

CLINICAL REPORT

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The Individuals With Disabilities Education Act (IDEA) for Children With Special Educational Needs

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abstract

The pediatric health care provider has a critical role in supporting the health and well-being of children and adolescents in all settings, including early intervention (EI), preschool, and school environments. It is estimated that 15% of children in the United States have a disability. The Individuals with Disabilities Education Act entitles every affected child in the United States from infancy to young adulthood to a free appropriate public education through EI and special education services. These services bolster development and learning of children with various disabilities. This clinical report provides the pediatric health care provider with a summary of key components of the most recent version of this law. Guidance is also provided to ensure that every child in need receives the EI and special education services to which he or she is entitled.



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Pediatric health care providers play a key role as advocates, promoting the well-being of all children in the educational setting as well as in health care. Children with disabilities, currently estimated as 15% of US children,¹ have been entitled to a free appropriate public education (FAPE) since 1975 when the US Congress mandated public special educational services for those with special needs through the Education for All Handicapped Children Act, later renamed the Individuals with Disabilities Education Act (IDEA).² IDEA has undergone several reauthorizations and amendments by Congress since its initial adoption, most recently in 2004. This clinical report will review the historic and legal background of this entitlement and will explore the role of the pediatric health care provider in supporting special education services for children in need. It is complemented by other American Academy of Pediatrics (AAP) reports and policy statements addressing related issues in early intervention (EI) and school health.³⁻⁸

FEDERAL LEGISLATION AFFECTING EDUCATION FOR CHILDREN WITH DISABILITIES

Congress passed IDEA in 1975 in response to public belief in the long-term benefit of educating children with disabilities, growing concern that states were not providing an adequate public education to these children, and a series of legal challenges. At the same time, states sought the assistance of the federal government to fund public education services for children with disabilities.^{9,10} IDEA authorizes federal funding to states for EI services for infants and toddlers with disabilities and developmental delays (part C) and special education and related services for school-aged children with disabilities (part B) and relates principles for providing such services.

IDEA has several key requirements,¹⁰ as follows:

1. Free appropriate public education: States and local school districts must offer FAPE to all children with disabilities between the ages of 3 and 21 years, inclusive.
2. Identification and evaluation: States and school districts must identify, locate, and evaluate all children with disabilities, without regard to the severity of their disability, to determine their eligibility and need for special education and related services. This requirement is referred to as “child find,” and the principle is known as “zero reject,” meaning that no child can be denied an education
3. Individualized education program: Each child with a disability who is deemed eligible will receive an individualized education program (IEP) describing his or her specific educational and service needs, with parent participation on the IEP team. Individualized family service plans (IFSPs) are used for infants and toddlers.

4. Least restrictive environment: Children with disabilities must be educated with children without disabilities “to the maximum extent possible” in the least restrictive environment (LRE).
5. Due process safeguards: Procedural safeguards must be put in place for children and their families, including the right to mediation, request for complaint investigation, and/or a due process hearing; the right to appeal to a federal district court; and, if they prevail, the right to receive attorneys’ fees.
6. Parent and student participation and shared decision-making: Schools must collaborate with parents and students with disabilities in the design and implementation of special education services. The parents’ (and, when appropriate, the student’s) input and wishes must be considered in IEP goals and objectives, related-service needs, and placement decisions.

Although IDEA is a federal law overseen by the US Department of Education, its requirements pertain only to states receiving related funds. However, at the present time, all states and territories accept federal IDEA funds. The statute also allows state flexibility and discretion for many of its components.

IDEA’s provisions are separated into 4 distinct parts: part A consists of its general provisions; part B authorizes the state grants for services to preschool-aged (3–5 years) and school-aged children (ages 6–21 years, inclusive) with disabilities (Table 1); part C authorizes services for programs of EI for infants and toddlers (children younger than 3 years) and their families; and part D focuses on personnel improvement, with awards to states for reforming and improving their systems for personnel preparation and professional development in EI, educational, and transition services and funding for at least 1 parent

training and information center (www.parentcenterhub.org) in every state to provide information, training, and assistance to families of infants, toddlers, children, and youth with disabilities.

Two other federal laws have roles in ensuring the educational rights of children with disabilities. Although IDEA serves as both a civil rights statute for children with disabilities as well as a funding statute centered on their education, section 504 of the Rehabilitation Act of 1973¹¹ and the Americans with Disabilities Act (ADA) of 1990 (as amended by the ADA Amendments Act in 2008)¹² address civil rights broadly, prohibiting discrimination against any individual with disabilities, and do not provide any federal funds to assist with implementation. Section 504 specifically prohibits discrimination against a person of any age with a disability, in any federally funded program or activity. Although childhood education falls within its purview, section 504 includes all levels of education, including colleges and universities, which are not covered under IDEA. In its regulations, section 504 requires the provision of an FAPE in the LRE for all children with disabilities attending public schools, but the regulations only require reasonable accommodations for younger children in child care settings, older youth in college, or for other public accommodations. In addition, section 504 extends to any private school that accepts any federal funds. The ADA also prohibits discrimination against individuals with disabilities of all ages and in all areas, including employment, public services, and public accommodations, such as schools. It covers all areas of public life and not just those receiving federal funding.

