

Young Epilepsy



What Helps? What Hinders?

Inclusion in Education for
Children with Epilepsy

Supported by

 Paul Hamlyn
Foundation

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Foreword

Epilepsy is complex, varied and widely misunderstood and can have a devastating impact on the lives of young people living with the condition. Seizures, side effects of antiepileptic drugs and social stigma are all known to significantly disadvantage academic progression and achievement in young people with epilepsy. Young Epilepsy is the only national charity working to support children and young people living with the condition and leading the way in medical, educational and social research.

The Paul Hamlyn Foundation, an independent grant-making organisation, exists to help people to realise their potential and enjoy a better quality of life, now and in the future. Under its 'Preventing school truancy and exclusion' priority, the foundation has generously funded this project. Working together to achieve our shared vision, this report seeks to have an impact not only on individual lives, but also on those who influence policy and practice, ensuring a legacy for all children with epilepsy in education in the UK.

Despite 63,400 children aged 18 and under living with epilepsy in the UK, it still remains an often misunderstood condition. Many children with epilepsy can struggle to be fully included in education and risk becoming marginalised. This report examines whether children with epilepsy are fully included in all aspects of school life, from learning and the curriculum, to social engagement and extra-curricular activities. Based on first-hand accounts from children with epilepsy and proxy reports from parents, it highlights that misconceptions concerning epilepsy can act as a significant barrier to inclusion in education for these children.

Young Epilepsy is the 'voice of childhood epilepsy' and the research outlined in this report is an important contribution towards gaining a better understanding of the experiences of children with epilepsy. We need to capture the perspective of children with epilepsy and their take on the barriers to inclusion in education in order to provide support and services that are sensitive to their needs as they define them. We also need to consider the views of families as advocates for children with epilepsy who may not be able to articulate their experiences but whose needs must also be highlighted.

The recommendations made within this report are important for not only those directly responsible for the children within schools, but also for the wider education community. Together we can make a positive and lasting difference for all children with epilepsy in schools across the UK. The intention of this report is that it forms the basis of good practice and acts as a reference for the voice of the young person. To this end, we will continue to campaign for improved services for children with epilepsy.

We are extremely grateful to all the children who participated in this project. By sharing their voice, they have allowed us an insight into their personal experiences. Without the generosity of the Paul Hamlyn Foundation and their support for this project we would not be able to challenge the barriers and create better futures for young lives with epilepsy.

**David Ford, Chief Executive
Young Epilepsy, March 2013**



Executive Summary

What helps children with epilepsy to be included in education?

What factors can hinder inclusion?

These are the questions that the research outlined in this report set out to address. We have investigated whether children with epilepsy are fully included in all aspects of school life. This includes all areas of learning and the curriculum, social engagement and extra-curricular activities. This study is based on first-hand accounts from children with epilepsy and proxy reports from parents of younger participants and those with communication difficulties. We aimed to get a better understanding of ‘what helps’ and ‘what hinders’ children with epilepsy to be included in education.

We found that there are many factors that influence how well a child with epilepsy is included at school. Although this research focused primarily on education, we asked about medical as well as educational experiences because medical management and seizure control are likely to have such a significant bearing on the extent to which children are able to engage with their education.

What children with epilepsy and their families told us was that there are often key individuals within a school who have a vital role in ensuring they are fully included in education. Parents as ‘advocates’ for their children play an important part in ensuring that they receive the services they need and are able to access their education. Barriers to inclusion in education are primarily related to misconceptions concerning what epilepsy is and a lack of awareness about the impact that the condition can have on learning and psychosocial well-being.

Key Findings –

- This research suggests that misconceptions concerning epilepsy can act as a significant barrier to inclusion in education for children with epilepsy.
- One of the primary barriers to inclusion is a failure by some education professionals and others to recognise the variety of ways epilepsy can present and in particular the mistaken belief that ‘tonic-clonic’ seizures (previously known as ‘grand mal’ seizures) are the only form of seizure.
- Another significant barrier noted was a failure to appreciate the connection between epilepsy and additional learning needs for some children. Seizure symptoms and difficulties related to epilepsy may be misinterpreted as ‘naughtiness’.
- Access to high quality medical treatment is a significant facilitating factor for inclusion in education for children with epilepsy; consultants, epilepsy nurse specialists and other medical professionals have been shown to play an important role for these children.
- Key individuals within schools such as Special Educational Needs Coordinators (SENCOs), Inclusion Officers and school nurses often play a significant role in ensuring that children with epilepsy are able to be fully included in education and school life.
- Parents play a key role as advocates for children with epilepsy by ensuring that they receive the medical care they require and have the opportunities they need to be fully included in education.



Case Study Hannah

Hannah is an articulate young woman of 15. She is able to explain her epilepsy and the impact that it has on her learning. She is, however, tired of doing this repeatedly. Her absence seizures mean that she finds it difficult to follow what is happening in class sometimes. This has been particularly problematic at secondary school when she goes from class to class and she is taught by a range of teachers. She says 'I get fed up from explaining'.

The idea for a 'communication passport' came from an Inclusion Officer who visited Hannah in class and has been in regular contact with Hannah and her family. The Inclusion Officer has also undertaken additional training to gain a better understanding of epilepsy and how to support Hannah. She is playing a key role in improving inclusion in education for Hannah.

Hannah is now gaining some independence for the first time as her seizures are better controlled following the implant of a vagus nerve stimulator (VNS). Her mother has started to let Hannah go shopping with her cousins – although she keeps in regular phone contact.

Factors that have helped Hannah at school include better seizure control due to access to appropriate medical treatment and the support she has received from the Inclusion Officer. Hannah also finds technology can help with specific learning problems. She finds it easier to type using a computer than to write by hand and would like to have this option for her GCSE exams. She is learning Spanish and uses a dictaphone to record phrases to help with her memory difficulties.

Hannah is aware that her peers are frightened by her seizures as they have witnessed 'drop attacks' and she would like them to know 'I'm still Hannah'.



Case Study Peter

Peter was diagnosed with epilepsy at age three following earlier febrile convulsions. He is now 15 years old. He has been on a 'roller coaster' of medications ever since his diagnosis and has also had epilepsy surgery. However, his seizures remain uncontrolled and the learning difficulties he had previously have worsened. He is now in a special school that can meet his learning needs better but they struggle with his epilepsy, according to his mum. Peter's mother says she has had to be 'on the ball' as a parent. She has learnt a lot '... online, little books, things people have told me'. She has had variable experiences with the medical profession; some consultants have been better at communication than others. She felt initially that 'being difficult' would mean the professionals would not treat her child so well.

Epilepsy has had a significant impact on Peter; at one stage he was having 80 seizures a day, unable to move from the sofa '... out of it from seizures and medication'. He now has better seizure control but this is varied and punctuated with rough patches. Peter remains socially isolated even though his special school is more accepting and despite his mum's best efforts to find other teenagers in the area who have epilepsy. This has been an ongoing problem – there were no 'birthdays or play dates' when he was younger. His epilepsy continues to disrupt his education due to poor seizure control.

Introduction

Exclusion takes many forms.

There are obvious as well as more subtle forms of exclusion. Children with epilepsy may be excluded from activities that are mistakenly considered to be unsafe for them. In some cases, their involvement in activities may be hindered by the lack of support needed to make the activities safe. They may also be excluded in more subtle ways, through failure to provide the specialist help they may need to learn and have the same opportunities as their peers. They may miss out on chances for social development. Exclusion from education in any form can have long-term detrimental effects that may limit the opportunities these young people will have in the future.

Inclusion in education also takes many forms. This is because the adaptations required to achieve inclusion will vary according to the needs of the individual. Epilepsy is a highly varied condition. 'It's different for everyone' is the message that Justine – one of the participants in this study – believes is important for people to appreciate. One of the challenges involved in ensuring that all children with epilepsy are fully included in education is that a 'one size fits all' approach is not possible.

