



The identification of educational problems in childhood epilepsy

**The Children with Epilepsy
in Sussex Schools (CHESS) Study**

Foreword

This study arose from a senior politician saying to us *“I know that people with epilepsy are not counted in schools and I know that they have a wide range of cognitive and behavioural problems but you have to do something that brings this to everyone’s attention”*. Our response was to have four international annual meetings that highlight these problems, a new course for professionals and this; The CHESS Study.

The purpose of this study was to document, on a population basis, difficulties with cognition and behaviour in children aged 4 to 16 years. The cognitive aspects included memory and processing speed, and the behavioural aspects included symptoms of Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Developmental Coordination Disorder (DCD), anxiety and depression.

The striking elements about this study are:

- Very high levels of problems with academic progress.
- 40% functioning within the learning disabled range.
- Memory underachievement in 58% of children on at least one of the four memory tests.
- 42% were underachieving in processing speed.
- A high level of academic underachievement with greatest difficulty in mathematics and sentence comprehension.
- 60% met the diagnostic criteria for a behaviour disorder or DCD.
- 95% of the children had difficulty in at least one of the assessed areas.
- most of the children had several problems.

Children were comprehensively assessed and the findings were shared with the young people, their parents and school staff with the aim of identifying support that would be useful. Of those with significant behavioural problems, only one-third had previously been professionally diagnosed and there was a very low rate of psychiatric and psychological input.

This study makes it clear that a clinically orientated educational psychologist is required, to perform assessments on all children with epilepsy.

We are most grateful to the researchers who have included: Dr Patricia Atkinson, Professor Christopher Gillberg, Professor Rod Scott and particularly Dr Colin Reilly, for their work. We also thank head teachers and school staff, the children themselves, parents who have been very open about their children’s problems and the funders of the project, the Esmée Fairbairn Foundation and the Roden Family.

The next stage in this process will be a combined approach with parents, children, teachers and other professionals, with the aim of fulfilling the rights of children with epilepsy by early, comprehensive assessments.

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Summary

Children with epilepsy are at greater risk of learning and behavioural difficulties than children without epilepsy. However, these difficulties are often missed because of the pressing medical needs of epilepsy.

The current guidelines for the management of epilepsy in children focus primarily on the medical needs of the child. The purpose of this study was to identify the prevalence and nature of learning and behavioural difficulties in school-aged children with the condition.

We identified 115 children with 'active' epilepsy in an area of West Sussex and their parents were asked if they wanted their children to undergo psychological assessment. A total of 85 (74%) parents indicated that they wanted their child to participate.

An educational psychologist visited 40 schools in the area, to screen and subsequently assess the children with epilepsy for learning and behavioural difficulties. Parents and teachers completed measures of behaviour and the children completed measures of cognition (e.g. global cognition, memory, processing speed) and academic achievement (e.g. reading and mathematics). The main findings included:

- 79% of parents and 67% of teachers reported difficulties with academic progress.
- Regarding behaviour, difficulties with attention and concentration were the areas of greatest concern. This was reported by 64% of parents and 37% of teachers.
- Global cognitive difficulties (IQ score below average) were found in 55% of the children and 40% were functioning in the learning disabled range.
- Memory difficulties were also common; 58% of the children were underachieving in at least one of the four memory tasks.
- 42% of the children were underachieving in the area of processing speed.
- 42% were underachieving in at least one area of academic achievement, with greatest difficulty in mathematics and sentence comprehension.
- 60% met diagnostic criteria for at least one behavioural or motor disorder (i.e. Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Developmental Coordination Disorder (DCD), depression or anxiety). However, only one-third of the participants, who met criteria, had previously received these diagnoses.

Difficulties were not confined to children with identified special educational needs and 95% of the children had a significant difficulty in at least one area of cognition or behaviour. The findings demonstrate that all children with epilepsy need a comprehensive psychological assessment. This would ensure cognitive and behavioural difficulties are not missed and consequently unsupported.

The study revealed that children with epilepsy have a very high rate of behavioural and learning difficulties which can often go unrecognised. Guidelines for the management of epilepsy need to incorporate assessment of cognition and behaviour and monitoring of school progress for all children with epilepsy. This will help identify problems so that effective support can be put in place.

Background

Epilepsy is the most common neurological disorder in childhood. It has been estimated that 1 in 200 children have epilepsy¹. Difficulties in learning and behaviour are common in children with epilepsy. Research has shown that children with the condition are at greater risk of learning and behavioural problems than children without epilepsy and children with other non-neurological chronic illnesses^{2,3,4}.

Previous research suggests that a quarter of children with epilepsy function in the learning disabled range⁵. As well as this global cognitive difficulty, children with epilepsy can have specific cognitive problems including difficulties with processing speed and memory⁶. Cognitive difficulties can arise due to the underlying cause of epilepsy, side effects of treatment and impact of on-going seizures⁷.

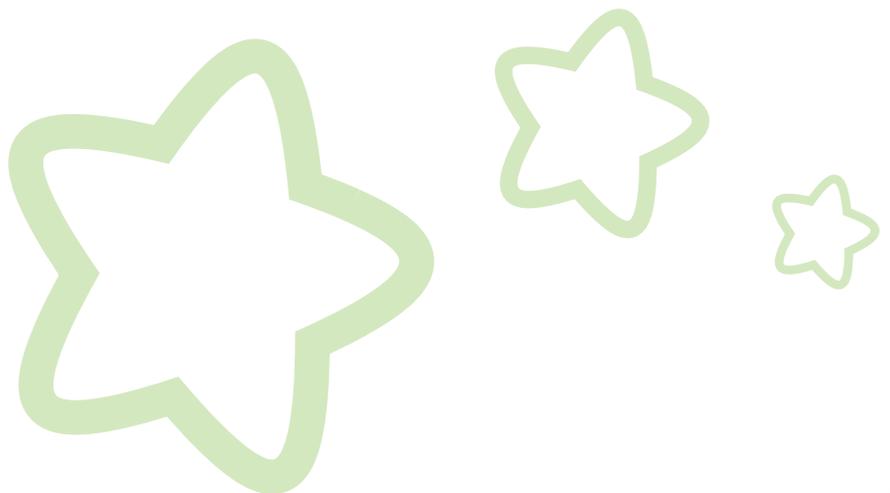
Common behavioural difficulties in childhood epilepsy include Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), depression and anxiety.

Motor problems, including cerebral palsy, are also common in epilepsy. A study comparing behavioural difficulties in individuals with epilepsy, and children with diabetes found that difficulties were more common in the epilepsy group (37%) than the diabetes group (11%)⁴.

These findings demonstrate that emotional-behavioural problems are not solely the result of having a chronic medical condition. They indicate that children with epilepsy are a very high risk group.

The reasons for the increased risk probably relate to an underlying difficulty in brain development but also to the psychological and social aspects of having epilepsy. Social stigma is common in epilepsy. It can lead to the child having low self-esteem and a reduction in motivation to engage with school learning and activities.

Learning and behaviour difficulties are not confined to children with severe epilepsy and/or severe cognitive difficulties. For example, some children with epilepsy, whose abilities are within the average range, have problems with processing speed, or memory, and need extra support at school⁸.



The study

The following school-based problems have previously been reported in children with epilepsy:⁹

