

The Rights of Your Child with Diabetes

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Your Child's Rights

An important part of building a good working relationship with your child's school is a discussion regarding the rights of your child. It is important that you are aware of these rights and the laws that protect your child relevant to her education. While most of you will never have a problem with your school, it is still a good idea to have a plan in place that protects your child and her educational services.

There are at least three federal laws that address a school's responsibility to provide care to students with diabetes:

1. Section 504 of the Rehabilitation Act of 1973 (also known simply as Section 504)
2. The Americans with Disabilities Act of 1990 (ADA)
3. The Individuals with Disabilities Education Act (IDEA)

This section will give a general overview of these laws and how they protect your child. Additionally this section will provide you with the knowledge of how to effectively advocate for your child and initiate the programs and plans that protect her while in the school setting.

Section 504

According to this law, parents of qualifying children have the right to develop a Section 504 Plan with their child's school. Any school that receives federal funding must comply with Section 504 laws, or they may lose the federal funds. This act further prohibits programs and activities that receive federal financial assistance from discriminating against anyone with a disability. You do not need to wait until discrimination occurs to seek the protections of this law. Rather, initiating a 504 Plan is a very proactive step in advocating for your child's rights. This law requires schools to identify educational needs and – when necessary – develop a “504” Plan. A 504 Plan is a legal (written) document specifying what “reasonable” modifications and accommodations the school must provide for a student with a disability (generally put into place for a student with a medical disability such as diabetes). A child does not need to require special education to be protected; children with type 1 diabetes are protected under this law.

Note on Standardized Testing

Under this law, high school students (and students in lower grades taking state tests) with diabetes can receive special accommodations when taking standardized tests (e.g., PSAT, AP, NMSQT, SAT, and ACT). These accommodations usually include “stop the clock” breaks for blood glucose testing, insulin administration, bathroom visits, or taking emergency glucose to treat low blood sugars. The organizations that administer the tests generally require that students have a 504 Plan on file before providing the accommodations. Students with type 1 diabetes should request the following

accommodations: “extra breaks,” “extended breaks,” and “breaks as needed” on the SAT, and “stop the clock breaks within sections” on the ACT. These accommodations are in addition to any additional testing time that may be granted for learning disabilities, ADHD, or other special needs.

Accommodations often take months to be approved, so it is a good idea to file for them early. It is especially important to have college entrance exam approvals in place well before the planned testing date. Since college entrance exams are in all likelihood the most important exam that students take throughout their high school careers, it is imperative that students with type 1 diabetes receive the testing accommodations they need in order to do well on them. After all, the student’s SAT and/or ACT scores will influence which colleges he or she is accepted into, and these outcomes can affect the path that his or her life will follow.

Americans with Disabilities Act (ADA)

This law specifically prohibits all schools and day care centers – except those run by religious institutions – from discrimination against people with disabilities, including diabetes. Its definition of disability is the same as in Section 504 (includes diabetes).

The laws within this act say that your child with diabetes has the right to go to school, play a sport, join a club, and do everything else that kids without diabetes do. It further states that public schools and other covered organizations must make “reasonable accommodations” for your child’s diabetes.

Individuals with Disabilities Education Act (IDEA)

Many students with diabetes do not qualify for IDEA protection, but it is important to know what it is in case you may qualify. This law covers children whose disability impairs their academic performance. It requires that such children be given a “free, appropriate public education.”

Qualification depends on how diabetes affects the student’s ability to learn. If a student qualifies, he has the right to develop an Individualized Education Program (IEP) with his school. An IEP is similar to a Section 504 but includes specific measures to address your child’s academic performance and needed special education and other related services.

Additional State Laws

Even though federal laws already provide protection for children with disabilities, some states provide greater protection to students with diabetes due to the passage of school diabetes care legislation. States with such legislation include:

- California
- Connecticut
- Hawaii
- Kentucky
- Massachusetts
- Montana
- Nevada
- North Carolina
- Oregon
- Oklahoma
- Rhode Island
- South Carolina
- Tennessee
- Texas
- Utah
- Virginia
- Washington
- West Virginia
- Wisconsin

Each state varies in its coverage. The most comprehensive laws are currently found in North Carolina, Virginia, and Washington.

The Parent/School Partnership Continues

504 Plans are a way for you to hold the school accountable for meeting your child's needs while in the school's care. Remember, though, that this is a partnership you are building with your child's school and all parties have a role in the 504 process.

