

Epilepsy Action’s Response in respect of: Children, Young People & Education Committee Consultation on the Additional Learning Needs and Education Tribunal (Wales) Bill

Epilepsy Action is the UK’s leading epilepsy organisation. We exist to improve the lives of everyone affected by the condition. An estimated 32,000 people in Wales have epilepsy. Of those people, approximately 2,762 are of school age (*Source: Epilepsy prevalence, incidence and other statistics, Joint Epilepsy Council of the United Kingdom and Ireland, 2011 / office of National Statistics, United Kingdom; estimated resident population by region; Mid2010 Population Estimates*). For some children, epilepsy can have an effect on how easy or difficult it is for them to learn. This could be for a number of reasons, including the condition itself, the cause of the epilepsy, the effects of seizures, side effects from epilepsy medicines and absences from school.

Epilepsy Action believes that it is imperative that the ALN Bill and accompanying Framework includes medical needs.

One: Consider 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

Epilepsy Action is disappointed that the Welsh Government’s proposed ALN Bill and accompanying Framework does not include medical needs.

If steps are not taken to rectify the proposed Framework, the ALN Bill will damage the existing fragile system of support for children with medical needs. We ask 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.

We welcome the aspirational language used by Welsh Government in presenting the reforms, such as having legislation that is fit for purpose, guarantees equity of rights, is fair and that underpins the rights of children. We note with dismay that the children and families who we represent will not be entitled to any of the benefits of these ambitious reforms.

The matters described throughout are astonishingly similar to those of children with medical needs. Sections 3.1 and 3.2 of the Explanatory Memorandum describe exactly the issues faced by children with medical needs. The reality of the culture of management of medical needs and SEN is not reflected in the reforms. The allocation of funding, the provision of support, the role of SENCOs in medical needs management etc. are not acknowledged in the Framework and, as such, the ALN Bill poses a threat to existing arrangements for the families who we represent.

It is difficult to reconcile the provision for additional learning needs with those for life-threatening medical conditions. 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 danger that this will result in the de-prioritisation of this group.

Should medical conditions be included in the proposed Framework, we would welcome the general principles of the Bill.

Whether there is a need for legislation

The current guidance 'Access to Education and Support for Children and Young People with Medical Needs' has failed because of ambiguity across multiple demonstrable areas. Evidence shows that it's voluntary, non-directive approach means that it is ignored by a number of disengaged schools because it is insufficiently directive, lacked clarity of roles and failed 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 in the draft allows for inaction by all involved parties.

As a UK-wide organisation, it is much more difficult to provide assistance and guidance to supporters, schools and Local Authorities in Wales, where there is no explicit duty to cover medical needs.

The purpose of any guidance document is to ensure that it is fit for purpose and that there is oversight of its implementation. This is key to the context of updating the 2010 guidance, which has failed children with chronic conditions in Wales. The 2017 guidance will also fail, irrespective of how well it is written.

Two: Any potential barriers to the implementation of the key provisions and whether the Bill takes account of them.

The potential barrier is that children with medical conditions will be left behind. The Bill does not take account of this, as there is no duty on the face of the Bill for medical conditions. We welcome the lessons for Wales listed in the ALN Research paper, where it states that schools and colleges should provide support for basic health needs, such as medication. (page 49: <http://www.assembly.wales/Research%20Documents/16-059%20SEN/16-059-Web-%20English.pdf>)

Three: Whether there are any unintended consequences arising from the Bill;

There are several unintended consequences from a medical conditions perspective:

a) 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 some wouldn't be. The proposed ALN Framework and the Supporting Learners with Healthcare Needs draft guidance fails to acknowledge, clarify or address this. This may result in:

b) A child with a chronic, life-threatening illness will always need additional provision as described in the Bill, but this is not recognised. Some SENCOs have responsibilities for children with medical conditions and no proposals on how this will be managed. 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 would like to.

c) What about children/young people with 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 to those described above. It may also risk unnecessary diagnosis of a learning difficulty in order to secure ALN funding.

d) 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. What is the relationship between the 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.

e) The battle for support. The Bill widens the have/have not gap and intensifies the battle for support. In addition to the scenarios described above, the following measures in the Bill will endanger children with medical conditions:

- The removal of statements: Some children with medical conditions currently have statements. If these are removed by the ALN Bill and medical conditions are not included in the reforms, there is a very real safety risk. We hear regularly from parents who have removed their child 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 lost their jobs because of this. The number of these cases will increase sharply if the Bill fails to address and resolve this. Please see enclosed case study.
- 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. It is well known that this is a less expensive option for schools/LEAs. 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.