Our aim therefore was to get a better understanding of the potential difficulties faced by children with epilepsy and identify the steps that could be taken to ensure that they have every opportunity to be fully included in all aspects of school life. Epilepsy can be a complex condition and ensuring positive outcomes for children and young people in education relies not only on 'getting it right' in schools but also on access to high quality medical care. From our knowledge and experience there is an intertwined relationship between the health and education consequences of this condition and so neither can be considered in isolation. Therefore the research has focused on both the educational and medical experiences of the children who participated.

This report includes a summary of the findings from the research and case studies which illustrate the range of both positive and negative experiences the children involved in this study have been through. We have concluded with a number of recommendations for education and other professionals concerning how they can ensure better inclusion in education for children with epilepsy.

'A group of boys were saying 'don't go near her, she's got germs' and that's when the bullying kinda started'

Melissa, 16

Definitions

Inclusion has been defined within this study as full involvement in all learning, activities and social aspects of school life. It has been considered as a broader concept concerning whether children with epilepsy are included or excluded within any educational setting rather than focusing on the type of provision. Inclusion in this context does not refer to inclusion in mainstream education but inclusion within any type of school. Barriers are defined as those factors that hinder, limit or prevent inclusion in education. Facilitators are the factors that will help to ensure inclusion for children with epilepsy in all areas of the curriculum and school life.

What is Epilepsy?

Epilepsy is the most common neurological disorder in childhood (Fejerman, 2002). A diagnosis of epilepsy will usually be made after the occurrence of two or more unprovoked seizures. Seizures are sudden bursts of electrical discharge in the brain which result in alterations in sensation, behaviour and/or consciousness (Solomon, 2011). Epilepsy is not a single condition but rather seizures are symptoms of an underlying neurological problem that creates vulnerability for repeated seizures.

There are many different types of seizures. They are described as either 'focal' if they affect only part of the brain and a level of consciousness is retained, or 'generalised' if the whole brain is affected and consciousness is lost. There is a wide range of seizure symptoms that can occur in epilepsy. In the case of generalised seizures they include stiffening (tonic), jerking (clonic), loss of muscle tone (atonic) and brief staring spells (absence seizures).

Tonic-clonic seizures involve stiffening followed by jerking and will typically result in the child falling to the ground. This type of seizure was described by the father of one of the participants in this study as a 'Coronation Street seizure', as they are the form of seizure most commonly depicted on television. One of the difficulties commonly identified is that focal seizures often pass undetected because they are not the tonic-clonic type.

Different parts of the brain control different functions and focal seizures will present as varied symptoms depending on where in the brain the seizure originates. Symptoms can include sensations, motor movements, alterations in mood, confusion, visual disturbance, muscle weakness and 'automatisms' (brief unconscious behaviours such as lip smacking) (Solomon, 2011). One of the themes that emerged from this research is that a failure to recognise the highly variable nature of seizure symptoms may lead to inappropriate management of children within the education environment. Seizure symptoms may be misinterpreted and the potential impact of what is commonly considered to be an ostensibly 'medical' condition on learning and psychosocial well-being may be misunderstood.



Impact of Epilepsy on Learning and Behaviour

One of the most prominent cognitive changes that occurs in people with epilepsy is a memory problem (Zemen et al. 2012). Difficulties with memory were identified by several of the participants in this study as a 'barrier to learning'. An examination system based on being able to recall information may be particularly difficult for young people with epilepsy. Discrepancies between grades achieved for coursework and the overall grade given following examination were reported by three of the older teenagers in this study.

It is important that teachers and others who have responsibility for supporting children with epilepsy are aware of the possibility but not inevitability of additional learning and behavioural difficulties (Reilly and Ballantine, 2011). Previous research has suggested that teachers lack understanding of epilepsy (Wodrich et al. 2011) and that they may not be aware of the additional difficulties children with epilepsy can have concerning learning and emotional problems (Wodrich et al. 2006). Childhood epilepsy is associated with a higher risk for 'internalising disorders' such as depression and anxiety and 'externalising disorders' such as attention deficit hyperactivity disorder (ADHD) (Berg et al. 2011). Autism spectrum disorder (ASD) also has a known association with epilepsy, although estimates concerning how many people with ASD also have epilepsy vary considerably (Pellock, 2004).

'Well what is it, is it the medication?

Is it is the epilepsy?

Is it just because he's a teenage boy?'

Parent to Michael, 13



As well as potential difficulties with working memory, children with epilepsy may have specific learning problems such as inattention and processing difficulties (Reilly and Ballantine, 2011). Participants in this study also identified the side effects of antiepileptic drugs (AEDs) as a barrier that can impact on learning. Tiredness, mood swings, irritability and difficulties concentrating were all attributed to side effects of medication. Disturbed sleep and resulting tiredness as a result of nocturnal seizures is another factor that was raised in relation to the impact of epilepsy on learning.

Research Questions

There were three primary questions that this study set out to address.

These were -

- What are the factors that act as barriers to inclusion in education for children with epilepsy?
- What are the factors that act as facilitators for inclusion in education for children with epilepsy?
- What recommendations can we make based on the findings of this research?

Methodology

A qualitative research methodology was chosen in order to gain a more 'in depth' understanding of the experiences of children with epilepsy. Interviews were conducted using a semi-structured schedule and later transcribed. They were then analysed. The first researcher coded the data and the second researcher undertook an independent audit of the analysis. Themes were developed from the coding and agreed between the two researchers. Participants were invited to take part in this study through advertisements on the Young Epilepsy website, social networking sites, word of mouth and through contacts with professionals who work with children with epilepsy and their families.

'If you complain about stuff, you then leave your child with them, you're reticent about making a fuss'

Parent to Jack, 17

Case Study Glen

At primary school, it was not only Glen who was affected by his epilepsy and frequent seizures, his twin brother would often be called out of class to care for Glen if he had a tonic-clonic seizure during school time. Eventually Glen's mother took action and started working at the school on a voluntary basis to help manage him. Lack of access to emergency medication training for staff was a barrier that contributed to limitations placed on Glen and his ability to go on school trips. Glen's mother describes the primary school he attended as 'old-school' and felt there was a reluctance to have him at the school and make adjustments for a child with a disability.

Glen has a rare epilepsy syndrome. One of the factors that has acted as a facilitator for his education has been his mother's ability and drive to become an expert on his condition in order to ensure that he gets the medical care he requires. She frequently has to explain his condition to doctors who have not come across it before and she carries a leaflet with her which gives an explanation.

Glen is now attending a special unit at a secondary school and he has access to the support he needs for the learning problems associated with his epilepsy. His mother credits the SENCo at his school as being key to involving and including Glen in every aspect of school life and there are now no limitations on school trips and activities.

Glen has been on 'most things' in terms of medication, some of which produced unacceptable reactions. On one drug he was, according to his mother '... like a zombie... just looked like the living dead. He went grey, he couldn't talk, he didn't have any fits on it but he wasn't doing anything on it really for whole days'. Glen's ability to access his education has been dependent not only on seizure control but also influenced by the medication that has been used to control his epilepsy.

Case Study Michael

Michael (13) has a slightly different view from his parents concerning the help that is available to him at his school. They are full of praise for his school and the support that has been given to their son. Although he appreciates the support offered, Michael feels that it can be 'over the top' on occasion with too much attention focused on him. He would prefer a more subtle approach and said this to his parents. They have worked with the school to make Michael more comfortable with the way his epilepsy is monitored.

Michael is able to visit the matron whenever he needs to and she has an awareness of who he is and the fact that he has epilepsy 'I go in there, she says hi Michael, how you been? She knows me out of the 2000 kids in the school'.