Although these laws overlap, they have different working definitions of disability. IDEA uses a categorical definition of a child with a disability, specifying an eligible child as having an

TABLE 1 Supports From IDEA Law Versus Section 504 (Rehabilitation Act) Versus the ADA

Federal Law	IDEA	Section 504 (Rehabilitation Act)	ADA
Law enacted since	1975	1973	1990
Usefulness	Requires educational programs for children with disability that are in addition to those without disability. Provides funding only if the condition of an FAPE is provided. Children receive special education and related services under this law.	Makes discrimination against people with disabilities illegal when federal financial assistance is involved (including schools). Children can receive “regular” education with related aids and services or special education to satisfy this law. Under the regulations, they are entitled to an FAPE in the LRE just as under IDEA.	Makes illegal discrimination against people with disabilities, not tied to funding type
Eligibility of a child/teen with a disability	Categorical; also, child must require special education and related services: Intellectual disability; hearing impairments (including deafness); speech or language impairments; visual impairments (including blindness); emotional disturbance; orthopedic impairments; autism; traumatic brain injury; specific learning disabilities; other health impairments	Functional: A physical or mental impairment that substantially limits ≥ 1 of the major life activities of such individual. The ADA Amendments Act specifically lists examples of major life activities including caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working. The act also states that a major life activity includes the operation of a major bodily function. This also covers section 504. All children covered by IDEA are covered by section 504, but some children covered by Section 504 are not covered by IDEA. Examples of disabilities covered (and not always covered by IDEA) include ADHD, diabetes, and asthma. In some circumstances, these may be covered under “Other Health Impairments” in IDEA.	Functional: A physical or mental impairment that substantially limits ≥ 1 of the major life activities of such individual. The ADA Amendments Act specifically lists examples of major life activities including caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working. The act also states that a major life activity includes the operation of a major bodily function. All children covered by IDEA are covered but some children covered by the ADA are not covered by IDEA. Examples of disabilities covered (and not always covered by IDEA) include ADHD, diabetes, and asthma. In some circumstances, these may be covered under “Other Health Impairments” in IDEA.
Age group covered	IDEA part B—generally 3 to 21 y of age IDEA part C—EI—infants and toddlers	All ages (so includes schools, colleges, and universities). The regulations require FAPE in LRE for school-aged children, but reasonable accommodations for younger or older children, or in nonpublic school settings such as child care or college.	All ages (so includes schools, colleges, and universities)
Name used for plan for child	IFSP; ages birth to 3 y of age IEP; ages 3 y and above	Section 504 plan or “504 plan” (note: an IEP under IDEA law can satisfy section 504 requirements)	
Reference	20USC §1400 et seq ^a Pub L 94-142 ^b with most recent amendment Pub L 108-446 ^c	29USC §794 ^d	42USC §12101 et seq ^e with most recent amendment 110-325 ^f

Not all children in need of supports in school qualify under IDEA law. Other laws, such as section 504 of the Rehabilitation Act and the ADA, can help determine supports necessary to a child with a medical condition in school. The table illustrates some of the differences between IDEA (requiring IEP development), section 504, and the ADA. ADHD, attention-deficit/hyperactivity disorder.

^a 20 USC §1400, Title 20 - Education, Education of Children with Disabilities, Subchapter I - Definitions, section 1400 - Short title; findings; purposes (2011).

^b Education of All Handicapped Children Act. Pub L No. 94-142 (1975).

^c Individuals with Disabilities Education Improvement Act of 2004. Pub L No. 108-446 (2004).

^d 29 USC §794, Title 29 - Labor, Chapter 16 - Vocational Rehabilitation and Other Rehabilitation Services, Subchapter V - Rights And Advocacy, section 794 - Nondiscrimination under federal grants and programs (2011).

^e 42 USC §12101, Title 42 - The Public Health and Welfare, Chapter 126 - Equal Opportunity for Individuals with Disabilities, section 12101 - Findings and purpose (1990).

^f ADA Amendments Acts of 2008. Pub L No. 110-325 (2008).

intellectual disability (“mental retardation,” in its original text), hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), emotional

disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities. IDEA also allows states to use the category of “developmental delay” for children 3 through 9 years of

age (although not all states elect to use this category; http://tadnet.public.tadnet.org/pages/513-products?main_search=states+use+of+developmental+delay&search_query=keyword&x=0&y=0). In

contrast, section 504 and the ADA define disability generally, using the functional description of disability as being a physical or mental impairment that substantially limits a person in a major life activity (self-care, manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working). Conditions such as attention-deficit/hyperactivity disorder, asthma, and diabetes are covered under section 504 and the ADA if these conditions result in functional limitation. They may also be covered under the IDEA category of “other health impairment” if the health condition affects the child’s ability to benefit from the education program.

