

Cynulliad Cenedlaethol Cymru | National Assembly for Wales

Y Pwyllgor Plant, Pobl Ifanc ac Addysg | Children, Young People and Education Committee

Bil Anghenion Dysgu Ychwanegol a'r Tribiwnlys Addysg (Cymru)| Additional Learning Needs and Education Tribunal (Wales) Bill

ALN 41

Ymateb gan: Rhwydwaith Diabetes Plant a Phobl Ifanc Cymru (a Grŵp Aberhonddu)

Response from: Children & Young People's Wales Diabetes Network (& Brecon Group)

This response is from the Children and Young People's Wales Diabetes Network (and Brecon Group), an all-Wales clinical network that includes paediatric consultants and specialist registrars, paediatric diabetes specialist nurses, paediatric dietitians and child psychologists. Our members represent all 14 paediatric diabetes units in Wales, in six health boards, working with all 1,500 children who receive care for diabetes in Wales. In total this is over 70 NHS staff directly responsible for the health of children with diabetes.

Type 1 diabetes is a life threatening, chronic, life-long health condition that can present spontaneously and unpredictably at any time during childhood. Type 1 diabetes occurs when the body is unable to produce insulin, a hormone vital for the regulation of blood glucose levels. Once diagnosed, children and their family/carers must balance all the factors that affect blood glucose levels.

The primary treatment for Type 1 diabetes is insulin replacement, which commences on the day of diagnosis and consists of 4-6 insulin injections per day or the permanent attachment of a device called an insulin pump, which introduces small amounts of insulin at regular intervals. Children, their family and any carers (including school staff) have to learn the practical elements of diabetes management. This includes injection technique or how to use an insulin pump, calculating insulin doses, blood glucose monitoring, carbohydrate counting, and managing activity. Even with high levels of support, Type 1 diabetes is a complex condition to manage well as there are many aspects of daily life that affect blood glucose levels, for example, stress and emotions.

Ensuring stability of blood glucose levels helps to protect children from developing health complications in their adult life and helps them to grow and develop normally, to feel well on a day-to-day basis, which will promote the engagement in normal childhood activities and fully engage in their schooling. Normalising blood glucose in childhood has a protective effect that helps to minimise the risks of developing the devastating health complications that arise from long-standing abnormal blood glucose levels. These include blindness, kidney failure, limb amputation and premature death.

Our Network has previously replied to the consultation regarding medical needs in schools. We informed that consultation that many of our members interact regularly, often several times a week, with schools and so we believe we are uniquely placed to comment on how the medical needs of children should be met during school hours. We value our partnerships with school staff to ensure that children and young people with diabetes receive an excellent chance of living as normal a life as possible, which is one of the primary aims of the Welsh Government's Diabetes Delivery Plan. Over fifteen per cent of a child's life is spent in school, so diabetes needs to be managed in this environment.

In addition to the physical effects of diabetes, schools need to actively support children and young people with diabetes or risk causing psychological harm to them. Children and young people with chronic medical conditions have a two to threefold increase in the risk for developing psychiatric disorders than their healthy peers. Childhood chronic illness can severely impair psychosocial functioning and impede development in all domains of functioning (psychological, social, developmental, academic). The effects of living with a chronic health condition can be mitigated by children experiencing as much normality in their lives as possible. Without a statutory duty for schools to support children with medical needs, the burden of care often falls to parents meaning parents are required to be present in the school environment which is not be a normative experience for a school aged child. Further psychological burdens caused by unsupportive schools include increased and extended dependency and reduced independence, reduced responsibility and autonomy, familial conflict caused by parents having to take an active role in treatment, greater

levels of stress and anxiety, and feelings of isolation and being different to their peers, which places them at greater risk for developing psychiatric disorders.

The treatment and management of diabetes can interfere with time spent within the school environment which is the child's primary social setting. If children have limited access to the school environment their ability to establish and maintain peer relationships will be impaired. When parents do not feel supported by their child's school it increases the likelihood that children will be kept home from school. Equally our Network members are aware of many situations where schools have not permitted the child to attend school without additional support, thereby increasing the time that the child is unable to access their primary social environment. These increased absences have a detrimental effect on the child's emotional, social and academic development. If a school does not support a child with diabetes, fluctuating blood glucose levels will have a negative impact on a child's ability to concentrate increasing the time that the child is unable to access the curriculum.

While our Network fully supports the general principles of the Additional Learning Needs and Education Tribunal (Wales) Bill, we are disappointed that the Bill and accompanying Framework does not include medical needs. Medical conditions are not included in the Bill and therefore, currently, a child with diabetes is not included under the parameters of the Bill. Evidence gathered by our Network shows many children with diabetes only receive care in schools through the current system, including Statements. This system will be withdrawn from all children once the Additional Learning Needs and Education Tribunal (Wales) Bill becomes law. Therefore we are certain that under the proposed Framework, the Bill will damage the existing fragile system of support for children with medical needs.

