

Cynulliad Cenedlaethol Cymru | National Assembly for Wales
Y Pwyllgor Plant, Pobl Ifanc ac Addysg | Children, Young People and
Education Committee

Blaenoriaethau ar gyfer y Pwyllgor Plant, Pobl Ifanc ac Addysg |
Priorities for the Children, Young People and Education Committee

CYPE 56

Ymateb gan : Epilepsy Action

Response from : Epilepsy Action

Question 1 – Within the remit set out above: what do you consider to be the priorities or issues that the Children, Young People and Education Committee should consider during the Fifth Assembly?

1. Medical needs in schools

Question 2 – From the list of priorities or issues you have identified, what do you consider to be the key areas that should be considered during the next 12 months (please identify up to three areas or issues)? Please outline why these should be considered as key priorities.

1. Medical needs in schools:

There is a need for a change in legislation in Wales to introduce a statutory duty of care for children with medical needs in schools. There is an opportunity to include this within the newly proposed Additional Learning Needs (ALN) Framework.

The Welsh Government's proposed ALN Framework documentation states that children with medical needs will not be covered by the ALN Bill (see page 30 of the draft ALN Code of Practice).

We ask the Committee to consider the inclusion of medical needs in the Additional Learning Needs Framework.

The current guidance framework for the management of medical conditions in a school setting differ in Wales and England. In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions,

meaning that in practice schools **must** make additional arrangements for supporting pupils at schools with medical conditions.

The legislation does not apply to schools in Wales. The rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England. The current system in Wales puts children with medical conditions in Wales at an academic disadvantage in comparison to their peers in England and does not protect them whilst they are at school. We regularly receive enquiries from families of children whose attendance, attainment and overall educational experiences are compromised because of their condition and the lack of guaranteed support from the current framework. It is vital that children are kept safe and healthy whilst they are learning to enable them to achieve their full potential.

As the UK's leading epilepsy organisation, Epilepsy Action exists to improve the lives of everyone affected by the condition. An estimated 32,000 people in Wales have epilepsy. Of these 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; Mid-2010 Population Estimates*) For some children, epilepsy can have an effect on how easy or difficult it is for them to learn. There could be many possible reasons for this, including:

- The condition itself
- The cause of the epilepsy
- The effects of seizures
- Side-effects from epilepsy medicines
- Absences from school

A 2014 study of school children with active epilepsy in West Sussex showed that:

- Over half of the children found it more difficult to learn than other children
- Over half of the children had problems with their memory
- Just under half of the children had problems with the speed with which they processed information
- Just under half of the children were not achieving as much as they could at school. The greatest difficulties were in mathematics and understanding their work
- Sixty five per cent (65/100) parents reported that their child had difficulties with attention and concentration

(Source: The identification of educational problems in childhood epilepsy, Young Epilepsy / Esme Fairburn Foundation, 2014)

The effects of seizures

Epileptic seizures can disrupt normal brain activity, and this can affect memory. The confusion that can occur after seizures may also cause memory loss.

Some children have a lot of epileptic activity in their brain, but don't appear to be having any seizures. This can happen both when the child is sleeping and when awake. If this happens very frequently, it can also affect their memory and how they learn.

Depending on the type of seizures a child has, they may feel very tired or confused after a seizure. They may also have interrupted sleep which will make them tired. Feeling tired or confused can affect how well a child can learn.

Side-effects from epilepsy medicines

Some children may have side-effects that affect their learning. These could include drowsiness, dizziness, memory problems, problems concentrating and mood swings.

Absences from school

Some children miss parts of their education because they need time off school to go to appointments with the nurses and specialists who manage their conditions. They may also be absent as a result of seizures, recovery after a seizure or injuries from a seizure.

Epilepsy and behaviour

For some children, epilepsy can have an effect on their behaviour. There could be many possible reasons for this, including:

- The condition itself
- The cause of the epilepsy
- The effects of seizures
- Side-effects from epilepsy medicines

We are sure that you will see from the above information how important it is that children with medical conditions are properly cared for and considered in the school setting.

We ask the Committee to consider the current situation and ask whether there is a need to bring the rights, support and protection provided to children and young people living with epilepsy in Wales in line with those in England?

There is currently a unique and rare legislative opportunity to do this during this Government's legislative programme.