

Educational Equity

By Jennifer C. Jaff

When I started up Advocacy for Patients with Chronic Illness, Inc., I had not anticipated the number of problems parents and their children with IBD have with their schools. This has been one of several areas of law that I have had to learn so that I can assist patients. Issues related to educational equity are complex, and relevant materials are voluminous. This summary is, of necessity, very generalized. To learn more, families should contact the state agency that is funded, in part, by the federal government to assist in ensuring that the requirements of federal law are met.¹

There actually are two related statutes, one called the Education of Individuals with Disabilities Act (also known as Individuals with Disabilities Education Act (“IDEA”)), and one known as 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. When speaking with parents, I have found that schools tend to use the Section 504 jargon more than they use the IDEA, but both statutes protect the rights of children in our schools. 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.

I. 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

¹ Of course, this is easier said than done. In Connecticut, the state agency is the Office of Protection and Advocacy. But the names of the state agencies vary greatly. Theoretically, you should be able to find your state’s agency by asking the schools in your district.

disability to include children with mental retardation, hearing impairment, speech or language impairments, visual impairment, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities who requires special education as a result. Although there are no cases directly on point, children with IBD come within this “other health impairments” catch-all.

Under the IDEA, states receive federal funding to cover, at least in part, the costs of providing services to disabled students. The first requirement imposed on the states is to “identify, locate and evaluate” children in need of special education services (called “child find”). There are many sources that assist with this initial step, including hospitals, physicians, parents, day care programs, and other health care facilities and providers. Once children are located and incorporated into the system, 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 initial evaluation before special education benefits are granted. The initial evaluation should determine whether the child qualifies as a “child with a disability” and whether the child has special educational needs. The process should be initiated by the school, which should provide notice to the parents. The child will then be tested and evaluated using a variety of assessment tools. The parents should have input into deciding what the scope of the assessment will be. Tests and tools may not be discriminatory, and must be administered by a professional according to accepted guidelines. After this evaluation phase 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 present level of educational performance; a statement of goals; a statement of the special education and related services and aids to be provided for the child; an explanation of the extent, if any, of the child's participation in mainstream programs; a statement of any individual modifications; and the projected date for commencement of these services, along with 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 regular education teacher, at least one special education teacher, a representative of the local educational agency who is qualified to assist in formulating IEPs, other experts brought in at the request of either the parents or the State agency, and, if appropriate, the child. Beginning at age 14, the transition service needs of the child should be part of the IEP, and should be reviewed annually. Beginning at age 16, the IEP should include a statement of needed transition services. Beginning at least one year before the child reaches the age of majority, the IEP should indicate whether the child has been informed of his or her rights under the IDEA, and which of those rights, if any, will transfer to the child upon reaching the age of majority.

Federal law requires that, at the beginning of each school year, the state or local educational agency must have an IEP in effect for all eligible children. Re-evaluation should be conducted when necessary. The IDEA requires re-evaluation no less than every three years. Parental consent is needed to conduct the evaluation.

In addition to requiring preparation of an IEP, the IDEA provides procedural 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 school discussions about their child's evaluation and education, mediation, the right to review the child's school records, the ability to file complaints and have an impartial hearing and more. Parents may challenge any aspect of an IEP – including challenging the presence of sufficient experts on the IEP team, which should include a special education teacher at the very least, by requesting a hearing, and if they remain dissatisfied, they may file suit in federal court. During the pendency of any complaint or civil action, the child remains in the educational setting he or she was in before the complaint.

II. 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. For present purposes, we focus only on Section 504 of the Rehabilitation Act, which pertains to education.

Section 504 provides that disabled children cannot be denied any of the benefits of any program that receives federal financial assistance, which includes public education. The standards that courts are directed to apply to decide if a child is disabled are those found in the Americans with Disabilities Act (“ADA”). In other words, 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 for purposes of section 504.

The limited space permitted here makes it impossible for me to explain the intricacies 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. Most courts have recognized the disposal of bodily waste as a major life activity in which IBD patients are substantially limited. In addition, patients with other related symptoms – joint pain, fatigue, etc. – would be limited in a number of major life activities.

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, for example. 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 Secretary of the U.S. Department of Education has promulgated regulations to guide schools that are required to comply with the law. Those regulations provide the “meat” of the rules affecting education. The regulations are divided between Preschool, Elementary and Secondary Education, and Postsecondary Education.

A. 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. This means that special education and related aids or services must be provided. Borrowing many of the procedural aspects of

the IDEA, the regulations suggest that one way to ensure that children with disabilities get a “free appropriate public education” is to develop and implement an IEP, as is required under the IDEA. In other words, a Section 504 plan may well be identical to an IEP under the IDEA. Schools do not have to use the IEP model as long as the necessary 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. Assistance may not be provided on school grounds, but free transportation must be provided.

