

# EARLY INTERVENTION

## Definition and Purpose

Federal legislation, the **Individuals With Disabilities Education Act (IDEA)**, encourages states to develop and implement a system of early intervention services that is community-based, coordinated, and family-centered. Early intervention is a system of services designed for young children birth to three years of age who have disabilities and/or developmental delays, or who are at risk for developmental delay, and their families. Early intervention services are educational, health, and social services that support and strengthen the development of very young children who have been identified as developmentally delayed or disabled and their families (Healy, Keese, & Smith, 1989). Each state may choose whether to include children at risk for delay in their program of early intervention. Federal policies encourage states to expand opportunities for children under 3 years of age who would be at risk of having substantial developmental delay if they did not receive early intervention services.

As a physician, you have an important role to play in designing effective systems of early intervention within your community and on an individual basis for the patients in your practice.

**Refer to your state Part C agency for information specific to the eligibility of children who are at risk.**

The purpose of early intervention is to provide families whose infants and toddlers have disabilities, delays in development, or who are at risk for delay with information, support, and services related to their children's development.

James A. Blackman, MD, MPH, developmental pediatrician at the University of Virginia School of Medicine, and colleagues indicated that statewide systems of early intervention can “enhance child development from the earliest years, [to] avert the need for special education when the child reaches school age, [to] minimize the likelihood of institutionalization, and [to] provide support to families” (Blackman, Healy, & Ruppert, 1992, p. 98).

**The American Academy of Pediatrics (AAP)** and the **American Academy of Family Physicians (AAFP)** have emphasized their strong



commitment to children with disabilities and to the active role of the physician in their care.

### Research Regarding Early Intervention

Research supports the contention that the best time to work with children with cognitive, physical, or emotional disabilities is birth through early childhood (Linder, 1983.). Children’s developmental and maturational processes during these years are crucial in forming the foundation for the development and learning to come (Peterson, 1987).

Several studies clearly indicate that young children and their families benefit from receiving early intervention services (Resnick et al., 1992; Shonkoff, 1992; Upshur, 1991; Guralnick et al., 1988) and that early intervention can directly affect children’s educational outcomes in later school years.

Shonkoff (1992) notes in his article entitled, **Early Intervention Research: Asking and Answering Meaningful Questions**, that there is not a set of early intervention experiences that can be described as average or typical. Children and families served in early intervention programs receive a wide range of services, in a variety of settings and with varying frequencies, based on individual child and family needs and

priorities.

Early intervention is supported by efficacy data (Shonkoff, Hauser-Cram, Krauss, & Upshur, 1990 & Upshur, 1991) and cost effectiveness in terms of dollars; however, Shonkoff (1992) stressed the importance of measuring early intervention in terms of moral value as well. “Services for young children with more severe disabilities are provided not necessarily because it will save money later, but because it is the right thing to do” (p. 9).

In 1985, Guralnick and colleagues (Guralnick et al., 1988) conducted survey research involving all board-certified pediatricians in Ohio. A questionnaire was sent to a sample of 644 pediatricians resulting in a response rate of 54.9% (354 respondents).

Based on their responses, Guralnick and his colleagues found that pediatricians view early intervention positively and believe that early intervention produces at least a modest impact on children’s development. Respondents were even more positive about the effect of early intervention for families.

Guralnick et al. (1996) distinguish research regarding the effectiveness of early intervention services into first-generation research (research conducted prior

#### Physicians’ Perceptions of Early Intervention

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to the passage of P L 99-457 in 1986) and second-generation research (that began in 1986 or later and that continues into the future). First-generation research demonstrated the general effectiveness and feasibility of these programs for children with disabilities and those born with at risk conditions. That body of research provided a context for developing and evaluating various components of early intervention services, but did little to address (1) the complexities of providing day-to-day services; (2) the issues created by the emergence of substantial populations of children at risk; and (3) the information needed to guide policy decisions in the field (Guralnick et al., 1996).

Guralnick states that the task of second-generation research—determining what interventions work best, for whom, under what conditions, and toward what ends—still fails to capture the true magnitude of the problems encountered in providing early intervention services. This research must establish an agenda in the field of early intervention that adequately reflects the complexities and interrelatedness that exist among child and family characteristics, program features, and early intervention outcomes. **Caring for Infants and Toddlers with Disabilities: New Roles for Physicians** provides guidance to the physician for understanding these complexities.

