

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 40

Ymateb gan | Response from: Diabetes UK Cymru

General principles: We are disappointed that the Welsh Government's proposed ALN Bill and accompanying Framework does not include medical needs. We ask the Committee to address this as a matter of urgency and warn that a failure to do so will present an unprecedented safety risk to some of the most vulnerable children in Wales.

Providing assistance to children whose needs are additional or different in schools is delivered by the same systems, processes, agencies, funding streams and staff roles in practice. Systematic changes to any part will affect all of that system's beneficiaries, not some of them. This is not reflected in the ALN reforms. The Bill will remove and replace long-standing funding arrangements, such as statements. Medical conditions are not included in the reforms but some children with medical needs have statements. There is a real risk that the 'old' funding will be removed and that schools/LEAs will not be able to reallocate this for medical conditions support.

The difficulties of the current system are faced by any children needing additional support. Children with medical needs face the same issues as laid out in Sections 3.1 and 3.2 of the Explanatory Memorandum. These are exactly the issues faced by children and their families in the current system, which the reforms hope to change and improve.

The ALN Bill will introduce a new system of rights and benefits to children under the new Framework, such as rights of appeal to the Tribunal. Children with medical conditions will not have the same rights and benefits outside of the ALN Bill and under the revised Welsh Government guidance, even though they may be living with a life-threatening condition and may have more complex needs than the groups of children who will come under the ALN Framework.

It is difficult to reconcile the support for the proposed groups of children under the ALN Framework with that provided to children with medical needs. Elsewhere in the UK, medical conditions at school are protected in legislation but they aren't in Wales. We are concerned that aside from the tangible 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 real danger that this will result in the de-prioritisation of this group. As such, if steps are not taken to amend the ALN Bill, it poses a threat to existing arrangements for the families who we represent.

Should medical conditions be included in the proposed Framework, we would very much welcome the general principles of the Bill and believe that they would play a fundamental part in addressing and resolving key issues that have emerged in recent years.

Whether there is a need for legislation:

1. **Guidance alone has failed.** Evidence shows that having guidance alone has failed across multiple demonstrable areas and that it is ignored by a number of schools. The gaps in practical advice and specific allocation of roles, as well as optional duties contained in the draft allows for inaction by all involved parties. The 2017 guidance will also fail, irrespective of how well it is written, if it not underpinned by legislation.
2. **The need for reform.** Diabetes UK and a number of other leading children and health organisations across the UK are calling for reform in Wales of the current support for medical needs. The updating of the 2010 guidance document does not constitute reform. It has produced and is still producing variable care for children across Wales. This results in some children being disproportionately negatively affected, for example, by exclusionary practices or by high levels of parental involvement in the school day.
3. **Providing assistance to families.** Organisations providing UK-wide support agree that it is much more difficult to provide assistance and guidance to supporters, schools and Local Authorities in Wales, where there is no explicit duty on schools. It is much easier to support all parties when a legislative duty exists.
4. **Current legislation.** Welsh Government has stated that a number of laws already apply in this area and so there is no need to duplicate this. Current pieces of legislation are not fit for purpose for the following reasons:
 - (a) They do not contain an explicit duty for medical conditions/needs.
 - (b) They do not differentiate between a child with a medical condition and one without a medical condition.
 - (c) They do not adequately apply to the management of medical conditions (i.e. 'promotion of wellbeing' is not the same as medical conditions management/support in a school setting).

- (d) They have applied for a number of years in Wales (some upwards of 10+ years) but our contact with all involved parties' shows that they have had no clear impact on this area.
- (e) They all applied in England prior to the Children & Families Act 2014. Lessons from England show that the stated laws were inadequate in providing for medical conditions and therefore steps were taken to legislate specifically for medical conditions.
- (f) Several of them present challenges for the ALN Bill, for example the Equality Act 2010 (detailed below).

