

Dr Justin Warner  
Children's Hospital for Wales  
Heath Park  
Cardiff  
CF14 5UW

2nd March 2017

Dear CYPE Committee

**Re: Consultation Response: Additional Learning Needs & Education Tribunal (Wales) Bill**

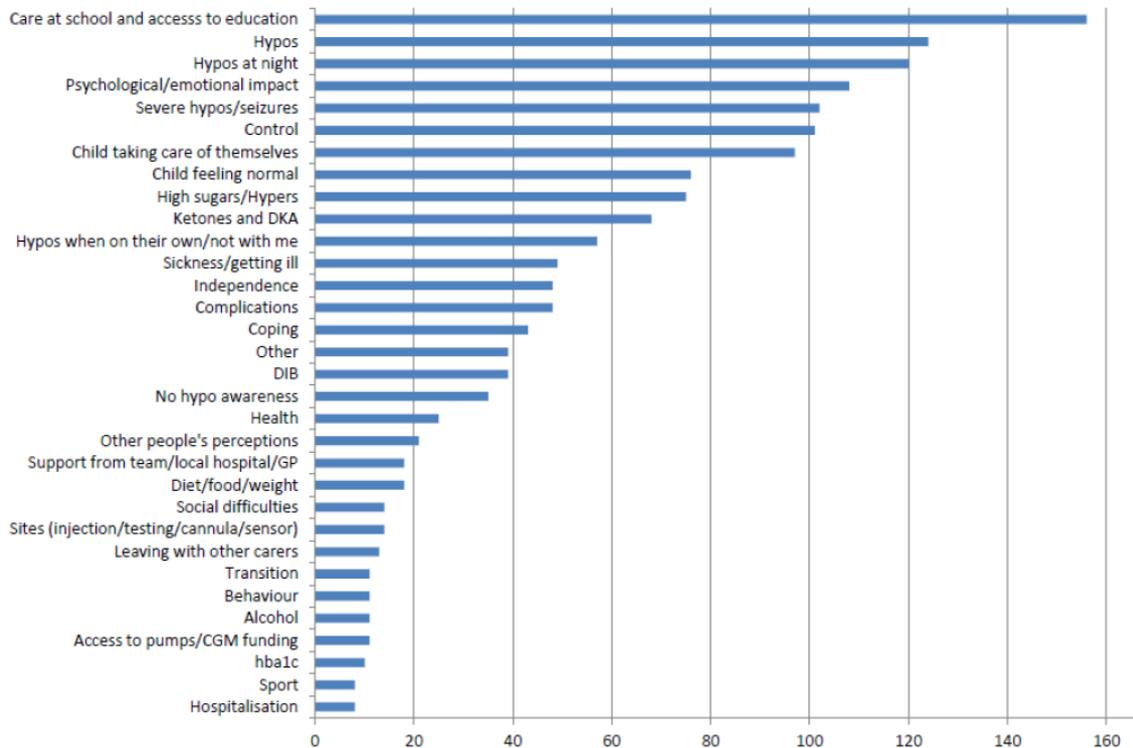
There are many children and young people who have healthcare needs that need addressing during the school day. I am a paediatrician working with children and young people with diabetes where healthcare needs require constant monitoring if a child is to achieve their full educational potential and reduce the risk of burdensome complications from the disease.

As clinical lead of the largest children's diabetes service in Wales and a Clinical Champion for Paediatric Diabetes, my team interact regularly, often several times a week, with schools and so I believe I am uniquely placed to comment on how the medical needs of children should be met during school hours. I have been a consultant in Paediatric Diabetes for 16 years and often have felt legally powerless when a school refuses or excludes a child with diabetes, or stigmatises a child as being different when they have a healthcare need in school.

With the massive surge in new technology and increased emphasis on good management of diabetes, we have seen considerable increase in the requirements for an interaction between health and education over the last 10 years. I value the partnerships that have built with school staff to ensure that children and young people with diabetes receive an excellent chance of living as normal a life as possible, which is one of the primary aims of the Welsh Government's Diabetes Delivery Plan (2013, updated 2016). However, although many schools are engaging in Wales, this is not ubiquitous and there is considerable variability in provision and lack of clarity around the legal positions that schools find themselves in when caring for diabetes and other healthcare needs within their school.

A recent survey by the Families with Diabetes National Network across England and Wales highlighted that the major concern that parents have about their child's care was during the school day. This concern cannot be ignored and parents need to have confidence in the people that will care for their child during the school day. The

results of the survey are shown below. The question asked was 'what concerns you most about your child's diabetes care?'



I am very disappointed that the Welsh Government's proposed ALN Bill and accompanying Framework does not include healthcare needs that require attention during the school day to allow a child to achieve his/her full academic potential. I would ask the Committee to address the issues presented as a matter of urgency and warn that a failure to do so will present an unprecedented safety risk to some of the most vulnerable children in Wales and disadvantage them compared to children with healthcare needs in England.