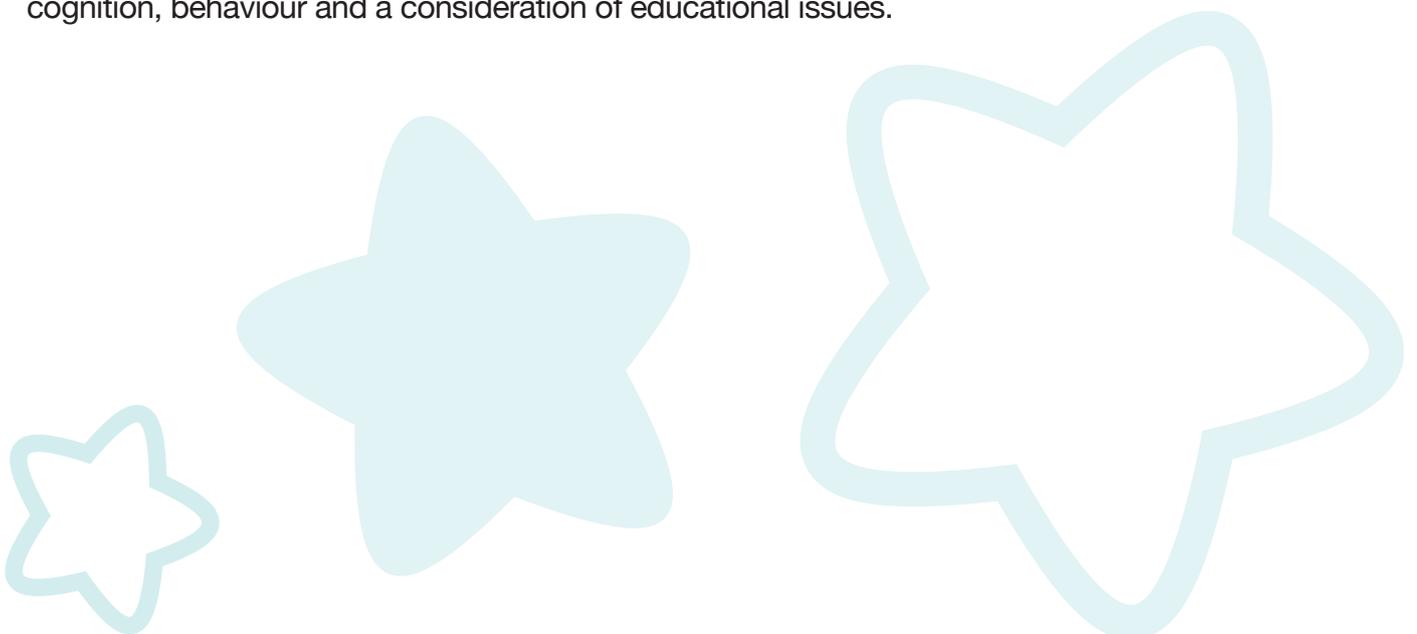
- Seizures.
- Specific or global learning problems – particularly variation in ability to learn and times when learned material is dramatically lost.
- Attention-Deficit Hyperactivity Disorder (ADHD).
- Autism Spectrum Disorder (ASD).
- Depression and anxiety.
- Motor coordination difficulties.
- A poor attendance record.

There are currently no agreed educationally based guidelines for children with epilepsy. There is a tendency to regard epilepsy as a purely medical condition. The current guidelines refer primarily to the medical management of seizures and there is no requirement for an educational record of how children with epilepsy are coping in school or even how many children with epilepsy there are in schools.

This study aimed for the first time to define the school-based difficulties of children with ‘active’ epilepsy in a defined population in the UK. This was achieved by assessing the children using common measures of cognition and behaviour.

The study also aimed to use the results of the assessments as a basis for discussion with the child, parents and school staff to identify possible support for the child. By undertaking the study we hoped to bring the medical and educational aspects of epilepsy together.

The purpose of the study was to explore whether the current epilepsy guidelines need to include an increased emphasis on the assessment of cognition, behaviour and a consideration of educational issues.

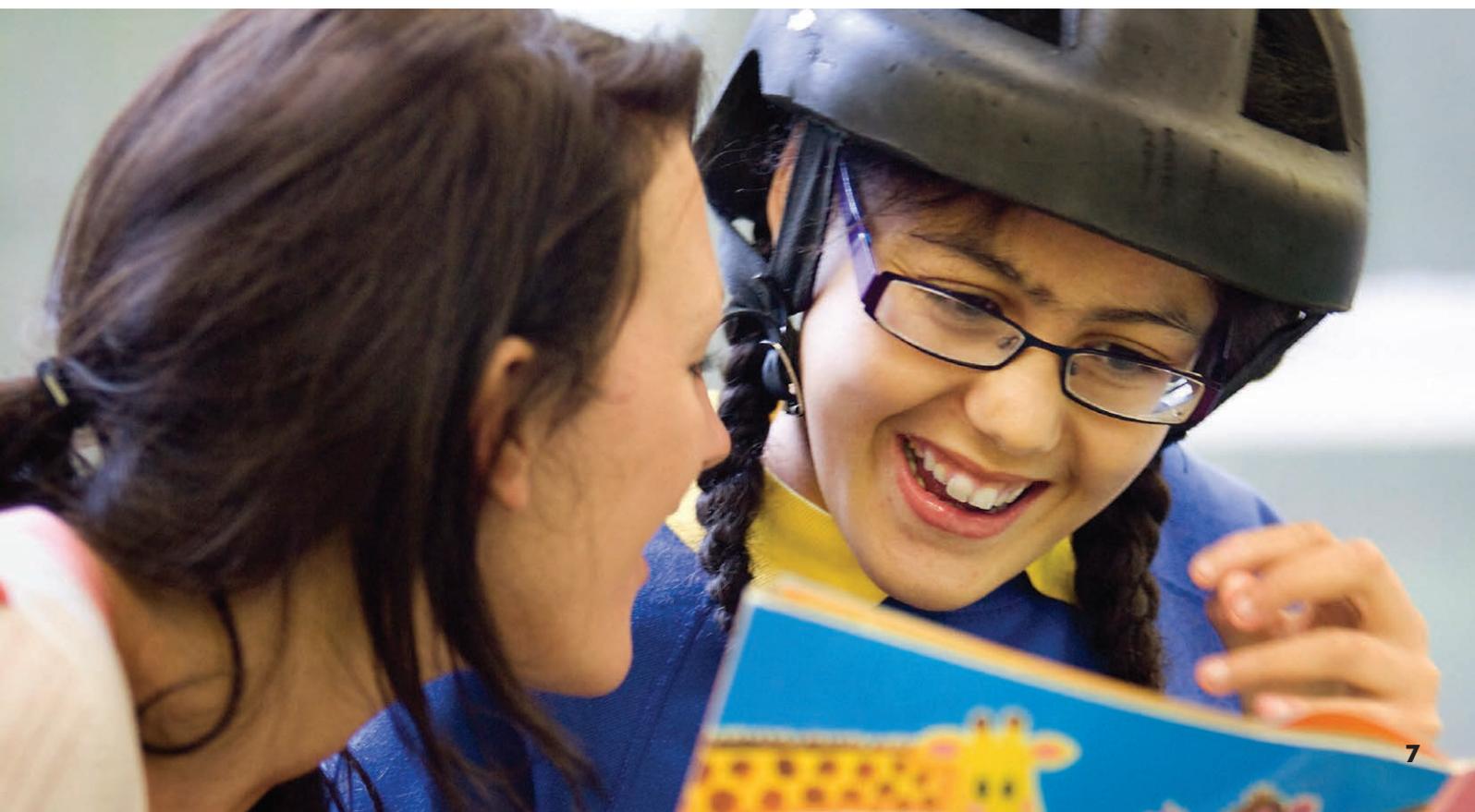


The current National Institute for Care and Clinical Excellence (NICE)¹⁰ guidelines acknowledge these aspects but state that psychological assessments should only be issued in cases of concern. Two examples of this from the NICE guidelines are presented below:

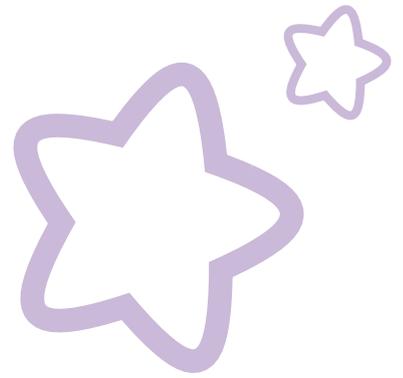
- Neuropsychological assessment should be considered in children, young people and adults in whom it is important to evaluate learning disabilities and cognitive dysfunction, particularly in regard to language and memory.
- Referral for a neuropsychological assessment is indicated:
 - o when a child, young person or adult with epilepsy is having educational or occupational difficulties
 - o when an MRI has identified abnormalities in cognitively important brain regions
 - o when a child, young person or adult complains of memory or other cognitive deficits and/or cognitive decline.

Thus assessments would appear to be advocated for children with obvious cognitive or educational difficulties. However, it is possible that all children with epilepsy are at significant risk of learning and behavioural difficulties regardless of current educational supports.

Early assessment via psychological assessment is likely to identify current, and potential, difficulties and allow support to ameliorate the potential for these difficulties to seriously reduce quality of life and impact on educational potential.



Methodology



The study was based in the Crawley and Horsham catchment area of West Sussex in the UK and took place from 2010 to 2013. All children from 4 to 16 years of age with 'active' epilepsy in this catchment area, regardless of their educational placement, were eligible for inclusion. For the purpose of this study, 'active' epilepsy was defined as 'on antiepileptic drugs (AEDs) and/or had a seizure in the last year'. A total of 85 participants from a total of 40 schools took part in the study providing a representative population-based sample.

The initial stage involved screening for learning and behaviour difficulties. In this initial stage the educational psychologist visited the child's school and parents and teachers completed an initial questionnaire.

