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Exploring family perspectives on secondary school non-attendance: Challenges and potential solutions

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University of Sunderland

Executive Summary

Anxiety is one of the most significant drivers of persistent non-attendance among secondary-aged children in England. In Northumberland, this mirrors national trends: persistent absence rates remain higher than before the COVID-19 pandemic.

This study explored the experiences of sixteen caregivers of neurodivergent children with a diagnosis of autism and special educational needs and disabilities (SEND). In-depth interviews with caregivers were analysed to identify recurring patterns in lived experience, and children's experiences were captured through the 'Pull Up a Chair' creative arts research film.

The findings from the interviews with families revealed a consistent pattern: non-attendance is rooted in a complex interplay of factors, not unwillingness. Many families said that EHCPs were not effective as their schools were unable to provide the support necessary for their child to thrive and achieve. Families described poorly connected services, with fragmented communication contributing to children reaching crisis point before meaningful support was offered.

Mainstream secondary school environments were frequently described as overwhelming. Noise, crowded corridors, sensory-aversive uniform policies, unpredictable transitions, and inconsistent sanction practices generated significant anxiety and dysregulation. Rigid attendance and behaviour policies particularly detentions, exclusions, toilet restrictions, and threats of legal action escalated children's distress. Some families reported their children experienced crisis episodes, developed self-injury behaviours, or physical symptoms such as vomiting and diarrhoea. Their view was that these responses were triggered by pressure to attend school.

Crucially, the study also identifies clear protective factors that enable re-engagement. Children were more likely to attend and learn when they had access to trusted adults, predictable routines, and smaller, sensory-friendly learning environments (e.g., ARC units). Flexible timetables, hybrid learning, early/late transitions, and home-school blended approaches reduced anxiety and supported gradual re-entry. When schools communicated compassionately, acted consistently, and collaborated with families, children showed improved emotional stability and learning outcomes. These examples demonstrate that many barriers to attendance are environmental and systemic, not intrinsic to the child.

The evidence from this research highlights an urgent need for the protective factors identified to be in place across all schools, such as early identification, an increase in specialist provision places, reasonable adjustments and neurodivergent-affirming practice. Without this, attendance challenges will continue, with long-term consequences for wellbeing, attainment, and equity. A systemic approach needs to be taken to enable all children and young people to access education safely, sustainably, and in ways that reflect their individual needs.

Recommendations

From the findings of the research, ten recommendations were identified for local and national response. In brief:

Recommendation 1.
Strengthen early identification and assessment pathways

Recommendation 2.
Improve EHCP quality, deliverability, and accountability

Recommendation 3.
Develop sensory-friendly and low-arousal school environments

Recommendation 4.
Embed trusted-adult models across secondary schools

Recommendation 5.
Create flexible, co-produced attendance pathways

Recommendation 6.
Reform 'behaviour policies' to be neurodiversity-aware

Recommendation 7.
Enhance communication pathways with caregivers

Recommendation 8.
Strengthen transitions from primary to secondary school

Recommendation 9.
Neurodiversity training

Recommendation 10.
Expand access to therapeutic and alternative provision

'Northumberland County Council have valued the opportunity to explore and understand in greater depth, the experiences of families whose children are experiencing significant barriers to school attendance. Our 'Belonging and Attending framework' offers schools a structured approach to reviewing their approaches to supporting attendance (from their universal provision to specialist support) by focusing on developing a sense of 'belonging'. We are pleased that the recommendations made by families are in line with work already undertaken to support our Special Educational Needs and Disability Strategy (2025-2028)' **David Street, Director of Education at Northumberland County Council**

*Where the text uses the word 'caregiver,' it should be read as inclusive of carers and any other person with parental responsibility.

Acronyms

ADHD Attention Deficit Hyperactivity Disorder
ARC Additionally Resourced Centre
CBT Cognitive Behaviour Therapy
CME Children Missing from Education
CYPS Children and Young People's Service
DfE Department for Education
EBSA Emotionally Based School Avoidance
EBSNA Emotionally Based School Nonattendance
EWO Education Welfare Officer
EHCP Education, Health and Care Plan
EHE Elective Home Education
KS Key Stage
LA Local authority
NHS National Health Service
OCD Obsessive Compulsive Disorder
SEMH Social, Emotional and Mental Health
SEND Special Educational Needs and Disabilities

Glossary of Terms

Term	Definition
Authorised absence	Absence approved by the school (e.g., illness, medical appointments).
EHCP (Education, Health and Care Plan)	A legal document outlining a child's special educational needs and the support required.
Elective Home Education (EHE)	When parents choose to educate their child at home rather than in school.
Emotionally Based School Avoidance (EBSA)	School attendance difficulties driven primarily by emotional distress or anxiety.
In-school exclusion / internal exclusion	When a pupil is removed from their usual lessons but remains on school premises.
Masking	When neurodivergent individuals consciously or unconsciously hide their difficulties to appear "fine" in social settings.
Persistent absence	Defined by DfE as missing 10% or more of school sessions.
School-Based Anxiety	Anxiety triggered by school environments, demands, or social interactions.
SEN Support	School-level support for children with additional needs who do not have an EHCP.
Severe absence	Defined by DfE as missing 50% or more of school sessions.
Suspension	A fixed-term exclusion where a pupil is temporarily removed from school.
Unauthorised absence	Absence not approved by the school (e.g., truancy, parent-condoned absence).

1.0 Background

Understanding the rising levels of school non-attendance requires close examination of both national trends and local contexts. This section outlines the broader policy environment, recent attendance and exclusion statistics, and the range of language used to describe anxious children, providing essential context for interpreting the experiences of children and caregivers in Northumberland. By situating the study within current evidence and national concern about persistent absenteeism, the background establishes why this research is timely and necessary.

The term used by Northumberland County Council to describe children not attending school due to anxiety is 'Emotionally Based School Non-Attendance' (EBSNA). The preference for the families in this study was 'School-Based Anxiety' as they felt their children's anxieties were caused by the school environment rather than external factors. In recognition of the preference of those who took part in the study, School-Based Anxiety will be the term used in this report.

Rising numbers of young people encounter barriers to attending mainstream education. There is little research into the contributing factors from the perspective of families. The Children's Commissioner's attendance audit highlighted that following the Covid-19 pandemic, increasing numbers of children were not attending school or were regularly absent. Key drivers for not attending school included not having a positive experience at school or unmet needs in school (Children's Commissioner, 2023a)

The Children's Commissioner (2023a) reported increasing concern regarding the number of children nationally not in school or not attending regularly. Between 2015/16 and 2023/24, there has been a 57% increase in school absence rates in England, rising sharply around the COVID 19 pandemic and not yet returning to pre-pandemic levels (Bond et al., 2024). The Department for Education (DfE) statistics show that national absence continues to hover between 6–7% (DfE, 2025). This trend is not unique to England and has been mirrored globally (Kearney, 2025). Higher absence rates are associated with poorer academic attainment, with stronger correlations in more deprived areas such as the North East and South West (DfE, 2025). Other negative effects include long-term physical and mental health impacts and reduced chances of employment (Kearney, 2025). School non-attendance and exclusion figures are also particularly high in the North East and South West of England. This study investigates risk factors for persistent absence in Northumberland County in the North East. Absence rates in Northumberland have risen from

4.57% in 2016/17 to 6.92% in 2023/24, reaching a high of 7.93% in the 2021/22 Autumn and Spring term. Absence figures in Northumberland typically surpass national averages; however persistent and severe absenteeism rates are often lower than respective national figures (DfE, 2025).

