

Cyflwynwyd yr ymateb hwn i'r [Pwyllgor Plant, Pobl Ifanc ac Addysg](#) ar gyfer yr ymchwiliad: [A oes gan blant a phobl ifanc anabl fynediad cyfartal at addysg a gofal plant?](#)

This response was submitted to the [Children, Young People and Education Committee](#) for the inquiry: [Do disabled children and young people have equal access to education and childcare?](#)

AEC 68

Ymateb gan: **Diabetes UK Cymru**

Response from: **Diabetes UK Cymru**

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## **About us**

Diabetes UK's vision is a world where diabetes can do no harm. We lead the fight against Wales' largest growing health crisis, which involves sharing knowledge and taking on diabetes together.

Further information on diabetes can be found on our website.<sup>i</sup>

## **Do disabled children and young people have equal access to education and childcare?**

There are around 1,400 children and young people with Type 1 diabetes in Wales. These children need support in school to manage their condition well and ensure they reach their full potential.

While some receive excellent support, many have needed help to be fully involved in school life. We regularly hear from parents who have had to attend school to support their children, and in some cases, children have been unable to participate in school for long periods. This all adds to the daily pressures of life with a serious medical condition.

The Equality Act 2010 legally defines children with diabetes as people living with a disability; as such, Education Institutions and the NHS must ensure that students living with diabetes are not disadvantaged.

Measures to ensure children are supported include reasonable adjustments such as adequate space and time to manage their blood glucose levels and administer medication. Welsh Government regulations which support institutions such as schools are set out in the guidance by the Welsh Government. Further, the Additional Learning Needs Education Tribunal (Wales) Act 2018 shows how children and young people under 25 years with ALN should be supported.

## **Diabetes is different for everyone.**

We must first be clear that there is no uniform way someone living with diabetes will be, especially children. Some require little to no help to manage their diabetes; other children will need extra support or even have written permission

from the parent for the staff/teachers to administer insulin. It is essential that the child's needs are communicated with the school and that the school has taken the correct steps to provide the care and support needed for the child to be supported during their education.

### **Overall Public Understanding of Diabetes**

In a recent survey conducted during the Summer of 2022 of people living with diabetes as part of the 'Missing to Mainstream', DUK Cymru found that 37% of people living with diabetes continued to face stigma associated with their diabetes.<sup>ii</sup> The survey also found that 77.6% of respondents feel that the General Public doesn't understand diabetes at all or not very well compared to 26% of respondents giving the same response for Health Care Professionals (general) understanding. Therefore, a greater understanding of the condition is needed with welcomed awareness of hidden conditions such as diabetes by educational institutions, especially for lecturers and peers who may be unaware of the overall impact of the condition.

### **Impact of Diabetes in School**

Recent research reviewing the impact of living with diabetes and educational attainment found a negative association between diabetes and overall grade attainment. The most significant divide is found in physical subjects such as sports/athletics, with the least difference in subjects such as Mathematics.<sup>iii</sup> The study found that students living with type 1 diabetes generally are more likely to have an increased number of days away from school related to the condition. These missed education days related to managing the condition and diabetes burnout, a psychological by-product of living with diabetes, affected academic performance.

In a Diabetes UK survey of parents/carers of children with type 1 diabetes conducted in November 2021, 50.73% of respondents said that their child's anxiety and mental health around school had been negatively impacted by their diabetes.

There has also been an increase in the number of children with type 2 diabetes presenting at school, a relatively recent development; there is a growing need for support for children living with obesity and at risk of or having developed type 2 diabetes. Positive encouragement is needed at this most crucial stage of development to ensure that a positive relationship with food and exercise is developed and no mental illnesses are developed due to living with obesity in school.

## Complications

Living with diabetes in school has several complications that most children with long-term health conditions experience. These are some of the experiences that parents and School Nurses have recently informed us:

- **Delayed School start (after school holidays) for children.** Training and adequate planning must be conducted to ensure the children's safety at school. Unfortunately, this isn't the highest priority and is only finalised during the first few days of term. This means that children living with a long-term health condition find themselves at home for the first few days, missing education and alienating them from their peers who have returned.
- **Inadequate Staff Training.** In the most extreme circumstances, parents have had to move children from their school of choice or have been refused on the grounds of insufficient provision to support a child living with a long-term health condition adequately. In daily practice, this can also result in the parents of the children being called in if a technical issue with the tech that a child is wearing to manage their condition is unknown to the teachers or if the teachers do not feel comfortable managing a condition during school time.
- **Education Exclusion.** This could mean that a child cannot participate in a school day, an away day, eat a treat that has been brought in, or generally participate in a physical activity. Most of the time, the reason for not supporting and excluding a child is a lack of awareness of the condition and understanding of a child's needs and how they can manage their condition.
- **Medical exclusion.** Children with a long-term health condition like diabetes have a higher number of medical appointments, which can lead to higher absenteeism. This can lead to frustration being wrongly placed on the child for not attending classes and, in extreme circumstances, being punished. Punishment and frustration by teachers are also felt when a child may be using a mobile to monitor their condition.
- **School Meals.** Information from catering at schools to support parents and children living with diabetes can be found inadequate. Understanding the calories and carbohydrates of meals is essential to support insulin injection and adequate medication intake. Not all parents receive the information in good time to adequately prepare their children for school for the day. Because of this, children with long-term health conditions tend to be sent with packed lunches, which undermines schemes such as free school meals.
- **After School Clubs.** Usually, these activities are arranged by volunteers or single teachers for supervision. Unfortunately, provision for children with long-term health conditions is not provided, and children tend to be

excluded from participation on these grounds. This can lead to further social isolation and places a child at a disadvantage to their peers, as after-school provision can support a child's development and give more support to families from low socioeconomic backgrounds.