The questionnaire included four questions based on whether the child had experienced significant problems with respect to behaviour, epilepsy management, academic progress or school attendance. As well as these four questions parents and teachers completed the *Strengths and Difficulties Questionnaire (SDQ)*¹¹, a screen for behavioural and emotional problems. Parents completed the *Quality Of Life in Childhood Epilepsy questionnaire (QOLCE)*¹², a questionnaire for assessing the child's quality of life.

All children also underwent a thorough psychological assessment. This assessment, which took approximately 90 minutes, involved measures of cognition (i.e. overall ability), memory and processing speed. The children also completed measures of word reading, sentence comprehension, spelling and mathematics.

Teachers and parents completed screening measures for ADHD and ASD. Parents and the young people completed screening measures of anxiety and the young people completed a screening measure of depression.

Parents also completed a screening measure for Developmental Coordination Disorder (DCD). In some cases all measures were not administered due to the child's level of ability (see Appendix for all assessment measures). After the psychological assessments the educational psychologist wrote a psychological report outlining the assessment findings and provided feedback to the young person (where developmentally appropriate), parents and the teacher to discuss the findings and possible ways of supporting the child.

Results

The prevalence of 'active' epilepsy in the study area was 1 in 286. Table 1 shows the characteristics of the 85 children with epilepsy who took part in this study.

Table 1: Characteristics of the children in the study	
Male/Female	44/41 (52%/48%)
Special school (including home schooling)	42 (49%)
Mainstream school	43 (51%)
Statement of special educational needs	45 (53%)
On special needs register (including statement)	61 (72%)
Primary school	46 (54%)
Secondary school	39 (46%)

In total 53% of the participants had a statement of special educational needs and 72% were on the special needs register at their school. The UK average is 2.7% for statements and 20% for special educational needs¹³.

Parents and teachers were also asked about previous inputs from health professionals and results are shown in table 2.

Table 2: Previous inputs from health professionals	
Support	
Speech and language therapy	43 (51%)
Occupational therapy	30 (35%)
Physiotherapy	30 (35%)
Psychological assessment	29 (34%)
Psychological support/therapy	5 (6%)
Psychiatry assessment or support	3 (4%)
Other therapy	3 (4%)

While more than half the participants had received input from a speech and language therapist, only 6% had received psychological support/therapy and 4% psychiatric assessment or support.

Initial screening

The results of the initial screening undertaken by the educational psychologist to identify school-based concerns with parents and teachers are shown in table 3.

Initial Screening	Parent report	Teacher report
Difficulties with school attendance	49%	4%
Currently displays difficulties with academic progress	79%	67%
Difficulties in seizure management	36%	2%
Currently displays more behavioural difficulties than peers	73%	40%
• Difficulties with attention and concentration	64%	37%
• Difficulties with activity levels	31%	18%
• Difficulties with oppositional behaviour	22%	14%
• Difficulties with verbal aggression	29%	9%
• Difficulties with physical aggression	24%	14%
• Difficulties with other behaviours	12%	6%

- Difficulties in academic progress were reported by 79% of parents and 67% of teachers.
- 49% of parents reported that their child’s school attendance had been affected by epilepsy but only 4% of teachers reported this problem. This noticeable difference may in part be due to teachers referring to that particular academic year when the screening took place whereas parents were reporting on difficulties in attendance over the child’s school history.
- Parents reported difficulties in seizure management for 36% of children whereas teachers only reported seizure management difficulties for 2% of children. This difference in parent and teacher reports may in part be due to parents being aware of difficulties in both school and at home and also due to the fact that teachers were referring to that particular academic year whereas parents were reporting on difficulties over the child’s school history.
- 73% of parents and 40% of teachers reported that their child/student was displaying more behavioural difficulties than their peers. The most frequent behavioural difficulty reported by parents and teachers was in the area of ‘attention and concentration’.
- Overall, the results indicate that parents reported more difficulties than teachers.



Detailed psychological assessment

Cognition

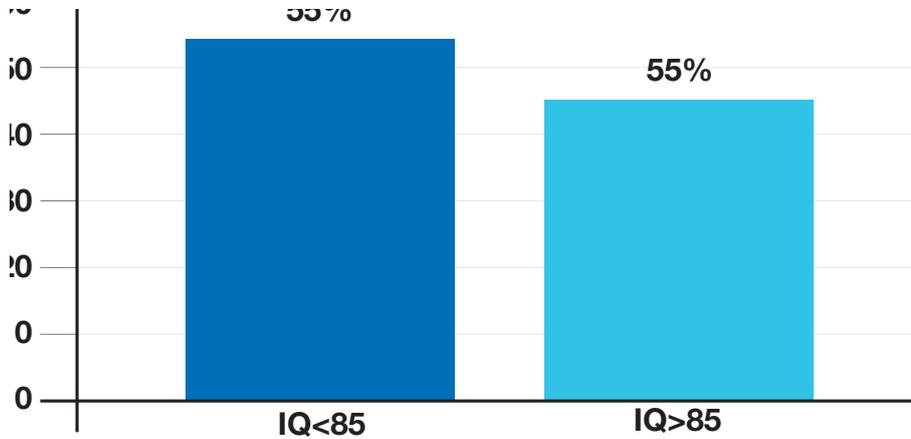
An IQ score is a measure of a person's intelligence or overall cognitive ability. The average IQ score in the general population is 100. Table 4 outlines the components of the Wechsler Abbreviated Scale of Intelligence (WASI)¹⁴, the IQ test administered to the majority of the participants in the study. Participants unable to complete this test were assessed with the Griffiths Mental Development Scale – Extended Revised¹⁵ or the Stanford Binet Intelligence Scale for Children: Fifth Edition¹⁶ as these tests have more developmentally appropriate items for children with significant cognitive difficulties.

IQ Test Component:	Description of subtest component:	What does it measure?
Vocabulary	The child must define commonly used words.	Expressive vocabulary and verbal knowledge.
Similarities	The child must identify what two objects or concepts have in common.	Verbal concept formation and verbal reasoning ability.
Block design	The child is presented with coloured cubes and cards with patterns on. The child has to use the cubes to replicate the pattern seen on the cards.	Visual-spatial awareness and visual-motor coordination.
Matrix reasoning	The child must complete visual patterns stating/pointing to the correct response from five possible choices.	Nonverbal reasoning.



In this study a child was considered to have a 'cognitive difficulty' if they had an IQ score below 85. Graph 1 illustrates the number of participants with an IQ below 85.

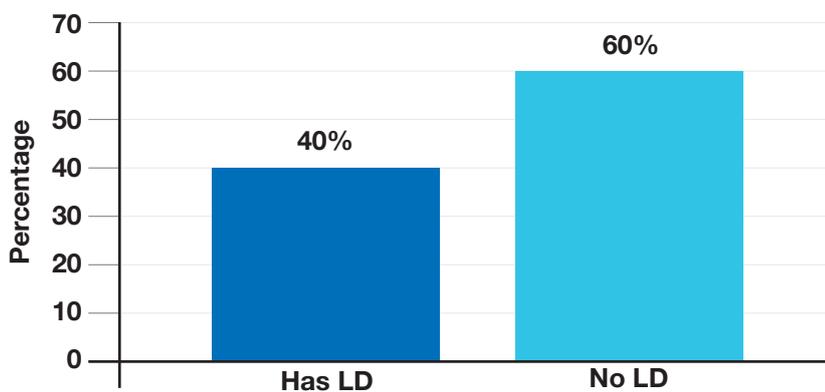
Graph 1: Percentage of participants with a cognitive difficulty (IQ <85)



In the study, 55% of the participants had an IQ score of below 85 while only 16% of children in the general population would score below 85.

The term learning disability (LD) (also known as intellectual disability) refers to individuals whose IQ score is below 70 and have significant difficulties with adaptive functioning (e.g., self-care skills, independence skills). The percentage of study participants functioning in the LD range is shown in graph 2.

Graph 2: The percentage of participants with a learning disability (LD)



40% of participants were functioning in the learning disabled (LD) range. Only 2% of children in the general population are functioning in the learning disabled range.

Specific aspects of cognition

Memory

Aspects of memory were assessed using the Working Memory Test Battery for Children (WMTB-C)¹⁷. The four subtests administered were: Digit Recall, Block Recall, Backwards Digit Recall and Counting Recall. Table 5 displays the aspects of memory assessed by each of the four administered subtests.

Memory Subtest	Description	What does it measure?
Digit Recall	The child is asked to recall a list of numbers in the same order as presented to them.	Aspects of short-term verbal memory.
Block Recall	The psychologist taps a series of 3D blocks. The child must attempt to tap them in the same sequence.	Aspects of short-term visual and spatial memory.
Backwards Digit Recall	The child is asked to recall a list of numbers in reverse order.	Aspects of verbal working memory.
Counting Recall	The child has to count the number of dots in a series of pages while remembering the number of dots on each page.	Aspects of visual working memory.