### Physician Involvement In Planning Statewide Early Intervention Systems

Wenger (1989) and colleagues conducted survey research to examine, among other factors, physicians' contributions to state planning for early

intervention services and their assessment of the relationship between the private health sector and the public human service system. A total of 146 physicians were asked to participate by completing a questionnaire. One hundred and twenty-five physicians responded, representing an 86% response rate. The sample included 86 physicians serving on state early intervention interagency coordinating councils (ICC) and 39 state chapter representatives who attended the 1988 **American Academy of Pediatrics' (AAP)** national conference on P. L. 99-457.

Based on survey responses, the authors concluded that:

- ⊗ It is important for community-based private physicians to be involved in state level planning;
- ⊗ States need to develop and support structures for physicians' participation in planning and coordination at the local level;
- ⊗ States need to identify and address reimbursement policies that discourage physician participation; and,
- ⊗ States can collaborate with state and local AAP chapters, Maternal and Child Health, and Programs of Children with Special Health Needs in the development of continuing education for physicians in the area of early intervention.

### Early Intervention Collaborative Study

Shonkoff and his colleagues (Shonkoff et al., 1990) have designed a longitudinal study to examine predictors of competence in young children with disabilities and to analyze mediating



influences of family ecology and early intervention services on children and families. One hundred ninety children and their families enrolled in 29 early intervention programs in Massachusetts and New Hampshire are being followed in a two phase study. Children in the study include infants and toddlers with Down syndrome, motor impairments, or developmental delays of uncertain etiology.

The initial phase of the **Early Intervention Collaborative Study** (Shonkoff et al., 1990) focused on the changes in 190 children and families during their first year of participation in an early intervention program. Data from the second phase, focusing on the development of the same children during preschool years, are not yet available. Phase one data were collected at the time of children's entry into early intervention services and after one year of early intervention services.

Shonkoff and his colleagues acknowledged that it is misleading to talk about average change for the group of children as a whole since some children made great developmental gains, whereas others did not change at all. He reminded us how crucial it is to consider early intervention outcomes in the context of health issues—a fact that has been ignored in most of the early intervention literature to date. Shonkoff's findings indicated that children served in early intervention who were born prematurely and children with less severe impairment made greater developmental gains than others in the study group.

Shonkoff and colleagues also reported that greater gains in cognitive development as

measured by the **Bayley** and **McCarthy** scales were associated with services provided to children individually rather than in groups and with services provided primarily through a single professional supported by consultations from members of a multidisciplinary team. This finding provides great support for the transdisciplinary team approach.

**Please refer to your state resources for information on service delivery models being used in your state.**

Although children with severe disabilities and/or seizure disorders demonstrated fewer developmental gains than did the less severely impaired children, early intervention services produced other beneficial results. Home visits through the early intervention program resulted in decreases in stress among families, and center-based services were associated with increases in the amount and perceived helpfulness of maternal personal support.

### **The Infant Health and Development Program**

The **Infant Health and Development Program** was designed to evaluate the efficacy of comprehensive early intervention services in reducing the developmental and health problems of infants born prematurely (37 weeks or less) with a birth weight of 2500 g or less (LBW).

This program, conducted across eight sites, “is the first multisite, randomized clinical trial designed to evaluate the efficacy of combining early child development and family support services with pediatric follow-up in reducing developmental, behavioral, and other health problems among LBW premature infants” (The



Infant Health and Development Program, 1990, p. 3036).

Nine hundred eighty-five infants from the following medical institutions that serve diverse demographic populations in different geographical locations constituted the sample for the study:

- ⌘ University of Arkansas School for Medical Sciences;
- ⌘ Albert Einstein College of Medicine;
- ⌘ Harvard Medical School;
- ⌘ University of Miami School of Medicine;
- ⌘ University of Pennsylvania School of Medicine;
- ⌘ University of Texas Health Science Center at Dallas;
- ⌘ University of Washington School of Medicine; and
- ⌘ Yale University School of Medicine.

