



Young
Epilepsy

What I need in school **(WINS)**:

The views of children with epilepsy,
their caregivers and teachers.

2024

The identification of needed educational supports for children with epilepsy.

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Foreword

Epilepsy in children is associated not only with seizures, often there is also a very significant impact on learning and behaviour. Our previous studies, Children with Epilepsy in Sussex Schools (CHESS) and Sussex Early Epilepsy and Development (SEEN) focussed on identifying developmental and educational problems in preschool and school-aged children with epilepsy. Indeed, these studies showed that children with epilepsy frequently have problems with learning and behaviour.

The What I Need in School (WINS) study was initiated in order to move beyond the identification of problems, to provide a better, more detailed understanding of the experiences of children with epilepsy in school. Specifically, the key objectives of WINS were to describe the impact of epilepsy on school functioning according to children with epilepsy, their parents and school staff, as well as describing current and desired educational supports for young people with epilepsy.

The key findings of the WINS study were that despite evidence of positive experiences there is still much to be done to ensure that children with epilepsy can reach their full potential in school. Parents noted significant challenges in obtaining educational supports and therapeutic provision for their child and indicated a desire for changes to current processes (e.g., better communication between home and school, additional resources to support behaviour and emotions). With respect to inclusion, significant concerns were expressed by respondents in relation to attendance problems experienced by children with epilepsy and their impact on academic progress and social inclusion. Additionally, children with epilepsy were often restricted from taking part in the same activities as their peers.

The majority of children with epilepsy also felt that epilepsy affected their learning and was associated with stigma and restrictions. Parental satisfaction with supports for learning in school was significantly higher in special rather than mainstream schools. Participants noted several ways learning could be supported in the classroom including adjustments to tasks, increased adult support, rewards and incentives.

With respect to sleep more than half of the children, parents and staff believed that epilepsy affects the child's sleep and almost all respondents believed that the sleep difficulties impacted the child's learning and behaviour.

Regarding seizure management, many of the school staff exhibited limited knowledge of the correct actions in the event of seizures. Knowledge of the relationship between epilepsy, anti-seizure medication and learning and behaviour was also deficient. School staff were most concerned about teaching a student with epilepsy, compared to eight other neurodevelopmental/medical conditions.

The findings of WINS highlight that children with epilepsy still face barriers regarding their full participation in school life. To begin to address this, school staff should be provided with training to improve knowledge of epilepsy and how it impacts on a child's learning, behaviour and inclusion. Young people with epilepsy should be provided with the necessary supports to access the same learning and social opportunities as their peers. It is, therefore, incumbent upon us all to ensure that the children, their parents and staff in school receive adequate support to ensure that these children can reach their full potential.



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Summary

Children with epilepsy are at a greater risk of learning and behavioural difficulties than children without epilepsy. Despite this, there is a lack of research exploring the views and experiences of young people with epilepsy, their parents and school staff with regards to educational supports that could aid learning in children with the condition.

What we wanted to know

- ✓ The impact of epilepsy on school functioning according to children with epilepsy, their parents and school staff (e.g., school attendance, achievement and social relationships).
- ✓ The current and desired educational supports for young people with epilepsy.

What we did

A total of 68 children with 'active' epilepsy living in the area of West Sussex participated in our study. These children, along with their parents and teachers were asked a range of questions via a questionnaire or focus group. These questions explored the impact of epilepsy on a range of aspects including learning and behaviour, emotional wellbeing and sleep.

Key findings

Educational and therapeutic provisions:

- ✓ All children with epilepsy should have an Individual Healthcare Plan (IHP). However, only 68% of our sample reported having one. 57% of children had an Education and Healthcare Plan (EHCP).
- ✓ Whilst approximately half of respondents have/had received therapeutic support (i.e., speech and language therapy, occupational therapy, physiotherapy, psychological assessment), parents particularly noted the challenges of obtaining educational supports and therapeutic provision for their child and indicated desire for changes to current processes (e.g., better communication between home and school, additional resources to support behaviour and emotions).

Inclusion:

- ✓ 90% of parents and 93% of teachers agreed that children with epilepsy were included in all classroom activities, with some adjustments needed to ensure full participation. Despite this, parents of children in special schools were more likely to agree that their child was included in school than parents of children attending mainstream schools.
- ✓ Some children felt that their epilepsy affected their friendships and, in some cases, has resulted in them being bullied.

