

Protecting the Rights of School Children with Diabetes

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Abstract

School children with diabetes are facing increasing difficulties in receiving care during the school day. Despite the existence of federal statutes ensuring their rights to a free, appropriate public education, many school districts throughout the country do little, if anything, to ensure that their condition is treated throughout the school day. The chronic shortage of school nurses has resulted in hardships on families, relatives, and friends to ensure that care, including insulin, is timely and appropriately provided. While many states have taken measures to provide care by unlicensed trained volunteers, efforts to accomplish this in California have resulted in prolonged litigation. A variety of nursing organizations oppose all efforts to train unlicensed volunteers, arguing that such is not permitted by California law. The issue is unresolved and currently pending in the California Supreme Court.

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More and more children in our country's public schools are being diagnosed with diabetes, and these schools are sometimes ill equipped to provide the services that these students need in order to attend school safely and participate fully in school activities. To avoid short- and long-term harm to the health and educational achievement of these students, parents, school administrators, and school health staff must be familiar with the legal protections for these students and how schools can best protect these children.

Diabetes is a serious chronic medical condition in which the body is unable to produce or use insulin effectively. Approximately 1 out of 400 children and adolescents in the United States have type 1 diabetes mellitus (T1DM).¹ During 2002–2005, there were 19.7 new cases of T1DM in 100,000 children under 10 years old and 18.6 new cases of T1DM in the same population of youth over 10 years old.² Primarily because of lifestyle factors such as diet and lack of physical activity, there is an alarming increase in type 2 diabetes mellitus (T2DM) among school children.³ "Diabetes is one of the most common diseases in school-aged children Approximately 15,600 US youth less than 20 years of age were diagnosed annually with T1DM, while 3,600 were newly diagnosed with T2DM."³ This health crisis has not escaped the attention of the Centers for Disease Control.⁴

Children with T1DM, regardless of their age, will have fluctuations in their blood glucose throughout the school day. They must be able to monitor their blood glucose levels and to respond to levels that are either too low or too high;

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Abbreviations: (ADA) Americans with Disabilities Act, (FAPE) free, appropriate public education, (HHS) Department of Health and Human Services, (IDEA) Individuals with Disabilities Education Act, (IEP) individualized education program, (T1DM) type 1 diabetes mellitus, (T2DM) type 2 diabetes mellitus

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if too high, they must be treated with insulin as prescribed by a health care professional.³ A number of resources are available to assist school children with diabetes.^{5,6}

California provides an example of both the impact that diabetes has had on school children as well as the challenges schools face in responding to the epidemic of an increase in diabetes in school-age children.

If there is 1 student out of every 400 school-age children who has diabetes, then with a school-age population of over 6 million children in California, there are 15,805 students with T1DM. Many of these children are able to manage most of their care independently. However, children who lack the capability and maturity to manage their own care will need the assistance of someone who is trained to monitor blood glucose levels and provide needed treatment such as the administration of insulin.

Many assume that school nurses are available to provide care for students with diabetes. However, in many states, including California, these nurses simply are not available. The United States Department of Health and Human Services (HHS) suggests a standard of 1 school nurse for 750 students.⁷ However, California has only 2474 full-time-equivalent nurses available to more than 9000 schools or 1 school nurse for every 2257 students.⁸

Two California counties demonstrate implications of these ratios. As of 2010, there were 380,964 students in Riverside County. Riverside County has only 105 nurses. Six of the 23 districts have no nurses at all. There is, thus, a ratio of 1 school nurse for approximately 3800 students.

Similarly, San Bernardino County, with a population of 423,780 students, has 129 full-time school nurses. Two of the 16 school districts have no nurses on staff. Thus there is a ratio of 1 school nurse for every 3285 students, five times the ratio recommended by the HHS.

Due to a shortage of nurses or simply to a lack of understanding about proper diabetes treatment, many schools have policies and practices in place that do not serve the needs of students with diabetes:

For example, some schools only allow students to check blood glucose levels in the nurse's office, fearing that "blood-borne pathogens" might hurt other children or that it is too disruptive in the classroom. ... Other schools prohibit school personnel (other than the nurse) from administering glucagon or insulin, fearing legal liability. Perhaps most dangerously, some schools fail to even train personnel to recognize glycemic symptoms. The negative effects of such policies and practices are two-fold: they threaten students' medical safety and deprive them of educational opportunities. ... Also, policies that prohibit school personnel (other than the nurse) from administering insulin or glucagon subject students to dangerous, prolonged periods of hypoglycemia or hyperglycemia. Such policies also prohibit students from participating in activities where a nurse is not available, such as field trips, extracurricular activities, and even attending a particular school!⁹

In addition to putting students at risk and harming their ability to learn, such policies and practices can violate federal discrimination laws. These rights are provided by section 504 of the Rehabilitation Act of 1973,¹⁰ the Americans with Disabilities Act (ADA),¹¹ and the Individuals with Disabilities Education Act (IDEA).¹²

These laws protect all children with any type of disability, including diabetes, from discrimination and require that they receive related aids and services (including medication administration) necessary in order to receive a free, appropriate public education (FAPE).

