

# **Impact of epilepsy on learning and behaviour and needed supports: Views of children, parents and school staff**

Emma Johnson<sup>1,2</sup>

Patricia Atkinson<sup>3</sup>

Amy Muggeridge<sup>1</sup>

J Helen Cross<sup>1,2,4</sup>

Colin Reilly<sup>1,4</sup>

## **Affiliations**

<sup>1</sup>Research Department, Young Epilepsy, Lingfield, Surrey, RH7 6PW, UK.

<sup>3</sup>Great Ormond Street Hospital for Children NHS Trust, Great Ormond Street, London WC1N 3JH, UK.

<sup>3</sup>Child Development Centre, Crawley Hospital, West Green Drive, Crawley, RH11 7DH, West Sussex, UK.

<sup>4</sup>UCL Great Ormond Street Institute of Child Health (ICH), 30 Guilford Street London WC1N 1EH UK.

**Correspondence to:** Colin Reilly, Research Department, Young Epilepsy, Lingfield, Surrey, RH7 6PW, UK. creilly@youngepilepsy.org.uk 01342 832243

**Keywords:** children, epilepsy, learning, behaviour

**Number of figures:** 1

**Number of tables:** 4

**Number of references:** 47

**Short title:** Impact of epilepsy on learning and behaviour in schools

## Summary

**Background:** There is limited data on the views of young people with epilepsy, their parents and school staff regarding the impact of epilepsy on learning and behaviour in school. The purpose of the study was to gain an understanding of the impact of epilepsy on learning and behaviour and needed supports according to children with epilepsy, their parents and supporting school staff.

**Methods:** School-aged children (n=20) with 'active epilepsy' (taking anti-seizure Medications (ASMs) for epilepsy), their parents (n=68) and school staff (n=56) were interviewed or completed surveys. The quantitative data was analysed using descriptive statistics and responses were compared for children attending mainstream and special schools using chi-square analyses. The answers to open questions were answered using thematic analyses.

**Results:** The majority (53%) of children with epilepsy felt that epilepsy affected their learning including aspects such as memory, attention and concentration but also physical and emotional wellbeing including increased tiredness and lowered self-confidence. In addition, children brought up possible negative aspects of taking ASMs including increased irritability and emotional reactivity. The children also mentioned that epilepsy in school was associated with stigma and restrictions. The majority (85%) of parents agreed that epilepsy affects the child's learning/behaviour while more staff agreed that epilepsy affects learning (61%) than behaviour (45%). Most parents agreed that their child's school provided the appropriate resources to support their child's learning (79%) and 72% agreed that they were satisfied overall with the support their child received at school. However, parents of children attending special schools were more likely to agree that the child's school provided appropriate resources to support their child's learning ( $p=0.034$ ) and be satisfied with the support their child received in school ( $p=0.02$ ), than parents of children attending mainstream schools. With respect to current or desired supports, analysis of the children's responses indicated that they want access to supportive environments outside the classroom, accommodations in tests/exams and increased support from trusted adults. Parent responses included approaches that promote child wellbeing, environmental accommodations, a high ratio of adult support and a consideration of the child's communication needs. Staff views regarding optimal strategies included a high level of adult support for the child, environmental accommodations, use of multimodal learning, adapting communication and approaches that promote psychological wellbeing.

**Conclusions:** The majority of children perceived that epilepsy affected their learning and behaviour in school including leading to specific learning difficulties, but also negative impacts on emotional and physical wellbeing. Levels of parental satisfaction with supports were significantly higher in special schools compared with mainstream schools. Children, parents and staff highlighted a number of supports which they felt can support the child with epilepsy's learning but also emotional wellbeing.

## **1. Introduction**

In addition to seizures children with epilepsy often have cognitive and behavioural difficulties which are likely to significantly impact on performance in school. These comorbidities include an increased risk for intellectual disability, specific cognitive difficulties, Attention Deficit Hyperactivity Disorder (ADHD), autism, Developmental Coordination Disorder (DCD), depression and anxiety<sup>1,2,3,4</sup>. Additionally, academic underachievement indicated by performance in academic areas lower than that expected by level of cognitive functioning is common<sup>5,6</sup>. The additional cognitive and behavioural difficulties often have a greater impact on health related quality of life than the seizures<sup>7,8</sup> but are often not recognised or supported<sup>1,9,10</sup> and can often have very significant impact on the child's schooling<sup>11</sup>.

In addition to co-occurring neurodevelopmental problems learning may be impacted by seizures and epileptic activity. Seizures may impact the child's learning directly but also indirectly through fatigue and a need for recovery. Epileptic activity independent of seizures can also affect a child's learning and behaviour<sup>12</sup>. The majority of children with epilepsy take Anti-Seizure Medications (ASMs) the side effects of which can include a negative impact of learning and behaviour<sup>13</sup>. Learning and behavioural problems are not confined to treatment resistant or early onset epilepsy but are also increased in self-limiting and pharmcoresponsive epilepsies<sup>14,15</sup>.

