American Academy of Pediatrics
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POLICY STATEMENT

Role of the Medical Home in Family-Centered Early Intervention Services

Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of All Children

Council on Children With Disabilities

ABSTRACT

There is growing evidence that early intervention services have a positive influence on the developmental outcome of children with established disabilities as well as those who are considered to be "at risk" of disabilities. Various federal and state laws now mandate the establishment of community-based, coordinated, multidisciplinary, family-centered programs that are accessible to children and families. The medical home, in close collaboration with the family and the early intervention team, can play a critical role in ensuring that at-risk children receive appropriate clinical and developmental early intervention services. The purpose of this statement is to assist the pediatric health care professional in assuming a proactive role with the interdisciplinary team that provides early intervention services.

EARLY INTERVENTION LEGISLATION

Various federal and state laws now mandate the establishment of community-based, coordinated, multidisciplinary, family-centered programs that are accessible to children with established disabilities or those who are "at risk" of disabilities and their families. Early intervention services are designed to meet the needs of children from birth to 36 months of age who have delays in 1 or more areas of physical, cognitive, communication, social, emotional, or adaptive development. Services are also available to children who have a diagnosed condition that has a high probability of resulting in delayed development. States must offer early intervention services to children with delayed development or those with an established disability. States also have the option of serving those who are at risk for poor developmental outcomes. The type and extent of services are determined through the development of an individualized family service plan (IFSP). In designing the IFSP, the family plays a lead role in the assessment of resources, priorities, and concerns in conjunction with a care coordinator.[1,2]

By federal statute, available services must include:

- early identification, screening, and assessment services;
- care-coordination services;
- medical services only for diagnostic or evaluation purposes;
- family training, counseling, and home visits;
- special instruction;
- speech and language pathology and audiology services;
- occupational and physical therapy;

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Key Words
early intervention

Abbreviations
IFSP—individualized family service plan
IDEA—Individuals With Disabilities Education Act
AAP—American Academy of Pediatrics

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- psychological services;
- health services that are necessary to enable the infant or toddler to benefit from other early intervention services;
- social work services;
- vision services;
- assistive technology devices and services; and
- transportation, interpretation services, and other related costs that are necessary to enable a family to receive other services.[3,4]

Access to these services has been mandated because early intervention is important if children with disabilities are to achieve their full potential. During the past 25 years, the US Congress has 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 the Education for All Handicapped Children Act (Pub L No. 94-142) established the right of children between 5 and 18 years of age to a free, appropriate public education and related services; providing services to children 3 to 5 years of age was optional. The Education of the Handicapped Amendments of 1986 (Pub L No. 99-457) supported the development of early intervention programs for infants and children from birth to 3 years of age with disabilities or delayed development. The law also mandated that a free and appropriate public education be 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 amended again as the Individuals With Disabilities Education Act (IDEA [Pub L No. 101-476]). One component of IDEA, Part H (now known as Part C), 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 effective, with greater interagency collaboration. Part H required early identification and provision of services to infants and toddlers with delayed development and those with established conditions with a high probability of delay and, at the state's option, those who would be at risk of experiencing delayed development if early intervention services were not provided. Part H required that identified children be referred for a free comprehensive, multidisciplinary evaluation by a team of professionals who, with the family, decide which services are needed. The services that are determined to be necessary are listed on the IFSP, and the needs are reevaluated at least annually. A care coordinator is appointed to help the family access services. Subsequently, Part C of the IDEA Amendments of 1997 (Pub L No. 105-17) encouraged the states that did not serve the at-risk population to track and monitor these children so that they could be referred when needed.[2,3]

The Individuals With Disabilities Education Improvement Act of 2004 (IDEA 2004 [Pub L No. 108-446]) broadened the eligibility criteria for early intervention services. The 2004 legislation required referral for all children involved in substantiated cases of neglect or abuse, children affected by substance abuse or exposed to family violence, and children who are homeless or wards of the state. IDEA 2004 also permitted, at the states' discretion, families to choose to have their child continue in early intervention services until they are eligible for kindergarten.[5]

RATIONALE FOR EARLY INTERVENTION

Until 3 decades ago, in the absence of laws that mandated 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 state hospital–sponsored custodial care or an isolated homebound existence. 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 children with special health care needs to participate more fully in public education. 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.[6–9] The early childhood years present a singular opportunity to influence lifelong development and prevent or minimize developmental problems in children with disabilities or those who are at risk of developing disabilities.

THE BENEFITS OF EARLY INTERVENTION

Pediatric health care professionals have a major role in early identification and referral for children with established delays in development as well as children who are at risk of delays. The National Early Intervention Longitudinal Study[10] found that the age at first concerns was later for children with developmental delays (11.1 months) compared with children with diagnosed conditions (eg, Down syndrome) (2.3 months) and children with at-risk conditions (eg, prematurity) (2.1 months). The time between first concerns and development of an IFSP was also longer for children with developmental delays (8.9 months) compared with children with diagnosed conditions (7.1 months) and children with risk conditions (5.9 months). Children with developmental

delays were older than children with diagnosed conditions and risk conditions at the time of the IFSP. Male children with delays entered services at later ages than did female children with delays. White children with delays entered services slightly later than did children of other ethnicities with delays. No gender or ethnicity differences regarding age at entry within diagnosed conditions or at-risk groups were found. Sixty-four percent of families found doctors or other health professionals to be very helpful. Most parents felt that early intervention services helped their child's development and that their family was better off with these services. These findings were not as strong for low-income families or if the child had poor health.

