



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

Council on Children With Disabilities

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

ABSTRACT

Children and adolescents with chronic diseases and disabling conditions often need educationally related services. As medical home providers, physicians and other health care professionals 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 physicians and other health care professionals in individualized family service plan, individualized education plan, and Section 504 plan development and implementation are recommended. Recent updates to the Individuals With Disabilities Education Act will also affect these services. Funding for these services by private and nonprivate sources also continue to affect the availability of these educationally related services.

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 American Academy of Pediatrics policy statement “The Pediatrician’s Role in Development and Implementation of an Individual Education Plan (IEP) and/or an Individual Family Service Plan (IFSP)” for additional background materials. The focus of this statement is the role that health care professionals have in determining and managing educationally related services in the school setting.

This policy statement is a revision of a previous statement, “Provision of Educationally Related Services for Children and Adolescents With Chronic Diseases and Disabling Conditions,” published in February 2000 by the Committee on Children With Disabilities (<http://aappolicy.aappublications.org/cgi/content/full/pediatrics;105/2/448>).

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 following¹:

... 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

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Key Words

IEP, IDEA, Section 504, related services, special education, ICDH-2, physician’s role, children with chronic diseases and disabilities

Abbreviations

IDEA—Individuals With Disabilities Education Act

IEP—individualized education plan

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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 1973.² This section prohibits discrimination that is based on disability within federal and federally assisted programs. Regulations promulgated by the US 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 must 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 states 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.³ Children with chronic medical conditions, who usually function well in the standard classroom, still need consideration for related services. Examples of such children are those with asthma and allergies, who often find themselves at odds with their schools and school districts because of issues related to classroom modifications (eg, no pets in the classroom, having hand-washing facilities), curriculum modifications (eg, alternatives to standard physical education on an as-needed basis rather than the usual exclusion or full participation), and access to medications.

On December 3, 2004, the IDEA (Pub L No. 108-446)⁴ was enacted. Most of the provisions of this law became effective July 31, 2005. The new law is likely to have a major impact on how students with disabilities are educated. Listed below are some of the key changes that occurred with the IDEA 2004.

- The long-established obligations for the individualized education plan (IEP) team to have short-term objectives for each child in his or her IEP will no longer be required as part of the annual goals.
- A child’s progress report toward meeting the annual goals must be reported to the IEP team as in the

previous IDEA legislation. With the new law, however, there is no longer a reference to “the extent to which the progress is sufficient to attain the goal by the end of the year.” The amendments clarify that the transition process for a student with a disability now begins at age 16. In the past, only transition planning, but not the actual transition process, would begin at age 16.

- A new section allows IEP team members to be excused from attendance if their area is not being discussed. When this section is applied with new provisions allowing alternate means of meeting participation (eg, conference calls), consolidation of reevaluation meetings and other IEP meetings, and a pilot program authorizing up to 15 states to use multiyear IEPs, the combined effect is a transformation of the traditional IEP meeting that had been a face-to-face meeting that required all participants to sit around a table at the school.
- The Secretary of Education is authorized to approve proposals from up to 15 states to allow local school districts to offer, with parental consent, a multiyear IEP not to exceed 3 years.
- The Secretary of Education is authorized to grant waivers of statutory and regulatory requirements, for a period not to exceed 4 years, to 15 states that propose to reduce excessive paperwork and noninstructional time burdens. The Secretary is prohibited from waiving requirements related to civil rights or the right of a child to a free appropriate public education.
- Parents of a child who is transitioning from part C (early childhood) to part B (school-age) services can request that an invitation to the initial IEP meeting be sent to representatives of the part C system to assist with a smooth transition of services. This provision does not require a part C representative to attend, but it does encourage collaboration.
- Services comparable to those described in the IEP that are in effect before a child’s transfer to a new school must be provided by the new school district. These services must continue until the previous IEP is adopted or a new IEP is developed, adopted, and implemented; regardless of whether the child is transferring in the same state or from another state, the child’s previous IEP will be valid. This new provision will help parents of transferring students know what they can expect from their new schools.
- The procedural safeguards notice, which explains the specific rights and responsibilities of the parent in the special education process, will be routinely distributed only once per year. However, a copy will be distributed after the initial referral, when a parent makes a request for an evaluation, when a due process complaint has been filed, or if a parent requests a copy.

