

28th September 2023

Dear Children, Young People and Education Committee,

Re: Evidence submission to the Inquiry into 'Do disabled children and young people have equal access to education and childcare?'

On behalf of Cardiff University please find our response to the current call for evidence. We are submitting information from our quantitative research study, '*Investigating the inter-relationship between diabetes and children's educational achievement*' and qualitative research, '*Steadfast: education outcomes in young people with diabetes*', which focuses on children living with Type 1 diabetes.

The research has significant findings in relation to the impact of living with diabetes and children's education. Despite diabetes being legally defined as a disability under The Equality Act 2010, we are finding from our research that many children with diabetes are experiencing discrimination because of their disability, which then impacts upon their attendance, school experience and future prospects. Furthermore, in the group of children with diabetes who have the greatest challenges in maintaining blood sugars within the optimum range, we also see significantly worse attainment, attendance, and significantly reduced likelihood of proceeding to higher education.

The Welsh Government's "*Supporting Learners with Healthcare Needs*" 2017 Guidance exists to ensure that all children with medical conditions are supported in school. However, evidence from our research demonstrates that this is not being consistently implemented across the country, creating barriers for children and young people attending school and achieving their academic potential.

We would be happy to expand on the points covered in our response if it would be helpful. If you have any queries regarding the response, please do not hesitate to get in touch.

Yours sincerely

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Children, Young People and Education Committee Inquiry into “Do disabled children and young people have equal access to education and childcare?”

Cardiff University’s response

Overview:

Cardiff University has been funded to conduct this research by the UKRI Medical Research Council (MRC £395k), the UKRI Administrative Data Research UK (ADR UK £181k) and UKRI Data and Analytics Research Environments UK (DARE £238k). This research has been completed in partnership with Diabetes UK, the Royal College of Paediatrics and Child Health (RCPCH), NHS Digital, Health Quality Improvement Partnership (HQIP), University College London (UCL) and Swansea University.

The research used quantitative methods to identify and link individuals from the National Paediatric Diabetes Audit, National Pupil Database and Higher Education Statistics Agency datasets. The quantitative survey used data from school children aged 6 to 18 year old in Wales between 2009 and 2016. 263,426 children without diabetes and 1,212 children diagnosed with Type 1 diabetes. Multi-level modelling techniques were then used to generate the findings about their schools and healthcare settings. Following the quantitative study, the research team held nineteen qualitative focus groups with over 70 children (aged 13-34) across the UK to discuss their experiences of the support they received in education settings and the impact on their school absence.

Key points:

- **Diabetes is one of the most common chronic childhood illnesses in the UK, affecting 1 in 250 children.** There are two main types of diabetes which affect how insulin regulates blood glucose levels. This research focuses on Type 1 diabetes which is the most common form in childhood, arising from immune-mediated beta cells (which produce insulin) destruction. Children with Type 1 diabetes cannot produce any insulin. This means that they must take insulin and check their blood sugar levels regularly throughout the day. A child with Type 1 diabetes must self-inject insulin regularly or use an insulin pump to keep their blood glucose levels within acceptable limits, depending on what they have eaten or physical activity.
- The research project aimed to provide a better **understanding of the issues affecting children self-managing their diabetes during childhood and how that could help reduce the need for costly interventions.** Type 1 diabetes is estimated to account for £1 billion direct costs (for example, diabetes related heart disease, kidney failure and foot amputations) to the NHS, and £0.9 billion indirect

costs (for example, absence from work due to ill health and impact on mental health).