The school inclusion team have been in close contact with his parents following a recent seizure at school. They have mentioned a 'buddy system' that they are happy to implement for Michael but both his parents and staff working at the school are aware that this option needs to be offered to Michael rather than enforced. His parents feel confident that Michael has friends who will contact them if he has a seizure when he is spending time with them. They have anxieties about letting Michael have more freedom but understand that they will need to find ways to let him have his independence while also keeping him safe. Good communication between Michael's parents and his school and a willingness to work together appears to be facilitating inclusion in education in this case.

Case Study Emily

Emily's family battled to get a Statement of Special Educational Needs for their daughter. The most difficult part - according to her mother - was convincing the SENCo at her daughter's school that epilepsy was more than merely a medical condition and had impact on her learning. In addition the process had a significant financial cost. Her mother emphasised a point that was made by other parents involved with this study who said that epilepsy is so often 'hidden' and may not be seen as a disability. Emily has learning difficulties related to the underlying neurological condition that is causing her seizures. Her parents knew she would struggle to cope with a large mainstream secondary school but despite their efforts this was the type of educational provision where she was initially placed. Her mother reported that '... it just made her ill. She came home from school every day and she was grey. Physically and mentally ill'.

Emily was offered a 'buddy' to help her find her way around the school. The system did not work in this case. Despite still needing help to find her way around the school after the first week, the peer who had been assigned to help her grew impatient with Emily 'following her around'. She had limited social opportunities and few friends. Once her parents had secured the Statement of Special Educational Needs they were able to find a place for Emily at a special school that has been able to support her learning needs and her epilepsy. The school has arranged epilepsy training for their staff and Emily's peers have attended special classes aimed at educating them about epilepsy. She is more socially successful according to her mother and gaining in confidence as a result of being in an educational environment where her needs are better understood.



Case Study Joe

With the support of his keyworker, Joe (11) was able to address the issue of his peers 'taking the mick' when it came to his epilepsy. He made this request as sometimes his classmates reacted badly to his absence seizures, thinking he was staring at them when he was having a seizure. Joe attends a special school where they have experience with epilepsy and a willingness to engage with further training to learn how to support Joe. Trainers from an epilepsy charity were brought into the school and delivered lessons and assemblies for the pupils and additional training for the teachers and support staff. Joe feels this has made a real difference. His keyworker has also noticed that there has been a change in attitude from the other pupils towards Joe and his epilepsy. She is keen to do all she can to support Joe and has a good awareness of how to manage him when he has one of his 'blips' – as he calls his seizures. She feels that the school have provided her with the training she needs to support Joe properly. If the school had not been as willing as they have been to learn more about epilepsy and how to meet Joe's needs she feels that 'Joe would have suffered'.

Joe's school tries to include him in all of the same activities as his peers but he can be reluctant to join in some activities as his seizures worry him. A bad experience when he had a seizure in a swimming pool has left him frightened to go into the water. His mother would like him to be as active as possible but understands his worries. One thing that has helped Joe to be included in activities during the holidays is a voluntary scheme involving older teenagers taking him out for the afternoon. It's not 'cool' to be hanging out with his parents but he will readily accept the company of older teenagers. This helps Joe to be socially included in his community.

Ethical Review

This study was reviewed by the National Research Ethics Service in March 2012 and approval granted for the research. Participants were given written information about the study and informed of their right to withdraw at any time. Informed consent was sought by children in the study where possible and parents were asked to consent on behalf of children who were younger or who had learning disabilities.

Research Participants

There were 18 participants in this study, who were aged between five and 18 years of age at the time of their involvement in the research. They are referred to as children in the reporting of this research as the older participants were reflecting on their earlier experiences in school. The participants took part anonymously and a pseudonym has been used for the purposes of reporting this research. Where a particular epilepsy syndrome has been specified by the participants and their families this is noted in the following table as well as details concerning other conditions and the type of educational provision they were in at the time of the study.

‘So I just got War and Peace out and waited until someone dealt with me’

Parent to Glen, 15



Participants

Pseudonym	Age	Gender	Diagnosis and syndrome if known and other conditions	School Provision
Thomas	18	M	Juvenile myoclonic epilepsy	Not in school, previously in independent mainstream secondary
Louise	18	F	Epilepsy (tuberous sclerosis)	Mainstream secondary
Jack	17	M	Epilepsy and Learning Disability	Special secondary
Melissa	16	F	Epilepsy - secondary to encephalitis	Mainstream secondary
Justine	16	F	Epilepsy – type not specified	Mainstream secondary
Glen	15	M	Epilepsy – Glut 1 transporter defect	Special unit at mainstream secondary
Peter	15	M	Epilepsy – type not specified	Special secondary
Hannah	14	F	Epilepsy – type not specified	Mainstream secondary
Daniel	13	M	Epilepsy and Learning Disability	Special secondary
Jason	13	M	Benign Rolandic Epilepsy	Mainstream secondary
Michael	13	M	Epilepsy – type not specified	Mainstream secondary
Emily	13	F	Frontal lobe epilepsy	Special secondary
Joe	11	M	Epilepsy and Asperger Syndrome	Non-maintained special school
Henry	10	M	Epilepsy and Asperger Syndrome	Independent mainstream primary
Lucy	8	F	Epilepsy and Cerebral Palsy	Mainstream primary
Rosie	8	F	Epilepsy – secondary to encephalitis	Mainstream primary
Jared	8	M	Epilepsy – Dravet Syndrome	Mainstream primary
Molly	5	F	Epilepsy – West Syndrome	Mainstream Primary

Barriers to Inclusion in Education for Children with Epilepsy

<p>Psychosocial Impact</p>	<p>Embarrassment about having seizures in front of peers can lead to children feeling uncomfortable in the school environment.</p> <p>Stigma – feelings of being different to peers – may lead to emotional problems, worry, stress and anxiety.</p> <p>Bullying and reluctance to attend school as a result can lead to school refusal.</p> <p>Frustration concerning the inability of school staff to understand epilepsy can impact on some young people.</p> <p>Impact on self-esteem through negative school experiences can lead to loss of confidence and self-doubt.</p> <p>Fear of seizures can impact on willingness to take part in activities.</p> <p>Stressful experiences at school can trigger seizures.</p> <p>Fear of Sudden Unexpected Death in Epilepsy (SUDEP) can have a negative impact.</p>
<p>Epilepsy and Related Conditions</p>	<p>Seizures can cause high rates of absenteeism and children may be removed from class following every seizure due to school policy.</p> <p>Epilepsy may be impacting on memory, concentration and attention.</p> <p>Epilepsy may be impacting on sleep if children are experiencing seizure activity at night and this may lead to tiredness during the day and impact on learning.</p> <p>Anti-epileptic drugs (AEDs) and side effects may be impacting on learning.</p> <p>Attention deficit hyperactivity disorder (ADHD) and autism spectrum disorder (ASD) will be impacting on some of the paediatric epilepsy population.</p> <p>Anxiety and depression will be impacting on some of the paediatric epilepsy population.</p>
<p>Financial Barriers</p>	<p>Cost to schools of providing additional support and supervision can be seen as prohibitive.</p> <p>Cost to schools and other services of accessing epilepsy training – particularly emergency medication training – may be seen as prohibitive.</p> <p>Epilepsy is perceived to be a low priority in schools – other conditions may take priority in terms of resources and training.</p> <p>Process of getting a Statement of Special Education Needs for children with complex epilepsy is expensive – some families report they need to get assessments completed privately.</p> <p>Access to services and therapies may be limited by lack of resources.</p>



Lack of Access to Appropriate Medical Treatment

A lengthy process to make the diagnosis of epilepsy can lead to delays in starting treatment and this will influence learning if seizures are undetected and the epilepsy is inappropriately managed.

Treating epilepsy is complex and finding the right medication can take a considerable amount of 'trial and error' and lead to delays in beginning the right treatment, which will impact on learning.

Lack of communication from medical professionals can lead to children with epilepsy and their families as well as educational professionals feeling 'in the dark' concerning the implications of diagnosis.