We welcome the intention of Welsh Government to create legislation that is fit for purpose, guarantees equity of rights, is fair and secures the rights of children. However, the children and families we work with on a daily basis will not be entitled to any of the benefits of these ambitious reforms. We ask the Committee to address the issues presented as a matter of urgency as a

failure to do so will present an unprecedented safety risk to some of the most vulnerable children in Wales.

Children with medical needs face very similar issues to children with additional learning needs. Sections 3.1 and 3.2 of the Explanatory Memorandum describe the issues that are faced by children with medical needs/chronic conditions, such as diabetes. The reality of the culture of management of medical needs and SEN is not reflected in the reforms. The allocation of funding and the provision of support are not acknowledged in the Framework. The Bill therefore poses a threat to existing arrangements, many of which have been secured at great effort and cost, for children with diabetes.

It is difficult to reconcile the provision for additional learning needs with a lack of provision for life-threatening medical conditions. We are concerned that children, families, school staff and Local Authorities will consider children with medical needs as less important and their education is of lower priority. We believe there is a tangible danger that this will result in children with medical needs not having the same protection and guarantees. The bill will therefore reduce equity in provision and remove support and funding from vulnerable children.

The committee has asked whether there is a need for legislation. In the case of a duty of care for children with medical needs, we believe this is indisputable. As a Network we are part of the wider Children and Young People's Diabetes Network, which includes ten regional networks in England. We know therefore that it is much more difficult to provide assistance and guidance to families, schools and Local Authorities in Wales, where there is no explicit duty to cover medical needs. Families in Wales are at a considerable disadvantage compared to families in England ever since the introduction of the Families Act in England in 2014.

The current guidance 'Access to Education and Support for Children and Young People with Medical Needs' has failed to protect children with medical needs from being denied care in schools or from being excluded from opportunities to participate in school activities. We have published evidence showing the guidance is ignored by a large number of schools because it is

not backed by statutory requirements on schools to care for children with medical needs.

Our Network has commented and advised on the revision of 'Access to Education and Support for Children and Young People with Medical Needs', which we note has now been delayed in publication again. We would advise the Committee that we have seen nothing in the draft versions of this guidance to suggest the new guidance will prove any more effective than previously. All it does is underline the fact that there is no explicit statutory requirement for schools to care for the medical needs of children during the school day. The Welsh Government team working on the new guidance seem to think existing legislation provides a statutory duty of care. This is not true. The legislation they cite is ineffective now and will be just as ineffective when the guidance is published. Our consistent advice throughout this process has been for a statutory duty of care in schools. This has been ignored.

We believe the Additional Learning Needs and Education Tribunal (Wales) Bill is the ideal opportunity to create a statutory duty of care for children with medical needs in schools and educational settings. We would point to the following benefits of creating such a duty:

- (i) Impact of inclusion of medical needs into the statutory framework on schools who already positively engage with families and healthcare teams
 - Provide assurance and protection to families, their staff and Local Authorities that they are doing as instructed and required by law.
 - Enable them to check/reference the care that they have in place or are planning to put in place to parents and set expectations for all parties.
 - Assist in dispute avoidance prior to the need for dispute resolution.

- (ii) Impact of a statutory duty on schools who do not engage with families and healthcare teams
 - Schools will be unable to ignore Welsh Government guidance.

- Children with chronic conditions will gain full access to all educational opportunities, including activities they are currently excluded from.
- Through better care during the school day, children will achieve better health outcomes – which will follow them throughout their lives. We know that improved diabetes control at a young age can dramatically reduce the risk of complications in later life, including blindness and vascular disease leading to limb amputation.
- There will be fewer costly and time-consuming disputes between families, schools and local authorities.
- Children with medical conditions will be much less likely to miss school. There are some children with diabetes who are prevented from attending school for several weeks at a time.

The committee has asked if there are any potential barriers to the implementation of the key provisions and whether the Bill takes account of them. We believe the failure to include provision for medical conditions on the face of the Bill is a major barrier to achieving the aims and objectives of the Bill. We would point the Committee to the ALN Research paper, where it states that schools and colleges should provide support for basic health needs, such as medication (see page 49:

<http://www.assembly.wales/Research%20Documents/16-059%20SEN/16-059-Web-%20English.pdf>)

The Committee has also asked whether there are any unintended consequences arising from the Bill. We believe there are several unintended consequences from a medical conditions perspective:

1. Some medical conditions are well established as disabilities under the Equality Act 2010. In practice, some conditions would be included under the ALN Framework and others will not. This will result in a ‘conditions lottery’ with certain children being protected in law and others left with no protection, depending on their diagnosis.
2. A child with a chronic, life-threatening illness will always need additional provision, but this is not recognised in the Bill. This will create a ‘two tier’ system and children with medical needs will be disadvantaged.

