AN EXPLORATION INTO THE EDUCATIONAL EXPERIENCES OF SCHOOL AGED CHILDREN WITH A DEMAND AVOIDANT PROFILE OF AUTISM IN ENGLAND

A research study submitted in part fulfilment of the requirements for my Masters in Education degree

M.Ed. Special Education: Autism (Children)
University of Birmingham

August 2024

Author: Amelia Green, MEd Sp. Ed. Autism, BSc Psychology, GMBPsS

Please be aware that this paper contains descriptions of trauma, self-harm, abuse and suicidal ideation.

ACKNOWLEDGEMENTS

I am extremely grateful to the following organisations and individuals:

- Willow and Raven for guiding me with the questions they thought were of importance to PDA children and for piloting the child section of the questionnaire.
- Sally Cat for her diligent checks of the questionnaire to ensure it was PDA friendly and accessible.
- All the parents who gave their time to complete the questionnaire and share their views.
- The children and young people who provided their views to support understanding their lived experience.
- The PDA Society for welcoming me into their research team, where I gained valuable knowledge and support, and for distribution of the research questionnaire.
- Sally Cat, Steph Curtis, Riko Ryuki and Nicola Reekie (PDA advocates/authors) for distribution of the questionnaire.
- The University of Birmingham (UoB) for support and encouragement with a topic I am deeply passionate about, along with the friendships that were formed and shared learning experiences.
- The Maths department at UoB for guiding me through the complexities of statistical testing.
- My mother for believing in me and encouraging me to keep going, particularly when times were tough.
- My daughter for inspiring me to undertake this research.
- My husband for coping with the many months that I spent hidden away researching, writing and being entirely unavailable.

ABSTRACT

Background: Pathological Demand Avoidance (PDA) may be considered a profile of autism where the individual also exhibits extreme demand avoidant behaviour. The PDA Society found that 70% of PDA children and young people (CYP) are not in school, yet there is little research that explores where they are educated, or that seeks to understand their educational experiences. This paper explores current arguments surrounding PDA, tackles the question of whether having a diagnosis matters, and ‘shines a light’ on this cohort of CYP to understand their educational experiences.

Methods: A small-scale cross sectional design frame was used, employing both a Freedom of Information request and online questionnaire, to survey 153 Local Authorities, 704 parents and 375 CYP. A mixed-method approach was adopted for data collection and analysis, with the use of both quantitative and qualitative data to capture the CYP’s experiences.

Results: The results were consistent with the limited research to date on the educational experiences of PDA CYP with school attendance struggles, exclusions and CYP left without education. It explores the children’s viewpoints and finds overwhelmingly negative experiences and distressing accounts given by both the CYP and their parents. CYP with an Education, Health and Care Plan (EHCP), that accurately describes their needs, were more likely to have positive experiences, and a formal diagnosis meant their needs were more likely to be accurately described in the EHCP, suggesting that a PDA diagnosis may be beneficial.

Conclusion: PDA CYP want to be in school but find themselves without the right support and environment to learn. They describe the real-life impact of the school attendance crisis meaning that systemic SEND reform is not only essential, but urgent to alleviate the significant distress that these CYP are experiencing. The support approaches recommended by the PDA Society provide a good starting point, but until a child-centred holistic approach is truly adopted it seems unlikely that this will be achieved and the arguments surrounding PDA will continue to impact implementation of the right support for these children.

TABLE OF CONTENTS

ABBREVIATIONS

ADD – Attention Deficit Disorder

ADHD - Attention Deficit Hyperactivity Disorder

AET – Autism Education Trust

APA – American Psychiatric Association

ASD - Autistic Spectrum Disorder

ASC – Autistic Spectrum Condition

BERA – British Education Research Association

CYP – Children and Young People; or

Child and/or Young Person

DfE – Department for Education

EDA – Extreme Demand Avoidance

EHCP – Education, Health and Care Plan

FOI – Freedom of Information

LA – Local Authority

NICE - National Institute for Health and Care Excellence

Parent – Parent, caregiver, or guardian of a child

PDA - Pathological Demand Avoidance; or

Persistent Drive for Autonomy; or

Pervasive Drive for Autonomy

PDAer – An autistic person who exhibits extreme demand avoidance behaviour

RDA – Rational Demand Avoidance

SEND - Special Educational Needs and Disabilities

UoB – University of Birmingham

WHO – World Health Organisation

CHAPTER 1 – INTRODUCTION

The 2018 PDA Society ‘Being Misunderstood’ report identified that 70% of autistic children with a demand avoidant profile of autism were not in school (PDA Society, 2018). A more recent survey, involving 1200 parents of autistic children struggling with school attendance, identified that 45% of these children were suspected, or identified, as having a demand avoidant profile of autism, also referred to as Pathological Demand Avoidance [PDA] (Green, 2022). As a parent to a PDA child who was unable to access a school for many years, these statistics validated our experience and led to the realisation that we were not alone. The journey to gain support and understanding was stressful, traumatic, and negatively impacted the family’s wellbeing. Therefore, due to its personal significance, the focus of this study is to explore the educational experiences of PDA children.

To set the background and context of this study, two subjects are introduced in this chapter, autism and PDA, then school absenteeism, before the aims and purpose of the research are presented.

Autism and PDA

From a clinical perspective autism is detailed in the diagnostic manuals, the Diagnostic and Statistical Manual of Mental Disorders [DSM-5] (American Psychiatric Association [APA], 2013) and the International Classification for Diseases [ICD-11] (World Health Organisation [WHO], 2019), as ‘Autistic Spectrum Disorder’ (ASD). They define it as a neurodevelopmental disorder characterised by deficiencies in social communication and interaction, restrictive and repetitive behaviours, and sensory processing differences (APA, 2013; WHO, 2018). The neurodiversity movement, led by autistic activists, raise that the general population naturally have neurological differences, referred to as neurodiversity, (Botha *et al*., 2024) and it is this paradigm that has influenced the removal of the medical disordered narrative and led to definitions of autism such as *‘the brain working in a different way, simply put, as a processing difference’* (Autism Education Trust [AET], 2024). Throughout this paper neurodivergent affirming language is used, so ‘autism’ as opposed to ASD, and identity first language is employed (Bottema-Beutel *et al*., 2021; Dwyer, 2022). The term ‘neurodivergent’ is used to refer to those whose brains process and respond differently to what is considered ‘typical’, or the predominant neurotype [PNT] (Beardon, 2019), and it encompasses autism, attention deficit differences (ADD/ADHD), dyslexia, dyspraxia and other neurodevelopmental differences.

PDA is described as sharing the characteristics of autism, but with the addition of excessive avoidance of everyday demands, whereby a PDAer will employ a range of social strategies to avoid a demand, or perceived demand, which may include delaying, negotiating, distracting and the use of charm (Newson *et al*., 2003). PDA was first identified in the 1980s by psychologist Professor Elizabeth Newson who observed a group of children who were ‘atypical’ in their presentation of autism, and it was proposed they be recognised under a new and distinct syndrome named ‘Pathological Demand Avoidance’. It was also noted that unlike autistic children, PDA children thrived with change and novelty, disliked routine, and felt threatened by the rules and demands of education (Newson *et al*., 2003). They raised that autistic support strategies must be considerably adapted for PDA children to ensure they are not excluded from education. Despite this, diagnostic manuals do not recognise PDA as a distinct diagnosis, and it currently sits under the umbrella term of ASD. The National Institute for Health and Care Excellence [NICE] guidelines for diagnosing autism in children and young people (CYP) describe PDA as a subgroup of autism (NICE, 2011), hence today, it is often referred to as a ‘PDA profile of autism’ (PDA Society, 2024).

The term ‘Pathological Demand Avoidance’ also invokes controversy, with some demand avoidant autistic adults feeling as though it accurately describes the extent of their behaviours (Cat, 2019), while others dislike the word ‘pathological’ due to its negative connotations and suggest ‘Pervasive Drive for Autonomy’ (Wilding, 2020) or ‘Persistent Drive for Autonomy’ (Lawson, 2020) as meaningful alternatives. Autistic academics have also contributed to this topic, proposing alternatives to PDA and widening the debate.

This paper respects all viewpoints and, as there is no clear agreement on terminology, chooses to use simply ‘PDA’, as well as ‘PDAer’ when referring to an autistic individual with extreme demand avoidant behaviours, while not prescribing the words used within the acronym. At times the terms ‘PDA profile of autism’ and ‘autism with a demand avoidant profile’ are also used. All terms are used as meaning the same and with the intention of facilitating a shared understanding and definition for the purpose of this study.

<u>School Absenteeism</u>

School absenteeism is increasingly making headlines in mainstream media with the clear message that children must be in school. The law is clear that parents are responsible for ensuring their children receive a suitable full-time education and being guilty of an offence if their child is registered at a school but fails to regularly attend (*Education Act, 1996*). Yet, in the school year 2022/23 1.6 million children were persistently absent and missing more than 10% of school sessions (Department for Education [DfE], 2023a). The Education Committee recognise that levels of support for children with attendance struggles varies across the country (House of Commons Education Committee, 2023) and the reasons behind school absence are complex (School Home Support, 2023). This complexity increases further when children have special educational needs and disabilities (SEND) and it is SEND CYP who have the highest absence rates (DfE, 2023a). 1 in 3 children with an Education, Health and Care Plan (EHCP), a legal document detailing the child's needs and provision required, have autism documented as their primary need (116,000 pupils) (DfE, 2023b) and academic and adulthood achievements are poorer for children who are missing education (Pellegrini, 2007; John *et al*., 2022). This means that the risk of poor outcomes is significant for autistic children.

To address this school attendance crisis the government commissioned an audit, 'Where are England's Children?', which found that these children want to learn but find themselves without the support they need in school (Children's Commissioner's Office, 2023). In response, they laid out plans for systematic SEND reform to create an inclusive education system ensuring CYP can access '*the right support, in the right place, at the right time'* (DfE, 2023c). This was followed by the 'Moments Matter, Attendance Counts' campaign to tackle persistent absence (DfE, 2024a). However, if this response is to be successful, more needs to be done to understand and address the specific difficulties these children are facing.

Aims and Purpose of this Study

When considering that the PDA Society survey identified 70% of PDA children are not in school, and place this within the context of the government's school absenteeism statistics, it seems likely that PDA CYP represent a high number of absent pupils. If better outcomes are to be achieved for PDA individuals it is essential to understand more about this cohort of CYP and their educational experiences. To ensure this is relevant to the community it impacts, I joined the 'PDA Research Network' whose purpose is to bring together autistic, PDA, and non-autistic researchers to improve outcomes for PDAers through high-quality, inclusive research. This study is aligned to one their nine research priorities identified through consultation with PDA adults (PDA Society, 2023).

> *'How do people experience PDA, and the world around them, day-to-day?'*
>
> (PDA Society, 2023)

The aim of this research is therefore to 'shine a light' on the educational experiences of PDA CYP in England. To achieve this, the study first reviews the literature to establish what is known today, identify gaps in research and, to inform specific research questions. It then details the approach chosen to address the research questions by presenting the research design and methods used for data collection and analysis. The findings are next presented before their implications are explored in the discussion chapter. Finally, the paper presents its conclusion, considers the limitations of the study and makes recommendations for future research.

CHAPTER 2 – LITERATURE REVIEW

As articles in peer reviewed journals are viewed as the gold standard for quality research (Thomas, 2017), the EBSCO Educational database was used to search for articles using the following search terms:

- Pathological Demand Avoidance or PDA or Extreme demand avoidance AND education
- PDA educational experiences
- PDA learners

During the search only limited results were returned so the search was extended to the Web of Science database and FindIt@Bham, the University of Birmingham's library database, and search terms were expanded to include:

- Pathological demand avoidance and school refusal
- School refusal or school avoidance or school non-attendance AND pathological demand avoidance or extreme demand avoidance

In addition, appropriate references cited within the literature were sourced and explored. By adopting this approach three key themes were identified which are examined in this chapter and informed the study's research questions.

