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OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

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Committee on Children With Disabilities

*Pediatrics* 2001;107;1155-1157

DOI: 10.1542/peds.107.5.1155

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# AMERICAN ACADEMY OF PEDIATRICS

Committee on Children With Disabilities

## Role of the Pediatrician in Family-Centered Early Intervention Services

**ABSTRACT.** There is growing evidence that early intervention services have had a positive influence on the developmental outcome of children with established disabilities or those considered "at risk" for disabilities and their families. Various federal and state statutes now mandate that community-based, coordinated, multidisciplinary, family-centered programs be established, which are accessible to serve children and families in need. The pediatrician, in close collaboration with the family and the early intervention team, plays a critical role in guiding the clinical and developmental aspects of the early intervention services provided. This role can be best served in the context of providing a medical home for children with special health care needs. The purpose of this statement is to assist the pediatrician in assuming a proactive role on the multidisciplinary team providing early intervention services.

ABBREVIATIONS. IFSP, Individualized Family Service Plan; PL, Public Law; IDEA, Individuals With Disabilities Education Act; IHDP, Infant Health and Development Program.

### BACKGROUND

Early intervention services are designed to meet the developmental needs of children from birth to 3 years of age who have a developmental delay in physical, cognitive, communication, social, emotional, or adaptive development or have a diagnosed condition that has a high probability of resulting in developmental delay. States must offer all early intervention services to children with developmental delay or those with an established disability; they have the option of serving those at risk of having poor developmental outcomes. The type and extent of services varies on the basis of the Individualized Family Service Plan (IFSP). However, by federal statute all must include but not be limited to assisted technology, audiology, family training counseling and home visits, health services, medical services for diagnosis and medical evaluation, nursing services, nutrition, occupational therapy, physical therapy, psychological services, service coordination, social services, special intervention, speech and language pathology, transportation and related costs, and vision services needed by these children and their families. They must be provided in conformity with the IFSP.<sup>1</sup>

These services have been developed because early intervention is recognized to be important if children

with disabilities are to achieve their full potential. During the past 25 years, Congress and administrations have taken a series of steps to promote improved infant and child developmental outcomes through early intervention services. The first major federal legislation was passed in 1975 when Public Law (PL) 94-142, The Education of the Handicapped Act, established the right of children between 5 and 18 years to a free, appropriate public education and related services; services to children aged 3 to 5 years were optional. This law was amended in 1986 as PL 99-457, which supported the development of early intervention programs for infants and children with disabilities or developmental delays, from birth to 3 years. The law also mandated a free and appropriate public education provided by the states' education departments for 3- to 5-year-olds by the 1990-1991 school year. It established guidelines and regulations for the development of far-reaching, coordinated, multidisciplinary services for these children and their families. In 1990, it was again amended as PL 101-476, The Individuals With Disabilities Education Act (IDEA). One component, Part H, the Program for Infants and Toddlers With Disabilities, required states to develop and implement community-based systems of care that are coordinated, family centered, and culturally competent, with greater interagency collaboration. It requires early identification and provision of services to infants and toddlers with developmental delays and those with established conditions (conditions with a high probability of developmental delay occurring), and at state's option, those who would be at risk of experiencing developmental delay if early intervention services were not provided. It required that the identified children be referred, free of charge, for a comprehensive, multidisciplinary evaluation by a team who, with the family, decides which services are needed. These are listed on the IFSP and reevaluated at least annually. A service coordinator is appointed who helps the family access them. Most recently, The IDEA Amendment of 1997, PL 105-17 (Part C, formerly Part H), encouraged the states who did not serve the at-risk population to track and monitor these children so that they can be referred when needed.<sup>2,3</sup>

### STATEMENT OF THE PROBLEM

Until 3 decades ago, in the absence of laws mandating access to educational services for all children regardless of the degree of disability, many children with developmental disabilities and their families had few choices, except either state hospital-sponsored custodial care or an isolated homebound exist-

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tence. Since then, much has been accomplished in the field of health care and special education for children with disabilities. Recent advances in medical expertise and technology have improved the developmental potential, health, and survival rate of infants and children with special health care needs. These advances have enabled these children to participate more fully in public education. Recently, neurocognitive research has demonstrated that there are optimal periods for all children during which the brain is particularly efficient at specific types of learning. Well-designed, timely early intervention can improve the outcome and the quality of life of young children at risk of developing cognitive, social, or emotional impairment.<sup>4-6</sup> The early childhood years present a singular opportunity to influence lifelong development and to prevent or minimize developmental problems in children with disabilities or at risk of developing disabilities.