Despite the comprehensive impact of epilepsy on cognition, behaviour and academic achievement, there is a lack of systematic research on views of children, their parents and school staff concerning the impact of epilepsy on learning and behaviour in schools. The 'What I Need in School' (WINS) - Experiences of children with epilepsy in schools' study focusses on the experiences of children with epilepsy, their parents and staff in schools in a defined geographical area of the United Kingdom (UK). We have previously reported parents' views on educational and therapeutic provision, understanding of epilepsy and seizure management, and inclusion and participation of affected children<sup>16,17</sup>. The aims of the current study are to describe views regarding the impact of epilepsy on learning and behaviour in schools and to garner views regarding supports and strategies for affected children.

## **2. Methodology**

### **2.1 Recruitment**

Recruitment in the WINS study has been comprehensively described previously<sup>16</sup>. All children were born between 2003 and 2014 with 'active' epilepsy (had two or more unprovoked seizures more than 24 hours apart and on 1 or more ASM for epilepsy). Eligible children were resident in the RH10 to RH13 postal districts of the county of West Sussex in the south of the United Kingdom between April 1<sup>st</sup> 2018 and December 31<sup>st</sup>, 2019. The study area is located south of London and has total population of 202 919 (Census 2011). It has two main urban centres, Crawley (106,597) and Horsham (48,941) The area is similar to the UK average with respect to ethnic make-up (study area: white 87%, nonwhite 13%, United Kingdom: white 86% nonwhite 14%) and socioeconomic index. The prevalence of 'active epilepsy' in the study area during the study period was 4.20 per 1000 (1 in 238, 95% CI 1 in 200 to 1 in 285) or 0.42%.

Participating children and parents/school staff were interviewed/surveyed between September 11<sup>th</sup> 2018 and April 30<sup>th</sup> 2020. All parents who were approached were offered a study interest form and asked to complete an interest form if they wished to find out about the study. All parents who returned a form were contacted by telephone and met in their home if they wished to participate. At this informed consent meeting, the study was described in detail and parents were asked for written consent for entry of their child into the study. Anonymised information was obtained on non-participants (n=68), including data on sex, ASM usage, deprivation, ethnicity, age at median point in study, age of diagnosis/first seizure.

## **2.2 Measures**

Study interviews/surveys were developed in partnership with children with epilepsy, their parents and staff at focus groups. As a result of this process the final interview/questionnaire schedules were developed (See supplement 1). All participants were offered the choice of being interviewed in person or via telephone.

## **2.3 Analysis**

The demographic and clinical characteristics of participating children with epilepsy, parents and school staff are reported as descriptive statistics. For analysis, Likert-type scale variables were condensed as follows – ‘strongly agree’ and ‘agree’ condensed into ‘agree’, and ‘strongly disagree’ and ‘disagree’ into ‘disagree’. Chi-squared tests (or Fisher Exact tests) were used to compare special and mainstream provision. The alpha level for all analyses was  $p < 0.05$ . All analyses were performed with IBM SPSS version 25.0 (Armonk, NY, USA). The open questions from the interviews and surveys were analysed using Thematic Analysis<sup>18,19</sup> by two research psychologists (EJ and CR).

## **2.4 Ethical Approval**

The study was approved by the Leeds East Research Ethics Committee and was registered with the collaborating hospital primary care organization: The Sussex and Surrey Community NHS Trust.

## **3. Results**

### **3.1 Characteristics of the sample**

In the study period 134 children with ‘active’ epilepsy were identified in the study area and 68 (50% of eligible population) children with epilepsy underwent psychological assessment (see figure 1). Sixty-eight parents participated in the study - 61 (90%) mothers and 7 (10%) fathers. Fifty-six school staff participated in the study. Of the 68 children, 20 (29%) were interviewed or complete questionnaires. The 48 remaining children did not respond and reasons are given in supplement 2. The main reason for non-participation was level of cognitive functioning. The main characteristics of the children in the WINS study are shown in Table 1.

### **3.2 Child with epilepsy views regarding the impact of epilepsy on learning, behaviour and emotions (see Table 2 and Table 3)**

Ten children with epilepsy (CWE) (53%) reported that their epilepsy affects their learning whilst three CWE (19%) reported that their prescribed ASM affects their learning. Only two CWE (11%) reported that their epilepsy affected their behaviour at

school but eight (47%) reported that their epilepsy affected how they feel in school. Six major themes with associated subthemes were identified with respect to child views on the impact of epilepsy/seizures in school (see table 2). The six themes were: Stigma/Social Effects, Impact of having seizures in school, Restrictions, Impact of ASMs in school, Impact of epilepsy on learning and Physical and emotional well-being.