<u>PDA</u>

Prevalence

It is estimated that 1%-2% of the world population, and 1.76% of children in schools in England, are autistic (Roman-Urrestarazu *et al*., 2021). Gillberg *et al*. (2015) found that 1 in 5 autistic people are PDA and, despite their study being undertaken only with the population of the Faroe Islands, its alignment with the well-researched statistics for the prevalence of autism and, in the absence of any other studies that seek to determine the prevalence of PDA, their figure of 0.2% of the general population is plausible. With 206,763 autistic pupils of compulsory school age in England (DfE, 2024b), this would indicate that there are over 41,000 PDA CYP in the English education system today. However, there is considerable debate and controversy regarding PDA.

Defining PDA

Newson's view was that PDA should be recognised as a standalone condition, and that autism specific strategies for support can be detrimental to PDA children, hence the need for a distinct clinical diagnosis (Newson *et al.,* 2003). Despite this, the recent prevailing narrative has been to view PDA as a profile of autism (NICE, 2011). This approach is supported by some who argue that there is not enough evidence to warrant it as a distinct syndrome (Green *et al*., 2018) and that it accurately falls under the broad autism spectrum umbrella (Stuart *et al*., 2020). By viewing PDA as a profile of autism it provides a useful guide to understanding the individual's specific needs (Green, 2018; Green *et al.,* 2020), and in turn supports ensuring appropriate strategies are employed by clinicians and educators (O'Nions *et al*., 2018).

PDA has also been suggested to be a co-occurring condition of autism, a 'double hit', whereby the person is autistic and PDA (Wing *et al.,* 2011). There is research supporting this viewpoint suggesting it may be more closely correlated to attention deficit hyperactivity disorder (ADHD) than autism (Egan *et al*., 2020), and anecdotal evidence exists that many PDA children also meet the diagnostic criteria for ADHD (PDA Society, 2022). It has also been hypothesised that the PDA '*need for control'* as described by Newson *et al*. (2003) could be due to anxiety (O'Nions *et al*., 2014a). This link between anxiety and demand avoidance behaviours has recently been investigated and conclude that these behaviours are anxiety-driven (Johnson and Saunderson, 2023; White *et al.,* 2023). However, White *et al.'s* (2023) study was partially carried out during the Covid-19 pandemic which may explain elevated anxiety levels. An overlap was also identified with autism, Oppositional Defiance Disorder (ODD), and anxiety (Malik and Baird, 2018), yet there are few studies that have specifically investigated the relationship of PDA with other conditions (Kildahl *et al*., 2021).

Woods (2020) uses the term 'Demand Avoidance Phenomenon' (DAP) when referring to individuals with demand avoidant behaviours. He argues that PDA is a '*culturally bound concept'* driven by those who may have something to gain, such as organisations holding chargeable PDA training, or clinicians offering diagnosis (Woods, 2017). Woods argues that parents and caregivers will continue to promote the *'PDA profile of autism'* narrative as a way of understanding the behaviours of their child and gaining support. This viewpoint does not undermine that demand avoidance behaviours require recognition, research and appropriate support, and Woods suggests a transdiagnostic approach could be adopted whereby traditional diagnostic boundaries are removed (Woods, 2021). This approach could allow a move away from formal taxonomic diagnostic systems and provide a platform for a biopsychosocial model, where consideration is given to the impact of biological, psychological and societal aspects, to be adopted. By removing the boundaries and thresholds of the medical model, where only biological aspects are considered, the complexities of co-occurring conditions and a multi-disciplinary approach could be adopted leading to a more successful and inclusive system (Kenny *et al*., 2016; Doyle and Kenny, 2023).

This increasing debate surrounding PDA seems to be impacting viewpoints and mindsets are shifting. In November 2023, the National Autistic Society (NAS) removed all references to ‘Pathological Demand Avoidance’ and ‘PDA’ from their website and opted for simply ‘demand avoidance’, while still recognising that they are referring to a characteristic that is a persistent and extreme resistance to everyday demands observed in some of the autistic population (NAS, 2023). So, while this controversy continues, it is unlikely that PDA will be recognised from a clinical perspective.

Terminology

As noted in the introduction, there is also disagreement regarding the term ‘pathological demand avoidance’, with some autistic academics arguing the word ‘pathological’ promotes ableist attitudes and disempowers the expression of autistic agency (Milton, 2013; Moore, 2020). ‘Extreme demand avoidance [EDA]’ has been suggested as a more appropriate term (Gillberg, 2014; O’Nions *et al.,* 2014b; Brede *et al.,* 2017). Autistic academics have also raised that demand avoidance may be a rational response for autistic individuals to exert autonomy when presented with uncomfortable situations and have referred to it as ‘rational demand avoidance [RDA]’ (Milton, 2013; Woods, 2018). However, there is little research that investigates the views of the PDAer and their motivation for the behaviour, and a transactional perspective is required to understand the driver of the behaviour (Milton, 2013; Green *et al*., 2018; Green, 2020). It is also essential that consideration be given to the viewpoints of the autistic community in discussions surrounding PDA

(Moore, 2020), yet this is challenging with the diverse range of opinions within the community itself. The overarching feeling is not to return to a deficit view of autism, that takes away the ground gained by autistic advocates and the neurodiversity movement (Botha *et al*., 2024), and to recognise that although autistic people share characteristics, they have different abilities and challenges. As Steven Shore (2003) stated '*if you have met one person with autism, you have met one person with autism'.*

Diagnosis

Despite this controversy, the numbers of parents of demand avoidant children requesting a PDA diagnosis is increasing (Green *et al*., 2018; Stuart *et al*., 2020) and parents consider a diagnosis important to enable the right educational support (Gore Langton and Frederickson, 2018), despite the English education system not requiring a diagnosis to support SEND (*Children and Families Act 2014, s20*). In response to this, some private clinicians offer an autism diagnosis, with a PDA profile identified, which has been made possible by screening tools, such as the Extreme Demand Avoidance Questionnaire [EDA-Q] (O'Nions *et al*., 2014b) and the modified Coventry Grid Interview (Eaton *et al*., 2018). Clinical guidance for identifying and assessing PDA has also been published (PDA Society, 2022) and autism screening tools updated to identify PDA traits including the Diagnostic Interview for Social and Communication Disorders [DISCO] (Wing *et al.*, 2002). However, these tools often rely on the parent view and may therefore introduce bias in assessment and, with no consensus as to how to diagnose, there is considerable variation across the country depending on the clinicians used, the geographical area, and the funds available to a family (Moore, 2020). Assessment tools also vary in the thresholds to confirm a diagnosis, meaning there is no agreed standardised assessment or diagnostic criteria available today (Summerhill and Collett, 2018; Woods, 2021). What is undisputed is that all clinical assessments should identify individuals' strengths and challenges, which would include if they presented with demand avoidant behaviours (NAS, 2024), and this should inform the support approaches taken. So, while LAs and NHS trusts across England have published position statements on PDA confirming this view, many parents continue to find validation in the term 'PDA' and seek diagnosis for their children, despite there being no research that confirms if diagnosis makes a difference to their CYP's experiences or outcomes.

Educational Provision

Research since 2020 has moved towards gaining an understanding of the reasons for demand avoidant behaviour to identify appropriate support. Stuart *et al.* (2020) provided the starting point for this by identifying the relationship between 'Intolerance of Uncertainty' (IU) contributing to anxiety and leading to demand avoidance behaviours. Despite meeting criticism from Green (2020), that a self-identifying sample was utilised due to the lack of a standardised assessment, it is apparent that strategies for managing anxiety are well suited to supporting PDA CYP (Ozsivadjian, 2020). O'Nions and Eaton (2020) posit a 'low demand, low arousal' approach and there is evidence now emerging to support these anxiety-based strategies (White *et al.,* 2023). Authors, with experience of working with PDAers, have published books for guiding educators which promote strategies focussed on reducing anxiety and demands. They recommend allowing the child flexibility, autonomy and choice, and promote a collaborative approach by establishing positive, trusting relationships to achieve a sense of safety for the child (Christie, 2007; Fidler and Christie, 2019; Truman, 2021; Kerbey, 2023). These support strategies are also promoted in the

PDA Society's published materials for clinicians, educators, and parents of PDA children (Appendix A).

PDA and Education

To find out more about PDA CYP in education, I sought articles specifically researching PDA and education. However, only a few studies were found and all undertaken in the UK. To address this gap in research Gore Langton and Frederickson (2016) undertook a small-scale study with 42 parents of PDA children. They found that 95% of CYP started their education in mainstream schools, yet this number reduced with each placement change with children moving from mainstream to specialist provision, or an alternative education setting, and 5% of the sample without any educational provision. The PDA CYP had high rates of placement breakdown and exclusion from school with 71% of parents reporting their child had refused to attend school. Despite this study only having a small sample, it is important as the first to specifically seek the experiences of PDA children in education, and it raises concerns as the CYP experienced significant and long-standing difficulties at school. Brede *et al.* (2017) built on this research and sought to understand the factors that contributed to children being excluded from school. Their findings supported Gore Langton and Frederickson, identifying high levels of placement breakdowns that were mostly due to unmet needs, the demands of school, and lack of understanding of the child's difficulties. Although their study was small, and included only 9 child participants, all children scored highly on the EDA-Q. The study is unique as the only one that sought the viewpoints of the children and is the first to refer to the emotional impact of the negative school experiences.

Using the same questionnaire as the previous two studies, Truman *et al.* (2021) surveyed 211 parents of school aged autistic children in the UK. However, unlike the earlier studies, they included a comparison group of children with autism only, and separated the PDA children into two groups, those with autism that scored above the threshold for PDA using the EDA-Q, and those with both an autism and PDA diagnosis. Results were consistent with the earlier studies, finding that the children with extreme demand avoidance, whether diagnosed as PDA or not, had higher levels of behaviour that challenges, including refusal to attend school. All groups were reported to have negative school experiences, but the parents of the group with demand avoidant behaviours gave more negative descriptions of the CYP's experience. They carried out a thematic analysis to explore this further identifying five themes that contributed to negative school experiences:

> *'Being misunderstood by school staff, children masking their difficulties in school, lack of appropriate support in school, anxiety and mental health difficulties caused by negative school experiences and parents disenfranchised by the education system.'*
>
> (Truman *et al.,* 2021)

As found by Gore Langton and Frederickson (2018), parents reported that they find professionals who supported gaining a diagnosis for their child the most helpful, as they felt this led to better understanding and support. Despite the limitations of this study, which again sought the view of parents as opposed to the children, the findings support the claims of the PDA Society, that PDA children are more likely to struggle with school than autistic children who do not display extreme demand avoidance (PDA Society, 2018).

Two further studies were found in relation to PDA and education, both were individual case studies seeking strategies for support. Harvey (2012) worked with a PDA child who was unable to attend school for over three years. The initial approach, utilising autism strategies was failing, but by adopting a PDA friendly approach which acknowledges anxiety as the driver of behaviour, and builds strong and trusting relationships, the child was reintegrated to mainstream education. Similarly, Lyle and Leatherhead (2018) undertook a single case study of a PDA child who experienced fixed term exclusions from mainstream school. The child had not responded well to traditional autism strategies, so PDA specific support was introduced. By developing positive and trusting relationships focussed on reducing anxiety, and removing sanctions and punishment recognising that behaviours were not his choice, he was able to engage in education alongside peers. Although both studies were single case studies, they highlight the importance of understanding that the behaviours are not the child’s choice, building strong and trusting relationships, and adopting appropriate support strategies. Yet neither of these studies obtained the child’s view and success was judged as the reintegration of the child to mainstream education, the adult’s success criteria.

School Absenteeism

As a key trait of PDA is resisting and avoiding the everyday demands of life, and the limited research on PDA CYP’s educational experiences has highlighted that PDA children are specifically at risk of being excluded from education and having attendance struggles, the final theme explored in this literature review is school absenteeism.

