

Special Education Plans:

Parents Are the Best Advocates

By Annaben Kazemi

Being a parent can be the most wonderful, and yet most difficult, job in the world. For parents of a child with a chronic disease, the job is no less wonderful, but it can be more complicated, particularly in addressing your child's education needs. However, knowing the basics of the special education process and keeping your child's educators informed allows you to be effective partners with the child's school.

Students with chronic diseases often fight a vicious cycle. Thies (1999) writes, "Chronicity of the illness saps energy, making it difficult to participate fully in the academic life of the school. The combination of chronicity, absence and side effects of illness and treatment are subtle, but the cumulative effect is potentially damaging. Falling behind academically leads to catching up, and catching up takes away from keeping up. Self-confidence and achievement are undermined."

The course of chronic illness can be uneven and unpredictable, and the burden is on parents to teach their child's educators what to expect. Parents should talk with their child's teacher in order to make any necessary accommodations for bathroom breaks, health-related absences from school, school trips, and flexible homework arrangements during any periods of hospitalization. Teachers must also be taught that a student's illness may not be obvious.

Federal Law: IDEA

Thanks to a federal law called the Individuals with Disabilities Education Improvement Act, or IDEA, children with disabilities are entitled to a "free appropriate public education" (often called FAPE). This means that schools must provide eligible children with specially designed instruction, known as "special education," to meet their unique needs at no cost to the child's parents.

The IDEA definition of a "child with a disability" includes a list of 13 different disability categories under which a child may be found eligible for special education and related services. Children with a chronic illness that impacts their

schooling may be found eligible for services under the category "other health impairment."

Although many students with chronic diseases can participate in their classrooms with minimal modifications, many other students will experience a drop in performance associated with their illness, either because of the disease itself or medical treatment. For these students, Individualized Education Programs (IEPs) may be necessary to assist them in fully accessing the curriculum.

Individualized Education Programs

Parents or guardians must ask the school administrator to have their child evaluated for special services. After the formal request has been made, the school district must respond in a specified period of time. A school psychologist will perform an assessment of the child, including psychological and academic testing, and conduct a thorough review of the child's medical, developmental and school history.

Parents and the school's IEP team then meet to create the child's unique IEP. Parents may bring a doctor, nurse or any professional they choose. The IEP team will review the child's assessment and discuss any findings and other relevant information. The resulting IEP is the map for your child's education, and you are a very important member of the team that develops it. Your child's IEP lists the specific special education services your child will receive, based upon his or her individual needs. This is why it is so important that you understand and help develop your child's IEP.

An annual review of the IEP is required by law, to make sure the child's needs are indeed being met, and to plan for the coming school year. Additionally, the parent has the right to call for an IEP meeting at anytime that the child's needs have changed, requiring adjustment to the IEP.

If the IEP team decides that your child needs a particular *modification* or *accommodation*, this information must be included in the IEP. Sometimes people get confused about what it means to have a modification and what it means



to have an accommodation. Usually a modification means a change in what is being taught to or expected from the student. Making an assignment easier so the student is not doing the same level of work as other students is an example of a modification. An accommodation is a change that helps a student overcome or work around the disability. Allowing a student with trouble writing to give answers orally is an example of an accommodation. The student is still expected to know the same material and answer the same questions as fully as the other students, but he or she doesn't have to write the answers.

Just because a child has a chronic illness does not mean that he or she automatically qualifies for special education services under the IDEA. For instance, a child with a primary immune deficiency disease who does not need special education services will not qualify for special education and related services under the IDEA. He or she may, however, receive protections under Section 504 of the Rehabilitation Act.

Protection Under Section 504

Section 504 of the Rehabilitation Act of 1973 is a federal civil rights law. It extends the rights for full inclusion, and may help in supporting a specific plan for a child. The purpose of a Section 504 plan is to protect people with disabilities against discrimination for reasons related to their disabilities. Unlike IDEA, Section 504 does not guarantee that a child with a chronic illness will receive an IEP. However, under a Section 504 plan, a child with a chronic illness may receive accommodations and modifications that are not available to other children who are not characterized as disabled. Some examples of such accommodations and modifications include:

- Tests taken in a separate location with time limits waived or extended
- Giving the child frequent breaks out of the classroom to go to the bathroom, rest in the nurse's office, etc.

- The use of a word processor due to fine motor, visual motor deficits
- Shortened assignments
- Standardized test answers written directly in the test booklet and transferred onto answer sheet by teacher or assistant
- Class notes provided to the student, rather than having the student copy from the chalkboard or overhead
- Allowing the child to leave the classroom two to three minutes early to avoid crowded hallways
- Preferential seating in the classroom

Eligibility for a Section 504 plan depends on the child in question having a physical or mental impairment that must substantially limit at least one major life activity. Major life activities include walking, seeing, hearing, speaking, breathing, learning, reading, writing, performing math calculations, working, caring for oneself and performing manual tasks. The question that must be addressed by the school's special education team is whether the child has an "impairment" that "substantially limits one or more major life activities."

While a Section 504 plan does not require a meeting before a change in a child's placement, a child who receives Section 504 protections has fewer rights than the child who receives special education services under the IEP. However, a child who receives special education services under the IDEA is automatically protected under Section 504.

Limitations of IDEA Law

Children with chronic illness face two issues that are not well addressed by the IDEA law. First, children who do well in school are presumed not to need help. Jaff (2005) writes, "The IDEA defines 'child with a disability' to mean a child with health problems 'who, by reason thereof, needs special education and related services.' A student who does not need special education because she is performing well academically is not a 'child with □a

disability' under the IDEA," despite diagnosis of a chronic illness. Because many children with chronic disease issues do not suffer academically, they may not be covered under the IDEA.

Second, neither statute provides guidance for children with a chronic disease that remits and relapses. There will be times when a student needs home schooling and other times when the student has no need for help. This presents a challenge for both the parents and the school, since neither the IEP nor the Section 504 plan is intended to apply only some of the time, and flexibility is difficult to build into a plan. Convincing the school to respond quickly to the student's ever-changing circumstances is challenging, but worth the effort.

The impacts of chronic illness can vary considerably and are a factor in deciding whether an IEP or a Section 504 plan is appropriate for each individual child. However, the single most important tool in obtaining the best possible education for your child remains constant: you! ■

For more information about special education law...

A Parent's Guide to Special Education: Insider Advice on How to Navigate the System and Help Your Child Succeed

by Linda Wilmshurst and Alan W. Brue

Available on Amazon

The Everyday Guide to Special Education Law

By Randy Chapman, Esq.

<http://www.thelegalcenter.org/thelegalcenter-cgi-bin/shop?item=15>

IDEA 2004 Resources

<http://www.ed.gov/policy/speced/guid/idea/idea2004.html>

News and information on the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), the nation's law that works to improve results for infants, toddlers, children and youth with disabilities

U.S. Department of Health and Human Services, Office of Civil Rights

<http://www.hhs.gov/ocr/504.html>

Your rights under Section 504 of the Rehabilitation Act

Wrightslaw

<http://www.wrightslaw.com/>

Parents, educators, advocates, and attorneys come to Wrightslaw for accurate, reliable information about special education law and advocacy for children with disabilities