### 3.3 Parental and staff views regarding the impact of epilepsy on learning, behaviour and emotions (see Table 3)

Fifty-five parents (85%) reported that their child's epilepsy impacted their learning and/or behaviour. Reported ways in which epilepsy affected learning included causing difficulties with memory and attention, slower processing, difficulties with word-finding and missed learning due to seizures. Ways in which parents perceived that epilepsy affected their child's behaviour included mood changes, lowered self-confidence, increased impulsiveness and causing the child to be withdrawn and easily upset. Additionally parents mentioned that epilepsy/seizures can cause agitation, irritability, anxiety, hyperactivity and defiance. In some cases, parents believed that ASMs caused their child to be less responsive and more sedated.

Thirty-three school staff (61%) agreed that epilepsy affected the child's learning. The majority of staff were unsure whether the child's ASMs affected their learning (54%) or behaviour (57%). Sixteen staff (29%) reported that a child's prescribed ASMs affected their learning. Twenty-four staff (44%) agreed that epilepsy affected a child's behaviour, and 22 staff (42%) agreed that epilepsy affected a child's social relationships within the school. Twelve staff (21%) reported that the child's prescribed ASMs affected their behaviour. There were no significant differences between children attending mainstream and special schools with regard to any of the questions.

#### 3.3.1 Staff views on the potential impact of ASMs on the child's their learning and/or behaviour (see supplement 3)

School staff were asked to indicate their views in relation to the possible impact of the child's ASMs (both side effects or non-adherence i.e., not taking ASMs) on the child's learning and behaviour and thematic analysis resulted in four main themes which are shown in supplement 3. The four themes were increased tiredness/fatigue, difficulties with expressive communication and understanding of language, impaired cognition including difficulties with attention, memory and processing speed and behavioural and emotional difficulties including sadness and a view that the child could become more demanding.

### 3.4 Views on Supports for learning and behavioural emotional functioning (see Table 4)

#### *3.4.1 Child views*

*The responses to the questions* 'What support (or help) do you get for your learning in school?', 'What helps you most with your learning in school?', 'What helps you most with your behaviour in school?' and 'If you don't feel happy in school what can help?' were analysed together as children responses often did not distinguish between what support as they received and what helped them. Thematic analysis resulted in five main themes (Supplement 4). These themes were Access to specific support

environments (including access a supportive environment outside of their main classroom), Authorized accommodations (including being granted use of a laptop), Having additional time to complete tasks and tests, Increased adult support, Use of rewards/incentives for desired behaviour in school and Talking to a trusted person such as a friend or a familiar staff member.

#### 3.4.2 Parental views on supports for learning and behavioural emotional functioning Table 3)

Fifty-three parents (79%) agreed that their child's school provided the appropriate resources to support their child's learning, and 59 parents (88%) agreed that their child's school was flexible enough to meet their needs. Forty-eight parents (72%) agreed that overall they were satisfied with the supports their child receives in school. Parents of children in special schools were more likely to agree that the child's school provide appropriate resources to support child's learning ( $p=0.034$ ) and be satisfied with the support child receives in school than parents in mainstream schools ( $p=0.02$ ) There was no other significant differences between parents of children attending mainstream and special schools.

Parental report of supports received for their child's learning and behavioural emotional functioning in school were analyzed via thematic analyses and results are shown in Table 4. Six themes with associated subthemes were identified (see Table 4 and Figure 3). The themes were: Child receives no additional support (because they did not need it or the child's school were not providing this support), Increased support from school staff in the classroom, Additional supports provided outside of the classroom, Access to therapies within school, Access to support in development of emotional and social skills and Special school provision.

#### 3.4.3 Parental and staff views on effective strategies and supports for learning and behaviour

Analysis of parental responses with respect to views on strategies and supports for their child's learning and behaviour revealed 11 main themes and these are shown in supplement 5. The themes included: No specific strategies used/approaches no different to those used with peers, Managing child's psychological well-being, Time considerations (including the need to progress at child's pace) and and Optimize environment (including the provision of a classroom environment that meets child's sensory needs (e.g., quiet environment) and of space where child can be alone if necessary (e.g., within or outside classroom)). Other themes were Occupational Therapy adaptations, Appropriate academic expectations and supports, Consideration of child's communication needs, Higher ratio of adult support, Using structure to support child's learning, Use of Rewards and sanction and Peer modelling

The analysis of staff responses regarding strategies and supports resulted in six main themes which are shown in supplement 6. The six themes were. Having work/tasks adapted when needed, Promoting emotional and behavioural well-being, High level of adult support, Environmental accommodations, Multimodal Learning and Adapting communication