Terminology

The term originally used to describe children struggling with school attendance, as opposed to those who were truants, was ‘school phobia’ (Johnson *et al*., 1941), with the term ‘school refusal’ being introduced in 1969 (Berg *et al*., 1969). More recently, ‘emotionally based school avoidance’ (EBSA) has emerged as an alternative (West Sussex County Council, 2020), recognising there is an emotional element to the behaviour, and ‘anxiety related absence’ (ARA) has been used in the Scottish National Autism Implementation Team’s [NAIT] guidance for supporting autistic children who struggle with school (Johnston and Rutherford, 2020). Despite these recent terms being introduced, none capture the extreme emotional distress related to school that these children experience, and ‘School Distress’ (SD) has recently been posited as more accurate terminology (Connolly *et al.*, 2023). This lack of standardised terminology causes difficulties in identifying children requiring support and acknowledging the reasons for the school attendance struggles, despite it being known for some time that the reasons for the behaviour are critical to understand if the problem is to be resolved (Kearney and Silverman, 1990).

Causes

Since the 1930s, it has been recognised that school avoidance can stem from anxiety (Broadwin, 1932) and that the child experiences significant emotional distress (Maynard *et al*., 2015). SEND is a known risk factor for school attendance difficulties (Kearney, 2008; Epstein *et al*., 2019) with autistic children more likely to struggle with school attendance than the PNT (Munkhaugen *et al*., 2017; Amundsen *et al.,* 2022). Although there is limited research specifically exploring school non-attendance for autistic children, there appears to be emerging evidence of a correlation between autistic children's anxiety and school attendance struggles (Adams, 2021; Totsika *et al.,* 2023) which may be due to the children's needs not being met by schools (Totsika *et al*., 2023). The impact of bullying and poor relationships may also contribute to school non-attendance (Ochi *et al.,* 2020; Amundsen *et al.,* 2022), and autistic girls may be more at risk of bullying, leading to anxiety and attendance difficulties, due to their desire for social inclusion with peers (O'Hagan *et al.,* 2022). Managing the sensory differences of autism in a school environment may also lead to increased stress and anxiety manifesting in school avoidance for some pupils (Brede *et al*., 2017).

In 2023, Connolly *et al*. undertook the largest study to date to understand school attendance struggles in the UK. 947 parents of CYP with school attendance difficulties took part in their online questionnaire and they found that 94.3% of the children suffered severe distress related to school, with 92.1% identified as neurodivergent and 83.4% autistic. The overwhelming percentage of children exhibiting significant distress suggests the terminology 'School Distress (SD)', as opposed to the other terms used, is appropriate. These statistics support the earlier studies, and the government statistics, whereby children with SEND, and specifically autism, have higher rates of absence than the PNT (DfE, 2023a). The correlation between demand avoidance behaviours and anxiety was also supported by their study with PDA CYP having significantly higher levels of anxiety and SD, which is consistent with both the PDA Society's 'Being Misunderstood' report (2018) and

Truman *et al.'s* (2021) findings. This is the first study to portray the extent of the school attendance crisis in the neurodivergent pupil population and they found that some parents are choosing to electively home educate (EHE) their autistic CYP to meet the child's learning needs and sensory differences.

Research Questions

The literature review established that autistic children are more at risk of school absenteeism than the PNT, and PDA CYP are even more likely to struggle with school attendance than their autistic peers, so PDA CYP are highly represented in school absence statistics. Struggles with school attendance cause emotional distress and leads to negative educational experiences, with unmet SEND needs, poor relationships and bullying, and the school environment all contributing to attendance difficulties. Despite the controversy surrounding PDA, and lack of agreement for standardised diagnostic assessment, parents continue to seek a PDA diagnosis believing that this will lead to accessing appropriate support for their children. This raises the question if diagnosis is of importance for supporting CYP as government regulations state that SEND support is based on the child's needs, as opposed to their diagnosis *(Children and Families Act 2014, s20*).

Although the literature review identified several gaps in research, most striking was that the child's viewpoint was rarely sought and studies relied on parents which could introduce bias with parents exaggerating the child's struggles to gain support. While recognising that it may be challenging to engage directly with PDA CYP as participants due to the demand avoidant nature of PDA, this should not be a reason to leave the children out of research.

To redress this, and to identify if the debate surrounding PDA terminology and diagnosis is of importance, I intend to further understand the educational experiences of PDA CYP, not only from the parental viewpoint, but importantly, from the viewpoint of the children themselves.

To achieve this, the following research questions have been informed by the literature review and will be addressed in this study.

- What terminology regarding PDA is used and does a PDA diagnosis matter?
- Where are PDA children currently being educated?
- What are the experiences of PDA children with education?

CHAPTER 3 – METHODOLOGY

This chapter details the methodology adopted for this study as Thomas (2017) raises the importance of transparency in research.

Rationale

Following the literature review it was apparent that knowledge today surrounding PDA is controversial and parents are seeking diagnosis to support their children. The limited research on the educational experiences of PDA CYP mainly sought the parent view and missed the child's viewpoint. Therefore, the aim of this study is to shine a light on these CYP to gain an understanding of their educational experiences and consider if diagnosis is important, by capturing the views from LAs, parents and importantly from the CYP themselves to address the research questions.

Positionality

As the parent of a PDA autistic child, who faces barriers to accessing education, it is accepted that my position not only influenced my choice of research topic but also influenced the chosen methodology and method selected for data collection, as well as the meaning I interpreted from qualitative data collected. Thomas (2017) states that this is acceptable in social research if the reader is aware of your position and subjectivity.

Trustworthiness

According to Bryman (2016), trustworthiness is gained from four distinct criteria of which credibility and dependability are key. To address the research questions, triangulation was used by gathering data from three distinct sources. Using this approach is considered better than utilising a single viewpoint and increases credibility of the findings (Thomas, 2017). For dependability, an auditing approach was adopted to data collation and analysis (Bryman, 2016). To achieve this an online tool was used for data collection from the LAs making the responses accessible to the public, while for the qualitative data collection, the coding for thematic analysis was reviewed and discussed with my research supervisor and the university's programme leader.

Epistemology

Epistemology is a '*theory of knowledge'* and may be specifically concerned with what is acceptable knowledge (Bryman, 2016, p.690). With this definition in mind, Milton (2014) raises that autistic people have historically been left out of the process of knowledge production and have become distrustful of researchers. He argues that research should not be carried out without the involvement of those it impacts if it is to be both ethical and have epistemological integrity (Milton, 2014). The emergence of '*Critical Autism Studies'* provides the foundation for raising autistic voices (Davidson and Orsini, 2013), and the term '*Nothing about us without us'*, is gaining momentum in both research and practice (Autistic Self Advocacy Network [ASAN], 2023). Autistics, working collaboratively with academic researchers, has the power to influence change (Arnold, 2019) and ensure research does not lead to inaccurate assumptions and harmful approaches (Chown *et al*., 2017). Therefore, my aim was to ensure epistemological integrity throughout the study.

Research Paradigm

A transformative paradigm was adopted as I intend to raise awareness and contribute to bringing about change through this study. The transformative paradigm is also sometimes referred to as '*advocacy research'* and researchers often use active involvement from those they are representing to foster empowerment (Denscombe, 2021, p.16) so it is well suited to attaining epistemological integrity. As I intend to bring meaning to the CYP's educational experiences through interpreting their experiences, it is important to recognise that the world we live in is subject to our own interpretation (Opie, 2004). Employing an interpretivism approach does not absolve the researcher from approaching the study in a fair, balanced, and thorough way (Thomas, 2017), so it was essential to maintain an open mind, while acknowledging that my positionality was of influence.

Participatory Research

Although not a methodology, participatory research is important as a framework that can support different methodologies and epistemological integrity. Participatory autism research involves those the research impacts by ensuring their inclusion in the focus of the research, the approach taken, the analysis and interpretation of the results and the drawing of conclusions (Fletcher-Watson *et al*., 2019). The Economic and Social Research Council (ESRC) recently funded a series of seminars, '*Shaping Autism Research'* to devise more inclusive models for best practice in participatory research. They identified that honesty and transparency are central to any research being undertaken and ensuring the 'lived experience' is core (Pellicano *et al.,* 2017). Despite the aspirations of participatory research, it presents challenges such as achieving true power sharing between the researcher and participants (Fletcher-Watson *et al*., 2019), and how to capture the voices of non-verbal autistic children, to ensure research is meaningful to the CYP, instead of the parents alone (Lewis and Porter, 2004). Nind (2017) expands on the participatory research model and uses the term 'inclusive research' as an overarching term for research that produces knowledge based on lived experience, that is both relevant and has a moral commitment to the community it impacts. She elaborates that research must be carried out honestly and transparently and in an accessible way. Nind and Vinha (2014) suggest that a more appropriate naming would be '*doing research inclusively'* as they argue that there is no *'right way'* to carry out research and researchers may be flexible in their vision and strategy.

I wanted to ensure this study adopted participatory research principles, so have applied them as far as practicably possible within the timeframe and resource limitations available. To achieve this, I engaged with the PDA community, as described in the introduction. Chapter 4 details how I also ensured inclusiveness within the research method, and consulted with those who are impacted, while ensuring the CYP's lived experience was sought.

Research Design

Initially a phenomenology design frame was considered as it focusses on individual's experiences to produce rich descriptive data (Denscombe, 1998). However, as I am not a practitioner with established relationships with PDA CYP, gaining accurate and honest experiences would be challenging within the timeframe available. In addition, when autistic masking is considered, whereby the child may mask their challenges and people-please (Pearson and Rose, 2023), it would be unlikely that a true reflection of their experiences would be achieved. So, considering these limitations, a small-scale cross sectional design frame was chosen to survey a sample of the population of PDA CYP in education, ensuring their lived experiences were at the centre of the research. This approach is sometimes referred to as a '*survey strategy'* (Denscombe, 2021, p.53) and the method of data collection is often by questionnaire. Online questionnaires are a practical way to reach a wide range of remote participants and the autistic population are positive about computer-mediated communication that relates to their interests and advocacy (Gillespie-Lynch *et al*., 2014). Therefore, an online questionnaire was chosen to gain a snapshot view of the educational experiences of PDA CYP and, by combining both qualitative and quantitative data, it was anticipated that the findings would be more powerful (Denscombe, 2021).

Ethical Considerations

Ethical consideration was given in line with the University of Birmingham's [UoB] code of ethics (UoB, 2018) as well as the British Educational Research Association [BERA] ethical guidelines (BERA, 2024). Thomas (2017) raises that for research to be ethical it must not cause harm to either the researcher or the participants. As the topic of this study may be emotive for some parents, participation was voluntary, anonymity was assured, and informed consent was acquired. After completion of the study, participants were signposted to free emotional support and guidance (Appendix B). As CYP took part in the study, it was essential to obtain their assent (BERA, 2024) so parents were specifically directed to explain the study to their CYP and gain their assent for their data to be used. To ensure the research was ethical in the wider sense, an inclusive research approach was adopted and accessibility for participants was given specific attention (Nind and Vinha, 2014). Ethical approval was gained from the UoB (Appendix C) before commencing the study and there were no objections to be considered.

CHAPTER 4 – METHOD

This chapter explains the implementation of the chosen methodology for this study.

Data Collection

A mixed method approach was chosen for data collection of both quantitative and qualitative data from three distinct sources, Local Authorities (LAs), parents of PDA CYP and PDA CYP. To identify where PDA children are educated and the terminology used in EHCPs, a Freedom of Information (FOI) request to all LAs in England was made and parents completed an online questionnaire. To understand the experiences of PDA CYP with education, the same online questionnaire was utilised with two separate sections, the first for the parents of PDA CYP and the second for the CYP to complete. Thomas (2017) applauds the use of mixed methods, and it was hoped that by taking this approach not only could a deeper understanding be gained, but also the findings would have increased credibility (Bryman, 2016). Denscombe (2021) raises the disadvantages of this approach with additional time and skills required for data collection and analysis. However, it was considered that this time was a worthwhile investment and achievable within the timeframe.