#### NEW INFORMATION

Coordinated, community-based, multidisciplinary programs for early intervention have been established for children and their families. The types and severity of the conditions affecting children with disabilities are varied, and so are the intensity and extent of the services provided. Despite these differences, however, studies that evaluated the efficacy of early intervention programs show that from a public policy standpoint, they have achieved much. Recent literature documents that these programs may be effective not only in improving some individual child cognitive outcomes, but can also lead to important improvements in family function.<sup>7-10</sup> Results of The Early Intervention Collaborative Study showed that, despite the great variability of child and family function and of the types and extent of services offered, most young children in early intervention programs improved in all domains of functioning.<sup>11</sup> The Infant Health and Development Program (IHDP) is a multicentered, randomized, controlled, nationwide study of low birth weight premature infants and their families who received coordinated health and developmental services for the first 3 years of life. Those who had received comprehensive, multidisciplinary early intervention services scored higher at 3 years of age on tests of mental abilities than those who received health services alone. The cognitive and academic achievement in the higher birth weight group was maintained at 8 years of age.<sup>1,12-16</sup> School outcomes of children in the intervention group were consistently better than those who did not receive intervention. Several aspects of family development were also enhanced by the IHDP. The Carolina Abecedarian Project recently showed that "poor children who received early educational intervention starting in infancy had higher scores on mental, reading, and math tests than children who didn't receive the intervention and, more importantly, these effects persisted until at least age 21."<sup>17</sup>

The family, as the primary caregiver, plays a vital role in ensuring the health and well-being of children. The focus of health and developmental services

has evolved from a child-centered, traditional "medical" model to a family-centered "developmental" model. That is, it also takes into consideration the important contributions of the family unit, the stressors that affect families (be they social, financial, and/or psychological), and the ability of families to adapt to new challenges. The pediatrician, as the central figure in the medical home, is attuned to special family circumstances that influence children with special health care needs. He or she must involve family members in all areas of planning, delivery, and evaluation of health and developmental services. Communication between parents and pediatricians should be open, comprehensible, culturally sensitive, and sincere, showing mutual respect.<sup>17,18</sup>

The pediatrician, because of his or her unique training, interest, and commitment, should be a vital member of the early intervention health team. He or she is the most appropriate health care consultant, coordinator, and source of referral for clinical services for children with special health care needs and their families. Whether in a local pediatrician's office or in a multispecialty referral center, these children and their families should be offered comprehensive care that is family centered, continuous, compassionate, and culturally sensitive. Regardless of the pediatric health care setting, this care can be provided in accordance with the precepts of the medical home.<sup>19-21</sup>

#### RECOMMENDATIONS

The role of the pediatrician caring for children with disabilities and their families should include:

- screening and evaluating infants for established disabilities or those at risk of developmental delays, using whatever tools are deemed most appropriate by the practitioner;
- referring the child promptly to early intervention services;
- arranging for a medical etiologic diagnostic evaluation as appropriate;
- establishing, in concert with the family and the early intervention team, an IFSP that focuses on medical, developmental, and family services;
- being aware of the services and resources available in the community for the child and family and helping to coordinate the health component of the services;
- advocating for the child's access to the appropriate medical and surgical specialists;
- providing continuity of health care including prescribing specific rehabilitative therapies as appropriate and periodically reviewing the need to continue such services on the basis of the achievement of common goals;
- periodic and ongoing counseling for the family regarding the child's progress and treatment and management options;
- helping to provide ongoing services aimed at preventing secondary disabilities;
- maintaining a central medical database containing pertinent diagnostic and consultative information;

- advocating for equal access to early intervention programs for all eligible children in need;
- advocating for ongoing evaluation of early intervention programs through quality assurance and other performance measures;
- representing their state AAP chapter on local and state interagency coordination councils; and
- negotiating for proper reimbursement for time and effort spent on care coordination, counseling services, and other nonmedical services.

### CONCLUSION

By providing leadership for the medical home and as a member of the early intervention team, pediatricians can help set the standard of care in their communities for children with disabilities or those at risk of developmental delays. Through ongoing consultation with rehabilitation therapists, services and therapy prescriptions should be provided with specific treatment goals in mind. The treatment plans should be regularly and periodically reviewed, revised, or renewed if indications show that they are accomplishing their intended purpose.

It is vital for pediatricians to be sensitive to their role as the medical care provider on the team promoting rehabilitative therapies for children with disabilities. An environment should be created in which the physician, family, and other service providers work together in a caring, collegial, and compassionate atmosphere that ensures that early intervention services are of high quality, accessible, continuous, comprehensive, and culturally competent.

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