

9<sup>th</sup> September 2022

Dear Consultation Team,

**Re: A new approach to area SEND (Special Educational Needs and Disabilities) inspections – Ofsted and Care Quality Commission consultation document.**

On behalf of Cardiff University's School of Medicine, please find our response to the current consultation.

We are submitting evidence from our quantitative research, '*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 experiences of education.

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. Likewise, if you have any queries regarding the response, please do not hesitate to get in touch.

Yours sincerely,

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# **A new approach to area SEND inspections Cardiff University response**

## **1. About us**

Cardiff University is an ambitious university with a bold and strategic vision. A top 20 university in the UK 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, UK, Wales, and the wider world.

## **2. Overview**

Cardiff University has been funded to conduct this research by the UKRI (UK Research and Innovation) Medical Research Council, The UKRI Administrative Data Research UK and UKRI Data and Analytics Research Environments UK. This research has been completed in partnership with Diabetes UK, the Royal College of Paediatrics and Child Health, NHS Digital, Health Quality Improvement Partnership, University College London, 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. Statistical modelling techniques were used to make findings about individuals and their schools and healthcare settings. Following the quantitative study, the research team held nineteen focus groups with over 80 children (aged 13-24) across the UK to discuss their experiences of the support they received in education settings and the impact on their school experience.

The quantitative research findings 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. Diabetes affects all aspects of a child's life, from family, friendships, and their self-esteem.

## **3. Our response**

We welcome Ofsted and CQC's broad and holistic approach to improving SEND inspections through the proposals set out in the consultation document. From our research evidence and findings, we have gained a detailed understanding about what the issues are relating to this group of children and young people and what additional support they require.

In particular, we support the new inspection framework's emphasis on ensuring that both statutory responsibilities are implemented, and in addition, how this then impacts upon children and young people's experiences of their education setting (Proposal 1). It is the reality of their experience that is the most important indicator of whether a school is sufficiently supporting young people. A local area may be able to state on paper that they are fulfilling their statutory obligations, however the reality of the lived experience of children, young people and their families may be hugely different.

We welcome the broadening of focus of inspections to include the impact of local area partnerships on the lives of children and young people with SEND, and to focus on the core criteria (Proposal 2) and outcomes (Proposal 3). It is encouraging to see that clear recommendations on weaknesses and systematic issues will be made (Proposal 4) and in turn that local area strategic plans will be updated as a result (Proposal 5).

Our response mainly focuses on '*gathering more evidence directly from children, young people and their families*' (Proposal 6). This is crucial in fully understanding the situation at a school and how effective the support children receive is.

#### **4. Our research**

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, we 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.

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 and therefore their school experience. Further, in the subset of children with diabetes who have the greatest challenges in maintaining blood sugars within the optimum range, we also see significantly worse attainment (in addition to much worse attendance) and so face a vicious circle of poor health, attendance, and attainment.

Our research shows that:

- Children living with diabetes are absent from **9 additional sessions a year** compared with children without diabetes.
- 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.
- **Children experiencing challenges managing their blood glucose levels are less than half as likely to attend University** compared to children without diabetes.

The Statutory Guidance '*Supporting pupils at school with medical conditions; statutory guidance for governing bodies and proprietors of academies in England*' (2015) 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. 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 (p23, 2015).

## **5. Unacceptable practices**

- **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 the child or their parents, or ignore medical advice or opinion**

*'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 specially 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**

- **If the child becomes ill, send them to the school office or medical room unaccompanied or with someone unsuitable;**

*'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**

- **Penalise children for their attendance record if their absences are related to their medical condition, e.g., hospital appointments;**

*'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 sciences 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**

*'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**

*'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**

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

*'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**
- **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 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 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 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**

- **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 need 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.**
- **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.

## **6. Conclusion**

We welcome the proposed new approach to area SEND inspections, with the focus on impact, outcomes and children and young people's views. We would propose that their experiences should be used as a starting point for inspections under the new framework. It would be useful to develop in partnership with children, young people, and their families a checklist of questions that they think each school should be asked when being inspected for their local area inspection. These could be based upon what support they receive to ensure that the Statutory Guidance on supporting children at school with medical conditions is fully implemented.