

[Sendreview.consultation@education.gov.uk](mailto:Sendreview.consultation@education.gov.uk)

15th July 2022,

Dear SEND Review Team,

**Re: Special Educational Needs and Disabilities (SEND) Review: right support, right place, right time.**

On behalf of Cardiff University's School of Medicine, please find our response to the current consultation on the **SEND Review: right support, right place, right time.**

We are submitting evidence from our research about children living with Type 1 diabetes (who are legally defined as disabled as set out in The Equality Act 2010) and the impact on their educational achievement.

The research has been completed in partnership with Diabetes UK, the Royal College of Paediatrics and Child Health and NHS Digital. The findings detail how living with diabetes and diabetes management affect children's experience of education and the challenges these children face, including additional days of missed schooling, the impact on school achievement and their overall health and well-being.

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

Yours sincerely,

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# SEND Review: Right support, right place, right time

## Cardiff University response

### About us

Cardiff University is an ambitious and innovative university with a bold and strategic vision. A top 20 university in the United Kingdom for the overall quality of our research (19th), impact (11th), and environment (16th), as assessed by the Research Evidence Framework 2021. We provide an educationally outstanding experience for our students. Driven by creativity and curiosity, we strive to fulfil our social, cultural, and economic obligations to Cardiff, Wales, the UK, and wider world.

### Overview

Cardiff University has been funded by the Medical Research Council (MRC) and Administrative Data Research UK (ADR UK) *'to investigate the inter-relationship between diabetes and children's educational achievement.'* 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 survey methods to identify and link individuals from the National Paediatric Diabetes Audit, National Pupil Database and Higher Education Statistics Agency datasets. 'Multi-level' modelling techniques were used to make findings about individuals and the 'groupings' that children were within, i.e., schools, families, and healthcare settings. This includes using multiple measures of health and education for an individual over time. The findings of this research will be published shortly in the Journal of Diabetes Care, 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. The impact of living with diabetes will affect all aspects of a child's life, from family, friendships, and their self-esteem.

## 1. 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 in direct costs to the NHS (for example, diabetes-related heart disease, kidney failure and foot amputations), and £0.9 billion in 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 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 pumps.** 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, particularly for younger children, children who are newly diagnosed and children with learning difficulties.

- 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, 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, not taken enough insulin, 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 also affect education, particularly through the 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 the teenage years. This is in contrast to most childhood health conditions where the child's clinical team manages the timing and dosage of medication. 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. These issues persist into higher education and may impact a young person's ability to leave home and live independently in order to attend University or College.

## 2. Research findings

### **Educational outcomes for children living with diabetes versus children without diabetes.**

- Children living with diabetes are absent from **9 additional sessions a year** compared with children without diabetes (the baseline rate for all children is 20 sessions). Sessions may be missed for medical appointments related to the condition or illnesses 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).

- 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 challenges with 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.
- **The relationship between a child managing their diabetes and their educational achievement is complex:**

- **Health affects education:** Diabetes management may influence a child’s educational attainment, e.g., incidences of hypoglycaemia affect the ability to concentrate in class.
  - **Education affects health:** Aspects of the school and pupil performance will affect the child’s health, e.g., higher attaining students may have a greater capacity to self-manage their diabetes, teachers in higher attaining schools will have greater freedom to support students.
  - **Other factors affecting education and health:** There may be other factors which affect both the child’s educational attainment and their diabetes management, e.g., highly motivated parents will improve both the child’s diabetes management and their exam scores.
- 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 been recently diagnosed or diagnosed earlier in childhood.** This suggests that the associations observed between diabetes management and educational outcomes are more likely to be the result of social mechanisms affecting diabetes management and learning rather than due to biological impacts of diabetes on brain function.

### 3. Policy overview

**The Equality Act 2010 (England, Scotland, and Wales)** legally defines children with diabetes as being disabled. The NHS, local authorities and schools have responsibilities toward these children to ensure that they are not put at a substantial disadvantage compared to other students. The relevant part of this act is that schools must make reasonable adjustments to ensure that children and young people with a disability are not directly or indirectly disadvantaged compared to other students. It is necessary that reasonable adjustments should be ‘*anticipatory*’, meaning that they should be put in place in advance to prevent the student being at a disadvantage. In relation to schools, it will be important that there are enough fully trained teachers to support children with diabetes to enable them to take part fully in all activities. Children with a disability must not be discriminated against, harassed or victimised.

Section 100 of **The Children and Families Act 2014** places a legal duty on governing bodies of schools, proprietors of academies and management committees of pupil referral units (PRUs) to support children with medical conditions. This is inclusive of children with diabetes. The Statutory Guidance ‘*Supporting pupils at school with medical conditions; statutory guidance for governing bodies and proprietors of*

*academies in England'* (2015) is intended to help governing bodies meet their legal responsibilities. The aim of the Guidance is to ensure that all children with medical conditions, in terms of both physical and mental health, are properly supported in school so that they can play a full and active role in school life, remain healthy and achieve their academic potential. Schools must make arrangements for supporting pupils at schools with medical conditions, and in meeting that duty, they must have regard to this Guidance.

