Lahle Wolfe hopes that now she will be able to reenroll her daughter Elizabeth in public school.
An ADA lawsuit helps keep kids with diabetes safe at school

By Carolyn Butler

Victory in California
Ahle Wolfe couldn’t believe what she was hearing. She was meeting with the principal and district nurse for Valencia Elementary School in Upland, Calif., where her youngest daughter Elizabeth was slated to start kindergarten. They had gathered to discuss Elizabeth’s newly diagnosed type 1 diabetes, and Wolfe was getting some unexpected answers.

“I requested a 504 plan”—a standard legal document that outlines specific services for students with special needs—“which they denied, and the district nurse, who had a very hardcore, hands-off policy, said ‘If it’s not you or me, then the school can’t provide any medical care at all’—not even the licensed vocational nurse on site,’” says Wolfe, adding that the district nurse in question oversaw 13 other schools and was rarely present at Valencia. “Their plan was that if Elizabeth felt shaky or sick in any way, her teacher would assume she was low, feed her marshmallows, and call me to come check.”

As a result, Wolfe, 47, had to abandon plans of returning to nursing school and instead find a job that allowed her to work from home, so that she’d be available to visit school every hour or two. “Clearly,” she says, “that just doesn’t cut it.”

Indeed, after several weeks of this routine—with Elizabeth running extremely high blood sugars almost every single day—Wolfe stopped by school on a hot afternoon and found her daughter nearly unconscious on the playground, surrounded by a group of anxious-looking 5-year-olds. “It turned out that her blood sugar was almost 600—she could have gone into a coma—and there was no adult to be seen,” says Wolfe, who immediately withdrew Elizabeth for homeschooling and later sent her to a private school where she got the care she needed—albeit to the tune of some $9,000 in tuition a year. “Pushing the burden of care to parents really disrupts families,” she says. “No one should have to quit their job or risk losing a job or move to be closer to school, just to ensure that their child is safe and healthy from 9 to 3.”

More than 15,000 school-age children in the state of California have type 1 diabetes, yet there are only 2,800 full-time nurses in 9,000 schools, or just 1 nurse for every 2,257 students—well below federal guidelines, which call for a 1-to-750 ratio. Add in the fact that the state Department of Education has not had a policy on diabetes treatment, and the result has been widespread confusion among districts about their legal obligations, with some schools providing comprehensive, hands-on management and others refusing to help test or minister to students.

Efforts by the American Diabetes Association led to the passage of a state law in 2003 allowing students to carry their own diabetes supplies and self-treat, and permitting school personnel other than nurses to administer glucagon in an emergency. But other aspects of care, including the administration of insulin, remained unresolved.

Convinced that the situation was not only unfair but also illegal, ADA, along with four students and their families, brought a class-action lawsuit against the California Department of Education and two school districts in 2005, alleging that they were failing to meet the health needs of students with diabetes. The landmark settlement, announced this summer, establishes that children with diabetes do have the right to proper care—and that schools have an obligation to provide it.

In the past, it was up to individuals to negotiate care during school hours. “There was absolutely no clear guidance from the state, and that was a major problem, particularly when it came to the administering of medication,” says Jim Stone, whose son, Andrew, was diagnosed with type 1 in 1998, at 20 months. His family spent Andrew’s entire first-grade year battling the Stanislaus Union School District in Modesto for an acceptable 504 management plan, with his wife providing the bulk of care in the interim. “Every family had to fight the same war on their own,” he says, observing that it was the students who typically lost: “These schools were putting an obstacle in front of children that diabetes alone doesn’t.”
Not only can failure to provide diabetes care be immediately life-threatening, but, as Lori Laffel, MD, MPH, points out, consistently poor care for children with diabetes can lead to decreased concentration and cognitive function as well as long-term complications like vision loss, kidney failure, and nerve damage—not to mention reduced life expectancy.

Laffel, an associate professor of pediatrics at Harvard Medical School and chief of the Pediatric, Adolescent and Young Adult Section at the affiliated Joslin Diabetes Center in Boston, says that “children with diabetes in a school setting need to have optimal support to attend to the demands of diabetes management, while maintaining the least restricting environment, in order to maximize learning and the development of their potential.”