- Parents now have 2 years in which to exercise their due process rights after they knew or should have known that an IDEA violation has occurred. Other due process changes can be found at www.pacer.org/idea/2004/summary.htm. The due process hearing is an impartial procedure used to resolve disagreements over issues related to special education services that arise between a parent and a school division. The right of the parents or the school division to request a due process hearing is guaranteed by federal and state laws that govern the education of children with disabilities.
- The right of a student with a disability to stay in his or her current educational placement pending an appeal is eliminated for alleged violations of the school code that may result in a removal from the student's current educational placement for more than 10 days. Before this update of the IDEA, the student with a disability would have been allowed to stay in his or her current educational placement pending an appeal regardless of how many days the violation would have removed him or her from the current placement.
- A child is entitled to receive programming and services necessary to enable him or her to receive a free appropriate public education consistent with section 612(a)(1) during the period in which he or she is in an interim alternative education setting.
- Before the IDEA 2004, the burden was on the school district to show that the behavior resulting in a disciplinary action was not a manifestation of the child's disability before being allowed to apply the same disciplinary procedures as it used for nondisabled children. Other changes in discipline can also be found at www.pacer.org/idea/2004/summary.htm.⁴

Medically Necessary Versus Educationally Needed

Health care professionals frequently view educationally 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 mandated to be provided by public education systems. The additional proviso that the service must be necessary for education or special education is a key component in the laws. Related services are those services indicated as necessary for the child to maximize his or her special education program (ie, IEP). In other words, without the related services, the child might not be able to maximize his or her special education program. This difference in perspective and interpretation by physicians and other health care professionals 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, physicians and other health care professionals need to be

familiar with these issues, their legal basis, and the special educational process and system. Maintaining this knowledge is a key function of the medical home provider for children with chronic diseases and disability conditions.⁵ Readers are referred to the American Academy of Pediatrics policy statement "The Pediatrician's Role in Development and Implementation of an Individual Education Plan (IEP) and/or an Individual Family Service Plan (IFSP)"⁶ for additional background materials.

In addition, functional classifications as suggested by the World Health Organization in its International Classification of Impairments, Disabilities, and Handicaps²⁷ offer many advantages to the current diagnostic systems used by the medical home provider for children with disabilities. In 2001, the World Health Organization approved the International Classification of Functioning, Disability, and Health as the international standard for conceptualizing, classifying, and coding function. It evaluates all children within the same structure and metric regardless of diagnosis. It highlights a child's unique strengths and needs for the purpose of directing interventions. This is particularly advantageous in the case of spectrum diagnoses such as autism and cerebral palsy in which a label alone is not sufficient to direct service interventions. A functional assessment of the child provides a more complete picture so that providers can better match resources and needs. Functional classification also looks at individuals within the context of their social and physical environment, taking into account the impact of human and technologic supports on an individual's "activities and participation." In addition, functional classification catalyzes interdisciplinary communication and collaboration by providing a common structure and language for discussion.

Challenges for Schools

Providing related services presents significant opportunities for the children served as well as 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 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:

- lack of clarity about which circumstances should result in a child's exclusion from school for medical reasons;
- uncertainty about the responsibility for, and administration of, complex nursing treatment or therapy in school⁸;
- 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;
- uncertainty about medical liability for therapies administered in school;
- conflicting opinions about the appropriateness of some therapies used for children;
- concern about the rising cost of special education services and whether all treatment required in IEPs is warranted; and
- 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.⁹