LAs - Procedure

FOI requests are made possible by the *Freedom of Information Act, 2000*, whereby information held by UK public authorities must be made available if requested. Procedurally, LAs must respond to the request within 20 working days. However, 33% of LAs failed to respond within this legal timeframe and some required a follow up for clarification of their data. Therefore, the request remained open for a period of 4 months for a higher response rate to be achieved (Figure 4.1).

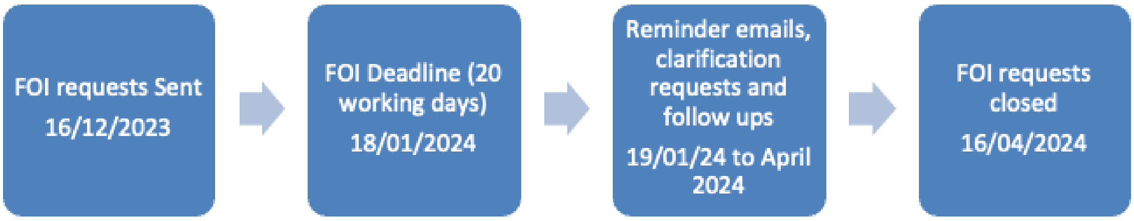
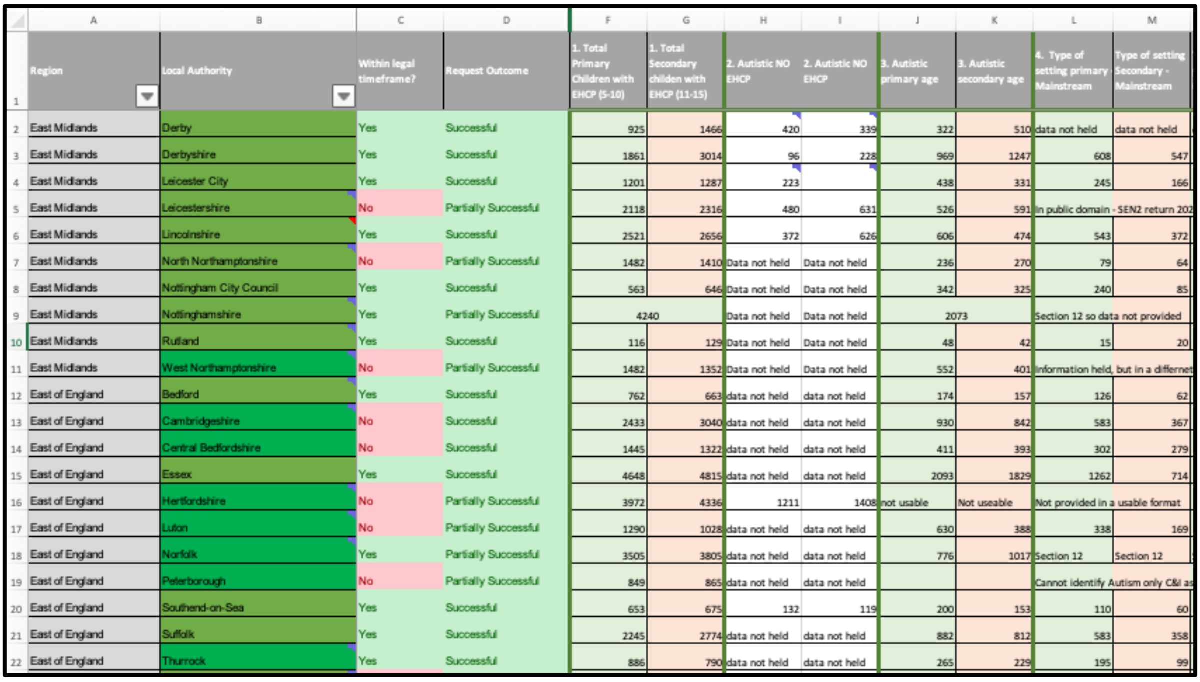


FIGURE 4.1: Timeline of FOI requests made to Local Authorities in England

All responses were collated into a spreadsheet in preparation for data analysis (Figure 4.2).



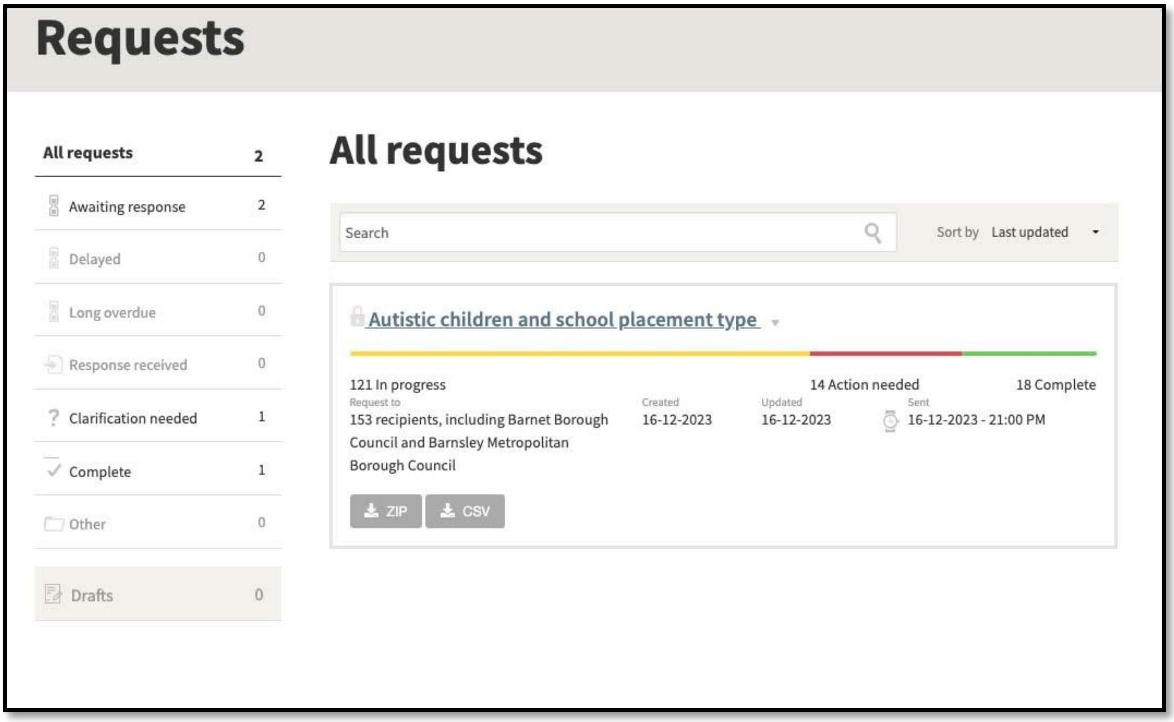
	A	B	C	D	F	G	H	I	J	K	L	M
1	Region	Local Authority	Within legal timeframe?	Request Outcome	1. Total Primary Children with EHCP (5-10)	1. Total Secondary childen with EHCP (11-15)	2. Autistic NO EHCP	2. Autistic NO EHCP	3. Autistic primary age	3. Autistic secondary age	4. Type of setting primary - Mainstream	Type of setting Secondary - Mainstream
2	East Midlands	Derby	Yes	Successful	925	1466	420	339	322	510	data not held	data not held
3	East Midlands	Derbyshire	Yes	Successful	1861	3014	96	228	969	1247	608	547
4	East Midlands	Leicester City	Yes	Successful	1201	1287	223		438	331	245	166
5	East Midlands	Leicestershire	No	Partially Successful	2118	2316	480	631	526	591	In public domain - SEN2 return 202	
6	East Midlands	Lincolnshire	Yes	Successful	2521	2656	372	626	606	474	543	372
7	East Midlands	North Northamptonshire	No	Partially Successful	1482	1410	Data not held	Data not held	236	270	79	64
8	East Midlands	Nottingham City Council	Yes	Successful	563	646	Data not held	Data not held	342	325	240	85
9	East Midlands	Nottinghamshire	Yes	Partially Successful	4240		Data not held	Data not held	2073		Section 12 so data not provided	
10	East Midlands	Rutland	Yes	Successful	116	129	Data not held	Data not held	48	42	15	20
11	East Midlands	West Northamptonshire	No	Partially Successful	1482	1352	Data not held	Data not held	552	401	Information held, but in a differnet	
12	East of England	Bedford	Yes	Successful	762	663	data not held	data not held	174	157	126	62
13	East of England	Cambridgeshire	No	Successful	2433	3040	data not held	data not held	930	842	583	367
14	East of England	Central Bedfordshire	No	Successful	1445	1322	data not held	data not held	411	393	302	279
15	East of England	Essex	Yes	Successful	4648	4815	data not held	data not held	2093	1829	1262	714
16	East of England	Hertfordshire	No	Partially Successful	3972	4336	1211	1408	not usable	Not useable	Not provided in a usable format	
17	East of England	Luton	No	Partially Successful	1290	1028	data not held	data not held	630	388	338	169
18	East of England	Norfolk	Yes	Partially Successful	3505	3805	data not held	data not held	776	1017	Section 12	Section 12
19	East of England	Peterborough	No	Partially Successful	849	865	data not held	data not held			Cannot identify Autism only C&I as	
20	East of England	Southend-on-Sea	Yes	Successful	653	675	132	119	200	153	110	60
21	East of England	Suffolk	Yes	Successful	2245	2774	data not held	data not held	882	812	583	358
22	East of England	Thurrock	Yes	Successful	886	790	data not held	data not held	265	229	195	99

FIGURE 4.2: Extract from spreadsheet collating Local Authority responses

The request was to discover the type of educational setting attended by school aged autistic CYP and PDA CYP and the terminology used for PDA by LAs. As LAs are not required to hold data on where all their autistic children are educated, it was decided to limit the request to only those CYP with an EHCP. The full FOI request is shown in Appendix D.

LAs - Distribution

The ‘What Do They Know’ online platform (mySociety, 2023) was chosen to facilitate distribution of the requests as it provided a user dashboard to manage responses and a published audit trail (Figure 4.3).



Requests

All requests	**2**
Awaiting response	2
Delayed	0
Long overdue	0
Response received	0
Clarification needed	1
Complete	1
Other	0
Drafts	0

All requests

Search

Sort by Last updated

Autistic children and school placement type

121 In progress 14 Action needed 18 Complete

Request to: 153 recipients, including Barnet Borough Council and Barnsley Metropolitan Borough Council

Created: 16-12-2023

Updated: 16-12-2023

Sent: 16-12-2023 - 21:00 PM

FIGURE 4.3: Dashboard showing status of FOI requests on 7th January 2024

LAs - Participants

The UK government recognises 153 LAs in England (Get Information about Schools, 2023) which are assigned to 9 geographical regions. All 153 Local Authorities were selected for participation as shown in Figure 4.4. Local Authorities not in England were excluded due to having different educational systems.