In total 66 participants were able to complete the memory tasks in the study. The average score on each of the memory subtests is 100. In this study, a child was considered to have 'below average' memory on one of the subtests if they had a score on a memory subtest below 85.

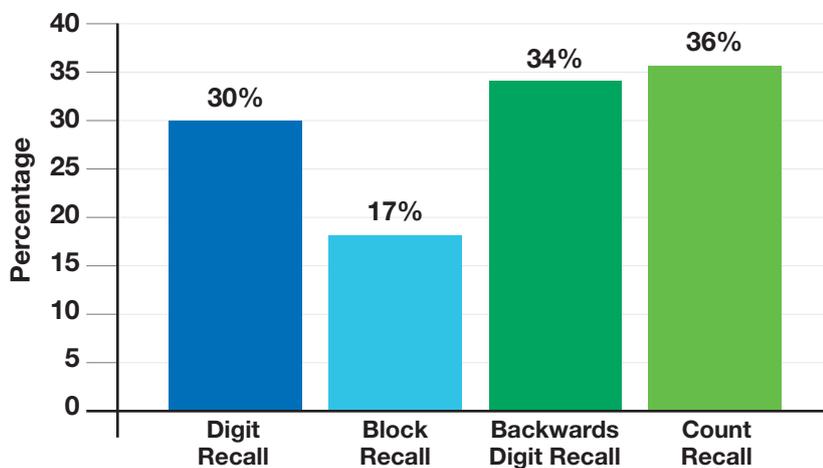
Only 16% of children in the general population score below the 85 on any of the subtests. Table 6 shows the number of participants who scored 'below average' on each of the four memory subtests administered.

Memory Subtest	Percentage who scored 'below average'
Digit Recall	59%
Block Recall	47%
Backwards Digit Recall	60%
Counting Recall	61%

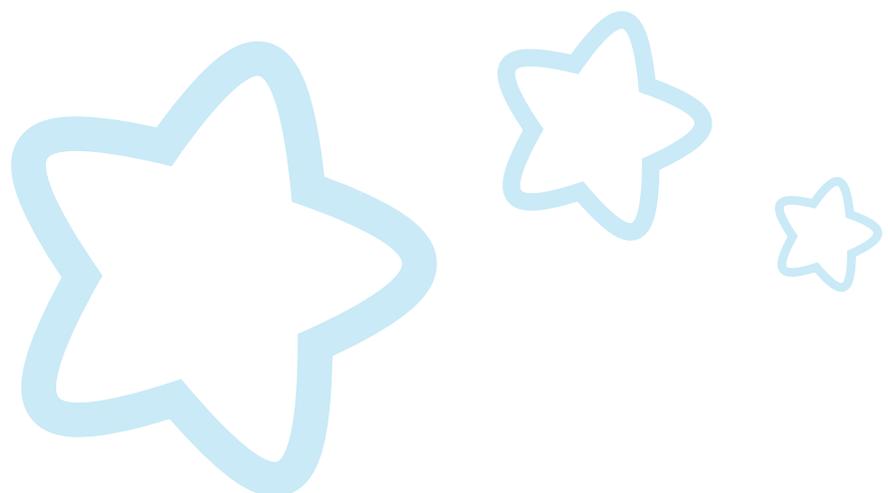
As well as focusing on memory scores below average it is also useful to report the number of participants who displayed memory underachievement or who scored significantly below the level expected based on their level of overall cognition.

Memory underachievement was indicated in this study when an individual scored 15 points below their IQ score in one of the four areas of the memory test. In total 58% of the participants scored more than 15 points below their IQ in at least one area of memory or displayed memory underachievement. Graph 3 shows the memory subtests and the percentage of participants who displayed memory underachievement on each of the administered memory subtests.

Graph 3: Percentage displaying memory underachievement



The subtests with the greatest level of underachievement were the Counting Recall and Backwards Digit Recall subtests. These subtests require the child to process and hold information in their working memory, ready for recall and use in a subsequent task.



Processing speed

Processing speed requires similar skills to those needed in handwriting (e.g. fine motor skills and hand-eye coordination) and an ability to work efficiently under timed conditions. The two subtests used in the study were coding and symbol search and they make up the Processing Speed Index from the Wechsler Intelligence Scale for Children-Fourth Edition (WISC-IV)¹⁸, a commonly used measure of cognitive ability in children. The aspects of processing speed assessed by each of these subtests are outlined in table 7.

Subtest	Description	What does it measure?
Coding	Children copy a code with each symbol representing a number.	Coding measures visual working memory, fine motor skills and attention.
Symbol search	Children are given symbols and a row of target symbols, and asked to mark whether or not the target symbols appear in each row.	Symbol search measures scanning speed and visual perception.

A total of 60 participants were able to complete the processing measures in this study. The average score on the Processing Speed Index is 100. In this study, a child was considered to have a 'below average' processing speed if they had a score on the Processing Speed Index below 85.

Of the participants assessed, 61% had 'below average' processing speed whereas only 16% of children in the general population score below 85 on this index. Processing Speed underachievement was indicated in this study when a child scored 15 points below their IQ score on the Processing Speed Index. Of those assessed, 42% displayed processing speed underachievement.



Academic achievement

The study participants completed the four subtests from the Wide Range Achievement Test–Fourth Edition (WRAT-4)¹⁹, a test of academic achievement. The four subtests are word reading, spelling, sentence comprehension or mathematics.

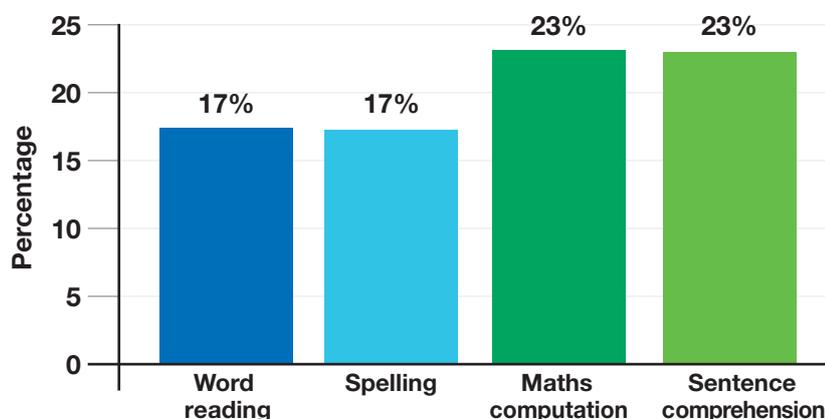
The average on all of the subtests is 100. In this study, a child was considered to be ‘below average’ in an academic area if they had a score on a subtest below 85. Table 8 shows the number of participants who scored ‘below average’ on each of the four achievement subtests administered.

Table 8: Percentage of participants who scored ‘below average’ on each of the academic subtests

Memory Subtest	Percentage who score ‘below average’
Word reading	48%
Sentence comprehension	59%
Spelling	46%
Mathematics	54%

A child was designated as displaying academic underachievement if their score on one of the academic subtests was 15 points or more lower than their IQ score. In this study, 42% displayed academic underachievement on at least one subtest. In graph 4 the levels of underachievement on each of the four subtests is shown.

Graph 4: Areas of academic underachievement

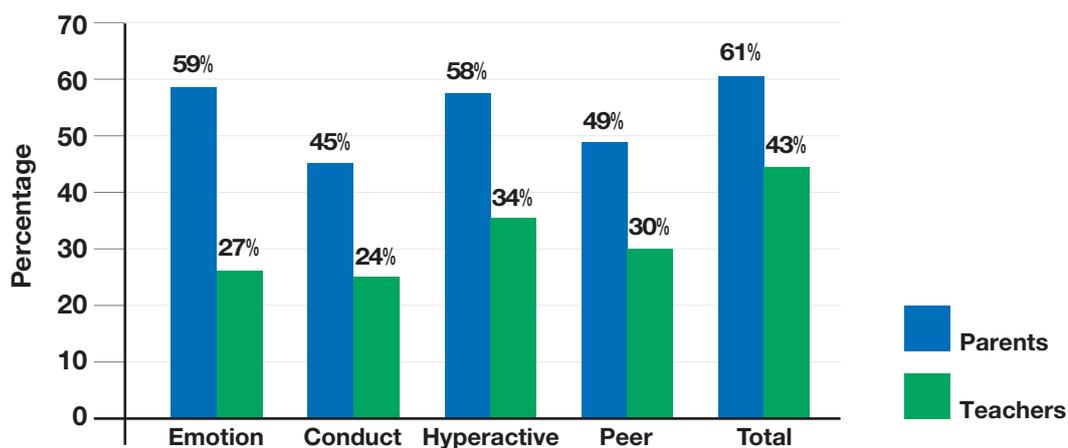


The areas with the greatest level of underachievement were maths computation (23%) and sentence comprehension (23%). In addition, the psychological assessment revealed 6% of the children with epilepsy met criteria for a diagnosis of dyslexia which is a similar level to that in the general population.

