

# AMERICAN ACADEMY OF PEDIATRICS

## Pediatric Services for Infants and Children With Special Health Care Needs

Committee on Children With Disabilities

The discipline of infant and child development has expanded greatly during the last 3 decades.<sup>1</sup> Much of this growth is due to new knowledge regarding special services that can improve early development of children with, or at risk for, disabilities.<sup>2</sup> Passage of Public Law 101-476, the Individuals With Disabilities Education Act (IDEA) revising Public Law 99-457,<sup>3</sup> particularly Part H, coupled with existing federal child care mandates and increasing public expression of concern regarding all forms of child care, shows a significant national commitment to the concept that early services are critical if children with disabilities are to reach their full potential.<sup>4</sup>

While there may be debate over the relative importance of environmental vs hereditary factors in a child's developmental outcome, any approach used to promote child development must consider how these factors interact. A child's intelligence, temperament, and motor skills combine in a complex fashion with family and peers, to influence his or her development. There is much to learn about how to positively influence child/caregiver/societal interactions. As work in the area of early intervention\* grows, attempts to prove that such efforts can help a child with disabilities overcome innate cognitive and motor skill limitations have met with inconsistent and often controversial results.<sup>5</sup> Improved outcomes are most likely to occur when services are based on the premise that parents or primary caregivers are the most important factors influencing a child's development. All services, even those as clear-cut as a specific health intervention, must follow this premise.<sup>6-8</sup>

Future studies documenting successful outcomes of programs influencing child development—namely measures of effects on cognitive and motor development—need to be expanded to include at least the following variables:

This statement has been approved by the Council on Child and Adolescent Health.

The recommendations in this policy statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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\* Early intervention services are health, educational, and psychosocial services made available to infants and toddlers with or at risk for disabilities and for their families. These services are based on a written plan of management determined by an interdisciplinary team including a pediatrician or their designee that has appropriately assessed the strengths and needs of the child and family.

- the child's acceptance into the family
- the child's interpersonal skills
- stabilization of rather than "curing" health problems
- building capacities, even within the context of significant limitations, to maximize the potential for independence and productivity in adult life.

Because of a growing awareness that the family is the most important influence for the child with a developmental disability, research in early intervention increasingly has focused on understanding the family environment. The availability of one or two parents, the family's socioeconomic status, family members' mental and physical health status, and parental intelligence and knowledge of the basics of child care and development are among the important factors that should be considered when evaluating those services that a child may need. Families of children with "special needs" are also becoming strong advocates for participation in the planning of services for their children. As the family's role expands, methods of measuring the effectiveness of early services must increasingly relate not only to specific outcomes for the child, but also to the family's adaptation to the child's disability, to improvement in the family's coping abilities, and to the general strength of the family unit. As services focus increasingly on family models, they must move from the traditional curing model to one of coping, stabilization, and constructive adaptation.

Resources for young children with special health care needs include social, educational, and health services delivered through a variety of agencies, preschool facilities, medical and other health programs. Eligibility criteria for these programs can include such factors as family socioeconomic status or the child's disability. Under the provisions of IDEA, Part H, individual states retain the right to determine eligibility criteria for services funded by this legislation. Funding for these services comes from a number of different sources.

The emphasis in all services for disabled individuals, including those in the very young age groups, should be focused on integrating the child into appropriate community supports as well as health care services used by all children and their families. An important challenge for those developing the health care portion of early intervention services for children with disabilities is to develop a system that responds both to the generic and specialized health

care needs of these children in a way that provides expert and appropriate care while respecting the principles of normalization and community integration.

Pediatricians frequently are asked to support or prescribe therapeutic interventions, such as physical and occupational therapy, for infants and children with significant functional limitations. Although objective guidelines are not currently available, it is clear that therapy prescriptions should be written only to facilitate specific needs, be frequently reviewed, and be renewed only if there is indication that the therapy is accomplishing its intended purpose.

The American Academy of Pediatrics supports the belief that the planning and delivery of health care services to children with disabilities at the community, state, and national levels should include, at a minimum, the following principles.

1. Every infant, including those with disabilities or at risk to have a disability, should:

- be born to parents who have access to information and services that allow their infant the best opportunity to be free of inherited and acquired disease or disability;
- be born in settings that support the process of immediate parent-child interaction and provide access to ongoing parenting education;
- have access to immediate emergency care for life-threatening or high-risk conditions;
- have access to programs that identify, ameliorate, or cure when possible, disease states or conditions that might compromise health and development;
- have parental access to programs designed to enhance their ability to nurture the child physically and emotionally; and
- receive perinatal care in a system that shares parent and child information with practitioners and public systems providing ongoing health care supervision and monitoring of developmental risk factors during the developmental period.

2. In addition to services required by every infant, every infant or toddler suspected of having a disability should receive care in a system that:

- recognizes the need for the early detection and treatment or correction of health disorders, including problems associated with feeding, sleeping, elimination, and temperament; and the identification of conditions with a high probability of causing developmental delay;
- provides for the timely detection of sensory, cognitive, and emotional disorders;
- assists families in identifying their child's developmental strengths and needs;
- develops and monitors a written plan of service addressing child and family needs determined by early interdisciplinary evaluations, including an appropriate medical component;

- develops a plan of required services without primary concern for the mechanism of payment;
- coordinates the plan of services with the professionals most involved at any one time in the child's development;
- includes in the plan the requirement for at least annual reevaluation by appropriately qualified medical personnel in order to determine continuation or change in services;
- respects the parents' key role in the child's development, and their right to participate in decisions affecting their child and family;
- provides parents with information and support upon suspicion or diagnosis of developmental delay or disability;
- encourages and promotes the family's right to participate in the development and coordination of the individualized service plan or equivalent, to the full extent of its desire and ability;
- coordinates the delivery of services with local agencies and other community health providers, including access to necessary pediatric subspecialty services; and
- promotes and develops appropriate, community-wide services for the prevention of disabilities.

Pediatricians providing clinical services to infants or toddlers, as well as all others involved in planning, funding, or approving such services at the community, state, or national level, should be familiar with the previously stated principles of care. Parents depend on physicians to routinely monitor their child's development and physical and emotional growth and to inform them when deviations are detected and corrective actions required. Only with appropriate physician surveillance can parents be assured that needed early intervention services will be initiated at appropriate times. In addition, parents can be assured that their child's entitlement to the provisions included in IDEA, Public Law 101-476, will be protected only if physicians recognize the need for their personal involvement in the planning, implementation, and monitoring of all health-related early intervention services.

The American Academy of Pediatrics encourages pediatricians to learn about the developmental needs of children with special needs in order to participate in early intervention.<sup>8</sup> This knowledge, coupled with an understanding of the principles previously presented, can serve to strengthen working relationships with the child's family and involved child care professionals which will benefit the child.

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