

Provision of Related Services for Children With Chronic Disabilities

Committee on Children With Disabilities

Since 1975 all children with disabilities specifically delineated by law have had available to them "a free, appropriate public education that includes special education and related services to meet their unique needs." This access has been made possible by the passage of Public Law 94-142,¹ The Education for All Handicapped Children Act of 1975. This law was amended in October 1990 with passage of Public Law 101-476, The Individuals With Disabilities Education Act (IDEA). Part B of Public Law 101-476 primarily details the identification and provision of services for children with disabilities. Unfortunately, the implementation of Part B of this law has been limited for many children by a number of significant and complex issues.

The term "related services" as currently defined in Part B of the IDEA includes the following:

... transportation and such developmental, corrective, and other supportive services (including speech pathology and audiology, psychological services, physical and occupational therapy, recreation and social work services, and medical and counseling services, including rehabilitation counseling, 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.

Health care providers frequently view the related services listed above as medically necessary and/or helpful for children with disabilities without the proviso that these services must be necessary for special education. 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.

Providing related services presents significant opportunities for the children served and challenges for the educational system. With an increasing number 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 may ultimately prevent children from receiving potentially beneficial and needed services. Finally, the current trend of integration and inclusion of many children with a wide range of disabilities in "regular" classrooms and programs will make the provision of related services outside of traditional "special" educational settings a larger and more complex future issue.

The difficulties in implementation of Public Law 101-476 are as varied and complicated as the disabilities of the children involved. Among others, these problems include²⁻⁴ (1) lack of clarity as to what circumstances should result in a child's exclusion from school for medical reasons; (2) uncertainty concerning responsibility for and/or administration of medical treatment in school; (3) inconsistencies in state and local guidelines and interpretations regarding who can and 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 concerning the propriety of some therapies being used for children; (6) concern about the rising cost of special education services and whether all treatment recommended in Individual Education Plans (IEPs) is warranted; and (7) the lack of provision of related services for children who may not require special education but who have chronic disabilities that impair their ability and readiness to attend and/or participate in school.

This statement primarily addresses the problem of children with chronic disabilities who may not require special education and the lack of provision of related services for them. For families and health care providers who believe that related services are desired and/or necessary, other legal justifications exist both within and beyond Public Law 101-476.

ISSUES

While initially it seems clear within the above definition that related services are those necessary to aid a child with a disability to benefit from special education, there are a number of additional conflicting issues. These conflicts exist as a result of additional amendments to IDEA, as well as Section 504 of the Rehabilitation Act of 1973, and a variety of court rulings.

In 1986, Public Law 94-142 was amended through the enactment of Public Law 99-457 (and its subsequent reauthorization, as Public Law 102-119, which included Part H programs for infants and toddlers with disabilities). The purpose of Part H is to strengthen incentives for "statewide comprehensive

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The recommendations in this policy 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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coordinated multidisciplinary interagency program(s) of early intervention services for all infants and toddlers with disabilities and their families." In effect, implementation of Part H extends the availability of services to infants and toddlers with disabilities and their families from birth. Part H specifies the services to be those necessary to meet the developmental needs of each eligible child and the family needs related to enhancing the child's development in conformity with an Individualized Family Service Plan (IFSP). The IFSP is developed through evaluations assessing the following five domains: physical development; cognitive development; communication development; social or emotional development; and/or adaptive development. The philosophy behind providing these services is to maximize the developmental potential of these children and their families. This process recognizes the potential global benefits of these services, even if that child has deficits in a single domain (for example, physical development) and therefore may not require special educational or cognitive services.

While there are many similarities, significant inconsistencies exist between Part B and Part H in the requirements governing the provision of related services. Part H specifically includes interventions that under Part B are defined as related services without the restriction that the child receives special education (cognitive services). In fact, those services defined as related services in Part B are considered primary interventions in Part H. It makes little sense to consider services such as speech, physical, or occupational therapy important components of a program for a child younger than 3 years of age, but not necessarily important for a child older than 3 years of age unless the child's needs have changed. A change in the focus or location of the agency providing these services does not lessen the child's need for services. Children with chronic diseases and disabling conditions are best served by the acknowledgment of the consistency of their needs at all ages, rather than by the inconsistency of service delivery created by these statutes and regulations.

A further legal justification for the provision of related services without special class placement can be found in Section 504 of the Rehabilitation Act of 1973. This section prohibits discrimination on the basis of disability within federal and federally assisted programs. Regulations promulgated by the Department of Education have more broadly defined both the individuals 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 individuals. Thus, Section 504 implies that children with spe-

cial needs 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.

