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Inclusion and participation of children with epilepsy in schools: Views of young people, school staff and parents

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ABSTRACT

Objective: To gain an understanding of the views of children with epilepsy, their parents and staff regarding inclusion and participation of children with epilepsy in school.

Methods: During the study period, 136 children with ‘active’ epilepsy (taking anti-seizure Medications (ASMs) for epilepsy), were identified in the study area and of these 68 (50% of those eligible) families agreed to participate. Children ($n = 20$) with ‘active epilepsy’ their parents ($n = 68$) and staff ($n = 56$) were interviewed or completed surveys. The quantitative data were analysed using descriptive statistics and chi-square analyses. The answers to open questions were analysed using thematic analyses.

Results: Staff in mainstream schools were more concerned about the child’s attendance than staff in special schools ($p = 0.008$). Parents and school staff cited a number of negative aspects of the child’s attendance difficulties including social–emotional and academic aspects. The majority of parents and staff felt that young people with epilepsy were included in school to the same extent as peers. Parents were however, significantly less likely than staff to agree that children were included in all playground activities ($p = 0.045$). Parents of children in special schools were more likely to agree that their child was included in school than parents of children attending mainstream schools ($p = 0.041$). Thematic analysis revealed that parents felt that their child could be excluded in school due to staff decisions, child’s own choice and peer led exclusion. The majority of children (64%) and parents (56%) agreed that the child with epilepsy was restricted from doing things their peers could do because of their epilepsy. While more than half of children with epilepsy (63%) reported that they had been bullied, most did not attribute this bullying to having epilepsy. Parents were more likely to agree that their child was bullied because of their epilepsy ($p = 0.035$) and non-epilepsy reasons than staff ($p < 0.001$). Parents of children with epilepsy attending mainstream schools were more likely to agree that their child was bullied because of their epilepsy ($p = 0.017$) and non-epilepsy reasons ($p = 0.026$), compared to parents of children with epilepsy attending special schools.

Conclusions: School attendance difficulties for children with epilepsy can contribute to academic and social-emotional difficulties. Most parents and teachers feel that children with epilepsy are included in classroom activities to the same extent as peers. Children with epilepsy and their parents believe that they are more restricted in non-classroom activities compared with their peers. Difficulties with participation, friendships and bullying for children with epilepsy may be due to presence of other conditions as opposed to epilepsy per se. There is a need to increase understanding of the wide ranging impact of epilepsy on school life in order to enhance attendance and inclusion and to reduce bullying.

1. Introduction

Population-based studies of long-term outcome in childhood

epilepsy indicate that the condition is associated with significant adverse outcomes in a range of domains including education and employment [1,2]. Children with epilepsy frequently have cognitive,

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behavioural, motor, sleep and academic difficulties [3–5]. These additional difficulties often have a greater impact on quality of life than the seizures [6,7]. The additional behavioural and mental health difficulties are often not identified possibly due to the focus on treating the seizures [8,2]. Learning and behavioural difficulties and seizures are all likely to impact on the affected young person's ability to participate in society unless appropriate support is provided from an early age.

Childhood epilepsy can have very significant negative implications for schooling. A systematic review of teacher knowledge and attitudes revealed deficits in knowledge and negative attitudes were pervasive across all studies [9]. School staff often have a negative attitude towards the participation of children with epilepsy in physical activities/sport, and teachers often feel ill-equipped to deal with management of seizures and administration of emergency medication, highlighting the risk that students with epilepsy could be excluded [9] from learning and social opportunities. The studies which have compared epilepsy to other chronic medical conditions indicate that not only have school staff limited knowledge of epilepsy but have more negative attitudes towards it [10].

In addition to the learning and behaviour issues and negative attitudes toward epilepsy among school staff, children with epilepsy are more likely to be bullied than healthy children and children with another chronic condition [11]. School attendance difficulties have also been noted in children with epilepsy [12] and are significantly associated with difficulties with academic achievement independent of global cognition [13]. In addition children with epilepsy are likely to face negative attitudes and stigma from peers. A study of adolescents in the general population suggested that the social environment for adolescents with epilepsy is characterized by stigma and lack of familiarity and knowledge about epilepsy [14]. Young people with epilepsy may be reluctant to reveal that they have epilepsy and report feeling shame and embarrassment [15].

Given the potential impact of epilepsy on affected children's inclusion and participation in schools it is important to understand the views of young people with epilepsy, parents, and school staff regarding aspects of inclusion and participation. There has been very little previous research on these aspects on the lives of young people with epilepsy. 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 staff views on educational and therapeutic provision, understanding of epilepsy and seizure management [16]. The overall aim of the current study was to describe the views of children with epilepsy, their parents and school staff regarding aspects of inclusion and participation. The responses of parents and school staff were compared and a further comparison was made between special and mainstream schools.

2. Method

2.1. Identification and recruitment of eligible children

The recruitment process for the WINS study has been described previously [16]. In summary, children were eligible for inclusion if born between 2003 and 2014, had 'active' epilepsy (on 1 or more anti-seizure medications (ASMs) for epilepsy) and who were resident in the RH10 to RH13 postal districts of the county of West Sussex in the south of the United Kingdom between April 1st 2018 and December 31st, 2019. Children, their parents and teachers participated between 11th September 2018 and 17th March 2020. 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%.

Eligible children with 'active epilepsy' were identified at the two paediatric hospitals in the study area and recruited between 21st December 2017 and 31st December 2019. Eligible children were identified and verified by community paediatricians with a special interest in

epilepsy and a registrar working at a specialist center for children with epilepsy. Parents who expressed an interest in their child's participation were contacted by telephone, and arrangements made to meet 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. Participating children, where developmentally appropriate, also gave assent. Anonymised information was obtained on non-participants with 'active epilepsy' ($n = 68$), including data on sex, ASM usage, deprivation, ethnicity, age at median point in study, age of diagnosis/first seizure.

2.2. 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.