Lack of access to specialist services and medical professionals with expert knowledge may hinder appropriate treatment and understanding of the condition.

Institutional Barriers

Misconceptions among school staff concerning epilepsy due to a lack of understanding.

Fear of epilepsy can lead to unwillingness from school staff to take responsibility and include children with epilepsy in all activities and trips.

Failure by some educational professionals to appreciate that epilepsy presents in a variety of forms apart from tonic-clonic seizures.

Failure by some educational professionals to appreciate the potential impact of epilepsy on learning and behaviour.

Misinterpretation of epilepsy, particularly absence seizures, as 'naughtiness' is a barrier.

Schools may be unwilling to engage with epilepsy training if they do not perceive the need due to a lack of understanding.

Assessment systems in place (exams) may present difficulties for children with epilepsy-related memory and learning problems.



Case Study Louise

Louise's seizures have been relatively well controlled and unlike many of the young people included in this study, her school attendance has not been adversely impacted by her epilepsy. When she is asked about her educational experiences however she quickly refers to an incident that has stayed with her 'I got bullied because of my epilepsy in year eight... I didn't realise that, I lost my bodily control basically and... I just ran out, I ran out of my maths class'. As a result she says 'I started not trusting people, I just started decreasing friends really'. Louise is now 18 and looking forward to studying at college. She feels she has regained her confidence but it has taken her some time.

Louise has been given additional time for exams following a request from her mother but she does not find that this has helped to improve her grades. She struggles with her memory and there is a discrepancy between how well she does in course work and the results she achieves in exams. Despite being predicted a 'double C' in one of her courses she feels certain that her exam results will bring her marks to a D/E. However, Louise remains positive about the future and determined to help other young people with epilepsy. She believes that change needs to come at policy level to make a difference for young people with epilepsy.

Equal opportunities and the role of legislation are topics that Louise has learnt about in her Health and Social Care course. Her final word when asked about inclusion in education for children with epilepsy is to point to the importance of these factors in terms of what happens in the classroom. She does not feel that her teachers understood epilepsy. They did not 'get' the 'full extent' of the problems that can go with a diagnosis of epilepsy. This is a situation she would like to challenge and to change.

Case Study Melissa

Now 16, Melissa's epilepsy is well controlled and she has been weaned off antiepileptic medication after responding to the fourth drug her doctors tried. However, she experienced significant problems in year eight and describes memories of social isolation at this time. She found it stressful when she just wanted '... to go and play in the playground' and frequent hospital stays prevented this. Melissa experienced mood swings and was aggressive towards her mother, particularly when she was trying to administer medication. One of the few positives from this time was an important relationship she formed with a nurse during her hospital stays and this helped her to cope with ongoing medical treatment and situations she sometimes found stressful. Melissa gained weight due to the medication for her epilepsy and struggled to cope with this emotionally.

Melissa's mother took a proactive approach to ensuring that she received the help and support she needed at school. When a small group of classmates began to bully her – spreading the message that they would 'catch' epilepsy from her – Melissa's mother stepped in to talk to the class. The bullying stopped after this but it is something that Melissa remembers well and it has shaped how she feels about issues relating to epilepsy. She would like people to be aware of epilepsy in the same way they are aware of other conditions. Melissa is now studying Health and Social Care at college and she is keen to be involved in supporting charities that campaign to raise awareness of epilepsy. She feels she has learnt a lot from her experiences and has become a stronger person who will speak up for others and she is '... a lot more confident'.

Facilitators of Inclusion in Education for Children and Young People with Epilepsy

Access to Services	<p>Assessment by an Educational Psychologist may reveal support strategies schools can implement.</p> <p>Support available through charities, such as helplines, online forums may be helpful.</p> <p>Access to therapies such as Speech and Language Therapy, Occupational Therapy and Physiotherapy.</p> <p>Social workers identified as key to gaining access to services for children with epilepsy and complex needs.</p>
Adaptation to Needs within the Educational Environment	<p>Appropriate epilepsy training accessed by school and support staff.</p> <p>Technology used to overcome memory impairments and processing difficulties – i.e. individuals able to use computers rather than writing by hand.</p> <p>Emergency medication accessible within the school environment.</p> <p>Additional time given in exams to account for epilepsy-related learning difficulties.</p> <p>Availability of ‘inclusion officers’ and ‘inclusion teams’ to promote inclusion. A knowledgeable and sympathetic SENCo who can support staff, children and families.</p> <p>Access to space to rest and sleep following seizures is an important environmental adaptation for some children with epilepsy.</p>
Parents as Advocates	<p>Key role in ensuring appropriate access to services including medical, therapy and education.</p> <p>Parents who are willing to be perceived as ‘pushy’ to get the services they need.</p> <p>Parents as ‘experts’ who know their child’s epilepsy and are able to work effectively with schools.</p> <p>Parents as ‘researchers’ who develop an expert understanding of their child’s condition.</p> <p>Parents speaking out on behalf of their children as ‘advocates’.</p>
Peer Support	<p>Willingness of peers to support in practical and emotional ways.</p> <p>Buddy system may be a way to support some children.</p> <p>Peer support allowing more independence for older teenagers with epilepsy.</p> <p>Online forums may provide support for teenagers.</p>
Effective Medical Treatment	<p>Timely access to assessments and appropriate treatment.</p> <p>Access to sensitive medical consultants who listen and communicate well with children.</p> <p>Access to epilepsy nurses who provide information and emotional support as well as medical knowledge.</p> <p>Access to assessment for surgery and other treatments – Vagus Nerve Stimulation (VNS), ketogenic diet – could be ‘life changing’ for some individuals.</p> <p>Access to emergency medication may allow freedom to take part in activities and give ‘peace of mind’.</p>

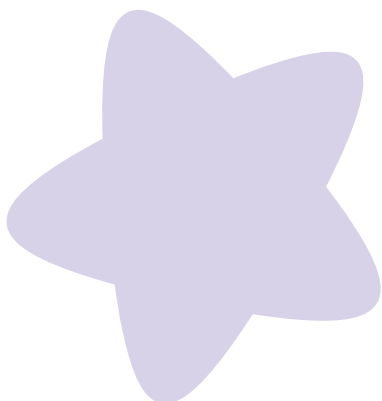
Discussion

Lack of Access to Appropriate Medical Treatment

One of the significant difficulties faced by many children with epilepsy is the length of time it can take to get an accurate diagnosis. A question mark may be hanging over the diagnosis for some time. Thomas said 'It should not take seven years before I get a diagnosis of my epilepsy'. He was frustrated by his neurologist and her apparent inconsistency 'One minute she'd say, OK, you've got temporal lobe this that and the next thing, and then she'd write my seizures off as psychogenic seizures, and then she'd write them back in again, and then write them off again'. Over a period of time he felt that he was '... constantly written off. I started to doubt myself because doctors are the source of all knowledge – who was I?'

The participants in this study and their families referred to a 'mixed experience' with the medical profession. Delays in assessment and diagnosis, dealing with consultants who did not listen and a feeling of being 'lost in the dark' at the point of diagnosis were reported as common experiences. It must be noted, however, that none of the participants or their families characterised their experiences of medical management as wholly negative but rather they were represented as highly variable. They also mentioned sensitive consultants and epilepsy nurse specialists who had played a vital part in providing information and support, and in one case a particularly helpful pharmacist.

Epilepsy services in the UK have historically been underfunded and not prioritised. A number of government reports stretching back over decades have identified that health services for people with epilepsy are fragmented and poorly coordinated (Rajpura and Sethi, 2004). In 2007, the All Party Parliamentary Group on Epilepsy reported on the human and economic cost of inadequate and unequal access to services and support for people with epilepsy (Wasted Money, Wasted Lives, APPG on Epilepsy, 2007). In 2012 the Epilepsy12 Audit of 193 epilepsy services in the UK found significant variation in the availability of services, appropriate assessments, information about epilepsy and access to clinicians with expertise in epilepsy. The participants in this study reported experiences that reflected the challenges faced by many people with epilepsy with regard to accessing appropriate health services.