The Guidance exists to protect and ensure that children and young people's education is not negatively impacted by their medical condition, and they can thrive. If the Guidance is implemented appropriately and adhered to, it provides a sound basis for doing this.

Our partner agency [Diabetes UK](#), has created this checklist for what diabetes care in schools should look like. Their '*Make the Grade*' campaign includes resources and sample policies to help all schools implement the Statutory Guidance.

- **No child** with diabetes should be excluded from **any** part of the school curriculum.
- **Every child** with diabetes should have access to **extracurricular activities**, including overnight stays and trips aboard.
- Schools, local authorities and health services should **work together** to make sure they meet the needs of children with diabetes.
- Paediatric diabetes teams should provide **training and support to schools**, so school staff have the **skills and confidence** they need to look after a child with diabetes.
- **No parent** should be relied on to go into school to treat their child's diabetes.
- **Every child** with diabetes should be allowed to **inject insulin**, in public or in private, depending on their wishes.
- **Every school** should have a **medical condition at school policy**, which is updated every year.
- **Every child** with diabetes should have an **individual healthcare plan**, which details exactly what their needs are and who will help them.
- **Schools should hold up-to-date information** about their children's diabetes needs and all the supplies needed to manage diabetes in school.
- **Schools should not assume** that all children with diabetes have the same needs.
- **All school staff** should know what to do in case of emergency and at least two people should be trained in how to care for a child with diabetes. Planned staff absences should be co-ordinated so that there is always one trained person in school.

- Schools and parents should agree on a **clear method** of communication
- Children with diabetes should **never** be left alone when having a hypo or be prevented from eating or drinking to prevent or treat a hypo.
- Children with diabetes should **never** be prevented from blood testing or taking insulin and should be able to look after their equipment themselves.
- When children with diabetes have exams, **specific plans** should be included in that year's individual healthcare plan and agreed upon between the schools, the child and their parents.
- Children with diabetes **should not** be sent home frequently or penalised for poor attendance when absence is related to their diabetes.
- **Every child** with diabetes should be listened to and their views are taken into account.

#### 4. Unacceptable practice

In the Statutory Guidance '*Supporting pupils at school with medical conditions; statutory guidance for governing bodies and proprietors of academies in England*' (2015), p23 lists a number of practices that are deemed unacceptable when supporting pupils with their medical conditions.

Cardiff University, in partnership with Diabetes UK, are currently undertaking a research project: '*Steadfast: education outcomes in young people with diabetes*'. As part of this work, they have conducted focus groups with over 80 children and young people aged 13-24 years old who are living with Type 1 diabetes. Emerging findings from the focus groups highlight the fact that many of the children have experienced direct discrimination and unacceptable practices. To illustrate this, we have included a summary of their views and quotes from the children underneath the unacceptable practices as detailed in the Statutory Guidance.

- **Preventing children from easily accessing their medication when and where necessary**

*'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**

- **Ignoring the views of children and young people**



*'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**

*'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 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**

- **If a child becomes ill, sending them out of the classroom to get help unaccompanied**

*'I just need time to sort myself out. I would go out on my own, but I thought that maybe I should have someone with me'* **Young person, 18**

- **Children being penalised for their attendance record, despite absences being related to their medical condition**

*'My attendance statistic report doesn't look great. My tutor commented that my predicted grades for science were a bit lower than my other grades because I'd missed more science lessons. He said maybe if your attendance was better, your grades would be better. But my attendance was because of my diabetes. So, it was like he was saying. "You know, if you handled your diabetes better, or if you didn't have diabetes, then you would be doing better in school", and it really frustrated me because he said something like that previously. My mum had challenged it, but he still put it, and I found it really frustrating, as I was having a really bad time and felt unwell with my diabetes'* **Young person, 18**

*'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**

*'A lot of pressure was on more of attendance because, you know, 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 a an authorized absence. So it just looked like I hadn't turned up, but really I was at an appointment.'* **Young person, 16**

- **Preventing children from drinking, eating or taking toilet breaks or other breaks to manage their medical condition.**

*'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 years old**

- **Preventing children from participating, or creating unnecessary barriers to children participating in aspects of school trips**

*'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**

- **Lack of awareness and training of teachers about children's medical needs**

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 on 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 fingerprick (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 fingerprick 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 me 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 Statutory 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 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*

- **Lack of support in how to manage their condition.**

*'They made me feel like I was an inconvenience. I had a lot of problems when I needed to leave my lessons, to sort out my diabetes. I had a lot of problems with a lot of my teachers, saying that I couldn't leave and that I was putting myself before my education'*  
**Young person, 17**

*'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, 21**

*'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 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*

- **Lack of support around children's Individual Health Care Plans**

*'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**

- **Children missing education due to a lack of awareness and training**

Due to a lack of awareness, training, policies and procedures within the school, children have been prevented from participating in school.

- **Requiring parents to attend school to administer medication or provide medical support for their child.**

*'Yeah. When I was first diagnosed when I was eight, I used to be, like, nervous to inject myself. So my Mum would come home from work – and it was like half an hour drive at lunchtime - to my school to give me my injections and then go back to her work. Um, and that was like every day for at least a couple of months.'* **Young person, 21**

- **Impact of living with diabetes on children and young people's mental health**

*'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**

- **Lack of support during exam period**

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.