These data suggest that pediatric health care professionals can improve early identification and referral for children at biological and environmental risks as well as those with delayed development without known risk factors. The American Academy of Pediatrics (AAP) has published an algorithm for developmental surveillance and screening in early childhood that can assist the medical home in this process.[11]

Coordinated, community-based, multidisciplinary programs for early intervention have been established for children and their families. The types and severity of the conditions that affect 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 showed that, from a public-policy standpoint, they have achieved much.[12] Recent literature has revealed that these programs may be effective not only in improving some individual child cognitive outcomes but also in leading to important improvements in family function.[11,13–15] Reviews of the literature suggest that for children from birth to 3 years of age, global interventions that are focused on positive family interactions generally are more effective than those that are focused only on the child, but services must be individualized. Early intervention services generally are more effective for children with milder disabilities than for those with severe disabilities.[16] The greatest effect occurs when early intervention services combine child-focused educational activities with explicit attention to parent-child interaction patterns while strengthening the caregiver-child relationship.[6]

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.[17] The Infant Health and Development Program is a multicentered, randomized, controlled, nationwide study of low birth weight preterm infants (and their families) who received coordinated health and developmental services for the first 3 years of life. Children who had received comprehensive, multidisciplinary early intervention services scored higher at 3 years of age on tests of mental abilities than did children who received health services alone. Within the intervention group, cognitive and academic achievement in children with higher birth weight was maintained at 8 years of age.[18–22] School outcomes for children in the intervention group were consistently better than for children who did not receive intervention. Several aspects of family development were also enhanced by the Infant Health and Development Program.

Another long-term study, the Carolina Abecedarian Project, recently revealed that poor children who received early educational intervention starting in infancy had higher scores on mental, reading, and math tests than did children who did not receive the intervention. The participants were assessed at 21 years of age and were found to have completed more years of education, were more likely to attend a 4-year college, and were older when their first child was born.[23]

There has been considerable growth in the field of research regarding efficacy of various treatment modalities for children with specific disabilities. It is important to consider this research when prescribing or providing advice regarding early intervention services. For example, for those with cerebral palsy, data suggest that a functional/behavioral approach warrants initial consideration. Muscle strength training should also be considered for children with cerebral palsy.[1] Additional guidelines for prescribing therapy services for children with motor disabilities were published by the AAP in 2004.[24]

Lipkin and Schertz's review[1] of the literature on early intervention for children with Down syndrome suggested that early intervention may be beneficial in preventing declines in IQ. Preliminary findings have raised promise for treadmill training and augmentative communication to improve outcomes.

Evidence for the benefits of early intervention for children with autism is stronger. The evidence suggests that early, intensive (at least 20 hours/week) behavioral and/or developmental services are helpful in improving communication and social skills,[1,25] but more research is needed (including ongoing research) regarding the types and intensity of services.

The parents and family, as the primary caregivers, play 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, those who coordinate services take into consideration the important contributions of the family unit, the stressors that affect families (social, financial, and/or psychological), and the ability of families to adapt to new challenges. The pediatric health care professional, as the central figure in the medical home, must be attuned to special family circumstances that influence children with

special health care needs. The pediatric health care professional must involve family members in all areas of planning, delivery, and evaluation of health and developmental services. Communication between parents and pediatric health care professionals should be open, comprehensible, culturally sensitive, and sincere, showing mutual respect.[26]

The pediatric health care professional, because of his or her unique training, interest, and commitment, should be a vital member of the early intervention health team. The pediatric health care professional 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 pediatric health care professional'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.[2,27]

RECOMMENDATIONS

The role of the pediatric health care professional caring for children with disabilities and their families should include:

- Surveillance and screening of all infants to identify established disabilities or risks of delayed development following the AAP algorithm.[11] The algorithm contains recommendations to perform surveillance at all well-child visits and administration of a standardized screening tool at the 9- and 18-month visits and again at either the 24- or 30-month visit.
- Referring children with delayed development or established risk factors promptly to early intervention services. The AAP and the US Department of Education Office of Special Education Programs have collaborated to develop a referral form, which accompanies this statement.
- Arranging for medical etiologic diagnostic evaluation as appropriate. Guidelines for evaluation of children with delayed development have been published by the AAP[28] and the American Academy of Neurology.[29] Guidelines for diagnostic assessment of cerebral palsy also are available.[30,31] In addition, the AAP,[32,33] the American Academy of Neurology,[34] and the American Academy of Child and Adolescent Psychiatry[35] have published guidelines for assessment of children with autistic spectrum disorders.
- 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.
- Collaborating with the family and care coordinator to provide medical input into development of the IFSP while ensuring that goals are functional in nature. Efforts at collaboration have been hampered by lack of payment for these services.
- Advocating for the child's access to the appropriate medical subspecialty and surgical specialty services.
- Supporting families in choosing evidence-based and best practices that meet the specific needs of their child.
- Ensuring that periodic, objective measures of progress are made and used to guide ongoing intervention design.
- 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 that are aimed at preventing secondary disabilities.
- Maintaining a central medical database that contains pertinent diagnostic and consultative information.
- Negotiating for proper payment for time and effort spent on care coordination,[36] counseling services, and other direct services.
- 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 state AAP chapters on local and state interagency coordination councils.
- Monitoring and supporting research that uses optimal methodologies to further clarify appropriate treatment modalities for children with specific disabilities.

CONCLUSIONS

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

It is vital for pediatric health care professionals to be sensitive to their role as the medical care provider on the

early intervention team, promoting appropriate education and therapy for children with disabilities. An environment should be created in which the pediatric health care professional, 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 effective.

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