Behaviour

As part of the initial screening the Strengths and Difficulties Questionnaire (SDQ)¹¹ was used to identify areas of possible concern as reported by parents and teachers. The percentage of parents and teachers who reported a significant concern in each area is shown in graph 5.

Graph 5: Areas of concern reported by parents and teachers on the SDQ



According to parents, 61% of the participants had a total SDQ score above the 'normal' cut-off suggesting that the child's behaviour was a significant worry or concern for the parents. However, teachers only reported a significant concern on the total score for 43% of the participants.

With respect to areas of concern, parents reported most difficulty in the area of emotion (59%) and hyperactivity (58%). It must be noted that the hyperactivity subscale of the SDQ includes difficulties with attention. Hyperactivity was the area of difficulty most often reported by teachers (34%) followed by peer problems (30%).

Parents, teachers and young people completed screening measures for a range of behavioural problems as part of the psychological assessment. Table 9 summarises the most common behavioural and emotional difficulties in the sample.

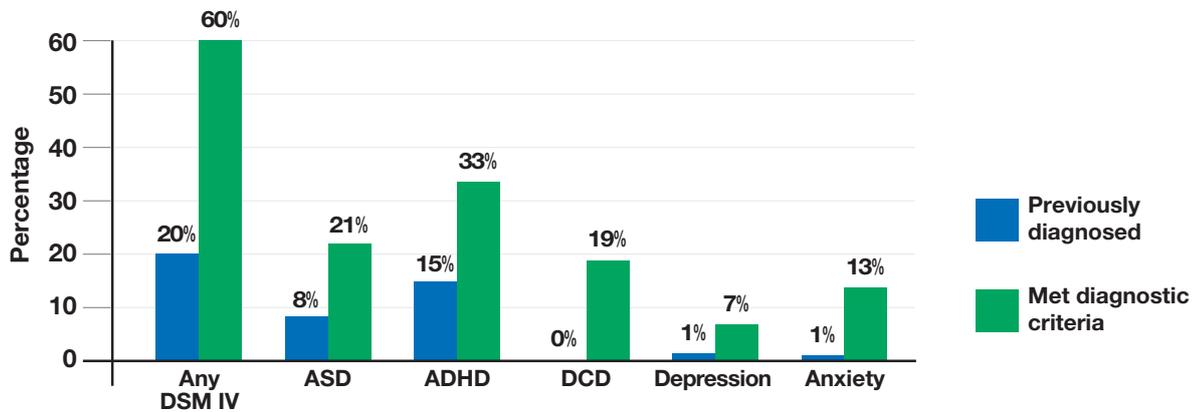
Table 9: Behavioural difficulties most often referred to by respondents		
Condition	Most common symptom	Second most common symptom
ADHD (Parent)	The child is easily distracted.	The child fails to give close attention.
ADHD (Teacher)	The child has difficulty sustaining attention.	The child is easily distracted.
ASD (Parent)	The child is surprisingly good at some things but poor at others.	The child has clumsy, ill coordinated, ungainly, awkward movements or gestures.
ASD (Teacher)	The child lacks best friend.	The child has clumsy, ill coordinated, ungainly, awkward movements or gestures.
DCD (Parent)	Difficulties with writing fast.	Difficulties in learning new skills.
Anxiety (Parent)	My child worries.	My child is scared.
Anxiety (Child Report)	When I have a problem my heart beats really fast.	I have to keep checking that I have done things correctly.
Depression (child report)	I have difficulty making up my mind.	I have difficulty with schoolwork effort.

Screening measures can give an indication if a child might have a problem in a particular area. However, a final decision on whether or not the child actually has a significant problem, which needs treatment/support, must be made by professionals competent in the area of child development and psychological functioning.

Results for the screening measures for ADHD, ASD, DCD, depression and anxiety were discussed by the educational psychologist, a community paediatrician and a child and adolescent psychiatrist. This team decided on which children’s difficulties were serious enough to warrant a diagnosis of a specific condition according to international diagnostic criteria (i.e. DSM-IV criteria²⁰). The percentage of participants diagnosed with each condition by the team is shown in graph 6 (in green) as well as the percentage of participants who had previously been diagnosed with the conditions (in blue).



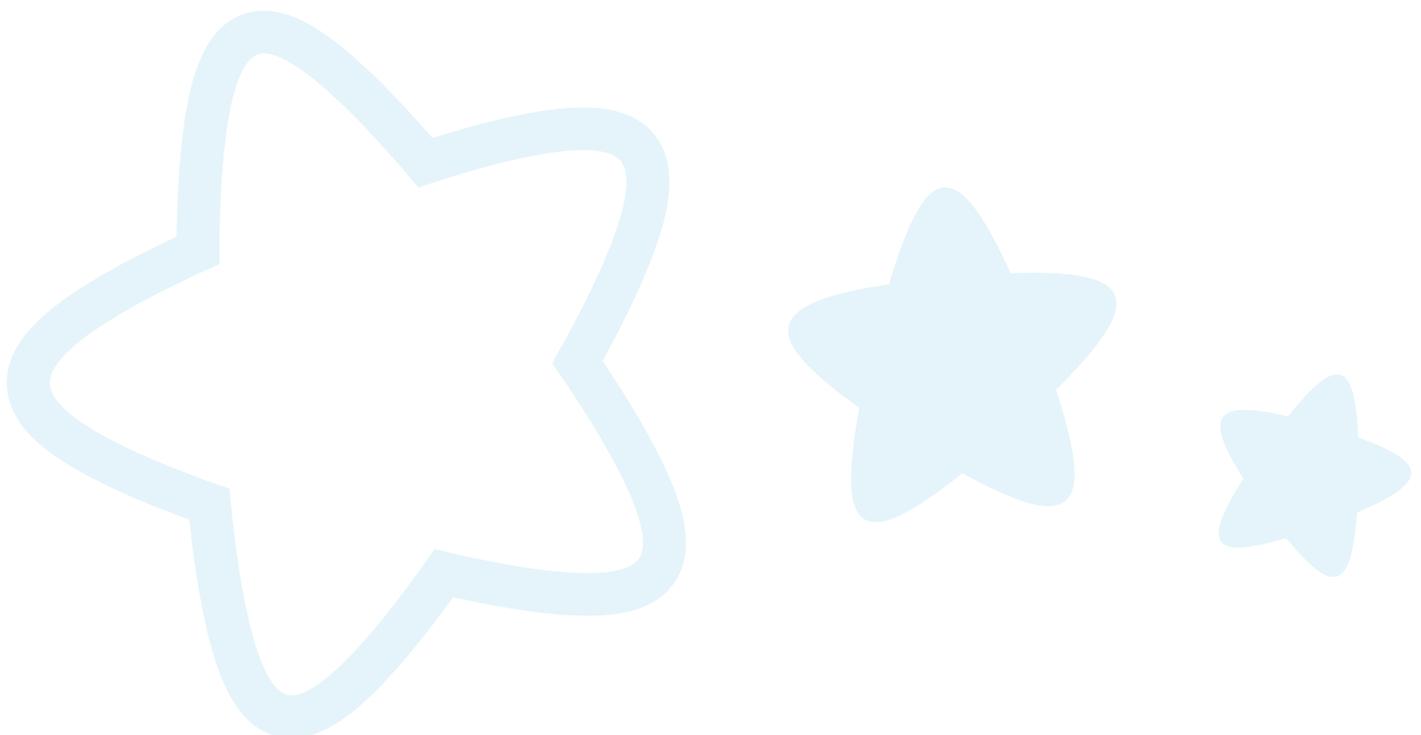
Graph 6: Professional diagnosis of behavioural disorder



Overall, 60% of the participants met diagnostic criteria (i.e. DSM-IV criteria) for at least one behavioural disorder. The most common diagnosis was ADHD (33%). Children with ADHD were more likely to have difficulties with inattention than hyperactivity or impulsivity.

Only 20% of participants had previously been diagnosed with a behavioural disorder whereas 60% met diagnostic criteria for at least one behavioural disorder in the study. Furthermore, 26% of the children met diagnostic criteria for more than one behavioural disorder.

In addition to the disorders outlined in graph 6, four children were considered to have difficulties found in children with Pathological Demand Avoidance (PDA) and one child presented with Psychogenic Non-Epileptic Seizures (sometimes called Non Epileptic Attack Disorder or NEAD).



