AMERICAN ACADEMY OF PEDIATRICS

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

Committee on Children With Disabilities

Approximately 10% of young persons between the ages of 6 and 17 years receive special education and related services. An additional 750 000 neonates each year may have or be at risk for having developmental disabilities. Therefore, pediatricians have many patients who have disabling conditions or are at risk for them.

Federal legislation requires each child identified as having a disability to have a written plan of service: an Individual Education Plan (IEP) for children aged 3 through 21 years or an Individual Family Service Plan (IFSP) for children aged birth through 2 years. The pediatrician is in a unique position to be involved in planning and providing care for both groups of children.

BACKGROUND

The Individual Education Plan

In 1975 Congress passed Public Law 94-142, the Education for All Handicapped Children Act, as an educational bill of rights to guarantee handicapped children a free and appropriate education. The law required that identification, diagnosis, education, and related services be provided for children 5 to 18 years of age. In 1977, the age range was extended to include children aged 3 to 21 years, with services for children aged 3 to 5 years remaining optional. Not only were these services to be provided, but states also were encouraged to seek out children who had not been served previously.

Conditions eligible under Public Law 94-142 include mental retardation, hearing deficiencies, speech and language impairments, specific learning disabilities, visual handicaps, emotional disturbances, orthopedic impairments, and a variety of other medical conditions categorized as "other health impaired." To be eligible for service under the legislation, a child must have an identifiable condition that has the potential to interfere with his or her educational process and normal school performance to the extent that special education services are required.

The recommendations in this publication 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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Other components of the legislation include the following provisions. (1) Each child must be evaluated by a multidisciplinary team. This team is responsible for designing an IEP that contains specific educational and therapeutic strategies and goals. All such plans are reviewed annually. (2) Each child must be educated in the least restrictive environment or with nonhandicapped students to the greatest extent possible. This criterion supports the concept of integration. (3) Related services, such as transportation, speech pathology, audiology, counseling, physical therapy, and medical services (for diagnosis only), shall be provided when deemed necessary by the evaluating team. (4) The parents' and the child's rights to "due process" shall be protected. This ensures the parents' right to be involved in educational decisions and to obtain redress through an appropriate hearing process when the team's decision is viewed as inappropriate or harmful. A 1987 American Academy of Pediatrics statement encouraged pediatricians to be aware of and partake in the process of formulating an IEP, reviewing it with parents, providing counsel, and coordinating the educational program with the medical treatment plan.3

The Individual Family Service Plan

In 1986 Congress enacted the Education of the Handicapped Act Amendments, Public Law 99-457.4 The statute calls for "a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for all handicapped infants and their families." The bill does not mandate services but does strengthen incentives. Almost all states have established a program for children aged birth through 3 years. These services are specified as "developmental services ... to meet a handicapped infant's or toddler's developmental needs in any one or more of the following areas: physical development; cognitive development; speech and language development; psycho-social development; or self-help skills." The purpose of these services is to enhance the development of handicapped infants and toddlers to minimize their potential for developmental delay. It also should reduce education costs to the public schools by minimizing the need for special education services after the youngsters reach school age, minimize the need for institutionalization, enhance the potential for independent living, and the families' abilities to meet special needs.

The law requires that each state create its own definition of developmental delay as a basis for determining eligibility for services. The pediatrician has a significant role in determining this eligibility by advocating for a broad definition of developmental delay. If states participate, services must be provided for children already experiencing developmental delay as well as for those diagnosed with a condition that has a high probability of causing delay. In addition, states may elect to provide services to those children who are at risk of manifesting developmental disabilities at a later time.

A major difference between Public Laws 99-457 and 92-142 is that Public Law 99-457 focuses on the family. Under this law, the evaluation, assessment, and planning take place with full family participation and approval.

Children identified as "at risk" receive a comprehensive multidisciplinary assessment. The assessment describes the abilities and needs of the child and family. Following assessment, an IFSP is created. IFSP elements include statements on the following:

- 1. the child's present attainments
- 2. family strengths
- how to enhance development of handicapped infants and toddlers
- 4. major outcomes expected, including criteria, procedures, and time lines to achieve specific goals
- specific early intervention services that will help the child and family
- projected dates for initiating services and their duration
- 7. name of the case manager responsible for helping the family implement and coordinate the plan
- 8. 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 may also be provided.

MEDICAL ROLE AND RECOMMENDATIONS

There are several roles for the pediatrician under Public Laws 94-142 and 99-457.⁵ Not every pediatrician will be comfortable being engaged fully in each role. However, all pediatricians should ensure that every handicapped child in their practice has access to the following services:

- Conventional health care.
- 2. Screening and surveillance. The pediatrician should screen all children from the first encounter checking for risk of a handicapping condition or developmental delay. Pediatricians are in key positions to identify at the earliest possible age those children who may benefit from services under Public Laws 94-142 and 99-457. Pediatricians should provide screening and surveil-

- lance using a combination of methods best designed to take advantage of multiple sources of information.
- 3. Participation in assessment. A child identified through screening or observation as being "at risk" 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 a multidisciplinary team. Not all pediatricians may be comfortable participating in an in-depth assessment. However, all pediatricians should remain in communication with the assessment team.
- 4. Counsel and advice. During the assessment process, families will need a knowledgeable source of medical advice and counsel. Most assessment teams nominate a member as case manager to work with families. There should be a strong link between the assessment team and the primary care pediatrician and an open sharing of concerns between parents, the pediatrician, and the assessment team.
- 5. Creating the IEP and IFSP. Pediatricians who participate in the assessment process should be consulted when these documents are created. The assessment team and pediatrician can consult via various routes of communication, ie, in person, by telephone, or by mail. Such consultation is vital to preparing an appropriate and effective plan. When the pediatrician does not serve on the assessment team, he or she should review the plan developed, counsel the family, and prepare to comment as needed. The pediatrician should determine if the health-related services proposed are appropriate and sufficiently comprehensive. He/she should assist parents in performing their advocacy tasks when there is evidence of inappropriate planning. Ideally, when schools or educational agencies are involved in developing the IEP or IFSP, a pediatrician should serve as a member of the assessment team.
- 6. Coordinated medical services. When health services are part of the IEP or IFSP, they should be carried out by the primary care pediatrician or an appropriate subspecialist. Services and communication should be coordinated in those cases where the patients have complex medical needs involving several physicians or centers.
- 7. Advocacy. Pediatricians have many local and state opportunities to serve as knowledgeable and thoughtful advocates for improved community services for handicapped children. Pediatricians who select this role need to be aware of the structure of services in the community and the key persons who implement them.

CONCLUSION

Only by participating in interdisciplinary efforts for children with disabilities can the pediatrician focus on the needs of the whole child and improve the coordination of all forms of service and care.

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