

Subject: Current levels of access and attainment for students with disability in the school system - Type 1 diabetic children
Date: Tuesday, 21 July 2015 2:12:17 PM

Senators,

I am a parent of 2 children who each have been fighting Type 1 diabetes since before they entered the school system, at the age of 4 years for my son and 19months for my daughter. My children were diagnosed with this wretched disease in 2005.

Type 1 diabetes is a chronic medical condition that if uncontrolled can result in death or brain damage. It is different to type 2 diabetes, with the pancreatic beta cells being destroyed (in theory by the immune system) and no longer able to produce insulin. Children who contract this disease may appear to be perfectly healthy. They are not able to do anything to avoid contracting this disease. They are left to deal with it for the rest of their lives. It is controlled through injection of insulin and carbohydrate consumption to maintain blood sugar levels. Insulin effectiveness in controlling blood sugar levels is also affected by exercise, variation of daily environmental temperatures, stress, illness, adrenaline, excitement, and growth stages, to name but a few.

High blood sugar levels of more than 8mmol/l damages major organs, eyesight, nerves and can result in heart disease, blocked arteries and stroke. Low blood sugar levels of less than 4mmol/l can result in unconsciousness, fitting, severe brain damage, and death. Both situations result in a negative impact on a student's academic ability for many hours after restoring blood sugar to correct levels.

The education of our children has been a story of struggle to get the schooling system to recognise the danger and seriousness of Type 1 diabetes, and what's needed to keep Type 1 diabetic children safe while at school.

Our initial experience with our Son diagnosed while at a state primary school was marred by the School Principal organising a meeting with teachers, excluding us as parents, to determine how the school was to deal with our Son's condition. While we received no formal notice, we were informally told that our son was to be dealt with as per a previous student, where his blood sugar would be allowed to run high in order to avoid low blood sugar events. This in effect would compromise his long term health and academic ability for the sake of keeping him at school.

From there my wife has tried distance education, however the strain of being a teacher on top of mother, nurse and carer only lead to damage the relationship between a mother and her child.

We then accessed independent schooling at unique and rare facilities where my wife's presence at the school was not seen as a negative influence. In this way she was able to help keep our children's blood sugars relatively stable. The expense of independent schooling however could not continue to be met.

Through advice from a relative in the Queensland education system we were able to get hold of an Education Queensland official who informed us that a state school (Gabbabar) had systems in place and was receiving funding for teacher aid support to help keep Type 1 diabetic children safe. After a short meeting the Deputy Principal at Gabbabar kindly got my children a place. The work of the dedicated Teacher Aides has been life changing for us as parents.

I learnt that the funding that Gabbabar was accessing for my children was to the exclusion of other schools in our area. Indeed I had to drive my children every day past 5 other state schools in order to get my children to Gabbabar State School where they could be safe. In writing of this to the then Qld Minister for Education we received a response (see attachment) that after follow up saw that any school with Type 1 diabetic children could access extra funding for teacher aide support. Even with this funding however I have learnt that the Teacher Aides are required to use their own mobile phones, not EQ supplied units, in order to communicate with my wife regarding blood sugar levels and control needs.

Among other things, my children's education has been compromised through all this exercise, and while I may have been successful in getting an improvement in funding, I do not think it should be a requirement of parents to have to lobby ministers directly and individually in order to get funding to keep children safe, let alone learning. It is hard enough having to raise awareness of Type 1 diabetes and its consequences within our local schooling system. I dread to think of other children with disabilities struggling through the school system, with parents who struggle with day-to-day tasks, who are not able to advocate to ministers and government officials to get funding for change.

I give a Gonski.

Sincerely
Johnny Wapstra