When a parent or the child’s pediatric health care provider is concerned about a child’s developmental or school needs, supports may be covered under IDEA, section 504, or the ADA (Tables 1 and 2). If the child is in need of educational support services, such as special education, speech-language therapy, or occupational therapy, guidance for obtaining services falls within IDEA. Examples include a child whose academic achievement is not appropriate for his or her age, a child who cannot follow classroom instructions or has disruptive behaviors preventing learning, or a child who cannot write legibly. In contrast, a child with a motor disability who needs ambulation assistance or a child with diabetes who needs school nursing assistance for the administration of medication usually receives school accommodations under section 504. Finally, a school system is violating the ADA and section 504 if a child cannot participate in school activities because of physical barriers preventing his or her entry into the building or room. This situation may also be covered under IDEA, given its provision that children with disabilities must be able to

TABLE 2 Examples of Children or Teenagers Who May Qualify for Special Health and/or Behavioral Accommodations and Support in a School Setting

- Child with intellectual or developmental disability, including the following:
 - autism spectrum disorder
 - cerebral palsy
- Child with learning disabilities
 - Oral expression
 - Listening comprehension
 - Written expression
 - Basic reading skills
 - Reading fluency skills
 - Reading comprehension
 - Mathematics calculation
 - Mathematics problem solving
- Child with condition affecting behavior in school, including those with a mental health condition, including the following:
 - teen who is suicidal
 - a child aggressive to others
 - child shortly after injury, with residual issues, including the following:
 - child postconcussion³⁸ and other traumatic brain injury
 - after automobile or other injury
- Child with chronic condition affecting performance, including those with episodic or occasional issues, including the following:
 - child with asthma or diabetes
 - child with seizure disorder
 - child with allergy to food
 - child with physical disabilities such as juvenile arthritis and muscular dystrophy/neuromuscular disorders
- Child with chronic infection, either on treatment or noncompliant, including the following:
 - child with HIV/AIDS
 - child with multidrug-resistant tuberculosis
- Child requiring technological supports, such as
 - tube feeding or special modified diet (ie, textured or pureed foods or low salt)
 - ventilator or oxygen

These students may be served by IDEA law, section 504, or the ADA depending on the child’s needs in a school setting.

participate in all nonacademic and extracurricular activities open to children without disabilities. Given the legal nuances of each regulation, a parent of an affected child or health care provider may benefit from consultation with an attorney or educational/disability advocate. The health care provider or parent can obtain further information from resources such as the Council of Parent Attorneys and Advocates (www.copaa.org) or the National Disability Rights Network

(www.ndrn.org). Connecting parents to their state parent training and information center (www.parentcenterhub.org) can provide them with access to critical information about the process, their child’s rights, and their rights under IDEA, section 504, and the ADA.

INFANTS, TODDLERS, AND THE IFSP

Although IDEA focuses most of its attention on children aged 3 years and older, part C was developed in 1986 for the promotion of EI for children with developmental disabilities from birth to 3 years of age. As described by Congress, it is intended to enhance the development of infants and toddlers with disabilities, minimize the need for special education, and maximize the individual’s long-term potential for independent living. Part C recognizes the unique needs of infants and toddlers, with greater emphasis on the family and community, particularly emphasizing care in the home and community settings, rather than schools, and mandating family involvement. Therefore, the inclusion of families as team members is critical in developing and implementing the IFSP. The IFSP is a written plan with several key components or statements, as follows:

1. Service coordinator (ie, a professional responsible for program implementation).
2. The child’s present levels of development, in the following areas: physical (including vision, hearing, and health status), cognitive, communication, social or emotional, and adaptive.
3. Family’s resources, priorities, and concerns related to enhancing the child’s development.
4. Measurable results or outcomes expected to be achieved by the child and family, with criteria, procedures, and timelines to be used.

5. EI services necessary (“based on peer-reviewed research [to the extent practicable]”), including the beginning date, length, duration, frequency, intensity, method of delivery, and location.
6. Provision of services in the natural environment (ie, settings where young children without disabilities are typically found) or justification of why this will not be provided.
7. Educational component for children 3 years or older, when it is elected to continue EI services into the preschool period. Recent changes in IDEA allow states to continue EI services via an IFSP after 3 years of age and until a child enters kindergarten, with parental approval.
8. Other service needs, including medical, that are not required or funded under part C.
9. Payment arrangements, if any. Under IDEA, states may establish “family cost share” based on a sliding fee scale, but families cannot be denied needed services because of inability to pay. Families may also be asked to allow the EI system to bill their public or private insurance to cover needed services. Child find services, evaluations and assessments, development and review of the IFSP, and service coordination are provided at no cost to families in all states and territories.

In addition, a transition plan for services, necessary transition steps, and program options must be written in the IFSP for children nearing 3 years of age, not fewer than 90 days and not more than 9 months before the third birthday. Eligible children must be experiencing developmental delays in 1 or more areas of development, as measured by appropriate tests and procedures, or have a condition that has a high probability of resulting in developmental delay. IDEA does not provide a more specific definition for

eligibility, leaving it to the state’s discretion. As a result, the eligibility criteria vary by state. Further information on national and local laws and services can be found via the Center for Parent Information and Resources (<http://www.parentcenterhub.org/nichcy-resources/>). The Center for Parent Information and Resources has relevant information as well as information on how to contact parent technical assistance centers (<http://www.parentcenterhub.org/ptacs/>).

