What happens when a school fails to provide diabetes care?

By Tracey Neithercott • Photographs by Welton Doby III
The education of Loretta Taylor has been fraught with interruption, missed school, and exclusion from field trips all because she has diabetes.

I had heard that Loretta Taylor’s mom had a story to tell. The 36-year-old single mother had been caring for her daughter’s type 1 diabetes for eight years, so like all parents of children with a chronic illness, she’d had her fair share of difficulties. But this time Loretta’s health was in constant risk, and Latesha Taylor felt powerless. And angry.

The only problem: I couldn’t track her down. A week after setting up a time to talk, I wasn’t any closer to understanding why Taylor was going head-to-head with the District of Columbia Public Schools.

Sure, Taylor was busy. Busy as in regularly dropping everything—work included—to pick up her daughter from school when the nurse is absent. (Which she does.) Busy as in searching for a new job every time she’s fired from the last one because business owners won’t keep an employee who’s late or misses work whenever the school nurse goes on vacation. (Which has happened more than once.)

I couldn’t get in touch with Taylor because life had sucker punched her again: Loretta, 9, was having seizures. Taylor dropped
everything to be at her daughter’s side as she was whisked away to the hospital, underwent tests, and was examined by doctors.

When I finally spoke with her, Taylor was exhausted. She’d left the hospital with an antiseizure medication for Loretta but no concrete diagnosis. She’d lost yet another job and worried how she’d support herself, Loretta, and her 19-year-old son. And she was in the middle of a fight with the Washington, D.C., public school system for what she and the American Diabetes Association believe is a discriminatory policy that denies diabetes care to students across the D.C. system.

**Between a Rock and a Hard Place**

Taylor wasn’t always locked in a battle royal with the D.C. public schools. When Loretta was in kindergarten and until second grade, her school was accommodating, even though Loretta was its first student with type 1 diabetes. They’d reviewed her Section 504 Plan—essentially an agreement between school and parent that a child with diabetes will receive the same education as classmates without the disease—and talked about her diabetes management needs in school. The school nurse called Taylor with any issues and kept Taylor updated on any out-of-school meetings she’d need to attend, which gave Taylor time to arrange for Loretta to stay at home with a family member.

Then Loretta entered third grade, and the school’s administration changed. Suddenly, communication with the nurse dwindled. Instead of being warned about days the nurse would be absent, Taylor received last-minute calls from the school requesting she pick Loretta up and take her home.

The administration stood firm in the belief that caring for a child’s diabetes wasn’t the school’s job and that only a nurse could test Loretta’s blood glucose and inject insulin or glucagon. Administrators gave Taylor an ultimatum: Take your daughter out of school whenever a nurse leaves the building or come into school each day to check your daughter’s blood glucose and administer insulin. If Taylor couldn’t do one of those things, the school threatened to call 911 if—at any time—Loretta was left unattended and needed insulin or emergency glucagon.

It was an impossible situation, and Taylor knew it. She couldn’t leave her daughter at school without a nurse to administer insulin because Loretta’s blood glucose would be dangerously high, compromising her ability to learn and putting her at risk for diabetic ketoacidosis. She couldn’t pull her daughter from school because Loretta was racking up too many absences. And she couldn’t visit Loretta’s school three or more times a day to test her blood glucose levels and dose insulin because she had a job.

Taylor was dealing with these frustrations one day when she visited the school and discovered that the nurse wasn’t in and the school didn’t know when to expect her. “My daughter was left at school with nobody to oversee her. Nobody called me to say, ‘The nurse is leaving. We have nobody to watch her,’” she says. When the principal and a representative from the school district told her there was nothing the school could do, Taylor became angry. After a run-in with the principal, Taylor faced another obstacle: She was banned from school grounds.

**With the Law on Her Side**

By the time Taylor reached out to the American Diabetes Association for legal help, the school had sent her daughter home for diabetes so many times that she was cited for truancy. The elementary school, just around the corner from her home, then contested her residency in Washington. And after her argument with the school’s principal, Taylor refused to send her daughter into a building she couldn’t enter herself. (District of Columbia school officials did not respond to questions about the Taylor case.)

