

# AMERICAN ACADEMY OF PEDIATRICS

Committee on Children With Disabilities

## Provision of Educationally-Related Services for Children and Adolescents With Chronic Diseases and Disabling Conditions

**ABSTRACT.** Children and adolescents with chronic diseases and disabling conditions often need related services. As medical home professionals, pediatricians can assist children, adolescents, and their families with the complex federal, state, and local laws, regulations, and systems associated with these services. Expanded roles for pediatricians in Individual Family Service Plan, Individualized Education Plan, and 504 Plan development and implementation are recommended.

The complex range of federal, state, and local laws, regulations, and systems for special education and related services for children and adolescents in public schools is beyond the scope of this statement. Readers are referred to the policy statement "The Pediatrician's Role in Development and Implementation of an Individual Education Plan (IEP) and/or an Individual Family Services Plan"<sup>1</sup> by the American Academy of Pediatrics for additional background materials.

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ABBREVIATIONS. IDEA, Individuals With Disabilities Education Act; IEP, Individual Education Plan.

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### FEDERAL LAWS

Related services such as speech therapy, occupational therapy, physical therapy, and nursing care are provided to students in school because they are related to the student's education. The term *related services* as currently defined in Part A of the Individuals With Disabilities Education Act (IDEA) includes the following<sup>2</sup>:

... transportation and such developmental, corrective, and other supportive services (including speech-language pathology and audiology services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, social work services, counseling services, including rehabilitation counseling, orientation and mobility services and medical services, except that such medical services shall be for diagnostic and evaluation purposes only) as may be required to assist a child with a disability to benefit from special education, and includes the early identification and assessment of disabling conditions in children.

The legal justification for the provision of related services without qualifying for special education placement can be found in Section 504 of the Rehabilitation Act of 1973.<sup>3</sup> This section prohibits discrimination based on disability within federal and federally assisted programs. Regulations promulgated by the Department of Education have more broadly defined the persons covered by this act, as well as the

services that are to be provided. According to Section 504, all children should be provided with an appropriate education that "could consist of education in regular classes, education in regular classes with the use of supplementary services, or special educational and related services." Psychological testing and evaluation, counseling, physical and occupational therapy, medical services, speech pathology, audiology, and orientation mobility instruction are listed among the types of "developmental, corrective, and . . . support services" that may be provided to qualified persons. Thus, Section 504 implies that children with chronic diseases and disabling conditions are entitled to appropriate modifications within their educational program to accommodate their special needs, regardless of whether their classroom placement is considered regular education or special education. Some school systems have developed flexible, function-oriented "504 Modification Plans" for students. Unfortunately, some school systems still provide few services.

### MEDICALLY NECESSARY VERSUS EDUCATIONALLY NEEDED

Health care professionals frequently view these related services as medically necessary or helpful for children and adolescents with chronic diseases and disabling conditions. Although this is appropriate in the health care setting, it is not the standard for services that are mandated to be provided by public systems. The additional proviso that the service must be necessary for education or special education is a key component in the laws. This difference in perspective and interpretation by pediatricians and parents often leads to misunderstandings, frustrations, conflicts, and problems in the development and implementation of related services within school programs for children with disabilities. To best serve children with disabilities and their families, pediatricians need to be familiar with these issues, their legal basis, and the special educational process and system. This is a key function of the medical home provider for children with chronic diseases and disability conditions.

### CHALLENGES FOR SCHOOLS

Providing related services presents significant opportunities for the children served and challenges for the educational system. With greater numbers of children with chronic diseases and disabling conditions entering the school system and the increasing complexity of these conditions, many issues and

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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problems have developed. The availability of services, designation of responsibility for their payment and provision, and conflicting legal imperatives, as well as other obstacles, result in vastly different services in various communities. The current trend of integration and inclusion of many children with a wide range of disabilities in "regular" classrooms and programs is making the provision of related services outside of traditional "special" educational settings a larger and more complex issue. Adequate classroom and school modifications (eg, ramps and accessible sinks and toilets) and support personnel (eg, instructional assistants, school nurses, and special education teachers) are needed in more classrooms and schools.

