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Settlement with feds restores parental input on insulin dosage for school kids with diabetes

By JOSH KOVNER
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Parents of school children with diabetes can once again share input with school nurses on changes in the daily insulin dose at school — the product of a settlement between state education and public-health officials on the one hand, the U.S. Department of Justice on the other.

Parents who monitor their children's blood sugar had long been able to share that information with the school nurse, lest it change the insulin dosage prescribed on the form that is filed for every child with diabetes at the beginning of each school year.

The state education department abruptly reversed course about a year ago, telling families that nurses will no longer collaborate with parents and only work under the direction of the child's doctor.

Twenty families got together, hired lawyer Jonathan Chappell, and filed a complaint with the justice department under the Americans With Disabilities Act.

In a June 20 settlement following a brief investigation, Assistant U.S. Attorney Jessica Soufer thanked education and public-health officials and state Attorney General William Tong "for taking swift action" to resolve the matter.

"This isn't complicated," said Chappell. "It's a reasonable accommodation" under the Americans with Disabilities Act.

Parent Michell Cheney of Naugatuck said she is as happy with the settlement as she was disappointed in the reversal a year ago. "We do become subject-matter experts in helping our children manage this condition -- we don't have a choice," said Cheney, who has an 8-year-old daughter with diabetes.

"It's an everyday learning experience. We're constantly monitoring their blood sugar and we see the changes [in insulin] dosages that are approaching. We're used to making these decisions and should be able to collaborate with the school nurses."

According to an updated email from the Department of Education, while school nurses retain discretion and can use their professional judgement, they are "required ... to adjust the timing and/or dosage of diabetes medication ... within specified limits by consulting with such student's parent/guardian."

She said many factors influence blood sugar and, hence, the insulin dosage, including a child's activity level, diet, how they're feeling — even the freshness of the insulin itself.

Within two weeks, the Department of Education must send out an email "updating" its position on parental input, the settlement letter says. While school nurses retain discretion and can use their professional judgement, they are "required ... to adjust the timing and/or dosage of diabetes medication ... within specified limits by consulting with such student's parent/guardian," the updated email reads in part.



School nurse aids child with diabetes. (Axel Koester / For the Times)

On the updated form filed at the beginning of each school year, the the child's doctor or diabetes-care provider affirms that the parent or guardian has sufficient training or experience "in adjusting insulin doses and/or revising the diabetes management plan of their child."

That affirmation should give school nurses a dose of confidence in working with parents.

"School nurses do a great job — in fact, in general, children with diabetes do worse during the summer when they're not in school — but parents are highly qualified to suggest dosing variations," said Dr. Cem Demirci, head of the diabetes program at Connecticut Children's in Hartford.

The updated form "is a win-win. Parents aren't ordering the nurses around, they are just saying what they would do at home," Demirci said.

As part of the settlement, the Department of Public Health has asked nursing regulators to "issue a declaratory ruling providing that it is within the scope of practice for school nurses to adjust insulin doses for school children with parental input" as long as the updated form contains the proper authorizations from a doctor.

Advocates for children's rights said the settlement is another step forward. Some summer camps and daycare centers have had to be pushed to accept children with diabetes.

"Yes, we're making strides," said lawyer Bonnie Roswig of the Center for Children's Advocacy in Hartford. "Is everyone compliant? No. A lot of this is educating the public and private sector on what it means for a child to have diabetes and the obligation to allow children to participate fully."