- To manage their medical condition, children living with diabetes will need **to administer insulin by injection or pump four or more times a day, plus monitor their blood glucose levels** (by finger prick testing or continuous glucose monitors) especially around mealtimes and physical activity. Children who need to inject at school will need to bring in their insulin and injecting equipment. In most cases the equipment will be an insulin pen device rather than a needle syringe. Those who use an insulin pump, will deliver extra insulin via a cannula which sits under the skin. Children may wish to check their blood glucose levels and administer insulin privately; others may be comfortable injecting in public. Both situations should be allowed.
- **Children may need help with monitoring their blood glucose levels, injecting insulin, or managing their pump depending on age, whether they are newly diagnosed or have learning difficulties.** Children living with diabetes will have varying levels of understanding or ability to independently manage their condition, they will be reliant upon the support and training of teachers in their school.
- The **medical impact on children living with Type 1 diabetes** will primarily be through affecting their metabolic state, having abnormal glucose levels may lead to an impact on concentration levels in school or affect school attendance. If a child experiences a 'hypo' (hypoglycaemia, or low glucose levels in the blood) the child may start feeling shaky, become dizzy, tired or have blurred vision. This may happen if a child has had too much insulin, or not eaten enough carbohydrate food or been more active than usual. Hypos must be treated very quickly, left untreated the blood sugar will continue to fall and the child could become unconscious or have a seizure. In contrast, children may experience a 'hyper' (hyperglycaemia, or high glucose levels in the blood), this may happen when a child has missed an insulin dose, or has not taken enough insulin, has had a lot of sugary or starchy food, or over-treated their hypo. In these situations, treatment may not be needed, or they may take an extra dose of insulin or drink plenty of water. More extreme variations in blood glucose levels may lead to hospital admissions through severe hypoglycaemia or hyperglycaemia which when linked with ketoacidosis may lead to altered cerebral functioning and brain damage.

- The **social impact on children living with Type 1 diabetes** may affect education include stress arising from self-management, in contrast to many other childhood chronic conditions the proportion of care and management of the medication is done by the child especially in teenage years. Medication will be needed to be administered throughout the school day and glucose levels monitored. Children may feel self-conscious about their condition, or they may not have the maturity or knowledge to be able to manage it appropriately. In addition, their situation may be further exacerbated by not receiving the appropriate care and support from their school and teachers, which will negatively impact on their health and well-being. For young people, this will continue into higher education, and may impact upon a young people's ability to leave home and live independently in order to attend University or College.

Findings:

The findings of Cardiff University's quantitative research were published in the Journal of Diabetes Care¹, the world-leading clinical diabetes journal. The aim of the research was to understand the relationship between how childhood diabetes and diabetes management affected a child's experience of school. The link between diabetes developed in childhood and education is important because it relates to how well children do at school and what they will go on to achieve academically and into their future careers. Diabetes affects all aspects of a child's life, from family, friendships, and their self-esteem.

From our research findings, key issues that emerged were:

Educational outcomes for children living with diabetes versus children without diabetes

- **Children living with diabetes are absent from 9 additional sessions a year² compared with children without diabetes.** Sessions may be missed for medical appointments related to the condition or illness as a result of living with diabetes.
- Despite missing these additional sessions, on average, **children living with diabetes achieve the same levels of academic qualifications as children without diabetes.**
- Furthermore, **children living with diabetes are equally likely to attend higher education** as children without diabetes.

Educational outcomes by blood glucose levels

The research used a blood test to measure the average blood glucose levels for the last two to three months (HbA1c levels).

¹ French, R et al (2022) '[Educational Attainment and Childhood-Onset Type 1 Diabetes](#)', Diabetes Care, vol.45, no.12, pp 2852-2861.

² 1 session is equal to half a day of schooling

- Children experiencing challenges managing their diabetes missed **15 additional sessions of school a year compared with children without diabetes**. Even children with levels of blood glucose associated with the best future health outcomes missed 7 additional sessions a year.
- Children experiencing the most significant challenges managing their diabetes **achieved 5 grades lower at 16 years of age** than children without diabetes.
- This pattern continues into higher education; children experiencing challenges managing their blood glucose levels **are less than half as likely to attend University compared to children without diabetes**.

Conclusion:

The relationship between a child managing their diabetes and their educational achievement is complex. Diabetes management may influence a child's educational attainment, for example, incidences of hypoglycaemia, and poor adherence to the guidance by a child's school; more educationally able children may be better able to self-manage their diabetes; or there may be other factors which affect both the child's educational attainment and their diabetes management, for example, parental involvement, or a highly trained supportive teacher. Regarding the length of time since diagnosis. There is no difference in a child's academic attainment at 16 years of age as to whether they have recently been diagnosed or diagnosed earlier in childhood.

