

P 12

Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd,
Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport
Committee

Ymateb gan: Rhwydwaith Diabetes Cymru i Blant a Phobl Ifanc

Response from: Children and Young People's Wales Diabetes Network

Priorities for the Health, Social Care and Sport Committee

Consultation Submission

This is an official response made on behalf of the Children and Young People's Wales Diabetes Network (& Brecon Group), which represents all NHS Wales staff working in paediatric diabetes units in all health boards in Wales. Our network is composed of consultants and other doctors, diabetes specialist nurses, paediatric dietitians and paediatric psychologists.

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 Network would ask the Health, Social Care and Sport Committee to consider the following areas of healthcare, where we have identified improvements could be made to support children and young people with Type 1 Diabetes.

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

Members of the Network would be very pleased to provide evidence to the Committee about these concerns.

1. Medical needs in schools

Children in Wales do not have the same rights in law as children in England if they have Type 1 diabetes. The Families Act in England specifically states that children and young people with medical needs *must* receive support in schools.

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 have already produced 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 can also share with the Health, Social Care and Sport Committee.

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 NHS 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. Improved 'transition' from paediatric healthcare services to adult services for children with chronic conditions

'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. Equitable access to healthcare technology and medical devices across Wales

There is notable 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 health board financial considerations should not prevent people from receiving the best available treatments as recommended by NICE.

For further information

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