Learning and behaviour:

- ✓ Parents and teachers believed that epilepsy impacted the child's learning and behaviour, particularly in the areas of memory, concentration and emotional reactivity.
- ✓ Participants noted several ways learning could be supported in the classroom including adjustments to tasks, increased adult support, rewards and incentives.

Sleep:

- ✓ 56% of children who responded believed that epilepsy affects their sleep.
- ✓ 65% of parents believed that their child had more difficulties with sleep than other children of their age, with 95% believing that the difficulties impacted the child's learning and behaviour.
- ✓ 54% of school staff believed that the child with epilepsy they supported was more tired/fatigued than peers, with 86% of school staff believing that the child's increased tiredness affected their learning/behaviour.

Staff knowledge:

- ✓ School staff exhibited limited knowledge of the correct actions in the event of seizures. Knowledge of the relationship between epilepsy, anti-seizure medication and learning and behaviour was also deficient.
- ✓ Knowledge about and attitudes towards epilepsy were better among staff in special schools, staff who had previously witnessed a seizure and in those who had been in receipt of training.
- ✓ School staff were most concerned about teaching a student with epilepsy, compared to eight other neurodevelopmental/medical conditions.

Background

Epilepsy is one of the most common serious neurological disorders in childhood, affecting 1 in 200 children¹. As well as epileptic seizures, learning and behavioural problems are common in those with the condition².

These additional learning and behavioural difficulties often have a greater impact on quality of life than the epileptic seizures³ and contribute most to the economic cost of the condition⁴. However, these difficulties are often unrecognised despite having a very significant impact on school performance^{2,5}.



A previous study by Young Epilepsy (The Children with Epilepsy in Sussex Schools (CHESS) Study) found that 80% of school aged children with epilepsy had a significant cognitive or behavioural problem. When academic achievement was included, the number of children experiencing significant difficulty rose to 95%².

The participants in the CHESS study, including the young people's parents and teachers, reported a lack of knowledge regarding the impact of epilepsy on school functioning and the educational provisions that could support them in their learning. Additional work by Young Epilepsy has further supported these findings, again reporting a lack of knowledge in school personnel⁶.

Despite the well-documented impact of epilepsy on school functioning, there is a lack of research exploring the views and experiences of young people with epilepsy, their parents and school staff with regards to educational supports for childhood epilepsy. This is concerning, given the overwhelming consensus that involving these individuals (i.e., children with epilepsy, their parents and teachers) in decisions about educational services and provisions would have a positive effect on service improvement⁷. There is thus a need to ask young people, parents, and teachers about their experiences in school and what support/interventions they feel would be most useful. The involvement of

these stakeholders can help the development of appropriate programs of support for affected young people, and guide future research into interventions in school-based settings.

The What I Need in Schools (WINS) study builds on the findings of the CHESS study by moving beyond identification of school-based difficulties to the identification of specific support needs. By giving young people, parents, and teachers a voice, it will be possible to develop recommendations which reflect the reality of having epilepsy in schools. The WINS study, therefore, aimed to investigate the impact of epilepsy on school functioning and the current and desired educational supports by harnessing the views and experiences of school aged children (5 – 16 years) with epilepsy, their parent and teachers.

What we did

Recruitment

Children with 'active' epilepsy (prescribed one or more anti-seizure medication (ASM) for epilepsy) born between 2003-2014 and living in the RH10-RH13 postal districts in West Sussex were identified by the researchers/paediatricians and invited to participate.

134 children were eligible to participate and 68 (50%) of these consented to take part. The study took place between September 2018 and April 2020.

Child Assessment

Caregivers completed screening measures to identify their child's emotional-behavioural functioning and features of Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder (ADHD) and Developmental Coordination Disorder (DCD).

Interviews

Children with epilepsy, their parents and school staff took part in an interview which explored a range of topics. Areas covered included:

- ✓ Educational and therapeutic provisions
- ✓ The inclusion of children with epilepsy in school
- ✓ The impact of epilepsy on learning and behaviour
- ✓ The effect of epilepsy on sleep

The interview schedules and questionnaires were developed in partnership with children with epilepsy, their parents and school staff. In total, 20 children with epilepsy, 68 parents of children with epilepsy, and 56 school staff members took part in the interviews.