Section 504 refers, too, to various educational settings. The general rule is that the disabled student will be educated with the other students, in the same facilities, to the extent possible. Similarly, nonacademic settings and activities like meals, recess, etc. must be provided with the other students to the extent possible, too. 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 the regulations call a “preplacement evaluation.” Any child who needs or is believed to need special accommodation must be the subject of an evaluation *before* taking any action with respect to placement of the student, or before changing that placement. The school need not obtain the parent’s consent to conduct the evaluation, but it must provide notice to the parents. The evaluation should consist of testing, including tests and evaluation materials tailored to assess specific areas of educational need. These tests must be administered so as to ensure that the test results reflect the student’s aptitude or achievement level – in other words, a child’s disability must be accommodated in designing these tests. Once testing is concluded, schools are to use the tests, as well as teacher recommendations,

physical condition, social or cultural background, and adaptive behavior in designing the plan for the student. In addition, schools must ensure that information from all sources is documented and considered, and that the people making the decision are knowledgeable about the child, the data, and the placement options.

At the very least, notice and opportunity to examine the relevant records must be afforded to the parents, and there must be a hearing before an impartial decisionmaker at which the parents and/or other guardian, with or without a lawyer, can appeal, and there must be a procedure for review of the decision. The IDEA has similar, slightly more structured procedural requirements, allowing a parent a hearing and, ultimately, recourse to a court if necessary.

B. 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 recruitments, 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, and schools must adjust exams and other evaluation of students to ensure that the results of the evaluation reflect the student's performance in the course, not the

student's disability. Housing and financial assistance must be provided to disabled students to the same extent as they are provided to non-disabled students.

III. 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. However, a violation of section 504 or the ADA requires more. To prove a Section 504 violation, the plaintiff must show that he or she is a "qualified individual with a disability"; he was denied the benefits of the school (or other entity receiving federal funds); and 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 out this case, the school's only legitimate response is that a requested accommodation would constitute an undue burden to the school.

When a judge evaluates an IEP for sufficiency, its job is to decide whether the IEP is "reasonably calculated to enable the child to receive educational benefits." However, when, instead or in addition, a judge considers a case brought under Section 504 or the ADA, the focus is not so much on the individual student's well-being, but whether the student has been discriminated against.

The remedy under the IDEA may depend on what geographic jurisdiction your case is brought in. The majority rule appears to be that, in some circumstances, parents

can get reimbursed for private school tuition, but the IDEA does not provide a cause of action for damages. “[T]he touchstone of IDEA is the actual provision of a free appropriate public education.”² What you get – in addition to the procedural rights parents have to participate in decisions about their disabled child’s education, examine their child’s file, receive notice prior to changes in their child’s IEP, file complaints, appear at a hearing, and finally, go to court – does not include monetary damages. More typically, the remedies are the provision of special education services, for example. In other words, courts order what they have to in order to provide “free appropriate education,” but nothing more.

In addition, some courts have found that, even when both IDEA and Section 504 claims are brought, even though the analysis differs, the IDEA’s remedies are exclusive. In other words, you can’t just take the same facts and make them into a Section 504 case or a case under the broad civil rights statutes and get a remedy that is more than that provided under the IDEA.

IV. PROBLEM AREAS FOR IBD PATIENTS

There are at least two issues that face IBD patients that are not well addressed by either the IDEA or Section 504.

The first is that, generally, children who do well in school are presumed not to need help. The IDEA defines “child with a disability” mean child with one of the listed health problems “who, by reason thereof, needs special education and related services.” A student who does not need special education because he or 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.

² *Sellers v. School Board of City of Manassas, VA*, 141 F.3d 524, 527 (4th Cir. 1998).

The second is that neither the IDEA nor Section 504 has an established source of guidance for children with a disease that remits and relapses, so that the Plan – whether under the IDEA or Section 504 – can't be the same all the time. There will be times when a student needs home schooling and other times when the student has no need for help at all. 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.

The Department of Education Office of Civil Rights has opined that disabilities can be temporary. 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. In addition, where needed, there may be 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 most of what our children need. Children with IBD are not the ones who will come in and say that the only place where the student can get the services he or she needs is a special residential facility in another state, which would require the school to pay not only for tuition reimbursement, but transportation and housing. Those are the cases that go to court because so much money is involved.

However, 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 during the year. Again, the school agreed to allow the student to proceed to the next grade, requiring that she complete only the one course that she had not been able to complete during the school year.

V. CONCLUSION

If you have a problem that you believe your school should address, you should locate the section 504 liaison or coordinator in your school district. The federal government requires that there be someone in each school district identified as the person to whom such complaints should be brought.