



The psychosocial impact of epilepsy on young children and their families

**The Sussex Early Epilepsy and
Neurobehaviour (SEEN) Study**

Foreword



Epilepsy is associated with very significant impacts on child development. In our previous study, *Children with Epilepsy in Sussex Schools* (CHES), the focus was on the identification of educational problems in school-aged children with epilepsy. The CHES study showed that children with epilepsy frequently have problems with learning and behaviour. These problems are often greatest for children whose epilepsy starts in the first two years of life. Additionally, the CHES study suggested that epilepsy

can have a significant impact on the families of affected children. With this in mind, the Sussex Early Epilepsy and Neurobehavior (SEEN) study was initiated in order to identify problems in development and behaviour in young children with epilepsy, as well as the impact this has on their parents.

The purpose of the SEEN study was to document, on a population basis, the development and behaviour of young children with epilepsy. The study also focused on emotional wellbeing, sleep and fatigue in their parents. A comparison group of children with neurodisability were included; these children did not have epilepsy but had other neurological or neurodevelopmental problems. This comparison allowed us to study whether having a child with epilepsy, specifically, has an impact on parental functioning.

Parents of children with epilepsy often reported difficulties accessing information regarding the developmental and behavioural consequences of having epilepsy. In addition, of the children with epilepsy in the study few had previously undergone any psychological assessment. Our findings highlight the need for epilepsy services to take a family-based approach to care and a need to consider the developmental impact of epilepsy and its impact on parents.

The key findings of the SEEN study highlight:

- high levels of problems with development, adaptive behaviour and sleep among children with epilepsy
- higher levels of difficulties among mothers of children with epilepsy compared with fathers on all measures
- higher levels of depressive symptoms and stress among mothers of children with epilepsy compared with mothers of children with non-epilepsy related neurodisability.

I would particularly like to acknowledge the role of Professor Brian Neville who was the driving force behind the SEEN study but who sadly passed away before its completion. The drive and passion he displayed when undertaking multiple studies was an inspiration to all other members of the team. He will be sorely missed.

We are also extremely grateful to all the children and their parents who took part in the study. We anticipate their contribution will ultimately improve the outcomes of young children with epilepsy and their families.

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Summary

What we wanted to know

- the prevalence of development and behaviour difficulties in young children with epilepsy
- the prevalence of mental health symptoms, sleep and fatigue difficulties reported by their parents.

What we did

In a defined geographical area in West Sussex, 53 children with epilepsy were identified. Their parents were asked if they wanted their child to undergo assessment and for themselves to complete measures of emotional wellbeing, stress and sleep. A total of 48 parents (91%) of the children with epilepsy indicated they wanted their child to participate. A comparison group of children with non-epilepsy related neurodisability (neurodevelopmental or neurological difficulties) and their parents also consented to undergo assessment.

An educational psychologist and assistant research psychologist visited the children and their parents at home to assess child development and behaviour. Parents completed measures of their own emotional well-being, sleep, fatigue, and stress along with measures of their child's development and behaviour.

What we found

Children with epilepsy have a high neurodevelopmental need and are at increased risk of learning and behavioural difficulties. Those who have epilepsy in early childhood are a particular risk group for such difficulties. Despite this, children with epilepsy rarely have their learning and behavioural needs identified as the focus is often on the need to manage seizures.

Parents of children with epilepsy are at high risk of mental health and sleep difficulties. This study highlights the need for further understanding of the needs of families in order to provide better support. There is limited population-based research, or research which compares parents of children with epilepsy with parents of children with other neurodevelopmental or neurological conditions.

Key facts

Child development and behaviour



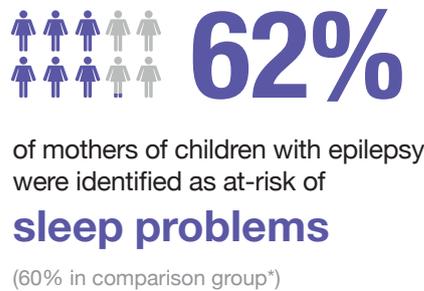
81% 

of children with epilepsy were identified as **at-risk of sleep difficulties**

The majority of children with epilepsy had **significant difficulties with social-emotional development** and often had significant features of **ADHD and autism**.

Parental functioning

 **Mothers** of children with epilepsy scored **significantly worse** than fathers on all measures of **emotional functioning and sleep/fatigue**

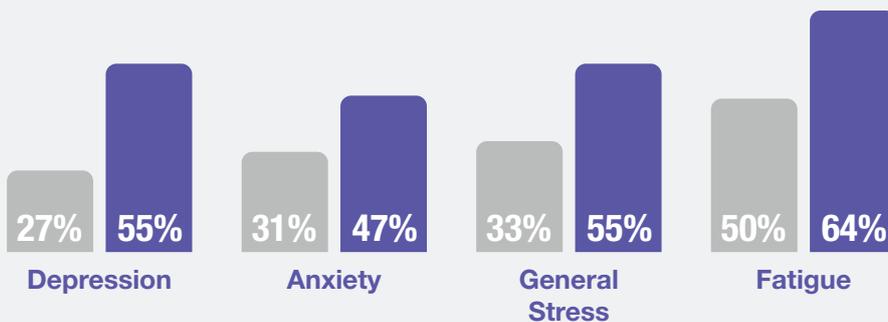


During interviews with parents of children with epilepsy, they revealed that:

01 They often had significant **difficulties accessing a professional knowledgeable about epilepsy**

02 They were often **not informed of the developmental and behavioural difficulties associated with epilepsy** and found it difficult to access further information

More mothers of children with epilepsy were identified as at-risk than mothers of children in the comparison group* in measures of:



03 **Few children** with epilepsy had previously **undergone psychological assessment**

04 Despite high levels of mental health symptoms in mothers, few reported that they had previously been diagnosed with difficulties

05 **Epilepsy has a significant impact on family functioning**

These findings highlight the **need for epilepsy services to take a family-based approach to care**; plus a further need to **consider the developmental impact of epilepsy** and its **impact on families as a whole**.

*comparison group of children with non-epilepsy related neurodisability and their families

Study background

Epilepsy is the most common serious neurological disorder in childhood. It has been estimated that 1 in 150 children have epilepsy¹. The majority of severe epilepsies start in the early years of childhood with a combination of seizures and developmental slowing, or regression², resulting in a very high risk for developmental and behavioural difficulties. These difficulties include problems with cognitive development³, adaptive behaviour⁴, motor functioning⁵, communication skills⁶, social skills⁷, difficulties with attention⁷, activity levels⁷, co-ordination⁷, impulsivity⁷, anxiety⁷ and emotions⁸. These additional needs can have a greater impact on school life and academic achievement than the seizures themselves. In addition to the impact on child development, epilepsy has a significant impact on parental wellbeing because of its unpredictable nature, potential for injury and associated cognitive and behavioural difficulties^{8,9,10}.

Despite the high risk of developmental and behavioural problems, children with epilepsy often have not undergone psychological assessment nor had their developmental needs comprehensively identified⁵. Like all children with developmental difficulties, children often have problems across a range of behavioural and developmental domains¹¹. This means they need multidisciplinary assessment and integrated support across health and education sectors¹².

Mothers of children with epilepsy are at high risk for both depression⁸ and anxiety^{9,10} and parental sleep will frequently be compromised¹⁰. Findings from studies investigating both seizures and family variables as predictors of child behaviour, show that family variables often have a greater influence¹⁴. Parents may find it difficult to provide the usual supports as they struggle to accept and understand the condition themselves. This can result in poorer quality parent-child relationships, less competence in parenting and more difficulties with family functioning and adaptation.

Despite the very significant difficulties faced by young children with epilepsy and their families, population-based research and data is lacking; particularly in understanding parental wellbeing and the prevalence of difficulties with global development, adaptive behaviour and social-emotional development in children. Population-based research is vital to health and educational services as it provides appropriate, accurate information which supports effective service planning.