2.3. Measures

The development of measures for this study through focus groups has been described previously [16]. In summary, child-, parent- and school staff-report questionnaires and child and parent interview schedules were developed in partnership with young people with epilepsy, their parents and school staff. Possible topics for inclusion in the surveys/interviews were piloted at focus groups and through interviews. Focus groups and interviews were conducted between May and July 2018. As a result of the piloting, the final interview/questionnaire schedules were developed (see supplement 1). Question types in the questionnaires included 'yes/no' responses and four-point Likert type responses ranging from 'strongly agree' to 'strongly disagree'. In addition, children, parents and school staff were encouraged to expand on their answers and these more open response are analysed via thematic analysis [17]. In addition to the interview/questionnaire measures, all children underwent psychological assessment which included assessment of cognition/development and behavior.

2.4. Analysis

Data obtained through child, parent and school staff questionnaire measures were analysed in terms of frequencies and averages and 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 presence of intellectual disability vs. non-intellectual disability and to compare parent and staff responses where both were asked the same question. The alpha level for all analyses was $p < 0.05$. All statistical analyses were performed with IBM SPSS version 25.0 (Armonk, NY, USA).

Responses to open questions were analysed via Thematic Analysis [17] by two research psychologists (EJ and CR). The approach to Thematic Analysis adopted in the current research is 'inductive' as opposed to 'theoretical' as the data were analyzed without trying to fit it into a pre-existing coding frame or the researchers' analytic preconceptions [17]. Additionally, themes and subthemes were identified at a semantic or explicit level and not at a latent or interpretative level. With a semantic approach, themes are identified within the explicit or surface meanings of the data and not beyond what a participant has said [17].

3. Results

3.1. Characteristics of the sample

During the study period, 136 children with 'active' epilepsy were identified in the study area (see Fig. 1) and of these 68 (50%) families agreed to participate. There were no significant differences between the

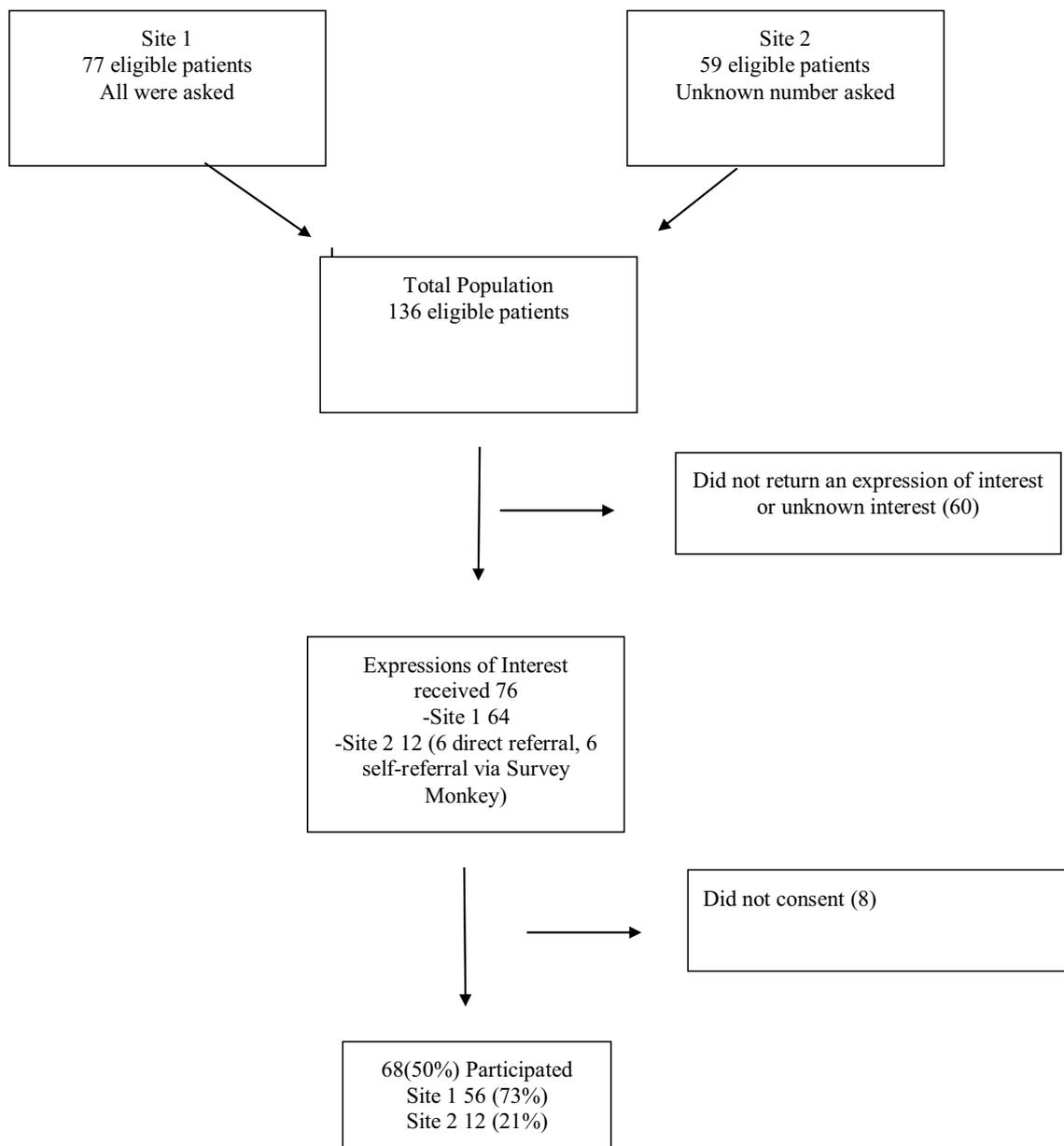


Fig. 1. Recruitment in WINS study.

participants ($n = 68$) and non-participants ($n = 68$) with respect to gender ($p = 0.441$), current number of ASMs ($p = 0.074$) or deprivation ($p = 0.872$). However, participants had a significantly younger age of epilepsy onset (mean=3.81years) than non-participants (mean=7.46) ($p = 0.015$).