School-System Responsibility

In March 1999, the US Supreme Court ruled that complex nursing service (ventilator care) is a related service.¹⁰ The difference between educationally related services and rehabilitation services is unclear. Court rulings have generally mandated that all therapies and equipment (eg, assistive devices) recommended in the IEP be reimbursed by the educational system.¹¹ However, this has not precluded the application of Medicaid or other public funding for payment of equipment or to support medical service provisions within the IEP 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. One example of private insurance carriers paying for these services would be during the summer when school is not in session. Even if insurance payment is an option, the parents 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 authori-

ties are increasingly concerned about the responsibility 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 insurance companies and managed care systems shifting funding responsibilities for rehabilitation and medical diagnostic services from health care to the school system. Each state's mandate to the local school system may vary in the degree that any such services are paid by the school system. The variability of school systems to assume responsibilities 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,¹² which depletes educational resources for other children.

The special needs of students with complex health conditions that require modifications in the school environment are also commonly documented in an individual student health plan, also known as a student services plan, nursing care plan, or student medications plan. Although these plans are not mandated by law in every state, such plans typically provide information on a student's chronic health condition, instructions on the administration of medication, and emergency contact information. A combination of IEP and individual student health plan is often necessary to help manage a student's health condition in the school and classroom settings.

The Physician's Role

The physician's role mandated by the IDEA as a related service is defined to include only the diagnosis and evaluation of the disability. However, in the context of the medical home, the physician's role also includes the medical management, supervision, and program planning for the child. The IDEA does not mandate that these additional roles be paid for by the public school. Parents often need an advocate for the child who can be objective in assessing the child's special needs and determining realistic expectations. Input from the medical home professionals 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. Currently, the funding for the physician and other health care professionals' time to complete this role is lacking in most health insurance programs and is not funded by most federal and state funds for education. However, physicians can bill for their consultative services and for other related services with some private insurance plans, Medicaid, and the State Children's Health Insurance Program.

CONCLUSIONS

A multidisciplinary assessment within the school system is required in the initial evaluation of children to deter-

mine 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 should 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, functional, and medical needs of the child or adolescent should be determined first, and then the appropriate services to meet these needs should be provided in a timely manner. 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. Physicians and other health care professionals should be well informed about the medical and educational needs of children and adolescents with chronic diseases and disabling conditions.
2. Educational opportunities should be developed and made available to physicians and other health care professionals at local, state, and national levels.
3. Physicians and other health care professionals should be aware of the issues and inconsistencies in the IDEA, parts B and C, and Section 504 of the Rehabilitation Act of 1973.
4. Pediatricians, including pediatric subspecialists, and other health care professionals should objectively appraise the special needs of children and adolescents, determine realistic expectations, and advocate for children and adolescents by assisting with establishing an appropriate balance between the recommendations made by the school team and the desires of the family.
5. The initial pediatric focus for services should be on the child or adolescent with a disability and on his or her specific needs, and these needs should not necessarily determine the child's placement. Once these specific 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.
6. Care coordination for children and adolescents with chronic and disabling conditions should take place in the medical home, and the medical home must include the primary care physician, pediatric specialists, and other health and human services professionals regardless of the location of, or source of payment for, these services.
7. Physicians and other health care professionals should take a more active role in the development and implementation of individualized family service plans.
8. Physicians and other health care professionals should get involved at the systems level. Physicians, especially pediatricians, should seek representation on local advisory and interagency committees that oversee programs for school placement of children and adolescents with chronic diseases and disabling conditions.

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ADVOCACY SUPPORT RESOURCES

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- Technical Assistance Alliance for Parent Centers. Available at: www.taalliance.org
- Parent Advocacy Coalition for Educational Rights. Available at: www.pacer.org
- Families and Advocates Partnership for Education. Facts on hand: related services. Available at: www.fape.org/pubs/fape_33.pdf
- Council for Exceptional Children. Available at: www.cec.sped.org
- Learning Disabilities Association of America. Available at: www.lidaamerica.org
- National Center for Learning Disabilities. Available at: www.nclld.org
- Office of Special Education and Rehabilitative Services. Available at: www.ed.gov/about/offices/list/osers/index.html?src=oc

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