The SEEN study thus focused on the prevalence of difficulties with child development and behaviour plus difficulties with parental emotional wellbeing and sleep. In order to have a better understanding of the impact of epilepsy itself on parental functioning we included a group of children with non-epilepsy related neurodisabilities who were matched on age, gender and developmental functioning. This allowed us to identify whether the impact of epilepsy on parents is similar in magnitude, or nature, to the impact on children without the condition who have similar characteristics.

The findings from this study are useful, for both health and educational services, with respect to understanding the impact of epilepsy on not only the affected child, but also the wider family.

Methodology



Recruitment

Of residents in the RH10 to RH14 postal districts of West Sussex between 31 August 2014 and 29 February 2016, 53 children with epilepsy born between 2008 and 2014 were identified by the researchers. The children had to be at least one year of age at the time of assessment. The parents of 48 young children (1-7 years of age) with epilepsy agreed that their children would take part in the study (91% of eligible children with epilepsy). A group of 48 gender and age matched children with non-epilepsy related neurodisability (neurological and neurodevelopmental difficulties) were also recruited from the same geographical area.

Child assessment

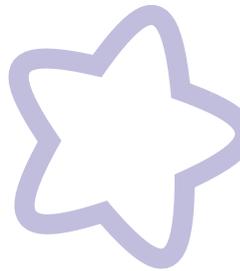
- Parents were interviewed about their child's everyday functioning using the Vineland Adaptive Behaviour Scales–Second Edition (VABS-II)¹⁶, a measure of adaptive functioning.
- All children underwent an assessment of their developmental functioning using the Griffiths Mental Development Scale (GMDS)¹⁷.
- All parents completed screening measures for features of Autism Spectrum Disorder¹⁸ in their child, for their child's sleep habits¹⁹ and for their child's emotional-behavioural functioning^{20,21}.

Parent assessment

- In both groups the mothers and fathers completed the short-term version of the Depression, Anxiety and Stress Scale (DASS)²², a screening measure for depression, anxiety and stress.
- They also completed the IOWA Fatigue Scale (IFS)²³ to screen for difficulties with fatigue and the Pittsburgh Sleep Quality Index (PSQI)²⁴ to measure the quality and patterns of their sleep.
- The mothers completed the Parent Stress Index-4th edition (PSI) - short form²⁵ to assess parenting stress.

Interviews with parents of children with epilepsy

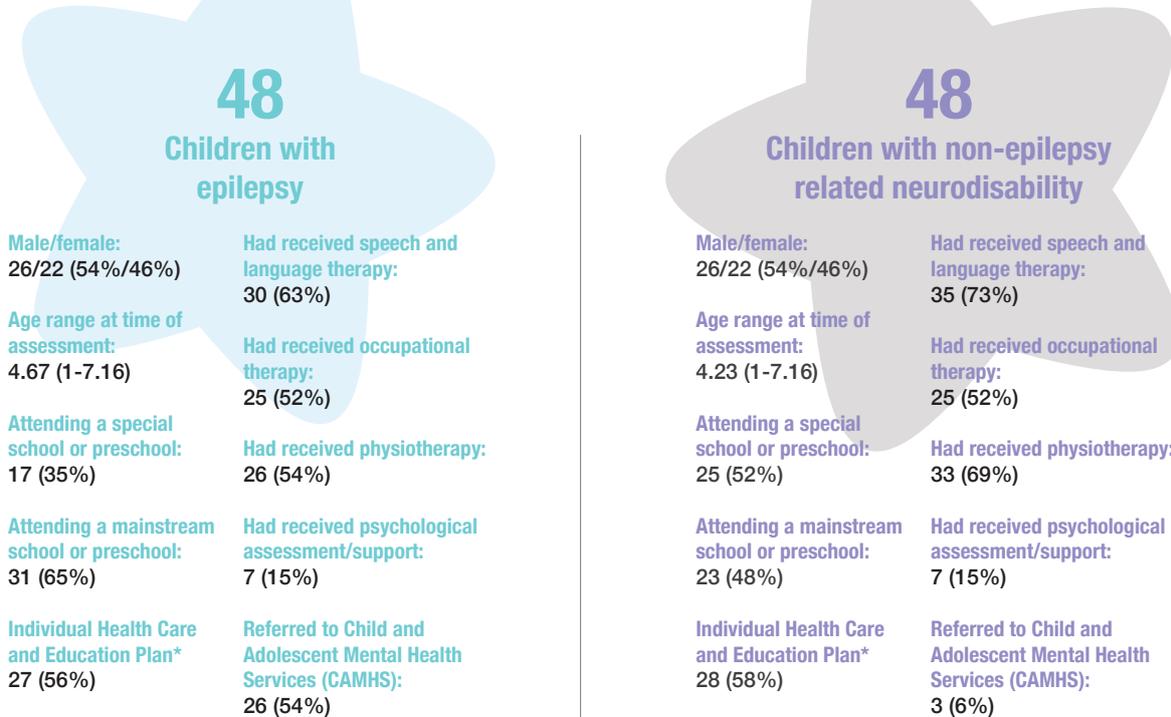
A small number of parents of children with epilepsy were invited to attend a focus group to discuss the challenges and supports needed. The research team then developed a semi-structured interview based on themes outlined by the group conducted with 40 parents of children with epilepsy. This was to gain a comprehensive understanding of the needs and experiences of having a child with early onset epilepsy. These interviews were transcribed and coded using thematic analysis²⁶.



Results

1. Child assessment

Characteristics of the 96 children who took part in the SEEN study:



*Have replaced Statements of Special Educational Needs; some children still had Statements at time of study

1.1 Global development

The Griffiths Mental Development Scale (GMDS)¹⁷ measures the rate of development from birth to eight. It highlights a child's strengths and weaknesses in six different areas. Table 1 outlines the six components of the GMDS administered with all children in the study. The total score is called 'The Developmental Quotient' (DQ) and gives an indication of a child's overall level of development. The average DQ score is 100 for normally developing children.

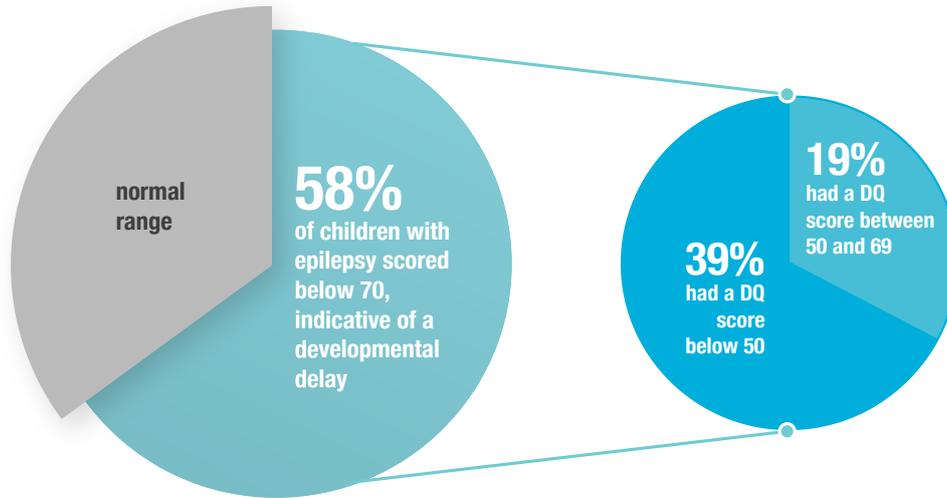
Table 1: Aspects of development assessed in the Griffiths Mental Development Scale (GMDS)

Subscale	What does it measure?
Locomotor	Gross motor skills - the ability to co-ordinate and control movements
Personal-social	Proficiency in the activities of daily living, level of independence and ability to interact with other children
Language	Understanding of language and their use of expressive language
Eye and hand co-ordination	Fine motor skills, manual dexterity and visual-perception skills
Performance	Skills in visuospatial awareness, speed of performance and precision
Practical reasoning*	Practical problem solving skills and basic mathematical skills

*Only completed by children two years and older

The performance of children with epilepsy with respect to global development:

Approximately 2% of children in the general population score below 70 and are considered to have developmental delay.



