

AMERICAN ACADEMY OF PEDIATRICS

Committee on Children With Disabilities

The Pediatrician's Role in Development and Implementation of an Individual Education Plan (IEP) and/or an Individual Family Service Plan (IFSP)

ABSTRACT. The Individual Education Plan and Individual Family Service Plan are legally mandated documents developed by a multidisciplinary team assessment that specifies goals and services for each child eligible for special educational services or early intervention services. Pediatricians need to be knowledgeable of federal, state, and local requirements; establish linkages with early intervention, educational professionals, and parent support groups; and collaborate with the team working with individual children.

ABBREVIATIONS. IDEA, Individuals With Disabilities Education Act; IEP, Individual Education Plan; IFSP, Individual Family Service Plan; OHI, Other Health Impaired.

Special education in each local school district is protected and regulated by strong legislative and judicial safeguards created by the federal Education for All Handicapped Children Act (PL 94-142). This act was reauthorized in the 1991 legislation PL 101-476 under the new title, Individuals With Disabilities Education Act (IDEA), which has four key components: 1) identification of children with learning-related problems; 2) evaluation of the health and developmental status of the child with special needs, determining current and future intervention requirements, and developing a plan to match services to needs; 3) provision of services that include educational and related services; and 4) guaranteed due process.¹ These federally legislated safeguards establish that children with disabilities and their parents share the same legal right to a free and appropriate education as children without disabilities.

Federal legislation requires that each child recognized as having a disability that interferes with learning has a written plan of service: an Individual Education Plan (IEP) for children aged 3 through 21 years, an Individual Family Service Plan (IFSP) for infants and toddlers birth through 3 years, and a Transitional Services Outcome Plan for young adults at 16 years of age. Federal legislation defines transition from school as a coordinated set of activities for a student designed to promote movement from school to postschool activities, including postsecond-

ary education, vocational training, integrated employment, continuing and adult education, adult services, independent living, and community participation. This transition plan highlights and validates the lifelong needs of individuals with disabilities and is the beginning of an integrated program that enables adults with disabilities to live, work, and play in our towns and cities.² The pediatrician is in a key position to participate in planning services and to provide care for these children and young adults.

BACKGROUND

The Individual Education Plan (IEP)

In 1975 Congress enacted PL 94-142, the Education for All Handicapped Children Act, as an educational bill of rights to assure children with disabilities a free and appropriate education in the least restrictive environment. In 1977 implementation of services was extended to children 3 to 21 years old, although services for children aged 3 to 5 years remained optional. States were also requested to identify children who had not previously received services.

PL 94-142 (currently Part B) allowed children with mental retardation, hearing deficiencies, speech and language impairments, specific learning disabilities, visual impairments, emotional disturbances, orthopedic impairments, and a variety of medical conditions that may interfere with education (categorized as Other Health Impaired [OHI]) to receive special education services. To meet the eligibility criteria, a child's disability must interfere with the educational process and normal school performance to the extent that special education assistance is needed.

Other portions of the law provide the following:

1. Every child must have a multidisciplinary evaluation by a team. This team, working in collaboration with the family, is responsible for designing an IEP that has specific education and therapeutic strategies and objectives. Each plan must be reviewed annually.
2. Every child must be educated in the least restrictive environment. This criterion supports the concept of integrating children with and without disabilities as much as possible and with extra supports and services when necessary to facilitate inclusion.
3. The evaluation team may recommend the following related services: transportation; developmental, corrective, and other supportive services (in-

The recommendations in this 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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cluding speech pathology, audiology, psychological services, and physical and occupational therapy); recreation (including therapeutic recreation); and social work services (including rehabilitative counseling) and medical services (for diagnostic and evaluative purposes only). These services may be required to assist a child to benefit from special education and include early identification and assessment of disabling conditions.³ If the parents approve the IEP, they sign a document and the school is committed to providing these outlined services.

4. The rights of the parents and child to “due process” shall be protected. This ensures the parents’ rights to be involved in developing the educational plan and for the meeting to be conducted in their native language or other mode of communication if it is not a written language understandable to the general public. The IEP/IFSP team leader is responsible for arranging and paying for an interpreter if English is not the native language of the home or if the parent has a hearing impairment. Furthermore, parents have the right to appeal when they view the team’s decision as inappropriate or harmful.