School Staff Survey

In partnership with school staff, a survey was developed to explore:

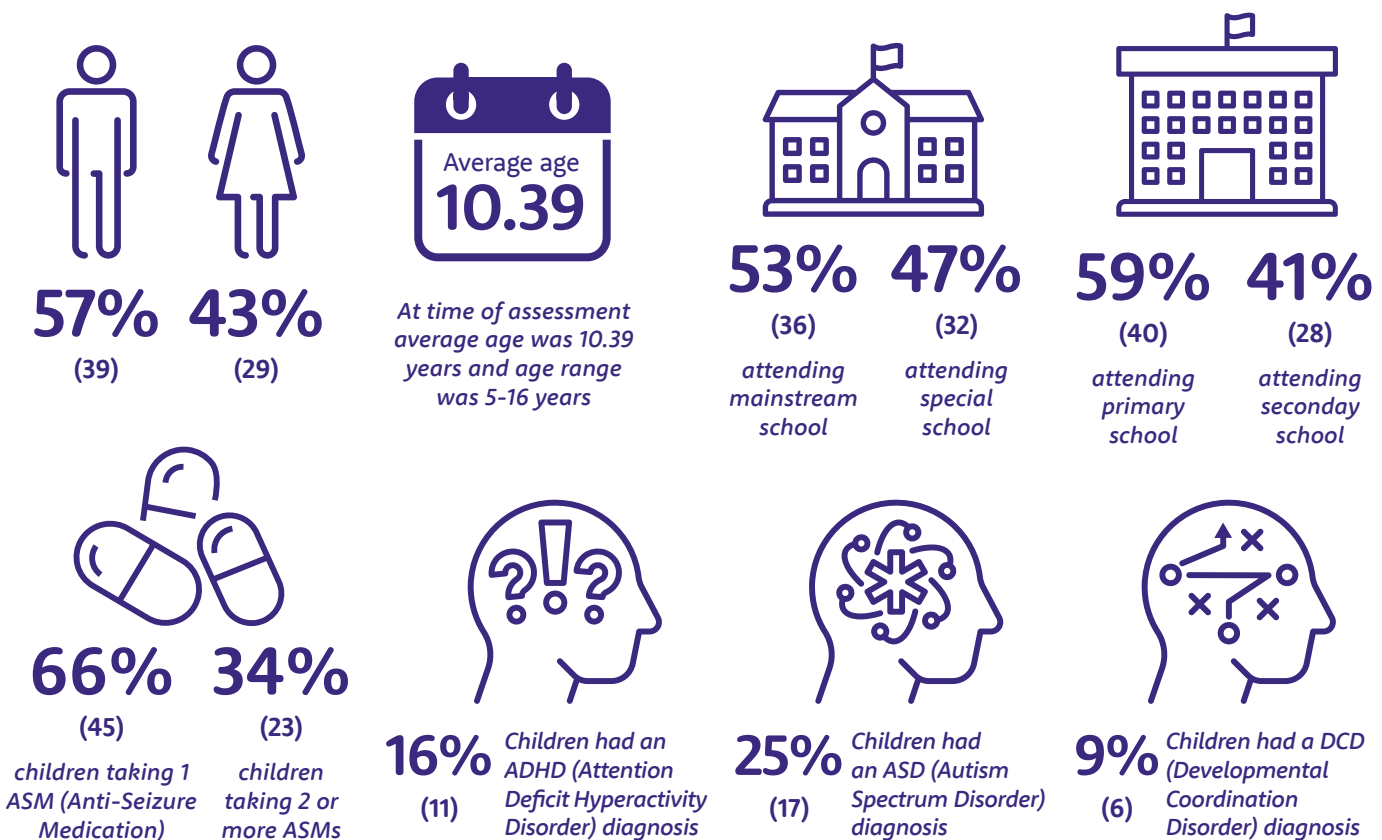
- ✓ Demographics of staff supporting children with epilepsy (e.g., job title, years worked in education, previously experience of teaching children with epilepsy etc.).
- ✓ Attitudes towards epilepsy (e.g., 'children with epilepsy are treated differently to other children').
- ✓ Knowledge about epilepsy (e.g., 'Do all children with epilepsy have an Education and Health Care Plan').
- ✓ Familiarity with a range of medical/developmental conditions
- ✓ Perceptions of training needs to support a child with epilepsy.

