

**Cynulliad Cenedlaethol Cymru | National Assembly for Wales**

**Y Pwyllgor Plant, Pobl Ifanc ac Addysg | Children, Young People and Education Committee**

**Bil Anghenion Dysgu Ychwanegol a'r Tribiwnlys Addysg (Cymru)| Additional Learning Needs and Education Tribunal (Wales) Bill**

**ALN 08**

**Ymateb gan: Unigolyn**

**Response from: Individual**

I am a Paediatric Diabetes Schools Educator nurse based at Cardiff and Vale University Health Board. The primary focus of my role is to provide education, training and support to school staff who are themselves supporting children with type 1 diabetes in their school.

Type 1 diabetes is a life threatening, chronic, life-long health condition that can present spontaneously and unpredictably at any time during childhood and is characterised by the body's sudden inability to produce insulin, a hormone vital for the regulation of blood glucose levels. Once diagnosed, children and their family must learn how to balance all the elements that affect blood glucose levels in an attempt to achieve as near normal levels as is possible. Normalising blood glucose helps to minimise the risks of developing the devastating health complications that arise from long-standing abnormal blood glucose levels. These include blindness, kidney failure, limb amputation and premature death.

The primary treatment for type 1 diabetes is insulin replacement, which commences on the day of diagnosis and consists of 4-6 daily insulin injections or the permanent attachment to an insulin pump. Children, their family and any carers (including school staff) must learn all the practical elements of diabetes management. This includes injection technique, how to use an insulin pump, calculating insulin doses, blood glucose monitoring, carbohydrate counting, managing activity etc. It is a complex condition to manage well as there are so many elements of daily life that affect blood glucose levels. Ensuring stability of blood glucose levels not only helps to protect children from developing health complications in their adult life, but it also helps them to grow and develop normally, to feel well on a day-to-day basis (which will promote the engagement in normal childhood activities) as well as allow them to fully engage in their schooling.

Many school children are too young to shoulder the burden of diabetes management during their time in school. It is imperative that children with type 1 diabetes receive appropriate help and support from school staff whilst they are in school as without it both their health and education will suffer – and this is totally unacceptable.

I am extremely concerned that the Welsh Government's proposed ALN Bill and accompanying Framework fails to include medical conditions. This omission, if not rectified, will have a considerable and severe impact on the health, wellbeing and education of children who are living with the burden of a medical condition. As a paediatric diabetes schools educator nurse, I see first-hand the surprising variability of care provided to pupils with type 1 diabetes. In some schools the focus is on complete inclusion of the pupil and a dedication to ensuring the medical condition is well managed to minimise its impact on the child's education and health, whereas in other schools, staff are unwilling to get involved in day-to-day support and management, which leaves the child vulnerable, missing out on their education and also prevents their parents from being able to go to work as they are required to attend their child's school throughout the school day to perform simple blood glucose tests and deliver insulin doses. In other scenarios, I see unsafe practice whereby pupils are denied access to glucose treatment which they are required to take immediately to prevent possible unconsciousness and in some schools pupils are being discriminated against and treated differently to their peers, for example, by being denied access to residential trips unless a parent accompanies them. The absence of a legal framework results in unacceptable variability across schools. The lack of clarity of the involvement school staff are permitted to provide to a child with a medical condition causes confusion and fear amongst the staff as they worry that if a mistake were to be made, they may cause harm to the child as well as potentially jeopardise their career and livelihood.

I believe the Welsh government must not overlook this vital opportunity to include medical conditions in the ALN Bill as not only will this improve children with medical conditions' access to education, it will also help to improve their current health which will help to protect their health in adulthood. In addition to this, approving an amendment to the ALN Bill to include medical conditions will bring Welsh law in line with English law,

where it has been mandated since the Children's and Families Act in 2014 that children with medical conditions in English schools must be provided with appropriate support whilst at school or engaged in school activities (eg off-site activities, residential trips etc). If the Welsh government fails to approve the proposed amendment, it will mean that children in Wales continue to be disadvantaged in schools compared to their English counterparts. I find it wholly unacceptable that Welsh pupils are being left behind compared to English pupils, as they are currently denied guaranteed access to support and care at school. If the Welsh Government do not support the proposed amendment to the ALN Bill, the impact this will have on Welsh children's health and education will be considerable and has the potential to cause a life-long impact on their health, wellbeing and future employment opportunities, as their access to education during childhood was not protected.

As a result of all that I have outlined above, I urge the Welsh Government to take this opportunity to revolutionise the care and support children with medical conditions receive at school and approve the inclusion of medical conditions into the proposed ALN Bill and accompanying Framework.