



15<sup>th</sup> September 2017

**Consultation Response: Inquiry into physical activity of children and young people**

1. Diabetes UK Cymru is Wales' leading diabetes charity. There are 188,644 people living with diabetes in Wales. Although there are many types of diabetes, the two most common are Type 1 and Type 2. The information provided in this response relates to the physical activity of children and young people with Type 1 and Type 2 diabetes.
2. Diabetes UK Cymru has also endorsed the submission of the Welsh NHS Confederation to this consultation. The information provided below expands on the points raised in that response.
3. Around 10 per cent of people with diabetes have Type 1. Around 1,500 children and young people have Type 1 diabetes in Wales. Type 1 diabetes is an autoimmune condition where the body attacks and destroys cells that produce a hormone called insulin, resulting in no insulin being produced. This causes glucose to quickly rise in the blood. Everyone with Type 1 diabetes needs to take insulin to control blood glucose levels. Nobody knows exactly what causes Type 1 diabetes, but it's got nothing to do with diet or lifestyle. Type 1 diabetes is usually diagnosed in younger people, particularly in children and young people.
4. Physical activity will affect blood glucose levels. This is because the body uses up glucose as fuel when active. For people with Type 1 diabetes, physical activity and sporting activities therefore need careful consideration and more planning than usual day-to-day activities. Food management is also a necessary consideration. Successful diabetes management relies on balancing insulin, food and physical activity. Access to food is vital for children and young people with Type 1 diabetes, particularly in a school environment. However, we regularly hear of schools denying children and young people access to food during lessons, including PE.
5. We know that children and young people with Type 1 diabetes face significant barriers in participating in physical activity during the school day, as well as taking part in school trips and after-school clubs. Diabetes UK Cymru's report, [\*An Excellent Chance: Type 1 diabetes in schools in Wales\*](#), details the experiences of 60 families (pages 15-18) and shows that 36% of children and young people with Type 1 diabetes are regularly sent home or are withdrawn from school because of their condition.
6. 13% of families also advised that their child had been excluded from going on both day and residential school trips. Parents are often expected to attend with their child to be on hand to provide support and treatment. Several parents describe similar scenarios to the following:

*"I had to go on a school trip, otherwise she couldn't go. I had to lose a day in work."*
7. One parent explained that whilst her son's school did include him in an activity, doing so was dangerous because they had not taken his diabetes into consideration:

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*"We had carefully planned a cycle ride of approximately 5 miles and made adjustments to his insulin basal rates on the pump. The ride was changed to a different location and the miles doubled but no one thought to ask if this was ok or to inform me. They didn't even inform my son of the changes."*

8. 13% of families advised that their child has been excluded from after-school activities due to their diabetes. One respondent, who is a member of staff in a school office, advised:

*"One of our children was offered an out-of-school active course over the weekend. Her mother was offered a place to attend but unfortunately they didn't take the offer as the mother couldn't go."*

9. Trips abroad also present difficulties for some families with Type 1 diabetes. A particularly difficult situation arose for one family:

*"In order for our daughter to go on a school skiing trip, we paid for the whole family (6 of us) to also go to the same resort so that she didn't miss out. Luckily, we were in receipt of DLA which we feel is to be used to support her. However, this has now been stopped so any further trips will mean annual leave for me and funding issues. This is such a shame. There are LSAs who are trained to look after children with diabetes but the school won't fund them to go on school trips (or even let us fund them!)"*

10. The variability in care provided by schools can be highlighted by comparing the above scenario with another family's experience, where the school was very inclusive. The school provided medical forms for the family to complete and provided an opportunity for the parents to speak to the organising teacher. They also purchased a blood testing kit for the child when this was left behind at their hotel.

11. In addition to families, the majority of Paediatric Diabetes Specialist Nurses (PDSNs) knew of cases where off-site activities and residential trips presented difficulties without parental involvement:

*"I have not seen them being refused to attend, but when this entails a younger child the parents have been requested to attend too. If the parents are unable to attend, I don't know if the school would refuse to take the child. I haven't come across this as yet."*

12. The majority of respondents have had to attend their child's school during the school day to carry out tasks relating to their child's diabetes. 62% of respondents have stayed at home from their own work because of issues relating to their child's diabetes and 53% of respondents have had to leave their own work place during working hours to attend their child's school.