Consultation questions:

- 1. The extent to which children and learners are currently able to access all parts of childcare and education provision, including the way in which the curriculum is taught and extra-curricular activities.**

Children living with diabetes will need to manage their health condition throughout the school day. Children with Type 1 diabetes cannot produce any insulin, therefore they need to administer insulin by injection or pump four or more times a day, plus monitor their blood glucose levels (by finger prick testing or a continuous glucose monitor), especially around mealtimes and physical activity.

Children and young people living with diabetes are missing on average 9 sessions a year (1 session = half a day of schooling) more than children without diabetes. These sessions are being missed due to factors relating to the management of their health condition, such as attending medical appointments, feeling unwell as a result of their diabetes, or requiring time to manage their health condition during the school day. Higher absence is not always due to high or low blood glucose levels. Children reported taking time off to look after their mental health because of the cumulative psychological effect of living with the condition.

“I remember especially having a hypo, and I needed to leave the lesson, and the teacher was trying to give me homework, I kept saying ‘I need to go, I need to go’. They made me feel like it was my fault that I had it and that I was an inconvenience.”

(Young person, 17)

This higher rate of absence has an impact on children’s ability to access all parts of education provision and extra-curricular activities. Children who have the support to manage their diabetes well will achieve the same levels of academic qualifications as children without diabetes and are equally likely to attend higher education. However, this is not without extra strain on mental health and well-being, due to the struggle to make up for lost time in school, catch up on missed lessons and short spells every day while they are managing their diabetes.

The impact of living with Type 1 diabetes an autoimmune condition is often beyond the control of the child, for example those living further from clinics may miss more schooling to attend appointments, and those families without access to a car may miss yet more schooling because of the time taken to travel by public transport.

Children who face challenges managing their diabetes are missing 15 sessions a year more than children without diabetes, they achieved 5 grades lower at 16 years of age and are less than half as likely to attend University compared to children without diabetes.

“I’ve recently been getting high blood sugars overnight, enough to make me feel rubbish in the morning and that affects me. Being able to get out of bed but not mentally, like not being able to wake up properly. So that slows me down and I’m late for school. My

teacher thinks I'm using my diabetes as an excuse to be late all the time and it's not.”
(Young person, 16)

Higher absence for children with diabetes reported in this study is only for 'official' or 'recorded' absence. In practice, young people with diabetes miss many additional short spells from the school day that are not formally recorded as absence; for example, a child may miss 20 minutes of a lesson before lunch to administer their insulin prior to eating; or a child may miss a single lesson while experiencing a hypoglycaemic incident (raised blood glucose levels) or 'hypo'. Thus, the actual amount of missed schooling is underreported, which means the additional work done by young people with diabetes to catch up is lower than the true figure.

2. The extent to which children and young people have been excluded from aspects of education or childcare due to their disability or neurodivergence

Due to persistently missing aspects of their education, as outlined above, children living with diabetes feel that they are excluded from their education due them needing to manage the condition, plus due to a lack of awareness and training of teachers about children's medical needs.

Schools, teachers, and support staff are not routinely trained in supporting children with health conditions. Educating teachers to support children with diabetes occurs on an ad hoc basis through local diabetes clinics and as a result is inconsistent. This lack of awareness and training leads to children being inadvertently excluded from aspects of education, i.e., missing lessons, physical education, and school trips.

“A lot of pressure was on more of attendance because, if you drop below this amount of attendance, you can't go on the end of year trip. But if I had said to my teachers in advance, i've got an appointment on this day at this time, i'll have to miss this lesson. They wouldn't count that as an authorised absence. So, it just looked like I hadn't turned up, but really, I was at an appointment.” (Young person, 16)

The Welsh Government's Diabetes Delivery Plan for Wales 2016 to 2020³ commits to early identification and intensive support for children and young people with Type 1 diabetes, stating that *“children living with diabetes should receive the best possible support and care in all environments including schools”*. It highlights that *“Educational settings need to be supported to train staff to support CYP with diabetes to avoid hypoglycaemic episodes and perform carbohydrate counting and administration of insulin for young children. Young people with diabetes must be supported to participate in all educational activities, including residential trips.”* However, despite this rhetoric, the evidence suggests that children with diabetes are not receiving the help they need to complete their education.