The sample included two groups of infants: the “heavier” group (infants weighing 2001-2500 g) and the “lighter” group that weighed less than 2000 g. One third came from the heavier group and two thirds came from the lighter group. Of the total targeted sample, one third of the infants were randomized to the intervention group and two thirds to the follow-up group. One hundred thirty-five infants were at each of the eight sites.

Upon discharge from the neonatal

nursery, infants and their families began receiving early intervention services and continued until 36 months of age (adjusted for prematurity). Intervention services consisted of weekly home visits for the first year and twice weekly thereafter, child participation at a child development center (beginning at 12 months), and bimonthly parent group meetings to address parent concerns and provide an opportunity for social support. The intervention and pediatric follow-up care focused on medical, developmental and social assessments, referrals for pediatric care, and any additional services needed. All services were provided at no cost to the families.

Clinical staff assessed each child in the two groups at 40 weeks conceptional age and at 4, 8, 12, 18, 24, 30, and 36 months of age. At each visit data was collected by the mother’s report regarding her child’s health and developmental functioning and about social and demographic characteristics of the family. Cognitive assessments were performed at 12, 24, and 36 months by a trained assessor. The assessments were administered in English. Of the 985 infants, 913 continued to participate through the 36 month assessment.

Findings of this study (The Infant Health and Development Program, 1990) showed that the children who

The Infant Health and Development Program study showed that children who received early intervention experienced significantly higher IQ scores and significantly fewer maternally reported behavior problems.



received early intervention experienced “significantly higher IQ scores; significantly fewer maternally reported behavior problems; and a small, but significant, increase in maternally reported minor morbidity, with no evidence of an increase in reported serious health problems” (p. 3040).

**The authors concluded that comprehensive and intensive early intervention programs show a substantive promise of decreasing the number of LBW infants at risk for developmental delays or disabilities later in life.**

### **Educational Outcome of Neonatal Intensive Care Graduates**

The **Educational Outcome of Neonatal Intensive Care Graduates Study** (Resnick et al., 1992) followed 457 infants born in 1975 through 1983 that were discharged from the neonatal intensive care unit located in Aluchua County, Florida, into the public school system and compared their educational outcomes with those of 656 newborn infants that had been discharged from the newborn nursery. The NICU sample included 54% premature infants with birth weights of less than 2500 g and 46% sick infants weighing over 2,500 g in Shands Hospital tertiary care NICU. The majority of the 3,000 infants born annually at this hospital are minority families and/or families with low incomes. The most common diagnoses among the neonatal intensive care unit included: respiratory distress syndrome and other respiratory conditions, jaundice, intraventricular hemorrhage, unspecified nervous system disorders, congenital abnormalities, and patent ductus arteriosus.

Most studies focusing on developmental follow-up are usually limited to the first two years of life, rarely follow-up beyond five years of age, and include small sample sizes (Resnick et al., 1992). The Florida study included a search of school records of NICU children placed through their middle school years. The researchers evaluated child outcomes by their placement in four academic categories: regular classroom, academic problems (student retained in grade, required to attend summer school or administratively promoted), speech/language impairment, and major impairment (student placed in special education in one of the following subcategories: intellectual disability (IQ < 69), emotionally disturbed, learning disability, physical impairment, sensory impairment or profound impairment).

The findings showed that “neither neonatal intensive care unit treatment nor low birth weight were major predictors of educational outcome” (Resnick et al., 1992, p. 373). The outcomes for children in both groups were the same; that is, the children were equally affected by variables such as income (above or below poverty level), race, and sex. The families’ socioeconomic status was the variable with the most impact on children’s educational outcomes. The study results strongly suggest that infants born to poor families are not doing well in public school whether they were NICU or newborn nursery infants (p. 377).

**The authors conclude that “in order to reduce poor educational outcomes, follow-up and [early] intervention programs should be targeted to children with diagnosable handicaps and from minority, low income families” (p. 373).**



## Iowa High-Risk Infant Follow-up Program

The **Iowa High-Risk Infant Follow-up Program** (Blackman, Lindgren, Hein, & Harper, 1987) began in 1978. The purpose of the study was twofold: to demonstrate the need for long-term follow-up of high risk children at least to the age of school entry and to yield information that may be useful to refine a follow-up system that will yield the highest rate of discovery in a cost efficient manner.