Epilepsy and Related Conditions

High rates of absenteeism as a result of seizures appear to have presented problems for many of the participants in this study. Melissa said that ‘... the area it affected me most was maths, because I’d missed a whole chunk of some of the important stuff (and) it made me less confident to... take part in class’. For some children there will be a deterioration of skills over time as a result of their epilepsy. Henry’s mother is concerned that he knows that his language skills are not what they used to be. He is a ‘bright boy who knows he’s not the same’.

A lack of understanding about the connection between epilepsy and related learning difficulties can result in misconceptions and the failure of school staff to appreciate the potential impact of epilepsy on learning. Peter’s mother recalled that he had one teacher who she felt ‘... didn’t understand the epilepsy’ and who seemed to think that he ‘... coincidentally has epilepsy plus these issues (and) hasn’t connected’.

Some children with epilepsy need to sleep during the day if they have had a seizure. They may need time to ‘recharge’ before they are able to rejoin lessons. One of the barriers to inclusion in education for children with epilepsy identified in this study was a lack of provision within schools to allow this, particularly as children get older - ‘You can be tired as a four-year-old, wanting to sleep on a cushion’ reported Jack’s mother, but it is less acceptable for older children to need to sleep during the day. Many children involved in this study were routinely excluded from school by being sent home following seizures and as a result missing parts of their education when this was not entirely necessary.

‘Politically, we’re in a five year cycle, they don’t have to answer for things twenty years down the line’

Parent to Jack, 17



Case Study Jason

Jason (13) is reluctant to talk about his epilepsy. He was diagnosed with Benign Rolandic Epilepsy and after responding to treatment he is now being weaned off his medication. His mother would like some help to know how to talk to him about his epilepsy. She has suggested in the past that they could arrange a talk at the school to raise awareness of the condition but Jason does not want this as he has seen other children in his school faint and says '... mummy it's terrible because people laugh'. His mother says he thinks he is the only one in the world with epilepsy. There are no opportunities for him to meet other young people who have epilepsy and what support there is where he lives in Northern Ireland is aimed at adults.

Jason and his family have been well supported by the schools he has attended – both primary and secondary schools – and staff have engaged with training and shown a willingness to learn about how to meet his needs. Access to medical care has been problematic with long waits for an MRI and variable experiences with medical professionals who '... always seem too busy' and '... don't know how to talk to a child'. His mother expected schools to have more difficulties than the medical professionals in understanding the condition and the impact on the family and was surprised that it seemed to be the '... other way round'. They now have a good relationship with their consultant but feel that the experiences they have been through have been made more difficult by uneven access to appropriate healthcare.

Case Study Molly

Molly's parents reported that she was very excited about starting primary school at age five but her first year has not gone well and her parents feel her self-esteem has suffered considerably. Despite an initial willingness to work with the family, according to her parents her school have shown a lack of awareness concerning how epilepsy should be managed in the classroom. It was her parents' belief that they treated Molly as a 'health and safety' hazard, meaning that she could not sit on the benches with her peers at lunch time in case she had a seizure. The school initially proposed that she should sit facing a wall as they mistakenly believed that seeing the activity in the classroom would trigger a seizure. This was despite her parents trying very hard to explain the type of seizures Molly has and that they were only occurring at night.

Molly has a diagnosis of West Syndrome and has associated difficulties. She has hypermobility and specific problems with learning. Her father is particularly determined to get an assessment from an educational psychologist for his daughter. He feels that the early days of her education are crucial for building skills for the future and that an understanding of Molly's learning needs is important if she is going to achieve her potential.

Molly's parents have fought for extra help for Molly in the classroom and although she was given some one-to-one support, this was being used for lunch time supervision rather than supporting her learning. They report she is struggling to follow what is happening in class and this is resulting in her becoming disengaged and her behaviour is starting to be problematic. Difficulties in the classroom were being relayed to her mother by the teacher in front of Molly on a daily basis. Her parents feel she has been labelled as a 'difficult child' and they are hoping that a move to a different school with smaller classes and more support available will help Molly to be included.

Case Study Jared

Jared (eight) has Dravet Syndrome and he has ever-evolving and changing types of seizures as a result. This can be challenging for his school to manage – identifying seizures and knowing when to treat can be difficult and his mother worries that he will be given his emergency medication unnecessarily. Jared needs to sleep following seizures and this has been very problematic within the primary school he attends. They do not have the facilities to allow him space to sleep and he is sent home regularly even if he only needs a short time to rest.

Jared has a Statement of Special Educational Needs and he has a teaching assistant to help him in the classroom. However, his parents describe the quality of the support he is given as variable. The teaching assistant who was employed did not have a background in education and as the classroom teacher did not have an understanding of special needs it was, his mother says, a case of the 'blind leading the blind'. Jared now has a new teaching assistant who is more in tune with his needs but she is frequently absent and his mother has been stepping in to fulfil the role. What she has observed in the classroom is that Jared is not as included in the activities of his peers to the extent she feels he could and should be. She is aware that he cannot always do the same things as his classmates, due to his learning and communication difficulties, but she would like him to be given something similar so that he is involved and included.



Case Study Rosie

Rosie (eight) developed epilepsy following encephalitis – an inflammation of the brain tissue related to a viral infection. She had only recently been diagnosed with epilepsy when she participated in this study. She is adjusting to having epilepsy and is keen to learn as much as she can about the condition, conducting her own research and reading up on what happens in the brain to cause her seizures. She is now taking medication and this appears to be controlling the seizures. Her school is also adjusting to the idea of managing Rosie within the classroom and they have now arranged support and training for the classroom staff. Initially, however, they were reluctant to accept Rosie back into the classroom without mum being there as well.

Rosie and her mum now have access to support from an epilepsy nurse and this has been important during a very worrying time in the early days following diagnosis. Her mother found it very stressful. She reported the feeling that '... this thing is just taking my Rosie away, is she going to come back properly?' Rosie's mum feels more in control now that she has access to information and support from medical professionals that was missing in the early days following diagnosis. Although she 'steered clear' of the internet at first – worried about what she would find – she is now doing her own research on epilepsy and looking for the support she needs from other parents who have been through similar experiences. It is too early to tell how Rosie's epilepsy will impact on her education but she is determined that it will not get in her way of doing anything she would like to do.

Institutional Barriers

Within every school there are people who act as ‘gatekeepers’ and exercise power over how the school is run. When those in a position of power are unable or unwilling to include children with epilepsy, they effectively become instigators of institutional barriers. Institutional barriers have been identified to be policies and staff in schools who prevent children with epilepsy from being fully included in education. Although policies that promote best practice may be available, the implementation is reliant on individuals. Thomas felt that ‘... it’s down to individuals, it’s who runs the place’. One parent, however, recognised that head teachers may have their ‘hands tied’ by those who are above them. The SENCo was identified by several parents involved with this study as key to gaining access to services and ensuring their children were included in education. If the SENCo is not knowledgeable and sympathetic this has been identified as a barrier ‘... the SENCo would say the epilepsy is medical, not educational’ recalled Emily’s mother and she reported that she struggled to get her message across to the school that ‘... one affects the other’ and you cannot separate them as isolated concerns. Some parents thought that epilepsy was being misinterpreted as ‘naughty’ behaviour. ‘When he couldn’t cooperate, they thought he was being difficult’ said Jack’s mother. She reported being ‘shocked’ that teachers could not appreciate how his absence seizures affected the way he responded to instructions.