One of the reasons that a child may not be attending mainstream education is that their caregivers have elected to home educate; these young people are not reflected in attendance figures. The DfE records these instances and publishes statistics on what they have named 'elective home education' (EHE) every year. Nationally, the percentage of children EHE has risen gradually from 1.0% (Autumn 2022/23 to 1.5% (Autumn 2025/26). In the North East, this figure rose from 0.8% to 1.5%, and in Northumberland it rose from 0.9% to 1.3% in the same period. In the most recent data collection, there were 550 children in EHE in Northumberland, which has risen from 360 since Autumn 2022/23 (DfE, 2026a).

A small proportion of children in the England are not on a school roll and are also not recorded as EHE. These children are referred to as 'children missing education' (CME). Between Autumn 2022/23 and Autumn 2025/26, the number of CME nationally rose from 24,700 to 34,700, an increase of around 40%, although this only corresponds to an increase of 0.3% to 0.4% in England's total proportion of CME in that period. These figures also rose in the North East, increasing 70% from 470 to 800 in this period, and the figure exceeded 1,000 in the Autumn 2024/25 data collection. In Northumberland, it is difficult to know the exact number of CME, as data are rounded to the nearest multiple of 10, therefore Northumberland's CME figures fluctuate between 10 and 30 for each census between Autumn 2022/23 and Autumn 2025/26 (DfE, 2026b).

Overall, the data indicate that neither permanent exclusions, suspensions, nor the number of children recorded as EHE are sufficient to explain the wider rise in school non-attendance. Suspensions (Code E in attendance data) do not contribute to CME figures, and those who are EHE are only counted as CME if the education is deemed unsuitable. A substantial proportion of the increase in absence is therefore likely to relate to children who remain on a school roll but are nevertheless not attending. These children appear in attendance data (as either authorised or unauthorised absences), but they are not counted as CME. Research has historically suggested that many of these children struggle to access school because of overwhelming sensory, emotional, or environmental demands, a pattern noted as early as Broadwin's (1932) work and consistently echoed in contemporary literature.

2.0 Methodology

This section explains the phenomenological approach underpinning the research and details how caregiver experiences were captured and analysed. It outlines the research aims, objectives, recruitment processes, and participant characteristics. By clarifying the methodological choices, this section demonstrates how the study prioritises the voices, lived experiences, and emotional realities of caregivers whose children struggle to attend school.

There is a significant gap in research regarding the views, wishes and feelings of caregivers of children and young people who are not in school. The methodological approach to the project is phenomenology as it strives to explicate the meanings as experienced in the everyday existence of our lifeworld (Husserl, 1970; Schutz and Luckmann, 1973) from the perspective of the person experiencing it (Moran, 2000).

2.1 Aim and objectives

The aim of this research was to better understand non-attendance at school among secondary-aged children in Northumberland. The objectives were as follows:

1. Explore current literature to identify factors contributing to non-attendance
2. Determine the characteristics of children and young people not attending school
3. Explore the health and well-being needs/ status of children not attending school
4. Examine the experiences of schooling and wider services from the perspective of children not attending school and their caregivers

The project had 3 connected phases:

Phase 1. Scoping review of current literature

Phase 2: A film co-created with children with School-Based Anxiety

Phase 3: Sixteen semi-structured interviews with caregivers of children with School-Based Anxiety.

2.2 Methods

This section outlines the methods used for the three phases of the research. The method for phase 1 was a scoping view of current literature on school absence (section 2.3); phase 2 a co-created film with seven children and their caregivers, known as Pull Up a Chair (section 2.4) and phase 3 sixteen interviews with caregivers of children who were persistently/severely absent from school (section 2.5).

2.3 Phase 1: Scoping review of current literature

The following section summarises the scoping review of existing research on school non-attendance. It explores known risk factors, key demographic influences, theoretical frameworks, and the role of terminology in shaping understanding of School-Based Anxiety.

2.3.1 Absence terminology

DfE (2024, p. 45) statutory guidance shares terms to describe persistent and severe absence from school:

Persistent absence: 'Where absence escalates and pupils miss 10% or more of school (equivalent to 1 day or more a fortnight across a full school year).'

Severe absence: 'Absent from school more than they are present (missing 50% or more of school).'

2.3.2 Characteristics of children not attending school

Research has identified specific demographics in the UK that may be more susceptible to school absence. A child is more likely to be absent if their family are frequent movers, Gypsy, Roma and Travellers, or refugees/asylum seekers. Risk is also heightened for children who are disabled, those with SEN, teenage mothers, young carers, children in care or young offenders (Ryder, Edwards and Rix, 2017). Socioeconomic disadvantage and free school meal eligibility are also strongly linked to persistent absence; the national persistent absence rate in 2023/24 was around 20%, rising to 37% for disadvantaged children and 35.7% for those eligible for free school meals. SEND classification may further increase a child's risk of non-attendance, with persistent non-attendance rates of 37.6% for children in special schools, and similar figures for children with an EHCP (DfE, 2025). Children with social care involvement are also more likely to experience non-attendance, particularly those with short-term involvement (Sanders-Ellis et al., 2023). There is considerable overlap between these demographic groups and those at higher risk of suspension or permanent exclusion (DfE, 2026c).

2.3.3 Barriers and enablers to attending school

While certain demographics may be at higher risk, barriers to mainstream schooling can affect any child. Barriers may include poor relationships between children and staff, large class sizes, inflexible behaviour systems, and academic pressure (Epstein and O'Flynn, 2019; Martin-Denham, 2020). Local area guidance has begun to acknowledge attendance difficulties caused by emotional factors (Hammond-Price et al., 2025). Many local authorities have produced guidance recommending assessment of needs, tailored support plans, and referrals to relevant services (Southampton City Council, 2022; Solihull Metropolitan Borough Council, 2023).

Recent research on the factors impacting non-attendance at school emphasises the importance of identifying early signs and risk factors. Ingul, Havik and Heyne (2019) provide a comprehensive framework identifying 17 early signs and risk factors for non-attendance, paired with potential interventions and their evidence base.

Attempts to conceptualise environmental risk factors vary. The largest meta-analysis of school non-attendance risk factors synthesised 75 studies and identified seven categories (Gubbels, van der Put and Assink, 2019):

- Physical and mental problems
- Substance abuse
- Antisocial or risky behaviours
- Problems at or with school
- Characteristics of the school
- Parenting problems and difficulties
- Family (structure) problems

Taken together, these seven categories illustrate that school non-attendance does not originate from a single source, but from the interaction between numerous individual, familial, and school-level influences. Many of the identified factors cut across multiple domains: for example, 'parenting problems' and 'family structure problems' sit within the home environment but are often shaped by wider socioeconomic pressures, while 'problems at or with school' may reflect both school-level practices and the quality of home–school relationships. Their meta-analysis underscores the need for a multifactorial approach that recognises how "key influential factors are interrelated' (p. 1638). This complexity also highlights the importance of understanding how schools, parents, and the children themselves interpret and navigate these influences.

Other meta-analyses have narrowed their focus to perspectives on school non-attendance for specific actors in a child's ecosystem. A meta-analysis of staff perceptions in England identified four domains (Alaimo and Kelly, 2025):

- Home environmental factors
- School-related factors
- School and staffing resource strain
- Within-child factors

These perspectives broadly mirror the risk factor domains identified in larger meta-analyses but strongly emphasise the importance of school-based effects, and their beliefs and attitudes towards school attendance, and potential solutions, tended to be shaped by the pressures and constraints of the school environment.

A meta-analysis of children and young people's perspectives identified seven themes: belonging, relationships, transitions, learning experiences, emotional wellbeing, others' perceptions, and personal beliefs about attendance (Corcoran and Kelly, 2023). Crucially, children and young people's contributions focused on the centrality of relationships and belonging and suggest that childrens' experiences of school attendance strongly relate to the extent to which they feel "accepted, respected, included and supported by others in the school social environment."(p. 33).

