

Rights of students with diabetes under IDEA and Section 504

On August 8 2007, the California Department of Education announced a settlement with the plaintiffs in federal litigation concerning the delivery of care to students with diabetes who need insulin during the school day. The settlement agreement impacts school districts and county offices of education statewide.

What was the lawsuit about?

The class action lawsuit, initiated by the American Diabetes Association (represented by the Disability Rights Education and Defense Fund and Reed Smith LLP) and parents of students in two Bay Area school districts, alleged a violation of federal law because the districts' alleged refusal to provide a school nurse or other trained personnel to help monitor their child's glucose levels and to assist with administering insulin.

As part of the settlement agreement, the CDE has issued a legal advisory providing guidance to districts outlining the rights of diabetic students and has agreed to monitor district compliance through the existing Quality Assurance Process (special education compliance monitoring) and Uniform Complaint Procedures.

What students are affected by the settlement?

The settlement affects students with diabetes who have been identified as disabled under Section 504 of the Rehabilitation Act of 1973 or the Individuals with Disabilities Education Act (IDEA).

In some circumstances, a student with diabetes may be identified as disabled under IDEA because of the effect of the diabetes or other disability or impairment on his or her educational performance. Students with diabetes who

qualify for services under IDEA must have an individualized education program (IEP) that identifies academic services to be provided as well as the types of "related services," such as school health services, that are necessary for the child to be provided a free appropriate public education.¹

A student with diabetes may also be identified as disabled under Section 504.² Section 504 prohibits discrimination against qualified students with disabilities. A student qualifies for 504 protection if he or she has a physical or mental impairment (e.g., diabetes) that substantially limits one or more major life activities (e.g., eating, caring for oneself, learning), has a record of such impairment or could be regarded as having such an impairment. Districts are required to provide identified students a free appropriate public education that provides appropriate educational services designed to meet the student's individual needs to the same extent as non-disabled students.³ Districts must identify and evaluate whether a student is eligible for 504 and, if so, develop a 504 accommodation plan describing the services that must be provided to the student.⁴ For students with diabetes, the 504 plan would need to identify any necessary health care services, in consultation with the student's physician, and, if learning is affected, any necessary academic modifications.

Each student's 504 plan or IEP must be based on the student's unique, identified needs.

What other laws are applicable?

Both the Education Code and Title 5 regulations specify that, if a student is required to take prescribed medication during a school day, the district may provide assistance either through a school nurse or other designated school personnel when the district receives written statements from the student's

¹ 20 U.S.C. §1412; 34 U.S.C. §300.320; Education Code §56345

² 29 U.S.C. §794

³ 34 C.F.R. §104.35

⁴ 34 C.F.R. §104.35

physician and parent/guardian pursuant to Education Code §49423-49423.1 and §5 CCR 600.

Although the Education Code is permissive regarding the administration of medication, the CDE's legal advisory makes clear that when a student's IEP or 504 plan specifies that the administration of insulin is a related service, the district must ensure that insulin is provided.

Some facts about diabetes:

According to the National Diabetes Education Program:

- In the United States, about 176,500 people under 20 years of age have diabetes
- About one in every 400-600 children has type 1 diabetes
- Each year more than 13,000 children are diagnosed with type 1 diabetes.⁵

Type 1 diabetes is an autoimmune disease in which the immune system destroys the insulin-producing cells of the pancreas that regulate blood glucose. Insulin is a hormone that is needed to convert sugar (glucose), starches and other food into energy for daily life. Since the pancreas has stopped making insulin, people with type 1 diabetes must take insulin in order to survive. Typically, people with diabetes take insulin (through injection, an insulin pump, or other methods) at prescribed times during the day (such as before meals) or in response to high blood glucose levels.

In type 2 diabetes, either the body does not produce enough insulin or the cells ignore the insulin. People with type 2 diabetes may control their diabetes with diet and exercise alone, oral medication, or insulin depending on how the disease impacts the individual.

People with diabetes must check or test their blood glucose levels throughout the day by using a blood glucose meter. If blood glucose levels are too low (hypoglycemia) or too high (hyperglycemia), they must then take corrective action, such as eating, modifying their activity level, or administering insulin, glucagon (a hormone used to treat severe hypoglycemia), or other medication.

Who may administer insulin at school?