The characteristics of the 68 participating children are in table 1. Sixty-eight parents participated in the study - 61 (90%) were mothers and 7 (10%) were fathers. Fifty-six school staff participated in the study. Of the 68 children, 20 (29%) were able to be interviewed or complete questionnaires. Of the 48 children who did not respond the reasons are given in supplement 2.

3.2. School attendance (see supplement 3)

Twenty-seven parents (41%) reported that their child was currently or had previously experienced difficulties attending school. Twenty-one parents (78%) stated that seizures were the cause of the attendance difficulties, 16 (59%) attributed the difficulties to having to attend hospital appointments and five (9%) reported other causes.

Of those parents who reported attendance difficulties, five (19%) reported their child's school were concerned about this, and 12 parents (44%) felt their child's school could have done more in prevention. Fifteen parents (56%) reported that attendance difficulties had affected their child's progress at school.

School staff of seven participating children (13%) reported that the child had difficulties with attending school. Hospital appointments were cited as the cause by five staff (71%), with seizures reported by a further three (43%). Only one staff member (14%) felt more could have been done to address these difficulties with attendance, and suggested more frequent phone calls to the child's family home would be beneficial. Two staff respondents (29%) reported that attendance difficulties impacted on a child's progress at school.

Staff in mainstream schools were more concerned about the child's attendance than staff in special schools ($p = 0.008$) but there were no other differences between mainstream and special school settings. There were no significant differences based on child's intellectual disability status.

Table 1
Characteristics of children (n = 68) in WINS study.

Child Characteristics	n (%)
Gender - male/female	39/29 (57/43)
Ethnicity - White British/Non-White British	49/19 (72/28)
Age at time of assessment in years – Median (Q25/Q75)	10.46 (3.17, 7.85–12.77)
Educational provision - mainstream/special	36/32 (53/47)
School type - primary/secondary	40/28 (59/41)
Duration of epilepsy in years at time of assessment – Median (Q25/Q75)	6.00 (3.75,9.42) ^a
Age at seizure onset – Median (Q25/Q75)	2.50 (0.96, 6.00) ^a
Age at seizure onset – Under 2years/2years or older	22/42 (34/66) ^a
Seizure Frequency - Monthly or more frequently/less than monthly	34/32 (52/49) ^b
No. of seizure types - One type/two types/three+ types	22/29/13 (34/45/20) ^a
Child had Electroencephalogram (EEG)	67 (100) ^c
Child had Magnetic Resonance Imaging (MRI)	40 (85) ^d
Vineland Adaptive Behavior Composite (ABC) – Median (Q25/Q75)	78.00 (60.00, 90.50) ^e
Developmental level (IQ/DQ/ABC) – Median (Q25/Q75)	60.00 (44.00, 82.00) ^c
Developmental level (IQ/DQ/ABC) – ≤85	54 (81) ^c
Developmental level (IQ/DQ/ABC) – ≤70	40 (60) ^c
Wide Range Achievement Test – any domain score ≤85	33 (73) ^f
Seizure type	
-Generalised	31 (46)
-Focal	35 (52)
-Unknown	2 (3)
Epilepsy type	
-Focal	34 (50)
-Generalised	26 (38)
-Combined generalised and focal	7 (10)
-Not enough data to classify	1(2)
Etiology	
-Structural,	23 (34)
-Genetic,	30 (44)
-Infectious,	1 (2)
-Metabolic,	0 (0)
-Immune	1 (2)
-Unknown	10 (15)
-Not enough data to classify	3 (4)
ASM burden – mono/polytherapy	44/23 (66/43) ^c
ASM burden – Mean (SD, range)	1.46 (0.7, 1–3) ^c
Required rescue therapy	34 (52) ^b

^an=64, ^bn=66, ^cn=67, ^dn=47, ^en=65, ^fn=45, IQ=Intelligence Quotient, DQ Developmental Quotient, ASM= Anti-Seizure Medication, SD= Standard Deviation, Q25/Q75 = Quartile 25/Quartile 75.

3.2.1. Parental views on attendance difficulties (see Table 2)

The analysis of parental responses to questions on attendance are in Table 2. Five major themes with associated subthemes were identified with respect to parental views on their child’s attendance difficulties.

Attendance difficulties impact on child academically

Parents felt that their children often had difficulty catching up after a period of non-attendance, and they also felt that the necessary resources were not available to ensure that they could catch up.

Social-emotional aspects affected by attendance difficulties

Parents felt that attendance difficulties affected their child’s confidence in a negative way and also contributed to a lack of ‘belonging’ in the class group.

Attendance difficulties not directly due to seizures

Parents mentioned a number of possible contributors to their child’s attendance difficulties which were not directly related to seizures. These included side-effects of anti-seizure medications, the presence of another health condition, their child’s tiredness/fatigue and their child’s emotional-behavioral difficulties.

School’s inability to support child’s epilepsy leading to lower attendance

Some parents felt that staff at their child’s school displayed a lack of understanding with respect to aspects of their child’s epilepsy (e.g., need for recovery time) and that more flexibility was needed to ensure better attendance. Some parents also were reluctant to send their child to

Table 2
Parental and teacher perception of attendance difficulties – Thematic Analysis.