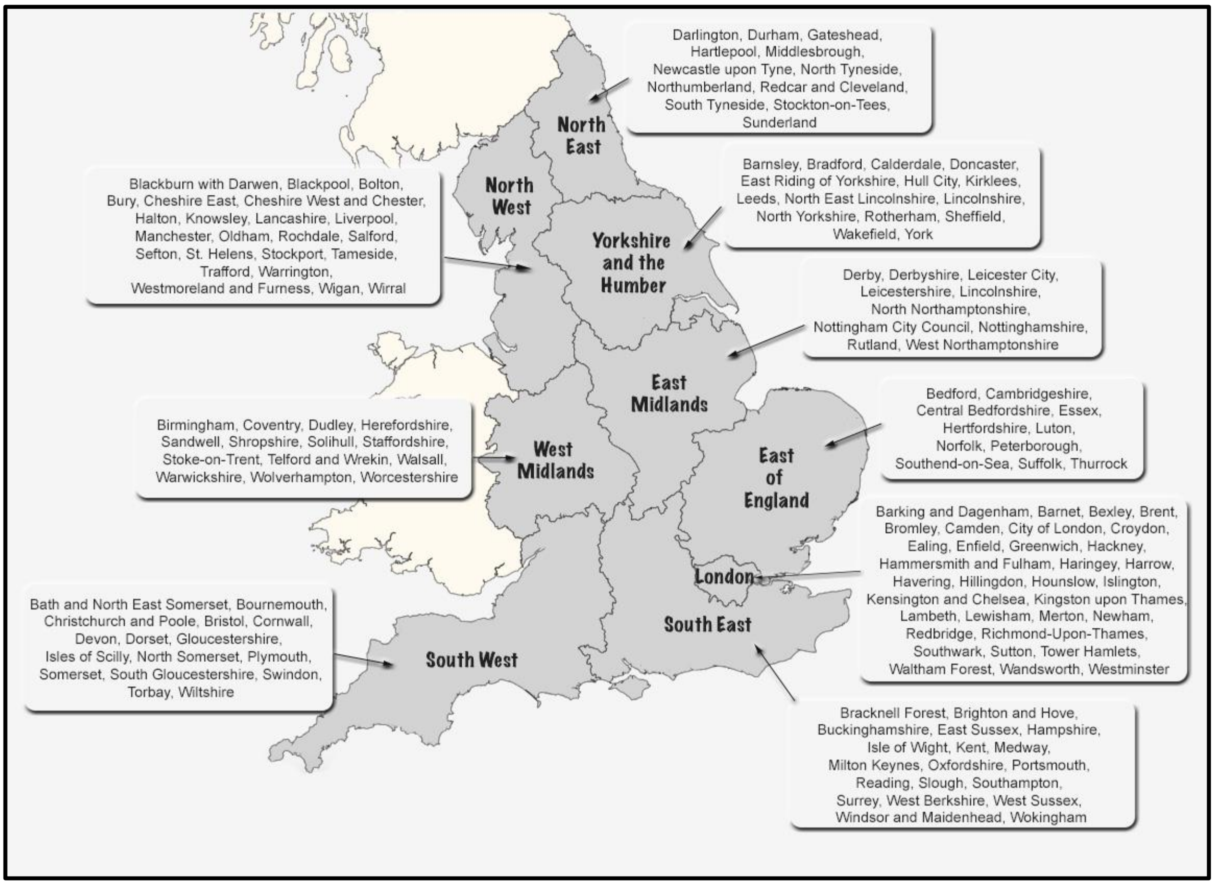


FIGURE 4.4. Local Authorities in England by Region

Parents and CYP - Procedure

A voluntary, online questionnaire was created to survey a sample of the research population of PDA CYP and their parents. I promoted participation by disclosing to participants my role as a parent of a PDA child with a desire to improve outcomes for our children, and language used was carefully considered to establish rapport (Bottema-Beutel *et al*., 2021). The questionnaire design and layout was analysed to ensure that it met Web Content Accessibility Guidelines [WCAG] (WCAG Working Group, 2023) so that it was accessible to everyone and could be read using a screen reader. Questions were reviewed to ensure their relevance and that they would not be bias to elicit a specific response (Bell and Waters, 2018). Approval was gained from the university prior to publication.

The questionnaire was hosted on SurveyMonkey, an online survey tool, chosen for its ability to provide easy remote access for participants and for its data security capabilities (SurveyMonkey, 2023). It was presented in five distinct sections, with one question per page, to ensure both clarity and simplicity to navigate. The first section provided information about the purpose of the research, outlined the criteria for inclusion in the study and gained participant consent (Appendix E). The second section presented four questions that ensured the participant was eligible for inclusion in the study. If criteria for inclusion were not met the questionnaire was ended early with an explanation for the early termination. The third section presented four questions to capture demographic data about the respondent and their CYP. The next section of the questionnaire presented participants with 19 questions designed to gather information from the parents to address all three research questions. This gave the opportunity for both quantitative data (by presenting response options in a list) and qualitative data (by presenting a free text box to allow an open response) to be collected for analysis. Appendix F shows the full questionnaire, with response options, presented to parents.

The final section of the questionnaire was designed to understand educational experiences from the CYP's viewpoint, and 7 questions were presented. The questions for the CYP were co-produced with two PDA children, Willow and Raven, who chose pseudonyms so they are not identifiable in this study. This final section was optional, and the parent was given clear instructions to ensure their CYP understood that their responses would be used for this study to ensure that the CYP had given their assent. All questions and instructions presented for the CYP are shown in Appendix G.

Questionnaire Pilot

By undertaking a pilot, issues that may be encountered can be resolved prior to distribution of the published questionnaire (Denscombe, 2021, p. 210). Therefore, a small pilot was undertaken with 6 participants, 50% of the pilot participants were PDA adults. This meant that the expected time to complete the survey could be conveyed accurately to participants. It also allowed for the wording and presentation of questions to be refined in line with feedback (Bell and Waters, 2018, p. 200) and ensured that the questionnaire was presented in a way that would not be demand triggering for a PDA participant. It was noted from the feedback that the colour scheme and text layout were inviting, accessible and soothing.

Parents and CYP - Distribution

Facebook was selected as a low-cost distribution platform to reach a sample of the research population. Facebook groups for parents of CYP who struggle with school attendance, or home educating groups, were avoided to ensure no selection bias was introduced whereby the responses may have been distorted towards poorer educational experiences (Thomas, 2017). Instead, the two largest PDA support groups on Facebook were chosen: ‘Pathological Demand Avoidance (PDA) support group’, with 41,000 members and, ‘PDA Support (pathological demand avoidance) families and practitioners’, with 22,200 members. In addition, 4 Facebook pages run by PDA authors, and the PDA Society (Figure 4.5), shared the questionnaire.

PDA Society
16 h ·

A member of our Research Network is conducting new research into the educational experiences of PDA children - and they want to hear from you.

We know from our 'Being Misunderstood Report' that 70% of PDA children are unable to attend school regularly, but research about the experiences of PDA children is still in it's infancy.

If you are the parent or caregiver of a PDA child educated in England, we invite you to take part in this 10 minute survey to share your views:

SURVEYMONKEY.COM
The Educational Experiences of PDA Children
This questionnaire is designed to capture the educational experiences of PDA children in E...

Nicola Reekie, Autism Level UP and 82 others 44 comments 73 shares

FIGURE 4.5: The PDA Society Facebook post distributing the questionnaire.

The questionnaire was open for voluntary participation for a period of 5 days in March 2024 (Figure 4.6). A good response rate was achieved so the survey was closed at 800 responses, due to the timescale limitations of the study.

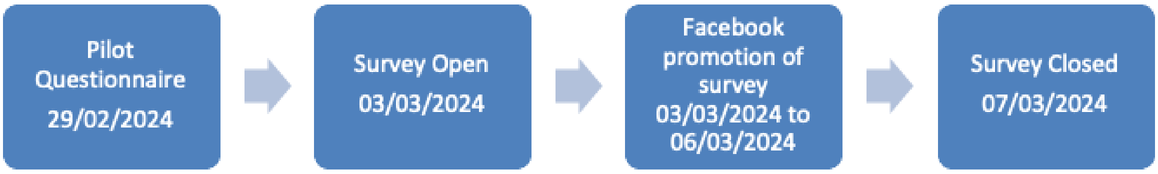


FIGURE 4.6: Timeline for parent and CYP questionnaire

Parents and CYP - Participants

As it was not possible to survey all parents of the research population, participation was based on convenience sampling, whereby taking part was voluntary and participants self-selected. This approach provided an exploratory sample which, although is not suitable for making definitive generalisations, is well-suited to providing insights (Bryman, 2016) and well placed to meet the aims of this study. To be eligible for inclusion, participants had to be a parent, or caregiver, of a compulsory school aged child (5 -16 years), who is, or was, educated in England and who is identified as autistic with a PDA profile. As PDA is not a distinct clinical diagnosis, parents were eligible to take part if they identified their child was PDA, whether recognised by a health professional or not. A total of 800 responses were received with 96 removed from the dataset for not meeting the criteria for inclusion, or not responding to questions beyond the demographic data. The remaining 704 participants were included in the sample.

Data Analysis

Analysis of Quantitative Data

The quantitative data collected from LAs was first '*eyeballed*' to identify outliers, and incorrect data. Although '*eyeballing*' is not in the statistical textbooks, Thomas (2017) argues that using your own eyes is a valuable tool to make sense of the data. Next, using Microsoft Excel, the raw data was grouped by geographical region in preparation for statistical analysis. Pivot tables were utilised to produce derived

statistics that gave meaning to the data. Bar graphs and pie charts were created to present the data for the reader, as recommended by Thomas (2017).
Data generated from the online questionnaire was exported from SurveyMonkey to Microsoft Excel. All responses were reviewed, and data recoded where required, so the time with no educational provision was altered to months when a participant had provided a response in years. New variables were also calculated; if the CYP was primary or secondary age, their current educational setting and the number of educational settings they had attended. Descriptive statistics were then produced using pivot tables, and bar charts, pie charts and tables were created to support reader understanding. Denscombe (2021) highlights the importance of being transparent about the dataset size, so the number of responses in each dataset was included for each chart ($n = x$).

To discover if any generalisations could be made from the sample (Thomas, 2017; Cohen *et al*., 2018) the data was next imported into IBM SPSS Statistics v29, a statistical data analysis software package (IBM, 2024) and recoded for analysis. As overall educational experiences were recorded as ordinal data, relationships between this and other variables were analysed using Spearman Rho correlations. Pearson Chi-square tests were also run to examine the relationship between two nominal variables. Relationships and correlations were of statistical significance if less than 0.05.

Analysis of Qualitative Data

The open-ended questions presented to parents and children resulted in descriptive, qualitative data. This data was imported to NVivo 14, a software tool designed to securely store and visualise the data and to facilitate thematic data analysis

(Lumivero, 2024). A constant comparative method was used to code the data and identify themes (Thomas, 2017). An inductive approach was adopted to ensure I remained data driven, and the themes identified were not pre-conceived. A cautious approach was taken to code generation to ensure the intention and context of the participant’s narrative was maintained (Denscombe, 2021). Braun and Clarke (2006) highlight the importance of transparency, so the interpretation of meanings and creation of themes, despite being data driven, are acknowledged to be my own interpretation and were provided in response to the specific questions posited.

As there are no set rules for undertaking a thematic analysis the process suggested by Braun and Clarke (2006) was adopted (Figure 4.7).