PRESCHOOL- AND SCHOOL-AGED YOUTH AND THE IEP

IEPs are critical for children with a disability or chronic health condition affecting school performance and learning. The IEP delineates the specific special education and related services (eg, physical therapy) that the child should receive. It is helpful for health care providers to be familiar with several commonly used terms related to IDEA. FAPE, or free appropriate public education, provided in the LRE, or least restrictive environment, are both requirements in IDEA law.

FAPE does not mean that the school is mandated to provide the “best” or “optimal” services for the child to learn and perform in the school. To decide on what “appropriate” means, the IEP team and other partners must decide what is important to consider and implement for any particular child. The Supreme Court, in *Board of Education of the Hendrick Hudson Central School District v Rowley*, 458 US 177 (1982),¹³ held that FAPE is satisfied when the school provides instruction individualized with enough support services to allow a child to benefit educationally. This instruction should enable the child to advance from grade to grade. IDEA does not require that each state have schools fully fulfill the potential of children with disabilities. An example is a child with quadriplegic spastic cerebral palsy who requires a

wheelchair to get from place to place. If the child’s required classroom is on the second floor, then the IEP needs to specify how the child will get to that classroom, taking the disability into account. This situation does not require the school to get an elevator, because the legal requirement is for “reasonable accommodations.” The IEP team will decide how the child will get to the classroom, whether this is by moving the classroom to an accessible first floor, getting an elevator, or having some other appropriate way of getting the child to the second-floor classroom. Because the child is also entitled to participate in the nonacademic and extracurricular activities available to children without disabilities, the school must also make those activities accessible to the child who uses a wheelchair.

IDEA law mandates that the child should be in the LRE or least restrictive environment. Children with disabilities should be educated with children without disabilities “to the maximum extent possible,” which means that they should be in the classroom that they would be in if not needing supports unless they cannot accomplish the goals in their IEP without a different placement. The goal of LRE is to preserve interactions with typical children and to ensure exposure to educational material and interactions that may not be found in a more restrictive placement. The following settings are listed from least to most restrictive environments: (1) typical education classroom with in-class supports; (2) typical education classroom with periodic pull-out to special education (resource) placement; (3) special education classroom with opportunities for “mainstreaming,” as appropriate; (4) special education school; and (5) special education school with residential placement on site. Even in more restrictive settings, the IEP must identify opportunities for the child with a disability to interact with nondisabled peers

(eg, by bringing a student who is placed in an “out-of-district” school back to the school district to participate in the after-school program).

The term IEP relates to an individualized program for each eligible child. Children with special health needs/disabilities or special health needs cannot be placed in a classroom with only general plans or instruction. There are wide variations in function, manifestation, and severity in any disability or medical condition; therefore, each child with a special need requires an individualized program taking into account his or her strengths and needs and the effects of the child’s disability on learning. Children with a certain condition (eg, hearing loss) should not all have the same educational program. Health care providers can provide factual information to the educational team documenting, verifying, or certifying what accommodations are essential on the basis of bona fide medical need. As child health experts, they can assist school personnel in connecting a child’s medical condition to his or her educational needs, related services, and accommodations. In discussions with school staff, the health care providers should provide specific advice or direction to the school district on necessary health and safety accommodations. Health care providers can play advisory, advocacy, and collaborative roles but should take care not to dictate or impose their own view of preferred educational methods, as this task is best left to the educational team, including the parents. The IFSP or IEP should take into account medical diagnoses, treatments, and supports to provide special education, but these are not the medical care plans or emergency action plans that school nurses and related service providers would implement for health care at the school. These are discussed in other AAP documents and other reports.^{5,8,9,14,15}

THE ROLE OF THE HEALTH CARE PROVIDER IN ASSISTING CHILDREN WITH SPECIAL EDUCATION NEEDS

1. Identifying Children in Need of EI or Special Education Services

Developmental surveillance and screening performed in the medical home by the primary care provider often lead to the identification of children with disabilities who require further evaluation to determine the need for appropriate EI or special education services.¹⁶ When a child is identified as having special needs, the health care provider can refer the child to appropriate resources such as a psychologist or pediatric subspecialist for further assessment. In addition, referral to the local EI (age 0–3 years) or school (3 years and older) agency may facilitate evaluation toward possible services. To do this, health care providers are advised to be familiar with the appropriate local or state agencies for referrals. Parents may also self-refer their child. Further guidance and forms for health care providers are provided by the AAP clinical reports “Provision of Educationally Related Services for Children and Adolescents With Chronic Diseases and Disabling Conditions”¹⁷ and “Early Intervention, IDEA Part C Services, and the Medical Home: Collaboration for Best Practice and Best Outcomes.”¹⁸