#### 4. Discussion

It is well established that children with epilepsy are a high-risk group with respect to co-occurring cognitive and behavioural difficulties. However, few studies have explored the views of children, their parents and school staff in relation to how epilepsy and associated difficulties impact on learning and behaviour in school. The current study thus fills a gap and provides an insight into the impact of epilepsy on learning and behaviour in the school environment. The majority of children felt that epilepsy affected their learning, mentioning impacts on memory, concentration and processing speed. The majority of parents agreed that epilepsy affects the child's learning/behaviour in school whilst more school staff felt that epilepsy affects learning than behaviour. Regarding aspects of epilepsy that impact on learning and behaviour, parent reports included seizures and ASMs. The majority of school staff however were 'unsure' regarding whether use of ASMs impacted on child's learning and behaviour. In terms of supports received or desired in school, children mentioned access to specific support environments, accommodation in exams, increased adult support and access to a trusted person in the school environment. Parents of children in special schools were significantly more likely to agree that the child's school provided appropriate resources to support child's learning and behaviour and be satisfied with the support child receives in school than parents in mainstream schools. Parents mentioned a wide range of effective strategies and supports including the need to provide structure, optimize the learning environment, a high level of adult support and peer modelling. Staff views on effective strategies/supports for the children with epilepsy included the need to adapt tasks and communication, the need for a high level of adult support and environmental accommodations.

More than half of children with epilepsy agreed that epilepsy affects their learning in line with studies that indicate that epilepsy is line with a high level of difficulties with cognition<sup>19,20,21</sup> and academic achievement<sup>5,6</sup>. More children reported that epilepsy impacted how they felt as opposed to their behaviour. This could be due to the fact that most of the respondents were older and cognitively more able and thus more likely to be able report on emotional problems. Additionally, behavioural concerns may be more easily observed and perceived by staff and parents than children. The majority of parents reported that epilepsy affects their children's learning and behaviour in line with previous studies employing standardised cognitive instruments<sup>22,23</sup> consensus diagnosis<sup>1</sup> and diagnostic interviews<sup>23,24</sup>.

In terms of how epilepsy affects learning, behaviour and emotions, children in interviews mentioned both seizures and the impact of ASMs. In relation to seizures the impact on learning and behaviour included missing school as well as tiredness associated with seizures. Previous research has shown children with epilepsy are at higher risk of school attendance problems<sup>25,26</sup> and side-effects of ASMs can include tiredness<sup>13,14</sup>. Children also mentioned that epilepsy can be associated with stigma particularly the stigma associated with having seizures in school. Stigma is a major concern for children with epilepsy and children with epilepsy often struggle to explain epilepsy to peers and fear the reactions of others<sup>27</sup>. Another potential impact of having epilepsy mentioned by children is the possibility of restrictions being placed on their activities. Children with epilepsy often face activity restrictions based on fear of perceived risk of injury or limited knowledge of the child's individual risk profile<sup>28</sup>. The children with epilepsy alluded to the broad impact of epilepsy on both physical and

emotional wellbeing, including a negative impact on self-confidence, increased tiredness and changes in appetite highlighting the wide ranging impact of the condition on children. Parental views on the impact of epilepsy in their children's learning and behaviour included a wide range of effects including impacts of memory and attention, slower processing and difficulties with word finding in line with previous studies on assessment with children with epilepsy<sup>21,22</sup>. They also felt that epilepsy had a significant impact of emotional-behavioural functioning which has previously been reported in studies employing standardised measures<sup>2,24</sup>. Parents' responses highlighted that both seizures and ASMs could affect learning and behaviour. Most staff were unsure however on the potential impact of ASMs on learning and behaviour despite evidence that ASMs can significantly adversely affect both<sup>13</sup> thus highlighting the need for education in this area.

While a small number of children did not feel they needed support the majority indicated that they did need to highlight the need for screening/assessment which has been recommended to identify difficulties and possible support<sup>29,30</sup>. Children identified the need for access to supportive environments outside the classroom. Children with epilepsy have often symptoms of ADHD including that they are easily distracted<sup>31</sup> emphasising the need to have environments with few distractions. They also would like accommodations such as use of a laptop including for assignments and extra time for examinations. Many children with epilepsy have difficulties with processing speed<sup>20</sup> and fine motor difficulties<sup>32</sup> meaning that without accommodations they will have difficulty showing their knowledge. Children also mentioned that they would like access to a supportive adult in the classroom to check for understanding and clarifying instructions. Young children with epilepsy often have specific cognitive and linguistic difficulties which may require support in the classroom including difficulties with auditory attention and short-term memory<sup>33</sup>.

The majority of parents agreed that their child's school provided the appropriate resources to support their child's learning and agreed that their child's school was flexible enough to meet their needs. However, parents of children in special schools were more likely to agree that the child's school provided appropriate resources to support child's learning and be satisfied with the support child receives in school than parents in mainstream schools. This suggests that there is a significant gap in provision for children with epilepsy attending mainstream school which needs addressing. In terms of supports currently received by their child, parent report indicated that children were provided support both within and outside of the classroom and some children attending special school had access to therapies onsite. In-classroom support focussed on the need for increased adult support, whilst extra support outside the classroom included access to other rooms with groups of children with additional needs, exam accommodation and supports in the playground. Some children were in receipt of support for social-emotional development which included access to groups focussing on the development of social and emotional difficulties. Children with epilepsy have increased of social and emotional difficulties including an increased risk for autism<sup>34</sup> and peer difficulties<sup>35</sup>. The peer difficulties may be related to social anxiety and inattention<sup>35</sup>. There is evidence that difficulties with social anxiety and peer relations can be improved in children with epilepsy via a cognitive behaviour therapy<sup>36</sup>.