Summary of measures of cognition and behaviour

Table 10 summarises the findings from the assessments of cognition, academic achievement and behaviour.

Table 10: Cognitive and behavioural difficulties

Cognition and behaviour	Percentage
Cognitive impairment (IQ<85)	55%
Learning disability (IQ<70)	40%
Memory underachievement	58%
Processing speed underachievement	42%
Academic underachievement	42%
Behavioural or motor condition	60%

School-based difficulties were not confined to children with identified special educational needs. Of the 24 children not on the special educational needs register, 50% displayed academic underachievement in at least one area, 63% displayed memory underachievement in at least one area and 46% met diagnostic criteria for a behavioural disorder. Only 5% of children in the study did not have a significant difficulty in at least one area of cognition or behaviour.



Discussion



This study is the first UK population-based study which comprehensively examines learning and behavioural difficulties in children with ‘active’ epilepsy. Population-based studies are important in epilepsy as studies from hospital-based centres are potentially biased and are likely to include children whose epilepsy is perceived to be more ‘severe’.

It was suspected that academic and behavioural difficulties in childhood epilepsy are overlooked due to the need to manage seizures. The findings of this study support the view that difficulties are under-recognised and also provide clear evidence of the extent of the problems in cognition and behaviour in childhood epilepsy.

Parents and teachers reported a very high level of concern with regard to academic progress and behaviour. Difficulties with attention or concentration were particularly prevalent and may not be noticed unlike more obvious examples of behaviour that presents challenges in classroom settings. Parental reports of difficulties with school attendance indicate that epilepsy can have a significant impact on the ability to attend school regularly for nearly half of all children living with the condition during at least some part of their school lives.

Over half of the children with epilepsy in this study had an IQ below 85 and this is likely to have a very significant impact on progress across the school curriculum. In addition, 40% of children were functioning in the learning disabled range which indicates the very significant learning needs often associated with epilepsy.

Specific difficulties with memory were very common and more than half of the children had memory underachievement in at least one area indicating that the memory difficulties are much greater than those expected based on their level of cognitive ability. Underachievement in processing speed was also identified in just under half of the children.



40% of children were functioning in the learning disabled range which indicates the very significant learning needs often associated with epilepsy.

Similarly, difficulties with processing speed were very common including approximately 40% of children with processing speed underachievement. Difficulties of this nature were often not recognised prior to psychological assessment but were clearly having an impact on academic progress and were leading to frustration on the part of the young person, parents and school staff.

Academic underachievement in at least one area was reported in nearly half of the children with epilepsy. The reason for underachievement may include memory or processing speed difficulties, behavioural difficulties, difficulties with school attendance or difficulties associated with epilepsy. Difficulties with academic progress and underachievement were not confined to children on the special educational needs register and often seem to have been overlooked.

Overall, 60% of the children with epilepsy in this study met diagnostic criteria for at least one behavioural disorder. However, in only one-third of cases had these difficulties been formally professionally diagnosed. This gap is likely to be reflected by the fact very few of the children had previously been assessed by a psychiatrist or received psychological support/therapy but may also reflect a failure to consider these problems in the context of epilepsy. The most common diagnosis in the study was ADHD with one-third of the children having significant problems with inattention or hyperactivity/impulsivity. One in five of the children met criteria for ASD.

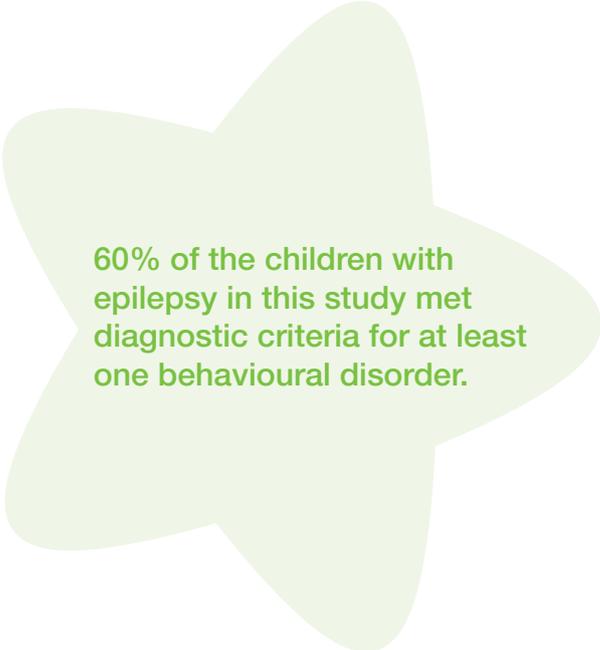
This is a higher level than previous studies but previous studies have not employed screening measures and/or professional diagnosis as was the case in this study. None of the participants had a diagnosis of DCD prior to the study but the assessments revealed that 18% of the children with epilepsy met diagnostic criteria for DCD. It has been reported that there is a lack of awareness of DCD among health professionals². The condition can have very significant implications for learning but also with respect to the development of confidence and self-esteem in school-aged children.

Academic underachievement in at least one area was reported in nearly half of the children with epilepsy.

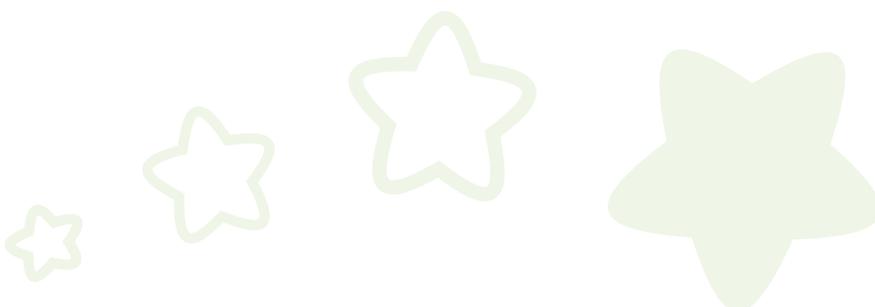
Anxiety and depression can have a very significant impact on child wellbeing and can result in lowered self-esteem, problems in academic progress and impact on quality of life. If symptoms are not treated, difficulties are likely to continue into adulthood and result in significant difficulties with daily functioning. Possible reasons for anxiety and depression in epilepsy include the unpredictability of seizures, stigma associated with epilepsy, underlying difficulty with brain development, fear of injuries or death and parental reactions of distress²².

In this study parents reported significantly more problems than teachers on all of the behavioural screening measures. This could reflect actual differences in experiences across the home and school environments. However, the fact that 60% of the children met professional criteria for a behavioural disorder indicates that problems reported by parents are likely to be real and should be followed up. It has previously been reported that difficulties with inattention are reported more often by parents than teachers²³. It may be that parents are more aware of difficulties in this area whereas teachers struggle to recognise these problems in the context of busy classroom environments.

In summary, current guidelines for the management of childhood epilepsy primarily focus on seizure management but fail to prioritise monitoring of educational progress in children with epilepsy. This lack of emphasis is likely to contribute to an under-recognition of difficulties as evidenced in this study. Consequently, children are not receiving treatment for, or being helped with, these difficulties. This gap in provision likely contributes to further difficulties with academic progress and has a significant negative impact on the quality of life of these children and their families.



60% of the children with epilepsy in this study met diagnostic criteria for at least one behavioural disorder.



Evaluation



Teacher training

As part of this study, the educational psychologist and the assistant research psychologist delivered epilepsy training to teaching and classroom staff in some of the schools involved.

This training provided a definition of epilepsy plus an overview of the different epilepsy syndromes and seizure types. The management of epilepsy was also discussed, in terms of epilepsy diagnosis, possible causes of the condition, anti-epileptic medication and advice on seizure management.

In addition, explanations of the impact of epilepsy on cognition and academic performance were provided. Finally, the training also focused on explaining the association between epilepsy and behavioural conditions, including ADHD, ASD, depression, anxiety and motor difficulties. Strategies which could be used in the classroom to help manage the difficulties were also discussed.

In order to see how useful this epilepsy training was, a 15-item questionnaire was given out before the training session. Each individual was asked to fill in the questionnaire in order to indicate what they already knew about epilepsy.

The same questionnaire was then administered after the training to see if their understanding of epilepsy had improved. The training session was delivered to a total of 75 teaching and classroom staff and results showed that the overall number of correct answers was much higher after training (87%) than before training (33%). Every individual performed significantly better on the follow up questionnaire, demonstrating that the training improved understanding of epilepsy and associated cognitive and behavioural difficulties.

‘The input has been most useful. I have to admit I, and I think most of our staff, had very little knowledge of the potential impact of epilepsy on a student’s learning. Unless you see actual seizures there is a tendency for it not to come into mind with respect to a student’s needs.’