In September 2011, Loretta started at a nearby elementary school with hopes of finding a support network. Instead, she was faced with many of the same problems. She missed the first day of school because there was no nurse present. And when the entire third grade went on a field trip to the John F. Kennedy Center for the Performing Arts,
Loretta, who’d been excited about the first field trip ever offered to her class, was left behind in a room full of fourth graders. “What’s happening to this little girl is appalling,” says Victoria Thomas, an attorney with the University Legal Services Protection and Advocacy Program (ULS), who began fighting the case when the ADA referred Taylor to her that fall. She sent the District of Columbia a demand letter outlining the system’s legal violations. “The only official policy in D.C. that we uncovered says that the school is responsible for the monitoring and treatment of high and low blood sugar and that the principal will have three staff members who can provide care,” Thomas says. “That was one of our arguments when we were trying to negotiate. We argued that we were just asking them to follow their own rules.”

On top of that, they argued, federal laws—such as the Americans with Disabilities Act and Section 504 of the Rehabilitation Act—require schools to meet the needs of children with disabilities, including diabetes. The solution, the Taylor camp argued, was to train additional staff as backup for times when the nurse wasn’t in. The American Diabetes Association and other diabetes experts agree that school personnel who aren’t health care professionals can—and should—be trained to provide diabetes care when a school nurse isn’t available.

This idea, was put forth in the demand letter to the head of D.C. Public Schools, Chancellor Kaya Henderson, and other public school officials. Loretta’s doctor, Gail Nunlee-Bland, MD, FACE, FAAP, chief of endocrinology and director of the Diabetes Treatment Center at Howard University Hospital, explained the third grader’s needs, such as testing blood glucose and when she’d need insulin. It was a final plea before ULS and the ADA filed an administrative complaint with the U.S. Department of Education’s Office for Civil Rights on behalf of Loretta and other children with diabetes against the D.C. public and public charter schools claiming discrimination.

But the school leadership wouldn’t budge.
The Value of an Education
Loretta Taylor is not alone. While the ADA’s Safe at School campaign has succeeded in making school a place for many children with diabetes to thrive, in other schools children with diabetes run into roadblocks in their education. Instead of providing a safe, accepting environment in which kids can learn, such schools are singling them out, forcing them to miss lessons, and putting their health at risk.

A safe environment is one of the few things children with diabetes require during the day, says Fran Cogen, MD, CDE, a pediatric diabetologist and director of the diabetes program at Children’s National Medical Center in Washington, who has dealt with school discrimination against kids with diabetes in D.C., Maryland, Virginia, and West Virginia. “Everyone with disabilities should be treated like they’re normal children,” she says. “These aren’t ‘diabetics.’ They’re children with diabetes.”

Part of protecting kids at school comes from a willingness to learn new skills, such as testing blood glucose, administering insulin and glucagon, and counting carbs. Aside from injecting glucagon, most of these are actions kids can take themselves when they’re old enough. But young children, like 9-year-old Loretta, need an adult’s help. Resistance from schools often has to do with arcane state laws or understandable feelings of fear on the part of administrators and teachers.

Most parents of children with diabetes have the same fear of the unknown. “What if I mess up? What if I hurt my child?” they ask themselves. “It’s not something to laugh at. It’s a real fear,” Cogen says. “But turn it around. If you don’t do something, what is going to be the outcome?” It’s that idea—that inaction is more likely to harm a child with diabetes—that Cogen wishes more schools would consider.

“It’s important to understand the nature of the illness so people can be more cognizant of how children with diabetes may feel,” says Cogen. Unfortunately, school staff members’ empathy for a child with diabetes isn’t always a given. As she settled into her new school, Loretta experienced quite the opposite.