In terms of parental views on effective strategies and support for learning and behaviour, they mentioned a wide variety highlighting the wide range of school-based



needs children with epilepsy often have. Many parents highlighted the need for psychological support for their child reflecting the high rates of mental health needs in this group<sup>10,11</sup>. Parents also wanted the child to optimise the time their child spent on tasks as well the need for regular breaks to ensure optimal attention and combat tiredness. There is limited research evidence for any classroom strategies for children with epilepsy, but there is evidence that an intervention focused on improving executive functioning including aspects of attention and working memory can improve performance on parent ratings<sup>37</sup>. Parents felt that occupational therapy adaptations could also help including support with writing and seating. Motor impairments are frequent in children with epilepsy and it has been recommended that assessment of these difficulties is crucial to maximize performance in everyday life<sup>38</sup>.

Many parents felt that it was important the child's schoolwork was pitched at the right level and that the child's interests were used in planning teaching. Children with epilepsy often have both general and specific cognitive difficulties<sup>21</sup> as well as academic underachievement<sup>6</sup> emphasizing need to understanding their abilities in the terms of their own profile as well as in relation to peers. The need to adapt communication mentioned by parents and a high level of adult support is line with what the children also stated. The need for structure and use of reward systems for parents may reflect the high association between epilepsy and symptoms of autism<sup>39</sup>. The use of structure and rewards are often seen as an effective part of educational planning for children with these difficulties<sup>40,41</sup>. Some parents expressed a desire for peer modelling and whilst there is as of yet no evidence for this approach for children with epilepsy there is some evidence that peer learning can lead to both cognitive and emotional gains in the general population<sup>42</sup>. Staff responses regarding effective strategies for children with epilepsy included much of what children and parents had reported but also the need for multimodal learning. Although there is no research with respect to the learning of children with epilepsy, multisensory learning is advocated for children with a range of learning needs and there is evidence that multisensory learning can be beneficial for learning<sup>43,44</sup>.

#### 4.1 Clinical implications and future research directions

The results of the current study suggest that epilepsy is perceived to have a significant impact on learning and behavioural functioning in schools. Therefore, it is very important that children with epilepsy have access to comprehensive screening for learning and behavioural needs. Give the wide range of potential needs and support, it is vital that individual assessments lead to tailored support for each individual child. The need for improved access to this may be particularly high in mainstream schools due to the perceptions that children with epilepsy are not as well supported in this environment as they are in special schools. The lack of knowledge of the impact of ASMs among staff suggest that there is a need for the potential impact to be conveyed to all staff who work with the child in the school environment.

There is currently a lack of evidence regarding how to best support the learning and behavioural needs of children with especially in the school environment. However, there is increasing evidence that the common difficulties with executive functioning<sup>37</sup> and emotional and behavioural problems<sup>45</sup> can be improved with interventions. It is important that future research in paediatric epilepsy focusses on testing approaches that work in children without epilepsy. These approaches may need to be adapted to suit the epilepsy population but are likely to contain the core element of interventions

that work for children without epilepsy<sup>46,47</sup>. Future research also needs to include the views of children with epilepsy with significant impairments and adaptations to the format of survey and interviews will be needed to ensure they can participate. In the current study we asked about the impact of epilepsy on learning and behaviour. However, there is increasing awareness that many of the epilepsies are associated with learning and behavioural comorbidities<sup>48</sup> and respondents may not be able to distinguish between the impact of epilepsy on learning and behaviour as opposed to the impact of the actual comorbidities. Future research can thus also benefit from the inclusion of a control group of children without epilepsy but with commonly occurring comorbidities such as autism spectrum disorder and intellectual disability. This will help determine issues which are specific to children with epilepsy and which are shared with children without epilepsy who have other learning and behavioural issues.