³ Welsh Government (2016) Diabetes Delivery Plan for Wales 2016-2020, Cardiff: Welsh Government

The Guidance “*Supporting learners with healthcare needs*”⁴ (2017) contains both statutory and non-statutory advice to assist local authorities, governing bodies and education settings. It sets out that “*learners with healthcare needs should be properly supported so that they have full access to education, including trips and physical education and Governing bodies must ensure that arrangements are in place to support learners with healthcare needs*”.

We need to ensure that this Guidance is fully implemented at a local level, with training and policies in place to reflect the needs of children living with diabetes. The Government must ensure that children’s education is not detrimentally affected because of their health condition and the school's response to their specific needs.

3. The extent to which families and children feel that they have been affected by direct, indirect or discrimination arising from disability.

From our qualitative research, children and young people have told us about direct or indirect discrimination resulting in schools' response to their disability. Children raised issues relating to their inability to gain access to a private room to administer medication, teachers not understanding their health condition and not allowing them to deal with a medical situation, teachers accusing children of using their medical condition as an excuse to miss lessons or get out of class. Children and young people told us that these could be a daily occurrence at their school and create more stress and antagonism between the child/teacher relationship. These young people are purely dealing with their medical condition while in the school environment, and due to a lack of training and awareness from teaching staff and schools this is having a detrimental effect upon their school experience and attainment levels.

“I didn’t get much support, and not many people tried to understand (well, not many of my teachers), and I didn’t really know who to go to if I needed help in the school day”.
(Young person, 18)

“My blood sugars were high, but the Medical Room was locked. Usually, I’ll just go into the medical room and sit and do my blood tests. But it was completely locked. So, then they just said right we’ll go and find a key to unlock it. I was waiting there for about 10 minutes.” (Young person, 16)

“I remember especially having a hypo and I needed to leave the lesson and the teacher was trying to give me homework, I keep saying ‘I need to go, I need to go.’ They made me feel like to was my fault that I had it and that I was an inconvenience.”
(Young person, 17)

⁴ Welsh Government (2017) [Supporting Learners with Healthcare Needs](#), Cardiff: Welsh Government

“I had a PE teacher who didn’t believe me that I couldn’t do PE when I was hypo. So gave me a detention for not doing cross-country that day.” (Young person, 21)

“I had a supply teacher for one lesson, and I really need the toilet. I asked them. I said it’s on my medical card that I’m allowed to go to the toilet because I’ve got diabetes, but she didn’t believe that I had diabetes. I showed them my Libre (Glucose Monitoring System), and I showed them my card and they checked the school system, and they still didn’t believe me.” (Young person 16)

“High blood sugars can make me thirsty sometimes, and I just finished my water bottle, and I said can I go and get a drink of water? And the teacher said, ‘No you are not allowed.’ So, I showed my medical card and she said that you can’t use your medical card for excuses. You’re just using it in the wrong way.” (Young person, 16)

“I had a PE teacher who shamed me for drinking full sugar coke when I was hypo. They said that’s the reason I have diabetes, when I was actually treating my hypo.” (Young person, 16)

4. The impact of any lack of or limited access on a child or young person’s mental health and well-being and educational outcomes.

Through our qualitative research with children and young people living with diabetes, we found that the condition and the lack of support from school resulted in a profoundly negative impact on their mental health and well-being. Higher absence is not always due to high or low blood glucose levels. Children reported taking time off to look after their mental health because of the cumulative psychological effect of living with the condition. Children and young people told us about the lack of support in school to support their medical condition, which in turn negatively impacted their mental health. They explained not knowing who to ask for help from, or those that were identified as the person to help them not supporting them in the way they found helpful.