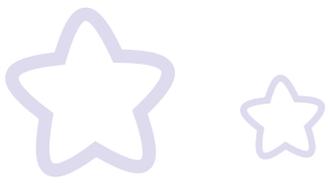
(Teacher, Mainstream Secondary School)

‘Thank you for coming to talk to our staff on Wednesday. All the staff were very positive afterwards and felt that it was a very interesting and informative talk. We feel we have a much better understanding of the potential impact of epilepsy on school performance.’

(SENCO, Mainstream Primary School)

‘Thanks for the two sessions on our INSET day. I got very positive feedback from staff and we found it gave us lots of information and help when dealing with our students.’

(Training Coordinator, Special School)



Parent evaluation

In order to obtain feedback from parents, the assistant research psychologist visited five randomly selected parents involved in this study. The five parents were asked about their child's involvement and their own views on the study.

They were asked to give feedback on what was good and most useful from the study and also asked for any recommendations they had for possible changes which could have improved the study. The comments were predominately positive, with all parents stating that the study was very useful with particular emphasis on the psychological assessments. Parents reported that it was very helpful to be aware of exactly where their child's strengths and weaknesses were in order to know how to help them improve their learning and behaviour.

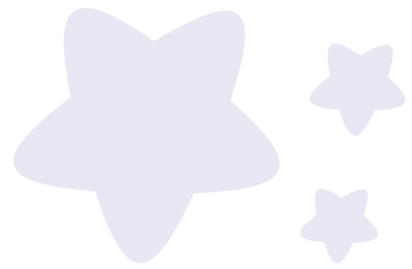
One of the parents reported that transitioning to school from home in the mornings had improved greatly after the psychological assessment revealed that the child had significant symptoms of separation anxiety. The advice given on how to manage the transition was particularly helpful. Parent responses suggested that their knowledge of epilepsy (particularly the impact of epilepsy on learning and behaviour) had improved as a result of participation in the study. Parents also felt that the study provided them with advice on how to access useful information about learning and behaviour in epilepsy.

The sensitive communication between the psychologist and the schools was also mentioned as a huge catalyst for some of the children's progress: ***'The school have taken into account all information provided by the study. Therefore, the school has a better understanding of the student, which enhances my child's learning in school'*** (parent of six year old male).

Overall, the feedback was very positive. With regard to suggestions for future research, parents reported that they would like more advice on how to manage their child's difficulties.

When asked what could be improved or extended from this study, the majority of parents expressed a need for increased support for parents: ***'There are no local parent support groups, but we need one. We need a chance to ask questions and talk to other parents going through the same thing'*** (parent of female 10 years old).

Additionally, ongoing assessment and monitoring were suggested for future work: ***'It would be nice to have more follow up assessments but being realistic with consideration of the study's time frame, the assessments were extremely helpful and the study went above my expectations'*** (parent of eight year old female).



'We are very grateful that our son was given the opportunity to take part in your project, without it I think we would still be feeling frustrated. My only regret is that it didn't happen when he was still in infant school.'

(Parent of 14 year old male)

'We are obviously now aware that it is harder for people like our daughter who have epilepsy to concentrate, focus and encounter memory problems. We very much appreciate the contribution and recommendations as we feel that you have already made an impact on our daughter in the way of moving things forward.'

(Parent of 14 year old female)

'Thank you, such a shame that the support cannot be extended, as a family we would like to thank you for all of your support and for helping us with the school and communication. It is very difficult sometimes being a parent and trying to get the help to support your child's disabilities so we are very grateful.'

(Parent of eight year old female)

'The input from the educational psychologist was incredibly helpful, clear and thoughtful. He helped us understand the way my daughter learns. His feedback to the school was constructive and positive. He educated the school, really helping my daughter to work to her full potential.'

(Parent of six year old female)

'The assessments revealed that my child has dyslexia. This dyslexia diagnosis has resulted in changes in teaching reading at school. The teachers are now using a 'look and say' strategy as opposed to teaching my child to read phonetically which was previously proving not to be effective.'

(Parent of six year old male)



Recommendations

Based on the findings of this study the following recommendations should be considered in order for school-aged children with epilepsy to reach their potential in educational settings:

- The current guidelines for the management of childhood epilepsy should be updated to reflect the high likelihood of cognitive and behaviour problems in the condition.
- Epilepsy should be recognised as a special educational need and accurate records need to be kept of all children who have the condition by schools and local education authorities.
- Guidelines on the management of epilepsy in school-aged children need to include the need for comprehensive psychological assessment. Psychological assessments should be offered to all children with epilepsy to identify any difficulties as soon as is practicable after diagnosis.
- There is a need for on-going monitoring of children with epilepsy in school-based settings after initial psychological assessment.
- Epilepsy training for schools should include both medical management and training focussing on common learning and behavioural difficulties associated with the condition.
- Communication between the young person, parent, school staff and medical staff needs to be facilitated in order that the child's condition is understood by all responsible for the child's care.

Future work

- There is a need for research into the efficacy of interventions to manage the school-based problems of children with epilepsy.
- The trajectory of learning and behavioural difficulties in childhood epilepsy over time needs to be investigated.
- Research is needed to identify how best to support the informational and emotional needs of parents and families affected by the condition.
- Young people with epilepsy often reported that they lacked contact with others with epilepsy. The support needs of young people with epilepsy should be recorded and possible support mechanisms systematically evaluated.
- The best methods of staff training in schools need to be evaluated so that knowledge, attitudes and practices reflect the best available evidence.



Additional Findings

Epilepsy specific issues

The purpose of this study was not to focus specifically on the management of epilepsy but a number of issues arose consistently during the research which should be considered when supporting children with epilepsy in educational settings. These issues are briefly outlined:

- Not all of the children had seizure management plans and in some cases the level of description and detail was not adequate in these plans.
- Schools occasionally reported difficulties accessing emergency medication training.
- Parents and school staff sometimes struggled with regard to understanding the manifestation of the child's seizures and recognising when a seizure was taking place.
- The young people, parents and teachers struggled to understand the role of epilepsy and seizures with respect to the student's learning and behavioural problems.
- A number of parents expressed a need for more support with respect to understanding their child's condition, its impact on their learning and impact on their family.
- Teachers in mainstream and special schools reported a difficulty with accessing psychological support for the children.
- School staff and parents often had a good understanding of the child's learning profile but struggled to identify specific problems with academic achievement, processing speed or memory.
- The young people often reported feeling isolated and lacked contact with others with epilepsy and they would like access to peers with epilepsy either online or in person.

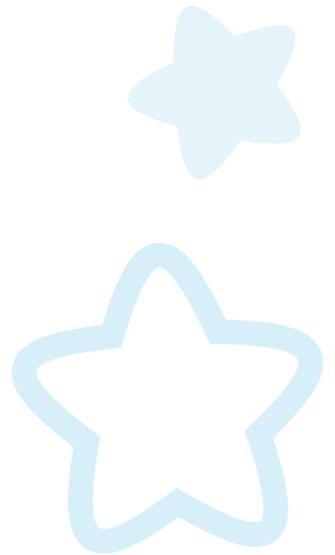


Factors associated with cognitive and behavioural difficulties

As well as assessing the children's cognition and behaviour, information about the child's history of seizures and treatment was also collected. This information was used to see whether any aspects of the child's epilepsy might be related to the child's school-based problems.

Data collected included seizure frequency, seizure type, number of antiepileptic medications and age when seizures first began. The strongest predictor of having significant cognitive problems was age of onset with children whose epilepsy started before 24 months much more likely to have problems with cognition.

Epilepsy factors were in the main not strongly associated with behavioural problems suggesting that it is not the seizures or medications that are the cause of the majority of behaviour problems but it is likely that there is some underlying problem affecting brain development causing both the seizures and the difficulties with behaviour.





Supporting children with epilepsy who have learning and behavioural difficulties

After the children underwent psychological assessment the psychologist met with the young person (where appropriate), the parents and child's teacher (or other member of school staff) to discuss the assessment findings. At these meetings ways of supporting the children were discussed and some of the common means of support discussed and subsequently implemented are outlined below. As with all supports in educational settings, a consideration of the child's age, developmental level, interests and resources available to the school will be necessary to ensure they are appropriate.

Difficulties with cognition (overall ability)

- Children whose overall level of ability is behind that of their peers may need extra support across the curriculum.
- If a child has a learning disability specialised education placement is likely to be a consideration.
- Learning tasks need to be set at the appropriate level for the child so they can achieve success.
- School-based assessment should be based on progress made with respect to their previous performance as opposed to the average for their age.