5. The impact of legislation on schools.

(i) Schools who positively engage:

- Minimal impact, if they are already managing medical conditions appropriately.
- Enable schools to provide assurance and protection to families, their staff and Local Authorities that they are doing as instructed, expected and required by law.
- Enable them to check/reference the care that they have in place or are planning to put in place and to set expectations for all parties. This in turn assists in dispute avoidance, reducing the likelihood of parties accessing dispute resolution options. Anecdotal evidence from multiple organisations shows that this is the case in England since a statutory duty was introduced in 2014.
- Provide assurance to schools who want to support their pupils but fear a litigious culture.

(ii) Schools who do not engage:

- High impact in targeting schools who are not engaging.
- Empower all parties to address non-compliance and set expectations.
- Mandatory for all parties to engage with medical needs.
- Address enforcement issues. Diabetes UK welcomes the language used across a number of areas in Welsh Government policy recently where it has been stated that when a voluntary system has not been effective, or where there have been enforcement issues, Welsh Government will look to include these within legislation.
- Dispute resolution via rights of appeal to the Tribunal.
- Over the longer term, this will result in culture change.

(iii) Impact of legislation in England: Lessons for Wales:

Early indicators document a clear increase in schools' engagement with medical conditions. Comparative evidence gathered annually by Diabetes UK shows that the situation in England is improving year on year in the following areas:

Indicators	2013	2014	2015
1. Percentage of parents who are satisfied with the diabetes care provided to their child at school	67%	71%	72%
2. Percentage of parents who state that an individualised care plan is in place at school which meets their child's needs.	51%	66%	85%
3. Proportion of schools that have access to Type 1 diabetes training	66%	66%	73%
4. Proportion of schools with appropriate policies and procedures in place to provide children with Type 1 diabetes with consistent, individualised care (including IHP that cover extracurricular activity)	7%	58%	71%

*Figures from 2013, 2014 and 2015 annual surveys of over 400 parents and schools conducted by Diabetes UK.

Recommendations for Wales

We strongly recommend that:

- A statutory duty be included on the face of the Bill to support pupils with medical conditions.
- 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.

• **Whether there are any unintended consequences arising from the Bill;**

The Bill has several unintended consequences from a medical conditions perspective:

Consequence 1: The definition of ALN

Although not explicitly mentioned on the face of the Bill, there are a number of ways in which medical conditions would come under the Framework. They are:

- (1) Via the Equality Act 2010
- (2) Via an Additional Learning Provision (ALP) requirement
- (3) Via the Code of Practice

A flowchart of the Bill's definition sections is included at the end of this document.

(1) **Equality Act 2010:** In determining ALN, the Bill uses the Equality Act 2010 as part of its definition (Part 2, Chapter 1, Section 2 (b)). Some medical conditions are well established as disabilities under the Equality Act 2010. This would introduce tiers of medical conditions into the ALN Framework. In theory, some conditions would be included under the ALN Framework and some wouldn't be. All documentation relating to the proposed ALN Framework fails to acknowledge, clarify or address this. The table below shows well-known conditions that fall into these categories and their status under the Equality Act 2010. It follows that this would also determine their status for the ALN Framework:

Disability	Sometimes a disability	Not a disability
Type 1 diabetes, ME & CFS, Epilepsy, Motor Neurone Disease, Fibromyalgia, Depression, Schizophrenia, Mental Health Conditions (anxiety, phobias, eating disorders, bipolar disorders, obsessive compulsive disorders, self-harm), Rheumatoid arthritis, Dementia, Muscular Dystrophy, Systemic Lupus Erythematosus (SLE), Respiratory Conditions, Cardiovascular Disease (thrombosis, stroke & heart disease), Cancer, HIV infection/AIDS, Multiple Sclerosis, Allergies, Stammering, Relatives of any of the above via associative disability discrimination	Arthritis Allergies	Asthma Addictions (unless a result of prescription medication) Hay fever (unless aggravates another condition) Other conditions that are not long-term

Also of note is the fact that the Equality Act, in determining whether a condition is a disability, places emphasis on the effect of an impairment and not its cause.