According to the CDE's legal advisory, under state law, there are seven categories of persons that may administer insulin to students at school: (1) the student; (2) the school nurse or school physician; (3) an appropriately licensed school employee (i.e., registered nurse) who is supervised by the school nurse, school physician, or other appropriate individual; (4) a contracted registered nurse from a private agency or registry or a public health nurse employed by the county health department; (5) a parent/guardian who so elects; (6) an individual designated by the parent/guardian who is not a school employee; or (7) an unlicensed school employee but only in emergencies such as an epidemic or public disaster.⁶ When such persons are not otherwise available and all other options have been explored and exhausted, then, according to the CDE's legal advisory, "it is a valid practice pursuant to federal law" for an eighth category of individuals to administer insulin: voluntary, unlicensed school employees (i.e., without a medical license), as required by the student's IEP or 504 plan.⁷

The training of unlicensed personnel is one of the main issues that led to the filing of the lawsuit. Over the last several years, organizations representing nurses have stated that the state's Nurse Practices Act prohibits school nurses from training or supervising unlicensed personnel to administer medication, such as insulin, since the administration of medication is within the practice of nursing. In response to the advisory, the American Nurses Association and American Nurses Association\CA have filed a lawsuit asking the court to declare that the eighth category violates the law and to direct the CDE from enforcing that part of the advisory. Those associations feel strongly that management of a student's diabetes and training on how to give a student insulin is a complex task, centered on the individual's needs, and would be difficult for people with a non-medical background, especially given the need to analyze different factors such as carbohydrate calculation and insulin dosage.

It is unfortunate that the settlement agreement, as evidenced by the filing of the second lawsuit, did nothing to resolve the underlying legal questions. CSBA is exploring other options, such as pursuing legislation, to try to resolve this issue.

If the district chooses to use unlicensed personnel to administer insulin, as required by a student's IEP or Section 504 plan, it is critical that such employees are appropriately trained and supervised, as discussed below.

⁵ National Diabetes Education Program, Overview of Diabetes in Children and Adolescents, August 2006

⁶ Business and Professions Code §2725; 5 CCR §604

⁷ CDE's Legal Advisory on Rights of Students with Diabetes in California's K-12 Public Schools, pg. 10-11 (August 8, 2007)

May a parent or other relative administer the insulin? May the student self-administer?

Yes. However, the CDE's legal advisory clarifies that a district may not require a parent or other relative to come onto school grounds to administer the insulin.⁸ In the case of the student who is able to self-test and monitor his or her blood glucose level, Education Code §49414.5 specifies that the student may be permitted to test his or her blood glucose level and otherwise provide diabetes self-care in the classroom, in any area of the school or school grounds, during any school-related activity, and, upon specific request by a parent or guardian, in a private location. Education Code §49414.5 requires that, before allowing a student to self-administer, the parent/guardian must provide a written request and an authorization from the student's licensed health care provider.

What type of training and supervision must the district provide to unlicensed personnel?

Neither the law nor the settlement agreement specifies what type of training is required for unlicensed personnel. The CDE's advisory notes that the standards specified by the American Diabetes Association in the publication *Diabetes Care Tasks at School: What Key Personnel Need to Know: Insulin Administration*⁹ might be an appropriate minimum standard. The CDE recommends that voluntary school employees who are trained to administer insulin in emergencies should be regularly, and at least quarterly, supervised by a school nurse, physician or other appropriate individual under contract with the district; be provided with training; and be provided with emergency communication access to the same school nurse or physician.¹⁰ The supervisor of the school employee is responsible for both training and supervision, and makes the final determination that the employee is adequately trained. The CDE also recommends that districts maintain documentation of training, ongoing supervision and verification of competency.¹¹ Unfortunately, many districts do not have regular access to a school nurse and it might be difficult to ensure that unlicensed personnel receive appropriate training and supervision.

AB 942 (Ch. 684, Statutes of 2003) added Education Code §49414.5 which encouraged the development of standards

for the training and supervision of school personnel providing emergency medical assistance and providing glucagon to students with diabetes suffering from severe hypoglycemia. These glucagon standards were finalized in May 2006. The standards include recognition and treatment of hypoglycemia, administration of glucagon and basic emergency follow-up procedures.¹²

The American Diabetes Association and the Disability Rights Education and Defense Fund have developed a list of diabetes education programs in California, such as hospitals, medical centers, and insulin pump companies, organized by region, as well as a list of diabetes educators who have agreed to provide training to district personnel.¹³ These groups may provide training either for school nurses, who can then train unlicensed school personnel if needed, or directly to school personnel. Some may be willing to train pro bono, while others will charge a fee. School districts that need to provide diabetes care training to care for a student may first want to contact the student's health care provider; many diabetes-related medical practices have nurses or others on staff who can train school personnel.

Because the law is unclear regarding training standards and district liability, it is strongly recommended that districts consult with legal counsel, appropriate medical personnel, and the district's risk manager in order to ensure that appropriate protections are in place. Appropriate training is critical in order to help ensure that students are safe and liability risks are minimized.

Can the district require a parent to sign a waiver of liability?

No. The CDE's advisory emphasizes that districts cannot have a blanket policy requiring parents/guardians to sign a waiver of liability before services are provided or stating that services will not be provided due to the lack of licensed personnel or the financial burden of providing the services.¹⁴ In addition, a district may not have a blanket policy that diabetes-related health care will only be provided by district personnel at one school in the district or will always require removal from the classroom in order to receive the services.¹⁵

⁸ CDE's Q&A on Diabetes Case Settlement, *K.C. et al. v. Jack O'Connell et al.*, Question #5.