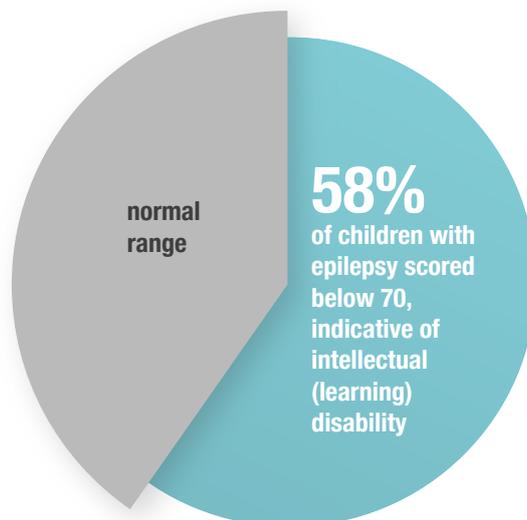
1.2 Adaptive behaviour

The Vineland Adaptive Behaviour Scale-Second Edition (VABS-II)¹⁶ measures adaptive behaviour which involves the performance of daily activities required for personal and social sufficiency. Deficits in adaptive behaviour are key in the diagnosis of intellectual (learning) disability. To determine an individual’s level of adaptive behaviour, someone who is close to the child, usually a parent, is asked to describe their activities. The Vineland Adaptive Behaviour Composite score for the general population is 100. A score below 70 indicates a high risk for a subsequent diagnosis of intellectual (learning) disability.

Table 2: Domains and subdomains assessed by the VABS-II

Domain	Subdomain
Communication	Receptive Expressive Written
Daily living	Personal Domestic Community
Socialisation	Interpersonal relationships Play and leisure time Coping skills
Motor skills*	Fine motor skills Gross motor skills

* Only completed by parents of children under seven years of age



1.3 Sleep

Parents of all children completed the Child Sleep Habits Questionnaire (CSHQ)¹⁹. The CHSQ is one of the most common tools used for assessing sleep problems in children. It is a parent-rated questionnaire that assesses the frequency of behaviours associated with common paediatric sleep difficulties.

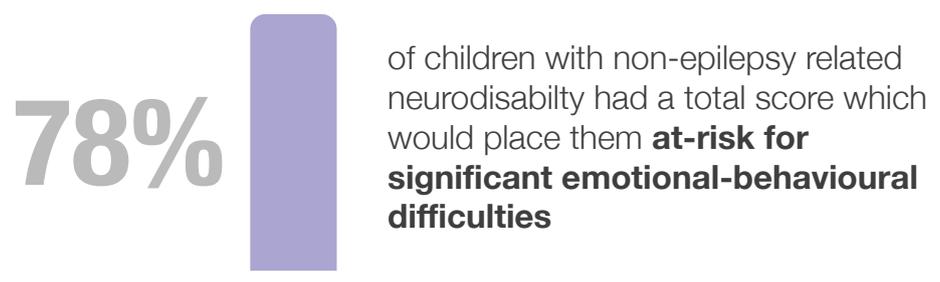


1.4 Behavioural and emotional development

If their child was aged two years or older, parents completed the Strengths and Difficulties Questionnaire (SDQ)²⁰. If their child was below two years of age or had a low level of developmental functioning, parents completed the Brief Infant-Toddler Social and Emotional Assessment (BITSEA)²¹. Both these measures are brief screening questionnaires for emotional and behavioural difficulties.

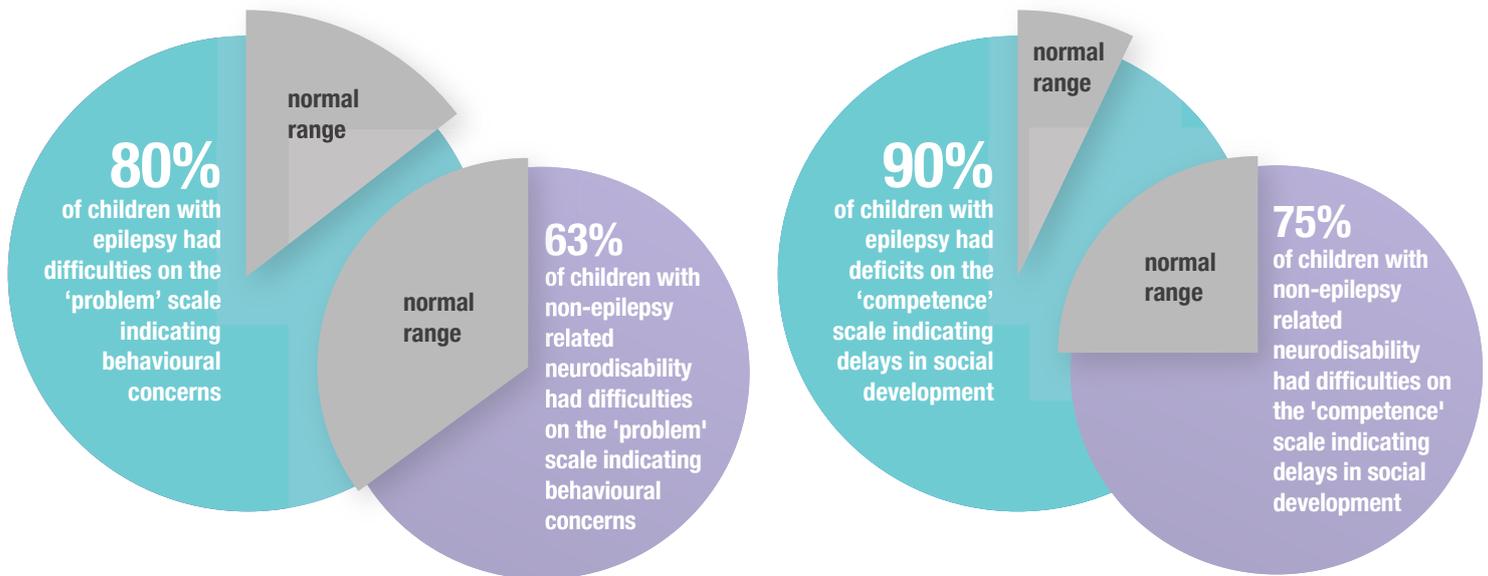
1.4.1 Results of Strengths and Difficulties Questionnaire (SDQ)

The SDQ includes four subscales and one overall score. The parents of 38 children with epilepsy and 32 children with non-epilepsy related neurodisability completed the SDQ.



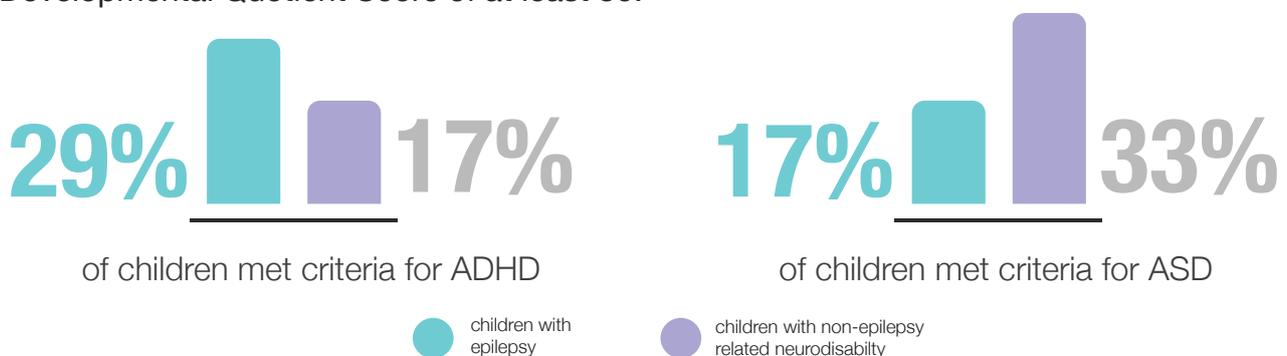
1.4.2 Brief Infant-Toddler Social and Emotional Assessment (BITSEA)

The BITSEA total score is split into 'problem' and 'competence'. The BITSEA 'problem' score identifies children who have behavioural problems. The BITSEA 'competence' score identifies aspects of social development expected to develop in early childhood. The results of these tests show the percentage of children with possible social-emotional problems (BITSEA problem) or possible deficit/delay (BITSEA competence) in social development. The parents of 10 children with epilepsy and 16 children with non-epilepsy related neurodisability completed the BITSEA.