13. Evidence suggests that parental involvement is a regular and relied-upon routine for some families, with parents having to provide regular and sometimes daily treatment for their child:

*"They [the school] won't administer insulin, so I have to go into school every lunch time to inject my daughter, who is 6 next week. I also had to go on a school trip, otherwise she couldn't go. Therefore, I had to lose a day in work."*

*"On diagnosis, we as parents had to attend school EVERY day to inject at lunch time from the start of October until the beginning of January."*

14. As well as attending the school to inject insulin, 62% of parents advised that they are being relied upon to carry out other diabetes-related tasks. 26% of these include supervising their child's diet or meal times at school. Some families described how they have had to attend the school in person to provide a small snack to their child because the school has refused to do so, leading to dangerous situations. One parent advised that her daughter's school won't "...allow her to have

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*a fast pass to get food as soon as lunch starts. She is questioned regularly by staff when food needs to be eaten."*

15. In extreme cases, some parents have left or lost their own job because of issues relating to their child's diabetes. One father told us that:

*"My wife doesn't work as she is so worried about anything happening with the children. We have two children who have Type 1 diabetes. She is at their beck and call, should they need her."*

16. It appears that whilst some schools rely on parental involvement immediately after diagnosis only, some are reliant on parents several months and even years after diagnosis to provide a high level of support during and/or throughout the school day.

17. To conclude on the information on Type 1 diabetes, it is vital that no child is prevented from having full access to education, including physical activities. The health and well-being benefits of physical activity are well-established, as is the evidence that poor diabetes control at a young age increases the likelihood of diabetes complications such as blindness, kidney failure, amputation and heart disease later in life. Good care at school for children and young people with Type 1 diabetes is achievable, but evidence shows that it is by no means universal and the current framework of support provided to children and young people with medical conditions is in urgent need of reform. Many of the issues faced by children and young people in Wales are identical to those faced by other groups, such as those with special educational needs, and many children with medical conditions rely on the same support system whilst at school. We therefore call for the proposed Additional Learning Needs & Education Tribunal (Wales) Bill currently being scrutinised by the National Assembly for Wales to include children and young people with lifelong medical conditions.

18. Type 2 diabetes is a serious, lifelong condition where your blood glucose level is too high. This is because your body does not make enough of a hormone called insulin, or the insulin it does make does not work properly. Around 90% of people living with diabetes have Type 2 diabetes. Type 2 diabetes develops gradually, usually later in life, although people are being diagnosed at a younger age. It is the most common type of diabetes in adults. Although there are a number of risk factors for developing Type 2 diabetes, such as gender, ethnicity and family history, the single greatest risk factor is being overweight or obese. According to the [International Diabetes Federation \(IDF\)](#), worldwide 80 per cent of people with Type 2 diabetes are overweight or obese at the time of diagnosis.

19. The number of children and young people with Type 2 in England and Wales is increasing year on year. The [National Paediatric Diabetes Audit \(2015/16\)](#) (NPDA) states that there are 26 children and young people in Wales with Type 2 diabetes (4.2% of the England and Wales percentage) in the audit. However the NPDA figures only relate to those treated in paediatric practice and not, for example, primary care. They also do not reflect the number of children with undiagnosed Type 2 diabetes. Therefore the actual number of children and young people with Type 2 diabetes is likely to be even higher. Characteristics suggest there is a predominance of female patients with Type 2 diabetes compared to males, and more young people with Type 2 diabetes live in deprived areas. In a [recent article](#), the Local Government Association described the continuing rise of Type 2 diabetes as "a hugely disturbing trend".

20. Whilst Type 2 diabetes is rare in children, it can lead to devastating complications in adults, like heart disease, kidney failure and blindness. Type 2 diabetes seems to be even more aggressive in children and young people, who develop high blood pressure and high cholesterol more quickly than the rates seen in adults with Type 2 diabetes. The diagnosis can also have a significant impact on a child's psychological health.

