LESSONS LEARNED

Teaching schools about the rights of children with diabetes  

BY TRACEY NEITHERCOTT

IT HAD BEEN a year since the school nurse told Kimberly Shekalus that the 504 plan she wanted to set up for her daughter was unnecessary. A full school year since Shekalus and her husband were coaxed into developing an Individualized Health Plan (IHP) instead. It had been a year, and yet conditions of the plan, set in place to ensure proper diabetes care for Shekalus’s daughter Payton, still weren’t being met.

Payton had graduated from fourth grade in Manheim, Pa., and was ready to move into middle school for fifth when the school nurse pulled Shekalus aside. In a move that contradicted her previous stance on diabetes care in the school, the nurse insisted Payton needed a 504 plan to protect her rights and keep her safe. The Shekaluses agreed, and as soon as the nurse sent them information about the plan, they approached the middle school staff.

“They said, ‘Absolutely not. How did you get this information? Parents aren’t supposed to know about this,’” Shekalus says. “I have never felt so belittled.”

It’s a common scene. Parents who don’t know their children’s rights may take schools at their word. Some schools argue they don’t do 504 plans. Others say children with diabetes don’t qualify. And yet others aim to reassure parents that convening a meeting to hash out the details of a legal document really isn’t necessary.

And it’s no wonder parents are often uninformed about their kids’ rights. A child’s safety at school may not come up at diagnosis, when learning about testing blood glucose and dosing insulin take priority. Because schools are supposed to approach parents of kids with disabilities regarding needed services, it makes sense that parents would trust that administrators understood their legal obligations. Unfortunately, that’s not always the case.

The bottom line: Students with disabilities are protected under federal law, and the law includes diabetes as a disability. That means all schools that receive federal funds are required to provide services for children with diabetes. And that is public information, not secrets whispered about in the teachers’ lounge. (For more information on 504 plans, turn to page 44.)

Of course, having rights is one thing. Having a school acknowledge them is entirely different. When a school won’t budge, regardless of a student’s rights under the law, parents are left with a choice: continue the time-consuming fight alone or enlist help.
Alan Yatvin knows too well the hurdles many parents must jump to ensure their children’s safety at school. He’s a Philadelphia lawyer and chair of the Legal Advocacy Subcommittee of the American Diabetes Association, and to many Pennsylvania families he may as well be Superman. He spends his free time working pro bono for the ADA, fielding cases in his area and fighting for the rights of children with diabetes.

Instances of discrimination, sadly, aren’t few and far between. “My perception is that it’s pretty common,” he says. That’s saying something: Yatvin only sees cases that
demand legal aid, when parents are unable to resolve issues with the school on their own.

Parents who have hit a wall when dealing with the school on their own often ask the ADA for help. In addition to a small staff of legal advocates who can provide information on legal rights, the ADA also calls upon advocates such as Yatvin who are experienced in antidiscrimination law for children with diabetes. They can educate the school district, provide backup documentation, and hash out the details of a 504 plan alongside parents and the school’s team. Sometimes, that’s all it takes. Other times, parents need more support.

Kimberly Shekalus had been struggling for three years by the time Yatvin got involved with her case. She’d pursued a 504 plan for her daughter in fifth grade, settled for an IHP that year and the next, and finally made headway when Payton entered seventh grade.

At the time, Payton had earned the right to test her blood glucose in class (which was prohibited in fifth grade by her school) and was told she could visit the nurse for the rest of her diabetes care. But she still couldn’t carry glucagon (which the school considered a weapon), had to sit on the sidelines during gym, and could attend field trips or extracurricular activities only if her parents were present.

Shekalus’s schedule was dictated by Payton’s needs. Field trip? She’d take off from her part-time job to tag along. Even when her schedule was packed—even though she had to tow her two younger daughters with her—Shekalus was on the sidelines at all of Payton’s soccer and softball practices and games, in the bleachers at Payton’s swim practices and meets, and in the audience for Payton’s chorus and band.
practices. She and her husband even took turns chaperoning school dances so Payton would be allowed to attend.

Her younger daughters suffered with the nonstop chaperoning: After a while, Payton’s sister decided to drop a couple of the activities her parents frequently missed. But even that was bearable if it kept Payton safe, Shekalus reasoned. Except that Payton’s welfare was still at risk, a fact hammered home to Shekalus the day the school nurse called her in a panic.

Payton had become hypoglycemic during gym class. She visited the nurse, as required, to test and treat, then agreed to come back to retest later in the period. She never showed. The nurse couldn’t reach the gym teacher. And Payton was nowhere to be found.

In the end, Payton was fine. She’d retested to find her blood glucose was in a safe range, then followed her gym class outside to the nearby high school for the day’s activity. But the idea of her daughter being stuck outside without glucose tablets or glucagon and with no way to communicate with the nurse scared Shekalus.

In 2012, when ADA advocate Robb Wilson, who had been meeting with staff at Payton’s school, suggested the Shekaluses enlist the help of a lawyer, Yatvin got the call. Often in cases like this, he writes the school district a letter listing the problem and suggesting fixes. “Sometimes I get a quick response, and meetings are set up,” he says. “Sometimes I get ignored.” In Payton Shekalus’s case, once a lawyer for the district got involved, the process sped up.

