

Cynulliad Cenedlaethol Cymru | National Assembly for Wales  
Y Pwyllgor Plant, Pobl Ifanc ac Addysg | Children, Young People and  
Education Committee

Blaenoriaethau ar gyfer y Pwyllgor Plant, Pobl Ifanc ac Addysg |  
Priorities for the Children, Young People and Education Committee

CYPE 18

Ymateb gan : Dr Justin Warner, Diabetolegydd Pediatrig Ymgynghorol,  
Eiriolwr Clinigol Diabetes UK, Arweinydd Clinigol ar gyfer yr Archwiliad  
Diabetes Pediatrig Cenedlaethol, Ysbyty Plant Cymru

Response from : Dr Justin Warner, Consultant Paediatric Diabetologist,  
Diabetes UK Clinical Champion, Clinical Lead for the National  
Paediatric Diabetes Audit, Children's Hospital for Wales

**Question 1** – Within the remit set out above: what do you consider to be the priorities or issues that the Children, Young People and Education Committee should consider during the Fifth Assembly?

Healthcare needs for children and young people whilst at school or during educational activities.

**Question 2** – From the list of priorities or issues you have identified, what do you consider to be the key areas that should be considered during the next 12 months (please identify up to three areas or issues)? Please outline why these should be considered as key priorities.

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.

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.

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.

Unlike in England there is currently no statutory requirement in Wales for schools to participate in the healthcare needs of children with diabetes who require help during the school day. Although many schools in Wales are extremely engaging with such healthcare needs, this is by no mean 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. It includes evidence from families and healthcare professionals showing that there is a need to support children and young people with diabetes in schools. 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.

This document has already been shared and discussed with the SCMO for Woman’s and Child Health, Dr Heather Payne and is attached (it has also been sent to the WG separately by DUK and the Children and Young People’s Wales Diabetes Network).

‘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 a need for a change in legislation in Wales to introduce a statutory duty of care for children with medical needs in schools. There is an opportunity to include this within the newly proposed Additional Learning Needs (ALN) Framework.

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.

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 in Wales in line with those in England.