School's Role in the 504 Process

It is the responsibility of the school and its personnel to have an understanding of diabetes and be trained in its management and in the treatment of diabetes emergencies. Knowledgeable, trained school personnel are essential to a student's safety and physical well being when dealing with immediate health risks of high or low blood glucose levels.

Furthermore, an individualized Diabetes Medical Management Plan (the 504 Plan) should be developed and signed by the school, the parent or guardian, and the child's diabetes management care team. The Diabetes Medical Management Plan (the 504 Plan) should address the specific needs of the child and provide specific instructions related to the following:

- Times/places for blood sugar monitoring, including accommodations for testing and treating
- Ensuring that staff members are trained in checking blood sugar levels, recognizing and treating high and low blood sugar symptoms, and administering both insulin and glucagon
- Allowing the student to eat whenever and wherever necessary, including eating lunch at an appropriate time and allowing enough time to finish eating
- Allowing extra trips to the bathroom or water fountain
- Ensuring the student's full participation in all sports, extracurricular activities, and field trips, with the necessary care and/or supervision
- Permitting extra absences for medical appointments and sick days when necessary, without penalty

Parent's Role in the 504 Process

In addition to submitting a formal request for a 504 Plan and a cover letter to the school, a parent or guardian is responsible for providing the school with the following:

- All materials and equipment necessary for diabetes care tasks, including blood sugar testing supplies and insulin administration (if needed). The parent is responsible for the maintenance of the equipment and must provide instructions to ensure the proper disposal of materials. A separate logbook should be kept at school for the staff or student to record blood glucose test results.
- Supplies to treat hypoglycemia, including a source of glucose and a glucagon emergency kit.
- Information about diabetes.
- Emergency phone numbers for the parent and the student's diabetes doctor (and staff) so that the school can contact these individuals with diabetes-related questions or during emergencies.

- Information about the student’s meal and snack schedule. The parent should work with the school to coordinate this schedule with that of the rest of the class as much as possible. For young children, instructions should be given for when food is provided during school parties and other activities.

Legal Rights of the Child with Diabetes

If a school attempts to discriminate against your child with diabetes or is unable or unwilling to commit to some agreement with the parents and child about how the child will be provided equal opportunity to participate in academic, extracurricular, or other school activities, then schools can be compelled by the legal system to provide these services.

It is suggested that the following steps be followed in such cases:

1. If the parents, school, and student cannot come to a mutual agreement about a 504 Plan or the parents suspect that the school isn’t abiding by the agreement, the parents must request in writing that a 504 meeting take place. Prior to the meeting, the parent should review sample 504 Plans (see Educate the Educator section) and prepare a list of modifications and accommodations they feel are appropriate. The parent has the right to bring a friend, advocate, or lawyer to the 504 meeting to assist in the discussion.
2. On rare occasions, the student’s academic performance may be so adversely affected by diabetes complications that he/she may need special education services. In such cases it is the parent’s responsibility to formally request special education testing. Before this testing can take place, parents must give written permission to the school to administer these tests. The student must complete the testing and meet certain criteria to be eligible for special education services. If he/she is deemed eligible, an IEP (individualized education plan) is written and certified special education teachers become involved in the education of the child.

Common 504 Plan Questions

Is a child with type 1 diabetes automatically eligible for a 504 Plan?

The law does not provide any automatic eligibility for a 504 Plan. 504 eligibility is made on an individual basis. A team of people knowledgeable about the student must convene and determine eligibility. That being said, it would be highly unlikely that a student with type 1 diabetes would not qualify for a 504 Plan. Several life functions are certainly impacted which would provide the basis for eligibility (e.g. “caring for oneself” and “learning” come quickly to mind.) If a school has not suggested a 504 Plan, the parent should request, in writing, a 504 evaluation to take place. There are numerous sources (some included in this Manual) which can help a parent with writing this request as well as provide information on what is to be considered by the team to determine eligibility.

Must the parent of a child with type 1 diabetes be a part of the 504 Team?

The law provides for the parent to be notified of the result of the 504 meeting/evaluation/discussion but does not specifically say a parent must be present at the meeting. However, the law does state that the 504 team is made up of persons knowledgeable about the student, which implies that if a parent is not allowed to attend, there may be cause for complaint and a hearing. It would be hard to argue that the parent is not a knowledgeable person about the child.

Must the 504 Plan be in writing?