- **Teaching Impact on Students.** Management of a condition without adequate staff provision can impact the overall education of the child living with diabetes and their peers. Disruption to class to support a child with their condition can impact comprehensive lesson planning and the educational attainment of the course. Continued disruptions can lead to misplaced frustrations by the teacher and the students, placing a further psychological and social impact on the child.

## Reform

Working with parents like Zoe, who are facing difficulties with the current reforms to education provision, several petitions have called for further support with the implementation of the [Additional Learning Needs and Education Tribunal \(Wales\) Act](#).

The Additional Learning Needs (ALN) reforms affect around one in five pupils. The current Special Educational Needs (SEN) system was subject to review and proposed reform for over a decade until the 2018 Act. The current SEN system prescribed a three-tiered system. Under the 2018 Act, every learner with ALN will be given a statutory Individual Development Plan setting out their needs and what interventions they require. The new arrangements are being phased over three years, from September 2021 to July 2024.

Unfortunately, the transition has not been smooth.

There are currently two ongoing open petitions with over 6000 signatures on each, calling for a reform of the implementation and sharing concerns about its inability to support children with additional learning needs.

- [Review the inadequate funding for Schools in Wales](#)
  - 7007 signatures (20.09.23)
  - Many schools have set deficit budgets for 2023-24 financial year. More, perhaps most schools will be posting deficit budgets for 2024-25. The impacts on children in Welsh Schools are grave – poorer teaching and learning, poorer buildings, safety concerns and staff burnout.
- [Reform of the additional learning needs Code of Wales 2021](#).
  - 10,684 signatures (01.10.23)
  - Despite only a couple of years into the changes and promises of earlier and better support for children and young people with ALN,

more and more ALN pupils are being missed in Wales. There are also issues with consistency and accountability.

- There is still a large focus on Universal Provisions as opposed to the holistic approach of person-centred IDPs for ALN pupils. Pupils with mental health / physical disabilities should have equal access to support and a quality education.

Three further closed petitions have been sent to the Committee for debate, one of which Diabetes UK Cymru is supporting.

- [Accessible guidance for parents and schools to help develop plans to support children with additional learning needs.](#)
  - 347 Signatures
  - Supported by Diabetes UK Cymru
  - There are around 1,400 children and young people with type 1 diabetes in Wales. Children living with such disabilities need support in school to manage their condition and ensure they reach their full potential. As a mother, I'm one of many parents whose type 1 diabetic children don't receive the support they need because of a lack of understanding of funding to support the care required in school. I and others have experienced a deficiency of care support, and I am seeking to change this.
- [Fund more specialist school places and staff for children with additional learning needs in Wales.](#)
  - 1,429 signatures
  - To look at funding provided for specialist provisions in Wales for children with additional needs it's far from acceptable children with a high level of need being forced to stay in a mainstream environment due to spaces in schools and schools being underfunded and understaffed!
- [Review Additional Learning Needs policies & make it compulsory to FULLY train all teachers and TAs in regulation techniques](#)
  - 6,353 signatures
  - A review of the ALN policies in schools and a huge increase in support for the 40% of children who are struggling daily is needed. They need to be taught regulation techniques from early years, creating happier, less disruptive classrooms & providing a tool box to take through life. Long term, decreasing mental health issues, drug and alcohol abuse and lowering crime rates.
  - There are very few Welsh language Specialist Training Facilities discriminating against a right to Welsh medium education.

## Conclusion

Diabetes UK Cymru is calling for clear, financed and adequate support for children living with diabetes in school.

We want every child with diabetes to feel confident and safe at school.

Below is what we think good diabetes care in school should look like for every single child with diabetes:

- **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, locals 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.
- Parents should provide **up-to-date information** about their children's diabetes needs and all the supplies needed to manage diabetes in school.
- **Don't 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 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 taken into account.

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<sup>i</sup> Diabetes in Wales, accessed October 2023, [https://www.diabetes.org.uk/in\\_your\\_area/wales/diabetes-in-wales](https://www.diabetes.org.uk/in_your_area/wales/diabetes-in-wales).

<sup>ii</sup> Missing to Mainstream Summer 22 PLWD Survey, DUK Cymru, 2022

<sup>iv</sup> Announcement of new ALN Act [https://www.diabetes.org.uk/in\\_your\\_area/wales/news/more-support-children-young-families-diabetes](https://www.diabetes.org.uk/in_your_area/wales/news/more-support-children-young-families-diabetes)

<sup>iii</sup> Oakley NJ, Kneale D, Mann M, et al. Type 1 diabetes mellitus and educational attainment in childhood: a systematic review. *BMJ Open* 2020;10:e033215. doi:10.1136/bmjopen-2019-033215.