Many children and young people shared that their views were ignored regarding their healthcare needs:

*“My mental health is worse because I’ve got diabetes. I’ve spent a lot of time not in school because of my condition. I think the way they handle attendance is horrible. They reward children for having 100% attendance and diminish others that don’t. I understand that there are people that skip school for the fun of it, but there are people who aren’t in school for real reasons and then not being allowed to go on school trips.”
(Young person, 19)*

“In terms of mental health support, I feel like that’s underestimated quite a lot. For me personally mental health is probably what’s most damaging about diabetes. As a diabetic you have to make so many more decisions and considerations compared to someone who’s not diabetic, which of course takes its toll on your mental health or your academic ability or your performance at work.”

(Young person, 18)

“A large proportion of your day is at school, it’s so important that they know how to keep you safe. It’s not so big a deal when you are 15 or 16, and you know what you are doing and can look after yourself. But when you are 12, you still need a bit of support there. And the people that are supporting you don’t know what they are talking about. That’s quite scary.” (Young person, 19)

“They’re not always the most understanding cause obviously it’s very unpredictable, and I can’t always do PE because of my (blood glucose) levels. I can’t always do things, but then some teachers aren’t always understanding and think that I’m just making it up to get out of something.” (Young person, 20)

“My set (insulin pump) wasn’t working, I’d have to go down to the nurse to change them. And the teacher showed no help towards me and one time she rang home to say that I shouldn’t be getting out of class as much to be changing my sets and telling me that I shouldn’t be doing that. I have an insulin pen and sets in the nurse’s office, but it just takes a lot to be able to go to the nurse and ask for my stuff to change it. It takes more (courage) because of what has happened. I feel nervous all the time trying to think about what I’m going to do because I don’t really want to go to the nurse.” (Young person, 16)

Children and young people highlighted that some changes made due to COVID have positively affected the support for children with diabetes in schools. For example, listing schoolwork online has made it easier for students to catch up on missed lessons. However, these changes are not available in most schools and may not continue in the post-COVID period. Furthermore, due to Covid measures in schools there have been a number of negative changes, for example reduced access to shared water fountains.

5. The barriers for schools and childcare providers in offering accessible provision

Children and young people have told us that there is a lack of awareness and training of teachers about children’s medical needs. Schools, teachers, and support staff are not routinely trained in supporting children with health conditions. Education teachers to support children with diabetes occurs on an ad-hoc basis through local diabetes clinics and as a result is inconsistent. Every school should have a medical conditions policy, which outlines the support and protection each child is entitled to in order to manage their condition. Adherence to this policy and how effectively it is implemented should be part of

the Estyn inspection framework, and children's and young people's experiences as to how effective they have been in improving their school experience.

Other barriers to inclusive provision raised by children and young people included support during transition between primary and secondary school and exam periods. Children and young people expressed concerns about the lack of support and awareness from teachers about their additional needs and how that impacted the exam period. For example, children were not given a private room to take their exam, not being given extra time to manage their diabetes, being questioned about why they were bringing in certain drinks and snacks, or not being allowed to have their phones (which link to their Glucose Monitoring Systems to manage their diabetes). Children spoke about how stressful the exam period was, in addition they then had to manage their diabetes during this time with little help from the school.

“Exams were really bad, because I didn’t know what I was, or wasn’t allowed to do. I’d ask my doctor one thing, then I’d ask my teacher and they’d say a different thing. It was very confusing. I remember being really stressed before the exam, not just about the exam, but about my needing my blood glucose levels to be in the right range so that I can focus properly. I wasn’t properly supported.” (Young person, 21)

Concerns around transitioning between primary and secondary school. Children and young people had mainly positive experiences of primary school support due to the smaller school environment and through dedicated trained teaching assistants to help them to check their blood glucose levels and to administer insulin.

“When I got diagnosed in Primary School, I had my own T.A. who did everything with me, she checked my bloods regularly and at dinner time. She’d make sure I had all my snacks on time. But when I went to secondary school, there was just none of that. They were completely useless. There was one point where I got told I wasn’t allowed to inject in the canteen. There was just no support, and nobody knew anything. I think if I was to collapse in school, I’d have probably ended up in A & E.” (Young person, 21)

Young people raised the issue of a lack of continuity of care in secondary school. During the school day they are taught by a number of different teachers, including new and supply teachers that are not adequately trained, or made aware of their needs.

