

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 12

Ymateb gan : Rhwydwaith Diabetes Cymru i Blant a Phobl ifanc  
Response from : Children and Young People's Wales Diabetes Network

**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?

1. Medical needs for children and young people with diabetes in schools and colleges
2. Improving diagnosis of Type 1 diabetes in primary care
3. Improved 'transition' from paediatric healthcare services to adult services for children with chronic conditions
4. Equitable access to healthcare technology and medical devices across Wales

**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.

1. Medical needs in schools:

Children in Wales do not have the same rights in law as children in England regarding discrimination against them if they have diabetes. The Families Act in England specifically states that children and young people with medical needs must receive support in schools.

The Children and Young People's Wales Diabetes Network is

in a unique position in Wales as our members work with all 1,500 children and young people with diabetes. The majority of children with diabetes (96 per cent) have Type 1 Diabetes, which is not linked to lifestyle factors, and requires multiple daily treatments with insulin, or continuous treatment through an 'insulin pump'.

The experience of NHS Wales staff supporting children with diabetes shows huge variation in the support offered to children with diabetes in school. Our members regularly report instances of schools refusing to help with the administration of insulin. Because of their medical needs, many children experience exclusion from activities in school, and also from school trips.

We believe 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. In England, the Children and Families Act 2014 contains a statutory duty to support pupils with medical conditions (section 100), meaning that in practice schools **must** make additional arrangements for supporting pupils at schools with medical conditions. This legislation does not apply to schools in Wales, meaning 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 benefits of protecting the rights of children in Wales through introducing a statutory duty for schools to support children with medical needs are as follows:

- Improving attendance, attainment and overall educational experiences for children in Wales, which will also reduce the academic disadvantage in comparison to their peers in England who are protected at school.
- Children with diabetes will be safer and healthier.
- Children and young people with Type 1 diabetes will be able to participate in all aspects of school life

There is an opportunity to include this statutory duty of care within the newly proposed Additional Learning Needs (ALN) Framework. Currently, the Welsh Government's proposed ALN Framework documentation states that children with medical needs will not be covered by the ALN Bill (p.30, draft ALN Code of Practice). As a Network we request the Committee to examine the Additional Learning Needs Framework with the intent of including all medical needs, and particularly diabetes.

As a network we were asked to produce evidence for Welsh Government about the need for a statutory duty of care in schools. We have co-authored a report with Diabetes UK Cymru, called "An Excellent Chance: Type 1 diabetes in schools in Wales", which we have submitted alongside this consultation response.

We ask the Committee to consider the current situation and ask whether the legislative opportunity provided by the Additional Learning Needs bill could be used to protect the rights and support children and young people living with Type 1 diabetes in Wales.

## 2. Early diagnosis of Type 1 diabetes in primary care:

Each year between 100–150 children in Wales are diagnosed with Type 1 Diabetes. Around 15 per cent of children are diagnosed after they develop life-threatening Diabetic Ketoacidosis (DKA). This rises to 24 per cent for children under the age of five. To avoid DKA, it is crucial that Type 1 diabetes is identified early and treatment is administered as quickly as possible

Early identification and symptom recognition are key to the prompt diagnosis of Type 1 diabetes. As a Network we are aware that many new diagnoses are delayed due to the proper testing procedures not being followed when diabetes is suspected. Children should be tested immediately, not referred for blood tests the following day or at a later date.

As a Network we are working to engage healthcare professionals in primary care to alert them to the life-threatening implications of delays in diagnosis. We believe it should be a priority for NSH primary care services. We would ask the committee to consider recommending all NHS Wales organisations investigate cases where children and young people are not tested and referred according to the established pathways, particularly if this has resulted in DKA. We believe that failure to comply with the testing policy should be investigated as a serious clinical incident. We would welcome the support of the committee in raising this issue with health boards and primary care leads across Wales.

3. 'Transition' is the term used to describe the period of life when a child moves into adulthood. Within a healthcare context, children with chronic conditions, such as diabetes, stop receiving care from paediatric teams around the age of 16–17 and begin being cared for by adult services.

There are a number of issues across Wales in 'Transition' services and we would ask the committee to consider examining this whole area as a matter of concern. The impact of poor transition is seen in poorer health outcomes and shorter life expectancy as adults. In some ways, 'transition' represents the 'end of childhood', and this time period tends to be neglected in comparison to the early years of childhood. We would argue that good work done in the early years is often undone by poor transition services, reducing the impact of the investment made in the lives of young children.

There is a national co-ordinator for Transitional Diabetes Care but this is a short fixed-term post. We would ask the committee to investigate the value of a long-term commitment by NHS Wales to improving transition services in diabetes and other chronic conditions.

4. There is huge variation between health boards in Wales regarding access to technology and medical devices that improve diabetes care and the quality of life for children and young people with

diabetes and their families. Devices such as insulin pumps and continuous glucose monitors are distributed in a haphazard way across Wales, with different criteria used in health boards. NICE guidance and nationally agreed criteria are often ignored.

We would ask the committee to consider investigating this geographical inequality and support efforts to produce an all-Wales approach to ensure fair and equitable distribution of technological treatment options across Wales. Where children and young people meet the NICE criteria, they should be offered the technology options that are recommended. Locally produced policies and management decisions should not be allowed to prevent people from receiving the treatments recommended by NICE.