

# The Crucial Role of Health Care Professionals in Advocating for Students With Diabetes

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When Tracy Milligan enrolled her elementary school-aged son Jared, who has type 1 diabetes, in his neighborhood school in Jacksonville, Fla., she was told that, because there was no school nurse onsite to administer insulin, Jared would be sent to another school where there was a full-time nurse—unless she was willing to leave work every day to come to school and administer his insulin herself. Jared, like other children who are too young to administer their own insulin, would be forced to leave his friends and familiar school setting because the school district refused to train other school staff members to administer insulin. Only 5 of the 103 schools in Jacksonville were willing to provide the care Jared needed. Ms. Milligan turned to the American Diabetes Association (ADA), which led a successful effort to pass a state law that provides for appropriate care for students with diabetes and prohibits the segregation that Jared and many others like him faced.<sup>1</sup>

Amy Coffey was told that her son Connor, a kindergartener, could not go on field trips unless he was accompanied by a parent and that he would be required to go to the nurse's office to check his blood glucose level, even if he felt hypoglycemia symptoms. There was no plan in place for caring for Connor when the nurse was absent, and Connor's bus driver knew nothing about how to recognize and treat hypoglycemia. After

Ms. Coffey contacted ADA for help, the Association and one of its local volunteer attorneys worked to ensure that the school developed a plan to address all of these concerns to keep Connor medically safe at school.

These problems are examples of those faced by children with diabetes, who are denied opportunities to academically thrive and safely participate in school activities with their classmates because there is no one at school to provide diabetes care. ADA receives hundreds of calls each year (a number that has steadily increased with the growing population of children with diabetes) from parents whose children face discrimination because of their diabetes. The Association, through its Safe at School campaign, is committed to ensuring that children with diabetes are medically safe at school and treated fairly, and it strives every day to find solutions like those achieved for Jared and Connor.

This article provides background on the Safe at School campaign and legal protections for students with diabetes and describes the essential role of health care professionals in helping to fight discrimination against their school-aged patients. It highlights a California school discrimination case as an example of how the expertise of the treating health care team, including doctors, nurses, and diabetes educators, has been instrumental in

improving diabetes care at school for their patients.

## Why Should Providers Be Concerned About School Care?

Keeping a child's blood glucose in target range is an ongoing challenge for both pediatric providers and parents. Providers understand that inadequate diabetes management at school jeopardizes blood glucose control and puts children at risk for serious short- and long-term complications, including retinopathy, nephropathy, neuropathy, and cardiovascular disease.

To facilitate good diabetes management during the school day, school officials need to permit capable students to self-manage their condition.<sup>2</sup> They also must ensure that school staff members—not just a school nurse—are trained to provide care and support to younger children, including insulin administration, and to help all children in the case of a diabetes emergency, including administration of glucagon. When schools refuse to support self-management and train adequate numbers of staff to support diabetes care, students face discrimination and are put in potential danger.<sup>3</sup>

## Safe at School Campaign

ADA's Safe at School campaign is based on three guiding principles that help ensure a safe school environment:

1. All school staff members who have responsibility for a child with diabetes should receive training

that provides a basic understanding of the disease and how to identify medical emergencies.

2. Although the school nurse is the key coordinator of care, a small group of staff members should be trained to provide care, including administration of insulin and glucagon, when the school nurse cannot be there.
3. Capable and mature students should be permitted to self-manage their diabetes anytime and anywhere.

These principles are based on recommendations from the diabetes health care community and form the cornerstone of effective school diabetes care.<sup>4</sup>

Nevertheless, many schools do not have practices in place to support these essential tenets of safe care. They may lack trained and knowledgeable staff to provide care during the regular day or during field trips and extracurricular activities. Some of these problems result from ill-advised, outdated state laws or policies permitting only nurses to provide diabetes care such as insulin administration in school, coupled with school systems' lack of funding to employ adequate numbers of school nurses. However, even if every school had a full-time nurse, this would not guarantee care during field trips or during the inevitable times when a nurse is not available. This is why it is crucial to ensure that other school staff members are trained to provide care.

Nearly all insulin injections are given by non-nurses—by people with diabetes themselves or by their family, friends, or caregivers. Glucagon was developed to be administered by people who are not health care professionals. Indeed, it is the consensus of the diabetes health care community that unlicensed school personnel

can administer insulin and glucagon safely and should be permitted to do so to ensure adequate care.<sup>5</sup> Safe diabetes care can be provided by a variety of school staff members.<sup>6</sup> Fortunately, some states, usually as a result of advocacy by ADA, already have laws or regulations in place authorizing such training and facilitating other aspects of diabetes care in school.