In total 160 staff completed the school survey.



Child Characteristics

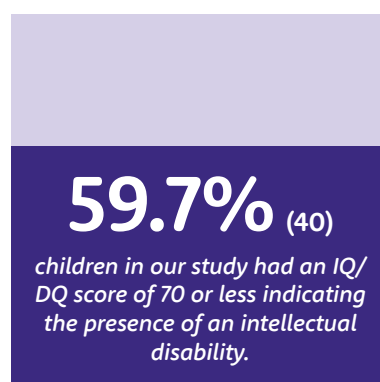
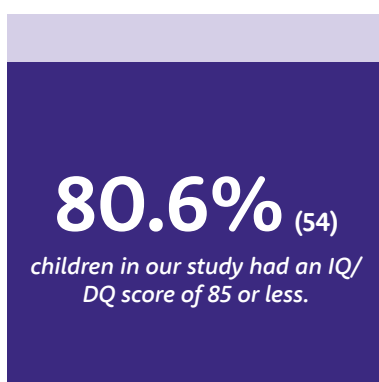
Characteristics of the 68 children who took part in the WINS study:



Intellectual Functioning

‘The Developmental Quotient’ (DQ) or Intelligence Quotient (IQ) gives an indication of a child’s overall level of intellectual functioning. The average IQ/DQ score is 100 for typically developing children and scores under 70 indicate the likely presence of intellectual disability (also called learning disability in the UK).

The performance of children with epilepsy with respect to cognition:



Behavioural and emotional development

The Strengths and Difficulties Questionnaire (SDQ) is a measure used to screen for emotional and behavioural difficulties in children and young people. The parents of our study were asked to complete the SDQ to provide an indication of their child’s emotional wellbeing.



Education and therapeutic provisions

Parents were asked to report if their child had previously or were currently receiving a range of educational and therapeutic supports. The results were as follows:

- ✓ Education and Healthcare Plan (EHCP) – 39 (57%).
- ✓ Individual Healthcare Plan (IHP) – 46 (68%).
- ✓ Speech and Language Therapy (SLT) – 47 (69%).
- ✓ Occupational Therapy (OT) – 37 (55%).
- ✓ Physiotherapy – 34 (50%).
- ✓ Psychological assessment – 36 (53%).
- ✓ Psychiatric assessment and treatment – 0 (0%).
- ✓ Received assessment and treatment from Child & Adolescent Mental Health Services (CAMHS) – 6 (9%).

Understanding/knowledge of epilepsy in schools

- ✓ More than half of responding children reported that some of their teachers did not know that they had epilepsy.
- ✓ According to both parents and teachers, knowledge about a child's epilepsy was better in special schools compared to mainstream schools.
- ✓ Teachers in special schools were significantly more likely to have received training on general aspects of epilepsy, seizure management, and impacts on learning/behaviour.



What is currently in place regarding the process of securing supports? What changes would parents like to see?

- ✓ Parents reported difficulties accessing educational and therapeutic supports, especially in mainstream schools.
- ✓ Parents often felt that they had to drive the process to gain supports.
- ✓ Parents reported a negative impact on the family as a result of the application process for education and therapeutic provision (e.g., family forced to finance assessments/supports privately).
- ✓ Parents would like more school staff to recognise the impacts of epilepsy on learning and behaviour.
- ✓ Parents felt better communication between home and school would be useful (e.g., knowing what supports are in place at school).
- ✓ Many parents wanted more resources for assessment and therapeutic provision in relation to their child's learning, behaviour and emotions.
- ✓ Parents also thought that a child's schoolwork needs to be realistic and flexible through recognition of the nature and characteristics of their child's epilepsy and learning/ behavioural needs.

Inclusion and participation of children with epilepsy in schools

School attendance difficulties:

Parental views

- ✓ 41% of parents reported that their child was currently or had previously experienced difficulties attending school.
- ✓ Parents attributed attendance difficulties to seizures, attending hospital appointments, side effects of ASMs, tiredness and fatigue, other health conditions and their child's emotional-behavioural difficulties. Parents also reported lower attendance due to concerns around the school's ability to support a child with epilepsy.