Research incorporating caregiver perspectives on risk factors related to school non-attendance is limited, and unlike staff and children's perspectives, there are few meta-analyses of such studies. Individual studies on the views of caregivers have found that school-level factors are their biggest concern, which can take the form of bullying, inflexible curriculum, and poor relationships between students and staff, associated with a distrust of school and negative school experiences. Continuing to investigate parent and carer perspectives is crucial, particularly since the small number of existing studies have found that they describe their predicaments as 'desperate' and felt that they were not being listened to. (Heyne et al., 2019; Lissack and Boyle, 2022).

These studies and meta-analyses implicitly or explicitly map onto Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1994). The theory posits that a child's development is shaped by multiple nested systems. Bronfenbrenner suggests the following interconnected systems from which influences can originate:

- Microsystem: Influences that have direct contact with the individual in their immediate environment (home environment, family members, peers, etc.)
- Mesosystem: The interaction between different settings in the microsystem (e.g., the impact of home environment on school)
- Exosystem: Broader social structures and institutional contexts (extended family, local government, social/mass media, etc.)
- Macrosystem: The overarching cultural and policy environment (Social norms, economic landscape, educational policy, etc.)
- Chronosystem: The change or consistency over time not only in the characteristics of the person but also of the environments in which the person lives (e.g., COVID-19)

Bond et al. (2024) highlight how ecological mapping can help identify needs at different levels of a child's ecosystem and emphasise the chronosystem, particularly the disruptive impact of the COVID-19 pandemic.

While many risk factors (including those identified in the previous meta-analyses) can be mapped to ecological systems, the mechanisms that generate them often originate from multiple levels. For example, "antisocial and risky behaviours" may be expressed within the microsystem but shaped by mesosystem interactions (poor communication between home and school), exosystem conditions (overstretched pastoral support), or macrosystem inequalities (punitive attendance policies). This illustrates the interdependence of systems and the complexity involved in identifying and evaluating risk factors associated with school non-attendance.

2.4 Phase 2: The Film: Pull Up a Chair (Out of Space)

Pull Up a Chair is a creative arts-based approach that empowers children and young people who otherwise might not have a voice to be heard. The approach is grounded in relational practice, trauma-informed approaches, and co-production. Many children, particularly those who have experienced challenges at school or home, may find it difficult to articulate their thoughts and feelings. Pull Up a Chair offers a range of creative ways for children to express themselves and communicate their views in a safe and supported space. Creative arts are a powerful tool for enabling children to express their voice, especially those who may not have the confidence to communicate their feelings through traditional means. Seven children spent five days working with the team (Sarah Martin-Denham, Ruth Johnson and Laura Degnan) and created the film Pull Up a Chair - Out of Space.

2.4.1 Recruitment for Pull Up a Chair

The children and caregivers were recruited through a flyer circulated on social media platforms and via the Northumberland Local Authority. The criteria for taking part were, first, to be of secondary school age and to be experiencing persistent or severe absence from school or not attending school. Secondly, to have a Northumberland home postcode. Potential participants contacted Dr Sarah Martin-Denham directly to discuss the project in detail and to find out relevant information needed in advance of the project, namely:

- Name, pronouns, age, strengths, hobbies and interests
- Support needs, transport arrangements and any physical/medical needs
- Food preferences and accessibility needs

2.4.2 Consent

Approval was sought and gained from the University of Sunderland Ethics Committee. All children and caregivers completed consent forms to participate in the project. Some chose verbal consent recorded on a Dictaphone. Consent was reaffirmed throughout the five days of the project. The consent was recorded on a tracker for film, audio and photographs of the children's artworks. The consent forms were stored at the University of Sunderland OneDrive with a ten-year deletion period.

2.4.3 Participant demographics

To safeguard personal information of the seven children, only limited demographic information will be shared. Of the seven children, five identified as female and two as male. All were White British (WB) Of the five caregivers all identified as WB and identified as female.

2.5 Phase 3: Interviews with caregivers

Approval was sought and gained from the University of Sunderland Ethics Committee. The interviews with caregiver included fifteen 1:1 phone interviews and one face-to-face interview with two caregivers during the Pull Up a Chair film project.

2.5.1 Participant recruitment for interviews

The participants were recruited through a flyer circulated on social media platforms and via the Northumberland Local Authority. The criteria for taking part were first, to have a child of secondary school age experiencing persistent or severe absence from school or not attending school. Second, to have a Northumberland home postcode. Potential participants contacted Dr Sarah Martin-Denham directly to discuss the project, obtain consent and arrange a convenient date/time for a semi-structured interview.

2.5.2 Consent

All caregivers completed consent forms to participate in an interview. Some chose verbal consent recorded on a Dictaphone. The consent forms were stored in the University of Sunderland OneDrive with a ten-year deletion period.

2.5.3 Interview participant demographics

All sixteen participants identified as female and White British (WB). Ten of the children had an EHCP, and six were designated SEN support. All children had a diagnosis of autism with social, emotional and mental health difficulties.

Table 1. Demographic information of participants (N = 16) and their child

Participant code	Relationship to child	Gender	Ethnicity	Year group/ Key Stage (KS) of child	SEN status	SEND	Attendance (%)
C1	Grandmother	Female	WB	Year 7 (KS3)	EHCP	Autism/SEMH	52.8
C2	Mother	Female	WB	Year 7 (KS3)	EHCP	Autism/Tics/ SEMH	55.6
C3	Mother	Female	WB	Year 7 (KS3)	SEN support	Autism/SEMH	40.0
C4	Mother	Female	WB	Year 7 (KS3)	SEN support	Autism/ADHD/ SEMH	50.0
C5	Kinship carer	Female	WB	Year 7 (KS3)	EHCP	Autism/ADHD/ Trauma SEMH	0.0
C6	Mother	Female	WB	Year 8 (KS3)	SEN support	Autism/ Tourette Syndrome	74.4
C7	Mother	Female	WB	Year 9 (KS3)	EHCP	Autism/ADHD/ Epilepsy/ Dyslexia/SEMH	0.0
C8	Mother	Female	WB	Year 9 (KS3)	EHCP	Autism /ADHD/ SEMH	4.7
C9	Mother	Female	WB	Year 9 (KS3)	EHCP	Autism/SEMH	74.4
C10	Mother	Female	WB	Year 8 (KS3)	EHCP	Autism/SEMH	0.0
C11	Mother	Female	WB	Year 9 (KS3)	EHCP	Autism/ADHD/ SEMH	0.0
C12	Mother	Female	WB	Year 8 (KS3)	EHCP	Autism/SEMH	0.0
C13	Mother	Female	WB	Year 10 (KS4)	SEN support	Autism/SEMH Physical disability	37.2
C14	Mother	Female	WB	Year 11 (KS4)	SEN support	Autism/SEMH	46
C15	Mother	Female	WB	Year 10 (KS4)	SEN support	Autism/OCD/ SEMH	65.1
C16	Mother	Female	WB	Year 11 (KS4)	EHCP	Autism/SEMH	64.4

2.5.4 Analysis approach

Reflexive thematic analysis was chosen to analyse the interview data, as it is a 'flexible, straightforward and accessible' method (Pirrie et al., 2011) and an accepted phenomenological approach (Guest, MacQueen and Namey, 2012). Thematic analysis values subjective, aware, situated and questioning researchers (Braun and Clarke, 2019).