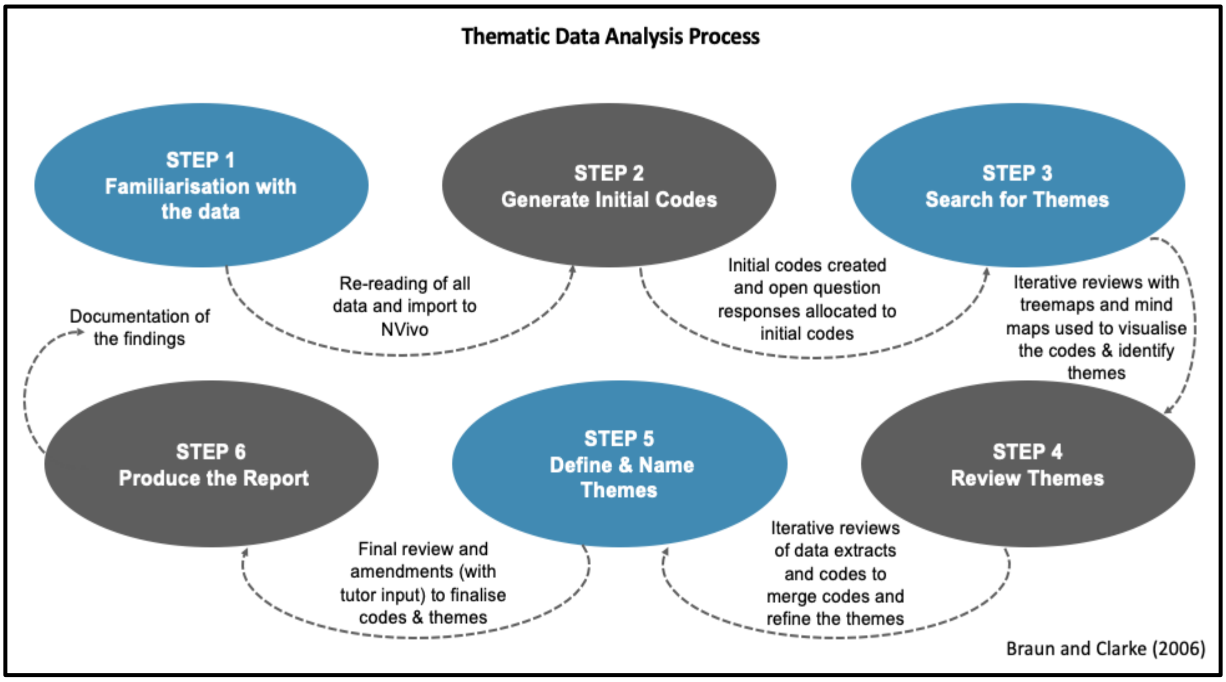
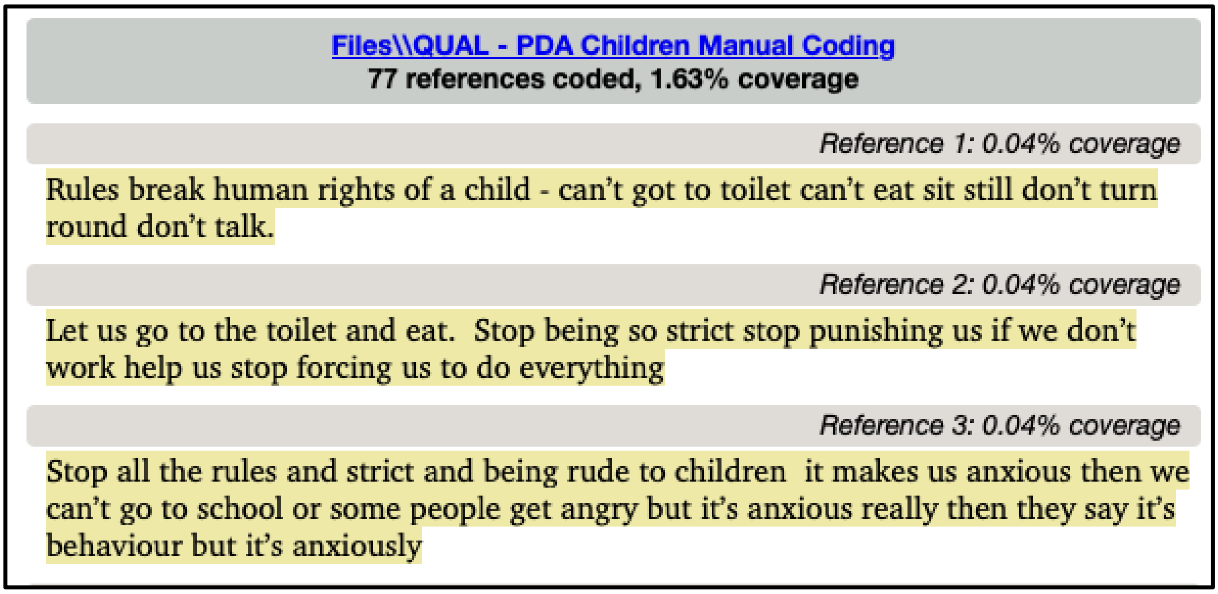


FIGURE 4.7: Process and actions undertaken for thematic data

Below are extracts from NVivo demonstrating the actions undertaken for quantitative data analysis:



Files\\QUAL - PDA Children Manual Coding
77 references coded, 1.63% coverage

Reference 1: 0.04% coverage

Rules break human rights of a child - can't got to toilet can't eat sit still don't turn round don't talk.

Reference 2: 0.04% coverage

Let us go to the toilet and eat. Stop being so strict stop punishing us if we don't work help us stop forcing us to do everything

Reference 3: 0.04% coverage

Stop all the rules and strict and being rude to children it makes us anxious then we can't go to school or some people get angry but it's anxious really then they say it's behaviour but it's anxiously

FIGURE 4.8: Highlighting text from the open-ended questions for initial code creation

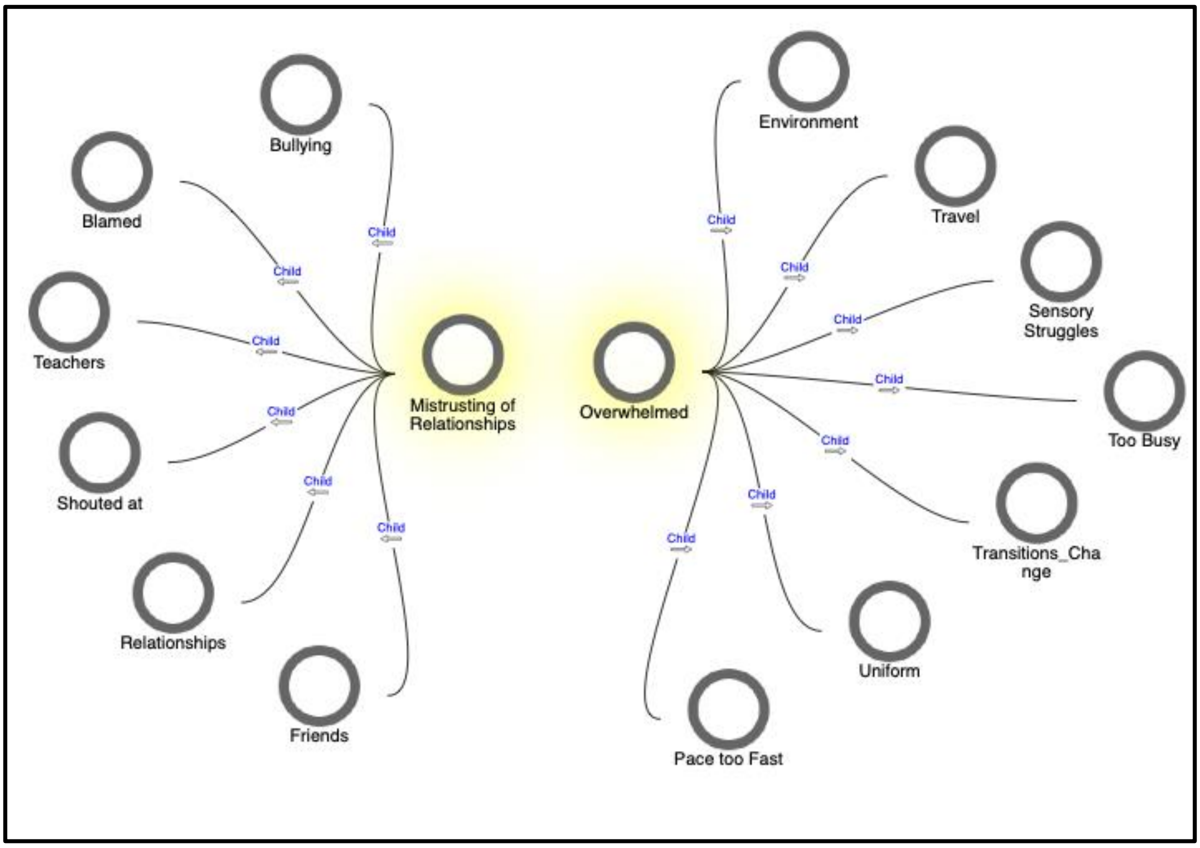


FIGURE 4.9: Using a mind map to explore and visualise the codes while searching for themes

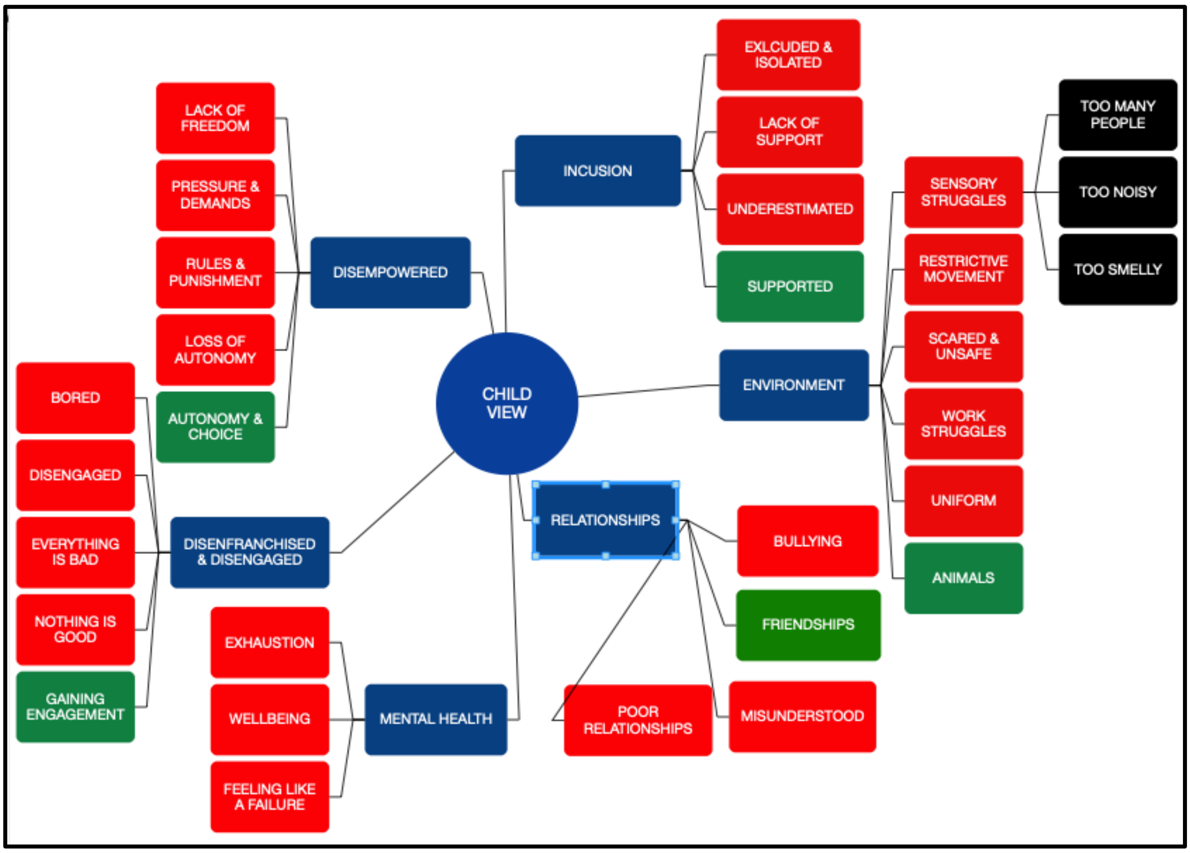
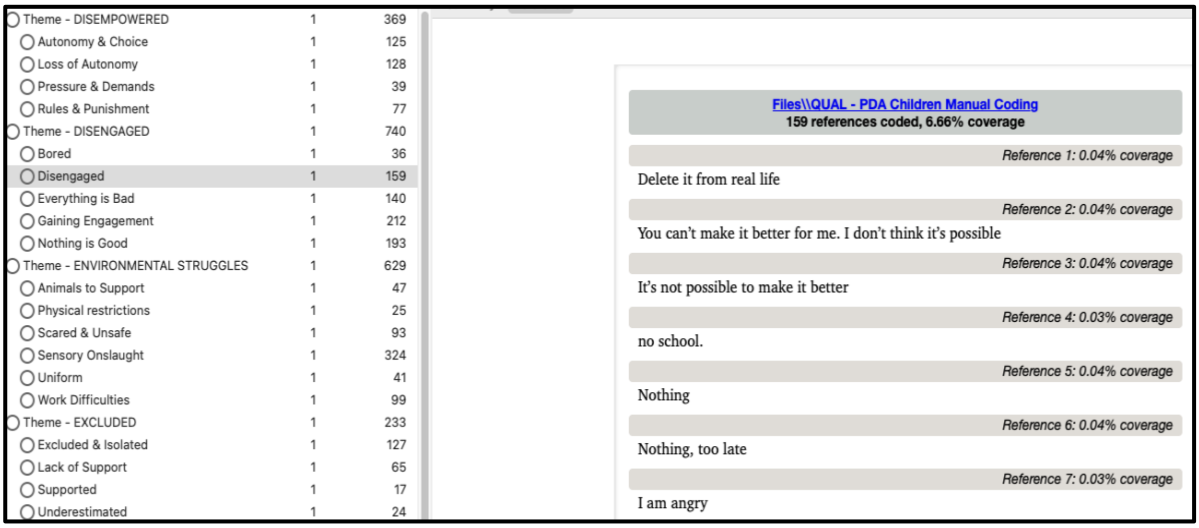