3. There is a risk that not including medical conditions will threaten the willingness of staff who currently provide care on a voluntary basis and will deter those who want to provide care. This means current care provision could be removed.
4. If the only way to gain support and funding, the Bill as it stands may cause families to seek diagnosis of a learning difficulty, even where this is hard to prove, in order to secure ALN funding.
5. The Code is a statutory document. Sections 6.38 – 6.42 describe medical conditions management under the title of ‘Initial considerations – medical needs’. Section 6.38 signposts the reader to the non-statutory guidance document. However, is not clear what the relationship is between the two documents. The statutory document instructs the reader to follow a non-statutory document that fails to guarantee any support to children with medical needs. Clarification is needed with regards to this mixed-messaging in order to support schools and educational staff to deliver appropriate support to children/young people with medical needs.
6. The Bill will make gaining support for children with medical needs even more difficult for families. In particular, the following measures in the Bill will endanger children with medical conditions:
 - (i) The removal of statements: Some children with medical conditions currently have statements. Statements will be made obsolete in the Bill and therefore children with medical conditions will have their support that is provided through Statements removed. We know of parents who have removed their child, or had their child excluded, from school because of a lack of available support or because they are fearful of the quality of available support. They in turn miss days in their own employment and in some cases have even stopped working because of this. These situations will increase sharply if the Bill fails to address and resolve this.
 - (ii) The removal of 1-2-1 support: Some parents tell us that they agreed for their child to receive 1-2-1 support following pressure

from the school and as a compromise. In practice, this support is issued under the same LEA funding and so will also be removed if medical conditions are not included in the reforms.

7. Comparison of rights/support

The table below compares the guaranteed level of support for children with ALN with that guaranteed to children with chronic and life-threatening medical conditions:

| ALN Framework | Medical Needs Guidance | Comments |
|---|--|---|
| Individual Development Plan (IDP): Issued to all children with ALN regardless of complexity of need. Document is legal and enforceable. | Individual Health Plan (IHP): States that “not all learners with healthcare needs require an IHP”. If IHP in place, it has no status/weight if non-compliance is an issue. | Decision to create IHP rests with Head Teacher and not health staff. Needs of some children with medical conditions may be greater than those on the less complex ALN spectrum. |
| Mandatory / Enforcement | Non-mandatory / no enforcement | Guidance does not address non-compliance by parties |
| Clarity | Insufficient detail | |
| Tribunal access and rights of appeal | No Tribunal access or rights of appeal | Education Tribunal has no jurisdiction over Health services or health cases. |
| DECLO role | No access to DECLO | The DECLO role is a health/clinical role but it's remit will not cover medical conditions if they are not included |

The committee has asked about the financial implications of the Bill (as set out in Part 2 of the Explanatory Memorandum. The long-term financial implications for the NHS if children with diabetes are not supported in school and therefore have worse health outcomes is enormous. There are increased risks of major complications in early adult life for children with poor glucose control. For example, diabetes is the leading cause of blindness in Wales for adults under the age of 40. These risks increase as people with diabetes grow older.

We also recognise the stated aim of the Bill to establish a genuinely age 0–25 system, and would suggest the Committee closely analyse whether the NHS systems currently in use are set up to support this. The Bill will require close working between educational services and the NHS, but this will be difficult over paediatric and adult domains. There will undoubtedly be financial costs if the Bill requires service change in the NHS. (This is not a comment on the desirability or not of change; it could be very beneficial, but it will still incur costs.)

The committee have also asked about the capacity of the workforce to deliver the new arrangements outlined in the Bill. Currently, paediatric specialist diabetes teams provide training to schools. If medical needs are included in the Bill, then the current arrangement would not change, but this would be an important step in formalising this arrangement. There may be an impact on the education workforce, as schools would have to ensure that sufficient provision is made to ensure children and young people can participate in the whole school day and its activities. The current culture of employing 1–2–1 support workers is an expensive approach. Many schools train classroom staff to care for children with diabetes, which is a much more cost-effective and satisfactory method of providing care.

However, many parents and health care professionals raise concerns around the challenges they face when senior staff members at schools, such as Head Teachers or Deputy Head Teachers, do not allow staff to provide or oversee care for medical needs. The training of supply teachers also presents difficulties.

The Committee has asked if respondents could identify how the Bill could be amended to improve any aspects which they identify as inadequate. We are

concerned that currently rights of appeal/access to the Tribunal will not be available to families with medical conditions. There is currently no formalised mechanism to resolve disputes in an independent environment for medical conditions.

If the rights of children with medical conditions were protected by the Bill, then we believe it would considerably reduce the number of families being forced to take extreme measures, such as legal advice, to resolve disputes. The clarity of the documentation in England following the introduction of the statutory duty has shown that it can in itself act as a tool for dispute avoidance in the first instance, without the need for dispute resolution options. This is a crucial lesson for the Committee to bring to the attention of lawmakers in Wales.

In conclusion, as healthcare professionals working daily with children with diabetes, our Network would strongly recommend the following:

- Inclusion of a statutory duty of care for children with medical needs on the face of the Bill.
- That accompanying statutory guidance be issued with the following minimum requirements to be put in place by schools:
 - (i) Medical Conditions Policy.
 - (ii) An Individual Health Plan for each pupil who has a medical need.

The Network would like to thank the Committee for extending this opportunity to raise these issues.