Themes and patterns in the dataset were identified through inductive analysis – reading and re-reading the data (Patton, 2002). This active approach allows for the identification of themes (DeSantis and Ugarriza, 2000). Clarke and Braun (2018, pp. 108-109) clarified that themes must not be domain summaries of responses on topics but should be conceptualised through a central organising concept that 'underpins and connects the observations', the 'so what' of the data. Refining of themes was continual, as Braun and Clarke (2006, pp. 22) urged, 'one test for this is to see whether you can describe the scope and content of each theme in a couple of sentences. If you cannot do this, further refinement of that theme may be needed'. To address this, ongoing refinement of the themes and subthemes took place until the test was satisfied.

3.0 Phase 3: Findings

The findings section presents the core themes drawn from the interviews. The themes and sub-themes were organised into two themes 'challenges in attending school' and 'potential solutions for non-school attendance.' The themes illuminate the daily realities of navigating School-Based Anxiety, the systemic barriers families face, and examples of support that made a positive difference from the caregiver's lived experiences.

3.1 Challenges in attending school

Families consistently described how their children experienced high levels of School-Based Anxiety that contributed to persistent, severe, or complete non-attendance. They identified these difficulties that were influenced by a combination of sensory overwhelm, unmet needs, inconsistent support, and systemic delays across education and health services.

3.1.1 Concerns raised about the SEND system

Families identified persistent delays and gaps in assessment, identification of needs, and support from education and health services.

3.1.1.1 Delays in assessment and identification

Families felt that due to delays in assessment and identification of SEN, many children entered secondary school without appropriate support. They struggled to understand how the waiting list was two years for autism and ADHD assessments, recognising that early identification would support adaptations being in place in school. Caregivers frequently reported that concerns raised during primary school were not acted upon, leading to children reaching crisis point before support was provided. In practice, this meant that support was often reactive rather than preventative. Families felt that 'masking behaviours' often concealed distress from school staff, delaying recognition of need. Many described significant emotional, academic, and relational harm arising from delayed assessment from health services. When allocated appointments, there was frustration at the inconsistent allocation of professionals (e.g., different therapists for each session) which hindered children's willingness to attend appointments.

3.1.1.2 Education, Health and Care Plans

Many caregivers felt mainstream secondary schools were unable to deliver the level of support set out in their child's EHCP. In some cases, schools agreed they could not meet needs, but families still faced long delays finding appropriate placements, contributing to prolonged absence. Caregivers repeatedly described feeling dismissed, not listened to, or deprioritised.

> ***'They don't listen to the parents; parents know more about their children. The SEN department at [County] don't listen. You can only email them and leave a message. You never speak to the same one twice.' (C1)***

They believed that this shortfall between EHCP specified provision and a lack of secondary mainstream school deliverability contributed to children being unable to attend school:

> ***'She needs a SEND school. These mainstream schools are not for her. I need this [EHCP] meeting so that I can get her into a different school, because it's not working.' (C2)***

> ***'It's too specialised [the EHCP], 1:5 teaching ratio, lots of interventions, one-to-one tutoring. That's just not what mainstream are capable of.' (C11)***

Continuing to pursue attendance at a school that cannot meet the child's needs perpetuates a child's distress and not feeling safe. This mismatch between EHCP provision and mainstream capacity was a tension:

> ***'He has an EHCP which names an inappropriate school. That school said they couldn't meet his needs. It's about fear. He said, "I can get over that fence." We're damaging him by bringing him in. He's terrified. We've never been back, but he's still on the school roll.' (C5)***

The process of applying for an EHC needs assessment was seen as time-consuming and difficult to navigate: 'I got an EHCP, which was a lengthy process. It took five months to get it, loads of paperwork, lots of evidence gathering' (C11). Another shared the barrier to applying for an EHC needs assessment was from the school, 'about three weeks ago the action was to look into EHCP. They've [the school] said, because there's not enough evidence, but I sent about 18 pages.' (C4)

Many reported feeling exhausted and disillusioned with the SEND system:

> *'When I got that court date yesterday, I was just like, Jesus, she'll be 15 by then. What am I fighting for?' (C11)*

> *'Because of the backlog we might not get one through [an EHCP] before the end of GCSEs.' (C15)*

3.1.1.3 Transitions and information sharing

Caregivers described being the main coordinators between services. They felt teachers were sometimes unaware of a child's diagnoses or needs, creating additional barriers to support and impacting attendance. They reflected that teachers and support staff would unintentionally overlook needs as information hadn't been effectively shared with them. Families described repeated referrals being lost, declined, or delayed.

> *'Realistically, how can a secondary teacher remember every child in every class, and all of their needs?' (C3)*

> *'Trying to coordinate all the different people was getting so overwhelming. I was in the middle, passing information backwards and forwards, rather than everyone communicating together.'*

> *'we've put the referral in. It was declined two years ago. Now we're just waiting. It's just a waiting game.' (C4)*

> *'Sometimes the teachers don't even know that she's got all these physical illnesses and she's on the spectrum. I'll be like, "well, why don't you know?" They just don't seem to pass the information on.' (C13).*

Many felt primary schools did not act upon their concerns to put plans in place in preparation for secondary school. They feel this resulted in children entering secondary school without the support to manage the transition. Several reported that schools or professionals initially downplayed their concerns, leading to children reaching crisis before meaningful support was offered. Caregivers described instances of secondary schools underestimating the level of need and required support despite this information being shared prior to transition:

> *'We did try to pre-empt the school that there may be some issues, but unfortunately those issues weren't looked at … by the end of the first three months she was nearly unable to attend' (C12)*

In several cases, examples were given where schools implemented punitive measures instead of support, which exacerbated difficulties and contributed to further disengagement from school. Although early intervention was frequently emphasised by professionals, some caregivers reported that support only materialised once a child's attendance had deteriorated significantly. This reactive approach often meant that needs were identified only once the child was already in crisis:

> *'Throughout everything we've been told that early intervention is key. I've found that your child's at breaking point, so you only get any school interest or support when they stop attending.' (C12)*

3.1.1.4 Intensified attendance pressure and threats of legal action

Many said they felt harassed by constant attendance demands and threats of legal action from schools and the Local Authority. At times, they had been advised from health professionals to keep their child off school and this conflicted with what the school expected:

> *'It's horrible because obviously, I'm getting stressed and the councils on my back, her schools on my back because she'll not go.' (C2)*

> *'When I told the school last week that the physiotherapist had said it would be detrimental to her health to do the extra hour, then the school emailed us back and said that I needed to provide medical evidence. I was like, do you think I'm lying? Why would I lie about something like that? Having her at school an extra hour a day would help me a lot. I'm not going to put her in school if she can't do it, and she'll end up being off school more than what she already is now.' (C13)*

> *'I've got the EWO coming to me home, threatening that it's going to go illegal, and I'll be fined.' (C7)*

3.1.1.5 Emotional and physical impact of attendance demands on children

Schools were described as pushing for full-time attendance despite children's medical or emotional issues: 'They want her back full-time. It's like, she can't do full-time. She's keeping up to date with all her work; she's in the top sets. She ends up vomiting or has horrendous diarrhoea' (C13). Anxiety brought about by pressure to attend school and school itself was believed to be the causal factor for physical illness and self-harming responses including vomiting, skin picking, bleeding and 'shutting down.' Some felt there was a link between pressure to attending schools and panic attacks, exhaustion, and even suicidal thoughts:

'They [attendance officers] wanted to try and get him to go in the car with them, and it just totally freaked him out … he ended up not even going to school that day. Is it worth him totally getting that stressed because he's even mentioned killing himself before?' (C6).