Teacher views

- ✓ Teachers in mainstream schools were more concerned about the child's attendance than teachers in special schools.
- ✓ Staff attributed attendance difficulties to several epilepsy related reasons, such as having seizures, side-effects of ASMs and fatigue resulting from seizures. However, several non-epilepsy related reasons were also given (e.g., general tiredness, physical illness or mental health conditions).

"She doesn't feel part of the class."

"Child has a lack of confidence, feeling different."

"Child can be anxious on return to school due to not being sure about what she's missed."

"Child can have difficulty forming friendships."

Parents and school staff cited a number of negative aspects of the attendance difficulties including social-emotional (e.g., increased anxiety and lowered self-esteem) and academic aspects.

Inclusion and participation in school

Parents

Sixty parents (90%) agreed that their child was included in all classroom activities, 55 parents (82%) in all playground activities and 62 parents (97%) in all school trips.

Parents of children in special schools were more likely to agree that their child was included in school than parents of children attending mainstream schools.

Parents shared the ways their child had been excluded and also some ways inclusion has been promoted:

- ✓ Child-led exclusion (i.e., child feels 'different' to peers or lacks confidence to participate).
- ✓ School personnel-initiated exclusion (e.g., separated from peers due to behavioural outbursts and learning difficulties).
- ✓ Excluded by peers (e.g., child with epilepsy is a victim of bullying).
- ✓ Restrictions/adjustments for physical education and sports (e.g., not allowed to participate in certain P.E activities).
- ✓ Restrictions/adjustments to school trips (e.g., parent of child with epilepsy is invited to accompany the child).
- ✓ Strategies used to enhance participation (e.g., preparation and managing expectations ahead of activity).

School staff

53 staff respondents (93%) agreed the child with epilepsy was included in all classroom activities, 53 (98%) in all playground activities, 52 (93%) in all sport/physical education (PE) activities, and 55 (98%) in all school trips.

Many school staff felt children were included in all activities, with some requiring additional supervision or adaptations to enable this participation.

Some felt that inclusion of the child was limited due to their epilepsy or a medical condition, or social or behavioural difficulties.

Restrictions

12 children with epilepsy (63%) reported that they were restricted from doing things compared to their peers because of their epilepsy. Children reported that some activities require consideration and adjustment (e.g., needing to be accompanied) to enable their participation, whilst some activities resulted in their exclusion altogether (e.g., sports involving heights).

37 parents (56%) agreed that their child's social activities outside of school were limited because of epilepsy.

Friendships

12% of children, 30% of parents and 20% of staff, reported that due to their condition, children with epilepsy have greater difficulty making friends compared to peers.

Bullying

63% of children with epilepsy reported that they had been bullied but most did not attribute this to epilepsy. Only 9% of parents thought their child had been bullied due to epilepsy.

Impact of epilepsy on learning and behaviour



Children were asked about the ways their epilepsy affects them in school. Their responses were organised into the following themes:

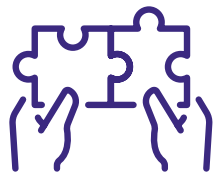
- ✓ Stigma – feeling awkward or embarrassed about having a seizure in front of peers.
- ✓ Impact of having seizures in school - experience daytime sleepiness and mood changes.
- ✓ Restrictions – additional consideration is needed before participating in the same activities as peers.
- ✓ Impact of ASM's – feeling irritable or being emotionally reactive.
- ✓ Impact of epilepsy on learning – experiencing difficulties with memory, attention and concentration.
- ✓ Physical and emotional wellbeing – having low self-confidence/self-belief.

Parents were asked about their child's current level of support:



79%

of parents agreed that their child's school provided the appropriate resources to support their child's learning.



88%

of parents agreed that their child's school was flexible enough to meet their needs.



72%

agreed that overall, they were satisfied with the supports their child receives in school.

Parents of children in special schools were more likely to be satisfied with the support a child receives in school than parents in mainstream schools.



Parents reported that current supports in school include increased staff in the classroom, additional supports provided outside of the classroom, access to therapies within school, and access to support in development of emotional and social skills and Special school provision.

What supports do young people with epilepsy, their parents and teachers feel is needed?