Psychosocial Impact of Epilepsy

Epilepsy has a recognised association with stigma (Morrell 2002). Hannah raised the issue that a teacher with pastoral responsibilities in her school had placed the photographs of children with epilepsy on display in her office. ‘She’s got ‘people with epilepsy’ and all our photos on the wall... I said no wonder we get stick ‘cos of our health’. It seemed that this teacher’s actions were intended to raise awareness of the need to support children with epilepsy but she had inadvertently contributed to stigmatising those with the condition. An observation from this study is that while some staff in school try to help young people with epilepsy, they do not always appreciate the best way to do this. Thomas reported that – ‘I needed some sensitivity with my condition. It’s a humiliating condition because you feel naked in the dark, because you lose control over yourself’.

All but one of the older teenagers in this study detailed experiences of being bullied at school. They felt that this had a negative impact on their ability to relate to their peers within the classroom and it led them to becoming withdrawn and isolated. Louise reported that the stress of school life was exacerbating her seizures ‘... it’s just stress that brings on my seizures’. In this case, educational experiences were impacting negatively on the health of a young person, making it more difficult for her to engage with her education.

‘Not everybody’s the same with epilepsy. What to do, how to act, how to react. People don’t know what they can say. People don’t know how to talk about it’

Justine, 16

Financial Barriers

Lack of prioritising to provide resources for children with epilepsy was seen by many of the participants and their families as a barrier to inclusion in education. One participant noted that epilepsy training courses were not readily available for staff at her school and she stated ‘... if they cost money, forget it’. Other priorities were higher on the agenda ‘... cos there’s no money in the budget but there’s money for new chairs... leather suites... big suede things’. Another financial barrier identified by families who have a child with special educational needs is the cost of the process of getting a Statement of Special Educational Needs. One mother reported that she was quoted £20,000 to get a statement for her son. It is recognised that parenting a child with a disability can be expensive (Parish and Cloud, 2006) and this was reflected by the views of families involved in this study. Jack’s mother reported that ‘... life with a disabled person is more expensive, it’s all the little things that drain the money away’.

It is worth noting that a very small proportion of the children in this sample had both parents in full time employment. Only three out of the 18 participants had mothers who worked full time and one worked part-time. In several cases this appeared to be due to the need to be ‘on call’ for the school in case their child had a seizure. It would seem that – within this sample at least – childhood epilepsy has a significant impact on opportunities for mothers to engage in paid employment. It is not possible to generalise from this sample but further research in this area may be warranted.

Effective Medical Management

One facilitating factor for inclusion in education was identified as effective medical management; access to an epilepsy nurse was seen as key for many of the families involved in this study. They were able to provide families and young people with information and ongoing support. They appeared to have the time to spend with these families, whereas the consultants did not. An accurate diagnosis of epilepsy was seen as key rather than ‘grasping in the dark’ for ways to treat. Justine was diagnosed with epilepsy when she was seven and after trying numerous antiepileptic drugs (AEDs) with a range of side effects she finally received an accurate diagnosis many years later and is therefore now prescribed a more suitable medication for her type of epilepsy. ‘It’s not stopped’ she said of her seizures, ‘... but I go to school’. Her school attendance has improved considerably as a result of better medical management.



Adaptation to Needs within the Educational Environment

Key individuals within the school environment were identified as important for ensuring that adaptations were made that would allow a child with epilepsy to be fully included in education. As noted, the SENCo in particular has a role to play in ensuring that the needs of children with epilepsy are met. Glen's mother summed it up 'It's all down to the SENCo, if you've got a decent SENCo who goes, well don't talk like that because it's inappropriate, and this is your job, pluck up and get on with it, because he is a kid'.

Educational psychologists were also identified by some parents as having an important role to play as they are able to identify specific cognitive problems, such as memory and processing difficulties which can impact on children with epilepsy. This means that support can be tailored and teachers are able to gain more of an understanding of the difficulties. There seemed to be variable access to the services of an educational psychologist however and regular assessment was only taking place for some of the participants in this study. Several families had 'gone private' to pay for assessments from educational psychologists, with one mother reporting to have spent £700 on an assessment but she felt this was 'money well spent' in order to get her son the help he needed.

Parents as Advocates

'When your child has 'something' – epilepsy or some other condition – you have to become a researcher'. This was the conclusion reached by Henry's mother and it echoed the views of several other families spoken to in this study. Parents often appeared to have developed a high level of expertise in relation to their child's type of epilepsy, which gave them the confidence to question medical professionals and pursue the best treatment for their children.

The frustration experienced by families was evident throughout the research. Parents reported the significant efforts required to get agreement to commence the process of getting their child assessed for a Statement of Special Educational Needs. Some parents reported the need to self-finance this process and the considerable burden on the family finances as a result.

The ability of parents to 'fight' for the services that their child needs appears to have a significant bearing on the help and support being given. Glen's mother reported 'They just did not want to give us our funding. But we got there in the end. Just persistence and being pedantic and being annoying. Just being there'. She continued 'You have to be bolshy, you'd be ignored otherwise'.



Peer Support

Although a number of participants in this study have referred to negative experiences involving being bullied at school, there were also many positive experiences reported when friends had provided the support they needed. Thomas particularly identified his friends as key to ensuring his own social inclusion in school life. The 'story of inclusion' for him was down to his friends. The 'buddy system' referred to by several participants appears to offer a way for children with epilepsy to be supported without drawing attention to them as 'different' from peers. This system only works however, providing the peer 'buddy' is willing and able to provide support. An element of monitoring needs to be built into the scheme to ensure success.

Although two of the participants in the study were not in favour of epilepsy awareness education in schools (both 13 year old boys), many of the others did want information and education for peers concerning epilepsy. Justine and her twin sister suggested 'workshops' for peers. Two of the participants commented that the only time they had come across references to epilepsy at school was within the Health and Social Care courses they were completing and this was a brief mention. Both wanted more information to be given to their peers at school and saw this as important in order for them to gain the support, acceptance and understanding they needed.

Access to Support Services

Children with epilepsy and their families may need additional support and the services of charities were identified as a key facilitator that would give them the help they need. Support groups were seen by several parents involved in this study as an important service. Lucy's mother is now meeting regularly with a support group for parents of children with epilepsy and says that this is her 'rock'. Several parents felt that their children would benefit from opportunities to meet other children with epilepsy. A support group could offer this but most available groups cater for adults and do not meet the needs of children or teenagers according to the families involved in this study.

Jason's mother reported that he felt he was the 'only one' with epilepsy. She wants him to meet other people his age with epilepsy and likewise Joe's mother has identified the need for Joe to have opportunities to meet with peers. Access to support services is important and although in some cases extended family were able to provide practical and emotional help this was not the case for others.

'Sometimes he wasn't allowed into school, so I'd take him out and try to get a policeman to ask me why he wasn't in school. To try and make the point. No one stopped me. I even put him in school uniform'

Parent to Glen, 15



Case Study Thomas

Thomas is 18 years old. He left school with no formal qualifications and could not - in his own words '... even get a job at McDonalds'. He was unable to complete his education due to poor health and left school before completing his GCSE exams. Like many of the young people included in this study, Thomas' epilepsy diagnosis took a number of years to be established. Although he was having focal seizures from the age of 11, he felt that the symptoms were not properly investigated and that he was '... written off as a hypochondriac'. Despite his mother giving details of a family history of epilepsy, this was only followed up after he started having tonic-clonic seizures.

Thomas felt 'shut out' by the boarding school he attended as they failed to make the adjustments that would have allowed him to stay on at the school. This was particularly evident with regard to nighttime care. He was experiencing nocturnal tonic-clonic seizures but rather than making arrangements for his care, those with management responsibilities at the school suggested that he would be able to phone for help, failing to appreciate that he would be unconscious at the time. He pointed particularly to the head of his school as someone with influence who effectively acted as the barrier to inclusion within the school. Although he was supported by some of his teachers and felt they were 'on his side', he states '... it's the individuals themselves... and if the individual just happens to be someone who is very important in a school then it means no one else can do anything about it'.

Thomas characterises his education as 'an experience of exclusion as opposed to inclusion'. What he would like people to know about epilepsy is this '... it's not as scary as it seems... it's not the stereotypical thing that you hear about in films'.