6. Whether parents of disabled and neurodivergent children and the children themselves receive effective information and support from local authorities and schools

Children and young people raised the issue of not knowing what help and support was available to them and what their rights were during the school day. The lack of awareness and training of teachers has a significant impact upon how children are able to manage their medical needs while at school.

“Even in lessons, if I needed a snack or had a hyper, teachers have sent me out and then there would be a whole rigmarole of going to see someone. Or being asked, ‘why did you get sent out?’ while I was having something to eat. Being told that ‘you shouldn’t be eating.’ On explaining that he had diabetes, he was told ‘well why does that make you special.” (Young person, 21)

Many children raised the issue of teachers being unaware of their medical needs in the classroom. If they needed to leave the classroom to manage their diabetes as they were experiencing a ‘hypo,’ many children said that this was met with hostility, or that they were disciplined for asking to leave.

“I was sitting in the class, when I realised, I was meant to do a finger prick (test) half an hour ago. So, in a rush, I put my hand up, and asked to go to the toilet to wash my hands to do my finger prick test. She said, “No, how dare you, let me explain this first.” I was trying to reason with her and not get angry. My blood glucose levels were 6, I was ok, but let’s say that my blood sugars were a bit higher, or a bit low and my monitor didn’t pick it up. It could have been urgent, she let my go in the end, but she was really, really annoyed with me for no reason.” (Young person, 20)

Many children were told to leave the classroom on their own to seek medical attention, all clearly unacceptable practices as stated in the Guidance. This adversarial relationship between teacher and pupil led to many not wishing to ask for help or being embarrassed to raise issues that they needed support with. Many children shared feeling frustrated and not supported about having to constantly explain their situation and why they needed certain help, i.e., access to drinking water, a private space, or snacks during the day.

“I basically taught all the Heads of Year and everyone, everything. They had no knowledge at all about it. I was one of the first diabetics to go through the school with the current teachers. I had to basically had to teach them everything. And I’d only been diabetic for a year or so and I was teaching them.” (Young person, 20)

“There are a lot of misconceptions around diabetes, like ‘did your mum feed you too much sugar as a kid,’ or ‘you can’t eat like that.’ I’d have my blood glucose monitor machine out and I’ve had multiple teachers try and confiscate it thinking it was a phone. There is no real clear communication about what support I need.” (Young person, 18)

“I didn’t get much support, and not many people tried to understand (well, not many of my teachers) and I didn’t really know who to go to if I needed help in school during the day.” (Young person, 18)

“My Mum’s been working for years to try and get a care plan that was simple enough for the teachers to be able to understand. They still don’t read it or pay any attention to it,

then tell me what to do even though they don't know because they haven't read the plan.”
(Young person, 19).

Conclusion

We would like to propose the following policy recommendations be considered by the Children, Young People and Education Committee in the development of their response to the Inquiry, these are developed from our research findings with children living with Type 1 diabetes, improve their experience of school and future outcomes:

- Schools, local authorities, and health services should work together to support both the child's health needs and their education needs, particularly for children who were already struggling with their education prior to a diagnosis of diabetes, to avoid the double disadvantage of reduced health and education outcomes as the young person enters the transition to adulthood.
- Paediatric diabetes teams should be resourced to provide training and support to schools to ensure that school staff have the skills and confidence they need to support children.
- Local authorities should support schools which do not have a sufficient 'Medical Conditions Policy' to make this available and ensure they are updated annually.
- Estyn should evaluate how effectively schools and educational settings are implementing the statutory guidance as part of their inspection process.
- Schools need to ensure that there are sufficient numbers of fully trained staff to support children to manage their diabetes, including for periods of staff illness and school trips.
- Local authorities should support schools to ensure that every child with diabetes has an individual healthcare plan, which details exactly what their needs are and who will help them.
- Schools must ensure that every child with diabetes is fully supported to manage their condition in public or private spaces within the school, depending on their wishes.