Difficulties with memory

- Handouts of class material may be needed.
- Specific memory strategies (e.g. chunking, mnemonics) may aid retention.
- The use of visual materials and practical hands-on learning may be particularly helpful.

Difficulties with processing speed

- The child may need extra time for assignments and extra time in examinations.
- In cases where handwriting is severely affected the child may need a scribe in examinations.
- The child may need to record and present material through a laptop or tablet computer.
- A referral to an occupational therapist may be needed so that child can receive appropriate support via advice on technological support and exercises to improve motor function.

Academic underachievement

- If the child is well behind peers they are likely to need intensive one-to-one or small group support in a particular academic area.
- If the difficulties they have appear to be related to dyslexia they may need specific supports with phonological awareness and visual approaches to reading.
- In the area of reading comprehension they may need help to use specific strategies and also may need support to increase their vocabulary.
- In mathematics, as well as additional intensive teaching support the child may need accommodations such as the use of a calculator, particularly in upper primary and secondary school.

Difficulties with social skills and behaviours associated with Autism Spectrum Disorder (ASD)

- Social skills training on an individual or small group basis may be helpful in targeting specific social behaviours.
- The use of social scripts and social stories may be helpful for teaching particular social skills.
- Classroom strategies for children with ASD are likely to involve visual supports (e.g. visual schedules/timetables) and structured teaching.
- If social skills difficulties are severe the child may need a referral for diagnostic assessment of ASD.

Problems with attention/concentration

- The classroom environment may need to be adapted to accommodate the child's difficulties with attention. The child may need to be seated towards the front of the class and away from potential distractions (e.g. windows).
- The child may need additional adult support (e.g. learning support or teaching assistant) in order to maintain optimal attention.
- In cases of severe inattention, there may need to be a consideration of the presence of ADHD and subsequent treatment for this condition which may include behavioural interventions, family support and medication.

Problems with impulsivity/hyperactivity

- The child may need help with managing their impulsivity and behavioural strategies (reward based behaviour programmes/ contracts) may be needed.
- The child may need regular breaks built into their daily timetable and use of visual timers to build up ability to attend.
- The child may need support with organisational skills by use of visual/written timetables.
- In more severe cases of impulsivity and hyperactivity there may need to be a consideration of the presence of ADHD and subsequent treatment for this condition which may include behavioural interventions, family support and medication.

Difficulties with anxiety and/or depression

- The child is likely to need the support of a trained professional who has experience supporting young people with difficulties with emotional well-being. Trained professionals may be based in the child's school or in the community through Child and Adolescent Mental Health Services (CAMHS). Interventions are likely to involve cognitive-behavioural approaches or in cases of severe anxiety/depression the child may need medication to reduce symptoms and reduce the impact on their lives.

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Glossary

Epilepsy

Epilepsy is a neurological condition characterised by the occurrence of repeated seizures. A seizure is a sudden electrical discharge in the brain that results in an alteration in sensation, behaviour or consciousness.

In order to be diagnosed with epilepsy, an individual must have had at least two seizures. One seizure alone does not constitute epilepsy. Over 40 different types of seizures have been reported.

Epileptic seizures can be classified into 'generalised' or 'focal':

- Generalised seizures: the whole brain is affected by abnormal electrical disturbance and the child becomes unconscious of their surroundings.
- Focal seizures: the seizure comes from one area of the brain.

Examples of generalised seizures are: tonic-clonic, tonic, myoclonic, absence and atonic. Focal seizures can occur in the frontal, parietal, temporal and occipital lobes.

Attention-Deficit Hyperactivity Disorder (ADHD)

Attention-Deficit Hyperactivity Disorder (ADHD) is a developmental disorder (meaning it develops early in a child's life) involving difficulties with attention, hyperactivity and impulsivity. Problems with maintaining attention can make it difficult to focus on classroom tasks and activities.

Hyperactive behaviour may be seen in the classroom when a child struggles to sit down in their seat for as long as their peers and appears to be always on the go. Impulsive behaviours may cause the child to respond to a question before it has been fully explained.

Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) is a disorder involving difficulties in communication, social interaction and imagination. Autism is described as a spectrum because the condition varies from child to child.

Some children have intellectual disability with ASD but others are more able. Some more able individuals may be diagnosed with Asperger syndrome which is sometimes referred to as 'High Functioning Autism'.

Developmental Coordination Disorder (DCD)

Developmental Coordination Disorder (DCD) is a condition involving motor difficulties. Individuals with DCD can present with behaviour which appears clumsy or uncoordinated.

This can make typical daily activities difficult (e.g. handwriting, organisation skills, playing with others and exercise). DCD can also affect memory and language function. Sometimes children with DCD may have been diagnosed with dyspraxia or it has been indicated that they have 'dyspraxic-like' difficulties.

Anxiety Disorders

Anxiety disorders are characterised by on-going excessive worry, uneasiness, fear and self-consciousness, which appear not to be triggered by specific or recent events. Self-consciousness and low self-esteem are also common in anxiety disorders.

Depression

Depression is a state of low mood, loss of interest, guilt, low self-esteem and can cause difficulties sleeping. If an individual has depression they are likely to be withdrawn and isolated from others.

This makes interacting with peers and school activities difficult. The individual may then lose their motivation to learn and lose confidence in their ability to succeed in classroom tasks. Physically, depression can be very draining and may result in the individual having low energy levels.

Pathological Demand Avoidance syndrome (PDA)

There is some debate regarding whether PDA is a separate condition or part of the autism spectrum but individuals with PDA usually present with better social and communication skills than other people on the spectrum.

When a child with PDA is instructed to do something, their anxiety levels rise and they may avoid these 'demands'. This presents difficulties if the child will not comply with classroom tasks and can have great impact on their learning. Mood swings and obsessive behaviour (on people as opposed to things) are commonly seen in individuals with PDA.

Learning (Intellectual) Disability

A learning disability involves significant difficulties with overall cognitive functioning (IQ Score < 70) and difficulties with adaptive functioning (e.g. communication, self-care skills, socialisation). The level of support needed for an individual with a learning disability depends on its severity.

An individual with profound learning disability may need full-time care and support, whereas someone with mild learning disability may only need help in some aspects of life (like finding a job or somewhere to live). Having a learning disability can mean that it may take longer for an individual to learn things than someone without a learning disability.

Psychogenic Non-Epileptic Seizures (PNES)

Psychogenic non-epileptic seizures look like an epileptic seizure but unlike epileptic seizures they do not involve a change in brain activity. The individual presenting with PNES has seizures due to psychological factors which they are involuntarily converting to physical symptoms in the form of (non-epileptic) seizures.

Examples of psychological factors which could cause PNES are school related difficulties (academic difficulties and bullying) and family/social conflict. Treatment for PNES relies on sensitive diagnosis, support for the young person and their family and in some cases psychological therapy. PNES may also be referred to as Non-Epileptic Attack Disorder (NEAD) or Non-Epileptic Seizures (NES).

Dyslexia

Dyslexia is a learning difficulty that affects the skills involved in accurate and fluent word reading and spelling. People with dyslexia have difficulty with language, particularly with the sound and structure of words. Verbal memory and verbal comprehension are other areas of difficulty for people with dyslexia. It is described as a continuum with difficulties ranging from low severity to high severity.

Appendix

Psychological measures used in the study.

Initial screening:

- Strengths and Difficulties Questionnaire (SDQ)¹¹
- *Quality Of Life in Childhood Epilepsy questionnaire (QOLCE)*¹²

Detailed psychological assessment:

- *Wechsler Abbreviated Scale of Intelligence (WASI)*¹⁴
- *Wechsler Intelligence Scale for Children (4th edition) (WISC-IV)*¹⁸
- *Autism Spectrum Screening Questionnaire (ASSQ)*²⁴
- *ADHD Rating Scale IV (ADHD-RSIV)*²⁵
- *Developmental Coordination Disorder Questionnaire (DCDQ)*²⁶
- *Children's Depression Inventory (CDI)*²⁷
- *Spence Children's Anxiety Scale (SCAS)*²⁸
- *Wide Range Achievement Test – Fourth edition (WRAT-4)*¹⁹
- *Working Memory Test Battery for Children (WMTB-C)*¹⁷

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About Young Epilepsy

Young Epilepsy is the national charity working exclusively on behalf of the 112,000 children, teenagers and young people aged 25 and under living with epilepsy. With over 100 years expertise it provides world-class diagnosis, assessment and rehabilitation for children and young people with epilepsy. The charity also carries out research into the condition and how it can be treated.

It has a unique blend of specialist services including St Piers School and St Piers College and residential services providing education and healthcare for children and young people with epilepsy, autism and other neurological conditions. The charity provides a range of support and information for parents, children and young people and training for professionals. It campaigns for better access to, and quality of, health and education services.

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