Thomas has spoken publically about his experiences and he is keen to speak to schools and others to highlight the issues for young people with epilepsy. Opportunities for those who work in education and support services to hear from young people like Thomas could be viewed as a facilitator of inclusion in education for children with epilepsy. It provides the chance to appreciate the impact of the attitudes of authority figures on their educational experiences.

Case Study Daniel

Daniel developed epilepsy at four and a half years of age following encephalitis. Now aged 13 he has processing difficulties that can make learning a challenge. His current educational placement is within a school that specialises in autism and although he is not on the autistic spectrum, many of the learning strategies to help children with autism also work for Daniel. The class sizes at his school are small and he has access to appropriate therapies. He takes part in all activities and school trips, including a recent visit to Paris. Daniel sometimes needs to sleep following seizures and his mother reports that the school are able to accommodate this as he has a '... little place he can lay down after he has a seizure'.

Daniel lived in the UK for four years following his diagnosis and in this time was not evaluated for epilepsy surgery. When he moved to the US, however, he was assessed within three weeks. His mother considers it to be a significant barrier to inclusion in education for children with epilepsy that there is such a long wait for a surgical assessment '... it's eight years to get surgical evaluation here, nine months in the States'. Although he has not been found to be a suitable candidate for epilepsy surgery, Daniel now has a vagus nerve stimulator and this is helping to give him the level of seizure control that will allow him to access his education. Now attending school in the UK he goes every day and has a wide social circle, often spending time with friends outside of school. According to his mother he now is 'fully included' at school and enjoys his education.

Limitations of the Study and Future Direction for Research

The participants in this study volunteered to participate. Those who have experienced difficulties might have felt a greater need or desire to come forward compared to those who experienced no such problems. Participants and their families were asked about their motivations for agreeing to be involved in the study and there seemed to be consensus that they wanted to raise awareness of educational and other issues that can impact on children with epilepsy in order to ensure that others do not go through the negative experiences that they had been through. Although providing valuable insight into the difficulties faced by children and teenagers in education it cannot give any indication as to prevalence.

This study is based on a sample of 18 participants and contained a higher proportion of children with additional and learning disabilities compared with the general population of children with epilepsy. Caution should be taken therefore in generalising these findings to the wider population. Larger scale studies are needed to establish the prevalence of the difficulties outlined within this study. Many of the facilitating factors identified in this study warrant further investigation in order to establish how to optimise the attitudes and abilities of individuals to ensure inclusion in education for children with epilepsy.

‘The wrong kind of person could ruin a childhood’

Parent to Jack, 17



Recommendations

The findings and recommendations of this report are intended to provide tangible steps that can be taken to facilitate the inclusion of children with epilepsy in all areas of education. It is not intended merely as a piece of academic research, but as a tool to support professionals and provide insight into the experience and perceptions of the children. The recommendations made relate to how schools and other professionals can work with families and children to ensure that they have access to the same educational opportunities as their peers. The recommendations are intended to provide practical guidance and a way of sharing the good practice that has been identified through the study. As it was identified that parents have such an important role to play in relation to inclusion in education for children with epilepsy, recommendations have also been made concerning their part in this process.

‘People didn’t seem to want to include him’

Parent to Jack, 17



Recommendations for Schools and Education Professionals

Misconceptions about epilepsy emerged as one of the most significant barriers to inclusion in education for children with epilepsy. In some cases it would seem that schools felt they were protecting children by limiting their access to activities. It is clear that there is considerable work needed to ensure schools support children with epilepsy effectively.

- Teachers need access to specialist epilepsy training, which includes potential learning and psychosocial difficulties. It appears some schools consider first aid training for tonic-clonic seizures is all that is necessary for epilepsy but this study has shown more awareness is needed about how varied the condition can be.
- The role of the SENCo was highlighted by a number of parents involved in this study and there is an argument for specialist epilepsy training for SENCos as a priority.
- Recognising possible manifestations of epilepsy and difficulties that may be associated with the condition is important if children with epilepsy are going to be fully included in education. Schools need to be monitoring for potential problems.
- Schools should have an 'epilepsy policy' that outlines how children with epilepsy will be monitored and how information is going to be coordinated and disseminated.
- Individual healthcare plans are important to communicate accurate information about a child's epilepsy and should include medication, how seizures typically present and emergency treatment.
- Although most of the young people included in this study were in support of activities that would raise awareness of epilepsy among peers, it must be recognised that some did not want this in their school; sensitivity is needed with regard to how this is managed.
- Several participants referred to the use of technology as potentially helpful for overcoming specific memory and processing difficulties – such as the use of dictaphones and laptop computers. These need to be available to children with epilepsy when appropriate.
- Assessment from an educational psychologist could be key to ensuring that children with epilepsy are accessing their learning as they should and that difficulties are identified and addressed. Schools need to be aware that access to an educational psychologist is important for children with epilepsy.
- While many schools work hard to eliminate bullying, children with epilepsy need to be recognised as particularly vulnerable and their social interactions need to be monitored.



- One of the frustrations mentioned by the older teenagers in this study was the need to tell the ‘story’ of their epilepsy repeatedly. An up-to-date individual education, health and care plan that is appropriately shared with the full range of professionals working with a child in school will reduced these frustrations. Where appropriate it should be developed with the child’s involvement to ensure their views are included.
- Teachers need to understand the possible implications of a diagnosis of epilepsy in the children they are responsible for and they should seek more information as required. They need to be accessing resources such as those produced by charities to gain insight into the condition and possible implications for the children they teach.
- Strategies to support specific learning difficulties such as memory problems need to be developed when appropriate.
- Support for children with epilepsy needs to be given in a way that is sensitive to their desire to ‘fit in’ with peers; it is important that monitoring is done in a way that does not draw attention to the child. In the same way as some parents are perceived as overprotective, it seems some teachers are too openly concerned and need to find a way to monitor the child more subtly.
- Open lines of communication between families and schools are important due to the variable nature of epilepsy and coordination of information relating to seizure patterns and other factors such as changes in medication is important for the effective management of children with epilepsy.



Recommendations for Parents

As noted, parents have a vital role to play in ensuring that their child is able to access their education and have the same opportunities as their peers. Parents are the experts when it comes to the life and condition of their child and therefore professionals must listen to the valuable experience and insight that they can provide.

- Information and advice needs to take into account that parents will have a varying level of knowledge and therefore need to have access to a range of support that is flexible and appropriate to where they are on their journey with the condition.
- Parents need to be confident and clear with those who provide services about the level of support and information they require to enable them to be the ‘voice’ of their child within the complex systems of education and health services. Taking on the role of ‘advocate’ is an effective mechanism for facilitating inclusion.
- Parents need to be aware of their own needs to ensure they do not become overburdened, jaded or pushed off track in pursuit of support for their child. Equally they need to be vocal and determined to ensure that they access services such as respite facilities.

Recommendations for Healthcare Professionals

Epilepsy needs to be seen as more than merely a medical condition and a holistic approach is needed wherein the role of the medical professional is an integral part of an effective multidisciplinary team.

- Medical professionals need to be aware that they are not only working with children and their families but are also included in the professional network that includes teachers and education support staff. Acknowledging the difficulties that exist for professionals working across different sectors, the aspiration is for integrated services that work together within existing guidelines such as those published by the National Institute of Clinical Excellence (NICE).
- Healthcare professionals need to ensure that significant medical information such as potential side effects of anti-epileptic drugs (AEDs), medication increases and decreases and other information is passed to the school and understood by those who are responsible for managing the child in the classroom.
- It is important that treatment for epilepsy is not limited to and solely focused on seizure control. Good communication and reporting between health and education professionals will ensure that any variation in cognitive ability or general performance will be taken into account when seizure control is being sought. In addition any long-term effects of medication and potential impact of medication during pregnancy need to be discussed as part of the transition plan for teenagers with epilepsy.