3.1.2 Within school barriers to attendance

3.1.2.1 Noise, crowds and changeovers

Many children became distressed during unstructured times of the day, including lesson changeovers, breaktimes, and lunchtimes due to the volume of children. Lunchtimes combining noise, crowds and cooking smells overwhelmed many children.

'The amount of people when they go to lessons. People are pushing each other, and trying to steal each other's bags, and purposely banging into each other and stuff like that, because they think it's funny, but for him it's too much.' (C6)

'She doesn't like crossing over from her lesson. She doesn't like the lessons itself. It's just everything at school.' (C14)

'Her anxiety started before we left the house in the morning and that was something that the school really struggled to understand.' (C16)

Many caregivers had predicted difficulties before their child started secondary school; confirmed during primary school transition visits.

'Me and my husband went up with her, and she wouldn't go in the hall where the headmaster was talking, because there were too many people. I took her round a few of the classrooms. We were going to the English department, and all the kids were coming out, and that was it 'No, I can't, I can't do this.' So, I had to take her out again.' (C1)

'He had a real problem with transitions. Even if it's something he wants to do, transitions are a big issue for him.' (C5)

3.1.2.2 Uniform requirements

Caregivers shared that their children with sensory sensitivities struggled with ties, tight collars, blazers, certain fabrics, or restrictions on removing items of clothing during warm weather. These sensory barriers could make preparing for school and staying in school extremely challenging:

'She could never wear a tie; I had a fight on my hands, but it was in her EHCP and from six, she couldn't wear ties. This is why we couldn't go to her next school [mainstream secondary], because she couldn't stand a tie around her neck.' (C1)

'She's very specific about the kind of tights she wears. We've got to get special tights for her because she doesn't like the feeling of certain clothing.' (C3)

'The uniform is a massive issue, she hates the tie, she hates the shirt around her neck. She doesn't like tags on her clothes. She doesn't like the blazer. I had to buy her huge shirts, just to give her that bit of room around her neck. She feels like the collar's choking her.' (C14)

3.1.2.3 Masking and burnout

Many talked about their children masking their difficulties at school, appearing fine outwardly while experiencing internal distress. They associated masking in school with 'autistic burnout' with subsequent mental health crises and non-attendance:

'In the first year of secondary school, she was masking and then she just went in all-out burnout, autistic burnout. She was cutting back on eating, to the point where we got really concerned about her weight.' (C13)

'She masks everything. It looks like she's fine on the outside, but on the inside, she's actually crumbling. When she's at school, she puts the mask on, but then when she comes home, I get it. She comes home, and I get the stress of her.' (C14)

'Our children are probably some of the most resilient children you will ever meet. They've been so resilient that they push so hard that they've burnt out.' (C12)

3.1.2.4 Learning and teaching

Classroom-based demands were frequently described as a significant source of anxiety.

Caregivers held the view that their child's attendance was negatively impacted by difficulties with processing, sequencing, short-term memory, and suspected dyslexia/dyscalculia. The result was elevated levels of anxiety, particularly in mathematics, a fear of failure leading to an inability or unwillingness to take part in school. This stress was compounded in key stage 4 and in extended school hours for GCSE preparation, as Caregiver 14 explained:

'This is a stressful year for her because she's doing her exams. They get an extra hour now at school, and this is a massive issue with her, because they're doing, like, half eight till three, and then they're doing three till four, just so they can catch up on their work and stuff. It is a strain for her. She's finding everything massive.'

Many believed that teachers misinterpreted behaviours, 'I realise now these teachers aren't trained to deal with neuro kids' (C11). There was an acceptance that teachers were overworked: 'She shouldn't have had to have been shouted at, because she hadn't done anything wrong. 'They're not trained enough [teachers], and then just overworked' (C13).

Many caregivers expressed that their children encountered challenges with forming and sustaining friendships both in and outside of school. Academically able children experienced challenges attending school due to separation from peers. They would often sit on their own and caregivers were concerned this would be detrimental to their social skills:

> *'She's got friends in there, but they're all in the lower sets. It means when she goes to class, to her lessons, the kids are all in their own little cliques, so she sits by herself for most lessons. Then when they have to do group work and stuff, she's just kind of left on her own.' (C13)*

> *'In primary school, it was littler things. She wasn't very good at managing relationships with other children, so if something happened, she would have quite a big meltdown that she'd had a little argument with a friend in the playground or something. She would make it massive because she's not very good at regulating her emotions.' (C15)*

Caregivers repeatedly highlighted insufficient or inconsistent provision of individualised educational support. Many described advocating for one-to-one support due to academic and emotional needs:

> *'I would like more support for her… I would like a one-to-one. She's struggled massively in maths.' (C14)*

Others noted that even basic adjustments—such as visual scaffolds or simplified explanations—were not implemented:

> *'It'd be a lot easier if she was to sit at the front and none of that even got done.' (C7)*

Some caregivers shared that they repeatedly requested that teachers share lesson materials when their child was unable to attend school; only a few teachers complied. This caused frustration over the lack of proactive communication and support for catching up on missed work.

> *'I've said, can the teacher at the end of each lesson email work home? She knows the next day what they're talking about. Up to now, there's only two teachers that send her any work home. I emailed them last week and asked them again.' (C13)*

Some caregivers said schools were not providing tutoring or alternative education despite EHCP funding.

> *'She's not been in school since February… they should be funding what it is for her to get some education, and they haven't done it. It's up to the school, and they've failed her once again… they've done nothing.' (C7)*

Perceived stigma or shame sometimes prevented children from using well intended help-seeking tools (e.g., red/green cards for academic support). Children could resist support because they fear being labelled, bullied, or seen as "different."

> *'it's a fine balance because Child needed the support, but she doesn't want to look like she needs the support to her peers.' (C3)*

> *'They're desperate to fit in, but that makes them stand out even more. So, any adjustments that school could offer would not work and made them feel worse.' (C12)*

Severe anxiety was described as disabling and often misinterpreted as defiance rather than an inability to go to school. Transitions, routine changes, and school holidays heightened anxiety, contributing to cycles of anxiety.

3.1.2.5 Sanctions and toilet access

Many caregivers raised concerns that their child's anxiety about attending school was heightened by school rules limiting or disallowing access to the toilet during lessons: 'Not being allowed to go to the toilet, having to wait for certain times, having to ask and be told no, that's a big struggle for them' (C12). Caregiver 3 supported their view:

> *'I've had to advocate for her, different teachers with different rules, particularly about the toilet. She doesn't have a problem with going to the toilet, but she worries about not being able to go to the toilet when she needs to go. So that makes her need the toilet more. Certain teachers were letting her and certain teachers weren't.'*

She explained a recent event in school:

> *'She started needing the toilet. She then had to go straight from there to her next lesson. In the next lesson, the teacher said no, and then she asked again and the teacher said, 'Are you desperate?' She said yes, and the teacher still didn't let her go. She sat there with tears streaming down her face. It was only another member of staff that came over and she said, 'Are you all right?' She said no, and then that other member of staff took her.'*

At times, sanctions were given as the child's behaviours were deemed to be defiant. The

caregivers believed they were due to their inability to complete work. Some teachers later acknowledged that the issue was academic struggle, not deliberate mis-behaviour. Misinterpretation of behaviours and punitive responses worsened children's anxiety.

> *'She had, and I'm using quotation marks, assaulted a teacher but in her eyes, she was just trying to get away from a situation.' (C15)*

Breaches of behaviour policies led to detention, then suspension from school leading to non-attendance.