The above points will further entrench the issues that brought about the very purpose of the reforms – i.e. the variation of care, the inequity of access to care and the culture of those parents who shout the loudest receiving the best level of support.

f) 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 its remit will not cover medical conditions if they are not included.
Campaign to raise awareness	No plan to raise awareness	

Four: The financial implications of the Bill (as set out in Part 2 of the Explanatory Memorandum)

We would expect Welsh Government to cost correctly if included, with appropriate stakeholder input.

Five: The appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation (as set out in Chapter 5 of Part 1 of the Explanatory Memorandum.

No comment.

Specific Issues:

Points Six, Seven and Eight:

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

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

The IDP/IHP relationship is not clear and needs consideration.

Ten: Whether Bill will establish a genuinely age 0-25 system;

NHS system is not set up to reflect this.

Eleven: The capacity of the workforce to deliver the new arrangements;

Currently, paediatric specialist staff provide training to schools for specific medical conditions. The Bill, if applicable, would not change this but would be an important step in formalising this arrangement. Schools should ensure that sufficient provision is made to ensure CYP can participate in the whole school day and its activities. The current culture of employing 121 support workers is an expensive approach.

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. How do we reconcile voluntary roles 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, rely on parents to attend school premises and where this is not viable, put a child's health and education at risk.

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 training of supply teachers also presents difficulties.

Twelve: 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.
- Mediation/advocacy role of third sector at the moment. We currently provide a high level of support in this area to families, schools and Local Authorities. This is increasing.
- Rights of appeal/access to the Tribunal access are not available to families with medical conditions. 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.

Case study:

S is a seven year old girl from Mid-Wales. Her seizures started within two weeks of her being born. S's concentration is not very good. Her memory has been affected by surgery, seizures and her medication which suppresses her brain activity. She needs a quiet time every day, usually around 11am where she will get drowsy and may sleep. She has poor balance and left sided weakness, with no strength in her left hand and fingers.

Her mother has never been able to return to her full time employment as a result of S's epilepsy. She stays at home on call waiting for the school to ring to ask her to come and pick S up from. The school is not providing adequate support for S. Her mum reports the following:

"The school at one point said that they refused to keep her emergency meds there as they had not received up to date training, even though they had done it 10 months previously. I was forced to take S out of school as her life is at risk without access to emergency medication."

"Inclusion is a very big issue in school, they leave her out of many situations"

"They [the school] took ages to get a 1:1 worker, didn't advertise in correct places only where they needed to and for the minimum time. They do not think it's important to get the right person in place to support"

“There is no sickness cover for S’s 1:1 worker. Her 1:1 was told “you’d better not take time off””

“The school wanted S to move to the Unit. She was slightly behind having had major brain surgery in June 2016. She made an amazing recovery and was back in school in September. No contact was made by the school following her operation, no discussion about the transition period even though I’d contacted the school! I had been told by her health professionals that it was important for S to have calm and familiarity to aid recovery. On her first day back after surgery I was called into the office and told that S needed to be moved to the unit – I said “no way, she needs familiarity before even thinking about moving her, and she needs assessing first anyway!” The school said a week later that they had assessed her, and she needed to move. I refused. Again at October half term they told me I had to go in and sign to say that S could move to the unit. It took getting the head of Paediatrics in Powys and the epilepsy specialist nurse in London to telephone the school; her neurologist in Cardiff to write a letter and the Education Inclusion Officer for Powys to stop the move. I should have to fight the school”

“Up until last term it was agreed that S could have 1:1 support in the swimming pool when the class goes for lessons. The 1:1 was an assistant from another class who is also qualified as swimming instructor and lifeguard. Her usual 1:1 was there to provide dry side support, and I was there as emergency meds administrator. Since the autumn, the school have refused to release the other classroom assistant. This means that her usual 1:1 now goes in the pool, but she’s not qualified to properly help her. Because S is very off-balance, most of the time this 1:1 is holding on to her because she could go under at any time. This is affecting her confidence and isolating her from normal school activity”

“S is unable to run because of her poor left leg. No special measures have been put in place to allow her to be included in different activities”

“I would like a passport-type document to accompany S’s care plan, so that all teachers in the school are aware of her condition, what her difficulties are, her weaknesses, what she likes doing and what she enjoys”

If S was having this experience in England, she would be covered by the law protecting children in schools with medical conditions. It is disappointed that she is not currently afforded the same consideration in Wales.