**Title:** Marginalisation, autism and school exclusion: Caregivers’ perspectives.

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**Abstract**

The article presents findings from interviews with five caregivers of children with autism excluded from schools in England. **Objectives**: to determine the barriers and enablers to mainstream schooling for children with autism and to explore the emotional effect of the journey to school exclusion on the child and caregivers. **Background**: research has highlighted that some mainstream schools do not listen to caregivers concerns about their child’s development, behaviours and mental health. **Methods**: interpretative phenomenological analysis was employed to understand how participants made sense of their lived experiences, revealing four superordinate themes: inadequate special educational needs and disability (SEND) support, psychological impact, health-imposed barriers to diagnoses, and effective support. **Findings**: theographs present the caregivers’ journeys, illustrating that the onus fell on the caregivers to advocate for effective support from schools. A lack of prompt diagnoses and effective school support is detrimental to the emotional and physical health of both children and caregivers. Training is needed to ensure thresholds for education, health and care needs assessments are understood, alongside evidence-based approaches to support children with SEND. There is a policy need to address barriers to prompt health assessments across services and the impact of decreased funding on schools.

**Keywords:** Autism, school exclusion, interpretative phenomenological analysis, theographs, qualitative research.

**Introduction**

This article draws on data gathered during a two-year study investigating the impact of schooling and school exclusion on the mental health and wellbeing of children Martin-Denham, 2020a; 2020b; 2020c). The original study involved 174 participants, including 55 children, 41 of their caregivers and 78 professionals from schools and health services. This research focuses on five interviews with caregivers of children with autism and school exclusions. It has two objectives: 1) to determine the barriers and enablers to mainstream schooling for children with autism and 2) to explore the effect of the journey to school exclusion on the child and caregivers.

Historically, the UK strategy for securing parental involvement (Department for Education and Skills (DfEE), 1997) had three areas of focus: better information, involving parents in their child's education, and parent-governors having a voice in the running of schools. The DfEE green paper 'excellence for all children' (1997b) acknowledged the need to support caregivers across education, health, care and voluntary sectors. This momentum continued within the principles of the Department for Education and Skills (DfES) special educational needs (SEN) code of practice (2001), which states 'parents have a vital role to play in supporting their child's education' (p.12). The Children and Families Act (CAFA) 2014 intensified the statutory requirement to involve parents in decisions that directly affect children with SEND. In 2015, the Department for Education (DfE) and Department of Health [DoH] statutory guidance, 'SEND code of practice' (herein referred to as 'the code'), emphasised: support for parents in early identification (of SEND), high-quality provision, decision-making, choice and control, and collaboration between agencies. Despite this, the House of Commons Education Committee (2019, p.3) reported failures in implementing the CAFA (2014), leading to 'unlawful practice, bureaucratic nightmares, buck-passing, lack of accountability, strained resources and adversarial experiences.'

**Early identification**

The Bercow Report (Department of Children Schools and Families (DCSF), 2008), the Lamb Inquiry (DCSF, 2009), the Salt Review (DCSF, 2010), the Office for Standards in Education (Ofsted) SEND Review (2010) and the Timpson Review (DfE, 2019) highlighted the critical role early identification plays in improving outcomes for children. Pirrie et al. (2011), Horridge (2019) and Martin-Denham (2020a, 2020b, 2020c, 2020d) agree that early identification reduces the likelihood of disrupted pathways in school, as needs made visible are more likely to be addressed. Research consistently shows that caregivers accurately predict the presence of developmental issues and disabilities in their children (Glascoe, 1999; Tervo, 2009; Woolfenden et al., 2014; Ireland and Horridge, 2016; Martin-Denham, 2020a, 2020d), though they view diagnosis as the only gateway to support (Driver Youth Trust, 2015). The Timpson Review (DfE, 2019, p. 39) clarified that, where a child’s behaviour raises concerns, there is an expectation that schools have clear processes for assessment of 'causal factors such as undiagnosed learning difficulties, difficulties with communication and mental health issues'. The Independent Provider of Special Education Advice (IPSEA) (2020) note, if a local authority is requested to carry out an Education, Health and Care (EHC) needs assessment, they must consider whether:

* The child or young person has or may have SEN; and
* Special educational provision may be required (EHC Plan).

CAFA (2014) established a legal obligation to assess needs where the above criteria are met.

Financial pressures on schools contribute to their inability and willingness to identify difficulties and provide support (House of Commons, 2018). The Future in Mind report (Department of Health and NHS England 2015, p. 57) recommended a multi-disciplinary approach, coordinating ‘assessment and planning around the individual child, facilitated by information sharing'. The House of Commons Education Committee (2019) reiterated the importance of multi-disciplinary support for children with disabilities.

Rising demand for mental health support services adds further barriers to accessing SEND diagnoses (Chief Medical Officer, 2012; Martin-Denham, 2020a), as does a lack of information on pathways to services (Boyd et al., 2011; Iskra., 2015; Anderson, 2017), resulting in caregivers seeking out information independently (Williams and Rheingold, 2013). Hutchinson and Crenna-Jennings (2018) reported that in the previous five years 55,800 children referred to Child and Adolescent Mental Health Service (CAMHS) were not deemed eligible for support, and long waiting times for appointments are the critical barrier to engagement with mental health support services (Golding, 2010; Iskra et al., 2015; Anderson et al., 2017; Martin-Denham, 2020b).

**School exclusion**

The Education Act 1986 first introduced the terms ‘fixed-period' and 'permanent' exclusions, paving the way for schools to remove a child when they were deemed to be persistently or severely deviating from the school's behaviour policy (DfE, 2017). A permanent exclusion refers to 'a pupil who is excluded and who will not come back to that school', while fixed period exclusion refers to a pupil who is excluded from a school for a set period (DfE, 2020). A pupil may be excluded for one or more fixed periods up to a maximum of 45 school days in a single academic year. A decision to exclude a child must be lawful, rational, proportionate and fair (European Court of Human Rights, 2010; Education Act, 2002; Education Act 2011).

A wealth of evidence in the UK shows that those excluded from school have increased risk of poor educational outcomes (Social Exclusion Unit, 1998; Daniels et al., 2003; Office of the Children's Commissioner, 2017; Martin-Denham, 2020a; 2020b; 2020c; 2020d). The Autism Education Trust (2020) highlights that children on the autism spectrum have increased vulnerability to exclusion from school due to a lack of awareness of autism, leading to situations where the child becomes overwhelmed by unstructured aspects of their school life.

**The prevalence of school exclusion**

Permanent exclusions declined from 1995-1996 then rose again in 2012-2013 (DfE, 2018). The number of permanent exclusions decreased by only 11 in 2018/19, with fixed-period exclusions rising from 410,800 to 438,300 (DfE, 2020). Hatton (2018) suggested that rates of fixed-period exclusions are at least three times higher for children with autism compared to those without SEN. Ambitious about Autism (2020) note that exclusions of children with autism have increased significantly in the last few years, reporting that 56% of children with autism are excluded unlawfully. Furthermore, the national data does not include unofficial exclusions such as managed moves, inclusion units, nurture rooms and isolation rooms (Power and Taylor, 2018). Atkinson (2012), Gill et al. (2017) and Martin-Denham (2020c) presented examples of caregivers being coerced to agree to a managed move as an alternative to a permanent school exclusion, which would remain on their school records.