> *'When she transitioned to secondary school, Year 7, she just didn't manage at all. She was looking forward to going, and then things just kept cropping up. After-school detentions and in-school detentions. Year 8, just fell apart completely. She was just getting so many exclusions by Year 8. Threats of being managed moved just tipped her over the edge. She just stopped going in February altogether.' (C11)*

Her daughter is still not able to attend school. She described that she is in a vicious cycle of being anxious about school and being sanctioned for forgetting equipment or failing to stay for detentions. In relation to the impact of suspension her mother commented 'it doesn't do anything for her because she doesn't learn from what she's done wrong; she just wants to be at home anyway because she's anxious about being at school, it kind of feeds into her anxiety.' Another example from C7, illustrates the impact of carrying forward sanctions year on year. Her daughter has been out of school for over a year. She is too anxious to return in fear of permanent exclusion. Her mother stated:

> *'They have got her on a Step 6, not because she's a naughty child, not because she's lashing out, not because she's doing what naughty kids do. She's struggling. What's going to happen when it's a new term, to all them steps, because she's not been at the school; they should be literally cleared off? The response I got [from the attendance officer] was, "Well, we'll obviously have a look and then we'll get back to you." I've heard nothing.'*

Most of the caregivers shared that for their children the fear of a sanction prevented them from going to school, despite the fact they had not been sanctioned. Caregiver 16, said that both her children voiced their fear of getting in trouble:

> *'With traffic light systems or demerits, hearing teachers shout down the corridor would induce panic in both of our girls. They find, contradictorily, that the pressure of getting merits, to get their certificates, to always be their best, they find that a huge pressure that they can't sustain.'*

3.2 Potential solutions for non-school attendance

3.2.1 Within school solutions to non-attendance

3.2.1.1 Relationships, belonging and trusted adults

Caregivers reported that their children attended more readily when they felt emotionally safe and connected to key adults. Trust, rapport, and identity understanding are protective; children need adults who are predictable, attuned, and emotionally safe.

> *'He's in a better place because she understands her difficulties.' (C3)*

> *'The tutor kept turning up, now she's fully engaging, in the right environment she can learn.' (C11)*

> *'Help them feel like they belong, without making them stand out.' (C12)*

The place the children felt safest was home as they could be themselves and not mask who they are. Many described home as the child's safe space: 'When she's home, this is what she calls her burrow. Like, she's in a burrow, and nobody can hurt her or pick on her. When she goes to school, she's fallen, but then when she comes home, she's hit the net to safety' (C3). Schools who provided emotional support for both the child struggling to attend school and the family were valued. It was mostly individual staff who were commended:

> *'Thankfully, somebody from pastoral, who had an autistic sister just listened and said, "She could well be autistic and really struggling," so I started educating myself about it more, and then the penny just dropped, and kept dropping and dropping, and then we got the SENCO involved, and she's been great.' (C11)*

> *'Their teacher has been amazing, I have to say. She's been fighting their corner all the way. She's very much about getting them in a good place mentally; she has been amazing on that side of things.' (C15)*

> *'When my grandma died the SENCO helped and got him referred to the primary care team and got a therapist to help him. They've been very supportive.' (C16)*

All consistently emphasised that the availability of a trusted adult in the school settings was a protective factor for their children attending school. Adults who provided consistent emotional support gave their children a sense of safety. One parent described a coordinated approach between home and school that contributed

to stability: 'She goes to see her teacher in the morning, gets things off her chest. We both work together' (C14). The trust between the child and teacher was essential to the child attending school. Teachers who could be trusted to follow through on actions were valued. For example, saying they would contact the parent if they were unable to manage in school and asked to go home. As caregivers 15 and 16 stated:

> *'They trusted them because they stuck to their word on the day that they couldn't manage. They did ring us straightaway. He knew that if anything changed throughout the day, they would contact us and I would be able to bring him back to his safe space.'*

> *'Be very clear in what you're asking and deliver, don't change it when they don't have a trusted adult there to support them.'*

The primary model of schooling had worked well for the children. Yet, the transition to mainstream secondary school was problematic. Talking about the difference between primary and secondary school caregiver one said: 'She'd been there for nearly seven years, so she knew all the teachers and they never changed class, of course. She was fine there.' Others agreed that positive relationships forged with teachers in primary school supported attendance. Caregiver 15 added:

> *'Year 6 was one of her better years. She had a teacher who she really trusted and she really felt quite comfortable with her. She just understood that they were a little bit sensitive and wasn't able to manage her emotions very well, so they would go to this teacher quite regularly, so she was able to diffuse things before they got out of hand.'*

For one child it was a trainee social worker that made the difference between attending school or not. As C1 said: 'She latches on to adults quite well. When we were struggling to get her into school, there was a trainee social worker who was on a placement there. She loved her. She would seek her out.' The charity Grace House were recognised by Caregiver 5 as a source of support for both her son and family. Also, a mentor provided by MindJam: 'You could just tell by looking at him that he was autistic. I thought, that's great, they're going to get on like a house on fire - and they did. They do it over Minecraft.'

Caregivers also recognised the importance of consistent and trusted adults across health services. For their children to share their feelings and thoughts with professionals they needed stability and familiarity to enable their children to form enduring bonds. Caregiver 15 reflected on her child's positive relationship with an occupational therapist: 'She got on amazingly with this girl, really, really well. She tried to do a little bit of brief CBT interventions with her.' She also valued the family doctor having regular check-ins as this built trust through consistency in the person overseeing their care.

3.2.1.2 Early intervention and adaptations

Removing attendance pressures

Caregivers emphasised that removing pressure, acknowledging mental health, and allowing flexibility enabled re-engagement with school. Co-produced approaches, personalised to individual circumstances, were valued (reduced hours, home learning).

> *'ED Class … eased the pressure … home in the morning, school in the afternoon.' (C15)*

> *'She just goes in the mornings … home by 12 and in bed.' (C13)*

Breaks and time-outs

Breaks and time-outs were frequently cited as effective intervention strategies, when teachers accommodated short periods away from class: 'She would just go for ten, fifteen minutes, calm herself down and then go back in' (C1). Caregivers described knowing that their children could identify when they needed time away from class. For some children, access to a trusted adult on these occasions was important: 'Sometimes, it just happens, like a switch going off. She's aware of things changing, and she knows she's feeling not great. Having that somebody she can go to who is somebody she trusts, because like I say, she doesn't really like people' (C15).

To overcome the anxiety at lunch and breaktimes caregivers appreciated the invitation for their child to attend school lunch club:

> *'If he doesn't want to play outside. They've got LEGO, and UNO, and all that stuff there. He's got an early lunch pass as well.' (C6)*

Many of the caregivers acknowledged that their child's mainstream school had tried to support the child to attend. They spoke of teachers who had listened and SENCOs who went above and beyond:

> *'She is a fantastic SEN teacher. There's no doubt about it. I know the mainstream secondary school really tried their best. I know they have been able to get other children to go in, it's just unfortunately she is more severe. But they did help, the SENCO was excellent.' (C1)*

For many children, knowing where they were going to sit in each lesson was reassuring. Caregiver 15 described the seating plan as a 'massive' factor in their child attending school. She felt that they needed the consistency, to know where should be sitting and that this would not change, 'Having a seat where she knows she can just go in and sit down, and she's in her own little bubble, it's fine.'