Parental Responses Themes	Subthemes	Quotes
• Attendance difficulties impact on child academically	• Child finds it difficult to catch up after absence from school • No additional resources available to help child with missed learning	• “My child fell behind, had to work hard to catch up” • “No additional support is offered after absence to help her catch up”
• Social-emotional aspects affected by attendance difficulties	• Feeling a lack of belonging with class group • Lower self-confidence	• “She does not feel part of the class” • “Child has a lack of confidence, feeling different”
• Attendance difficulties not directly due to seizures	• Side effects of anti-seizure medications • Other illness/ health condition • Tiredness/fatigue • Emotional, behavioural and mental health difficulties	• “Emotional/anxious about having seizures” • “Affects mental health negatively and leads to exhaustion”
• School’s inability to support child’s epilepsy leading to lower attendance	• Better understanding of epilepsy (e.g. recovery time) among staff and more flexibility needed • Parental worry about school’s ability to manage seizures due to lack of communication	• “School were uncertain about his needs/did not have support in place”
• Lack of integration of medical and educational care	• Therapy provided on site • Do not count medical appointments as attendance difficulties	• “School should not count unavoidable medical absences as attendance problems”
Staff Responses Themes	Subthemes	Quotes
• Non-epilepsy reasons for attendance difficulties	• General tiredness/fatigue • Child has other physical illness or mental health condition	• “Attendance problems be due to social, emotional and mental health difficulties”
• Low attendance impacts child’s school experience	• Missing lessons and learning activities leading to falling behind academically • Causes anxiety and lower self-esteem • Impacts on friendships	• “Child can be anxious on return to school due to not being sure about what she’s missed” • “Child can have difficulty forming friendships” • “Child’s absence from lessons, affects homework, understanding... lots of catching up on missed work/learning”
• Epilepsy related attendance difficulties	• Needs time to recover from side effects of ASMs • Fatigue due to seizures	• “Child needs recovery time from medication (Clobazam after seizure)” • “Fatigue from seizures and medication”

school, as they were unsure if their child’s school could manage the child’s seizures due to poor communication with school personnel.

Lack of integration of medical and educational care

Parents felt that the provision of therapies on-site would improve attendance. Some also felt that absence due to medical reasons should not be included as an ‘attendance problem’.

3.3.2. Staff views on attendance difficulties (see Table 2)

Three major themes with associated subthemes were identified with respect to staff views on the child’s attendance difficulties.

Non-epilepsy reasons for attendance difficulties

Staff respondents mentioned the child’s general tiredness/fatigue could impact on their attendance. They also indicated that the children often had other physical illness or mental health conditions which could

lead to lower attendance.

Low attendance impacts child's school experience

Staff felt that the child's attendance difficulties could lead to them missing lessons and thus falling behind academically, but also lead to increased anxiety and lowered self-esteem and also impact negatively on friendships.

Epilepsy-related attendance difficulties

School staff felt that some attendance difficulties were due to epilepsy related issues and the child needing time to recover from side effects of ASMs and fatigue as a result of the child having seizures.

3.3. Inclusion and participation in school (see supplement 4)

Sixty parents (90%) agreed that their child was included in all classroom activities, 55 parents (82%) in all playground activities and 62 parents (97%) in all school trips. Fifty-seven parents (88%) reported feeling satisfied that their child was included to the same extent as peers without epilepsy. Thirty-four parents (53%) agreed that their child was monitored or supervised more than peers.

Fifty-three staff respondents (93%) agreed the child with epilepsy was included in all classroom activities, 53 (98%) in all playground activities, 52 (93%) in all sport/physical education (PE) activities, and 55 (98%) in all school trips. Forty-five staff (80%) agreed that participating children with epilepsy (CWE) were monitored or supervised more than their peers.

Parents were significantly less likely than staff to agree that children were included in all playground activities ($p = 0.045$) and that their child was supervised/monitored than peers ($p = 0.002$). There were no other significant differences between parents and staff.

There were no significant differences between mainstream and special school except in regard to parental satisfaction that the child was included to the same extent as peers. Parents of children in mainstream schools were more likely to disagree with this than parents in special schools ($p = 0.041$). No differences were found with respect to presence/absence of intellectual disability.

3.3.1. Parental views on inclusion and participation

Seven major themes with associated subthemes were identified with respect to parental views on the child's inclusion and participation in school (see Table 3)

Child is included in everything other children are included in

Some parents were happy with current inclusion and felt that their child was included in all activities to the same degree as other children. Other parents described how their child had been excluded in a mainstream environment but now in are included in a special school environment. A small number of parents felt that the child was included in everything but should not be, due to concerns that child's epilepsy meant that they should not participate in certain activities.

Child-led exclusion

In some cases parents felt that their child close to exclude themselves due to sensory issues or lack of confidence. In other cases parents felt that the child did not engage in some activities due to lack of interest.

School-personnel initiated exclusion

Parents felt that some children were being excluded at school due to the child's behavioural and/or learning problems. In some cases children were being excluded as staff lacked the ability to include them safely as they did not feel they had received appropriate training in seizure management. In other cases, staff excluded children as they perceived the child was too tired to participate to successfully participate.

Excluded by peers

Some children were perceived by their parents to be excluded by peers. Parents felt that their child was a victim of bullying or that they felt that peers didn't like to play with them.

Restrictions/adjustments for Physical Education (PE) and sports

Some parents reported that their child was not allowed to participate

Table 3

Parental and staff views on child's inclusion and participation.