When a health care provider or parent makes a referral of a child to the school system, representatives of the school must determine whether an evaluation will be conducted. If it is decided that an evaluation will be conducted, the parent must give informed, written consent for the evaluation. Then the “comprehensive, multidisciplinary” evaluation must be completed by the school within 60 days of the parental consent (unless the state has a different timeline), followed by development of the IEP. More specifically, a meeting must be conducted to develop an IEP within 30 days of the eligibility

determination, after which special education and related services are to be made available as soon as possible. If the district decides it will not conduct an evaluation, it must provide written information, known as prior written notice, to the parent indicating its decision as well as why it has decided not to conduct an evaluation, including all the information about the child that was used to make that determination and the factors that influenced the decision, what steps the parents can take if they disagree with this decision, and sources for parents to contact to obtain assistance in understanding their rights under IDEA. At each step, the district must provide a written response to any parental written request. Follow-up of the referral by the health care provider can help determine whether the child is evaluated appropriately.

2. Sharing Relevant Information With EI or School Personnel

EI programs and schools rely on interactions with health care providers to create the plans for a child’s appropriate intervention and educational environment and support. Parents and guardians usually share medical and mental health information with EI programs and schools. Health care providers may share a patient’s protected health information (PHI) relevant to the child’s education program with school personnel only after securing appropriate authorization to disclose PHI from the patient’s parent or legal representative or guardian. In addition, youth sometimes choose to share health information with school personnel. When appropriate, the youth or family should be consulted around information sharing, particularly when the information is sensitive in nature. When a program or school has a medical professional on site, the child’s health information should also be shared with this professional, who can assist in

promoting collaboration with the medical home provider. Examples of reports that could be shared include developmental screening results, hearing and vision screening or assessments, hospitalization or other medical summaries (if there are consequences for the school), chronic medication treatments and treatment changes, emergency preparedness¹⁹ plans, palliative care (which may include do-not-attempt-resuscitation orders at times), and subspecialist consultations and referrals. Health care providers are advised²⁰ that although they are required to be compliant with the Health Insurance Portability and Accountability Act²¹ in speaking with schools, schools need to be compliant with the Family Educational Rights and Privacy Act.²² A form for EI referral that incorporates the Health Insurance Portability and Accountability Act and the Family Educational Rights and Privacy Act considerations has been developed by the AAP in conjunction with the US Department of Education Office of Special Education Programs and is available for use by health care professionals (see Supplemental Information).^{4,8,9}

When communicating with a school, the health care provider should consider including his or her contact information and the family's contact information and documenting the communication in the child's medical record. Care needs to be taken so that the privacy and security of PHI is preserved in transmitting information. Transmitting information on letterhead may be helpful for the school to receive pertinent medical details, including on how to reach you as a health care provider, and for providing a dated record in the medical chart of the concerns and requests. However, health care providers should also be sensitive to reasons why parents may not wish to share some or all of the PHI with the school, particularly when not pertinent to a child's health or development. In such cases, a

parent may instead provide copies of select records. For example, although it is against the law to do so, schools have been known to discriminate against students with HIV or AIDS. And although the law requires that students with disabilities be educated in the LRE regardless of their diagnosis, some school systems may make blanket decisions with which parents do not agree about placement on the basis of a particular disability (eg, autism).

The health care provider can consider several issues when requesting specific services for a child with special needs. Initially, the health care provider can talk to the person responsible for developing and overseeing implementation of the child's IFSP (service coordinator) or IEP, which differs depending on the state. In some situations, the principal has responsibility over the children and staff at the school and may want to be involved with important conversations between the school and outside professionals. The health care provider should understand that the school provides FAPE and not necessarily what would be "optimal" for the child. Health care providers can advise schools about the possible educational ramifications of medical or disabling conditions and suggest solutions; however, services in schools are decided collaboratively by the IFSP or IEP team. Writing a prescription for a school to provide a particular educational service for a child would be analogous to the school requesting a certain medical evaluation or treatment from the health care provider. This action can result in an antagonistic rather than collaborative relationship between the health care provider and the school.

3. Meeting With EI or School Personnel and Parents/Guardians

Although most busy health care providers share information with the school by phone or fax, in-person meetings with EI or school personnel

may also be considered for complex children who have many needs within the school environment or in situations when the team disagrees about how a health, disability, or mental health issue affects the IFSP or the IEP.

If an official IFSP or IEP planning meeting occurs, multiple professionals are usually involved, including an administrator, teachers, various therapists, school nurse, counselors, and others, making a meeting at the EI program or school more convenient. Health care provider involvement, through letters of support or direct advocacy by meeting attendance, may lead to improved medication compliance, medication monitoring (especially if done by school personnel), behavioral outcomes, parent satisfaction, and avoidance of corporal punishment and restraint situations in school settings. In states in which corporal punishment is legal, the health care provider can assist parents in advocating against it and in identifying an alternative educational placement.²³

4. Using EI or School Information in Medical Diagnostic or Treatment Plans

The diagnostic evaluation, performed by the EI program or school for determination of a child's eligibility for services, can be helpful to the health care provider because it offers a standardized assessment of a child's development or intellectual functioning. For the young child, the evaluation will involve several areas of development, including motor, communication, social, behavioral, adaptive, and sensory (hearing, vision) skills. Optimally, EI programs and schools share the results of evaluations with health care providers with informed written parental consent. Programs and schools may require a specific request from the parent to share these evaluations. When received, the health care provider can review and discuss the results with the family,

providing interpretation as needed, because such information may be useful in determination of a specific developmental diagnosis, intellectual or learning disability, speech-language disorder, or motor disability.

