

A young boy with short blonde hair, wearing a green long-sleeved shirt, is seen from behind, sitting at a desk in a classroom. He has his right hand raised high, palm facing forward. In the background, a teacher in a green shirt stands at the front of the room, and other students are visible but out of focus. The scene is brightly lit, suggesting a daytime classroom setting.

Doing Our Homework:

A Parent's Guide to Educational Equity

When I wrote *Know Your Rights: A Handbook for Patients with Inflammatory Bowel Disease*, and started up Advocacy for Patients with Chronic Illness, Inc., I did not anticipate the number of problems parents and their children with IBD have with schools. Issues related to educational equity are complex, and relevant materials are voluminous.

This summary is, of necessity, very generalized and eliminates many important details. To learn more, families should contact the state agency (unfortunately, there is no common name for these agencies) that is funded, at least in part, by the federal government to assist in ensuring that the requirements of federal law are met. The new edition of *Know Your Rights: A Handbook for Patients with Chronic Illness*, available from both www.advocacyforpatients.org and www.cdfa.org/store, contains a longer version of this article.

There are two related statutes, the Individuals with Disabilities Education Act (“IDEA”), and Section 504 of the Rehabilitation Act of 1973 (“Section 504”). Section 504 applies to recipients of federal funds, whereas the IDEA applies to state and local education agencies. Section 504 pertains to all levels of education — grade school to college and even to graduate schools that accept federal funding — but the IDEA applies only to grade and secondary schools.

THE IDEA

The IDEA provides that a child with a disability who needs special education is entitled to a free appropriate public education, including the preparation of an “individualized education program,” or “IEP.” The IDEA defines a child with a disability to include children with mental retardation, hearing, speech, visual or language impairments, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health

impairments, or specific learning disabilities who require special education as a result. Children with IBD would come within the “other health impairments” catch-all.

Under the IDEA, the first requirement imposed on the states is to “identify, locate and evaluate” children in need of special education services (called “child find”). Once children are located, the IDEA requires states to meet the needs of those children.

The core of the IDEA is the IEP. Under the IDEA, states are required to conduct an evaluation before special education benefits are granted. The evaluation determines whether the child is a “child with a disability” and has special educational needs. The process should be initiated by the school, which should provide notice to the parents. The child must be tested and evaluated using a variety of tools. After this evaluation is completed, the IEP is formulated.

The IEP should be a written statement for each disabled child that includes a statement of the child’s level of educational performance; a statement of goals; a statement of the special education and related services to be provided; an explanation of the extent, if any, of the child’s participation in mainstream programs; a statement of any individual modifications; the projected date for commencement of these services, and the duration of the services. In fashioning the IEP, the strengths of the child, the parents’ concerns, and the results of the most recent

evaluation of the child must be considered.

The IEP “team” includes the parents, at least one non-special education teacher, at least one special education teacher, a representative of the local agency who is qualified to assist in formulating IEPs, other experts brought in at the request of the parents or the state, and, if appropriate, the child.

The IDEA provides safeguards to ensure parental involvement at all stages of the child’s education: notice to the parent of any change in the IEP, the ability to participate in discussions about their child’s evaluation and education, the right to review the child’s school records, and the ability to file complaints and have an impartial hearing. Parents may challenge any aspect of an IEP by requesting a hearing, and if they remain dissatisfied, they may file suit in federal court.

SECTION 504

The goal of the Rehabilitation Act was to promote the inclusion and integration of people with disabilities into the mainstream. This statute reaches beyond education to any federally funded program, providing protection against discrimination based on disability. Here, we focus only on Section 504 as it pertains to education.

Section 504 provides that disabled children cannot be denied the benefits of any program that receives

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federal financial assistance, including public education. The standards courts apply to decide if a child is disabled are those found in the Americans with Disabilities Act ("ADA"). If your child meets the ADA definition of a person with a disability, he or she will meet the definition of a student with a disability under section 504.

The limited space permitted here precludes a detailed explanation of the test for whether a person is disabled under the ADA. In general, under the ADA, a person is disabled if he or she has a physical or mental impairment that substantially limits one or more major life activities. Major life activities include eating and disposal of bodily waste.

Once the student's disability is established, the next step is to determine whether he or she needs special education services. The goal is to ensure that a "free, appropriate public education" is provided for every child, regardless of disability.

A child may qualify under Section 504 but not under the IDEA. These are called "504-only students." Section 504's definition of disability is broader than the IDEA's. Some children need only medication, while others will need to be in special education classes. The two statutes are related, but they are not identical.

As required by Section 504, the U.S. Department of Education has certain regulations, which are divided between Preschool, Elementary and Secondary Education, and Postsecondary Education.