Parental responses Theme	Subthemes	Quotes
• Child is included in everything other children are included in	<ul style="list-style-type: none"> • Parents are happy with current inclusion • Included in everything but parents are concerned this may be due to lack of understanding • Included now in a special school environment but was previously excluded in mainstream environment 	<ul style="list-style-type: none"> • <i>They include him in everything, I've never seen him excluded from something because of his epilepsy. But that almost could be a negative because I feel that's because they don't understand his epilepsy and they don't think about his epilepsy</i> • <i>I don't think the school restrict her in any way, shape or form... they'd find a way for her to join in some way</i>
• Child-led exclusion	<ul style="list-style-type: none"> • Child uncomfortable in groups due to sensory and/or social difficulties • Child feels 'different' to peers or lacks confidence to participate • Child chooses not to do certain activities due to lack of interest 	<ul style="list-style-type: none"> • <i>He wouldn't involve himself, he wouldn't wanna be part of anything. If he could just curl up in the corner of a room and go invisible he would....</i> • <i>Because he's not comfortable to be put in a situation he doesn't want to be in</i> • <i>Sometimes she's withdrawn, other times she'll be loud and wanting to join in and take control but mostly she's just really quiet, doesn't wanna take part in things</i>
• School personnel initiated exclusion	<ul style="list-style-type: none"> • Separated from peers due to behavioural outbursts and learning difficulties • Restrictions for lunch/break times and extra-curricular activities due to lack of staff training in relation to epilepsy • Staff perceive that child is too tired to participate 	<ul style="list-style-type: none"> • <i>I don't think he chooses to sit out, I think he is sat out</i> • <i>He wasn't allowed to go to the school disco because the teachers all left and there was no one with training [for emergency medication] at one point they were going to stop him doing sports day cos they hadn't done a risk assessment</i>
• Excluded by peers	<ul style="list-style-type: none"> • Victim of bullying • Child feels like peers don't want to play with them 	<ul style="list-style-type: none"> • <i>She'll say 'I don't wanna... they don't want me to play'</i> • <i>when he goes to his friends they walk away and laugh at him</i>
• Restrictions/adjustments for Physical Education (PE) and sports	<ul style="list-style-type: none"> • Not allowed to participate in certain PE activities e.g. climbing, gymnastics (as per agreed healthcare plan) due to risk of seizures • Increased monitoring and support during certain activities e.g. swimming due to risk of seizures • Physical activities adapted to child's physical abilities and/or behavioral difficulties • Parents unsure of why child isn't included in PE 	<ul style="list-style-type: none"> • <i>If the children are on high apparatus [the child with epilepsy] is only supposed to go like knee high for obvious reasons... I'd like to think that his teacher does sort of stick with that cos that is in his plan</i> • <i>PE, he does as much as he can, there are certain things he can't do but they will distract him and give him something else to do</i> • <i>They've just got extra staff constantly watching her, there's someone in the water with her the whole time</i>
• Restrictions/adjustments for school trips	<ul style="list-style-type: none"> • Parent invited to accompany child (which can discourage independence and single a 	<ul style="list-style-type: none"> • <i>Going out they need to have two-to-one for [child] so that has stopped them being able to take him</i>

(continued on next page)

Table 3 (continued)

Parental responses Theme	Subthemes	Quotes
	child out) <ul style="list-style-type: none"> • Closer monitoring from teachers due to seizure risk • Restricted because school can't provide ratio of adult support required for child to go off-site • Need for individual risk assessment and consultation with parents regarding seizure management before trip 	<i>anywhere... he's not been able to get the support that he [needs so that he] can go on to the bus or when he's off of the bus, so he either gets left behind or has to stay on the bus with a member of staff which I don't think is really fair</i> <ul style="list-style-type: none"> • School trips they would always want to be one-to-one and they would ask me to attend • I don't think it's fair that I should have had to have been there, because he can't enjoy it as much with his mum there
• Strategies used to enhance participation	<ul style="list-style-type: none"> • Preparation and managing expectations ahead of activity • Utilising child's strengths • Environmental management e.g. calm, not over-stimulating, providing distractions/sensory toys • Limiting time child expected to participate 	<ul style="list-style-type: none"> • The good thing about school is it provides her with structure and she knows what they're going to be doing each day of the week... so she can prepare herself... so because she knows what to expect she'll get stuck in and she'll do it • ...not to talk to him as much going out on trips because we're just asking him loads of questions and interacting with him too much, sometimes it's too much when he has anxiety • If they ask her first or they show her what's happening, let her get used to the idea then she might feel comfortable knowing something bad is not going to happen to her
Staff Responses Theme	Subtheme	Quotes
• Included/participates in everything*		<ul style="list-style-type: none"> • The child goes on all trips, given same opportunities as peers
• Included/participates with adaptations/supervision	<ul style="list-style-type: none"> • Included/participated with one-to one adult support • Partial (often time limited) participation/inclusion 	<ul style="list-style-type: none"> • All trips/visits/activities adapted so he can take part • Supervised more in some activities as assessed on risk assessments
• Participation/Inclusion limited due to epilepsy/medical condition	<ul style="list-style-type: none"> • Missed time due to epileptic seizures leading to more limited friendship development • Other medical conditions limit ability to participate 	<ul style="list-style-type: none"> • Misses some play time in summer due to seizures
• Participation limited /Exclusion due to social or behavioural difficulties		<ul style="list-style-type: none"> • Behaviour requires close supervision and modification of activities • Often chooses not to participate

*Most prevalent in special schools.

in certain Physical Education (PE) activities or that these activities were adapted to child's physical abilities i.e. participated for a short period of time. Parents also reported that their child could only participate with increased support and supervision for certain activities' such as swimming.

Restrictions/adjustments for school trips

Regarding school trips parents were often asked to accompany the child and some parents felt that this discouraged the child's

Table 4

Restrictions and limitations for children with epilepsy in WINS study.

Respondent	Item	n (%)	Comparison between mainstream and special schools p	Comparison between ID and non-ID p
Child (N = 20)	Are there things you cannot do (that your friends can do) because of your epilepsy? (Y/N) ^a	12/7 (63/37)	N/A	N/A
Parent (N = 68)	Child's social activities outside of school are limited more than peers because of their epilepsy (agree/disagree) ^b	37/28 (56/44)	0.037	0.281
	Child's social activities outside of school are limited more than peers because of reasons other than epilepsy (agree/disagree) ^b	42/24 (64/36)	0.012	0.256

^an=19, ^bn=66, N/A= because numbers in mainstream schools are too small.

independence. Parents felt that teachers monitored the child closer than peers on trips. In some cases the child could not go on trips as the ratio of adult support would not be sufficient to ensure the child's safety. Parents highlighted the need for school staff to engage with them regarding seizure management before planning trips.

Strategies used to enhance participation

Parents mentioned a number of strategies used in school to enhance their child's inclusion. These included managing expectations ahead of activity, utilising the child's strengths and managing the environment. Additionally parents felt that their child could participate in some activities but only for a limited amount of time.

3.3.2. Staff views on inclusion of children with epilepsy (see Table 3)

Included/participates in everything

Some teachers felt that the child was included in all activities and included to the same degree as peers without epilepsy.

