordinate resources for infants and toddlers with disabilities and their families as well as to provide some direct services, such as speech and language therapy, occupational therapy, and physical therapy. The services aim to be individualized and family focused as indicated by the development of an IFSP for each family that has been created by both providers and family members. Pediatricians and other health care providers serve a critical role in identifying infants and toddlers who warrant such services as well as in providing information to parents and, when appropriate, to EI service providers about a child's health care needs in relation to EI services. By learning about available EI services and making direct connections with local EI providers, the pediatrician can provide an essential link between health care needs and optimal child and family functioning.

**REFERENCES**


