

P 11

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: Diabetes UK Cymru

Response from: Diabetes UK Cymru

Dear Members of the Health, Social Care & Sport Committee,

We are the leading charity in diabetes in the UK. Diabetes prevalence in Wales is currently 7.1% of the population aged 17 and over. This means that 183,000 people in Wales are living with diabetes. It is estimated that approximately 60,000 people in Wales have undiagnosed diabetes.

90% of people living with diabetes have Type 2 diabetes and 10% have Type 1 diabetes. 1,500 children and young people have Type 1 diabetes in Wales.

Diabetes accounts for 10 per cent of the annual NHS Wales budget. This is approximately £500m a year. Eighty per cent of this figure is spent on managing complications, most of which could be prevented.

Since the introduction of *Together for Health: A Diabetes Delivery Plan*, we have welcomed the focus and progress in improving diabetes services and systems in Wales. However, we believe that there are some areas that require reform to make a real difference to children and young people living with diabetes in Wales. We have detailed these below for the Committee's considerations and have attached our latest report for background and evidence.

1. Medical needs in schools:

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).

We ask 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. We regularly receive enquiries from families of children whose attendance, attainment and overall educational experiences are compromised because of their condition and the lack of guaranteed support from the current framework. It is vital that children are kept safe and healthy whilst they are learning to enable them to achieve their full potential.

Providing support to children and young people with Type 1 diabetes to enable them to participate in all aspects of school life requires a co-ordinated effort. As a patient organisation, we represent the views of families affected by Type 1 diabetes at school. We attach our recent evidence report, “An Excellent Chance: Type 1 diabetes in schools in Wales” to this consultation response.

It includes evidence from families and healthcare professionals showing that there is a need to support children and young people with diabetes in schools. We ask that you 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.

We ask 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.

There is currently a unique and rare legislative opportunity to do this during this Government’s legislative programme.

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

There are 1,500 children with Type 1 diabetes in Wales and each year approximately 100-150 are newly diagnosed. Around 15 per cent of cases of Type 1 diabetes in children are diagnosed after they develop life-threatening Diabetic Ketoacidosis (DKA). This rises to 24% 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. For this reason, it is vital that healthcare professionals across Wales, particularly GPs and other frontline staff working in a community setting, are made aware of the symptoms.

Since the death of Cardiff teenager, 13 year old Peter Baldwin in January 2015, we have been working with the Baldwin family to raise awareness of the identification of Type 1 diabetes.

The Petitions Committee is currently considering Petition P-04-682 – Routine Screening for Type 1 Diabetes in Children and Young People (<http://www.senedd.assembly.wales/mgIssueHistoryHome.aspx?IId=14661>).

The petition has received 2,750 signatures in Wales. An associated petition to the UK Government received 3,670 signatures and was presented to Downing Street by the family

earlier this year.

From the transcript of the Petitions Committee's first meeting to discuss the petition, we believe that there is a possibility that this petition may be referred to you or to the Health, Social Care and Sports Committee for further consideration as an important policy area.