Other school information can also be extremely helpful, if not critical, for medical, developmental, and behavioral health care. Examples include information about behavior for the diagnosis and follow-up for children with attention-deficit/hyperactivity disorder, autism spectrum disorder, depression, or seizure disorder. Often, a decrease in school performance or onset of a new behavioral concern is the first sign of a medical condition or a poorly managed chronic disease. Children may have worsening or reoccurrence of symptoms at school, and school personnel may be frontline reporters for certain situations.

5. Working Within an EI Program, School, or School-Based Health Clinic

Health care providers may be key personnel at an EI program or school, whether they are there because of a mandatory requirement, part of a school-based health center, or consultant for the school system. These personnel may be part of IFSP or IEP discussions, depending on the roles delineated by the position. Some physicians may be part of a “community school” system, a partnership between the school and other community resources (www.communityschools.org/aboutschools/what_is_a_community_school.aspx). In this role, the physician can assist in the resolution of health issues affecting performance of the school system. Further information about the role of physicians in schools can be found in the AAP policy statements “The Role of the School Physician”²⁴ and “School-Based Health Centers and Pediatric Practice.”²⁵

6. Working at an Administrative Level To Improve School Functioning Around Children With Special Needs

Some health care providers may work at an administrative level, as in a federal, state, or local agency, to ensure that local EI agencies or schools are well equipped to be responsive to the needs of students with special needs, including the need for related services (eg, speech-language, physical, and occupational therapy), nursing, medication, and any special modified diets or nutritional needs. Each state has an interagency coordinating council for EI and a state advisory panel for special education (www.stateadvisorypanel.org/index.php?option=com_content&view=article&id=21&Itemid=40). In addition to serving on the council, another opportunity is providing public comment during meetings.

SERVICES FOR CHILDREN WITH DISABILITIES IN PUBLIC VERSUS PRIVATE SCHOOLS

Currently, there are several ways that a child with a disability can attend a private school. A local educational agency (an entity that operates schools within the state) or another state educational agency can determine that a student may be placed within a private school to fulfill FAPE. In this situation, the school system pays for the costs of the services at the private school. Alternatively, the student’s parents or guardians may elect independently to place a child in a private school either before or after being determined eligible for special education. The state school system or local educational agency is not required to pay for this placement unless a hearing officer determines that “the agency had not made a free appropriate public education (FAPE) available to the child in a timely manner prior to that enrollment.”²⁶ Whether the requirement of FAPE is met within an educational program

that the public education system provides is a common source of contention. The requirement of FAPE is met when a child is provided with individualized instruction with enough support services to have educational benefits; when the services are paid at public expense; and when the services meet the state’s standards for education, are at the grade levels used in the state’s regular education services, and are conducted in accordance with the child’s IEP.¹³

The local or state educational agency can place the child in a different private school program than the one the parents want if it meets the requirement of FAPE.²⁷ Also, if the private school does not adequately address the child’s education requirements, then courts may not require reimbursement to the private school.²⁸ If the placement is not for educational reasons, for example, for medical or religious reasons, reimbursement to the private school may also not be required.²⁹

Finally, local educational agencies are required to identify children with disabilities, including those attending private schools. Health care providers can be quite helpful to children in private schools by working in conjunction with the parents or guardians to relay information to the public school system as described previously.

BEHAVIORAL AND MENTAL HEALTH ISSUES FOR CHILDREN WITH DISABILITIES IN THE SCHOOL ENVIRONMENT

When a student with a disability breaks a rule of conduct in a school, he or she would be subject to disciplinary action. However, IDEA does have bearing on this, and the process may not be identical to that of a child without a disability. Choices for the school regarding student infractions include the following:

- evaluation of the child’s behavior, with development of a new

- behavior plan within the IEP and class and school incorporation;
- removal from current placement to another classroom or school setting, or suspension up to 10 days;
 - placement in another educational setting for up to 45 days if the student used a weapon, drugs, or inflicted serious bodily injury on another or if the current placement would cause injury to the child or others; and
 - if the student's behavior is not a manifestation of the student's disability or of the failure of the system to implement the IEP, the local educational agency can implement long-term disciplinary action, including expulsion, after a manifestation determination review.