1.4.3 Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD)

The DSM-5²⁹ is the most up-to-date version of the international diagnostic criteria for mental health disorders. Diagnoses of ASD and ADHD were made with respect to relevant DSM-5 criteria^{18,30,31} based on consensus diagnosis by the study psychologist, paediatrician and child and adolescent psychiatrist. Children were considered for a diagnosis of ASD if they were at least two years old and had a developmental age of at least one year. Children were considered for a diagnosis of ADHD if they were at least four years old and had a Developmental Quotient Score of at least 35.



Of the children with epilepsy:

- 27% were too young to be considered for a diagnosis of ADHD
- 13% were functioning at a low developmental level and thus were not considered for a diagnosis of ADHD
- 6% were too young to be considered for a diagnosis of ASD
- 17% were functioning at a low developmental level and thus were not considered for ASD.

1.5 Co-occurring neurobehavioural difficulties

Young children with developmental and behavioural difficulties frequently have difficulties in more than one area. Children may, for example, receive a diagnosis of developmental delay but also have difficulties with speech, social skills and attention. The term ‘ESSENCE’ was introduced to alert clinicians to the reality that young children referred for developmental assessments often have problems in multiple areas. The children thus need comprehensive multidisciplinary assessment and intervention across a range of developmental domains. Parents of children in both groups completed the ESSENCE-Q²⁷, a questionnaire designed to cover the range of developmental and behavioural difficulties that may be experienced by young children referred for developmental assessments. Parents can select ‘No (N)’, ‘Maybe/A Little (M/AL)’, or ‘Yes (Y)’ with respect to their level of concern for each developmental area.

Table 3: Responses of parents to the ESSENCE-Q in the SEEN study. Bold figures indicate a significant difference in score between groups.

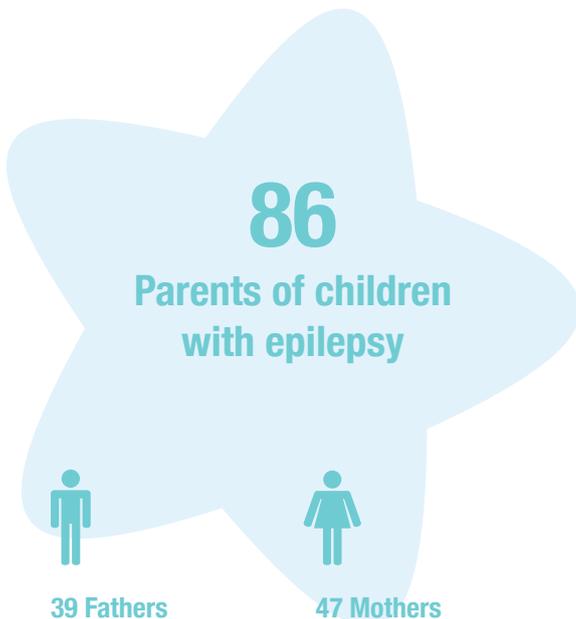
	Epilepsy			Non-epilepsy related neurodisability		
	No concern	Maybe/A Little	Yes	No concern	Maybe/A Little	Yes
General development	25%	8%	67%	17%	8%	75%
Motor development	35%	4%	60%	15%	19%	67%
Sensory reactions	52%	8%	40%	48%	8%	44%
Communication/language	25%	8%	67%	19%	10%	71%
Activity or impulsivity	48%	13%	40%	48%	8%	44%
Attention/concentration	17%	13%	71%	31%	21%	48%
Social Interaction	35%	19%	46%	46%	21%	33%
Repetitive behaviour	33%	19%	48%	40%	15%	46%
Mood	31%	27%	42%	60%	6%	33%
Sleep	42%	17%	42%	50%	10%	40%
Feeding	48%	10%	42%	48%	8%	44%

The parental concern reported by the ESSENCE-Q indicates that children in both groups frequently have problems in multiple developmental areas and would require support across a range of developmental domains.

Parents of children with epilepsy reported significantly higher concerns regarding attention and mood suggesting these may be particular areas of need in children with epilepsy.

2. Parent assessment

Characteristics of the 176 parents who took part in the SEEN study:



39 Fathers



47 Mothers

Average age:
37.95 years

Average age:
35.29 years

Education level
(Formal/Higher):
18/21

Education level
(Formal/Higher):
23/24

Average hours
worked per week:
35.32

Average hours
worked per week:
8.58

In paid
employment:
35

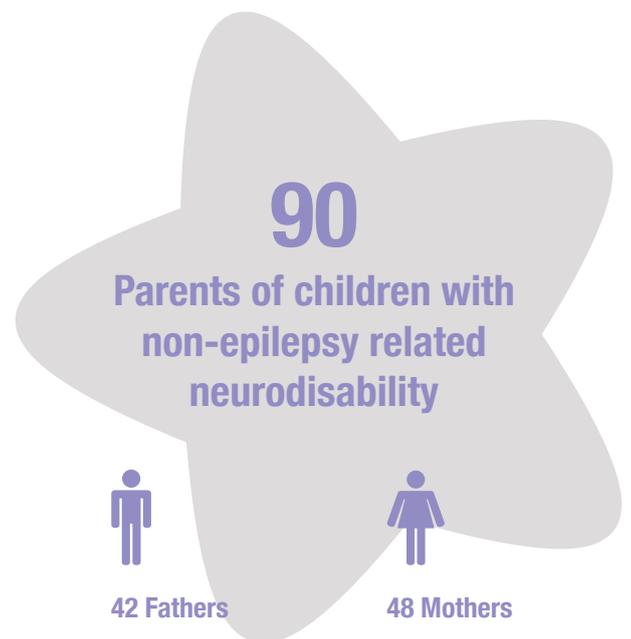
In paid
employment:
22

Diagnosis of
epilepsy:
2

Diagnosis of
epilepsy:
2

Mental health
diagnosis:
2

Mental health
diagnosis:
8



42 Fathers



48 Mothers

Average age:
37.61 years

Average age:
33.71 years

Education level
(Formal/Higher):
16/26

Education level
(Formal/Higher):
20/28

Average hours
worked per week:
37.94

Average hours
worked per week:
8.88

In paid
employment:
40

In paid
employment:
21

Diagnosis of
epilepsy:
0

Diagnosis of
epilepsy:
0

Mental health
diagnosis:
0

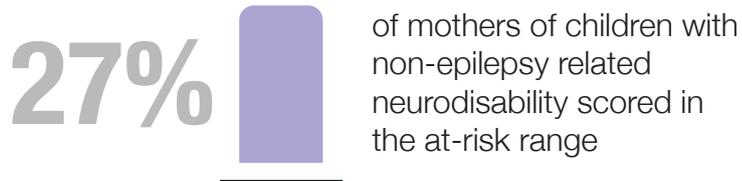
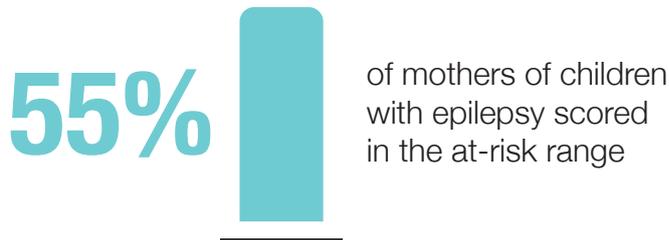
Mental health
diagnosis:
17

2.1 Depression, anxiety and stress

The Depression, Anxiety and Stress Scale (DASS)²² is a self-report questionnaire designed to measure the severity of the core symptoms. Separate scores are available for the three subscales - ie depression, anxiety and stress.