The Individual Family Service Plan (IFSP)

In 1986 Congress enacted the Education of the Handicapped Act Amendments, PL 99–457.⁴ It was reauthorized in PL 105–17 in 1997. Part C of this reauthorization legislation, formerly known as Part H, called for the creation of statewide, coordinated, multidisciplinary, interagency programs for the provision of early intervention services for all infants and toddlers with disabilities. Although the law did not mandate these services, partial reimbursement of costs was made readily available to states that wished to participate. All states have established programs for children birth to 3 years. These developmental services are designed to meet needs in the areas of physical, cognitive, communicative, and psychological development, and in self-help skills. The purpose of these services is to enhance the development of the infant and toddlers with disabilities; to minimize their potential for developmental delay; and to optimize the abilities of the families to meet the special needs of their children. It was also hoped that this would minimize the cost over time of special education services when youngsters attained school age, decrease the need for institutionalization, and enhance the potential for independent living.

The law requires each state to create its own definition of developmental delay as a basis for determining eligibility for services. Pediatricians played a significant role in determining this eligibility by advocating for a broad definition of developmental delay. Services are provided for children with developmental delay, as well as for those whose biological conditions have a high probability of having a delay. In addition, states have the option to provide services to those children who are at risk of manifesting developmental delays attributable to environmental factors.

A major difference between Part C of PL105–17

and Part B of PL94–142 is that Part C focuses on the involvement of the family and supports for the family. Under this law, the evaluation, assessment, and planning take place with family participation and approval. Early intervention services are all optional, subject to family approval, and are provided in natural settings such as the parents’ home and child care settings as well as more formal child development programs. The current discussions about early brain development center around children from birth to 3 years. It is during this period that the growth and organization of the brain is most influenced by environmental factors that Part C strives to make optimal.

Children referred as potentially eligible receive a comprehensive multidisciplinary assessment. The assessment describes the abilities and needs of the child and family. Following assessment, an IFSP is created, to include the following:

- the child’s present attainments,
- family strengths,
- how to enhance development of the child,
- major outcomes expected, including the outcome measures and criteria, and time lines to achieve specific goals,
- specific early intervention services that the child and family will receive,
- projected dates for initiating services and their duration,
- name of the service coordinator responsible for coordinating and helping the family implement the plan,
- steps to help the child and family with the transition to school services at an appropriate time.

The statute specifies a wide array of other services, but the only health services included are those that are “necessary for the infant or toddler to benefit from other early intervention services.” Diagnostic and consultative medical services are also included, but the extent to which these services are funded by the early intervention program varies.

MEDICAL ROLE AND RECOMMENDATIONS

Several roles for the pediatrician exist under IDEA. All pediatricians should ensure that in their practices, every child with a disability has access to the following services:

1. A medical home.^{5,6} A medical home provides care that is accessible, continuous, comprehensive, family-centered, coordinated, and compassionate. For children with special health care needs, many of whom have an IEP or an IFSP, the pediatrician’s central role as the provider of primary care means that he or she would participate in the plan development. In addition, the pediatrician should collaborate with community resources in treatment planning and in promoting early intervention programs that work.
2. Screening, surveillance, and diagnosis.^{7,8} The pediatrician should screen all children from the first encounter, checking for risk or existence of a disability or developmental delay. Pediatricians are

in key positions to identify at the earliest possible age those children who may benefit from services under IDEA. Pediatricians should provide screening and surveillance using a combination of methods best designed to take advantage of multiple sources of information.