The law says that the child must receive the accommodations agreed to but does not specifically state that the plan must be in writing. That being said, it certainly would be best practice (and common sense) to put the plan in writing. A written plan is the only way that a school can document that they are providing all of the accommodations agreed to. Not having the plan in writing could easily be cause for a complaint and violation of Section 504. As one of the representatives from the Department of Education Office of Civil Rights stated, "OCR would have no concept how a district/school would prove a 504 Plan exists and the accommodations being made without the Plan being in writing."

Is there a requirement for an ANNUAL review of a 504 Plan?

The law does not require an annual review. It does require a "periodic" review. If the 504 Plan is well written and includes a requirement for any new teacher or staff member who will be in contact with the child to be informed and trained, and nothing has changed in terms of the needs of the child, an annual review wouldn't be necessary. This is one of those areas where parents can be sympathetic to school personnel time constraints. If the school is doing everything necessary and willingly trains the child's teachers every year, and the 504 Plan already covers everything it needs to, then why make the school have an unnecessary meeting.

The law does require a "periodic" review. IDEA requires a review every three years and that should also probably be the maximum time frame a 504 Plan should go without a formal review. There would also have to be a formal review at any time a change is needed in the 504 Plan to meet the needs of the child. It also may be necessary to have a review when the child goes to a new school in the same district (e.g. elementary to middle school building or middle school to high school building.)

Must the school provide a nurse or other trained person to provide services for my child (e.g. give insulin, test blood sugar, give glucagon in an emergency)?

Yes. This should be written into the 504 Plan. Nurses get sick and are absent from school for that and other reasons, so it is very important to include in the 504 Plan that staff members in addition to the nurse be trained to provide these services.

Some states have laws that state that only licensed staff members can give medication and/or injections. California is one of those states. However, a recent California decision based on a lawsuit states that:

When federal and state laws are reconciled, it is clear that it is unlawful for an LEA [local school district] to have a general practice or policy that asserts that it need not comply with the IDEA or Section 504 rights of a student to have insulin administered at school simply because a licensed professional is unavailable. In such situations, federal rights take precedence over strict adherence to state law so that the educational and health needs of the student protected by the Section 504 Plan or IEP are met.

Can the school say they will not qualify a child with type 1 diabetes because the child is doing well academically and is socially responsible and personally independent?

Again, eligibility is not automatic for anyone and a team with knowledge about the child must evaluate and determine eligibility. However, Section 504 protects all persons with a disability who:

1. Have a physical or mental impairment which substantially limits one or more major life activities;
2. Have a record of such an impairment; or
3. Are regarded as having such an impairment.

In number one, above, major life activities are defined as functions such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning or working. A strong argument could be made that students with type 1 diabetes are substantially limited, especially when blood sugars are not normal, in caring for oneself, performing manual tasks, walking, seeing, hearing,

speaking, and learning. How can a school argue that when a student is in insulin shock, that this student's abilities in these areas are not substantially limited. A student in insulin shock cannot walk, speak, learn, or care for themselves. Learning would be substantially limited if a student with type 1 diabetes missed field trips, missed instruction due to high blood sugar, missed class due to being in the nurse's office testing blood, etc. A child with type 1 diabetes would also be eligible for a 504 Plan in numbers 2 and 3 above. Certainly a child with type 1 diabetes has a record of an impairment AND would be regarded as having an impairment.

There are certainly other arguments which can be made that a student with type 1 diabetes, who is doing well, is still eligible for a 504 Plan. Things do change and learning may be substantially impacted by changes in blood sugar due to a growth spurt, early adolescence (hormones), etc. School or teacher rules may prevent snacks in the classroom, which would need a 504 Plan to provide for an exception to this rule. School rules may prevent blood testing to occur in the classroom and again, a 504 Plan would be needed to provide for an exception to this rule.

A school that will not provide a 504 Plan because a student with type 1 diabetes is "doing well" is setting itself up for great trouble. This is a lawsuit against the school district waiting to happen if a school has not set up a 504 Plan with training for teachers, procedures for handling a child with type 1 diabetes ongoing needs as well as procedures for emergencies, and a written plan demonstrating that the school is providing full access to school activities and learning opportunities.

Can the school prevent my child with type 1 diabetes from wearing a diabetes ID bracelet?

Unless a school has a "no jewelry of any kind" rule (which VERY few schools have), a student should be able to wear an ID bracelet. If it's written into the 504 Plan, the child should be able to wear it, no matter what the school rule. On occasion, there may be a legitimate safety reasons for a particular teacher or coach to ask the child to temporarily remove the ID bracelet (e.g. a shop class where power tools are being used and where a bracelet may be dangerous; a sport with a lot of physical contact where another child may be injured by the ID bracelet.)