Preschool, Elementary and Secondary Education

Children with disabilities are entitled to a "free appropriate public education"

regardless of the nature or extent of the disability. Borrowing many of the procedural aspects of the IDEA, the regulations suggest that one option to comply with Section 504 is to develop and implement an IEP, as is required under the IDEA. However, schools do not have to use the IEP model as long as the evaluation is performed and a plan is in place. Under Section 504, any assistance a student receives from a school must be provided for free.

Section 504 refers to various educational settings. Disabled students will be educated, have meals, and participate in activities with the other students, in the same facilities, to the extent possible. Where attendance at some facility other than the usual classroom is required, it must be as comparable as possible.

What most parents refer to as the Section 504 plan is what regulations call a "preplacement evaluation." Any child who needs accommodation must be the subject of an evaluation before taking any action with respect to placement. The school need not obtain the parent's consent for the evaluation, but it must provide notice to the parents. The evaluation should include tests to assess specific areas of educational need, so the test results will reflect the student's aptitude. In other words, a child's disability must be accommodated in designing these tests. Once testing is concluded, schools use the results, as well as teacher recommendations, physical condition, social or cultural background, and adaptive behavior, in designing the plan for the student.

Parents must then have notice and opportunity to examine the records, there must be a hearing at which the parents and/or other guardian



can appear, and there must be a procedure for review of the decision.

Postsecondary Education

Section 504 does not require that undergraduate colleges prepare a plan to accommodate the student's disability, nor is tutoring required of college students. However, the regulations prohibit discrimination in admissions and recruitment, either by excluding disabled students or by setting a quota for admission of disabled students. Disabled students cannot be excluded from any academic, research, occupational training, housing, health insurance, counseling, financial aid, physical education, athletics, recreation, transportation, or other extracurricular activities. Academic adjustments must be made so as to eliminate and/or protect against discrimination. These adjustments may include extending the length of time permitted for completion of degree requirements, as well as adjustment of exams and other evaluation of students to ensure that the results of the evaluation reflect the student's performance, not his disability. Housing and financial assistance must be provided to disabled students to the same extent as they are provided to non-disabled students.

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THE COURTS

Most educational equity cases are brought under both the IDEA and Section 504, and courts have determined that the analysis under the two statutes differs substantially.

To prove an IDEA violation, the court must first determine whether the school had complied with the IDEA's procedural requirements, and, if so, whether the IEP is "reasonably calculated" to enable the child to receive educational benefits. To prove a Section 504 violation, the plaintiff must show that he is a "qualified individual with a disability"; that he was denied the benefits of the school; and that he was discriminated against because of his disability. This requires more than proof that the student is deprived of free appropriate education. The student also must show that the school's conduct was motivated by bad faith or "gross misjudgment." If the student can make this showing, the school's only legitimate defense is that an accommodation would unduly burden the school.

When a judge evaluates an IEP for sufficiency, she must decide whether it is "reasonably calculated to enable the child to receive educational benefits." However, when a judge considers a case brought under Section 504 or the ADA, the primary focus is whether the student has been discriminated against.

The IDEA does not provide a cause of action for damages. "The touchstone of IDEA is the actual provision of a free appropriate public education." What you get are the procedural rights, not monetary damages. For example, the remedy might be an order that the child be provided with special education services.

In addition, some courts have found that the IDEA's remedies are exclusive even when a claim under Section 504 also is brought. In other words, you can't just take the same facts, make them into a Section 504 case, and get a remedy that is more than that provided under the IDEA.

PROBLEM AREAS FOR IBD PATIENTS

IBD patients face at least two issues that are not well addressed by the law. First, children who do well in school are presumed not to need help. 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. Because many children with IBD 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 the IEP or Section 504 plan is not intended to apply only some of the time, and flexibility is difficult to build into a plan.

Disabilities can be temporary but still disabling. However, getting the school to respond quickly to ever-changing circumstances is a challenge. A plan under either the IDEA or Section 504 may include accommodations such as seating placement, extended time for testing, adjustment of class schedules, use of aids such as tape recorders, class and/or homework assistance, administration

of medication, behavioral support, tutoring, etc. The elements of a Plan for IBD students are all there; the problem is coordination and timing.

One thing I have learned about schools in representing children with IBD is that they have no interest in fighting over what children need. The few cases I have helped in were easily resolved. In one, a young IBD patient was told by her doctor that she had to eat several small meals per day, but the school would not allow her to eat in class, so she had to choose between missing food and missing class. I wrote a letter and the school capitulated. Then, to be fair to the other students, the school allowed all students to eat in class, making my little client the hero of her classmates!

In another instance, a child had completed all of the work in all but one of her courses for the year and gotten passing grades in all of them. However, the school was going to hold her back because she had missed more than 40 days of school that year. The school agreed to allow the student to proceed to the next grade, requiring that she repeat the one course she had not been able to complete during the school year.

Of necessity, this is only a summary. There is much more. However, we hope that this will get you started on the way toward a free, appropriate education for you or your child. ■

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