Everyone’s a Critic
Being singled out so often (when she needed to leave class to get her blood glucose tested in the nurse’s office, when she was removed from school because the nurse had left, or when she was asked to stay home because the nurse hadn’t come in) put Loretta on the defensive. Instead of being taunted by a playground bully, she was hassled by the people charged with making school a “caring and supportive environment” (as stated in the District of Columbia Public Schools’ “Core Beliefs”).

Thanks to ADA Diabetes Advocates, in 2012 alone Safe at School laws and policies have been passed in Alaska, Connecticut, Georgia, and Louisiana. The laws allow trained school employees to care for a child’s diabetes and/or grant capable students the ability to manage their own diabetes.

Ready, Set, Learn
A back-to-school checklist

1. Stay informed.
Knowing your child’s rights is the first step to ensuring a safe school environment. Under federal and certain state laws, children are protected from discrimination because of their diabetes. Not sure what your school is legally responsible for? Go to diabetes.org/safeatschool for information on these laws, training information, and tips for advocating for your child.

2. Write up a Section 504 Plan or an Individualized Education Program (IEP).
These plans set out how federal laws will be put into operation, ensuring that children with diabetes aren’t discriminated against in school. A plan should be drafted when a child enters school or is newly diagnosed. For more information and a sample 504 plan, go to diabetes.org/504plan. Learn about IEPs at diabetes.org/iep.

3. Create a Diabetes Medical Management Plan (DMMP).
Work with your child’s health care team to construct a plan that explains exactly how school staff should care for your child’s diabetes. The DMMP should include details such as which aspects of care your child can perform independently (blood glucose checks, carbohydrate counting, and insulin injections) and with which he or she needs adult help. For more information and a sample plan, visit diabetes.org/dmmp.

4. Review plans with the school.
Reaching an agreement on the 504 plan or IEP requires collaboration with your child’s school. Together you’ll need to decide who on staff will provide diabetes care and, citing the DMMP, specifically state what that care will be. (That is, can your child test his or her blood glucose or does an adult need to do it?) The final 504 plan or IEP should establish that a trained staff member will always be available to provide care for your child.
It happened in the cafeteria, where Loretta was eating with her friends. Knowing her daughter was a picky eater, Taylor had packed a bag full of lunch options, including a treat Loretta didn’t eat often: fried chicken. A teacher began snapping photos of Loretta’s lunch. “Did you see all that food that kid had?” Loretta overheard the teacher asking a colleague. The third grader came home in tears.

“If [the teacher] had any questions, [she] should have called me in reference to what I prepared my daughter for lunch,” Taylor says. “You don’t antagonize kids.” It’s not surprising, then, that Loretta doesn’t like school. Between that and her absences (at her new school, the nurse was out 13 times within a two-month period alone), Loretta’s grades have begun slipping.

**Hope for a Better Future**

In the meantime, the U.S. Department of Education’s Office for Civil Rights has been investigating the complaint filed on behalf of Loretta. And Thomas and the ADA have asked the District of Columbia to provide sufficiently trained staff at every D.C. public school attended by a student with diabetes.

Taylor’s hopeful, but she’s also focused on the present. She’s juggling Loretta’s diabetes and her yet-to-be-diagnosed seizure condition, and her own recent job loss. At the moment, it’s about survival. “I can’t live like this,” she says, her voice tinged with exasperation and worry. “Am I supposed to sit around and do nothing all day? I have to provide for [my kids]. How do I provide for them if I don’t have a job?” It’s not a rhetorical question. There’s desperation in Taylor’s voice. It’s a situation Taylor knows isn’t limited to her and Loretta alone. “It’s not just for Loretta. It’s for everybody,” she says of her fight for fairness. “I’m also trying to better the future for kids who come after her. I don’t want them to go through what I’m going through.”

Helping kids such as Loretta enjoy fair treatment and support for diabetes management is a key goal of the ADA Safe at School campaign.

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**FIND OUT HOW** one father fought for a safe summer camp experience for his child: forecast.diabetes.org/campsafety-aug2012.