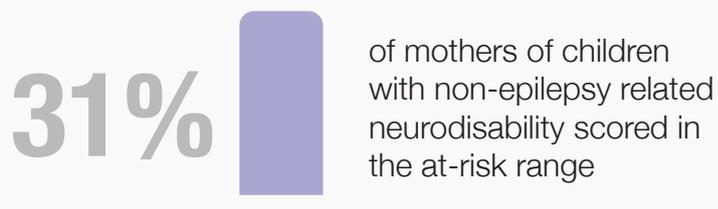
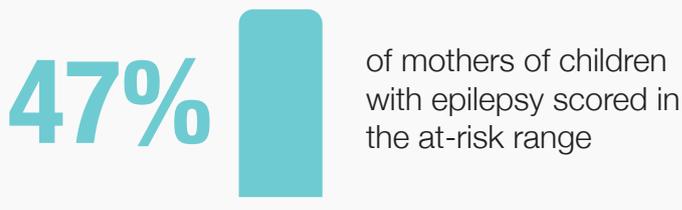
In the UK population

20% of people score in the at-risk range for **depression**



In the UK population

14% of people score in the at-risk range for **anxiety**



In the UK population

18% of people score in the at-risk range for **stress**



55%

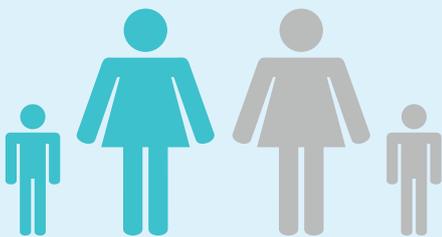


of mothers of children with epilepsy scored in the at-risk range

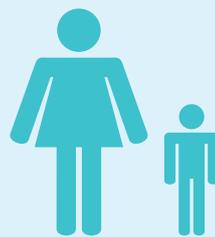
31%



of mothers of children with non-epilepsy related neurodisability scored in the at-risk range



Significantly **more mothers** scored in the at-risk range for both **depression** and **anxiety** compared to fathers, across both groups



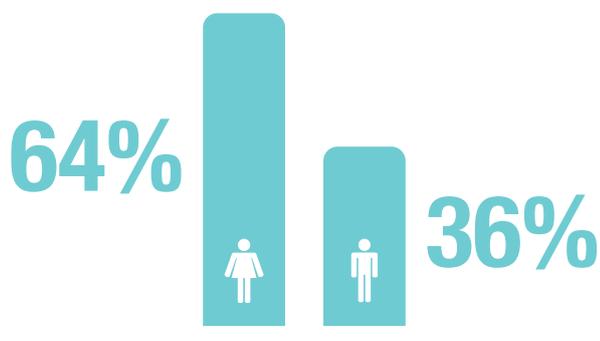
Significantly **more mothers** of children with epilepsy scored in the at-risk range for **stress** compared to fathers



Both mothers and fathers of children with non-epilepsy related neurodisabilities scored similarly for risk of **stress**

2.2 Fatigue

The Iowa Fatigue Scale (IFS)²³ is an 11-item measure of fatigue over the four weeks prior to assessment. It provides an assessment of fatigue in terms of cognitive function, drowsiness, energy level and productivity. Our results show the percentage of parents in both groups who scored in the abnormal range on the IFS. A score in the abnormal range means that an individual's fatigue significantly affects their day to day functioning.



of mothers and fathers of children with epilepsy scored in the abnormal range suggesting significant fatigue



of mothers and fathers of children with non-epilepsy related neurodisability scored in the abnormal range suggesting significant fatigue

2.3 Sleep

The Pittsburgh Sleep Quality Index (PSQI)²¹ is a questionnaire used to measure the quality and patterns of sleep in adults. Our results show the percentage of parents in both groups who had significant problems with sleep, indicating a requirement for professional advice or support.



62% of mothers of children with epilepsy had significant sleep problems



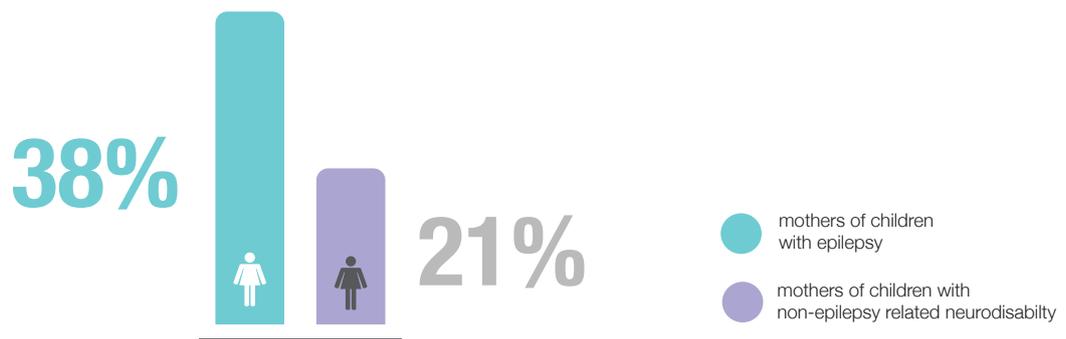
60% of mothers of children with non-epilepsy related neurodisability had significant sleep problems

Mothers had higher sleep problems compared to fathers, across both groups

2.4 Maternal parenting stress

Parenting stress in mothers was measured by the Parenting Stress Index-4th edition (PSI-4)²⁵. The PSI-4 is commonly used as a screening measure for evaluating the parent-child relationship and identifying issues that may lead to problems in the child's or parent's behaviour. Scores are available in three subscales: Parental-Distress, Parent-Child Dysfunctional Interaction and Difficult Child. A parenting stress score at the 85th percentile or above is considered a significant level of parenting stress.

Mothers of children with epilepsy scored in the **at-risk range more often** than the mothers of children with non-epilepsy related neurodisability **on all three subscales of parenting stress** measured by the PSI-4.



2.5 Parent reported stigma

Epilepsy is often associated with significant stigma. This stigma can include:

- **individualised stigma** (reflecting individual thoughts feelings and beliefs)
- **interpersonal stigma** (affected individual treated differently in interactions due to their epilepsy)
- **institutional beliefs** (public attitudes towards epilepsy).

Parents completed a five item measure²⁸ focused on the stigma associated with their child's condition. The highest possible score on the stigma scale is 25, indicating the highest level of stigma. The lowest possible score is 5, indicating least possible stigma. Results give the average stigma score from parents, for both groups, outlining what level of stigma they feel their child is exposed to.

The study showed there is no significant difference between the level of stigma parents feel their child is exposed to between the two groups.

The scores given by both parents of children with epilepsy and parents of children with non-epilepsy related neurodisability, indicated a middling level of stigma they felt their child was exposed to (14 and 13 respectively).



3. Parental interviews

Interviews with 40 parents of children with epilepsy were audio-recorded and transcribed using thematic analysis. Two people read the interviews and agreed on the themes. It is possible that a parent interview contained more than one subtheme within a theme.

Table 4: Parent interview themes and subthemes. Percentages indicate the proportion of parents who mentioned a specific theme or subtheme.