3.2.1.3 Supported transitions

Families shared co-produced and well-planned transitions were more likely to be successful. A common solution to the challenge of getting their child across the threshold into school was to arrive early or late. Many schools had put in successful approaches to mitigate children's anxiety during daily transitions: 'They used to get let out five minutes earlier to come to the car before the rest of the school and now they just come out normally' (C15) and 'she didn't have to go in through the main entrance with all the kids where it's all chaotic. At first, I would take her to the school office, and then somebody would meet her there and go and take her to the animals, and that helped to get her in.' (C3)

Structural adjustments such as teachers moving between classrooms, rather than the children were also experienced as beneficial transition supports: 'Teachers come to the classroom rather than the children going, that's one of the best things for her.' (C3)

> ***'She just latched on to this girl, and they were friends right up until Year 7. I think that made it easier for her going to school because she always had a friend there, and the friend knew that she didn't speak. If she needed something, she would tell her friend, and then her friend could go and tell the teacher.' (C13)***

3.2.1.4 Compassionate communication with caregivers

The frequency and quality of communication between parents and schools was a strong determinant of trust, problem-solving, and parental confidence. Supportive and empathetic communication fostered a shared understanding of barriers to school attendance. For example, 'I didn't feel judged. They were very supportive when I'd ring up and say I can't get them to school. They were very supportive of me asking if there was anything else they could do' (C16). Another described the benefit of quick catch ups before school with their teacher, 'I can have that quick catch-up of, "She's in a fettle this morning," or "She's had a weepy morning," or "She's started her period. She's in that fettle this morning," so I try and give the school a little bit heads-up' (C14). Several parents preferred email communication for clarity and record-keeping, especially those with their own neurodivergent profiles.

Caregivers valued school staff when they were listened to and taken seriously. Advice from caregiver 15 amplified this recommending:

> ***'When a parent comes to you and says, "I think this is more than just behaviour, I think it's more than just getting in with kids that you've not mixed with before," and there is a history, a documented history with the NHS that there have been issues in the past for your kid, listen to that parent. Get in there early. Start dealing with it earlier. I feel that the actual emotionally-based school avoidance side of it could have been minimised, and I've always felt like that about it.'***

When they were in place, check-ins from health services such as the Children and Young People's Service (CYPS) were valued by caregivers. Caregiver 1 expressed gratitude of a CYPS practitioner who would send messages and phone to find out how they were managing with school:

> ***'The girl who did both my girls at CYPS, she's a lovely girl and often messages. She often phones and asks about the girls. Because she had started making tic noises, working herself up about going to secondary mainstream school. I had to phone the lady and she was very good and she was very helpful and she says, "Try not to make nothing of it, she will calm back down." And she does.'***

Adapting how communication takes place supports caregivers in supporting their child to attend school. One school supported the caregiver video calling the SENCO to choose options rather than attending an open evening. This was often because the child would experience distress during unfamiliar gatherings at school. Caregiver 6 appreciated her child's school communicating through email as it allowed them to keep a record of events and discussions.

3.2.1.5 Bespoke provision and supporting engagement

Sensory-friendly, low movement, physically adapted environments (ARC, hubs, small classes) directly supported emotional regulation and participation. Access to a specialist provision within the mainstream school was identified as preventing escalation to total non-school attendance. Caregivers of children accessing in-school provision felt that they knew their children well and could identify early indicators of distress. Having school staff who were able to recognise dysregulation was beneficial to prevent escalation of anxiety. Being adaptable to changing children's needs was also a strength within school units.

Other examples of alternative learning and teaching provisions included smaller group settings and tutors. Success in tutoring or smaller group settings highlighted that children could learn effectively under the right conditions: 'It's just proof that if she's in the right environment, she can learn' (C11) and 'he's in the ARC side and I think that's helped him a lot, having the classes and he's actually made some friends stable now he's going' (C16). They believed that access to within school provision was the critical factor for them attending mainstream school: 'I think having that ARC in place, I think that's what made school better for him. He's thriving now at school, but I think the way they do the ARC I think it is essential

to children like him that that is a separate option that they can try and thankfully it works.' (C16)

Caregivers described how cognitive load, anxiety, and sensory needs affected learning and how scaffolding could help if implemented sensitively. This included access to resources to maintain emotional regulation, including fidgets. Fidgeting was described as a coping mechanism, 'she needed to fidget… it was to relieve the anxiety. I've told her, put a bobble on your wrist and flick that' (C3)

Where mainstream schooling could not meet their child's needs, parents sought alternative or therapeutic support.

Home tutoring played a key role in re-building confidence and academic engagement:

> ***'She's fully engaging… the fact she's engaged at all has given us hope.' (C11)***

Online support provided emotional connection for children unable to attend school:

> ***'He loves it [MindJam]… he engages with a mentor online through a game.' (C5)***

Schools that provided smaller or specialist settings, such as ARC units within the mainstream school, were perceived as significantly more effective at supporting a sense of safety than the mainstream school environment: 'Having the ARC, that's what made school better for him. He's thriving now.' (C16)

3.2.1.6 Teacher training and sharing information

All caregivers expressed concern that despite an effective SENCO, not all teachers were adequately trained to support children with autism and how this might negatively affect attendance. They suggested a range of solutions to upskill the education workforce.

By sharing information, adults would be better equipped to understand and responded to children's individual needs. Caregivers described the importance of teachers knowing about children's sensitivities to noise (including shouting), learning needs and physical disabilities: 'A lot of the time we go for parents evening, and sometimes the teachers don't even know that she's got all these physical illnesses and she's on the spectrum. I'll be like, well, why don't you know?' (C13)

4.0 Discussion

This section draws together the study's findings and situates them within the wider evidence base. It critically examines how individual, environmental, and systemic factors converge to influence school attendance and highlights the implications for policy, practice, and system design. The discussion explores tensions between need and provision, emphasising where mainstream schools struggle and where adaptive, relational approaches succeed.

The findings from this study highlight a complex interplay between individual needs, school environments, systemic processes, and wider policy structures shaping school-based anxiety and non-attendance among neurodivergent young people in Northumberland. These accounts reveal how unmet needs, sensory overwhelm, inconsistent support, and rigid school systems can create a cumulative burden that significantly affects some children's ability to attend mainstream secondary school.

A dominant theme is the gap between children's needs and the capacity of mainstream schools to meet them. Despite the legal framework designed to secure support through SEN support and EHCPs, families frequently encountered delays in assessment, limited early intervention, and provision that they felt was either insufficient or undeliverable within existing secondary mainstream school infrastructures. These experiences reflect broader national concerns around capacity in the SEND system and delays in health services, that caregivers described as contributing directly to emotional deterioration and crisis-point withdrawal from education.

Sensory and environmental barriers in mainstream secondary school environments can prevent attendance at school; especially when coupled with masking, burnout, and fear of sanctions.

A further systemic challenge concerns behaviour and attendance policies that emphasise compliance and enforcement without considering what is driving the behaviour. Caregivers reported that punitive responses to behaviours rooted in anxiety, sensory distress, or unmet need, such as detentions, escalated sanction systems, or legal threats exacerbated emotional distress and further entrenched non-attendance. These experiences raise questions about school policy alignment with neurodiversity-affirming practice and highlight the risk of misinterpreting distress with defiance. The accounts also underscore how fear of sanctions can itself become a barrier to attendance, even in the absence of actual disciplinary incidents.

At the same time, the study identifies several protective factors that facilitate engagement. Central among these is the presence of trusted adults who provide attuned, consistent emotional support and act as relational anchors in the school environment. Belonging, predictability, and relational safety emerged as critical enablers of attendance, consistent with wider research findings emphasising the role of relationships in school engagement. Caregivers valued teachers, pastoral staff, and external practitioners who listened, communicated openly, and demonstrated understanding of their child's profile and needs.

Additionally, flexible and tailored approaches such as reduced timetables, hybrid learning, structured transitions, small-group settings, and sensory-friendly spaces, were effective in supporting re-engagement. These findings highlight the importance of adaptive educational pathways and the need for schools to have access to specialist environments or in-house provisions (e.g., ARC units) that can offer low-arousal, individualised support. Where such alternatives were available, children demonstrated capacity to learn and thrive, reinforcing the view that disengagement was not due to lack of academic ability but lack of fit between the child and the environment.