● Children with epilepsy
● Parents ● Teachers

- ✓ Having a trusted person such as a friend or a familiar staff member to talk to (●)
- ✓ Increased adult support in the classroom (●, ●, ●).
- ✓ Authorised accommodations to tasks - e.g., additional time to complete work, use of a laptop (●, ●, ●).
- ✓ Use of rewards/incentives for desired behaviour in school (●, ●)
- ✓ Support for a child's emotional and behavioural wellbeing (●, ●)
- ✓ Consideration of the child's communication needs (●, ●).
- ✓ Environmental accommodations – such as quiet spaces for those with sensory needs (●, ●).
- ✓ Time considerations- such as progressing at the child's pace (●).
- ✓ Appropriate academic expectations and supports (●)
- ✓ Using structure to support child's learning (●)
- ✓ Occupational Therapy adaptations (●).
- ✓ Peer modelling (●).
- ✓ Multimodal Learning (●).



Impact of epilepsy on sleep

To explore the impact of epilepsy on sleep, the children, their parents and teachers answered questions about possible sleeping difficulties and their effects on a child's learning and behaviour.

Children

56% of children who responded believed that epilepsy affects their sleep.

The children noted a number of ways in which epilepsy affects their sleep, these included:

- ✓ General sleep difficulties.
- ✓ Feeling tired during the day.
- ✓ Nocturnal seizures.

Parents

65% of parents believed that their child had more difficulties with sleep than other children of their age, additionally 78% of these parents believed that the difficulties were due to epilepsy and 95% believed that the difficulties impacted the child's learning and behaviour.

Several themes emerged when discussing the impact of epilepsy on sleep with parents. These themes include:

- ✓ Many children appear/report being more tired than expected for their age.
- ✓ Children experience difficulties falling asleep/bedtime routine.
- ✓ Children experience difficulties staying asleep/wakes during the night.
- ✓ Children experience nocturnal seizures or have seizures upon waking.
- ✓ Children are prescribed melatonin or similar medication to aid sleep.
- ✓ Sleep difficulties impact cognition/learning.
- ✓ Sleep difficulties affects behaviour, emotional and social well-being.
- ✓ Medication impacts a child's sleep.
- ✓ The frequency, intensity and impact of sleep difficulties can be inconsistent.
- ✓ Some children experience no difficulties with sleep.

Teachers

54% of school staff believed that the child with epilepsy they supported was more tired/fatigued than peers and 62% believed that the increased tiredness or fatigue was due to epilepsy. Additionally, 86% of school staff believed that the child's increased tiredness affected their learning/behaviour.

Teachers reported several way they feel epilepsy affects the sleep of their students with epilepsy. These affects included:

- ✓ Child noticeably tired/fatigued during the school day.
- ✓ Decreased engagement.
- ✓ Impaired cognition.
- ✓ Behavioural and emotional difficulties.



Staff knowledge of and attitudes towards epilepsy

In total 160 school staff completed a survey to assess their knowledge of and attitudes towards epilepsy.

Staff exhibited good knowledge with regards to:

- ✓ The presentation of seizures (e.g., jerking or blank stares).
- ✓ The nature of anti-seizure medication (e.g., does not cure epilepsy, does not always result in seizure control, does not usually result in behavioural problems, does not typically reduce emotional/behavioural problems).
- ✓ The nature of epilepsy (e.g., not a lifelong condition for all).
- ✓ What not to do when a child is experiencing a seizure (e.g., holding them down).
- ✓ That most children with epilepsy do not need to attend a special school and do not have a learning (intellectual) disability.

Teachers exhibited limited knowledge in the areas of:

- ✓ The impact of epilepsy on memory problems.
- ✓ The diagnostic criteria for epilepsy.
- ✓ The correct actions following seizure (e.g., whether a child should remain in the classroom following a seizure, that an ambulance is not always needed following a seizure).
- ✓ Whether all children with epilepsy have an EHCP.