Themes	Subthemes	
Variable diagnostic journeys 73%	Epilepsy should have been identified sooner/getting to correct professional	45%
	Epilepsy identified quickly (positive)	22%
	Epilepsy identified quickly (overwhelming - too much too soon)	5%
Explanation of epilepsy 90%	Professional explanation was helpful	50%
	Need for more information as initial explanation not comprehensive	40%
	Own research via internet can be scary	15%
Parental perception of epilepsy management and treatment 68%	Lack of understanding and explanation of AED* side-effects	50%
	Lack of explanation/understanding of treatment/AED* regime	23%
	Need for integrated healthcare	15%
Awareness and impact of associated neurobehavioural difficulties 97%	Lack of information/awareness of associated neurobehavioural difficulties	60%
	Neurobehavioural difficulties often have more impact on child wellbeing	25%
Inconsistent availability of therapeutic and educational supports 60%	Inadequate educational provision (now or in the past)	45%
	Long waits for assessment and intervention	25%
	'Battle' to get adequate therapeutic supports	33%
Impact on family functioning 93%	Impact on parental sleep	30%
	Impact of child's 'challenging' behaviour and development delay	56%
	Negative impact on siblings	43%
	Restrictions on family activities	50%
	Negative financial/employment impact	50%
	Impact or disruption of function due to seizures)	40%
Need for parental support 93%	Future concerns for child	18%
	Need for continued emotional/informational support ie support groups or Facebook/internet forums	75%
	Epilepsy nurse provided good support	10%
	Medical professionals need to listen to parents	18%
	Support for managing child's difficult behaviour	28%

* AED - anti epileptic drugs

The key findings from these interviews were that parents found their children would often go undiagnosed until they gained access to a medical professional knowledgeable about epilepsy. It was also found that there is a lack of information, about associated developmental and behavioural difficulties, which often has a greater impact on child and family wellbeing. Parents want ongoing access to informational and emotional supports for both epilepsy and the associated developmental and behavioural difficulties.

Below are some quotes from parents illustrating each of the themes:

Variable diagnostic journeys

“...its good when you get [a diagnosis] but you know you have to wait so long for it, that’s the frustrating part. When you actually get to the top of the list I think, medically, its good.”

Explanation of epilepsy

“The doctor explained [epilepsy] in its clearest sense but you kind of migrate to the internet. I mean, self diagnosis, its terrible... but basically the doctor was magnificent.”

Parental perception of epilepsy management and to AED treatment

“We got told from the beginning we could either have a behavioural paediatrician or an epilepsy paediatrician... we went for a behavioural doctor and it felt like ‘you could have one, you can’t have both you know’ - and he should have had both.”

Awareness and impact of associated neurobehavioural difficulties

“... [doctors] did mention [possible developmental/behavioural problems associated with epilepsy], but they didn’t really explain it, they said it can possibly cause problems, but they didn’t really go into detail about what it could cause.”

Inconsistent availability of therapeutic and educational supports

“Oh yes she [receives the necessary therapeutic supports]. I mean I have to say, we had to fight to get that so we ended up filing for a tribunal for her statement... I suppose the thing that was really painful is the whole statementing process, kind of fighting for what we knew she needed.”

Impact on family functioning

“Epilepsy has had a big impact, sleepless nights. It really affects his sister’s sleep as well.”

Need for parental support

“It’s nice having the epilepsy nurse. We have her number and she said ‘any concerns any time, give her a buzz’. I called her after the diagnosis to go over some queries. It’s just knowing that we have got someone to speak to...”

Discussion

This study is one of the first UK population-based studies which comprehensively describes difficulties with global development and adaptive behaviour in young children with epilepsy. Population-based studies are important as hospital-based studies are likely to be biased towards more 'severe' cases. In addition to assessing difficulties with child development, the study is the first to comprehensively describe the difficulties faced by parents of young children with epilepsy.

Early onset epilepsy is often associated with frequent epileptic seizures which are difficult to treat. Children with epilepsy are likely to have a range of additional developmental and behavioural needs which can contribute significantly to the child's everyday functioning at home and at school. This study provides clear evidence of the extent of problems with development and behaviour in young children with epilepsy. It describes high risk of intellectual (learning) disability, neurodevelopmental conditions such as autism and ADHD, difficulties with social-emotional development and difficulties with sleep.

It was suspected that neurobehavioural difficulties are common in epilepsy and our findings indicate more than half of the children with epilepsy in this study have very significant problems with global development and adaptive behaviour. This means they are likely to reach the diagnostic criteria for an intellectual (learning) disability. Very few of these children had undergone any previous psychological assessment, so their development and behavioural needs had not been fully described. This will have significant implications in terms of access to therapeutic and educational supports.

A significant proportion of children with epilepsy met criteria for autism and ADHD. Both these conditions are associated with impairment in every day functioning. Correct diagnosis however, can lead to enhanced understanding and increased support in educational settings. Young children with epilepsy frequently have social-emotional difficulties. These are likely to be the precursors of the known high rate of mental health difficulties in school-aged children with epilepsy, often not identified. The results of the ESSENCE-Q assessment highlight that young children with epilepsy frequently have problems in multiple developmental domains, and will require comprehensive multidisciplinary assessment and support. Additionally, this study suggests young children with epilepsy may struggle to get adequate sleep. This could exacerbate learning and behavioural problems and further affect functioning in school and at home.

In this study, parents of children with epilepsy often reported significant symptoms of depression, anxiety and stress. Mothers reported significantly more problems than fathers and identified themselves as the primary carer in almost all cases, suggesting they face a particularly high burden. This may contribute to their increased mental health symptoms. The level of symptoms of depression and stress reported by mothers of children with epilepsy, was higher than mothers of children with non-epilepsy related neurodisability. This highlights mothers of children with epilepsy as a high-risk group for mental health needs. Despite this, few reported they had previously been diagnosed with problems; suggesting difficulties with accessing assessment and subsequent support.

The very high level of difficulties with sleep and fatigue reported by mothers of children with epilepsy in this study highlights the impact of epilepsy on sleep patterns of the whole family. There is a clear need for clinicians to be attentive to sleep problems in both children and their parents. Difficulties with fatigue can affect every day functioning, including productivity and memory, and is a significant factor in reducing quality of life for the entire family.

Interviews with parents of children with epilepsy revealed a range of concerns spanning both health and educational provision for their child, as well as the wider impact of epilepsy on the family. Nearly half of parents felt epilepsy could have been identified sooner if their child had been seen by an epilepsy professional. Delays in diagnosis are likely to have implications for treatment but also impact on parental stress and wellbeing. Many parents felt the information they received at diagnosis was not sufficient; particularly concerning the effects of anti epileptic drugs (AEDs). Additionally, parents were often not made aware of the link between epilepsy and developmental and behavioural difficulties. Three out of four parents reported they would like continued emotional and informational support, highlighting the need for support not only at diagnosis but as the child develops. Difficulties with educational and therapeutic provision were also identified by parents during interviews. Some parents reported long waits for assessment and intervention, as well as having to 'battle' to ensure adequate supports. Delays in accessing appropriate supports are likely to have a negative impact on child behaviour and development, and add to parental stress and wellbeing.

Parental reports of the impact of epilepsy on family functioning highlight that, in addition to epileptic seizures, epilepsy can have a pervasive impact on child functioning; a negative impact on the child's sibling(s); negative impact on family finances; and restrictions on family activities.

Families need ongoing support to cope with the psychosocial impact of epilepsy on their child and their family.