Meanwhile, another schoolkid faced unfair treatment. Nicholas Sudbury’s 504 plan was hitting snags. His mom, Rebecca, had approached the 13-year-old’s school about his need for insulin injections and glucagon. Officials pointed to the Pennsylvania Nurse Practice Act, which prohibited anyone but a nurse from giving children with diabetes insulin or glucagon injections at school. At first, to resolve the impasse, Sudbury agreed the school didn’t have to train other staff to give injections, provided they were trained in other diabetes care and the school nurse was present every day and available for field trips and after-school activities.

Yet that wasn’t always the case. Sudbury’s breaking point came when Nicholas stayed after school to attend a drop-in homework center. When Sudbury notified the school that Nicholas would be staying late, she was told 24-hour notice was needed. “No other child needs to say on Wednesday, ‘Hey, on Thursday I’m going to need to stay after for the homework center,’” Sudbury says. “If [the school] trained people like I asked, we wouldn’t be having this problem.”

Yatvin understands the demands placed on nurses. They work 7 a.m. to 3 p.m. and may have after-school plans of their own—a doctor’s appointment, their own child’s soccer game, night classes. “They can’t drop everything if you find out [your child] needs to stay late,” Yatvin says. “It’s just not viable in the real world.”

That’s precisely why the training of school staffers—which he thinks nurses should advocate for—is so important. “You listen to people talk about diabetes care like it’s brain surgery,” Yatvin says. “The fact of the matter is, parents, grandparents, siblings, teenage babysitters, and people who have developmental disabilities take care of diabetes care tasks for themselves or others every day across the country.”

It’s a point he argued with the Sudburys’ school district—that, and the fact that the federal 504 law supersedes state laws such as the Pennsylvania Nurse Practice Act. But at press time, the district was still violating the terms laid out in Nicholas’s 504 plan. “We may need to take another look at filing

Think like a lawyer: When dealing with your child’s school, maintain a firm but civil attitude. No matter how annoyed or angry you may be, you’re more likely to win when you’re respectful.
for due process [a complaint that requires attorneys on each side to attend a formal hearing] or we may need to file in federal court,” Yatvin says. The attorney has never had a school diabetes case go as far as a hearing or court, but it’s a logical next step when schools refuse children their basic rights.

Yatvin’s actions as a case progresses may be attorney-only territory, but parents can learn from his techniques and possibly avoid the need for a lawyer. Just as he does his research before approaching a school, so can parents. “Going in [to a 504 plan meeting] informed gives parents a leg up in the process,” Yatvin says. He urges his clients to give a copy of the National Diabetes Education Program’s “Helping the Student with Diabetes Succeed: A Guide for School Personnel” (available at www.ndep.nih.gov) and the ADA’s Safe at School* training materials to school officials prior to a meeting so they are educated about the student’s rights and their role in diabetes management. Then, he asks parents to bring their own copy of the NDEP guide plus ADA’s sample 504 plan to the meeting.

Though the goal is to resolve issues quickly and without an attorney, it’s smart to be prepared in case the problem escalates. Yatvin advises parents to save all e-mail and letters to and from the school, take notes during meetings or phone calls, and document their verbal requests with a follow-up e-mail. “The more information [parents collect], the easier it is for a lawyer to pick [the case] up and run with it,” he says.

And parents can take a page from Yatvin’s book when it comes to advocating for their child’s rights: This is not a negotiation in the traditional sense. “The child with diabetes has certain immutable needs. It’s not like I can give up carb counting. There’s not that level of negotiation,” he says. “I know what the child needs, I know what the child is entitled to, and I’m not very flexible.”

That said, he’s open to unconventional resolutions, provided parents are on board. In one case, parents of a kindergarten girl with diabetes fought the neighborhood school on its inability to provide a full-time nurse during the school day. The school couldn’t afford to hire a full-time nurse, so it offered instead to bus the girl and her three older sisters to a campus where three schools shared three nurses. Technically, the school wasn’t fulfilling its role under Section 504 (a law that forbids discrimination based on disability), Yatvin says, but his clients were satisfied.

Payton Shekalus has also had a happy ending. By the end of 2012, Yatvin and the Shekaluses had come to an agreement with the school district. In the months since they all signed the 504 plan, Payton has been able to attend field trips and extracurricular activities without her mom or dad tagging along.

“Every single one of the eighth-grade teachers stepped up and said, ‘I’d like to be trained [in Payton’s diabetes management],’” says Kimberly Shekalus, who can now attend her other daughters’ after-school activities and now feels able to take a full-time job. And though the family is prepping for a move to Ohio, Shekalus says getting the plan in place at Payton’s Pennsylvania school has made a difference. “I think she might be becoming, I’m hoping, more independent. This is a step in the right direction.”

To learn more about keeping your child safe at school, visit diabetes.org/safeatschool. To get help from the ADA, call 1-800-DIABETES (1-800-342-2383).