The findings also emphasise the emotional toll on caregivers, who often acted as the primary coordinators between services in the absence of coherent multi-agency communication. This role, combined with the stress of managing their child's distress and navigating complex systems, contributed to exhaustion, frustration, and feelings of being unheard, particularly when professional responses were reactive rather than preventative. These experiences echo national reports calling for improved cross-agency coordination and more proactive early identification within the SEND system.

Overall, the findings of this study suggest that for some children School Based Anxiety is associated with non-attendance. This could be a manifestation of systemic misalignment between children's needs, the design of mainstream schooling, and the structure of the current SEND landscape. Early intervention, relational practice, neurodiversity-affirming systems and approaches and flexible educational pathways that recognise the diversity of learners' profiles are highlighted as vital to ensure all children's educational needs can be met.

5.0 Conclusion

The conclusion synthesises insights across all four research objectives to emphasise what the study reveals about the nature of School-Based Anxiety and non-attendance. It reflects the implications for children, caregivers, schools, and services, highlighting key conditions required for re-engagement and the pressing need for systemic change. This section brings together the core message that, for young people experiencing School-Based Anxiety in this study, non-attendance was rooted in unmet need rather than unwillingness.

Objective 1. Explore current literature to identify factors contributing to non-attendance

The literature reviewed in Phase 1 highlighted a wide range of interacting influences—including unmet SEND needs, mental health difficulties, sensory sensitivities, negative school experiences, socioeconomic disadvantage, and school policies—that shape children's ability to attend school. These factors are best understood through ecological frameworks that recognise the interdependence of individual, family, school, and societal influences on attendance. The present study's findings strongly mirror the themes identified in the wider evidence base, particularly the central roles of anxiety, sensory overload, and poor system coordination in driving school avoidance.

Objective 2. Determine the characteristics of children and young people not attending school

The sample consisted exclusively of neurodivergent children, many with autism, ADHD, SEMH needs, or physical health conditions. All had EHCPs or were on SEN Support, and caregivers identified they had long-standing but historically unmet needs. Their attendance patterns ranged from severely reduced to complete non-attendance. These characteristics emphasise that school non-attendance was rooted in complex neurodevelopmental, sensory, emotional, and health related needs, reinforcing the need for specialist, flexible provision within and beyond mainstream settings.

Objective 3. Explore the health and wellbeing needs/status of children not in school

The study demonstrates that caregivers felt children's wellbeing was significantly compromised by school demands. Many experienced severe anxiety, physical symptoms (e.g., vomiting, stomach pain, shutdowns), self-injurious behaviours, and autistic burnout. Long waits for diagnostic and therapeutic input left children without timely support, worsening both mental health and attendance. Caregivers frequently described school as emotionally unsafe, while home offered the predictability and calm needed for recovery and regulation. These accounts highlight the urgent need for responsive mental health pathways, sensory-supportive environments, and proactive early intervention to prevent crises.

Objective 4. Examine experiences of schooling and wider services from the perspectives of children not attending and their caregivers

Caregivers described persistent barriers in both education and health systems, including delayed assessments, inconsistent communication, difficulty accessing EHCP provision, and behaviour and attendance policies that escalated rather than alleviated anxiety. Experiences of feeling dismissed or unheard by professionals intensified family stress and hindered collaborative problem-solving. Conversely, when schools offered relationally secure support—through trusted adults, flexible timetabling, small-group or ARC provision, and compassionate communication—children were better able to engage. These experiences confirm that relationships, predictability, and co-produced planning are foundational to meaningful attendance and participation, particularly for neurodivergent learners.

Taken together, the findings across all four objectives demonstrate children thrive when environments are adapted, predictable, and emotionally safe. Addressing persistent absence requires consistent earlier identification, coordinated multi-agency support, flexible educational pathways, neurodiversity-affirming and, relationship-centred practice. Implementing these changes would be essential to ensuring equitable access to education and improved wellbeing for children currently unable to attend school.

6.0 Recommendations

The recommendations section proposes practical, actions for schools, local authorities, and health services. Grounded in caregiver testimony, these recommendations aim to inform best practice around identification, support, communication, and learning environments. This section sets out the steps needed to create more inclusive and responsive educational pathways for children to prevent School-Based Anxiety and to support children not-attending school.

Recommendation 1. Strengthen early identification and assessment pathways

- Review, with a view to improving, waiting times for autism, ADHD, and mental health assessments through additional clinical capacity and clearer triage
- Introduce early-flag systems in primary schools to identify emerging needs before secondary transition through robust information sharing systems
- Provide training for staff to recognise masking, autistic burnout, and early indicators of School-Based Anxiety

Recommendation 2. Improve EHCP quality, deliverability, and accountability

- Create rapid-response panels in schools for children at risk of disengagement to adjust provision without long waits
- Ensure caregivers have direct access to consistent caseworkers to reduce duplication and communication gaps

Recommendation 3. Develop sensory-friendly and low-arousal school environments

- Introduce calm corridors, staggered transitions, and quiet spaces to reduce sensory overload.
- Review uniform policies to ensure that reasonable adjustments (e.g., no ties, breathable fabrics) are permitted and encouraged where applicable
- Review behaviour policies to ensure that punitive responses are discouraged when sensory or anxiety-based needs are driving responses
- Improve training on Equality Act duties for schools

Recommendation 4. Embed trusted-adult models across secondary schools

- Allocate every child experiencing School-Based Anxiety a named key adult who checks in daily
- Train staff in attuned, predictable and relationship-based practices
- Ensure continuity, avoid unnecessary staff changes

Recommendation 5. Create flexible, co-produced attendance pathways

- Enable personalised timetables (e.g., mornings only, hybrid learning) without threat of fines or sanctions
- Introduce pressure-free re-entry pathways for children returning after prolonged absence
- Provide alternative learning spaces (ARC units, smaller classes, tutoring)

Recommendation 6. Reform behaviour policies to be neurodiversity aware

- Train teachers to distinguish distress behaviours from defiance
- Ensure access to toilets and other essential self-regulation needs without punitive restrictions
- Remove or reset sanction 'steps' following prolonged periods of absence

Recommendation 7. Enhance communication pathways with caregivers

- Implement consistent multi-agency communication frameworks to prevent families from acting as coordinators
- Offer flexible communication options (e.g., email over phone) to meet caregiver needs
- Co-produce support plans with caregivers, recognising their expertise in their child's needs

Recommendation 8. Strengthen transitions from primary to secondary school

- Provide enhanced transition programmes for children who need it

- Ensure full transfer of SEND information before Year 6–7 transition

- Allow phased or alternative entrance routes at the start and end of the school day

Recommendation 9. Neurodiversity training

- All teachers receive ongoing training in recognising and responding to sensory needs and School-Based Anxiety

- Provide modules on masking, executive functioning, trauma-informed practice and co-regulation

- Ensure teachers know each child's needs and adaptations through improved internal communication systems

Recommendation 10. Expand access to therapeutic and alternative provision

- Increase capacity for mental health support

- Provide access to digital or hybrid learning tools for children unable to attend

- Identify community and third sector partners to provide relational and therapeutic support

7.0 Limitations

This section outlines the methodological limitations of the study, including issues related to sample size and demographic representation. Acknowledging these limitations ensures transparency and supports careful interpretation of the findings, while also highlighting areas for future research. There are limitations in this study primarily due to the small sample size and limited demographic diversity. While Northumberland is a majority white British local area, there were no males represented among the caregivers interviewed. Future research should include the formal analysis of children's voices to triangulate with the existing research evidence base.

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