Schools are breaking the law by not supporting children with medical conditions – new survey

Under strict embargo until 00:00, Friday 13 October 2017

- New report published by Young Epilepsy highlights reality of children with epilepsy in England not receiving the required support to be safe and included at school.
- Less than half of families who have children with epilepsy said their school had a policy on supporting pupils with medical conditions.
- One in three children with epilepsy (36%) don’t have an Individual Healthcare Plan (IHP) in school. Two out of three children’s IHPs do not consider how epilepsy affects learning.
- In England, it is a legal requirement for every school to have a policy in place which states how they support children with medical conditions.

Young Epilepsy is calling for every school to follow the law on medical support to ensure that children with epilepsy are safe and included alongside their peers. The new report, published by the charity, suggests that more than half of children with medical conditions are left in the dark when it comes to receiving sufficient support in schools.

Under the Children and Families Act 2014, every school is required to have a policy on supporting pupils with medical conditions, ensuring the support meets the standards set out in government guidance. These standards mean that all children with epilepsy should have an Individual Healthcare Plan (IHP) and school staff should be trained to meet their needs. Schools also need to take into account how a young person’s condition might affect their learning.

According to Young Epilepsy’s findings, published today, one in three children with epilepsy still do not have an IHP at school. This means that staff may not have the information they need to recognise and deal with an emergency at school. Despite epilepsy’s significant impact on cognition and behaviour, two out of three children’s IHPs do not consider how epilepsy affects learning. The report also highlights that staff may not be getting the training they need, with only half of families who have children with epilepsy saying that school staff had been trained in how to provide support.

Families commented on limited resources for school support and limited knowledge about epilepsy having an impact on children’s school lives.
The survey was completed by 661 individuals. 373 respondents were young people with epilepsy at state schools in England (where the law applies) or their parents and carers.

Carol Long, Chief Executive of Young Epilepsy, says:

“It is deeply concerning that many schools in England still aren’t complying with the legislation that was intended to give parents reassurance their child will be properly supported whilst in school. Even when the right systems are in place children with epilepsy are affected by lack of understanding about their condition. We heard from one family that their child was asked to wear a sash in the playground so they could be easily identified.

“Health conditions such as epilepsy must be taken seriously in the education system. It is important that health support provided is routinely checked as part of school inspections. Schools should also be required to publish their policies online to assure parents and young people of the support that is available to them.

“Some conditions are more complex than others and it is important that every child is treated as an individual without the additional and avoidable barriers that prevent them from achieving their full potential.”

Quotes from parents and young people surveyed:

“One teacher excluded my daughter in a competition because they thought she was being silly (she was six then) but she told me she was having a seizure at the time.”

“On one occasion due to lack of understanding of the condition I got told by my daughter's old teacher "I don't think she has epilepsy she just chooses not to do her work" this was after a meeting a specialist epilepsy nurse had gone into school to help give school a better understanding of her condition!"

“I wrote the risk assessment for her swimming lessons after the blanket one they did was awful and totally useless. Her ‘watcher’ at swimming was helping another child with their hat when mine had an absence [seizure] in the pool.”

NOTES TO EDITORS:

Available for interview:

- Carol Long: CEO of Young Epilepsy
- Rebecca Turnbull: Parent who has seen education system fail her son after his schools failed to comply with government legislation
- Stephanie Gibson, Director of Primary School Improvement for the Tandridge Learning Trust: A former head teacher whose previous school currently
adheres to the policies delivered in day-to-day practice and monitored by the governing body

About Survey:

Statistics mentioned in this story are of the 373 people that represented young people with epilepsy, or their parents and carers, who are at state schools in England. Therefore, they were qualified for this particular campaign. For figures including all 661 respondents, please contact Young Epilepsy’s press office. Details below.

Survey was sent and answered by parents between March and May 2017.

The findings are part of Young Epilepsy’s ‘Rules 4 Schools’ campaign. 

The report in full is available upon request.

Facts about epilepsy in schools:

- There are 112,700 young people with epilepsy in the UK
  - 1 in 220 children and young people aged 18 and under have epilepsy (63,400) (Source: JEC 2011)

- On average, one child at every primary school and five young people at every secondary school, will have epilepsy (Source: JEC 2011).

- Epilepsy is defined as a neurological condition that causes recurrent seizures. There are actually more than 40 different types of epilepsy.

- Young Epilepsy research (2014) found that 95% of children with epilepsy had a significant difficulty in cognition or behaviour.

About Young Epilepsy:

Young Epilepsy is the national charity working on behalf of children and young people with epilepsy. With 120 years of experience we are a leading provider of specialist health and education services. The charity offers support, information, and training for health, social care and education professionals and campaigns to improve access to, and quality of, health and education services.

Epilepsy is the most common serious neurological condition in childhood affecting 112,000 people aged 25 and under in the UK. On average one child at every primary school and five at every secondary school will have been diagnosed with epilepsy.

For further information on Young Epilepsy, please visit: www.youngepilepsy.org.uk

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