#### 4.2 Limitations

Only half of the children who met our eligibility criteria were assessed in the WINS study and our study participants had an average age of epilepsy onset significantly younger than non-participants suggesting that they had more significant neurodevelopmental difficulties than non-participants. Furthermore, the majority of children with epilepsy were unable to participate in surveys/interviews. We did not have responses from a representative staff member for all participating children and we do not have details on non-participating staff. The study is based in a defined geographical region of the UK, and although the UK has a national healthcare system and England a national education system, findings may not generalise to other parts of the UK or other jurisdictions. We did not have a comparison group of children without epilepsy which would have allowed us to identify what issues are specific to epilepsy. Although we carried out psychological assessments in the current study we did not perform diagnostic assessments for conditions commonly associated with epilepsy such as autism spectrum disorder and ADHD. We were not able to compare responses between matching parents/school staff and children as questions differed or when addressing similar areas had to be adapted to ensure understanding. Future studies should explore whether experiences and views regarding provision in school differ between parents, staff and their children

#### **5. Conclusion**

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

#### **Acknowledgements**

We would like to thank Kirsten McHale, Epilepsy Specialist Nurse for help with participant recruitment. We would also like to thank Dr Katy (Catherine) Grilli, Kent Community NHS Trust who was a research registrar for Young Epilepsy during study period and helped with clinical data extraction.

## **Funding**

The WINS study was funded by Ronald and Barbara Abbott, the George E. Neville Foundation, UCB Pharma (through an educational grant with no editorial involvement), Young Epilepsy, the Sobell Foundation, the Childwick Trust and two anonymous donors. JHC is supported by the National Institute of Health Research (NIHR) Biomedical Research Centre at Great Ormond Street Hospital.

## **References**

- <sup>1</sup>Reilly, C., Atkinson, P., Das, K. B., Chin, R. F., Aylett, S. E., Burch, V., ... & Neville, B. G. (2014). Neurobehavioural comorbidities in children with active epilepsy: a population-based study. *Pediatrics*, *133*(6), e1586-e1593.
- <sup>2</sup>Davies, S., Heyman, I., & Goodman, R. (2003). A population survey of mental health problems in children with epilepsy. *Developmental Medicine & Child Neurology*, *45*(5), 292-295.
- <sup>3</sup>Strasser, L., Downes, M., Kung, J., Cross, J. H., & De Haan, M. (2018). Prevalence and risk factors for autism spectrum disorder in epilepsy: a systematic review and meta-analysis. *Developmental Medicine & Child Neurology*, *60*(1), 19-29.
- <sup>4</sup>Berg, A. T., Caplan, R., & Hesdorffer, D. C. (2011). Psychiatric and neurodevelopmental disorders in childhood-onset epilepsy. *Epilepsy & Behaviour*, *20*(3), 550-555.
- <sup>5</sup>Fastenau, P. S., Shen, J., Dunn, D. W., & Austin, J. K. (2008). Academic underachievement among children with epilepsy: proportion exceeding psychometric criteria for learning disability and associated risk factors. *Journal of learning disabilities*, *41*(3), 195-207.

- <sup>6</sup>Reilly, C., Atkinson, P., Das, K. B., Chin, R. F., Aylett, S. E., Burch, V., ... & Neville, B. G. (2014). Academic achievement in school-aged children with active epilepsy: A population-based study. *Epilepsia*, *55*(12), 1910-1917.
- <sup>7</sup>Baca, C. B., Vickrey, B. G., Caplan, R., Vassar, S. D., & Berg, A. T. (2011). Psychiatric and medical comorbidity and quality of life outcomes in childhood-onset epilepsy. *Pediatrics*, *128*(6), e1532-e1543.
- <sup>8</sup>Reilly, C., Atkinson, P., Das, K. B., Chin, R. F., Aylett, S. E., Burch, V., ... & Neville, B. G. (2015). Factors associated with quality of life in active childhood epilepsy: a population-based study. *European Journal of Paediatric Neurology*, *19*(3), 308-313.
- <sup>9</sup>Ott, D., Siddarth, P., Gurbani, S., Koh, S., Tournay, A., Shields, W. D., & Caplan, R. (2003). Behavioural disorders in pediatric epilepsy: unmet psychiatric need. *Epilepsia*, *44*(4), 591-597.
- <sup>10</sup>Welch, A., Shafran, R., Heyman, I., Coughtrey, A., & Bennett, S. (2018). Usual care for mental health problems in children with epilepsy: a cohort study. *F1000Research*, *7*.
- <sup>11</sup>Berg, A. T., Smith, S. N., Frobish, D., Levy, S. R., Testa, F. M., Beckerman, B., & Shinnar, S. (2005). Special education needs of children with newly diagnosed epilepsy. *Developmental Medicine & Child Neurology*, *47*(11), 749-753.
- <sup>12</sup>Glennon, J. M., Weiss-Croft, L., Harrison, S., Cross, J. H., Boyd, S. G., & Baldeweg, T. (2016). Interictal epileptiform discharges have an independent association with cognitive impairment in children with lesional epilepsy. *Epilepsia*, *57*(9), 1436-1442.
- <sup>13</sup>Guilfoyle, S. M., Follansbee-Junger, K., Smith, A. W., Combs, A., Ollier, S., Hater, B., & Modi, A. C. (2018). Antiepileptic drug behavioural side effects and baseline hyperactivity in children and adolescents with new onset epilepsy. *Epilepsia*, *59*(1), 146-154.
- <sup>14</sup>Filippini M, Boni A, Giannotta M, Gobbi G. Neuropsychological development in children belonging to BECTS spectrum: long-term effect of epileptiform activity. *Epilepsy & Behaviour*. 2013 Sep 1;28(3):504-11.
- <sup>15</sup>Fonseca Wald EL, Hendriksen JG, Drenthen G, van Kuijk SM, Aldenkamp AP, Vles JS. Towards a better understanding of cognitive deficits in absence epilepsy. *Neuropsychology Review*. 2019;29:421-49
- <sup>16</sup>Johnson EC, Atkinson P, Muggerridge A, Cross JH, Reilly C. Epilepsy in schools: Views on educational and therapeutic provision, understanding of epilepsy and seizure management. *Epilepsy & Behaviour*. 2021 Sep 1;122:108179
- <sup>17</sup>Johnson E, Atkinson P, Muggerridge A, Cross JH, Reilly C. Inclusion and participation of children with epilepsy in schools: Views of children, school staff and parents. *Seizure*. 2021 Oct 10.
- <sup>18</sup>Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