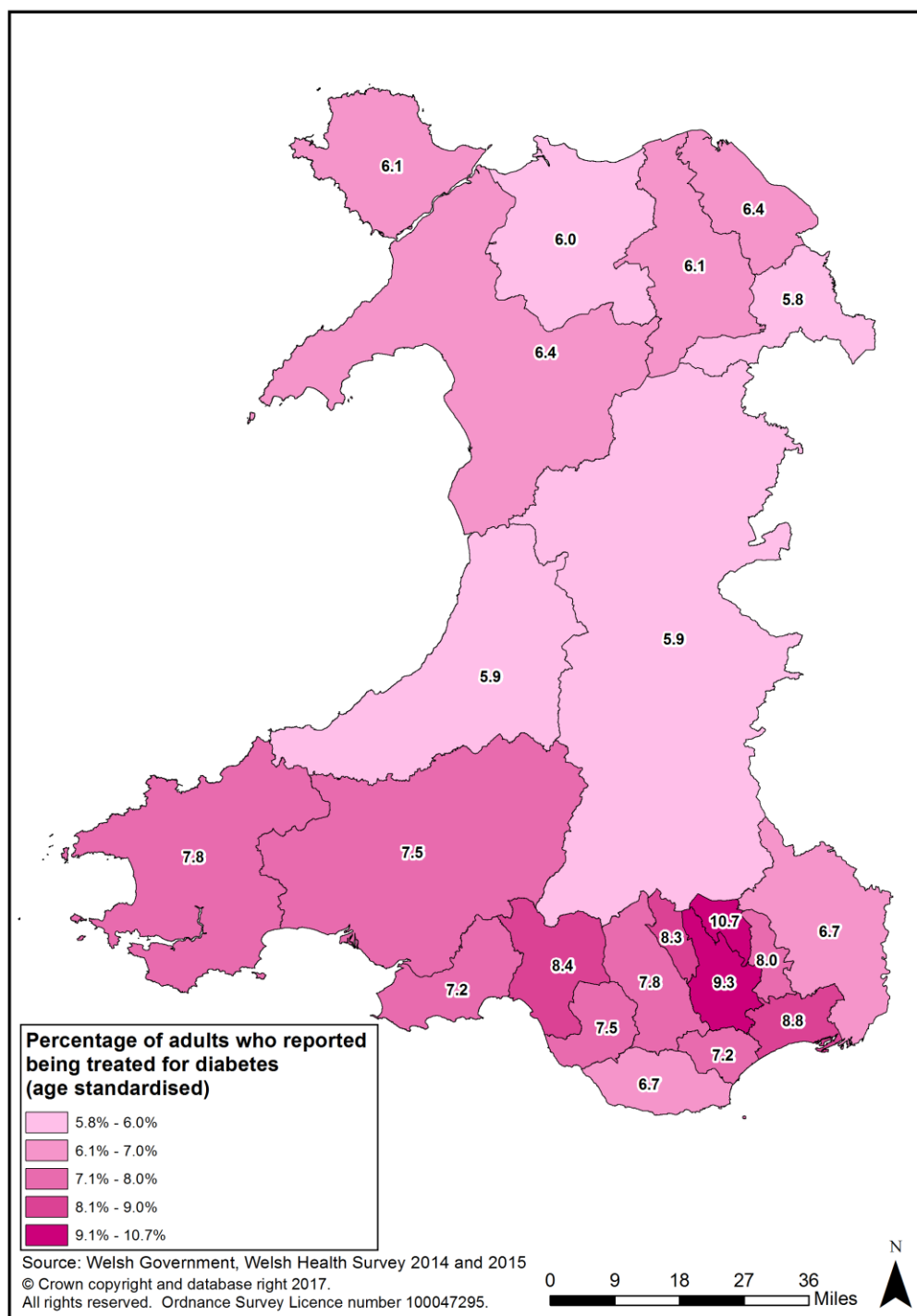
21. The rise in Type 2 diabetes in children is largely spurred on by rising childhood obesity levels, with '27.3 per cent of children in Wales now classified as being overweight or obese. The prevalence of overweight or obese children aged 4-5 in reception year at school (26

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*per cent) is higher than that in England (23 per cent) and higher than any individual English region, where the highest prevalence is 24 per cent. The prevalence of overweight and obese children rises with increasing deprivation, from 22.2 per cent in the least deprived areas to 28.5 per cent in the most deprived areas of Wales.* ([Obesity in Wales](#)).

22. The Public Health (Wales) Act 2017 requires Welsh Government to publish a national obesity strategy for Wales. Decisive action is urgently needed in this area, to make it as easy as possible for children and their families to make healthier lifestyle choices and reduce the risk of developing Type 2 diabetes and its serious complications. This will help prevent ill-health in childhood and reduce the risk of developing Type 2 diabetes and other serious health conditions later in life.
23. In Wales 41% of boys and 58% of girls aged 4 to 15 failed to meet their daily physical activity target of 60 minutes per day at least once in the past week ([Physical Activity Statistics 2015](#)). Welsh Government has a prime opportunity to improve our children's health in a holistic way, tackling both obesity and physical inactivity together. We therefore call on Welsh Government to produce an ambitious obesity strategy that includes action to increase children's physical activity rates.
24. In conclusion, Wales has the highest prevalence of Type 2 diabetes in the UK, with 7.1 per cent of people aged 17 and over living with the condition. In some areas of Wales, this percentage rises to 10.7 per cent (Blaenau Gwent) (see map below for further breakdowns). If current trends continue, by 2025, it is estimated that [300,000 people in Wales](#) (9.4 per cent of the population) will have diabetes. In addition to the human cost, the cost to NHS Wales is simply unsustainable and urgent action is needed to address the diabetes epidemic.

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Source: <https://assemblyinbrief.files.wordpress.com/2017/04/maphealth.png>