Increasing school exclusions continue to generate national concern. Findings from the Timpson Review (DfE, 2019) highlight a lack of specialist settings for pupils with autism and social, emotional or mental health (SEMH) needs, meaning they remain in unsuitable schools lacking in specialist knowledge.

**Methods**

Interpretative phenomenological analysis (IPA) was used to determine the barriers and enablers to mainstream schooling for children with autism, and to explore the effect of the journey to school exclusion on the child and caregivers. IPA is founded on the premise that humans can interpret and understand their world through biographical stories (King et al. 2019), enabling them to make sense of their major life experiences. The method enables in-depth analysis due to the rich detail within individual stories (Smith et al. 2009), giving rise to valuable insights into participants’ experiences, perceptions and behaviours (Cuthbertson, 2020). IPA is also useful when examining 'complex and emotionally laden’ topics (Smith and Osborn, 2015, p.1). Each case is analysed individually to gain as much as understanding as possible before progressing to the next (Cassidy et al., 2011). In the latter stage of cross-case analysis, the emphasis on the individual's experiences is retained alongside examination of how their thoughts and beliefs align with more general themes (Smith and Eatough, 2006).

One limitation of IPA is that analysts may interpret data differently, raising questions around validity and reliability, particularly if a small sample size is used (Charlick et al., 2016). Generalisability is therefore not possible here, due to the small sample and the localised nature of the study. However, claiming generalisability was not an objective; this research aims to share the lived experiences of the five caregivers of children with autism who had been excluded from school.

Theographs provide a visual representation of the data. Their value lies in their ability to identify gaps and patterns of events (Georghiou, 2020).

**Ethics**

Ethical approval for the original study was granted from the University of Sunderland's Ethics Committee. Gatekeepers provided consent for the caregivers to be approached and voluntary informed consent was sought and gained from all caregivers in both written and verbal form, as per the British Educational Research Association guidelines (2018).

**Sample selection and recruitment**

The original study used purposive sampling to ensure that the participants were a homogenous sample with first-hand experience of the process of school exclusion. Of the 41 caregivers who took part in the original study, five met the criteria for this article (see Table 1 for details of caregivers and children).).

1. They had a child with a diagnosis of autism
2. That child had received fixed period and/or permanent exclusions

**Table 1.** Caregiver (with pseudonyms to preserve anonymity) and child profiles

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Participant** | **Marital status** | **Employment status** | **Age of child (years)** | **Gender of child** | **Diagnoses** | **School exclusions** | **SEN status** |
| Father  (Justice) | Married to mother | Employed | 6 | Female | Autism and Physical Disabilities | Multiple illegal FeX | Awaiting referral for EHC needs assessment |
| Mother  (Sadie) | Single parent | Employed | 8 | Male | Autism | Multiple FeX1,2  1 PeX2 | SEN support (since infant school) |
| Mother  (Olwen) | Married to father | Employed | 10 | Male | Autism, ADHD, ODD | Multiple FeX1,2  1 PeX3 |  |
| Mother  (Viv) | Married to father | Employed | 16 | Male | Autism and ADHD | Multiple FeX1,3  1 failed MM | EHCP (Agreed age 16) |
| Mother  (Lucy) | Single parent | Resigned to homeschool | 17 | Male | Autism and Fragile X Syndrome | 1 PeX3 | EHCP  (Agreed age 7) |

**Note**Persistent Disruptive Behaviour1**;** Physical Assault Against an Adult2; Physical Assault a Pupil3. ADHD: Attention Deficit Hyperactivity Disorder, FeX: Fixed Period Exclusion, PeX: Permanent Exclusion, MM: Managed Move, ODD: Oppositional Defiance Disorder; EHCP Education, Health and Care Plan.

**Procedure**

Semi-structured interviews took place between September 2018 and June 2019. These were digitally recorded, transcribed verbatim, anonymised and stored securely. To allow in-depth responses to open-ended questions, no time limits were imposed on the interviews. The researcher took a neutral, non-directive stance, allowing the caregiver to share their stories as the primary expert (Alexander and Clare, 2004; Smith, Flowers and Larkin, 2009).

**Data analysis**

In accordance with IPA, the five transcripts were analysed using the six-step process advocated by Smith and Osborn (2003), and Smith et al. (2009).

1. Listening to, reading and re-reading the interviews
2. Initial noting of semantic content and language
3. Developing emergent themes
4. Searching for connections across emergent themes
5. Moving to the next case
6. Looking for patterns across cases

Table 2 shows stages 1-3 of the IPA process, recording what mattered to each participant in terms of relationships, processes, places, events, values and principles.

**Table 2.** Steps 1-3 of IPA (interview with Justice)

|  |  |  |
| --- | --- | --- |
| **Emergent themes** | **Quote from the interview transcript** | **Exploratory comments** |
| **Interview question**  Was it easy getting health assessments carried out? | | |
| Mourning for what could have been  Hope for the future | We had to pressure them, if she had been diagnosed earlier then she would have got that support. We still haven’t been able to get into a special school. Hopefully, though in September she will start one. | Onus on the caregiver to push for the child to have their SEND needs assessed.  Use of ‘if’ suggests Justice was reflecting on what could have been if his daughter was diagnosed sooner. |
| Loss of future  The current EHC needs assessment system can lead to securing appropriate provision that meets the needs of children with SEND. | She was supposed to start this September (special school), but she couldn’t because the application had been delayed and there wasn’t enough space. | Processes matter to them, application for an EHC needs assessment was delayed and he believes this resulted in there not being a place available for his daughter in a specialist school. |
| Lack of accountability  Schools holding children until special provision can be secured.  The National Curriculum is not suitable for all children. | It is the council’s responsibility to provide special education. Last year she was in reception and this year she is in reception; they haven’t moved her up. I guess it is not their fault because they are saying that if she moves up to year one, she will struggle. Her speech hasn’t developed, she just has simple words, so things have been on hold for a year. | Feels council failed in their duties.  Empathises with the school. |

The next stage involved drawing together the emergent themes (abstraction) from the transcript to identify patterns to create a potential superordinate theme (Table 3).

**Table 3.** Searching for connections across emergent themes (Justice)

|  |  |  |  |
| --- | --- | --- | --- |
| **Emergent themes from steps 1-3** | **Related themes** | **Potential superordinate them (step 4)** | **Keywords** |
| Mourning and grief for what could have been | Importance of early assessment and identification of SEND | Health-imposed barriers to diagnosis | Pressure, cuts, shortages, diagnosis, hopefully, earlier, late |
| Importance of early identification of SEND |
| Funding cuts can cause delays to identification and assessment of SEND | More funding needed for health to support early diagnosis |
| Caregivers feel teaching assistants are not best placed to meet child’s needs | Lack of qualified and skilled staff | Inadequate SEN support | 1-1, support, regressing, part-time schooling |
| School has a lack of funds to meet the needs of children with SEND |  |
| Lack of special educational provision | Illegal exclusions | Schools may have a lack of understanding of legal duties  Inadequate SEN support | Lunchtime, home, part-time, pressurising, remove |
| School unable to accommodate the needs of children with SEND | Pressure on caregivers to remove the child from school |
| School unable to meet child’s learning needs | Child unable to access with the National Curriculum | Unachievable curriculum expectations | Not developing, toys, count, interaction |
| Ineffective school placement processes |
| The school does not want the child | The child needs specialist educational provision | Inadequate SEN support  Psychological impact on child and caregivers | Friends, pressurising, Ofsted, hope |
| Any specialist school will do |
| Hope |
| Broken relationship with school is hard to repair | Importance of collaboration with caregivers | Psychological impact on caregiver | Honest, research, trying, interaction |
| Distrust of school |  |
| Caregivers upskilling to meet their child’s needs |  |

The next stage involved repeating the process with the next interview transcript. To be faithful to the idiographic commitment, ideas from the first case were bracketed, and the focus restarted on the following subject (Flowers et al., 2009). To identify patterns and connections across the cases, a table of superordinate themes was created (Table 4). All superordinate themes were present in over half of the sample.