3. Referral. The pediatrician should be knowledgeable about the referral process to early intervention programs in his or her community and knowledgeable about the parents' right for multidisciplinary team evaluation by the school- or state-designated agency if a disabling condition may be present. In addition, some of the best support of parents comes from other parents who are able to offer emotional and social support and practical advice. Many communities have programs in which parents support each other and help parents new to the system better navigate the system.⁹ Family Voices, a nationwide grassroots network of families and friends speaking on behalf of children with special health care needs, is a creditable organization that can assist parents and pediatricians and is accessible by telephone and the Internet (1-888-835-5669; www.familyvoices.org).
4. Diagnosis and eligibility. For early intervention, the pediatrician has an important role in the identification of children with established delays and in the diagnosis of conditions with a high probability of developmental delay, which will qualify a child for this program. Each state has developed a definition of these conditions, which should be obtained from the state's lead agency for this infant and toddler program. In addition, some states include "at risk" conditions as defined by the state as eligible for services. Further information about these issues can be obtained from the single point of entry into Part C locally or the state's lead agency. A list of lead agencies for state early intervention services can be obtained from the National Childhood Technical Assistance System (919/962-2001; www.nectas.unc.edu/).
5. Participation in assessment. A child identified through screening or observation as meeting the definition for developmental delay should receive a comprehensive multidisciplinary assessment. The pediatrician has an important role as a referral source or, if more extensive participation is elected, as a member of the multidisciplinary team. Few pediatricians have the flexibility in their schedules to participate in person in lengthy team meetings. Usually, these meetings are scheduled with a short lead time and at the convenience of the educators arranging them. However, all pediatricians should offer to be available by written communication or participate by conference call or other means to offer input to and receive feedback from the assessment team. Ideally, the pediatrician should be a member of the team and attend the IEP/IFSP meeting.
6. Counsel and advice. During the assessment process, families will need a knowledgeable person for medical advice and counsel. Pediatricians can alert parents to the benefits of a pre-IFSP or pre-IEP conference; of their right to sign the IFSP or IEP only when they are comfortable with the recommendations; and their right to have a friend or other advocate at the IFSP and IEP conference. Although a parent may bring their personal attorney to the conference, most parents do not. If an attorney is going to attend on behalf of the family, the family should notify the school agency of that fact before the meeting to give the school an opportunity to have their legal counsel or top administrator scheduled for the conference. The appeal process begins at the district school board where the child resides. The president of the school board and superintendent of schools should receive the written appeal document. If appeal at the district level fails to satisfy the family's concerns, their next appeal is to the State Board of Education. Rarely does an appeal by either the school district or family go to state or federal supreme courts. Each district school board has a published document that advises parents of procedural safeguards, which can be obtained at no cost to the family. Most assessment teams nominate a member as service coordinator to work with the families. A strong link should be developed between the assessment team and the primary care pediatrician, as well as an open sharing of concerns between parents, the pediatrician, and the assessment team.
7. Creation of the IEP and IFSP. Pediatricians who participate in the assessment process should be consulted by the assessment team when these documents are created. Such consultation is vital to preparing an appropriate and effective plan. The pediatrician should review the plan developed, counsel the family, and comment on health-related issues as needed. The pediatrician should determine if the health-related services proposed are appropriate and sufficiently comprehensive and assist parents in performing their advocacy tasks when there is evidence of inappropriate planning. Ideally, when schools or educational agencies are developing the IEP or IFSP, a pediatrician should serve as a member of the assessment team.
8. Coordinated medical services. When medical services are part of the IEP or IFSP, they should be conducted by the primary care pediatrician or an appropriate pediatric subspecialist. Medical services and communication should be coordinated by the primary care pediatrician or his or her designee in those cases in which the children have complex medical needs involving several physicians or centers. Special education personnel should be made aware of the restrictions of health care insurance including limited referral options and the role of the primary physician as "the gatekeeper" in some programs.
9. Advocacy. Pediatricians have many local and state opportunities to serve as knowledgeable, thoughtful advocates for improved community and educational services for children with disabilities. Pediatricians who select this role need to be aware of the structure of services in the commu-

nity and the key persons who implement them. Examples of advocacy roles for pediatricians include participation in the local or state early intervention interagency council, consulting with the local school system or state department of education, or becoming a school board member.

CONCLUSION

Participation in interdisciplinary efforts for children with disabilities can help the pediatrician focus on the needs of the child with disabilities or developmental delay and improve the coordination of all forms of service and care for the child and the child's family.¹⁰ The pediatrician's role in IEP and IFSP development and implementation includes knowledge of federal statutes and state and local mandates and regulations; establishing linkages with local early intervention and education professionals and parental support groups; and collaborating with the team serving the individual child. Collaboration among parents, pediatricians, and educators can lead to better quality of care and paves the way for a better quality of life for the child and young adult with a disability.

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