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Public school should be for diabetic children, too

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This winter, MPP David Levac is promoting a private member's bill to protect the rights of schoolchildren with diabetes. Without government backing, however, Bill 5 is likely to die a quiet death in committee.

A former school principal, Levac previously authored "Sabrina's Law," a landmark piece of legislation that obligated Ontario's schools to administer life-saving injections to students suffering from anaphylactic shock.

Like peanut allergies, Type 1 diabetes is a poorly understood and potentially lethal disease. Unlike the more common Type 2 diabetes, Type 1 is not triggered by poor diet, excess weight, or lack of exercise. Although its origins are unclear, scientists suspect a combination of genetic and environmental triggers.

Type 1 is an auto-immune disease; the body incorrectly identifies the pancreas as an enemy, and destroys its ability to produce insulin, a crucial hormone that transforms carbohydrates into energy.

Most newly diagnosed patients are children or youth; a minority are adults. The disease's prevalence among Canadians aged one to 19 is approximately 0.3 per cent -- meaning that roughly three of every 1,000 youth have Type 1 diabetes.

Patients and families learn to manage with the help of specialized health-care teams that teach them to inject insulin, test blood sugars, and count carbohydrates. Although children and most adolescents require support from parents or caregivers at home, older children can often manage their condition at school. Younger schoolchildren, however, require adult supervision.

In Ontario, there are approximately 7,000 school-age kids with diabetes. If the government refuses to support Dave Levac's bill, many will be unable to participate fully in school. This, in turn, will be a serious violation of their right to education.

The biggest problem is that Ontario's Ministry of Education has no binding school policy for children with diabetes; instead, each school board deals as it sees fit. In some cases, no institution will take responsibility, leaving vulnerable children without protection.

Over the last year, Shana Betz, co-founder of the advocacy group Diabetes in Ontario's Schools, has been collecting testimonies from parents across the province. According to her surveys, school experiences vary widely.

In some cases, schools say that helping children to monitor their blood is a medical procedure outside their area of competence. Some have even refused to give juice to stave off hypoglycemia.

In these cases, principals may refer parents to the local Community Care Access Centres (CCACs) that provide Ontario's schools with public health services. Each CCAC sets its own priorities, however, and some will not help children with diabetes.

Parents may also request the services of special education assistants, but the policy on providing this support for children with diabetes is also unclear. In some cases, school boards make the assistants available; in others, they do not.

Some schools are supportive, assembling a team of staffers willing to help children monitor their blood and watch for signs of hypo or hyperglycemia. These schools stock juice for low blood sugars, and offer water and bathroom breaks when sugars are high. In some cases, they may even help administer insulin via a high-tech "pump" embedded in the student's skin.

Yet Betz has also collected enough accounts of school neglect to suggest Ontario urgently needs binding policies. Her view is seconded by the Canadian Diabetes Association, which regards Ontario's policies as remarkably uneven. The Toronto school board, for example, has an exemplary policy, but Greater Toronto's eastern regions have no policy at all.

In recent months, New Brunswick and Nova Scotia have stepped up to the plate, drafting comprehensive policies on schools and diabetes. Principals must now draw up individualized care plans for affected children, and must offer support for children unable to manage on their own. These provinces also educate teachers and school staff about the disease, helping them to learn its symptoms and treatments.

As always, the neediest families are those in the middle and working class. Although well-off parents will hire caregivers or take part-time jobs, single parents, parents on a budget, or parents in inflexible jobs have little room to manoeuvre.

To help, McGuinty's government should support Levac's bill.

Although the bill's current language allocates no budgets and provides no enforcement mechanism, it can swiftly be amended.

Provincial ministries of education, children and youth services, and health should all provide funds, ensuring that a single policy is applied equally across all of Ontario's schools.

With funding, diabetes educators can teach school staff about the disease's effects, explaining the challenges children face. Principals could create individualized plans for affected children, and additional support could be mobilized from educational assistants, just as is now done for children with other chronic diseases.

Happily, most children in this country will eventually learn to manage their own condition.

The Canadian Diabetes Association offers camps for children aged eight and upwards, and Canada's children's hospitals do a good job of educating patients.

The bulk of our efforts, therefore, should be aimed at supporting schoolchildren in the earliest years. Children in kindergarten and primary school cannot manage diabetes on their own, and should not be asked to do so.

The current policy patchwork is shamefully inappropriate for a wealthy country in the 21st century, unnecessarily adding to the already heavy burden borne by parents of children with diabetes.

The issue is one of fairness and human rights. The time to act is now.

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