Section 504 and the IDEA provide a means for children and their parents to develop a school plan for monitoring and treating complications of diabetes. Under the law, the school must provide equal opportunities to a child with diabetes. The law's goal is to ensure that the child with diabetes can participate in all school activities, on and off campus, in a way that the school will care for all needs that arise from the child's diabetes. Under section 504, qualified students in elementary and secondary schools are entitled to receive a FAPE, including special education or related services.¹²

“The provision of an appropriate education is the provision of regular *or* special education *and* related aids *and* services that (i) are designed to meet the individual educational needs of handicapped persons as adequately as the needs of nonhandicapped persons are met and (ii) are based on adherence to procedures that satisfy the requirements of 104.34, 104.35, and 104.36.” (Emphasis added.) Nonacademic services such as health services must be provided when necessary to ensure FAPE.¹³

The 504 plan should be based on detailed medical orders provided by the child’s practitioner. These orders will specify treatment alternatives for various complications of diabetes that might arise during the day.

The 1990 ADA prohibits any form of discrimination by public and private schools against qualified individuals with disabilities.¹⁴ As a result of the law, a school must not discriminate against a child who has a disability. The protections provided by the ADA are very similar to those available under section 504. A school is also required to make reasonable changes in its practices and policies that have the effect of creating discrimination as well as to afford students with disabilities an equal opportunity to participate unless doing so would impose an “undue burden.”

Finally, the IDEA requires states, as a condition of receiving federal special education funding, to provide a FAPE to children with disabilities so that they can be educated to the greatest extent possible along with all other children. Children who qualify are entitled to special education and related services at no cost to their parents that is detailed in an individualized education program (IEP).

Under the law, a school district must follow specific procedures to determine a child’s eligibility for special education, to develop the child’s IEP, and to resolve conflicts. The rights of students in elementary and secondary education programs to receive FAPE and related services are concomitant with FAPE rights under IDEA.¹⁵

These rights are summarized by the American Diabetes Association on its Web site:

Basically, these laws say that your child has the right to go to school, play a sport, join a club, and do everything else that kids without diabetes do. They also say that public schools and other covered organizations must make “reasonable accommodations” for the child’s diabetes. Such accommodations are to be spelled out in the Section 504 plan, IEP, or other education plan. Accommodations may include:

- Assuring that there are staff members trained in checking blood glucose levels, recognizing and treating hypoglycemia and hyperglycemia, and administering insulin and glucagon
- Allowing your child to self-monitor blood glucose levels in the classroom and in other locations, and allowing him to treat hypoglycemia and hyperglycemia promptly
- Ensuring full participation in all sports, extracurricular activities, and field trips, with the necessary care and/or supervision provided
- Eating whenever and wherever necessary, including eating lunch at an appropriate time with enough time to finish eating
- Taking extra trips to the bathroom or water fountain
- Permitting extra absences for medical appointments and sick days when necessary without penalty.¹⁶

Despite these three laws, children with diabetes frequently do not receive the same education as those who do not have diabetes. Too often, schools and school districts are unable to provide timely access to health care services. They may also refuse to train teachers and other school staff in the basics of diabetes or how to evaluate or treat a child experiencing high or low blood glucose levels. As a result, parents of younger children are often forced to leave their

jobs to come to their child's school to provide needed diabetes care such as insulin administration. If a child goes on a field trip, the parent is often required to accompany the child to provide care. Even if a health care professional creates a plan to detail blood glucose monitoring procedures, procedures for treatment of hyperglycemia and hypoglycemia, precautions to be taken before exercise or recess, and/or guidelines for meals or snacks, many schools do not make school personnel available to implement the plan.

A key barrier to making sufficient numbers of school staff available to provide diabetes care whenever and wherever it is needed by students is a belief that school employees who are not nurses cannot legally or safely administer insulin to students. Various nursing organizations, including the American Nurses Association,¹⁷ the California School Nurses Association,¹⁸ and the National Association of School Nurses¹⁹ insist that only a licensed health care professional can administer insulin when it is needed by a student. Given the chronic unavailability of school nurses discussed earlier, this effectively means that students with diabetes are likely to go without care in the absence of a nurse. Indeed, there is broad agreement among experts in the care and treatment of persons with diabetes including the following: the United States Department of Education, the United States HHS and its Centers for Disease Control and Prevention and National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health, the American Medical Association, the American Academy of Pediatrics, the American Association of Clinical Endocrinologists, the American Association of Diabetes Educators, the American Dietetic Association, the Pediatric Endocrine Nurses Society, the Pediatric Endocrine Society, Children with Diabetes, and the Juvenile Diabetes Research Foundation.²⁰

To address the problems created by this shortage, several states have addressed the rights of students with diabetes.⁹

In California, on the other hand, litigation became necessary to remove perceived barriers in state law to insulin administration by unlicensed school personnel. In October 2005, the American Diabetes Association and four parents and their children with diabetes sued the California Department of Education and two school districts alleging that the school children had been denied their rights, in part, because of the refusal of the state to ensure that local school districts provided needed diabetes care and the refusal of the districts to train school employees in insulin administration during the course of the school day because of a belief that such training of unlicensed school employees violated state law.²¹ The lawsuit was based on the allegations that the Department of Education as well as the school districts each violated section 504, the ADA, and the IDEA. The lawsuit was filed as a proposed class action and sought declaratory relief as well as injunctive relief to ensure that each of the defendants complied with each of these laws. It also sought this specific relief: a mandatory injunction compelling the defendants to provide to every eligible child with diabetes living within each defendant's respective jurisdiction a FAPE in the least restrictive environment in conformity with the provisions of the law.