The difficulties in implementation of related services in schools are as varied and complicated as the disabilities of the children involved. These problems, among others, include the following: 1) lack of clarity about which circumstances should result in a child's exclusion from school for medical reasons; 2) uncertainty about the responsibility for and administration of complex nursing treatment or therapy in school; 3) inconsistencies in state and local guidelines and interpretations about which health care professionals should prescribe the type and amount of physical, occupational, and speech therapies; 4) uncertainty about medical liability for therapies administered in school; 5) conflicting opinions about the propriety of some therapies used for children; 6) concern about the rising cost of special education services and whether all treatment required in Individual Education Plans (IEPs) is warranted; and 7) the frequent lack of provision of related services for children who may not qualify for special education but who have chronic diseases and disabling conditions that impair their ability and readiness to attend or participate in school.<sup>4</sup>

#### SCHOOL SYSTEM RESPONSIBILITY

In March 1999, the Supreme Court ruled that complex nursing service (ventilator care) is a related service.<sup>5</sup> The difference between educationally related services and rehabilitation services is unclear. Court rulings have generally mandated that therapies recommended in the IEP be reimbursed by the educational system.<sup>6</sup> However, this has not precluded the application of Medicaid or other public funding to support medical service provisions for children with disabilities. Although private insurance carriers have generally declined reimbursement for therapies provided in the schools, in specific situations they may be responsible for payment of school-based services and frequently pay for community-based services. The parents, however, may decide not to make claims against their insurance because it would create a threat of financial loss, such as lowering the child's available lifetime medical benefits. Generally, school systems are not responsible for acute rehabilitation services.

In communities in which the school systems have borne the responsibility for implementing the IEP and funding most of the therapies, the educational authorities are increasingly concerned about the re-

sponsibility for overseeing the provision of complex nursing care and other related services for children with disabilities who attend public school. School systems also are concerned about managed care systems shifting funding responsibilities for rehabilitation and medical diagnostic services from health care to the school system. The assumption of these responsibilities by school systems has the potential to: 1) increase conflicts with local physicians and other agencies responsible for health care provision, 2) contribute to the disjointed nature of health care for children, and 3) result in unnecessary treatment at increased cost,<sup>7</sup> depleting educational resources for other children.

#### THE PEDIATRICIAN'S ROLE

The physician's role mandated by IDEA as a related service is defined to include only the diagnosis and evaluation of the disability. However, in the context of primary care, the physician's role also includes the medical management, supervision, and program planning for the children. IDEA does not mandate that these additional roles are paid for by the public school. Parents often need an advocate for the child based on an objective appraisal of the child's special needs and realistic expectations. Input from the medical home professional also assists with placing services in a developmental context in which changes in needs are to be expected over time. The important medical services extend beyond IDEA mandates.

#### CONCLUSION

A multidisciplinary approach is required in the initial evaluation of children to determine their eligibility for services within the educational system. It is also necessary to maintain a comprehensive multidisciplinary approach in the provision of these services, which must be coordinated with the child's medical home professional. The inequalities in the interpretation and provision of services between and within states and school districts need to be corrected. The developmental, educational, and medical needs of the child or adolescent should be determined first. Issues of who provides the appropriate services and how payment is to be made must be resolved in the context of maintaining the child in the appropriate educational environment.

#### RECOMMENDATIONS

1. **Educate ourselves.** To oversee the provision of services effectively, including related services, physicians should be well informed about the medical or educational needs of children and adolescents with chronic diseases and disabling conditions. Opportunities for physicians to learn more about these issues and what they can do to have a positive effect on the availability of services should be developed and widely disseminated.
2. **Learn the laws.** Health care professionals need to be aware of the issues and inconsistencies in Public Law 105-17, Parts B and C (IDEA), and Section 504 of the Rehabilitation Act of 1973. Pediatricians can determine local and state school system poli-

cies and procedures for children who are eligible under Section 504 or IDEA by contacting school administrators. This knowledge will enable them to serve as effective providers, resources, and advocates for children and adolescents with disabilities and their families. Additional advocacy may be provided by disabilities law centers or parent advocates (see resources). These actions should help ensure that children and adolescents with disabilities who do not have significant cognitive or achievement impairments, but would benefit from related services (such as children with chronic illnesses), will have their total educational needs met by the school.