(2) **Additional Learning Provision (ALP):** Section 6.13 of the Code of Practice states that: *If a person has a learning difficulty or disability which calls for ALP, the individual **must** be considered as having ALN for the purposes of the Act.*

It is not clear which additional groups of children this section applies to, as most who require this type of support are already explicitly listed in the Framework. ALP is defined as any support that is 'additional to or different from' (defined as 'that which goes beyond that generally made available') that which is

provided to others of the same age in mainstream education. A child with a chronic condition will always need this type of support. In the case of Type 1 diabetes, failure to provide appropriate monitoring and treatment for the duration of a school day can be fatal. A young child with Type 1 diabetes will always need intervention of some kind by an adult. Funding in Wales has been used for medical conditions support for several years in schools which constitutes ALP.

(3)**Code of Practice:** The Code is a statutory document. Sections 6.38 – 6.42 describe medical conditions management under the title of ‘Initial considerations – Healthcare needs’.

Section 6.38 signposts the reader to the non-statutory guidance document. What is the relationship 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 enable all parties to deliver appropriate support to children/young people with medical needs. In addition, the support described in the guidance document would constitute ALP, which would send the reader back under the statutory ALN framework.

Section 6.42 states that an IDP may be updated at the same time that another plan is updated, for example an Individual Healthcare Plan (IHP). The guidance document states that not all children with medical conditions will need an IHP. It goes even further in saying that the final decision on whether a child needs an IHP rests with the Head Teacher of the school. The Head Teacher is unlikely to have the clinical knowledge necessary to make this decision. They are also a key decision maker in granting funding for support and are influential in a school’s inclusion/engagement with medical conditions.

Potential consequences to the definition-based issues:

- Widen the existing gap between the ‘have/have nots’ in terms of support at school, which is already unacceptably wide.
- Intensify the battle to obtain the best available level of support. ‘Statement versus No Statement’ would be replaced by ‘disability or no disability’, with ‘ALN rights or no ALN rights’ inextricably linked.
- Result in confusion in practice and an assumption that non-clinical education roles have a level of specialist or clinical knowledge that they simply do not have.
- What message does this send to families in Wales?

Consequence 2: Medical condition in addition to ALN

What of children and young people who have a medical condition in addition to a learning difficulty/disability? There is no recognition of this group whatsoever, although it is not uncommon for a child to have both. This would introduce yet another additional tier into the Framework. It may also risk unnecessary diagnosis of a learning difficulty in order to secure ALN funding.

Consequence 3: The battle for statements & funding

The Bill widens the gap and intensifies the battle for support that goes against the very purpose of the reforms. In addition to the scenarios described above, the following measures in the Bill will endanger children with medical conditions:

- (i) The removal of statements: We hear regularly from parents who have removed their child from school because of a lack of available support/they are not confident that their child will be safe /fearful of the quality of available support. They in turn miss days in their own employment and in some cases have even lost or left their jobs because of this. We have heard from parents having to attend their child's school every 2 hours and have even had to move their child to another school.
- (ii) The removal of 1-2-1 support: Some parents tell us that they agreed for their child to receive 1-2-1 support as a compromise with the school to deter the parents from applying for a statement of SEN. It is well known that this is a less expensive option for schools/LEAs.

The above points will further entrench the issues that are currently in desperate need of resolving.

Consequence 4: Comparison of guaranteed support

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

Comparison of rights if ALN Bill passes in current format:

ALN Framework	Medical Needs Guidance
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. *Final decision rests with Head Teacher.
Mandatory / Enforcement	Non-mandatory / no enforcement
Clarity	Insufficient detail
Tribunal access & rights of appeal	No Tribunal access or rights of appeal
DECLO role	No access to DECLO
Campaign to raise awareness of new rights	No plan to raise awareness

NB: The DECLO role is a health/clinical role that will be based in each health board in Wales. Their remit will not cover medical conditions unless they are included in the reforms.