The rules on disciplinary action in IDEA are complicated, and some guidance is available from a US Department of Education Web site "Q and A: Questions and Answers on Discipline Procedures" (<http://idea.ed.gov/explore/view/p/.root,dynamic,QaCorner,7,>), which is not meant to be legally binding. If the pediatrician believes the school's actions are inappropriate, on the basis of the child's disability, he or she can initiate a discussion with school personnel on the child's behalf, advise the parents to request an IEP review, and/or seek legal counsel. Additional guidance can be found in an AAP policy entitled "Out-of-School Suspension and Expulsion."³⁰

IDEA states that the use of positive behavioral interventions must be considered³¹ and a functional behavioral assessment must be used to determine causes of behavioral issues and possible proactive interventions. In addition, a manifestation determination review must be conducted to decide whether the behavior is associated with the child's disability before any change in placement can be made. There has been much concern about the use of seclusions and restraints, especially

since the Government Accountability Office reported hundreds of alleged instances of death and abuse in schools using these techniques, especially among children with disabilities.³² The Government Accountability Office also reported that there is no federal law for either public or private schools regarding restraints and seclusions, and there are widely divergent state laws. Recommended standards regarding restraints, seclusion, and corporal punishment are provided in the AAP book *Caring for Our Children: National Health and Safety Performance Standards: Guidelines for Early Care and Education Programs*.¹⁵ In addition, the AAP Council on Children With Disabilities has a policy statement³³ opposing the maltreatment of children with disabilities by use of inappropriate restraints, seclusion, and aversive interventions. Therefore, although restraints, seclusion, and corporal punishment can be used in some states, when such interventions are used, the health care provider should advise the parents about the potential effects of these practices on their child's health, education, and development.

THERAPIES AND MEDICAL SERVICES IN THE IEP AND DURABLE EQUIPMENT IN SCHOOLS

Most medical professionals realize that various therapies, such as physical therapy, occupational therapy, and speech and language therapy, may be required to support a child with a disability to benefit from special education. These therapies are considered "related services" by IDEA. IDEA sets forth many related services that should be considered for children with disabilities (Table 3).

IDEA considers a medical service to be a related service if it is limited to diagnostic and evaluation purposes. Courts have helped identify which medical services the school is required to provide and which

TABLE 3 Related Services in IDEA

Counseling services, including rehabilitation counseling
Interpreting services (sign language)
Medical services (these cannot be services that are provided by the physician or hospital)
One-on-one instructional aide
Orientation and mobility services
Physical and occupational therapy
Psychological services
Recreation, including therapeutic recreation
School nurse services designed to enable a child with a disability to receive an FAPE as described in the IEP of the child
Social work services
Speech-language pathology and audiology services
Technological devices such as special computers or voice-recognition software
Nonsurgically implanted devices or replacement of one (including cochlear implant)
Transportation

20 USC §1401, Title 20 - Education, Education of Children with Disabilities, Subchapter I - Definitions, section 1401 - General provisions (2011).

services should be provided outside the school environment.

The Supreme Court case *Irving Independent School District v Tatro*³⁴ stipulated that medical services should be provided by the school if the child has a disability requiring special education, the service is required to help a child with a disability benefit from special education, and a nurse or other qualified person who is not a physician can provide the service. In a subsequent Supreme Court case, *Cedar Rapids Community School District v Garret F*,³⁵ the Court continued to state that services by physicians or hospitals are not allowable in IEPs but indicated that nursing services, such as clean intermittent catheterization and full-time nursing, can be related services if the child requires them to attend school.

Assistive devices and durable medical equipment such as wheelchairs in schools may be paid for by several routes including Medicaid, the State Child Health Insurance Program, State Assistive Technology Centers, medical insurance, civic and volunteer organizations, or assistive technology manufacturers.³⁶

ENTRY INTO AND TRANSITIONS IN SERVICES

There are several important entry points into and transitions for patients with disabilities to connect to necessary services. Children from families who relocate to different schools or cities or from home schooling around transition points are especially at risk of losing educational services and supports.

Initial Referral to EI or Special Education

When a parent or health care provider discovers developmental problems or a disability, linkage to EI or special education will lead to receipt of special services, which may occur at birth for a child with trisomy 21, when symptoms and signs of autism manifest in toddlers or preschool-aged children, or when symptoms of psychosis become apparent later in childhood or adolescence. A follow-up clinic visit or phone call can help to check that a family has connected their child with a disability to the EI program or school system.

Transition From EI to School

When a child is already involved with EI and has an IFSP, the IFSP team will usually ensure that the child's parents or guardians are oriented to transitioning their child's supports to special education as necessary, usually at 3 years of age. Ideally, members of the IFSP team will attend the IEP meeting at the child's school to share information and plan transition services. Discussing this transition with parents and a follow-up clinic visit or phone call can help this transition occur smoothly and ensure there is not a loss of services.

Transition to a New School

Families of children with special needs may be concerned about the transition from elementary to middle school or from middle school to high school, particularly if their child is physically or emotionally immature.

The family may worry about adjustment of their child to the new school, with other children developing more rapidly than their child, and may also worry about the subsequent stigmatization that often happens. Parents may fear that other children may take advantage of their child at the new school. Parents may also be unsure of the quality of IEP, special education, or related services at the new school. In collaboration with the personnel from the new school, the health care provider can uncover and explore these issues with the family so that solutions and transition plans can be made. The student and the parents can visit the new school to explore the possibilities and advantages of the new setting. Special education supports and related services at the new school can be explained and shown to the student and his or her parents.