**Table 4.** Identifying recurrent themes

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Superordinate theme** | **Justice** | **Sadie** | **Olwen** | **Viv** | **Lucy** | **Present in over half the sample** |
| Inadequate SEN support | Yes | Yes | Yes | Yes | Yes | Yes |
| Psychological impact | Yes | Yes | Yes | Yes | Yes | Yes |
| Effective support | Yes | Yes | Yes | Yes | Yes | Yes |
| Health imposed barriers to diagnosis | Yes | Yes | Yes | Yes | No | Yes |

**Development of theographs**

When the arising themes, related themes and superordinate themes had been developed, theographs were also created. These were made by noting and recording key events and milestones, as reported by the caregivers. Theographs were created as follows, using Sadie's interview as an example:

1. Reading and re-reading the original data, and listening to the audio files
2. Creating a spreadsheet with setting, event and quotes, as shown in Table 5
3. Colour coding the events and experiences: red for negative and green for positive on excel to create a theograph

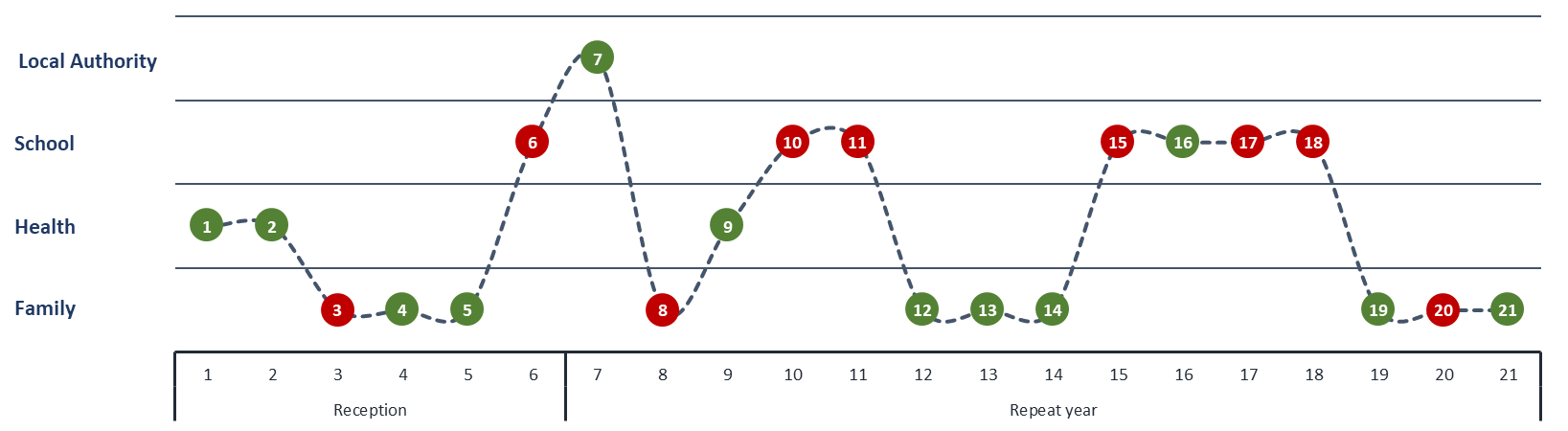
**Table 5.** Example of theograph table

|  |  |  |  |
| --- | --- | --- | --- |
| **Year group** | **Setting** | **Event** | **Quotes** |
| 1 | School 1 | **Child begins to have difficulties** | His needs changed as he went through school. Initially, it was not being able to sit still at carpet time and not being able to put his hand in the air. He would just shout out which was exactly what was happening when he joined the junior school |
| 2 | School 1 | **Autism diagnosis** | The route to his diagnosis was kind of convoluted. We had some private observations done by a neuropsychologist. They said he’s very high functioning but, on the autism spectrum. It was always borderline, always quirky. With him moving to the junior school, if there were a diagnosis, they would be obligated to take account of that which in theory is great if the school can be bothered to do it. |
| 2 | School 1 | **Referred to CAMHS** | We started trying to refer him to CAMHS. We were told he had to go through CYPS. Then CYPS rejected him. CAMHS wouldn’t have been relevant for him. It wouldn’t have been specific enough for him. CYPS might have been able to do something, but they rejected the case anyway. |
| 2 | School 1 | **CAMHS refer to CYPS** |
| 2 | School 1 | **CYPS reject CAMHS referral** |
| 2 | School 1 | **Junior school rejected caregiver requests for transition meetings** | I had been offering to go in since before the school holidays to talk to them about his needs and what he would require in terms of settling in properly. It was all declined. As a parent there is only so much you can offer and then the school don’t take it up. |
| 3 | School 2 | **His class is changed the day before he starts his new school** | The day before he started in September, the school phoned me and told me they were changing his class. It was just a complete lack of comprehension of how that would affect him. |
| 3 | School 2 | **No SEN support in place** | They didn’t find out from the infant school how they managed him. So, he was dumped into a classroom with 30 odd and left to get on with it. It went down-hill drastically very quickly. |