- <sup>19</sup>Braun, V., & Clarke, V. (2014). What can “thematic analysis” offer health and wellbeing researchers?. *International journal of qualitative studies on health and well-being*, 9.
- <sup>20</sup>Sherman, E. M., Brooks, B. L., Fay-McClymont, T. B., & MacAllister, W. S. (2012). Detecting epilepsy-related cognitive problems in clinically referred children with epilepsy: Is the WISC-IV a useful tool?. *Epilepsia*, 53(6), 1060-1066.
- <sup>21</sup>Reilly, C., Atkinson, P., Das, K. B., Chin, R. F., Aylett, S. E., Burch, V., ... & Neville, B. G. (2015). Cognition in school-aged children with “active” epilepsy: A population-based study. *Journal of clinical and experimental neuropsychology*, 37(4), 429-438.
- <sup>22</sup>Berg, A. T., Langfitt, J. T., Testa, F. M., Levy, S. R., DiMario, F., Westerveld, M., & Kulas, J. (2008). Global cognitive function in children with epilepsy: a community-based study. *Epilepsia*, 49(4), 608-614.
- <sup>23</sup>Caplan, R., Siddarth, P., Gurbani, S., Hanson, R., Sankar, R., & Shields, W. D. (2005). Depression and anxiety disorders in pediatric epilepsy. *Epilepsia*, 46(5), 720-730.
- <sup>24</sup>Jones, J. E., Watson, R., Sheth, R., Caplan, R., Koehn, M., Seidenberg, M., & Hermann, B. (2007). Psychiatric comorbidity in children with new onset epilepsy. *Developmental Medicine & Child Neurology*, 49(7), 493-497.
- <sup>25</sup>Fleming, M., Fitton, C. A., Steiner, M. F., McLay, J. S., Clark, D., King, A., ... & Pell, J. P. (2019). Educational and health outcomes of children and adolescents receiving antiepileptic medication: Scotland-wide record linkage study of 766 244 schoolchildren. *BMC Public Health*, 19(1), 595.
- <sup>26</sup>Hassen, O., & Beyene, A. (2020). The effect of seizure on school attendance among children with epilepsy: a follow-up study at the pediatrics neurology clinic, Tikur Anbessa specialized hospital, Addis Ababa, Ethiopia. *BMC Pediatrics*, 20(1), 1-7.
- <sup>27</sup>Benson, A., O'Toole, S., Lambert, V., Gallagher, P., Shahwan, A., & Austin, J. K. (2015). To tell or not to tell: a systematic review of the disclosure practices of children living with epilepsy and their parents. *Epilepsy & Behaviour*, 51, 73-95.
- <sup>28</sup>Brna, P. M., Gordon, K. E., Woolridge, E., Dooley, J. M., & Wood, E. (2017). Perceived need for restrictions on activity for children with epilepsy. *Epilepsy & Behaviour*, 73, 236-239.
- <sup>29</sup>Wilson, S. J., Baxendale, S., Barr, W., Hamed, S., Langfitt, J., Samson, S., ... & Smith, M. L. (2015). Indications and expectations for neuropsychological assessment in routine epilepsy care: report of the ILAE Neuropsychology Task Force, Diagnostic Methods Commission, 2013–2017. *Epilepsia*, 56(5), 674-681.
- <sup>30</sup>Reilly, C. (2015). Indications and expectations for neuropsychological assessment in routine epilepsy care: Report of the ILAE Neuropsychology Task Force, Diagnostic Methods Commission, 2013-2017. *Epilepsia*, 56(8), 1315-1315.
- <sup>31</sup>Sánchez-Carpintero, R., & Neville, B. G. (2003). Attentional ability in children with epilepsy. *Epilepsia*, 44(10), 1340-1349.
- <sup>32</sup>Beckung, E., & Urebrant, P. (1997). Hidden dysfunction in childhood epilepsy. *Developmental Medicine & Child Neurology*, 39(2), 72-78.