Recommendations

- Where a child is suspected to have epilepsy, they should be referred to an epilepsy professional without delay.
- Young children with epilepsy need a comprehensive multidisciplinary assessment, including input from paediatricians, child neurologists, psychologists, speech and language therapists, physiotherapists, occupational therapists and special educational professionals.
- Parents of children with epilepsy need to always be made aware of, and given accurate information about, developmental and behavioural difficulties associated with having epilepsy.
- Comprehensive multidisciplinary assessment should include all domains of behaviour and development assessed in the SEEN study, including sleep.
- Interventions for young children with epilepsy should be integrated so that, as far as possible, parents have access to one team who monitor the child's epilepsy and neurobehaviour.
- In addition to seizure management, epilepsy services need to consider child neurobehavioural needs and also their family's needs.
- The mental health and sleep functioning of parents of children with epilepsy should be monitored.
- Sleep is often compromised in both children with epilepsy and their parents. Supporting clinicians need to provide support via sleep education and resources to families.
- Parents of children with epilepsy should have access to ongoing information and emotional support via dedicated epilepsy support specialists (eg epilepsy support nurse) and have access to reliable information forums.

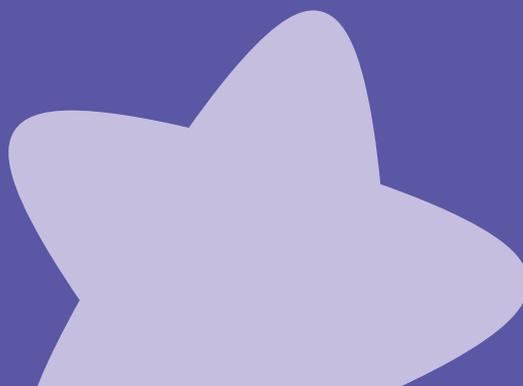
Future work

- There is a need for research into the efficacy of interventions to manage the behavioural and developmental needs of young children with epilepsy.
- Given the high level of problems with sleep in children with epilepsy and in their parents, there is a need for further research into pharmacological and psychological sleep interventions.
- Research is needed to identify how to support parents of children with epilepsy, especially mothers, who may be experiencing significant mental health problems.
- Parents report they want better information at diagnosis but also access to continued support.
- There is a need to understand how to best help parents with respect to informational and emotional needs.
- Parents reported siblings of children with epilepsy were sometimes adversely affected and there is a need to further explore the impact of epilepsy on siblings.

Our next steps

This work and its recommendations will be shared with epilepsy practitioners via Young Epilepsy's international networks. It will be published in peer reviewed scientific journals for the benefit of the wider scientific community and will be presented at scientific and special interest conferences.

As a charity, we will use this knowledge to further champion smarter and more integrated support for young people with epilepsy and their families, across every facet of their lives.



References

1. Boyle CA, Boulet S, Schieve LA (2011) **Trends in the prevalence of developmental disabilities in US Children, 1997-2008.** *Pediatrics*. 127:1034-42.
2. McTague A, Howell KB, Cross JH, Kurian MA, Scheffer IE (2016) **The genetic landscape of the epileptic encephalopathies of infancy and childhood.** *The Lancet Neurology*. 15(3):304-16.
3. Rantanen K, Eriksson K, Nieminen P (2011) **Cognitive impairment in preschool children with epilepsy.** *Epilepsia*. 52(8):1499-505.
4. Berg AT, Smith SN, Frobish D, Beckerman B, Levy SR, Testa FM, Shinnar S (2004) **Longitudinal assessment of adaptive behavior in infants and young children with newly diagnosed epilepsy: influences of etiology, syndrome, and seizure control.** *Pediatrics*. 114(3):645-50.
5. Reilly C, Atkinson P, Das KB *et al* (2015) **Features of Developmental Coordination Disorder (DCD) in active childhood epilepsy: a population based study.** *Dev Med Child Neurol*. 57:829-34.
6. Selassie G, Viggedal G, Olsson I, Jennische M (2008) **Speech, language, and cognition in preschool children with epilepsy.** *Dev Med Child Neurol*. 50(6):432-8.
7. Reilly C, Atkinson P, Das KB *et al* (2014) **A population-based study of neurobehavioural comorbidities in children with active epilepsy.** *Pediatrics*. doi:10.1542/peds.2013-3787.
8. Davies S, Heyman I, Goodman R (2003) **A population survey of mental health problems in children with epilepsy.** *Dev Med Child Neurol*. 45:292-5.
9. Ferro MA, Speechley KN (2009) **Depressive symptoms among mothers of children with epilepsy: a review of prevalence, associated factors, and impact on children.** *Epilepsia*. 50(11):2344-54.
10. Jones C, Reilly C (2016) **Parental anxiety in childhood epilepsy: a systematic review.** *Epilepsia*. 57(4):529-37.
11. Larson AM, Ryther RC, Jennesson M, Geffrey AL, Bruno PL, Anagnos CJ, Shoeb AH, Thibert RL, Thiele EA (2012) **Impact of paediatric epilepsy on sleep patterns and behaviours in children and parents.** *Epilepsia*. 53(7):1162-9.
12. Gillberg C (2010) **The ESSENCE in child psychiatry: early symptomatic syndromes eliciting neurodevelopmental clinical examinations.** *Research in Developmental Disabilities*. 31(6):1543-51.
13. Bali A, Hargreaves DS, Cowman J, Lakhanpaul M, Dunkley C, Power M, Cross JH (2016) **Integrated care for childhood epilepsy: ongoing challenges and lessons for other long-term conditions.** *Archives of disease in childhood*. 101(11):1057-62.
14. Reilly C, Atkinson P, Das KB, Chin RF, Aylett SE, Burch V, Gillberg C, Scott RC, Neville BG (2015) **Factors associated with quality of life in active childhood epilepsy: a populationbased study.** *European Journal of Paediatric Neurology*. 19(3):308-13.
15. Rodenburg R, Marie Meijer A, Deković M, Aldenkamp AP (2006) **Family predictors of psychopathology in children with epilepsy.** *Epilepsia*. 47(3):601-14.

16. Sparrow SS, Cicchetti DV, Balla DA (2005) **Vineland Adaptive Behaviour Scales (2nd ed.)**. *Minneapolis, MN*.
17. Luiz D, Barnard A, Knoesen N, Kotras N, Horrocks S, McAlinden P, Challis D, O'Connell R (2006) **Griffiths Mental Development Scales – Extended Revised - Administration Manual**. *Oxford: Hogrefe*.
18. Robins DL, Fein D, Barton ML, Green JA (2001) **The Modified Checklist for Autism in Toddlers: an initial study investigating the early detection of autism and pervasive developmental disorders**. *J Autism Dev Disord*. 31:131-144.
19. Owens JA, Spirito A, McGuinn M (2000) **The Children's Sleep Habits Questionnaire (CSHQ): psychometric properties of a survey instrument for school-aged children**. *Sleep*. 23:1043–51.
20. Goodman R (1999) **The extended version of the Strengths and Difficulties Questionnaire as a guide to child psychiatric caseness and consequent burden**. *J Child Psychol Psychiatry*. 40:791-9.
21. Carter AS, Briggs-Gowan M J (2006) **Brief Infant-Toddler Social and Emotional Assessment**. *San Antonio, TX: Harcourt*.
22. Henry JD, Crawford JR (2005) **The short-form version of the Depression Anxiety Stress Scales (DASS-21): Construct validity and normative data in a large non-clinical sample**. *British journal of clinical psychology*. 44(2):227-39.
23. Hartz A, Bentler S, Watson D (2003) **Measuring fatigue severity in primary care patients**. *Journal of Psychosomatic Research*. 54(6):515-21.
24. Buysse DJ, Reynolds CF, Monk TH, Berman SR, Kupfer DJ (1989) **The Pittsburgh sleep quality index: a new instrument for psychiatric practice and research**. *Psychiatry Res*. 28:193–213.
25. Abidin, RR (2012) **Parenting stress index (4th ed.)**. *Lutz, FL: PAR*.
26. Braun V, Clarke V (2006) **Using thematic analysis in psychology**. *Qualitative research in psychology*. 3(2):77-101.
27. Hatakenaka Y, Fernell E, Sakaguchi M, Ninomiya H, Fukunaga I, Gillberg C (2016) **ESSENCE-Q a first clinical validation study of a new screening questionnaire for young children with suspected neurodevelopmental problems in south Japan**. *Neuropsychiatric Disease and Treatment*. 12:1739-46.
28. Austin JK, MacLeod J, Dunn DW, Shen J, Perkins SM (2004) **Measuring stigma in children with epilepsy and their parents: instrument development and testing**. *Epilepsy & Behavior*. 5(4):472-82.
29. American Psychiatric Association (2013) **Diagnostic and Statistical Manual of Mental Disorders (Fifth ed.)**. *Arlington, VA: American Psychiatric Publishing*. 74–85.
30. Ehlers S, Gillberg C, Wing L (1999) **A screening questionnaire for Asperger syndrome and other high-functioning autism spectrum disorders in school age children**. *J Autism Dev Disord*. 29(2):129-41.
31. DuPaul G, Power T, Anastopoulos A, Reid R (1998) **ADHD Rating Scale-IV: Checklists, Norms, and Clinical Interpretation**. *Reprinted with permission from The Guilford Press, New York*.