**Note** CAMHS – Child and adolescent mental health services,CYPS - Children and Young People's Service

**Theographs for each of the caregivers' interviews (Figures 1-5)**

**Figure 1.** Theograph presentation of the interview with Justice

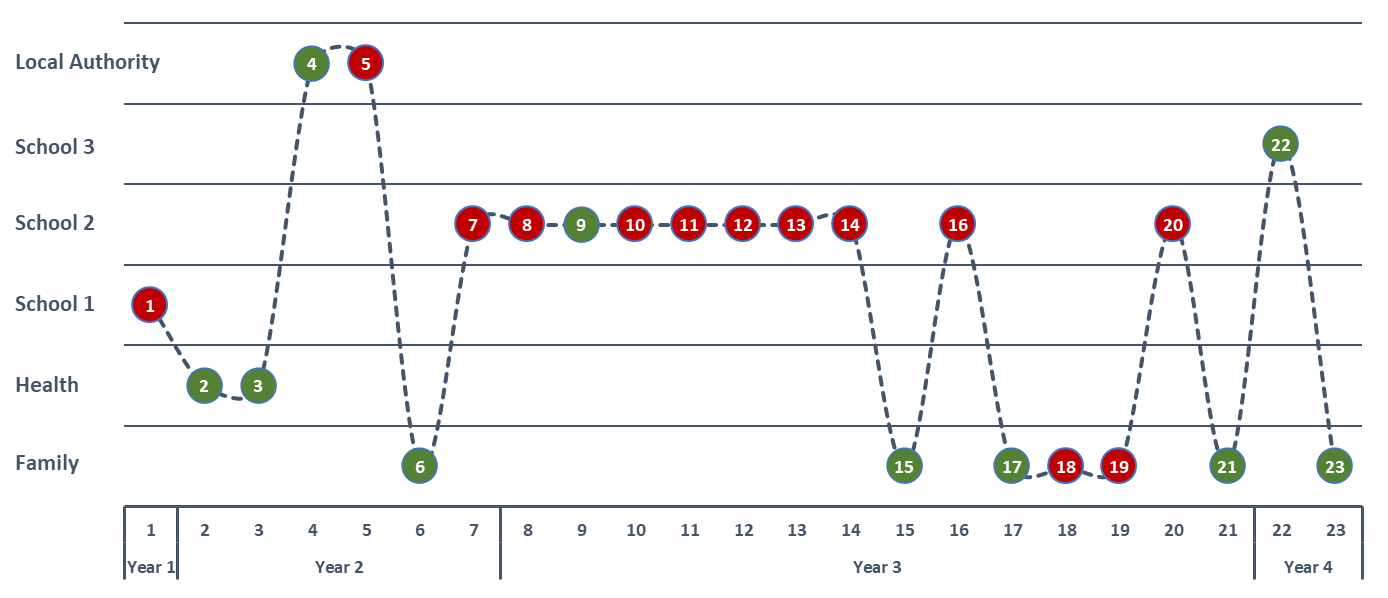


**Table 6.** Figure 1 data key

|  |  |  |  |
| --- | --- | --- | --- |
| **Key** | **Event** | **Key** | **Event** |
| 1 | **Support from multiple health consultants for physical disabilities** | 12 | **Caregiver offers to home school their child, mother works with LA to find a suitable school** |
| 2 | **GP refers child to SaLT** | 13 | **Child added to waiting list for a school specialising in autism** |
| 3 | **Caregivers share developmental concerns with school** | 14 | **Caregivers request funding support for 1:1 tuition** |
| 4 | **Mother carries out independent research into how to support daughter** | 15 | **School rejects request – insufficient funds** |
| 5 | **Mother volunteers at special school to learn how to support her child’s needs** | 16 | **School provides support from a teaching assistant** |
| 6 | **School take decision to retain child in reception for a second year** | 17 | **School suggests ½ day attendance, parents decline** |
| 7 | **LA educational psychologist assessment, recommends transfer to a specialist unit** | 18 | **School imposes illegal fixed-period exclusions (insisting on part-time attendance)** |
| 8 | **Caregivers decline specialist placement, feel the school do not want child** | 19 | **Mother buys more educational toys to support development at home** |
| 9 | **Paedriatician diagnoses ASD, recommends child remains in mainstream school with support** | 20 | **Caregivers share concern with school that child is regressing** |
| 10 | **School recommends alternative placement, caregivers refuse as the school is not for children with autism** | 21 | **Caregivers request dual placement for child** |
| 11 | **School pressures caregivers to take place, citing concerns over upcoming Ofsted inspection** |  |  |

**Note.** General practitioner (GP); speech and language therapist (SaLT); local authority (LA); teaching assistant (TA)

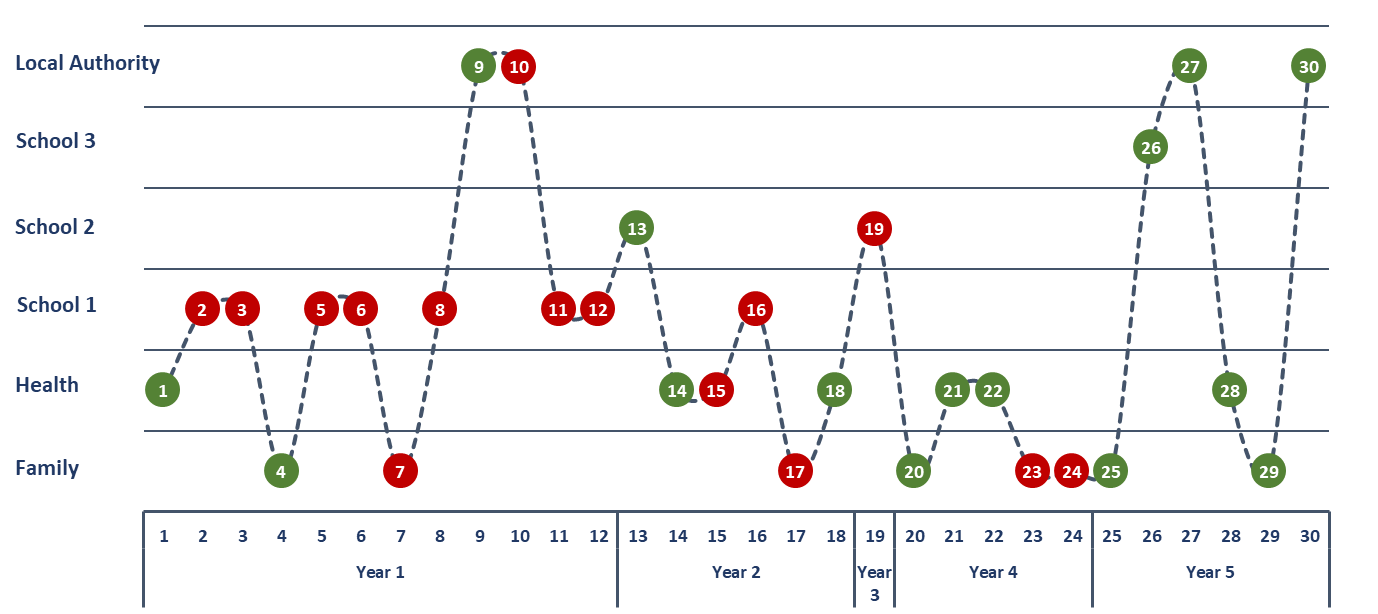
**Figure 2.** Theograph presentation of the interview with Sadie



**Table 7.** Figure 2 data key

|  |  |  |  |
| --- | --- | --- | --- |
| **Key** | **Event** | **Key** | **Event** |
| 1 | **School report behaviour concerns to mother** | 13 | **Child moved to back of class** |
| 2 | **Child diagnosed with ASD** | 14 | **Multiple fixed-period exclusions** |
| 3 | **Referred to CAMHS** | 15 | **Mother requested school seek external support** |
| 4 | **CAMHS refer to CYPS** | 16 | **School decline request** |
| 5 | **CYPS reject referral** | 17 | **Mother contacts Autism Outreach** |
| 6 | **Mother requests transition meeting with school 2 (juniors)** | 18 | **Mother feels school do not want child** |
| 7 | **Junior school reject request for transition meetings** | 19 | **Child assaults another pupil** |
| 8 | **School change child’s class the day before term starts** | 20 | **Permanent school exclusion** |
| 9 | **Child starts school 2** | 21 | **Mother homeschooling, considers tribunal case** |
| 10 | **No SEN school support in place** | 22 | **Child starts school 3** |
| 11 | **First fixed-period exclusion** | 23 | **Child participating and learning** |
| 12 | **School tell parent child is difficult to manage** |  |  |

