

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 74

Ymateb gan: Unigolyn

Response from: Individual

P-06-1341 Accessible guidance for parents and schools to help develop plans to support children with additional learning needs – Correspondence from the petitioner to the Committee, 31.08.23

Chair of the Petitions Committee

Welsh Parliament

Cardiff Bay

Cardiff

CF99 1SN

CC Diabetes UK Cymru,
Wales@diabetes.org.uk

Dear Mr Jack Sergeant.

31st of August 2023

I am writing to you regarding the ALN Act and the negative impact the current implementation is having on [REDACTED] and other families with children living with long-term health conditions like diabetes.

My son [REDACTED] was diagnosed at one and a half years of age; he was in DKA (diabetic coma). His Doctor was found to have been negligent in his duties and understanding of type 1 diabetes; during a medical examination before he went into DKA, his exact words were, "Kids don't get diabetes," and he refused to do a dip test.

This isn't the only challenge/difficult time my son has faced since being diagnosed with this lifelong condition, we have been struggling to gain adequate care since his school placement at the age of five to a school in [REDACTED]. I was told on the first induction day that it would be fine to accept him; after his first day, I was told not to bring my son back for the second induction day. I asked the school why this was, and their response was that he has type 1 diabetes and wouldn't be able to participate in cooking and other activities. As you can imagine, I was very upset by this, but that did not change their outcome.

During Covid, we started looking into other schools, and I settled on a Primary school in [REDACTED]. We sold our house in [REDACTED] and started making preparations for the move. The house in [REDACTED] had to be near the school as he couldn't walk long distances. With the new school placement, we thought things were looking up for [REDACTED] as they arranged training for the staff and had a care plan in place. Unfortunately, the plan wasn't being followed, and my son's blood glucose levels were left to drop to dangerous levels (1.9), when I enquired I was told he hadn't been given his hypo treatment. Unfortunately, this was a consistent pattern, where there were continuous errors in his care to the point where I considered homeschooling; however, although in [REDACTED]'s medical best interest, this would impact his education and lifelong learning as he would miss interacting with friends, classmates and teachers.

We shouldn't have to consider this because of his lifelong condition.

Frustrated, I started a petition highlighting the lack of support for my son and other children like him and the challenges they were going through. It wasn't until I sought out help from outside sources (Diabetes UK) that I was given support. Like many families, we have no way of knowing how to get the help and support needed to tackle/help the situation we face. With the ALN Act's slow

implementation, schools still fail to give basic care. In my son's school, the current ALNCO who is in charge of the care of the children with medical/additional needs, has had long periods of absenteeism with no remedy to support the children's needs. One of the ongoing issues is the need to train a teacher to help manage [REDACTED]'s Type 1 diabetes (pump training), which his diabetes team still hasn't been contacted to arrange. This is after twice verbally informing the school that they have tried contacting the ALNCO and need to arrange it before term begins.

My son isn't the only one. Another child who is losing their eyesight is also facing difficulties, which should have been supported three weeks ago and is still (at the time of writing this letter) waiting for support. The child and their family are also facing similar problems that we are facing with [REDACTED], with parents kept in the dark waiting for the school to get its act together.

This is also not an isolated incident in [REDACTED]'s school. Several other parents from different schools across Wales have been in touch, sharing similar problems we have faced. We are all finding it difficult to support our children and gain the funding the ALN Act has in place to support them in school. It is frustrating, especially when we have been fighting for basic care for years. It is unfair for our children, as they face concerns and troubles managing their long-term health condition whilst also learning in an environment that is challenging to any child.

My son is losing the TA (teaching assistant), who has been his main caregiver for the last two years. The school's assessment found that [REDACTED] requires additional support; unfortunately, the school has informed me that they cannot grant 1:1 care due to funding constraints. His care for next year has not been planned out. Working with his diabetic team, I have been chasing for an update on his care to no avail. When writing this letter, we had no update days before [REDACTED] is due back on the 6th of September. Current staff shortages mean that the school cannot adequately provide and assess support for children like [REDACTED]. This is not fair and needs to change.

Type 1 diabetes is a serious condition; my son's, H1ba1c levels are inconsistent, which are influenced by everything from exercise to the weather, which impacts him on a daily basis, missing out on a lot of activities such as playtimes, school plays/practices and more importantly time in the classroom.

He has a low immune system and picks up illnesses easily, which has a knock-on effect with his ketones as his body finds it harder to fight things off; this is the same for all kids like [REDACTED] with additional health issues. What frustrates me more is that these concerns are stated in his school report, that his health condition is affecting his ability to learn, something I thought that the ALN Act provisioned for. Sadly, I am informed that there is nothing I can do about my son's diagnosis but what can be changed is the support system in place for kids like [REDACTED], who clearly need extra support in school.

I and other parents like me need to be informed of how we can access the care and provision that the ALN Act is meant to provide for and, failing a provision by the Act, continued support under the Equality Act 2010. Which [REDACTED]'s school and other institutions like it are failing to meet.

Thank you for taking the time to review my petition; I hope we can develop positive changes that can help my son and other children living with long-term health conditions like diabetes.

Kind regards,

[REDACTED]

[REDACTED].