That fact has now been legally established, once and for all, says Larisa Cummings, staff attorney for the Disability Rights Education and Defense Fund in Oakland, a public interest law and policy center that corepresented the plaintiffs in their suit along with Reed Smith LLP, an international law firm.

“The outcome has been very successful in sending the message that students with diabetes have protections under both federal education and civil rights laws … so that their health is not jeopardized by the failure of schools to provide needed health care services,” she says, noting that the focus has now shifted towards educating school personnel and monitoring implementation. Cummings adds that she hopes that the California settlement will serve as a national model, inspiring other states to attend to the problem without the need for legal action.

","
responsibilities, such as providing help with blood glucose testing and insulin shots to those who need it. It also spells out eight categories of individuals who may administer diabetes medications at school, including trained unlicensed (non-medical) school personnel. In addition, the settlement makes it perfectly clear that school districts must evaluate students on an individual basis and provide services accordingly (as opposed to using blanket policies), and that students cannot be sent to a particular school simply because of their condition.

Cummings says that she’s heard some early success stories—as well as lots of remaining questions and concerns—and acknowledges that implementation will be an ongoing process: “We recognize that it’s going to take time to get things ironed out and resolved, but we’re optimistic that this solution is going to be very effective, very soon, for all concerned.”

Still, not all interested parties are on board. “We’re very supportive of 98 percent of the settlement … but to train an unlicensed person [to administer insulin and other medications] is insane,” says Nancy Spradling, executive director of the California School Nurses Association. She sees this provision of the Department of Education advisory as a clear violation of the Nurse Practice Act, a set of laws which regulate nursing responsibilities and practices in California. As a result, her organization is counseling members to refuse to train unlicensed volunteers and to seek their own legal counsel. At press time, the American Nurses Association and its California affiliate filed a suit seeking to stop the state education department from allowing anyone other than nurses to administer insulin in schools. The ADA plans to strenuously oppose this effort.

WHILE IT’S CERTAINLY preferable to have all care and medications administered by a licensed professional, it is not always going to be possible, says Linda Davis-Alldritt, school nurse consultant for the California Department of Education, citing issues like the limited availability of school nurses, as well as a lack of hospitals and other health care resources in rural counties. “The intent [of the provision for training unlicensed volunteers] is … to support districts that have exhausted all other options. The bottom line is that kids’ needs have to be served. This way, there’s no reason they can’t be.”

The ADA and other organizations that specialize in caring for students with diabetes maintain that non-medical personnel can—and should—be trained to administer diabetes medications in the absence of a school nurse. Jim Stone concurs. His son’s initial 504 plan established that the school would train several personnel—including his teacher, the principal, and a secretary—on insulin, glucagon, and other management issues. “It’s been smooth sailing since then,” says Stone. “I feel like I have pretty good care at school—if I need anything I get it—and I think that makes me do better,” adds Andrew, now 11 and a straight-A sixth grader who plays baseball and is a boy scout, among other activities. “I don’t worry about any of that [medical] stuff at all. I just go to school and have fun and learn like any other kid.”

As for Lahle Wolfe, she’s still battling with the Upland Unified School District over a 504 plan for Elizabeth, as well as what, exactly, constitutes proper treatment and management. But she feels that the recent legal settlement will ultimately make her case for her, and hopes to reenroll her daughter in public school by next fall. “I’m not heartless towards schools—it’s a scary thing to take a child with a serious medical condition, especially when you don’t have a [full-time] nurse—but that doesn’t change their responsibility,” she says. “Now that schools have these guidelines and tools and resources, there’s absolutely no excuse for them to put any child in danger.”

FOR MORE INFORMATION about discrimination based on diabetes go to diabetes.org/discrimination.
If you or a family member are facing discrimination call 1-800-342-2383 to obtain written information and to request assistance from a legal advocate.
And if you are interested in helping out in ADA’s legal advocacy efforts, contact Edith Hong at ehong@diabetes.org.

Washington-based freelancer Carolyn Butler writes often about education and health.