What is the difference between IDEA and Section 504? What should I be requesting for my child with type 1 diabetes?

IDEA is an education act (and sometimes known as Special Education) and Section 504 is a Civil Rights Act. In practical terms, the vast majority of students with type 1 diabetes will fall under the Section 504 umbrella which is to prohibit discrimination on the basis of a disability. Most students with type 1 diabetes will have no reason to be involved in the world of IDEA. There are only two reasons a diabetic student might be eligible for IDEA.

- The impact on diabetes is so great that the student's learning is severely impacted (which might qualify the diabetic child for special education services under the other health impaired category, or
- The diabetic child has an additional disability (most likely not related in any way with diabetes) which demands an individualized education plan (IEP) e.g. mental retardation, autism, emotional disturbance, learning disability, etc.

What should I do to make sure that my child with- type 1 diabetes has accommodations available for ACT/SAT tests and state standardized tests?

Accommodations for state standardized tests should be listed in a student's 504 Plan For the ACT test, there is a form to complete which is available at <http://www.act.org/aap/disab/opt1.html>. Note that one of the requirements is to "Enclose written documentation from your school describing in detail the accommodations you normally receive in school." Some high schools may require a 504 Plan stating these accommodations before they would provide them to ACT. Note that another requirement is to provide "The name and phone number of a school official familiar with your

current testing accommodations.” It would be a good idea to meet with the child’s counselor a few months before the test will be given to make sure that the counselor (or another identified school staff member) is able to respond if contacted by ACT.

The SAT has similar requirements such as:

- have documentation on file at your school that supports the need for requested accommodations and meets the Guide- lines for Documentation, and
- receive and use the requested accommodations, due to the disability, for school-based tests.

Where do I go when I believe that the school is discriminating against my child with type 1 diabetes and not providing the appropriate services?

Step 1: Try one more time at the school level. Try to have a one-on-one, heart-to-heart with the school principal. Acknowledge that school people are busy and working hard. Be nice, be respectful, be reasonable.

Step 2: In almost all school systems, there is a special education coordinator or someone who is charged with being in charge of Section 504 issues. Again, be nice, be respectful, be understanding of school limitations, and have your list of items that are on your non-negotiable list.

Step 3: Contact the school superintendent with the same attitude and issues as above.

Step 4: Obtain the services of an attorney and file for a due process hearing.

Step 5. Contact an appropriate person at the state department of education. Be prepared with any documentation you have (request for a 504 meeting, dates of any meetings, paperwork from these meetings) along with your non-negotiable list. Based on the advice of this agency, filing a formal complaint may be the next step.

Step 6: Contact the regional office of the Department of Education Office of Civil Rights for your state.

Contact information is available at <http://www.ed.gov/about/offices/list/ocr/addresses.html>. Based on the advice of this agency, filing a formal complaint may be the next step.

Do private schools have to provide the same services as public schools?

1. If the private school does not receive federal funding, then the 504 Act does NOT apply. Therefore, the school would not have to consider or provide a 504 Plan. If the private school DOES receive federal funding, then they would have to provide the same services as public schools.
2. The ADA (American with Disabilities Act) applies to all schools EXCEPT those run by religious institutions. If this private school is run by a religious institution, then the parent is pretty much at the whim of what the school is willing to do and the parent/child have little recourse. If the private school is NOT run by a religious institution, then ADA applies and the school would be prohibited from discrimination against people with disabilities, including diabetes. “Reasonable accommodations” must be provided.

References for Those Who Desire More Information

A great deal of information about schools and students with diabetes is available, including sample 504 Plans, checklists for school personnel, details on the law and schools, information for teachers and other school personnel, help for parents, help for the child with diabetes, etc. The following list is just a sampling of such resources:

- Helping the Student with Diabetes Succeed: A Guide for School Personnel: This guide was produced by the National Diabetes Education Program and is a joint program of the National Institutes of Health and the Centers for Disease Control and Prevention and more than 200 other partner organizations. It is available at <http://www.ndep.nih.gov/resources/school.htm>

- Juvenile Diabetes Research Foundation:
www.jdrf.org (Check the Diabetes in School link.)

- Children With Diabetes:
www.childrenwithdiabetes.com

- American Diabetes Association:
www.diabetes.org