- <sup>33</sup>Selassie, G. R. H., Viggedal, G., Olsson, I., & Jennische, M. (2008). Speech, language, and cognition in preschool children with epilepsy. *Developmental medicine & child neurology*, *50*(6), 432-438.
- <sup>34</sup>Clarke, D. F., Roberts, W., Daraksan, M., Dupuis, A., McCabe, J., Wood, H., ... & Weiss, S. K. (2005). The prevalence of autistic spectrum disorder in children surveyed in a tertiary care epilepsy clinic. *Epilepsia*, *46*(12), 1970-1977.
- <sup>35</sup>Drewel, E. H., Bell, D. J., & Austin, J. K. (2009). Peer difficulties in children with epilepsy: association with seizure, neuropsychological, academic, and behavioural variables. *Child Neuropsychology*, *15*(4), 305-320.
- <sup>36</sup>Jones, J. E., Blocher, J. B., Jackson, D. C., Sung, C., & Fujikawa, M. (2014). Social anxiety and self-concept in children with epilepsy: A pilot intervention study. *Seizure*, *23*(9), 780-785.
- <sup>37</sup>Modi, A. C., Mara, C. A., Schmidt, M., Smith, A. W., Turnier, L., Glaser, N., & Wade, S. L. (2019). Epilepsy Journey: A proof of concept trial of a Web-based executive functioning intervention for adolescents with epilepsy. *Epilepsia*, *60*(9), 1895-1907.
- <sup>38</sup>Beckung, E., & Uvebrant, P. (1993). Motor and sensory impairments in children with intractable epilepsy. *Epilepsia*, *34*(5), 924-929.
- <sup>39</sup>Reilly, C., Atkinson, P., Das, K. B., Chin, R. F., Aylett, S. E., Burch, V., ... & Neville, B. G. (2015). Features of autism spectrum disorder (ASD) in childhood epilepsy: a population-based study. *Epilepsy & Behaviour*, *42*, 86-92.
- <sup>40</sup>Watkins, L., Ledbetter-Cho, K., O'Reilly, M., Barnard-Brak, L., & Garcia-Grau, P. (2019). Interventions for students with autism in inclusive settings: A best-evidence synthesis and meta-analysis. *Psychological bulletin*, *145*(5), 490.
- <sup>41</sup>Harrison, J. R., Soares, D. A., Rudzinski, S., & Johnson, R. (2019). Attention deficit hyperactivity disorders and classroom-based interventions: Evidence-based status, effectiveness, and moderators of effects in single-case design research. *Review of Educational Research*, *89*(4), 569-611.
- <sup>42</sup>Rohrbeck, C. A., Ginsburg-Block, M. D., Fantuzzo, J. W., & Miller, T. R. (2003). Peer-assisted learning interventions with elementary school students: A meta-analytic review. *Journal of educational Psychology*, *95*(2), 240.
- <sup>43</sup>Carter, M., & Stephenson, J. (2012). The use of multi-sensory environments in schools servicing children with severe disabilities. *Journal of Developmental and Physical Disabilities*, *24*(1), 95–109.
- <sup>44</sup>Broadbent, H.J., White, H., Mareschal, D., & Kirkham, N.Z. (2017). Incidental learning in a multisensory environment across childhood. *Developmental Science*, *21*(2), e12554
- <sup>45</sup>Bennett, S. D., Au, C., Byford, S., Chorpita, B., Coughtrey, A. E., Cross, J. H., ... & Shafran, R. (2021). Feasibility of telephone-delivered therapy for common mental health difficulties embedded in pediatric epilepsy clinics. *Epilepsy & Behaviour*, *116*, 107743.
- <sup>46</sup>Bennett, S. D., Cross, J. H., Coughtrey, A. E., Heyman, I., Ford, T., Chorpita, B., ... & Shafran, R. (2021). MICE—Mental Health Intervention for Children with Epilepsy: a

randomised controlled, multi-centre clinical trial evaluating the clinical and cost-effectiveness of MATCH-ADTC in addition to usual care compared to usual care alone for children and children with common mental health disorders and epilepsy—study protocol. *Trials*, 22(1), 1-16.”

<sup>47</sup>Shafran, R., Bennett, S., Coughtrey, A., Welch, A., Walji, F., Cross, J. H., ... & Moss-Morris, R. (2020). Optimising evidence-based psychological treatment for the mental health needs of children with epilepsy: principles and methods. *Clinical child and family psychology review*, 1-12.

<sup>48</sup>Scheffer, I. E., Berkovic, S., Capovilla, G., Connolly, M. B., French, J., Guilhoto, L., ... & Zuberi, S. M. (2017). ILAE classification of the epilepsies: position paper of the ILAE Commission for Classification and Terminology. *Epilepsia*, 58(4), 512-521.