Recommendations for Policy Makers

There are changes currently taking place in relation to the system for supporting children with special educational needs (SEN) and this will have a significant impact on many children with epilepsy. This research highlights the need for awareness of the types of difficulties that can be faced by these children as they may not be obvious.

- The potential for other significant related and psychosocial difficulties associated with epilepsy means that it must be recognised and acknowledged as a special educational need and treated differently from other chronic health conditions in childhood.
- Policy makers need to look to the future and consider the cost of 'getting it wrong' in relation to childhood epilepsy and education. There are potential social and economic costs associated with managing children with epilepsy poorly in relation to their education and these need to be appreciated. Additional funding for support at an early stage needs to be seen as a long term investment.
- Policy makers are perhaps the most important audience for this research as they have the capacity for influencing how money is spent in relation to children and education. Our primary recommendation for policy makers is that they need to listen to the voices of the children and their families when deciding the direction for future policy.

'Epilepsy is exclusion... it's just the fear around epilepsy'

Thomas, 18

Case Study Henry

Henry has epilepsy as well as Asperger Syndrome. He attends a private school and reports that he feels under pressure to 'keep up' academically with the other children in his school. He is only 10 but has already started to worry about his GCSE exams. He does not like missing school and knows he will be sent home if he has a seizure of any kind. He reported '...Mummy's had to come and pick me up like 10 times because the school don't like me being there if I have one little one'. His mother suggests that '... 10 times is an understatement'. Henry worries that missing school will impact on his academic progress so he hides the fact that he has seizures '... I never tell the teachers... I try not to tell anyone'.

Henry's epilepsy is not like other types of epilepsy '... his standard seizure is not tonic-clonic' according to his mum and his seizures are not always apparent. This makes it difficult to explain his epilepsy to his school. Henry has been bullied and although the school have tried to address this, Henry was not consulted about the best approach to use. He reports that '... matron talked to the school in assembly and made me come to the front and answer some questions'. He was not prepared for this however and says that '... everyone was looking at me, it made me very nervous'. Henry does not appear to be fully included in the school due to a lack of understanding about his condition and how to manage it sensitively.

Case Study Justine

Justine (16) has epilepsy and she is not afraid to make jokes about her condition. She reported '... it makes people relax' and they realise they can talk to her about it. Justine and her twin sister are now keen to raise awareness about epilepsy. They have taken their friends along to some training organised by an epilepsy charity so they will know how to manage seizures if they go away together. Justine is taking a proactive approach to ensure that she does not miss out socially.

Justine feels she is included now that she is at secondary school but her epilepsy caused difficulties back in primary school. At one point she was not allowed to go out into the playground at lunch time and break times unless her mother came to the school to take responsibility for her. Otherwise she would have had to spend break times in the principal's office.

Justine now has good seizure control as she has been put on a medication that works well for her. It has been a long process to find the right treatment however and her father thought that at one time she had been put on the 'too hard list'. The number of medications she has tried is in the double figures and many caused adverse reactions. She is now waiting for surgical assessment and her family are hopeful that surgery could help to control her seizures.

Justine is positive about the future and clear about what needs to happen to make sure young people with epilepsy are fully included in education. She feels that workshops should be run in schools to teach young people about epilepsy. She says that '... people with epilepsy need to know it's ok to talk about (it), people need to let others with epilepsy know that they can talk about it, not be ashamed of it'.

Case Study Jack

Jack has epilepsy and a severe learning disability. Although his mother reported that his infant school was very 'open-minded', his junior school did not show the same willingness. His mother reports that '... people didn't seem to want to include him'. The contact book she used to keep in touch with the school was a 'minefield' and included comments that suggested they did not understand that Jack's inability to follow instructions was related to difficulties in comprehending what was said to him. They treated him as if he was being 'naughty' and wanted him to 'promise to be good'. If the class behaved, they would be given 'Golden Time' as a reward and get to take part in a special activity. However, the activities chosen were ones in which Jack was unable to participate.

Jack initially did better when he moved junior schools but there were limitations to the amount of support they could give him. He ended up being 'babysat' rather than educated. The teaching assistant who was employed to support him, in mum's opinion, did not seem to understand him and '... thought he was being a pain'. His mum worries about the impact of Jack's educational experiences and feels that the 'wrong kind of person could ruin a childhood'. Jack, now 17, is attending a school where his epilepsy is understood and he is appropriately supported. He has access to therapy for the first time. His mum recognises that resources are expensive but if they are not available it is '... easy for the person who needs the help to slip through the net'. It's not just about the money, however, it's about '... the attitude from the top down'. Inclusion in education for Jack means being understood.



Case Study Lucy

Lucy is eight and has a recent diagnosis of epilepsy as well as cerebral palsy. Her epilepsy developed during the summer holidays but after her mum contacted the school they were able to arrange training for the staff. Although most of her seizures have been nocturnal, she has now had one at school during a hot assembly and staff responded to make sure she was kept safe. Lucy attends a mainstream primary school but there are several other children with disabilities in the school, including one who also has epilepsy. This means that the school has experience and previous training concerning how to support children with epilepsy in education.

Lucy is slightly behind her classmates academically and has additional help in a small group to give her the support she needs. She sometimes gets tearful if she has had a seizure during the night and may be reluctant to go into school. Her mother has explained this to the school and also the fact that she gets tired and they are getting better at taking her out when she needs air. Her epilepsy medication appears to be having a negative impact on her behaviour and teachers are reporting to her mother that Lucy is getting 'fiery' at school. She can also be an 'emotional wreck'.

Lucy's mother has struggled to find the support she needs and says that '... professionals don't point you in the right direction' at the point of diagnosis. However, she has access to an online forum and finds it helps to talk to other parents, to know '... you're not the only one, you're not alone'.

Conclusion - Innocently Ignorant

The mother of one participant in this study described her daughter's school as 'innocently ignorant' when it came to their understanding of her daughter's epilepsy. She knew that the staff within the school wanted to help her daughter but that they struggled to understand her needs and how to meet them. We recognise that many educational and other professionals are trying hard to work effectively with children and young people with epilepsy but they may need guidance on how to do this.

This study included children and young people in a range of educational settings and with different types of epilepsy and other special educational needs. They came from across the UK and from many different family situations. They ranged in age from five to 18 years of age. What they had in common was a need for the understanding and support that would make it possible to include them in all aspects of school life – having access to opportunities for learning, participating and contributing to their school community.

It is important that professionals who have responsibility for the care and education of children with epilepsy are aware of the children's views. One of the most important aims of this research was to ensure that the voices of these children are heard and that they inform practice for those professionals who work with them. It would seem that the extent to which children with epilepsy are included in education in the UK is variable. This research revealed examples of good practice, poor practice and misguided practice. It is hoped that the recommendations based on this research will provide a practical way to address some of the issues that have an adverse impact on the educational opportunities for children with epilepsy and they will, in the future, be fully included in education.



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Young Epilepsy – Partnerships

Young Epilepsy is always keen to work in partnership with other organisations in all sectors including schools, colleges and local authorities. There are many different ways we can provide support and we would encourage you to get in touch if you need any help regarding epilepsy and education.

How we help schools

For schools right across the UK we can provide:

- Epilepsy training for teachers, teaching assistants, SENCos or any other school staff.
- Epilepsy awareness training for school pupils including assemblies, lessons and workshops.
- Free resources for schools including epilepsy-focused educational videos and lesson plans.
- Free e-learning packages for Key Stage 2 and Key Stage 3 pupils.
- Free epilepsy magazines for Key Stage 2 and Key Stage 3 pupils.

With one pupil in every primary school and five pupils in every secondary school having been diagnosed with epilepsy, we know there is a real need to raise awareness of the condition within the education system.

To get in touch and find out more about our services and how we could help your school or local authority, please email: info@youngepilepsy.org.uk

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