FIGURE 4.10: A refined mind map to support visualisation of codes and their allocation to themes



○ Theme - DISEMPOWERED	1	369
○ Autonomy & Choice	1	125
○ Loss of Autonomy	1	128
○ Pressure & Demands	1	39
○ Rules & Punishment	1	77
○ Theme - DISENGAGED	1	740
○ Bored	1	36
○ Disengaged	1	159
○ Everything is Bad	1	140
○ Gaining Engagement	1	212
○ Nothing is Good	1	193
○ Theme - ENVIRONMENTAL STRUGGLES	1	629
○ Animals to Support	1	47
○ Physical restrictions	1	25
○ Scared & Unsafe	1	93
○ Sensory Onslaught	1	324
○ Uniform	1	41
○ Work Difficulties	1	99
○ Theme - EXCLUDED	1	233
○ Excluded & Isolated	1	127
○ Lack of Support	1	65
○ Supported	1	17
○ Underestimated	1	24

Files\\QUAL - PDA Children Manual Coding
159 references coded, 6.66% coverage

Reference 1: 0.04% coverage

Delete it from real life

Reference 2: 0.04% coverage

You can't make it better for me. I don't think it's possible

Reference 3: 0.04% coverage

It's not possible to make it better

Reference 4: 0.03% coverage

no school.

Reference 5: 0.04% coverage

Nothing

Reference 6: 0.04% coverage

Nothing, too late

Reference 7: 0.03% coverage

I am angry

FIGURE 4.11: Reviewing data extracts and codes against identified themes for refinement

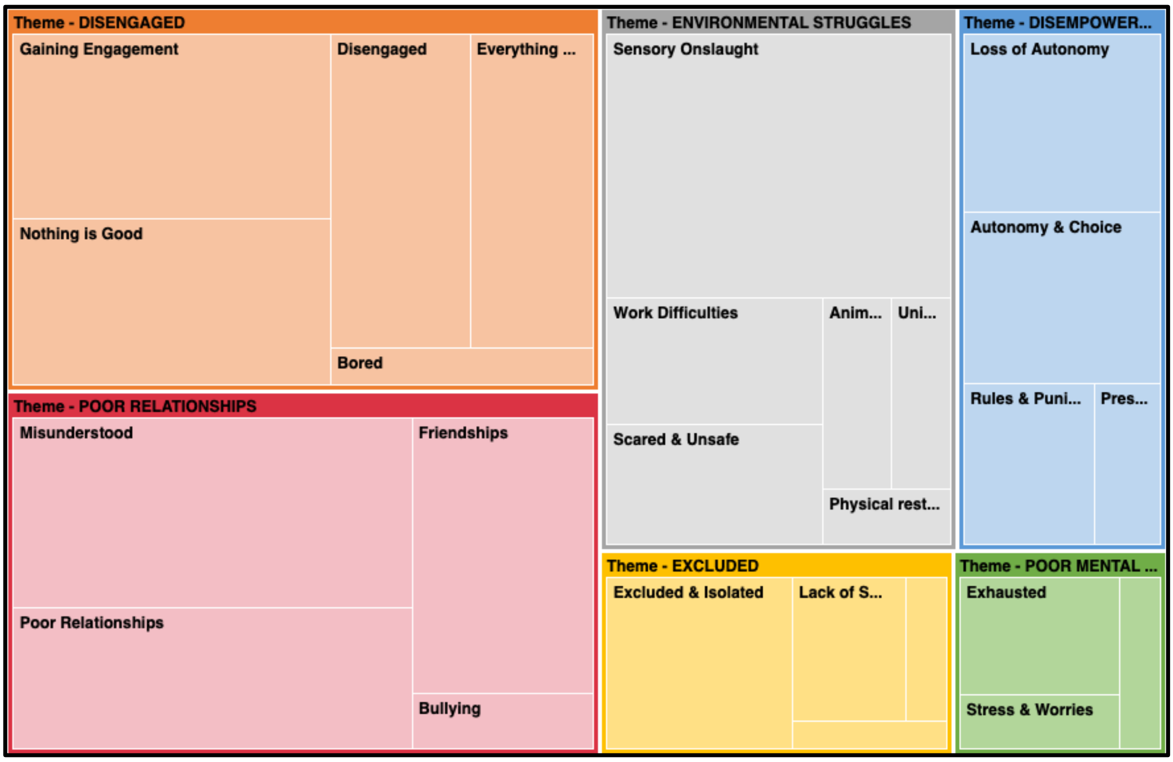
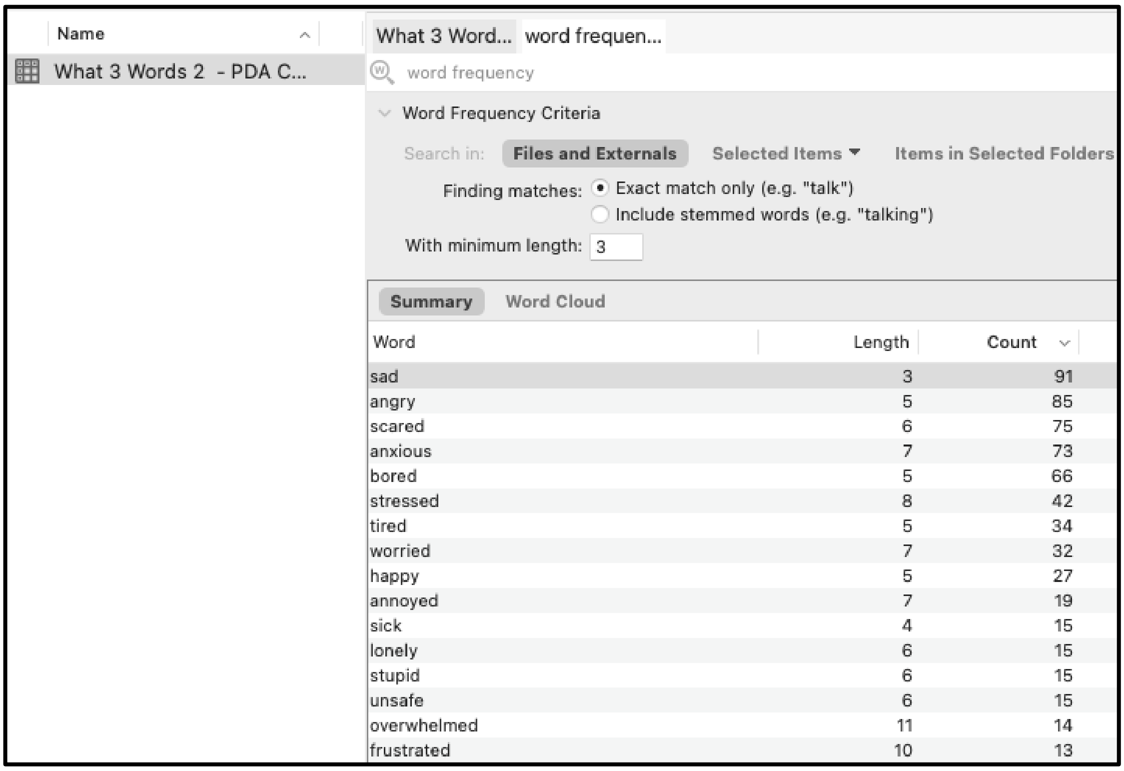


FIGURE 4.12: Visualising the defined codes and themes using a treemap

Analysis of Single Word Data

For the question asked of CYP that required single word responses, the data was imported into NVivo 14 and analysed for word frequency (Figure 4.13). A table and word cloud were exported to facilitate reader understanding of the findings.



Search in: **Files and Externals** | Selected Items | Items in Selected Folders

Finding matches: ● Exact match only (e.g. "talk")
○ Include stemmed words (e.g. "talking")

With minimum length: 3

Word	Length	Count
sad	3	91
angry	5	85
scared	6	75
anxious	7	73
bored	5	66
stressed	8	42
tired	5	34
worried	7	32
happy	5	27
annoyed	7	19
sick	4	15
lonely	6	15
stupid	6	15
unsafe	6	15
overwhelmed	11	14
frustrated	10	13

FIGURE 4.13. Data analysis in NVivo for the single word question responses

CHAPTER 5 – FINDINGS

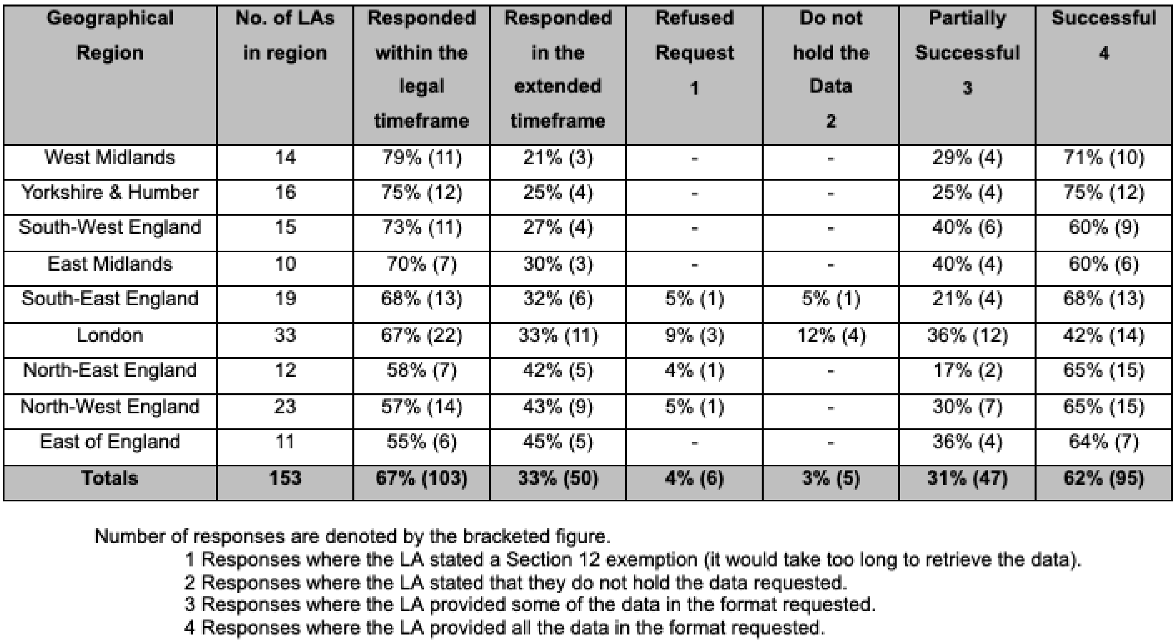
The findings from the data analysis are presented in this chapter in three sections according to their source, so LAs, parents and then the CYP.

Local Authorities

Demographics

The FOI request elicited responses from all 153 LAs. Table 5.1 summarises the outcomes of the requests by geographical region, with 7% of LAs either refusing the request or stating that they do not hold the information, and 62% providing all the information as requested.

