

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 50

Ymateb gan: Cymdeithas Ddeieteg Prydain

Response from: British Dietetic Association (BDA)

About the BDA and BDA Bwrdd Cymru

The British Dietetic Association (BDA) is the trade union and professional body representing the professional, educational, public and workplace interests of dietitians in the UK. Founded in 1936, we are one of the oldest and most experienced dietetic organisations in the world. The BDA has over 8,500 members.

BDA Bwrdd Cymru is made up of practicing dietitians representing the interests of the profession and members in Wales. This includes relationships with key stakeholders and representing the members in Wales at a UK level.

The general principles of the Additional Learning Needs and Education Tribunal (Wales) Bill and whether there is a need for legislation to deliver the Bill's stated policy objectives;

General principles

Dietitians work with children with a wide range of medical conditions of varying severity that have an impact on their ability to attend school and partake in normal school activities. Support from teachers and the school as a whole is very often vital if children are to successfully manage their condition(s) while maintaining the same standard of education as other children.

To take as an example a medical condition which dietitians deal with on a day to day basis, diabetes. There are estimated to be 1400 children with type 1 diabetes in Wales¹, all of whom will require ongoing healthcare support for the rest of their lives. Dietitians will often work with these children to help them manage their blood glucose levels by carbohydrate counting. In order to do this, the children require specific support from teachers and other school staff. This is not to mention other support with injecting insulin and other important elements of managing their diabetes. However, it is clear that not all school currently provide enough support. Surveys by

¹ https://www.diabetes.org.uk/In_Your_Area/Wales/Campaigning/Childrens-Campaign/

Diabetes UK Cymru found that 51% of families interviewed had had an issue with the care provided to their children, and 39% reported that their child's diabetes disrupted their schooling every day.²

We are therefore disappointed that the Welsh Government's proposed ALN Bill and accompanying Framework does not include medical needs. We believe that if steps are not taken to rectify the proposed Framework, the ALN Bill will unintentionally damage the existing fragile system of support for children with medical needs. We urge the Committee to address the issues presented as a matter of urgency and warn that a failure to do so will present an unprecedented safety risk to the most vulnerable children in Wales.

Most worryingly, the reality of the current culture of management of medical needs and SEN is not reflected in the reforms. The role of the current model in the allocation of funding, the provision of support and the role of SENCOs in medical needs management etc. is not acknowledged in the Framework and, as such, the ALN Bill poses a threat to existing arrangements. There is a real risk that current provision for children with medical needs could be removed with no means of replacing it under the new system put in place by the ALN bill.

More generally, it is difficult to understand why the provision for additional learning needs should differ from that for children with those for life-threatening medical conditions. We are concerned that aside from the specific impacts of the proposed reforms, the message to children, families, school staff and Local Authorities is that children with medical needs are less important. In practice, there is a danger that this will result in the de-prioritisation of this group by schools and local authorities.

Whether there is a need for legislation

While the BDA understand that the Welsh Government plans to update the current guidance for children with medical needs in the near future with the release of *Supporting Learners with Healthcare Needs*, we believe the current statutory framework will remain too ambiguous.

We believe that the current voluntary approach means that the guidance is ignored by a number of disengaged schools because it is insufficiently directive, lacks clarity of roles and fails to set out basic requirements in delivering effective support. The gaps in practical advice and specific allocation of roles, as well as optional duties contained

² <https://www.diabetes.org.uk/Documents/campaigning/make-the-grade/Type%201%20diabetes%20in%20schools%20in%20Wales%20-%20An%20Excellent%20Chance.public.pdf>

in the draft allows for inaction. Any revision of the 2010 guidance which does not address the lack of oversight, direction and the underpinning legal framework will not succeed in improving the position of children with medical conditions.

We support the reasons outlined by Welsh Government for reforming the system of support for children with Additional Learning Needs, such as having legislation that is fit for purpose, guarantees equity of rights, is fair and that underpins the rights of children. We strongly believe there is a need for reform of legislation as it applies to children with medical needs for exactly the same reasons. Indeed, sections 3.1 and 3.2 of the Explanatory Memorandum describe exactly the issues faced by children with medical needs as much as children with SEN.

Benefits of inclusion of healthcare needs in the statutory framework set out in the ALN bill:

- Will provide assurance and protection to families, school governors and staff, healthcare professionals and Local Authorities that they are doing as instructed and required by law.
- Enable families 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.
- Ensure consistency across Wales that is currently lacking.
- Assist in dispute avoidance prior to the need for dispute resolution through the renamed Education Tribunal for Wales.
- Children with medical conditions will achieve better health and education outcomes, with decreased costs to the NHS as a consequence.

Whether there are any unintended consequences arising from the Bill;

Medical Conditions classed as a disability

Some medical conditions are well established as disabilities under the Equality Act 2010 and therefore in practice, some conditions would be included under the ALN Framework and some wouldn't be. The proposed ALN Framework fails to acknowledge, clarify or address this. The Supporting Learners with Healthcare Needs draft guidance also fails to do this. This has a number of potential consequences:

- Widen the existing gap between the 'have/have nots' in terms of support for medical needs, which is already unacceptably wide (as described above).
- Intensify the battle to obtain the best available level of support. 'Statement versus No Statement' would be replaced with 'ALN rights or no ALN rights'. It

may also risk unnecessary diagnosis of a learning difficulty in order to secure ALN funding.

- Result in confusion in practice and an assumption that non-clinical education roles have a level of specialist or clinical knowledge.
- Risk that not including all medical conditions will threaten the willingness of staff who currently provide care on a voluntary basis and will deter those who would like to.

The existing legislation also fails to take account of children/young people with a medical condition in addition to a learning difficulty/disability. There is no recognition of this group, although it is not uncommon for a child to have both.

Mixed messaging

The proposed ALN Code is a statutory document. Sections 121 - 124 describe medical conditions management under the title of 'Initial considerations - medical needs'. Section 121 signposts the reader to the non-statutory Supporting learners with healthcare needs guidance document. 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.

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 & 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 |
| Campaign to raise awareness | No plan to raise awareness | |

Whether there is enough clarity about the process for developing and maintaining Individual Development Plans (IDPs) and whose responsibility this will be;

We would argue that the relationship between IDPs and IHPs (in either their current guise or any future iteration) remains unclear and warrants further consideration.

The capacity of the workforce to deliver the new arrangements;

Whilst we recommend that a statutory duty be introduced, we fully acknowledge that this cannot work in isolation and needs to be supported by an adequate workforce.

The proposed draft document does not offer a solution if no school staff members are willing to volunteer as the person responsible for medical needs. We believe it is important that the government considered how it will reconcile voluntary roles with the provision of consistent and effective support for a child with complex medical needs when away from home. The voluntary capacity means that some schools do not deliver support as they should or rely on parents to attend school premises.

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, are very reluctant for any staff to be responsible for medical needs. Some

explain that they experience delays in schools signing off staff members who have received training, whilst others describe capacity issues where no staff are available to provide the required level of care.

The proposed new arrangements for dispute resolution and avoidance. It would be helpful to the Committee if respondents could identify how the Bill could be amended to improve any aspects which they identify as inadequate.

Parents approaching NHS with issues and not education, as there is no 'Putting Things Right' equivalent in Education.

Rights of appeal/access to the Tribunal are not available to families with medical conditions under the current draft of the bill. There is currently no formalised mechanism to resolve disputes in an independent environment for medical conditions.

If medical conditions were part of the Framework, we believe that 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 crucial to the lessons for Wales in taking the reforms forward.