3. **Be an advocate.** Help parents find advocates. Pediatricians, including pediatric subspecialists, can objectively appraise the special needs of children and adolescents and determine realistic expectations. They can be advocates for children and adolescents and can assist with establishing an appropriate balance between the recommendations made by the school team and the desires of the family. These actions may be especially helpful when controversial services or litigation is involved. In some instances, pediatricians need to maintain an independent perspective on behalf of the child, avoiding too close an alliance with the parents if they have an adversarial relationship with the school system.
4. **Focus on the child's needs.** The initial pediatric focus for services should be on the child or adolescent with a disability and his or her specific needs, not the relationship of these services to the child's educational placement. Once needs have been defined, the role of the school system and the role of community providers should be determined. The specific class placement should not determine the provision of related services in school.
5. **Coordinate care.** The supervision of medical care and health-related services for children and adolescents with chronic and disabling conditions is the responsibility of the medical home professional, primary care pediatricians, pediatric specialists, and other medical providers, regardless of the location or source of payment for these services. When this responsibility extends to services provided by the school system, careful collaboration and coordination by the medical home professional with the educational authorities are necessary. Issues such as the source of payment, liability, location(s) for treatment, and the specific staff performing the treatment(s) should be resolved with the responsible state and local agencies. Although schools are responsible for accommodations and modifications under Section 504, health insurance plans should provide payment for direct therapies when needed for health reasons. School systems and physicians should explore a range of participation, including methods such as teleconferencing and faxing.
6. **Be proactive.** The physician's role in the care of children and adolescents with disabilities within

the schools can be expanded. The child, the child's family, and the school may benefit by medical consultation to determine and supervise the specific medical, nursing, and therapy needs of the child within the educational setting. Physicians can take a more active role in the development and implementation of Individual Family Service Plans, IEPs, and 504 Plans.

7. **Get involved at the systems level.** It is important that physicians, especially pediatricians, seek representation on the local advisory and interagency committees that oversee programs for placement of children and adolescents with chronic diseases and disabling conditions in schools.

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5. *Cedar Rapids Community School District Versus Garret F*, 119 S Ct 992, 143 Led 2d 154; 67 USLW 4165, March 3, 1999
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## SUGGESTED READINGS

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- US Department of Education, Office for Civil Rights. *The Civil Rights of Students With Hidden Disabilities.* Section 504 of the Rehabilitation Act of 1973; 1995

## INTERNET RESOURCES

- The Physician's Guide to Special Education Services. Available at: <http://members.aol.com/pepofwi/phys/Physician.html>
- Overview of ADA, IDEA, and Section 504. Available at: <http://www.cec.sped.org/digests/e537.htm>
- The Education of Children and Youth With Special Needs: What Do the

- Laws Say? Available at: <http://www.nichcy.org/pubs/newsdig/nd15txt.htm>
- IDEA '97 Overview. Available at: <http://www.ed.gov/offices/OSERS/IDEA/overview.html>
- IDEA '97 Regulations. Available at: <http://www.ideapractices.org/idearegsmain.htm>
- Related Services for School-aged Children With Disabilities. Available at: <http://www.nichcy.org/pubs/newsdig/nd16txt.htm>
- Providing Early Services to Children With Special Needs and Their Families. Available at: <http://www.nectas.unc.edu/pubs/pubslis1.html#provi>

## ADVOCACY SUPPORT RESOURCES

- Family Voices  
[www.familyvoices.org](http://www.familyvoices.org)
- Technical Assistance Alliance for Parent Centers  
[www.taalliance.org](http://www.taalliance.org)  
612-827-2966
- Parent Advocacy Coalition for Educational Rights (PACER)  
[www.pacer.org](http://www.pacer.org)
- Special Education Resources on the Internet (SERI)  
[www.hood.edu/seri](http://www.hood.edu/seri)

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