Researchers followed two groups of high-risk children, both those who passed early developmental screening and those who did not. Three hundred and sixty-two children who had previously passed screening were evaluated at five years of age. Children who had previously failed screening at or before 30 months of age were followed-up through telephone interviews with referral agencies and records review.

Ninety percent proved to have significant problems and 67% were in special education programs at five years of age (Blackman et al., 1987). These findings support the evidence that there is indeed a need for a comprehensive follow-up system.

### Project ACCESS

While research indicates the need for comprehensive follow up, there is evidence that many families do not initiate discussion of their children's development with their physicians. The purpose of **Project**

**ACCESS**, funded by the Virginia Office of Developmental Disabilities in 1989, was to explore, via an initial survey, parents' expectations for their infants' future medical and developmental needs. Of the 69 infants included in the study, parents of eight were planning on enrolling their children in early intervention services. Most thought that they would not ask their doctor about developmental concerns such as motor behavior and cognition (Meyers & Carney, 1989). These findings emphasize the importance of regular developmental screenings by physicians and of discussion between parents and physicians about children's developmental progress.

### Child Development Resources Efficacy Study

**Child Development Resources (CDR)**, found that children entering its **Infant-Parent Program** with significant developmental delays experienced almost normal patterns of growth while enrolled in a comprehensive early intervention program (Child Development Resources, 1991).

The study involved 52 children enrolled in CDR's early intervention program for an average of 11.5 months. Children and families served received a combination of home visits, center-based developmental play groups, and parent groups. Services

#### Initiating Discussion

Research confirms that families may not initiate discussion of their children's development with their physicians. These findings emphasize the importance of regular developmental screenings by physicians, as well as discussion between parents and physicians about children's developmental progress.



varied based on families' individual needs and priorities. Children represented in the study were those who exited the program between 1987 and 1990.

The procedures used in the CDR study included an assessment of each child's development upon enrollment and every six months thereafter during their time in the program. **The Early Learning Accomplishment Profile (ELAP)** and the **Gesell** instruments were considered equivalent in content and were used to assess children's development. All test scores were sent to an external evaluator for analysis. The score, or developmental quotient, provided the ratio between a child's chronological age and developmental age. Children entering the program had mean developmental quotients ranging from 56%-64%. Study post-tests showed a significant increase in the mean developmental quotients—65%-77%.

During the time children were enrolled, average developmental gains were eleven or more months in motor and self-help skills; ten months in cognitive skills; and nine months in language skills.

**These findings support the evidence that early intervention services contribute to developmental gains for children with disabilities.**

### **Families' Perspectives**

Qualitative research that involved extensive interviews with families receiving early intervention services clearly indicates that families view early intervention as beneficial for parents and their children (Gamel-McCormick, 1992). The sample included twenty-five parents with limited education and lower socioeconomic status living

in rural Virginia communities.

Families interviewed seemed eager to learn more about their children's disabilities, services available to them in the community, and parenting techniques—including how to teach and play with their children to foster developmental gains. Parents interviewed referred to the relationships they had with professionals as a great source of support. Parents did not talk about techniques that educators or therapists employed but about the importance of the relationships between the families and other members of the early intervention teams, especially their service coordinators (case managers).

The view that most families see early intervention as beneficial for their children and/or families is supported by research conducted by Upshur (1991). Ninety-one families participated in a study designed to focus on parents' ratings of the benefits of early intervention services during their first year of enrollment in an early intervention program. Upshur found that "mothers and fathers rated the overall helpfulness of their first year of early intervention services as strongly positive" (p. 353).

**Upshur also noted that parents rated a higher level of helpfulness when service components were directed to parents and children together rather than to parents alone.**

### **Conclusion**

Legislation, research, and endorsement by the **AAP** and **AAFP** provide support for early intervention services. Children with disabilities, developmental delays, and children who are at risk all stand to benefit from services that are



individually designed to meet each child's needs and the family's capacity to meet those needs. Although some children may make greater developmental gains than others, participation in early intervention services benefits families as well, providing information and support and reducing family stress.

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The physician's role in initiating discussion of a child's development, in identifying developmental difficulties, and in referring for early intervention services when appropriate, has important consequences for a child's developmental outcome and for family well-being.



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