Included/participates with adaptations/supervision

Some children were included only with adaptations to activities (e.g., participation of child with epilepsy was time limited) or with adult support.

Participation/Inclusion limited due to epilepsy/medical condition

According to some teachers, children with epilepsy often had attendance difficulties leading to limited opportunities for friendship development and thus reduced inclusion. Some teachers also felt that having other medical conditions may also limit their ability to participate.

Participation limited/Exclusion due to social or behavioural difficulties

For some children with epilepsy, participation in activities is limited due to their difficulties with behavior or social skills (e.g., children with autism or autistic features).

3.4. Restrictions and limitations –see Table 4

Twelve children with epilepsy (63%) reported that they were restricted from doing things compared to their peers because of their epilepsy. Thirty-seven parents (56%) agreed that their child's social

activities outside of school were limited because of epilepsy whilst 42 parents (64%) agreed that their child’s social activities outside of school were limited for reasons other than epilepsy. Parents of children in special schools were more likely to agree than their child’s social activities were limited more than their peers because of their epilepsy ($p = 0.037$) or for other reasons ($p = 0.012$). No difference was found for children with intellectual disability and children without intellectual disability.

3.4.1. Thematic analysis - child views on restrictions –Table 5

Five major themes with associated subthemes were identified with respect to child views on restrictions and limitations (see table 5)

Child able to do the same activities as peers

Some children with epilepsy did not feel that they face any restrictions and were able to do the same activities as peers.

Sleepovers with friends require consideration/adjustment

Some children reported that they can become over tired and need to go to sleep earlier than peers which can affect participation in sleepovers. Additionally some young people reported that it was often not possible to participate unless their friends’ parents were familiar with administration of their medication.

Limitations regarding physical activities/sport

Young people reported that there was a perception that they should not over exert themselves physically and this could limit their participation in physical education classes. They also reported that they were unable to participate in activities at height (e.g., jumping on a trampoline).

Child unable to be alone/unaccompanied

Young people with epilepsy mentioned that it was difficult for them to do activities alone as they always had to be accompanied.

Concerns regarding photosensitivity

Some young people with epilepsy reported that they were prohibited from watching certain films/television programmes in school regardless of whether the or not they had photosensitive epilepsy.

Excluded from some out-of-school activities as organisations unable to accommodate child with epilepsy

Table 5
Restrictions and limitations due to epilepsy according to young people with epilepsy in WINS study.

Themes	Subthemes
<ul style="list-style-type: none"> • Child able to do the same activities as peers • Sleepovers with friends require consideration/adjustment 	<ul style="list-style-type: none"> • Child cannot become over-tired, may need to go to sleep earlier than peers • Friend’s parents must be familiar with administration of child’s medication
<ul style="list-style-type: none"> • Limitations regarding physical activities/sport 	<ul style="list-style-type: none"> • Perception that child cannot over-exert themselves, needs breaks during physical activities • Child cannot participate in activities at height (e.g. jumping on a trampoline)
<ul style="list-style-type: none"> • Child unable to be alone/unaccompanied 	<ul style="list-style-type: none"> • <i>If I’m tired it affects my epilepsy... I have to go to bed like before [the others]... like not a certain time but I can’t stay up all night</i>
<ul style="list-style-type: none"> • Concerns regarding photosensitivity 	<ul style="list-style-type: none"> • <i>I would have to sit at the side a second and stuff like that</i>
<ul style="list-style-type: none"> • Excluded from some out-of-school activities as organisations unable to accommodate child with epilepsy 	<ul style="list-style-type: none"> • <i>Just doing stuff by myself when there’s no one with me</i> • <i>Companies really don’t want to have to deal with a person with epilepsy... it just means a pile of extra paperwork</i>

Young people reported than they were excluded from certain out of school activities as some companies/organizations did not want to ‘deal with’ an individual with epilepsy

3.5. Friendships and bullying (see table 6 (Friendship) and supplement 5 (Bullying))

Two children (12%) reported that their epilepsy affected their friendships in school. Twelve children (60%) reported knowing someone else with epilepsy, and in seven instances (42%) the person known with epilepsy attended the same school as the child.

Twenty parents (30%) agreed that their child had more difficulties making friends compared to peers because of their epilepsy whereas forty parents (61%) agreed this was the case for reasons other than epilepsy. Eleven staff (20%) agreed that children with epilepsy had more difficulties making friends compared to peers because of their epilepsy whereas twenty four staff (43%) agreed that this was the case because of reasons other than epilepsy.

There were no significant differences between parents and teachers. There was also no significant differences between mainstream and special schools or between children with or without intellectual disability regarding views on friendships.

Twelve children (63%) reported having been bullied at school, with two (18%) attributing the bullying to their epilepsy (see supplement 5). Six parents (9%) agreed that their child had been bullied because of their epilepsy whilst 25 parents (38%) agreed that their child had been bullied for reasons other than their epilepsy. No staff (0%) agreed that the child with epilepsy had been bullied because of their epilepsy. One staff member (2%) agreed that a child with epilepsy had been bullied for reasons other than epilepsy.

Parents were more likely to agree that their child was bullied because of epilepsy ($p = 0.035$) and reasons other than epilepsy ($p < 0.001$) than staff. Parents of children in mainstream schools were likely to agree that their child was bullied because of their epilepsy ($p = 0.017$) and non-epilepsy reasons ($p = 0.026$) compared to parents in special schools. Parents of children without intellectual disability were more likely to agree that their child was bullied because of their epilepsy ($p = 0.029$).