**Figure 3.** Theograph presentation of the interview with Olwen

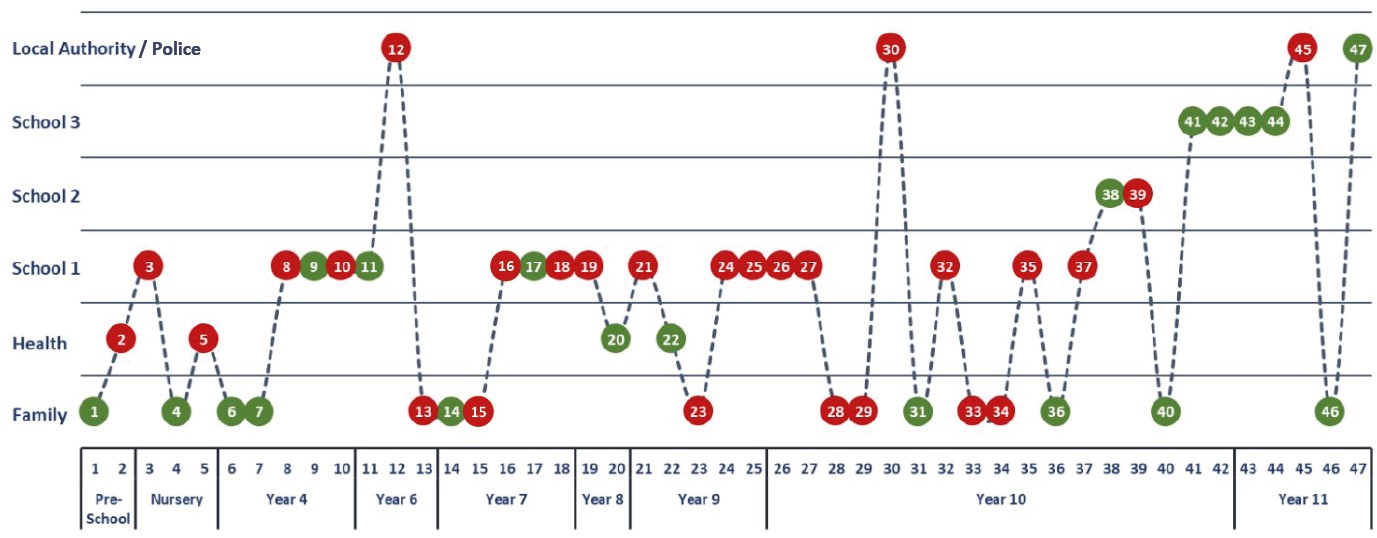


**Table 8.** Figure 3 data key

|  |  |  |  |
| --- | --- | --- | --- |
| **Key** | **Event** | **Key** | **Event** |
| 1 | **Accessed CAMHS who referred to CYPS who referred back to CAMHS** | 16 | **Multiple fixed-period exclusions** |
| 2 | **Teacher reports being hit by child** | 17 | **Caregivers continue to raise concerns over schools ability to meet child’s needs** |
| 3 | **Multiple fixed-period exclusions** | 18 | **Child diagnosed with ASD, ADHD and ODD** |
| 4 | **Caregivers request school refers EHC needs assessment** | 19 | **Multiple fixed-period exclusions** |
| 5 | **School refuses EHC needs assessment referral** | 20 | **Caregiver returns to GP multiple times due to school exclusions** |
| 6 | **School unable to meet needs, segregates child at breaktime, caregivers complain** | 21 | **GP referral to CAMHS** |
| 7 | **Mother becomes anxious that school will ring about child’s behaviour** | 22 | **CAMHS refer to CYPS** |
| 8 | **School attributes behaviour to home life and parenting** | 23 | **Caregivers feel school does not want child** |
| 9 | **Early help carry out a home visit** | 24 | **Child becomes unable to attend school. Caregiver withdraws child from school** |
| 10 | **Early help unable to support** | 25 | **Child starts at school 3** |
| 11 | **School describe child as “naughty”, won’t allow sensory breaks** | 26 | **Mother seeks external agency report which secures LA involvement** |
| 12 | **Mother told to start parenting course by school** | 27 | **LA provide a PRU place** |
| 13 | **Child starts school 2** | 28 | **CYPS give mental health support to child, external agency support parent** |
| 14 | **CAMHS access resumed** | 29 | **Child formally withdrawn from mainstream schooling to attend a PRU** |
| 15 | **CAMHS discharge – no issues** | 30 | **EHC plan secured** |

**Note.** Pupil Referral Unit (PRU)

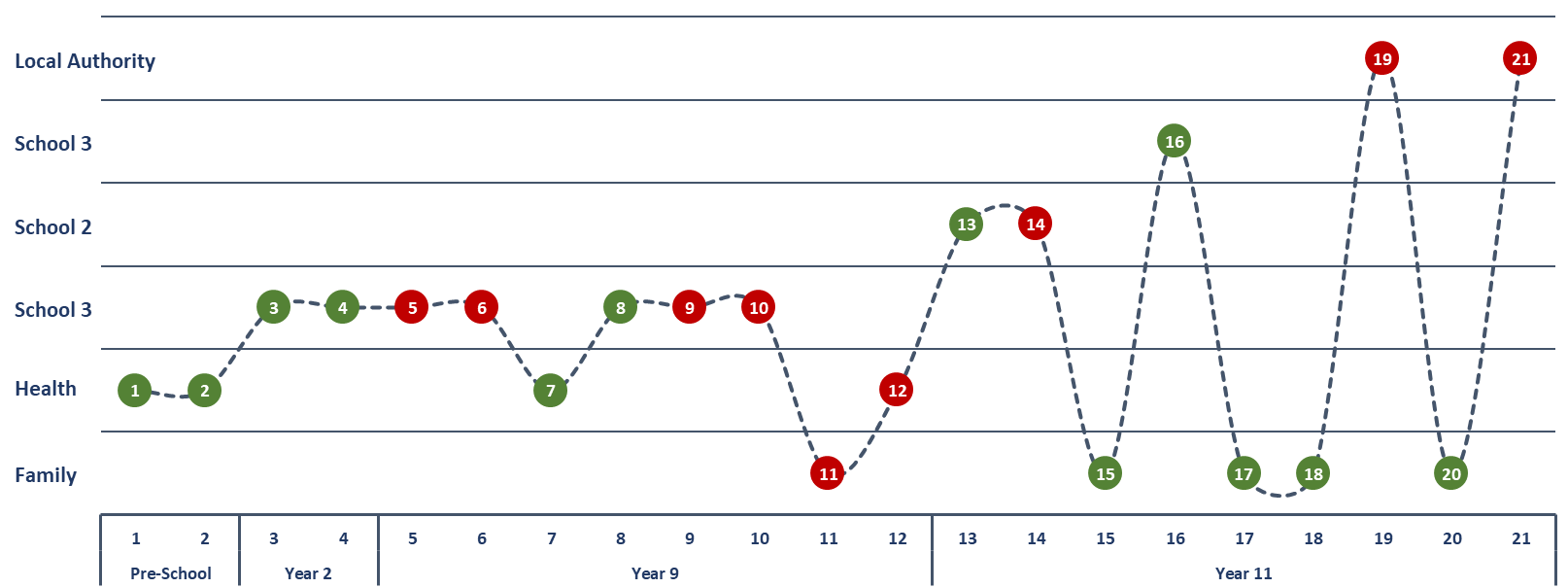
**Figure 4.** Theograph presentation of the interview with Viv