Despite state law and policy restrictions, schools are not simply free to deny appropriate diabetes care to students in need. Federal laws protect students with diabetes from this type of discrimination. Section 504 of the Rehabilitation Act of 1973 (“Section 504”) and the Americans with Disabilities Act are civil rights laws that ensure access to equal opportunity for students with disabilities. The Individuals with Disabilities Education Act protects students with diabetes who need special education because of the impact of their diabetes (or another disability) on their ability to learn. All three laws require that students receive a free, appropriate public education, which requires that the school take responsibility for providing needed diabetes care at no cost to families. Accommodations for students with diabetes should be documented in a written plan developed under applicable law such as a Section 504 Plan or an Individualized Education Program.<sup>7</sup>

#### **How Health Care Providers Can Help Ensure Safety and Fairness for Students**

To help ensure that children are safe at school, the ADA has developed a broad array of informational and advocacy resources such as template care plans and training guides for parents, health care professionals, and school personnel. ADA's commitment to train school educators and decision-makers is reflected in

its joining forces with the preeminent public and private organizations with expertise in diabetes care to write the National Diabetes Education Program's *Helping the Student with Diabetes Succeed: A Guide for School Personnel*. This important tool not only outlines diabetes care best practices for schools, but also serves as a consensus statement on the best approach to management in the school setting.

ADA has supplemented the guide with a diabetes training curriculum geared for school personnel, *Diabetes Care Tasks at School: What Key Personnel Need to Know*, which is available online at [www.diabetes.org/schooltraining](http://www.diabetes.org/schooltraining). These tools and a wealth of other materials are available on ADA's Web site at [www.diabetes.org/safeatschool](http://www.diabetes.org/safeatschool) or by calling 1-800-DIABETES. Diabetes health care professionals who volunteer for the Association have led the effort to develop each of these tools.

Students' health care team members serve as both educators and diabetes experts. A student's provider can perform a great service by informing parents and guardians about ADA's school advocacy materials and template care plans to help them navigate through the back-to-school process. When parents or guardians understand their rights and how to use written plans to document needed care and modifications, they are empowered to ensure that their child is treated fairly at school and is educated in a safe school environment.

Next, it is crucial that a student's health care provider spell out detailed information about the student's individual diabetes care regimen through written orders, ideally before the school year starts. Providers should not be expected to change these orders in a way that impedes optimal diabetes

management because of a school's reluctance to provide required care. Providers and diabetes educators can also help by training school personnel in insulin and glucagon administration and other care tasks.<sup>8</sup>

Beyond helping individual patients, health care professionals play a key role in changing district and state policies by explaining diabetes care to decision- and policy-makers such as legislators, courts, and school administrators. For example, health care professionals have been instrumental in achieving favorable policy changes by providing expert testimony in support of school legislation and in lawsuits challenging discriminatory school policies.<sup>9</sup>

#### **A California Case Study: Health Care Professionals Provide Expertise**

Nowhere has the role of health care professionals been more important than in ADA's long fight to make California children safe at school. In California, several nursing organizations insist that state law prohibits unlicensed school personnel from administering insulin to students with diabetes at school. A lawsuit now before the California Supreme Court will determine whether this position can stand. The stakes are high, because there are not enough school nurses available to provide needed care. There is only one school nurse for every 2,200 students in California, only 5% of schools have a school nurse, and nearly half of all school districts have no nurse at all.

In 2005, ADA sued the California Department of Education and several school districts in federal court because children with diabetes were not getting the care they needed. Students were experiencing unnecessary hyperglycemia at school; others were taken off multiple daily injections and forced to get by with only one or two

injections a day because schools refused to administer insulin during the school day. Still others were pushed into self-administering insulin when they were not developmentally ready. Some parents had to give up their jobs to be available to come to school to care for their child.

In 2007, after the lawsuit brought statewide attention to the problem, a landmark settlement with the state was reached. The settlement, recognizing the need for schools to comply with the mandate in federal law to provide diabetes care, permitted schools to train employees to administer insulin in situations in which no nurse was available. This allowed willing school personnel to raise their hands and offer to help these children in need.

Unfortunately, after the settlement was announced, several nursing organizations (the American Nurses Association, the American Nurses Association/California, the California Nurses Association, and the California School Nurses Organization) sued the state in state court, arguing that permitting school personnel who do not have medical licenses to administer insulin violates state law. A state appeals court sided with the nursing groups in 2010, but the case has been accepted for review by the state Supreme Court, and a decision is expected in 2012.

Health care professionals have played an essential role throughout the litigation. Prominent ADA health care professional volunteers served as experts in the litigation, giving the courts crucial background information on diabetes and explaining how the medical community believes that insulin can be safely administered by trained individuals who do not have medical licenses. Several other nurses from across the state provided testimony about their experiences

training people to administer insulin and working with school districts that were unwilling to provide care and about the necessity of having trained school personnel available to give insulin at all times.