3.5.1. Thematic analysis children with epilepsy’s views on impact of epilepsy on their friendships

Two major themes with associated subthemes were identified with respect to child views on friendships (see Table 7)

Epilepsy does not affect friendships

Some young people with epilepsy did not feel that epilepsy affects friendships

Felt Stigma

Young people with epilepsy felt that their peers will not want to be their friend or will ‘tease’ them because of epilepsy and also felt that peers might uncomfortable spending time with the child because of seizure risk

4. Discussion

This study is one of the first studies to comprehensively consider the impact of epilepsy and associated conditions on affected children’s participation and inclusion in school. A significant proportion of parents of children with epilepsy were concerned about their child’s school attendance and believed that more could be done to prevent attendance difficulties. Additionally, both parents and staff believed that attendance difficulties had a detrimental effect on children with epilepsy both academically and with respect to social-emotional development. Most parents and staff respondents agreed that children with epilepsy were included to the same extent as peers. However, parents were significantly less likely than teachers to agree that children were included in all playground activities, and parents of children attending special schools were more likely to agree that their child was included than parents of

Table 6
Effects of childhood epilepsy on friendships.

Respondent	Item	n (%)	Comparison between mainstream and secondary schools p-values	Comparison between Parents and Staff p-values	Comparison between ID and non-ID p
Child (N = 20)	Epilepsy affects friendships in school (Y/N) ^a	2/15 (12/88)	NA		NA
	Knows someone else with epilepsy (Y/N)	12/8 (60/40)	NA		NA
	Person known with epilepsy is... ^b	At school 7 (42) Outside of school 5 (58)	NA		NA
Parent (N = 68)	Child has more difficulties making friends compared to peers because of their epilepsy (agree/disagree) ^c	20/46 (30/61)	0.261	0.177	0.520
	Child has more difficulties making friends compared to peers because of reasons other than epilepsy (agree/disagree) ^c	40/26 (61/39)	0.679	0.050	0.485
Staff (N = 56)	Child has more difficulties making friends compared to peers because of their epilepsy (agree/disagree)	11/45 (20/80)	0.155		
	Child has more difficulties making friends compared to peers because of reasons other than epilepsy (agree/disagree)	24/32 (43/57)	0.122		

^an=17, ^bn=12, excluding children who don't know anyone else with epilepsy cn=66.
NA = Not applicable due to small numbers of young people in special schools.

Table 7
Child views on whether epilepsy affects their friendships.

Themes	Subthemes	Quotes
<ul style="list-style-type: none"> Epilepsy does not affect friendships Felt Stigma 	<ul style="list-style-type: none"> Child worries peers will not want to be their friend or will tease them because of epilepsy Peers uncomfortable spending time with the child because of seizure risk 	<ul style="list-style-type: none"> <i>I just feel like maybe people might not like me as much because I have epilepsy</i> <i>I'm quite scared in case they might, like, walk away or make fun of me</i>

children attending mainstream schools. Exclusion of children with epilepsy was believed to be due to having epilepsy/seizures or having learning/behavioural difficulties, and it was believed to be initiated by the child or by school staff. The majority of child, parent and staff respondents agreed that epilepsy restricted children's activities. The children themselves mentioned activities such as sleepovers and participation in sport as activities where restrictions could exist. Most children with epilepsy did not feel that having epilepsy affected their friendships. Whilst more than half of children with epilepsy reported that they had been bullied, most did not attribute this bullying to having epilepsy.

Just over 40% of parents in the current study reported that their child currently had or previously had difficulties with school attendance. A previous study in Scotland highlighted that children with epilepsy are at increased risk for school absences [18]. Attendance difficulties for children with epilepsy have also previously been noted in a Brazilian study where 88% of parents reported that their child with epilepsy had ever missed at least one day due to seizures [12]. Regarding reasons for difficulties, the two most frequently mentioned reasons were seizures and hospital appointments and this is in line with the previous Brazilian study which also noted these two reasons as the primary contributors to attendance difficulties [12]. In addition to the impact of seizures directly on the child, it has also been noted that school staff are often concerned about seizure management and thus may not be able to support the child adequately if they have seizures in school [19].

The majority of parents who reported difficulties in school attendance believed that the difficulties affected their child's progress at school. This is in agreement with previous studies that showed attendance difficulties are associated with difficulties in academic achievement [13,18]. Responses to the open questions indicated that as well as

the impact on academic progress, both parents and staff felt that attendance difficulties could have a negative impact on the child's sense of belonging and social-emotional development. The potentially negative impacts on the child's sense of belonging and social-emotional development add further to the known problems with aspects of self-esteem [20], bullying [11], stigma [14], social isolation [15] and social-emotional difficulties [21] in children with epilepsy. Some parents felt that better knowledge of epilepsy among staff and more integration of health and education supports could help with the child's attendance difficulties. The need for better staff knowledge has been highlighted in a previous review [9] as has the need for better integration of care [10].

A positive finding of the current study is that the vast majority of parents and school staff agreed that the child with epilepsy is included in all classroom activities. Parents were however, significantly less likely than staff to agree that children were included in all playground activities. It is not clear why differences emerged between parental and staff views with regard to playground activities. The playground environment may be less structured than the classroom and some parents may feel that their children need more support to enable participation. Parents of children attending special schools were more likely to agree that their child with epilepsy was included and this may reflect the fact that parents of children with epilepsy believe that there is more knowledge of epilepsy in special than mainstream schools [16].

Responses to the open questions suggested that while many parents and staff believe the child was included to the same extent as peers, there are some parents who believe that their child can be excluded at certain times. Reasons for exclusion included child-led inclusion, often due to the child having sensory issues and lacking confidence. Sensory modulation disorders occur in nearly half of children with epilepsy, according to a Dutch study, including difficulties with sensory sensitivity, sensory avoidance and poor registration [22]. These sensory modulation difficulties were often associated with autism and ADHD which are common, underdiagnosed comorbidities in children with epilepsy [3]. In relation to lacking self-confidence, children with epilepsy often have reduced self-confidence which is often associated with increased mental health symptoms [23]. Parents also believe that some exclusion of children with epilepsy may also be initiated by staff due to child behavioural problems as well as lack of training in seizure management. Children with epilepsy have an increased risk of behavioural difficulties [24] and have often not been assessed by a psychologist, leading to a subsequent lack of identification and support for comorbid behavioural and emotional difficulties [8]. The lack of training among staff in relation to seizure management has also previously been highlighted [25]. Parents

did report a number of possible strategies to support the child's inclusion and both parents and staff reported that children with epilepsy could be included with certain adaptation to activities. There is very limited research on supports to include children with epilepsy in school settings and activities. Parental reports of strategies, and both parent and staff reports of adaptations in the current study, might suggest future research directions.

