

1. Summary

Young Epilepsy urges the Committee to support the introduction of a clear duty in the Bill for schools to support learners with healthcare needs. This would ensure accountability across Wales and would set clear expectations for schools, children and families.

2. About Young Epilepsy

Young Epilepsy is the national charity working on behalf of the 112,000 children and young people in the UK with epilepsy. With over 120 years expertise it provides world class diagnosis, assessment and rehabilitation for children and young people with epilepsy. It also has a specialist school and college, providing day and residential services, up to the age of 25, offering education and healthcare for children and young people with epilepsy and associated conditions. Young Epilepsy aims to achieve better futures for young lives with epilepsy and to raise awareness and understanding of epilepsy and issues associated with the condition. The charity provides support, information and training for parents, professionals and children and young people. It campaigns for better access to, and quality of, health and education services.

3. General principles of the Bill and the need for legislation

We are concerned that the Bill makes no provision for support for children with healthcare needs. It is crucial that schools have a clear legal obligation to provide support for these children.

4. There are more than 40 different types of epilepsy and its impact on children can be wide-ranging and profound. Schools must ensure that they have the necessary support in place to respond to seizures, as well as to meet the educational needs of children with epilepsy.

Research shows that 95% of children with the condition have a significant difficulty in cognition or behaviour, but these needs often go unrecognised. 42% of children with epilepsy are underachieving in at least one academic area.¹

5. We welcome the opportunity to improve the current guidance for schools on supporting learners' healthcare needs. However, without an explicit legal duty on schools to provide support to this group of children, the support across Wales will be inconsistent and the guidance will be unenforceable.
6. A legal duty to provide support for children with healthcare needs would set clear expectations for schools, learners and families. Supporting children with long term conditions at school can reduce absences, improve achievement and reduce the need for emergency medical intervention.
7. **Unintended consequences arising from the Bill**
Without an explicit provision for children with medical conditions, there is a risk that the Bill will increase confusion around what level of support schools should be providing for these children. For example, the draft ALN Code states that medical conditions 'may affect [children's] cognitive abilities, physical abilities, behaviour or their emotional state'.² However, the Code does not clarify whether this would be considered an additional learning need.
8. Another section of the Code highlights that children who have a medical diagnosis of visual, hearing or multi-sensory impairment are more likely to have additional learning needs. This section makes no reference to other specific conditions such as epilepsy which also increase the likelihood of having an additional learning need.³ Epilepsy is the most common serious neurological condition that affects children.

¹ Young Epilepsy (2014) *The identification of educational problems in childhood epilepsy: The Children with Epilepsy in Sussex Schools (CHESS) study*

² Welsh Government (February 2017) *Draft Additional Learning Needs Code*, para. 6.40

³ Welsh Government (February 2017) *Draft Additional Learning Needs Code*, para. 6.30

9. Without the inclusion of medical conditions in the Bill, school staff may be less willing to put themselves forward to provide support to children, unsure of their legal footing. In a number of schools, for example, SENCOs have responsibility for children with medical conditions, but this is not reflected in the legal framework set out in the Bill.
10. The Bill gives children with ALN the right to a statutory plan, ‘regardless of the severity of need’,⁴ but there is no right to a statutory plan for children with medical needs.
11. Under the proposed legal framework,⁵ there is provision for the medical needs of children with an Individual Development Plan (IDP) but not for the medical needs of children without an IDP. The Bill makes provision for a Designated Education Clinical Lead Officer (DECLO) to have responsibility for co-ordinating the Local Health Board’s functions in relation to children with ALN, but not in relation to the medical needs of children at school without ALN.⁶ This risks creating a two-tier system of support which would have a detrimental impact on the latter group of children.

Conclusion

As currently drafted, the ALNET (Wales) Bill risks creating inequalities in healthcare support at school between those children with identified ALN and those without. The Children, Young People and Education Committee should ensure that the Bill is amended to include a statutory right to school support for all children with healthcare needs.

⁴ Welsh Government (December 2016) ALNET (Wales) Bill Explanatory Memorandum, para. 3.56

⁵ ALNET (Wales) Bill, clause 23

⁶ ALNET (Wales) Bill, clause 55