**Table 9.** Figure 4 data key

|  |  |  |  |
| --- | --- | --- | --- |
| **Key** | **Event** | **Key** | **Event** |
| 1 | **Parent requests SaLT referral** | 25 | **Child placed on school report** |
| 2 | **SaLT report no concerns** | 26 | **Multiple fixed-period exclusions** |
| 3 | **School reports disruptive behaviour to caregivers** | 27 | **Child physically assaulted by another child, resulting in a dislocated finger** |
| 4 | **Parent requests consultant referral** | 28 | **Mother reports incident to school, dismissed as an accident** |
| 5 | **Consultant discharges with no concerns** | 29 | **Caregivers contact police about disability discrimination** |
| 6 | **Mother arranges referral to consultant, child diagnosed with autism** | 30 | **Police interviews result in no further action against the child** |
| 7 | **Caregivers request school refers EHC needs assessment** | 31 | **Mother requested a managed move/EHCP assessment to school** |
| 8 | **School refuse to support EHC needs assessment referral** | 32 | **School declines managed move and referral for EHC needs assessment** |
| 9 | **Educational psychologist assessment arranged by school** | 33 | **Mother prescribed beta blockers for anxiety** |
| 10 | **Educational psychologist assesses and identifies no learning difficulties** | 34 | **Child assaults another pupil** |
| 11 | **SENCO requests EHC needs assessment** | 35 | **Permanent school exclusion** |
| 12 | **LA decline EHC needs assessment** | 36 | **Caregiver's re-request school referral for EHC needs assessment** |
| 13 | **Child discloses suicidal feelings to caregivers** | 37 | **School refuses EHC needs assessment referral** |
| 14 | **Caregivers tell child about their autism diagnosis** | 38 | **Child moves school** |
| 15 | **Child assaults a pupil in school** | 39 | **Child bullied for being different** |
| 16 | **First fixed-period exclusion** | 40 | **Mother requested managed move, managed move agreed to PRU** |
| 17 | **School refers to CAMHS** | 41 | **Child moves school** |
| 18 | **Multiple fixed-period exclusions** | 42 | **Bespoke curriculum implemented; vocational college training agreed** |
| 19 | **Multiple fixed-period exclusions** | 43 | **Child passing exams** |
| 20 | **CAMHS suspect ADHD and refer to CYPS** | 44 | **School 3 submits EHC needs assessment** |
| 21 | **Multiple fixed-period exclusions** | 45 | **EHC needs assessment rejected by LA** |
| 22 | **CYPS diagnose ADHD, child medicated for ADHD** | 46 | **EHC needs assessment refusal appealed, school 3 provide supporting evidence** |
| 23 | **Caregivers report bullying to school** | 47 | **EHC needs assessment decision overturned, EHCP granted** |
| 24 | **School removes break times but reinstates after parental complaint** |  |  |

**Figure 5.** Theograph presentation of the interview with Lucy



**Table 10.** Figure 5 data key

|  |  |  |  |
| --- | --- | --- | --- |
| **Key** | **Event** | **Key** | **Event** |
| 1 | **Diagnosis fragile X syndrome** | 12 | **Six different social workers in a year - recommending residential care against caregiver’s wishes** |
| 2 | **Diagnosed autism spectrum disorder** | 13 | **Child starts school 2** |
| 3 | **EHC plan secured** | 14 | **Permanent school exclusion (following 16-18 holds (restraints) in 12 weeks.** |
| 4 | **Moved to specialist provision** | 15 | **Mother resigns employment to homeschool, child is regulated and seems happy** |
| 5 | **School building entrance system changed the day before he starts a new school year** | 16 | **Child starts school 3 (tutored approach 1:1)** |
| 6 | **Class teacher off with long term sickness** | 17 | **Child regulated and home and with tutor** |
| 7 | **Psychiatrist prescribes child anxiety medication** | 18 | **Mother was going to appeal permanent exclusion but changed her mind** |
| 8 | **Educational psychologist recommends safe spaces via EHCP** | 19 | **Residential provision recommended by social care** |
| 9 | **School unable to provide safe space, child unable to regulate emotions** | 20 | **Mother declines residential, requests respite** |
| 10 | **Child frequently restrained by school staff** | 21 | **No respite available** |
| 11 | **Child self-harms (biting) occasionally lashes out at others** |  |  |

**Findings**

The following superordinate themes arose: Inadequate SEND support, psychological impact, and health-imposed barriers to diagnoses and effective support.

**Inadequate SEND support in school**

All caregivers commented that most mainstream schools offered inadequate SEND support. Sadie recounted that there was no support for her son with autism, despite a medical report informing the school that, without strategies to support him, he would experience significant behavioural difficulties:

'They didn't put any support in place; they didn't put any time-out breaks in place, no sensory support in place. So, he was dumped into a classroom with 30-odd, it went downhill drastically. There were lots of things that we talked about the day before they excluded him, putting in place for him, an individual visual timetable which he didn't have.'

Similarly, Lucy explained that her child's EHCP and educational psychologist report stated the need for a safe space and time outside. She perceived that the school did not appreciate the importance of supporting self-regulation: 'For the last six months they didn't have this in school; they were put in a classroom which has less space. They never explored letting him outside.'

Olwen recalled that her son, who was diagnosed with autism, ADHD and ODD following multiple fixed period exclusions, was 'not allowed to move and not given movement breaks. Those days he found particularly difficult. I knew I'd get that phone call that day to go and get him.' Olwen raised concerns to the school regarding the lack of sensory breaks: 'If you're going to lock him up in a room, well, he'll just be like a crazed animal.' Viv, whose son also received multiple fixed period exclusions prior to diagnosis of autism and ADHD, disclosed that her son’s school removed break time in case he became 'wound up'.

'I went absolutely mad. I know that it's hard for them sometimes. They haven't got the resources. There needs to be something in place. These children can't be ignored and put in a room. There must be thousands of these children'.

Justice’s daughter was diagnosed with physical difficulties in pre-school and autism in reception. He believed that having only a teaching assistant for support was detrimental to her social skills and academic development. 'They have teaching assistant support. That's it. No extra support in helping her to develop, she needs constant interaction to help her and she's not developing because of that.’ He also had a recommendation from a paediatrician that she remained in mainstream schooling with support. Despite this, the school repeatedly suggested reducing her full-time schooling to part-time. 'At one time, they were trying to push for her to only to attend for half a day, because of a lack of lunchtime facilities to support her to eat'.

***Inadequate staff training for schools***

All caregivers shared the view that many barriers to mainstream schooling occurred due to a lack of staff training on how to support children with SEND. Sadie felt that teachers needed a better understanding of the impact of transitions on children with autism:

'They need to understand the transitions from one school to another, one class to another, and what impact that has. They need to understand not just the strategies but how to apply them.'

Sadie felt that a reason her son encountered difficulties was the lack of transition support to the junior school, despite her numerous attempts to meet with the school. The change in her son's class teacher, the day before the start of term compounded his anxiety: 'there was a complete lack of understanding of what impact that would have on him.' Furthermore, she was aggrieved that the successful support plan in the infant school was not adequately followed by junior school staff:

'From my perspective, the underlying issue was the support plan that was in place in the infant school did not follow him adequately to junior school. The junior school did not put any support in for him from day one. They didn't find out from the infant school how they managed him.'

A barrier to securing an EHC needs assessment was one head teacher’s belief that the child would not meet the threshold for assessment. Justice: 'We suspected that something else is wrong, was she autistic or something, we had to push the school because she wasn't like the other children.' They quoted the head teacher as saying: 'We cannot meet his needs. He will never reach the thresholds for an EHCP.’ Viv had a similar experience, as the school declined to support her in requesting an EHC needs assessment:

'We went to the school and said that we would like to go ahead and try and get an EHCP. The head teacher tried to laugh it off. He said ‘he hasn't got a learning difficulty, so I don't think he will be able to get a statement’. They were reluctant to apply for one, to do all that work.’