Court rulings have generally mandated that therapies recommended in the IEP be reimbursed by the educational system.⁵ However, this has not precluded the application of Medicaid or other public funding to support medical service provisions for the disabled child. While private insurance carriers have generally declined to reimburse for therapies provided in the schools, in specific situations they can be responsible for payment of such services. The parents, however, have the right to decline to make claims against their insurance if it would create a realistic threat of financial loss by, for example, lowering the child's available lifetime medical benefits. Since the school systems have been bearing the responsibility for implementation of the IEP and funding most of the therapies, the educational authorities have increasingly been concerned with the responsibility for overseeing the delivery of medical care and other related services for disabled children attending public school. The assumption of these responsibilities has the potential to (1) increase conflicts with local physicians and other agencies responsible for health care delivery; (2) contribute to the disjointed nature of health care for children; and (3) result in unnecessary treatment at increased cost.⁶

The physician's role is currently defined as a related service and is interpreted to be diagnostic and consultative only. This interpretation becomes problematic in its failure to recognize the physician's role in the medical management, supervision, and program planning process for these children. The lack of physician input on treatment-related issues has posed the following important questions: (1) Does the health or the education system have the primary responsibility to oversee the delivery of health-related services in the school? (2) From what source should payment for such services be derived—educational funds, health-related entitlement programs, public health funding, or third-party insurers?

CONCLUSION

Just as a multidisciplinary approach is mandated and necessary in the initial evaluation of children to determine their eligibility for services within the educational system, it is necessary to maintain a comprehensive, multidisciplinary approach in the provision of these services. The inequalities in the interpretation and provision of services between and within states, and even school districts, present a cogent reason for clear, equitable interpretation of Public Law 101-476. Providing related services for children who may not receive special educational services and allowing for greater medical involvement may require new models of interaction and collaboration between the medical and educational systems. However, the increasing number of children with complex medical needs now within the educational system and the more frequent inclusion of these children within regular programs is

blurring the distinction between medical and educational services and regular and special educational services. There is an increasing amount of data to suggest subtle impairments in the school performance of children with chronic conditions who might otherwise appear to be intellectually unaffected.⁷ The requirement of special educational services as the entree for other services implies that schools are to provide only cognitive educational services and that children do not learn from, need, or benefit from other school services and activities. This assumption is narrow and inconsistent with current thought and the provision of a free and appropriate education for children with disabilities because it does not adequately address the unique and complex total needs of these children. Providing these children with related services by utilizing a comprehensive approach to their chronic and disabling conditions will afford them the best opportunity to achieve their maximum potential.

RECOMMENDATIONS

1. The focus for services should be on the child with a disability and his or her specific needs, not the relationship of these services to the child's educational placement. The specific class placement should not determine the provision of related services in school. Health care providers need to be aware of the issues and inconsistencies in Public Law 101-476, Parts B and H, and Section 504 of the Rehabilitation Act of 1973. Such an awareness will enable them to serve as effective providers, resources, and advocates for children with disabilities and their families. This should help ensure that children with disabilities who do not have significant cognitive or achievement impairments, but would benefit from related services, would more likely have their total educational needs met.
2. It is important that physicians, especially pediatricians, seek representation on the local advisory and interagency committees that oversee programs for placement of children with disabilities in schools. This would allow physicians to take a more active role in the development and implementation of the IEP process.
3. To be effective in overseeing the provision of services, including related services, physicians should be well informed concerning the needs of children with disabilities. Educational opportunities about these issues should be made readily available for interested physicians.
4. The supervision of medical care and health-related services for children with chronic and disabling conditions is the responsibility of physicians and the medical community, regardless of the location or source of payment for these services. When this oversight responsibility extends to services provided by the school system, clear and careful collaboration and coordination with the educational authorities is 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.

5. The Academy recommends that the potential for the physician's role in the care of children with disabilities within the schools be expanded by revising and clarifying the definition of medical services. The child, his or her family, and the school may benefit by medical consultation to determine and supervise specific medical, nursing, and therapy needs of the child within the educational setting. Medical services should not be limited to diagnosing the child's medically related disabling condition that results in the need for special education and related services. Medical services should be defined to encompass diagnosis, evaluation, consultation, and the medical supervision of those other services that are by statute, regulations, and/or professional traditions the responsibility of a licensed physician.

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REFERENCES

1. The Education for All Handicapped Children Act of 1975. 20 USC §1400 et seq
2. Bergdorf RL. *The Legal Rights of Handicapped Persons, Case Materials, Test*. Baltimore, MD: Paul H. Brookes Publishing Co; 1980
3. Wright GF. The pediatrician's role in Public Law 94-142. *Pediatr Rev*. 1982;4:191-197
4. Low MB. The Education for All Handicapped Children Act of 1975: a pediatrician's viewpoint. *Pediatrics*. 1978;62:271-274
5. *North v District of Columbia Board of Education*. 471 F suppl 136 (DC 1979). ELHR 1979;551:157
6. Palfrey JS, Singer JD, Raphael ES, Walker DK. Providing therapeutic services to children in special educational placements: an analysis of the related services provisions of Public Law 94-142 in five urban school districts. *Pediatrics*. 1990;85:518-525
7. Stoff E, Bacon MC, White PH. The effects of fatigue, distractibility, and absenteeism on school achievement in children with rheumatic diseases. *Arthritis Care Res*. 1989;2:49-53

SUGGESTED READINGS

1. Horne RL. The education of children and youth with special needs: what do the laws say? *NICHY News Digest* 1991;1:1
2. Kupper L, ed. Related services for school-aged children with disabilities. *NICHY News Digest*. 1991;1:2

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