It is important for families to understand their rights during this process. If the family moves to another neighborhood in the same district, their child's IEP is transferred to the new school and implemented as written. (There may be some instances in which the parent and district may agree that a child should stay at his or her current school even after moving, either because of how a school transfer would affect the school or because of the lack of availability of needed services at the school closest to the family's new neighborhood.)

If the family moves within the same state but to a different school district, that district may either adopt their child's IEP or develop a new IEP in collaboration with the parent(s). Until it opts to develop a new IEP, it must provide services and settings comparable to those described in the current IEP developed by the previous school system, pending an IEP meeting with the parents to review and revise the IEP if needed.

If the family moves to a different state, the new school in that state must also provide services and settings comparable to the IEP from the previous state until a new evaluation is conducted (if needed) and a new IEP is developed and implemented (if needed). The district decides whether it can accept the evaluation from the district in another state or needs to conduct its own evaluation. If the district decides that an evaluation is not needed, a meeting still needs to take place with the parents to develop a new IEP. If the district decides that it must conduct a new evaluation to determine whether the child is still an eligible child with a disability in that state, and the evaluation determines that the child is eligible in the new state, then a meeting must take place with the parents to develop an IEP according to that state's policies and procedures.

Regardless of the reasons a child is starting a new school, the child should not be sitting at home without services pending these decisions. In each case, the child's IEP, or services and settings comparable to those in the child's IEP, must be implemented pending these further discussions and decisions.

Transition From School to Adulthood

The transition from school to adulthood is a critical transition that requires individualized goals and supports for each student. Parents (and sometimes school staff) may overestimate or underestimate a child's ability, causing inappropriate programming for special education and related services. The health care provider can assist in the formal planning and bridge-building needed for successful completion. Health care providers, school personnel, and parents or guardians are advised to begin discussion of this transition at 14 to 16 years of age (depending on the state) and to continue communication during the transition process. One cannot overstate the

importance of knowing the youth and knowing what the family understands about their child's potential. The best transitions to adulthood occur when IEPs fit students' capabilities and are based on their interests, priorities, and hopes and dreams for the future.

Ideally, the educational system should prepare youth with disabilities for competitive employment, if not postsecondary (after high school) education. A vocational rehabilitation expert should be a collaborative member of the student's team if community college or university settings do not match the student's aptitude. Problems with supports toward employment have been explored in several analyses.^{17,37} These include issues with using an adult vocational system for youth with disabilities. In addition, families are worried about Supplemental Security Income and other benefits being lost when their teenager is employed.

Additional considerations for an IEP that is focused on the transition to adulthood include a comprehensive behavioral plan focused on improved interactions with others and therapies to help students become mobile in the community. For some students with intellectual or other developmental disabilities, guardianship may be an important consideration. In most states, a student is considered an emancipated adult (ie, his or her own legal guardian) at 18 years of age. At the age of majority, youth with disabilities are empowered to make their own IEP decisions, regardless of their parents' wishes, unless the parent secures their written consent for the parents to continue to make IEP decisions or secures guardianship. Some individuals do not have the capacity to safely care for themselves or make their own decisions even after reaching the age of majority. A court proceeding is necessary for another person to gain or maintain guardianship and requires serious

considerations of the person's needs and capacity for decision-making. Health care providers can help often fearful parents understand the value of the young adult being able to make as many decisions as possible. Some states have limited guardianships, which do not take away all of the young adult's rights. Alternatives to guardianship should be considered and may include power of attorney or health care proxy. The school can assist with this process by providing information for the proceeding, such as psychological testing or other evaluations performed.

CONCLUSIONS

Services provided under IDEA and other federal laws are essential supports for children with special needs to learn and be integrated and contributing members of their communities. Health care providers have an important role in supporting the education of children with disabilities and other health issues and their families and in supporting EI and school programs. Health care providers are advised to understand the basic elements of federal law, including the public school mandate to provide an FAPE to qualified students in the LRE. Although providers are advised to respect the educational expertise of school professionals, they can safeguard that children with disabilities and other health or behavioral issues receive appropriate services from EI and school programs throughout their childhood years. Providers can particularly support these children and their families through critical transitions from the initial referral to EI and school systems through the transition into adulthood.

RESOURCES

Center for Parent Information and Resources: www.parentcenterhub.org
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National Center for Learning Disabilities: <http://www.ncl.org/>

US Department of Education, Office of Special Education and Rehabilitation Services (OSERS): <http://www2.ed.gov/about/offices/list/osers/index.html>

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ABBREVIATIONS

AAP: American Academy of Pediatrics

ADA: Americans with Disabilities Act

EI: early intervention

FAPE: free appropriate public education

IDEA: Individuals With Disabilities Education Act

IEP: individualized education program

IFSP: individualized family service plan

LRE: least restrictive environment

PHI: protected health information

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