Four caregivers shared the view that schools need more knowledge and understanding of effective practice for children with SEND. Olwen said, 'Schools need more trained staff, specific specialist staff, for ADHD autism and things like that.' She felt this included an understanding that children's reactions can be based on anxiety: 'It's probably something so easy to fix; a funny smell or somebody's getting on their nerves. Somebody's behind them scraping on the desk.' This compounded her child’s anxiety, leading to the school using restraint as a method of 'keeping him safe'. The school had disclosed with her that this was their only way of dealing with him, wrongly claiming that it was a ‘Team-Teach’ method. 'They started holding him one person either side; they found the only method to keep him safe was to hold him in a restraint face down in school as part of Team Teach. His head would be turned to the side face down with one member of staff checking he was still breathing.'

Sadie recalled that when her son hit the head teacher, she was asked to collect him from the middle of the playing field because they didn't know how to approach him:

'He was sat on the floor, rocking backwards and forwards, and sobbing. I asked what happened and he told me he hit the teacher. He said, “I can't help it, mum, I can't stop myself from doing it, I get so frustrated with them I've done it again, I'm a bad boy”.'

Viv suggested that older teachers have a greater need for training: 'They don't believe in ADHD and the spectrum; they are just naughty children.' Sadie added that for developing teacher understanding of children with autism, identifying who is in crisis, anxious and/or frustrated was important. She reflected that her son was disciplined for writing negative comments when asked to write his thoughts down: 'He wrote “I hate school. I hate my teacher". He did what he was told. He wrote down the things he wasn't allowed to say out loud and they told him off. So it's not just about the strategy in place; it's about understanding what it means to that child.'

Sadie recalled a time that her son was given a fixed-period exclusion for hitting a teacher when he was seven:

'They'd recognised he was getting anxious; they recognised he needed to calm down. They put him in a pop-up tent in the middle of the classroom of 64 children and then were surprised when he started hitting and kicking the inside of the tent. When the teacher went over to stop him, he hit her. He's not thinking rationally at that point. The strategy was there; get him somewhere safe, allow him to vent a bit, but the execution of it lacked any kind of comprehension of what they were dealing with.'

**Psychological impact**

***The psychological impact of school exclusion on the child***

Three of the caregivers talked about their children disclosing suicidal thoughts. Sadie's son received two fixed-period and one permanent school exclusion in the space of ten days after starting junior school. She described that he was in a state of crisis when he left the school: 'We haven't told him that he was excluded. He was in crisis. Absolutely in crisis when he left school. He was saying things like “I want to live in heaven where I can be away from all the nastiness in school.” He was in pieces, it was dreadful.'

Viv also shared that her son accessed CAMHS, as his mental health was suffering following the transition to secondary school: 'He was saying things like he didn't want to be here. He didn't fit in. Nobody liked him; he had no friends.' By age eight, Viv’s son felt he was different from the other children, which was another factor in his deteriorating mental health: 'There was nothing positive in his life. Apart from his home life. But there was nothing positive in his school life.' On being told he had autism, he had responded: ‘“I haven't, I'm not. I'm not on the spectrum; there is nothing wrong with me.” Just denial, he didn't want to be different. He wanted to be the same as everybody else.'

Olwen also identified that her son was struggling: 'You can see the anxiety, and when your son says he wants to die that is hard to listen to. So, every day he would come home with this planner and it would be “he has done this and that…” There would be no positives, nothing to bring his spirits up. So, he felt down all the time.’

***Victimisation***

Viv and Sadie both recollected that other children victimised their children in school. Sadie said, 'I think he was being teased, but because of his condition he was being bullied, he was seen responding to that… and it just snowballed really rapidly.' Likewise, Viv felt her son was targeted; other children would wind him up, knowing he would react by lashing out because he couldn't cope:

'They had a focus. Someone to bully, someone to wind up. They thought it was funny when he went ‘bang’. They knew that he couldn't take it so they would do it. And they would call him names, like retard, spacker. All these awful names.'

Viv shared that the psychological impact on her son, due to the constant victimisation, was that he was always anxious. She explained how another child dislocated his finger by pulling it back during a football match: ‘In the car on the way home I asked “are you okay?” and he said “yes” but he sounded upset. I asked “what's wrong?” At this point, he was 6 foot 2; a child in a man-sized body. And he just put his head in his hands and had a full meltdown. The awful thing was that he just wanted to have one friend, just to fit in. It was heart breaking, really.'

***Impact of restraint***

Lucy was the only caregiver whose son had experienced multiple restraints. During eight weeks in year 11, it was recorded by the school that he had 16-18 holds. The restraints progressed from one person either side to lead him away, to holding him face-down in what they wrongly described as the ‘Team Teach’ approved method:

'When he was permanently excluded. I found out afterwards it would be up to seven male staff holding him down. His head would be turned to the side face down with one member of staff checking he was still breathing. You wouldn't do it to a prisoner but you can do it to a young person with a disability, it is scary. As you can imagine, he was in a very anxious state if he had a bad day'**.**

The reason for the restraint with seven adults was not explained; the school reported that he had ‘ruffled a child's hair’ but it was not reported that he had hurt anyone. Lucy recalled that during a care, education and treatment review, social care raised concerns about the increasing restraints in school. The EHCP and educational psychologist report also recommended the use of safe spaces to support emotional regulation. However, the school was unable to make these provisions due to a lack of space. Since the restraint, Lucy’s son does not trust adults and is distressed if she holds his hand too tightly. She had initially appealed the exclusion but after accessing his records and reading about the extent of the restraints, she has decided to homeschool.

***Psychological impact on parent***

All caregivers recalled a detrimental effect on their mental health and wellbeing. Lucy had to end her three-decade career in the NHS due to taking time off to homeschool her son: 'They said “you need to get back to work” and I can't. I'm very upset. I'm going to claim benefits. I have no other income apart from child tax credit for my other son.'

Olwen described the dread of getting phone calls during work hours to collect her child: ‘It would be “you have to come and get him immediately!” My heart starts racing, anxiety straight away. When I came back to my desk and I'd had, like four phone calls and a text message.' She shared how she would ‘put on a brave face and go to work but ultimately inside you're almost dying because I'm sending him somewhere that is not able to meet his needs.'

Viv raised the emotional toll of victimisation experienced by her child and the many failed requests to gain an EHC needs assessment: 'I was shaking. I was so angry. I could have cried with anger. I was on medication and beta-blockers; it was such a bad time. We were totally failed by them (schools).’ The EHC needs assessment was granted in year 11, following requests in years four, six and ten.

'It's taken so long. It's been so hard, emotionally. Last year I was ill, it wasn't my son's fault. It was that he wasn't getting support. We weren't getting the support. I was ill with worry. I couldn't sleep. That's what happens when you get these poor children in the middle.'

Justice agreed that parents need emotional support. He found that the level of care necessary for his daughter meant he would have benefited from support after school and on weekends. He also felt that the school were pressuring him to move his child with physical difficulties to a new school. 'They were saying that if Ofsted came, they would ask who had responsibility for looking after that child.'

Similarly, Sadie said that emotional support was needed, as caregivers can't always fight the system or afford private assessments:

‘These children are being marginalised and treated in a way that is shoddy and unlawful, and there is no one stopping it from happening. It can't be the parents because they can't do it. It's not just about the money, it's about the ability to do it, and to figure out what the hell am I going to do now? Many parents wouldn't do that or couldn't do that or couldn't fight their way through the red tape.'