⁹ www.diabetes.org/advocacy-and-legalresources/discrimination/school/schooltraining.jsp

¹⁰ CDE's Legal Advisory, pg. 10.

¹¹ *Id.*

¹² *Glucagon Training Standards for School Personnel: Providing Emergency Medical Assistance to Pupils with Diabetes* May 2006 <http://web.diabetes.org/Advocacy/school/glucagon.pdf>

¹³ Please contact those associations for a copy of the list.

¹⁴ CDE's Legal Advisory, pg. 3.

¹⁵ *Id.*

What related provisions should be included in the student’s Section 504 plan or IEP?

The student’s Section 504 plan or IEP must describe the medical accommodations and services that the student may need. Such plans must be individualized and based on the student’s specific needs. Decisions about what health care services a student will receive at school, such as the timing and dosage of insulin to be administered, are usually based on the physician’s written orders.

One good resource is the publication *Helping the Student with Diabetes Succeed: A Guide for School Personnel*, produced by the National Diabetes Education Program in a partnership with the National Institute of Health, the Centers for Disease Control and Prevention, and more than 200 partner organizations.¹⁶ This publication recommends that districts assemble a school health team to work collaboratively to ensure effective diabetes management and to implement the diabetes management plan developed by the student’s health care provider and family.¹⁷ Team members could include the student, parent/guardian, school nurse, other health personnel, administrators, the student’s teacher(s), guidance counselor, and other relevant staff. The team will implement the student’s diabetes management plan, as provided by the student’s physician, and will also be part of the group that develops the Section 504 plan or IEP. The publication recommends that such plans include at least the following elements:

- Where and when blood glucose monitoring will take place, including whether the student is able to self-monitor and self-treat
- Care to be provided, such as conducting blood glucose checking, administering insulin and glucagon, treating hypoglycemia and hyperglycemia, actions to be taken in the event of an emergency
- Identification of trained personnel to provide care
- Location and storage of the student’s diabetes management supplies
- Access to the restroom and water fountain, including during times other than during recess or breaks
- Nutritional needs, including provisions for meal, snack, and water breaks
- Full participation in all school-sponsored activities, including extracurricular activities and field trips, with coverage provided by trained personnel

- Alternative times for academic exams if the student is experiencing hypoglycemia or hyperglycemia
- Absences for doctor’s appointments
- Documentation and log of medication administration
- Maintenance of confidentiality and the student’s right to privacy¹⁸

Policy considerations:

CSBA’s sample BP/AR 6164.6 – Identification and Education Under Section 504 has been modified to reflect the terms of the settlement. CSBA’s sample BP/AR 5141.21 - Administering Medication and Monitoring Health Conditions will be updated upon resolution of the litigation. In any event, districts are strongly encouraged to tailor policies to meet their local needs. Policy development on this issue should provide opportunities for input from principals, school nurses, other staff, teachers, special education staff, health professionals, parents/guardians and students.

In adopting policy, some issues the governance team should consider include:

- What is the prevalence of diabetes in the district? Does the district’s health education curriculum include information about diabetes care and prevention? Is diabetes prevention incorporated into the district’s wellness policy?
- How will students with diabetes be identified and, once identified, how will parents and students be notified of their rights?
- How will the policy be incorporated into professional development opportunities for principals and teachers? For school nurses? Other staff?
- How will the policy be evaluated and monitored?

Once a student with diabetes is identified at a particular school:

- Will a school health team be formed to implement the student’s diabetes management plan and/or IEP or 504 plan, as recommended by the student’s health care provider? Who will be part of the team?
- How will the school health team or principal alert appropriate staff about the student’s needs, including teachers, substitute teachers, coaches, food service managers, playground supervisors, and bus drivers?

¹⁶ *Helping the Student with Diabetes Succeed: A Guide for School Personnel*, U.S. Department of Health and Human Services, June 2003, www.ndep.nih.gov/diabetes/pubs/Youth_NDEPSchoolGuide.pdf

¹⁷ See Id. pg. 12, 49 for a sample diabetes management plan.

¹⁸ Id., pg. 14.

- How will the superintendent recruit and identify individuals and staff to provide services to students whose IEP or 504 plans specify that services need to be provided? How will the superintendent exhaust all available options before identifying unlicensed personnel to provide the services?
- What type of training will identified individuals receive? How will staff who have received training be supervised and monitored? What type of documentation of the training will be maintained?
- What is the role of the school nurse in providing care to students? What is the role of the nurse in training and supervising unlicensed school employees?
- How will student confidentiality be maintained?

Resources:

American Association of Diabetes Educators

www.diabeteseducator.org

American Diabetes Association, school resources

www.diabetes.org/advocacy-and-legalresources/discrimination/school.jsp

California Department of Education, diabetes management in schools

www.cde.ca.gov/ls/he/hn/diabetesmgmt.asp

National Diabetes Education Program, National Institutes of Health

www.ndep.nih.gov

U.S. Department of Education, disability resources

www.ed.gov/about/offices/list/ocr/disabilityresources.html