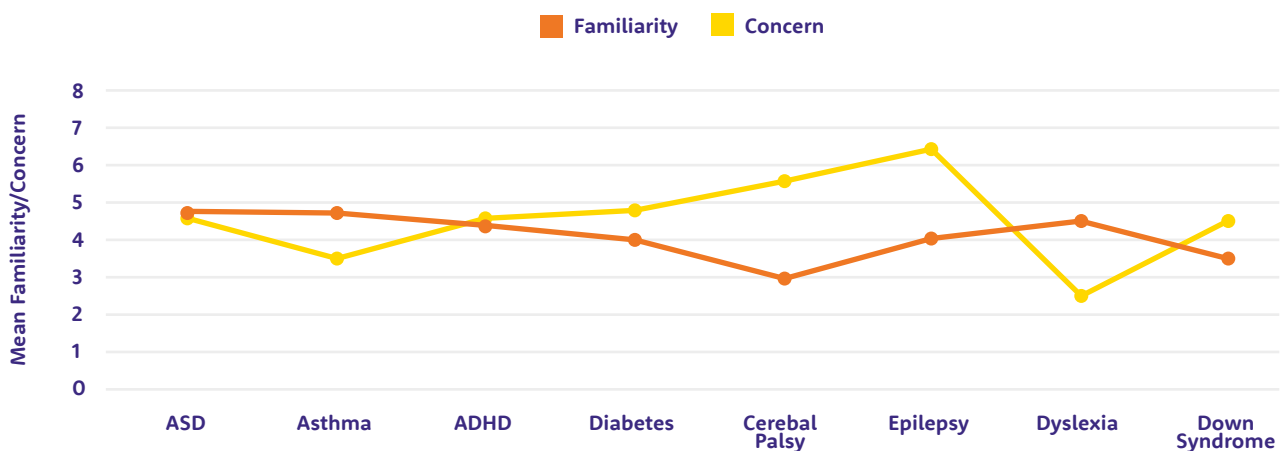
Associated factors with knowledge and attitudes:

Teachers were found to have better knowledge of epilepsy and held more positive attitudes towards the condition if:

- ✓ Had previously witnessed an epileptic seizure.
- ✓ Worked in a special school as opposed to mainstream school.
- ✓ Previously received training on aspects of epilepsy.

Familiarity with and concern about medical/neurodevelopmental conditions

School staff were asked to indicate their familiarity with and concerns about eight medical/neurodevelopmental conditions. As the figure below shows, School staff were most concerned about teaching a student with epilepsy, compared to eight other neurodevelopmental/medical conditions.



Staff training – 73% of respondents expressed a desire for more training on epilepsy. This training was felt to be most needed by staff in special schools as opposed to mainstream schools.

Discussion

Educational and therapeutic provision

Although the majority of parents report positive aspects of their child experiences at school, there were also a number of concerning aspects. Inadequate communication between home and school and between health and education services was a commonly reported concern. Additionally, more than half of the responding children reported that some of their teachers and friends did not know that they had epilepsy. Knowledge of epilepsy is felt by parents and staff to be significantly higher in special schools. Parents highlight the need for increased knowledge of the impact of epilepsy on learning and behaviour and want more resources for assessment of these difficulties.

Inclusion

It would appear that many children with epilepsy are included to a similar degree as peers in school settings. However, some experience or have experienced attendance difficulties which can have a negative effect on their academic progress and their social and emotional development. Children with epilepsy face restrictions and limitations with respect to their activities, although limitations to their social activities may be more often due to associated neurobehavioural difficulties as opposed to their epilepsy. Children with epilepsy are also more likely to be bullied due to the presence of associated emotional and behavioural difficulties as opposed to seizures. There is a clear need for education for parents, teachers and peers regarding the nature and impact of epilepsy in order to increase inclusion in educational settings.

Learning and behaviour

This study highlights that children with epilepsy often have significant needs for support in school arising from the often-associated learning, behavioural and emotional needs as well as seizures. Whilst most parents felt that their child was well supported, parents of children in special schools were more likely to agree with this than parents of children in mainstream schools. In terms of current and desired supports children, parents and school staff mentioned a wide range of potentially effective approaches and highlighted the need for early screening and assessment across a range of learning and behavioural domains.

Sleep

Children with epilepsy, their parents, and school staff perceive that epilepsy confers a high risk for sleep difficulties and daytime tiredness. Difficulties with sleep are perceived to have a negative impact on the child's learning and emotional and behavioural functioning. Children with epilepsy who also have an intellectual difficulty are perceived to be at significantly higher risk for sleep difficulties. Asking children with epilepsy and their parents about the child's potential sleep difficulties and associated impact would appear to be an important first step in the assessment and subsequent development of supports for this group.