The latest National Paediatric Diabetes Audit report 2015-16 has demonstrated massive improvement in overall diabetes control for children and young people in Wales. This has been achieved by collaborative working across the all Wales Paediatric Diabetes network to improve outcomes and patient experience for children with diabetes across Wales. However, Wales still lags behind some other European countries where diabetes care is better including statutory requirements for care during the school day. Without continuous quality improvement initiatives there is a risk that Wales could undo the massive improvements already demonstrated.

Children spend 30% of their day in school and therefore it is of paramount importance that schools participate in the daily management of children with diabetes. This requires training and constant updates as children move through different classrooms and levels of education. In Wales there are approximately 1500 school age children with type 1 diabetes.

Keeping children and young people safe during the school day and reducing the long term risk of complications from diabetes requires intensive disease management. Modern technology and intensive diabetes management provides overall better blood glucose control. Since the level of blood glucose control is directly related to the risk of complications, such as blindness, kidney failure requiring dialysis or limb amputations, it becomes vitally important to manage it as effectively as possible throughout the day and night, seven days per week and 365 days per year. Poor diabetes control in childhood will lead to a high risk of complications and reduce life expectancy placing a large social burden and stress on families but also a massive financial burden on the NHS.

Poor management of diabetes during the school day not only puts the child at risk of acute life-threatening complications related to low or high blood sugar control (hypoglycaemia or ketoacidosis) but also affects the ability of a child to concentrate and learn whilst at school. It is very important that children and young people receive support to manage their condition during school hours to avoid such risks. In addition, unregulated glucose levels can cause cognitive difficulties, poor concentration, volatile moods and 'bad behaviour', and extreme tiredness affecting a child's ability to learn and participate in educational activities.

Unlike in England there is currently no statutory requirement in Wales for schools to participate in the healthcare needs of children with diabetes or any other chronic disease, who require help during the school day. Although many schools in Wales are extremely engaging with such healthcare needs, this is by no means universal.

I, along with Diabetes UK, performed a survey amongst families of children with diabetes and specialist nurses about school engagement and published 'An excellent chance' documentation on the results and recommendations from this survey. The committee will have already been sent this document in previous correspondence with DUK. It includes evidence from families and healthcare professionals showing that there is a need to support children and young people with diabetes in schools to maximise their ability to learn, and highlights variability in this provision across Wales. I ask the committee to read the report with a focus on the Executive Summary. The report is co-authored by the Children and Young People's Wales Diabetes Network, as well as senior paediatric clinicians in Wales.

'An excellent chance' clearly highlights there are inequalities across Wales in the provision of care for children with diabetes, in some circumstances children being excluded from school activities. This is unacceptable and requires action.

There is clearly a need for a change in legislation in Wales to introduce a statutory duty of care for children with medical needs in schools. The Welsh Government's proposed ALN Framework documentation states that children with medical needs will not be covered by the ALN Bill (see page 30 of the draft ALN Code of Practice). I would urge the Committee to consider the inclusion of medical needs in the Additional Learning Needs Framework.

The current guidance frameworks for the management of medical conditions, including Type 1 diabetes, in a school setting differ in Wales and England. In

England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools **must** make additional arrangements for supporting pupils at schools with medical conditions.

Whilst the implementation of the legislation in England is in its infancy, nevertheless there are early indicators of an increase in school engagement with medical conditions. Diabetes UK have seen a marked increase in the number of healthcare professionals who are nominating a school for the Diabetes UK 'Good Care in Schools Award', and comparative evidence gathered annually by the charity shows improved parent experience of working together with schools. Anecdotally, speaking to my England counterparts, the new legislation has allowed this to happen by putting a mandate on schools to interact with health in a more positive manner.

Indicator	2013	2014	2015
Percentage of parents who are satisfied with the diabetes care provided to their child at school	67%	71%	72%
Percentage of parents who state that an individualised care plan is in place which meets their child's needs.	51%	66%	85%
Proportion of schools that have access to Type 1 diabetes training.	66%	66%	73%
Proportion of schools with appropriate policies and procedures in place to provide children with Type 1 diabetes with consistent, individualised care (including IHP that covers extracurricular activity)	7%	58%	71%

The legislation does not apply to schools in Wales. The rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England. The current system in Wales puts children with medical conditions in Wales at an academic disadvantage in comparison to their peers in England and does not protect them whilst they are at school. It is vital that children are kept safe and healthy whilst they are learning to enable them to achieve their full potential.

In my role as a senior clinician in Wales and appointed as a Diabetes UK clinical champion to improve the quality of care for children with diabetes, I urge the Committee to consider the current situation and ask whether there is a need to bring the rights, support and protection provided to children and young people living with Type 1 diabetes and other chronic healthcare needs in Wales in line with those in England.