**Health imposed barriers to diagnoses**

Most caregivers felt that if health professionals had diagnosed their children's disabilities sooner, they might have been able to access better support and more appropriate school provision. Justice claimed: 'You need experts to diagnose children quicker. We had to pressure them; if she had been diagnosed earlier then she would have got that support, she could have gone to a specialist school.’ His daughter was kept in reception class for a second year due to her limited speech development. When Viv's son was three and a half, she took him to a speech and language therapist but was told there were no concerns. At eight-years-old, he saw another speech and language therapist and a consultant, who diagnosed autism.

On being rejected by CYPS and learning about the 12-week waiting list for CAMHS, Sadie organised private observations and assessments of her son, driven by the belief that the junior school would have to consider his needs if he had a formal diagnosis. 'They said “he's very high functioning but on the autism spectrum”. It was always borderline, always quirky.' Olwen recalled that her son was discharged twice from CAMHS, who could not identify any underlying needs: 'You can't get into CYPS unless referred from CAMHS. You don't just get that it's not automatic because they kept saying, “he's too young”.’ Fixed period exclusions followed and she returned to health services for support:

'Finally, they decided to refer because I kept going back, and I kept going to my GP saying he has been suspended again. So they referred him to CAMHS. We had to wait for ages for an appointment and eventually we got referred to CYPS. You're talking years 4-4 1/2 years. It's terrible really when I was crying on my knees for help.'

**Effective support**

All caregivers could identify periods where diagnosis, provision and practice *were* sufficient for their child.

***Meeting individual needs***

Sadie recalled the positive relationship she had with her sons' infant school: 'They were fantastic. I had a good relationship with his teacher. We spoke quite regularly because I picked him up from school… His teacher was also the SEND coordinator, so that was helpful and we just had an eye on it.' This gave Sadie and her son opportunities to ask the teacher questions.

'They gave him a little they said to write it down, “we can't talk to you all of the time. We'll have 10 minutes to talk to you afterwards”, and that really settled him and he was absolutely fine. He didn't need that book for very long; he sort of got into the swing of it and he was fine.'

Viv felt alternative provision was effective for her son because: 'This school takes children more as an individual. Because all the children in here all have different issues.' They started the EHC needs assessment application when he arrived at the school: 'They decided to help. Get evidence. Get an educational psychologist. Did all the groundwork. We had meetings; my son inputted; everyone put everything together.'

Lucy felt there was a lack of suitable provision in the local area so decided to homeschool, which she felt was best for her child’s mental health: 'The majority of the time it's him and me at home, and he's quite happy; he likes just him and me. I have no problems taking him out; he's mostly fine 99.9% of the time.'

***Health good practice***

Lucy and Olwen were both positive about health services. Lucy noted, 'After his crisis [being restrained by seven adults], the psychiatrist came out to the house to discuss medication with us.' Olwen also highly valued CYPS in securing support for her son: 'They are great, I have to say. CYPS are brill! They are the most helpful professionals who work alongside children with ADHD and other issues.'

***Voluntary organisations***

Access to voluntary organisations has been helpful for the caregivers at varying points. Lucy named Sunderland Carers Centre, Young Carers and the National Autism Society as supportive organisations. Sadie felt that Autism Outreach was helpful, as they went into the school to put a comprehensive plan in place to support her son. Olwen commended the Sunderland SEND Information, Advice and Support Service: 'She is an angel. She is just brilliant. She's independent, she's for the school and the parents. You know, she's amazing. Sunderland Carers as well – they were really good just to talk to somebody.'

**Discussion**

The study set out to determine the barriers and enablers to mainstream schooling for children with autism and to explore the effect of the journey to school exclusion on the child and caregivers.

The CAFA (2014) created a statutory duty for the involvement of caregivers in decisions that affect their children. Supporting caregivers via early identification, high quality provision, decision-making, choice and control, and agency collaboration are explicit in the (DfE and DoH, 2015) code. However, the findings from this study suggest that the caregivers met barriers to gaining prompt assessment and identification of SEND across education and health.

The caregivers encountered challenges gaining school support to apply for an EHC needs assessment, despite the child meeting the legal test of 'has or may have an SEN' and 'may need special educational provision' (IPSEA, 2020) while also having fixed-period and in some cases permanent school exclusions. The theographs (Figures 1-5) illustrate that, beyond infant school, the burden and responsibility was on the caregivers to seek and fight for support across health and schools. The weight of the evidence in this study and others (Pirrie et al., 2011; Martin-Denham et al. 2017; Horridge, 2019; Martin-Denham, 2020a, 2020b, 2020c, 2020d) affirm the importance of early identification to prevent disrupted pathways due to children’s disabilities, which remain misunderstood in some school contexts. A lack of early identification raises concerns as to the short- and long-term impact of disabilities on wellbeing and academic outcomes.

The caregivers in this study had noticed and reported concerns about their children's development and behaviours as soon as they became apparent. Based on the children's later diagnoses, this study supports other research findings, showing that caregivers can accurately predict when their child has disabilities (Glascoe, 1999; Tervo, 2009; Woolfenden et al., 2014; Ireland and Horridge, 2019). The findings indicate an implicit understanding among caregivers that the burden of securing a diagnosis fell predominantly to them, and they believed this would be a gateway to support.

The analysis and the theographs (Figs 1-5) suggest that both education and health professionals often rejected these caregivers’ referral requests for identification and assessment of needs. This finding echoes those of Hutchinson and Crenna-Jennings (2018) and Martin-Denham (2020a, 2020d), who declare that children are rejected by mental health services when they do not meet service thresholds. These results bring into question the level of knowledge and understanding of some schools regarding the legal basis for EHC needs assessment: ‘the child or young person has or may have SEN; and special educational provision may be required’ (IPSEA, 2020). The theographs also illustrate that children often must be in crisis and experience school exclusions to secure assessments of needs.

Caregivers of children in secondary education identified that mainstream schools were not equipped with the knowledge, skills, understanding and funding to provide robust evidence-based practice and care for their children. The tension between the needs of the child, available provision and evidence-based practice was clear, and creates a barrier to the successful implementation of the CAFA (2014) reforms. Despite medical and educational psychologist reports, and EHCPs explicitly stating that the child needed support from the school to be regulated and to therefore access learning, it was claimed that this did not consistently occur. However, good practice was identified in infant schools, perhaps due to the increased presence of teachers at school drop-off and pick-up, and collegiate working between all parties. In general, there is a need for ongoing training for schools to ensure that they understand and apply reasonable adjustments for children as required by the Equality Act 2010.

The findings from this study support the view of the Autism Education Trust (2020), that children with autism are at an increased risk of school exclusion. There appears to be a lack of understanding regarding the individual nature of autism and how it can cause a child to become overwhelmed due to unsupported transitions, learning environments, lack of reasonable adjustments, and the availability of highly trained and qualified staff.

This study also highlighted an illegal exclusion for a child with a disability who was unable to feed herself at lunchtime without support. This contradicts the DfE (2017) statutory guidance, which makes explicit that children can only be excluded for disciplinary reasons, and the DfE (2015) statutory guidance on supporting children with medical conditions to have full access to education. Continued efforts are needed to ensure that all mainstream schools across the age phases are accessible and inclusive for children and young people with autism and co-morbidities. The findings of this research indicate that this lack of support and understanding was detrimental to the children’s wellbeing and mental health. Consequences for these children ranged from being anxious to suicidal, which is of serious concern. Positive interventions from voluntary organisations and crisis psychiatrists were reported as making an impact. However, they are called-upon when the damage is already done, after the children have been excluded and their mental health is adversely affected.

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