Staff knowledge

Attitudes towards epilepsy among school staff were largely positive but more negative attitudes towards seizure management and administration of emergency medication were evident. Limited knowledge of the correct actions in the event of seizures and knowledge of the relationship between epilepsy, ASMs and learning and behaviour were also concerning. Additionally, epilepsy is the condition staff expressed most concern about. Knowledge and attitudes were better among staff in special schools, staff who had previously witnessed a seizure and in those who had been in receipt of training. Staff expressed a desire for more training particularly in the areas of seizure management and impact of epilepsy on learning and behaviour.

Recommendations

Educational and therapeutic provision

- ✓ The reported lack of provision of Individual Health Care Plans for one in three children highlights that despite legislation many children with epilepsy still lack this basic support in school and, therefore, there is a need for continued advocacy.
- ✓ Parents often feel unsupported when seeking educational and therapeutic supports and thus there is a need for a keyworker/caseworker to support them in school-related matters and also at the interface between health and education services.

Inclusion

- ✓ There is a need to try to reduce attendance difficulties by ensuring that there is a good understanding of epilepsy in school settings. This includes seizure management but also an understanding of the wider impact of epilepsy.
- ✓ It is important that when children experience periods of absence from school, support is available to help them catch up both academically and socially.
- ✓ Children with epilepsy may be excluded from certain activities unnecessarily, with parents and staff not understanding the nature of the risks that the child may face if they participate. It is, therefore, important that supporting clinicians ask children and parents about restrictions and provide advice where needed.
- ✓ It is also important that children with epilepsy are assessed for possible co-occurring cognitive and behavioural difficulties and that they subsequently receive appropriate support for identified additional difficulties, as these difficulties are more often associated with bullying than seizures

Learning and behaviour

- ✓ Children with epilepsy should have comprehensive access to screening and assessment for learning and behavioural needs.
- ✓ Individual assessments should lead to tailored support for children with epilepsy.
- ✓ The lack of knowledge of the impact of ASMs among staff suggest that there is a need for the potential impact to be conveyed to all staff who work with the child in the school environment.

Sleep

- ✓ There is a clear need for children with epilepsy to be screened for sleeping difficulties given the potential negative impact on quality of life, learning, and behaviour.
- ✓ Given that some of the reported difficulties appear to be related to behavioural insomnia as opposed to nocturnal seizures, it is likely that for many children supports to improve sleep should focus on educating caregivers and young people (where developmentally appropriate) about simple sleep hygiene measures such as avoiding screens in the last hour before bedtime, exposure to morning sunlight and engaging in regular physical activity.
- ✓ The reports of caregivers and young people suggest that in some cases the children with epilepsy are displaying symptoms of parasomnia (e.g., excessive or abnormal movements), primary sleep disorders (e.g., obstructive sleep apnoea), or even unidentified seizures. Thus, in some patients, overnight EEG polysomnography may be needed in order to clarify the cause of their disrupted sleep.

Attitudes and Knowledge

- ✓ There is a need for training for school staff to be rolled out on a large scale in an accessible way. Online training may be particularly useful in terms of reaching a large number of educational professionals. Training should focus not only on seizure management but also on learning and behavioural aspects of childhood epilepsy.
- ✓ Given the unpredictable nature of seizures it is important that epilepsy is not seen as the responsibility of one staff member or a small group of staff but that all staff have knowledge about the condition.

Future work

- ✓ It would appear that knowledge and attitudes of epilepsy in schools can be improved by educational interventions but there is a need for more research, including trialling remote training which may allow a larger number of staff access.
- ✓ When designing teacher training, it is important to include the views of children with epilepsy and their parents as well as educational staff.
- ✓ It is important that future research on learning and behavioural interventions in paediatric epilepsy focusses on testing approaches that work in children without epilepsy. These approaches may need to be adapted to suit the epilepsy population but contain well-tested components that are also likely to work for these children with epilepsy.
- ✓ It would be useful to evaluate a keyworker model who can support parents not only within the process of securing supports, but also with respect to facilitating integration of support from health and education sectors for the child and transition between schools.
- ✓ Future studies are needed to explore the relationship between sleep difficulties (as measured by objective methods) and cognition and behaviour (including specific domains of cognition such as aspects of memory, and processing speed) in children with epilepsy.



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Young Epilepsy, the children and young people's epilepsy charity

We exist to create a society where children and young people with epilepsy are enabled to thrive and fulfil their potential. A society in which their voices are respected and their ambitions realised.

together we create possible.

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