The injunction sought these specific remedies:

Order the two school districts to implement policies that will advise parents of children with diabetes so that an individualized [treatment plan] for each eligible student may be developed in conjunction with the parents and the student's health care professional. It also seeks to have schools develop IEPs and Section 504 Plans that would include these elements:

- a. Afford each student with diabetes access to diabetes care, including testing of blood glucose levels and responding with appropriate care including needed medication, food, and liquids, with such care to be self-administered or provided by trained adults;
- b. Permit diabetes care to be administered in the classroom, in any location where a student is participating in a school activity, or in a private area close to where the student is located when the student's DMMP [(Diabetes Medical Management Plan)] so provides;
- c. Permit any student with diabetes to see a nurse or other school staff member trained in diabetes treatment;

- d. Ensure that in every school with at least one student with diabetes, there are sufficient numbers of Trained Personnel who are willing and able to provide care for the student;
- e. Ensure that in every school that has at least one pupil with diabetes Trained Personnel are immediately available to administer insulin and glucagon;
- f. Permit any student with diabetes: (a) to miss school without consequences for required medical appointments related to the student's diabetes when the student presents a doctor's note if such note is generally required by school policy; and (b) be allotted extra time for tests and other graded work if necessary due to hypoglycemia or hyperglycemia.

The lawsuit was eventually settled with the California Department of Education.⁸ It provided that

Business and Professions Code section 2725(b)(2) and the California Code of Regulations, Title 5, section 604 authorize the following types of persons to administer insulin in California's public schools pursuant to a Section 504 Plan or an IEP:

1. self-administration, with authorization of the student's licensed health care professional and parent/guardian;
2. school nurse or school physician employed by the LEA [(Local Educational Agency)];
3. appropriately licensed school employee (i.e., a registered nurse or a licensed vocational nurse) who is supervised by a school physician, school nurse, or other appropriate individual;
4. contracted registered nurse or licensed vocational nurse from a private agency or registry, or by contract with a public health nurse employed by the local county health department;
5. parent/guardian who so elect;
6. parent/guardian designee, if parent/guardian so elects, who shall be a volunteer who is not an employee of the LEA; and
7. unlicensed voluntary school employee with appropriate training, but only in emergencies as defined by Section 2727(d) of the Business and Professions Code (epidemics or public disasters).

When no expressly authorized person is available under categories 2-4, *supra*, federal law - the Section 504 Plan or the IEP - must still be honored and implemented. Thus, a category #8 is available under federal law:

8. voluntary school employee who is unlicensed but who has been adequately trained to administer insulin pursuant to the student's treating physician's orders as required by the Section 504 Plan or the IEP.²²

Shortly after the settlement, the American Nurses Association (later joined by the California Nurses Association and the California School Nurses Organization) sued to invalidate the settlement.²³ In November 2008, the court ruled that, under its interpretation of California state law, an unlicensed school employee may not administer insulin to a student. The American Diabetes Association appealed, and in June 2010, the California Court of Appeal affirmed the decision.²³ The Court held "the plain language of [California Business and Professions Code] section 2725, subdivision (b)(2) includes in the functions of a nurse as defined generally by subdivision (b) 'the administration of medications' ordered by a physician. (§ 2725, subd. (b)(2).) While the NPA [(Nursing Practice Act)] does not define the term 'administration,' we find guidance (see 64 Ops.Cal.Atty.Gen., *supra*, at p. 242, fn. 5) in the Pharmacy Law (Bus. & Prof.Code, § 4000 et seq.) which defines 'administer' as 'the direct application of a drug ... to the body of a patient ... by *injection*, inhalation, ingestion, or other means'" (Business and Professions Code section 4016; italics added). Similarly, the

California Uniform Controlled Substances Act (Health and Safety Code section 11000 *et sequens*) defines “administer,” in pertinent part, as “the direct application of a controlled substance, whether by *injection*, inhalation, ingestion, or any other means to the body of a patient for his immediate needs” (Health and Safety Code section 11002; italics added). There is nothing in the Nursing Practice Act to indicate a different meaning of the term “administer.” It is a general rule of statutory construction to construe words or phrases in one statute in the same sense as they are used in a closely related statute pertaining to the same subject. The parties do not dispute insulin is a medication. Therefore, the injection of insulin into diabetic students would appear to fall within the “administration of medications”—a practice of nursing.

In 2010, the California Supreme Court granted review in the matter. To date, the case has not been heard. Meanwhile, with the worsening economy and direct impact of the recession on school services, California students with diabetes face an even greater risk to their health and the consequences of the ongoing violations of their rights in California schools.

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