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 are known.

Epileptic seizures can be classified into 'generalised' or 'focal'. In generalised seizures the whole brain is affected by abnormal electrical disturbance and the child becomes unconscious of their surroundings. In 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, seeming 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 unco-ordinated. This can make typical daily activities difficult (eg 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.

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.

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.

Learning (intellectual) disability

A learning disability involves significant difficulties with overall cognitive functioning (IQ Score < 70) and difficulties with adaptive functioning (eg 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).

Developmental delay

Developmental delay refers to when a child does not reach their developmental milestones at the expected times. Developmental delay can have many different causes, such as genetic causes (like Down's Syndrome), or complications of pregnancy and birth (like prematurity or infections). Often, however, the specific cause is unknown.

Neurobehavioural difficulties

Neurobehaviour difficulties refers to impairments seen in association with a brain disease or condition. It may include developmental and learning problems as well as behavioural difficulties. Neurodevelopmental difficulties is a similar term which refers to problems with development thought to be due to brain developmental problems or a brain condition.

Stress

Stress is the feeling of being under too much mental or emotional pressure, and pressure turns into stress when someone feels unable to cope. A bit of stress is normal and can help push someone to do something new or difficult, but too much stress can take its toll.

Parenting stress

Parenting stress refers to stress associated with parenting and can arise when problems occur in relationship between the parent and child.

Fatigue

Fatigue is a subjective feeling of tiredness and has a gradual onset. Fatigue can have physical or psychological causes and can be alleviated by periods of rest.

Thematic analysis

Thematic analysis is one of the most common forms of analysis in qualitative research. It emphasizes pinpointing, examining, and recording patterns (or 'themes') within data.

Appendix

Psychological measures used in the SEEN study.

Child measures:

- Vineland Adaptive Behaviour Scale-Second Edition (VABS-II) (Birth to 90 years) - a measure of adaptive functioning based on parental report¹⁶.
- Griffiths Mental Development Scale-Extended Revised (GMDS-ER) (Birth-8years) - a measure of developmental functioning¹⁷.
- The Modified Checklist for Autism in Toddlers (MCHAT) (16 months +) - a well validated screen for ASD in young children completed by parents¹⁸.
- Strength and Difficulties Questionnaire (parents) (24 months+) - a screen for behavioural and emotional problems, including a broad screen for ADHD²⁰.
- Brief Infant Toddler Social Emotional Assessment (BITSEA) (12-36 months) - a measure of social emotional development in infants and toddlers²¹.
- ESSENCE Q-REV scale/checklist (Birth+) - a screen for ESSENCE type problems²⁷.
- Children's Sleep Habits Questionnaire (CSHQ) - a validated tool for both behaviourally and medically based sleep problems in children¹⁹.
- Autism Spectrum Screening Questionnaire (ASSQ) for children aged four years and over at time of assessment - a 27 item parent report measure for symptoms of ASD and social communication problems³⁰.
- ADHD Rating Scale-IV for children aged four years and over at time of assessment - an 18 item parent report measure for symptoms of ADHD³¹.
- DSM-5 - the international diagnostic criteria for mental health disorders²⁹.

Parent measures:

- Depression Anxiety Stress Scales-21 (DASS-21)²² - a self-report measure of depression, anxiety and stress.
- Parenting Stress Index-4th edition (PSI-4)²⁵ - short form - the PSI is designed for the early identification of parenting and family characteristics that do not promote normal development and functioning in children.
- IOWA Fatigue Scale (IFS)²³ - the 11 item (IFS) is a valid, clinically useful measure of screening and monitoring chronic fatigue in adults.
- The Pittsburgh Sleep Quality Index (PSQI)²⁴ - is a self-report questionnaire that assesses sleep quality over a 1-month time interval in adults. The measure consists of 19 individual items, creating 7 components that produce one global scores.
- Parent Epilepsy Stigma Scale²⁸ - a four item stigma scale with good reliability and validity.
- DSM-5 - the international diagnostic criteria for mental health disorders²⁹.

Acknowledgments

We would like to thank the children and their parents who participated in the study.

We would also like to thank all the medical professionals at *Sussex and Surrey Healthcare NHS Trust* for help with recruiting the children and their parents.

We are also extremely grateful to the *The George E Neville Foundation* who funded the project.

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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 and neurodevelopmental 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.

About our research

Our research programme operates under the auspices of The Prince of Wales's Chair of Childhood Epilepsy, Professor Helen Cross OBE. It is a collaborative scheme between Young Epilepsy, Great Ormond Street Hospital for Children and UCL GOS – Institute for Child Health.

We are committed to optimising long-term outcomes and reducing the overall burden of epilepsy on young lives and families. Our research focusses on all aspects of childhood epilepsy, championing a holistic and multidisciplinary approach to understanding the causes of epilepsy, diagnosis, treatment and support.

Our six research goals:

- gain a better understanding of the medical causes of epilepsy
- gain a better understanding of how epilepsy affects development and behaviour
- determine the benefits of early interventions in improving long-term outcomes
- gain a better understanding of barriers to learning and determine the benefits of educational interventions in improving academic achievement
- reduce the burden of epilepsy to the young person, family and agencies involved
- develop a network of multidisciplinary professionals to strengthen our research and shape the education of future practitioners.

We continue to vanguard practical outcomes for young people reflected in public policy based on research evidence. We cannot hope to make lasting, meaningful change without services governed by defensible fact in all disciplines of our work. It is central to all that we do.

For more information about epilepsy, what we do, and how to get involved, please visit youngepilepsy.org.uk

Professor Brian George Richard Neville

1939-2016

Emeritus Professor in Childhood Epilepsy



The SEEN study was conceived, initiated and led by Brian Neville, however he sadly passed away following a long illness before the study was completed.

Brian was the first Chair of Paediatric Neurology in the UK and subsequently the first Prince of Wales's Chair of Childhood Epilepsy; being instrumental in its inception. He recognised the need to understand the wider impact of epilepsy as a condition which involved much more than epileptic seizures.

Brian specifically championed multidisciplinary team-working across neurodisability services. His work pioneered the understanding of the rate of learning and behavioural difficulties in children with epilepsy, leading to a much greater appreciation of the impact epilepsy can have on learning and child development. This has paved the way for better support for young people and improved communication between professionals.

Brian was passionate about training the future bright minds of neurology and ingrained into his teaching the discipline to keep the patient at the centre of every action.

Brian's legacy is colossal and his work will continue to shape the field of neurology for generations to come.

Professor Helen Cross OBE

The Prince of Wales's Chair of Childhood Epilepsy

At Young Epilepsy we want to create better futures for young lives.

As a national charity and a centre of expertise for all young people with epilepsy, we have over 100 years' experience to share;

let's work together.

For more information on our research or if you want to get involved please contact:

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