The majority of children with epilepsy and their parents agreed that the child with epilepsy faces restrictions with respect to friendships and social activities due to their epilepsy. Parental responses highlighted that the social activities were more limited due to both epilepsy, but also other reasons, highlighting that epilepsy is often associated with psychosocial difficulties beyond seizures. Parents of children in special schools were more likely to agree that the child's social activities outside of school were more limited than parents of children in mainstream schools. These findings are in line with previous studies that indicate that children in special schools often have fewer friends outside of school than children in mainstream schools [26,27]. Responses to the open questions by children with epilepsy indicated that they faced restrictions and limitations in relation to sleepovers, some physical activities and some out of school activities. Previous research suggests that activity restrictions faced by children with epilepsy are often based on fear of injury among parents [28]. There are very few physical activities which children with epilepsy cannot do [29], highlighting the importance of asking parents and staff about restrictions and providing education for parents and school staff in targeting misperceptions and on developing appropriate precautions [30]. Additionally restrictions not optimally adapted to seizure-related risks may hamper children with epilepsy achieving independence [31].

Most children with epilepsy, their parents and school staff did not believe that the child's epilepsy affected their friendships. However, a majority of parents believed that the child did have more difficulties making friends because of other reasons, highlighting the potential role of neurodevelopmental problems in impeding the creation of friendships. Epilepsy in childhood is associated with a higher risk for both autism and ADHD [2] and both these conditions are associated with social difficulties and difficulties with friendships [32]. A previous study suggested that children with epilepsy are at higher risk of bullying [11]. In relation to views on bullying in the current study, the majority of child, parent and staff respondents did not agree that the child had been bullied due to their epilepsy. This is in line with a previous study which found that epilepsy factors such as early age at seizure onset, seizure type, and refractory epilepsy were not found to be predictors of victim status [11]. It may be that as epilepsy is often a hidden disability and thus children with epilepsy are not bullied because of the presence of epilepsy but because of other more overt characteristics e.g., learning and behavioural difficulties. Parents reported however, a much higher proportion of bullying due to reasons other than epilepsy, highlighting the potential role of other co-occurring neurodevelopmental conditions in increasing the risk for bullying [33]. The increased risk for bullying in children with other behavioural conditions has been noted previously [33] suggesting that children with both epilepsy and behavioural comorbidities may be a specific risk group. Parents of children in mainstream schools were more likely to agree that their child was bullied because of their epilepsy as well as non-epilepsy reasons, compared to parents in special schools. An increased risk for bullying in mainstream schools has also been noted for children with autism [34] and it has been suggested that mainstream schools have fewer resources to protect children against the risk of bullying [34]. In particular it has been suggested that special schools provide specialist teaching staff and more support for social interactions compared with mainstream schools [34] and thus these which may be protective factors with respect to the risk of being bullied for children with epilepsy.

4.1. Implications for practice

The results of the current study highlight that whilst many children with epilepsy appear to have positive experiences in school, there are a number of areas of concern. There is a need to try to reduce attendance difficulties by ensuring that there is a good understanding of epilepsy in school settings. This includes seizure management but also an understanding of the wider impact of epilepsy. Furthermore, it is important that when children experience periods of absence from school, support is available to help them catch up academically and socially. Children with epilepsy may be excluded from certain activities unnecessarily, with parents and staff not understanding the nature of the risks that the child may face if they participate. It is therefore, important that supporting clinicians ask children and parents about restrictions and provide advice where needed. In relation to friendships and bullying, it is important that peers of children with epilepsy are educated about epilepsy with the aim of minimising fear associated with the condition. It is also important that children with epilepsy are assessed for possible comorbid cognitive and behavioural difficulties and that they subsequently receive appropriate support for identified additional difficulties, as these difficulties are more often associated with bullying than seizures.

4.2. Future research directions

Future studies should include a control group of children with non-epilepsy related neurodisability to see if the issues around inclusion, attendance, bullying and friendships found in the current study are epilepsy-specific or are shared by children with other neurodisabilities. We used surveys and interviews to garner views and experiences but the employment of focus groups might yield different findings. It will be important to develop and evaluate educational interventions for school staff in robustly designed studies to evaluate the impact on attendance and inclusion, but also knowledge of epilepsy and associated comorbidities and attitudes towards children with epilepsy.

4.3. Limitations

A number of limitations need to be understood when reviewing the results of this study. We did not have accurate data on actual school attendance. The majority of children with epilepsy were unable to participate in surveys/interviews due to their impaired cognitive abilities. The children who participated in the WINS study had a mean age of epilepsy onset significantly younger than non-participants, and given that age of onset is associated with greater neurodevelopmental impairment [3] it is likely that participants had more significant learning and behavioural difficulties than non-participants. We did not have responses from a representative staff member for all of the participating children and we do not have details on non-participating staff. The study is based in a defined geographical region of England, and although England has a national healthcare system and a national education system, findings may not generalise to other parts of the country or other jurisdictions. We had a much higher participation rate in our study at site 1 compared with site 2. One reason for this may be that whilst all parents were informed in person about the study at Site 1, an unknown number were informed and invited to participate at site 2 by varying methods. This difference in participation rates may have affected the representativeness of our study population.

We were able to consider the role of intellectual disability in our statistical analyses. However, we were not able to include the potentially important role of neurodevelopmental disorders e.g., autism, ADHD or mental health problems e.g., depression and anxiety in our analyses as we did not perform diagnostic assessments for these conditions in the study.

5. Conclusion

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

Conflicts of interest

The authors have no conflicts of interest. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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Supplementary materials

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