Diabetes experts joined with federal and state governments, civil rights groups, and school boards in supporting ADA's position before the California Supreme Court by filing six separate friend-of-the-court briefs.<sup>10</sup>

Health care providers throughout the state have advocated for their patients to get the care they need and provided resources to help schools meet their obligations. Diabetes educators have volunteered their time to go to schools to train staff to administer insulin. Physicians have provided detailed medical orders covering a range of situations to make it as easy as possible for school personnel to take on the responsibility of insulin administration. Just as importantly, they have held firm when pressed by school districts to change a child's treatment regimen for the school's convenience, putting the needs of their patients first and helping to ensure that schools follow the law.

#### **Your Patients Need You to Fight Discrimination Against Children With Diabetes**

Because health care professionals are so important in securing the rights of people with diabetes, ADA created its Health Care Professional Legal Advocacy Network. The network is made up of providers around the country who have agreed to volunteer their expertise and devote their passion to fight discrimination based on diabetes. Providers help by creating tools for families and schools, training schools, consulting with attorneys on discrimination cases, acting as expert witnesses, and advising on policy and legislative

issues. More information about the network can be obtained by visiting [www.diabetes.org/patientrights](http://www.diabetes.org/patientrights).

## REFERENCES

<sup>1</sup>Bunker K (ed.): Safer at school: new laws in two states protect students with diabetes. *Diabetes Forecast* 63(11):80–83, 2010

<sup>2</sup>Nabors L, Lehmkuhl H, Christos N, Andreone TL: Children with diabetes: perceptions of supports for self-management at school. *J School Health* 73:216–221, 2003

<sup>3</sup>American Diabetes Association: Diabetes care in the school and day care setting. *Diabetes Care* 34 (Suppl. 1):S70–S74, 2011

<sup>4</sup>These principles have been endorsed by the American Academy of Pediatrics, the American Association of Clinical Endocrinologists, the American Association of Diabetes Educators, American Diabetes Association, the American Dietetic Association, Children with Diabetes, the Disability Rights Education and Defense Fund, the Endocrine Society, the Juvenile Diabetes Research Foundation, the Pediatric Endocrine Society, and the Pediatric Endocrine Nursing Society.

<sup>5</sup>This position was expressly endorsed by *Helping the Student with Diabetes Succeed: A Guide for School Personnel*, a 2010 publication of the National Diabetes Education Program, a federally sponsored partnership of the National Institutes of Health and the Centers for Disease Control and Prevention. The guide lists as its supporters the major governmental and nongovernmental organizations with expertise in the care and treatment of people with diabetes, including the American Academy of Pediatrics; American Alliance for Health, Physical Education, Recreation and Dance; American Association of Clinical Endocrinologists; American Association of Diabetes Educators; American Diabetes

Association; American Dietetic Association; American Medical Association; Barbara Davis Center for Childhood Diabetes; Children with Diabetes; The Endocrine Society; Indian Health Service, Division of Diabetes Treatment and Prevention; Joslin Diabetes Center; Juvenile Diabetes Research Foundation International; National Association of Chronic Disease Directors Diabetes Council; National Association of Elementary School Principals; National Association of School Psychologists; National Association of Secondary School Principals; National Education Association Health Information Network; Pediatric Endocrine Nursing Society, Pediatric Endocrine Society; and U.S. Department of Education.

<sup>6</sup>Hellem MA, Clarke WL: Safe at School: a Virginia experience. *Diabetes Care* 30:1396–1398, 2007

<sup>7</sup>Kaufman FR: Diabetes at school: what a child's health care team needs to know about federal disability law. *Diabetes Spectrum* 15:63–64, 2002

<sup>8</sup>Jameson P: Helping students with diabetes thrive in school. *On the Cutting Edge*. Summer 2006, p. 26–29

<sup>9</sup>Arent S: The role of diabetes health care professionals in diabetes discrimination issues at work and school. *Diabetes Spectrum* 15:217–221, 2002

<sup>10</sup>The six briefs were filed by the following organizations:

- The American Academy of Pediatrics—California District, American Academy of Pediatrics—Section on Endocrinology, the American Association of Clinical Endocrinologists, the American Association of Diabetes Educators, the Endocrine Society, and the Pediatric Endocrine Society
- The Children's Rights Clinic, Disability Rights Advocates, Disability Rights California, Disability Rights Legal

Center, Disability Rights Texas, the Los Angeles Unified School District, and the Legal Aid Society—Employment Law Center

- The Child Care Law Center
- The U.S. Departments of Justice and Education
- The California Department of Education and State Superintendent of Public Instruction
- The California School Boards Association

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