- the provisions for collaboration and multi-agency working, and to what extent these are adequate;

Health services are mentioned throughout but not children with medical needs.

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

IDP/IHP relationship is not clear and need consideration (as above). We support the use of an editable all-Wales template for an IDP/IHP.

- whether Bill will establish a genuinely age 0–25 system;

The NHS system is not set up to reflect this. Services are divided into paediatric and adult services.

- the capacity of the workforce to deliver the new arrangements;

- Currently, paediatric specialist staff provide training to schools for specific medical conditions, where possible. We know of instances where a small number of schools have declined this service and have even prevented NHS staff from entering the premises to carry this out. If included in the Bill, this non-compliance would be addressed and would be far less likely to happen. The majority of schools have welcomed the training. The Bill (if applicable to

medical conditions) would not change this but would be an important step in formalising this arrangement.

- School staff (ideally 2–3) volunteer to receive training for Type 1 diabetes management. We hear from school staff who are deterred from doing this by their teaching unions because of the lack of legal clarity in this area. We also hear from parents, school staff and NHS staff that school staff who want to volunteer are prevented from doing so by senior staff at the school. Not including medical conditions will threaten the willingness of staff who currently provide care on a voluntary basis and will deter those who would like to, both now and in the future. What message will excluding medical conditions send to those who are already concerned about their own legal protection?
- Situations do arise whereby there are no volunteers amongst existing school staff. In this scenario, funding is usually applied for external staff to come in to the school to provide support or the child's parents are expected to attend the school (sometimes as frequently as every two hours) to carry out diabetes-related tasks.
- Current culture of employing 121 support workers is an expensive approach.
- There is no recognition that SENCOs currently have responsibilities for children with medical conditions and no proposals on how this will be managed should medical conditions be excluded from the reforms.
- Education Tribunal has no jurisdiction over health services/medical conditions cases.
- Despite a high level of support provided by NHS staff and Paediatric Diabetes Specialist Nurses (PDSNs), this issue remains.

How do we reconcile a voluntary system with the provision of 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. There is an over-reliance on parents to attend school premises to provide treatment and where this is not viable, a child's health and/or education are put at risk when schools refuse to engage, resulting in parents removing their child from school.

• 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.

- Evidence shows that having a statutory duty in England has resulted in fewer parents resorting to dispute resolution (i.e. legal action) simply because all

parties are able to clearly reference their legal responsibilities and are aware of their duties.

- The escalation process in the Bill is a clear and sensible approach to dispute avoidance and dispute resolution for ALN. We know that the process can be time consuming. We welcome the time limits placed at certain points in the process but these are longer than we would hope for when a family is having to wait (i.e. 10 weeks).
- The guidance does not outline dispute avoidance/resolution but states the following:

Schools should also consider how the learning experience can be maximised to support children and young people to develop the knowledge, skills and emotional resilience required to uphold their own rights, the rights of others and to appropriately resolve conflicts. It should give specific focus to combating: "depression, eating disorders and self-destructive behaviours, sometimes leading to self-inflicted injuries and suicide...violence, ill-treatment, abuse and neglect, including sexual abuse, unrealistically high expectations, and/or bullying or hazing in and outside school." UNCRC General comment 4 (Creating a Safe and Supportive Environment).

- Families currently approach NHS channels and the third sector with disputes regarding medical conditions. Both sectors currently provide a high level of mediation and advocacy for families.
- The Additional Support Needs Tribunal in Scotland, to which children with medical conditions have access issued a landmark ruling for medical conditions in 2014. The Tribunal ruled in favour of a child with Type 1 diabetes when a local authority and school failed to put the right support in place. More information: <http://govanlc.blogspot.co.uk/2013/07/glc-scottish-test-case-win-for-school.html>. Whilst this does not set a legal precedent for the England/Wales judicial system, the decision can be considered a persuasive one and is a welcome step.