TABLE 5.1: LAs responses to FOI request by geographical regions



Geographical Region	No. of LAs in region	Responded within the legal timeframe	Responded in the extended timeframe	Refused Request 1	Do not hold the Data 2	Partially Successful 3	Successful 4
West Midlands	14	79% (11)	21% (3)	-	-	29% (4)	71% (10)
Yorkshire & Humber	16	75% (12)	25% (4)	-	-	25% (4)	75% (12)
South-West England	15	73% (11)	27% (4)	-	-	40% (6)	60% (9)
East Midlands	10	70% (7)	30% (3)	-	-	40% (4)	60% (6)
South-East England	19	68% (13)	32% (6)	5% (1)	5% (1)	21% (4)	68% (13)
London	33	67% (22)	33% (11)	9% (3)	12% (4)	36% (12)	42% (14)
North-East England	12	58% (7)	42% (5)	4% (1)	-	17% (2)	65% (15)
North-West England	23	57% (14)	43% (9)	5% (1)	-	30% (7)	65% (15)
East of England	11	55% (6)	45% (5)	-	-	36% (4)	64% (7)
Totals	**153**	**67% (103)**	**33% (50)**	**4% (6)**	**3% (5)**	**31% (47)**	**62% (95)**

Number of responses are denoted by the bracketed figure.

1 Responses where the LA stated a Section 12 exemption (it would take too long to retrieve the data).
2 Responses where the LA stated that they do not hold the data requested.
3 Responses where the LA provided some of the data in the format requested.
4 Responses where the LA provided all the data in the format requested.

Educational Settings

Figure 5.1 shows LAs identified the number of pupils (autistic and not autistic) in primary and secondary schools who have an EHCP (*n*=307,253). However, only

27% of LAs could provide the number of autistic pupils who do not have an EHCP. They often commented that this data is reported directly to the DfE by schools.

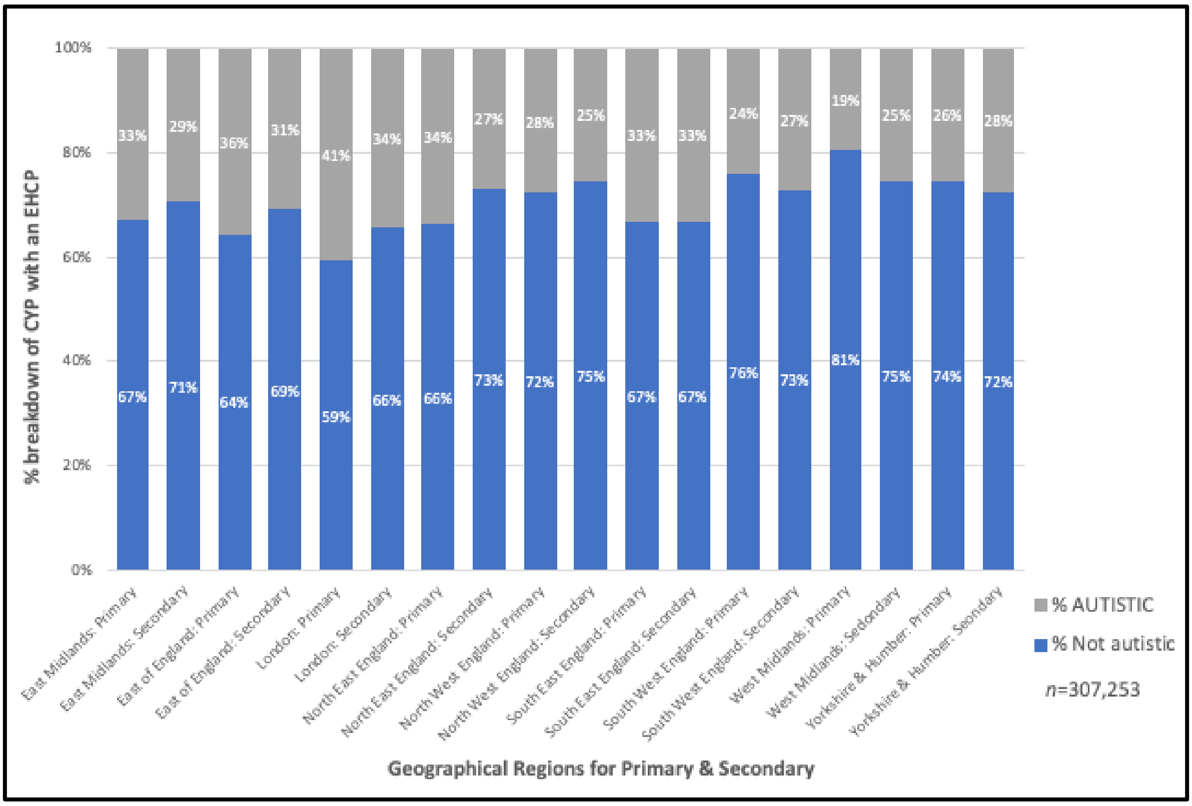


FIGURE 5.1: Percentage breakdown of EHCPs for autistic CYP

This meant that educational setting types could only be identified by LAs for their autistic CYP who have an EHCP, as shown in Figure 5.2 (*n*=139,662). 54% of primary children are in mainstream schools which reduces to 38% for secondary aged pupils. Conversely for special school placements (special schools, independent special schools and SRPs) numbers increase from 43% of primary aged children to 55% when in secondary. There were 586 (0.84%) of CYP with no placement available and a further 496 (0.71%) where the LA did not know their educational setting. These have been removed from Figure 5.2 due to the small numbers.

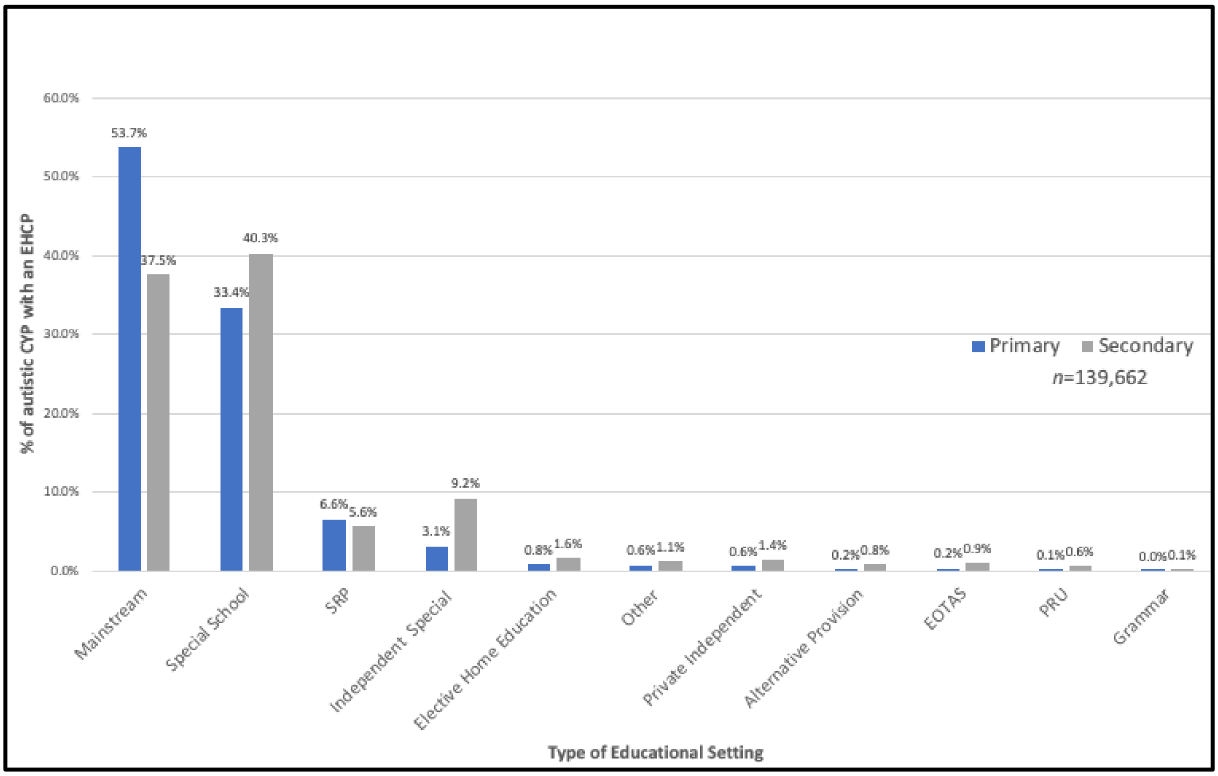


FIGURE 5.2: Educational setting types of primary and secondary aged autistic children with an EHCP.

Autistic CYP with an EHCP who are educated outside of a school setting; alternative provision (AP), Educated Otherwise than at School (EOTAS) and electively home educated (EHE), increases by 173% between primary and secondary ages, with the largest increase in AP, 336% (Figure 5.3).

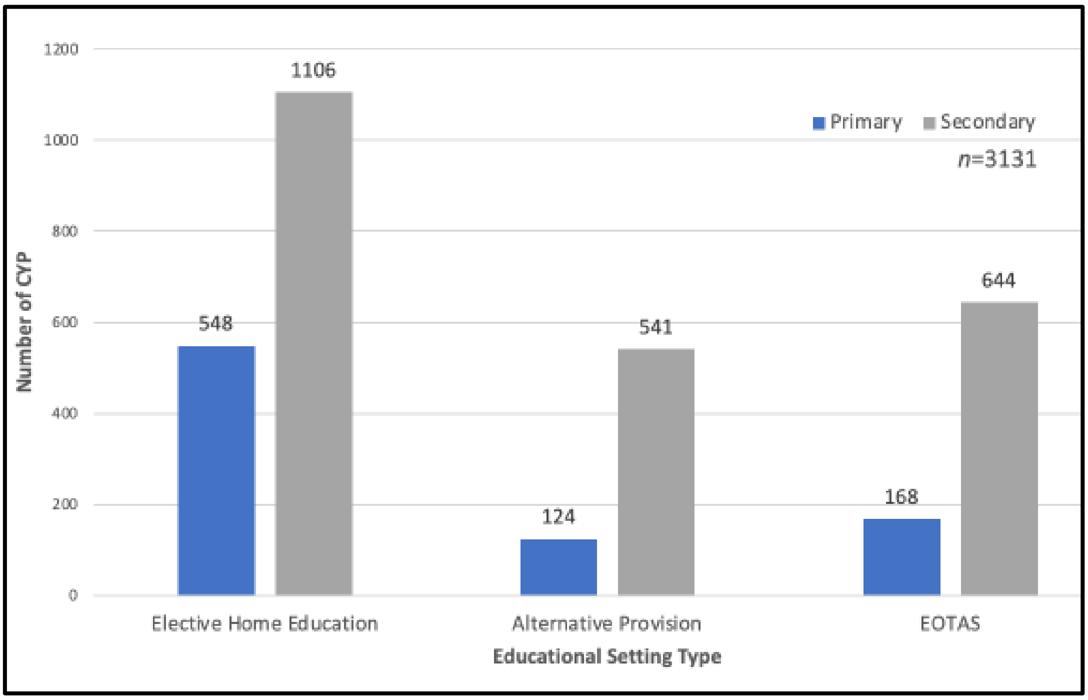


FIGURE 5.3: Number of autistic CYP with an EHCP educated outside of a school setting.

When LAs were asked about their PDA CYP only two were able to provide the number of children (with EHCPs) that have demand avoidance, or PDA, or autism with a demand avoidant profile mentioned in their EHCPs. As this was less than 5 for one of the LAs, this data was excluded. Therefore, the sample size for this subset of CYP is much smaller, *n*=719. For the single LA shown in Figure 5.4, 9% of their primary autistic children's EHCPs identified PDA, increasing to 14% of secondary autistic CYP with an EHCP (*M*=12%). The other 96 LAs that responded to this question either stated that the time to identify PDA in their EHCPs would exceed the costs permitted for the request, or that they do not hold the information. The reason for not holding the information was repeatedly given as PDA not being a SEND category required by the DfE, or a diagnosis in the DSM-5. Despite only one LA providing this data the findings are impactful, as 65% of their CYP educated outside of a school setting are PDA (Figure 5.4).

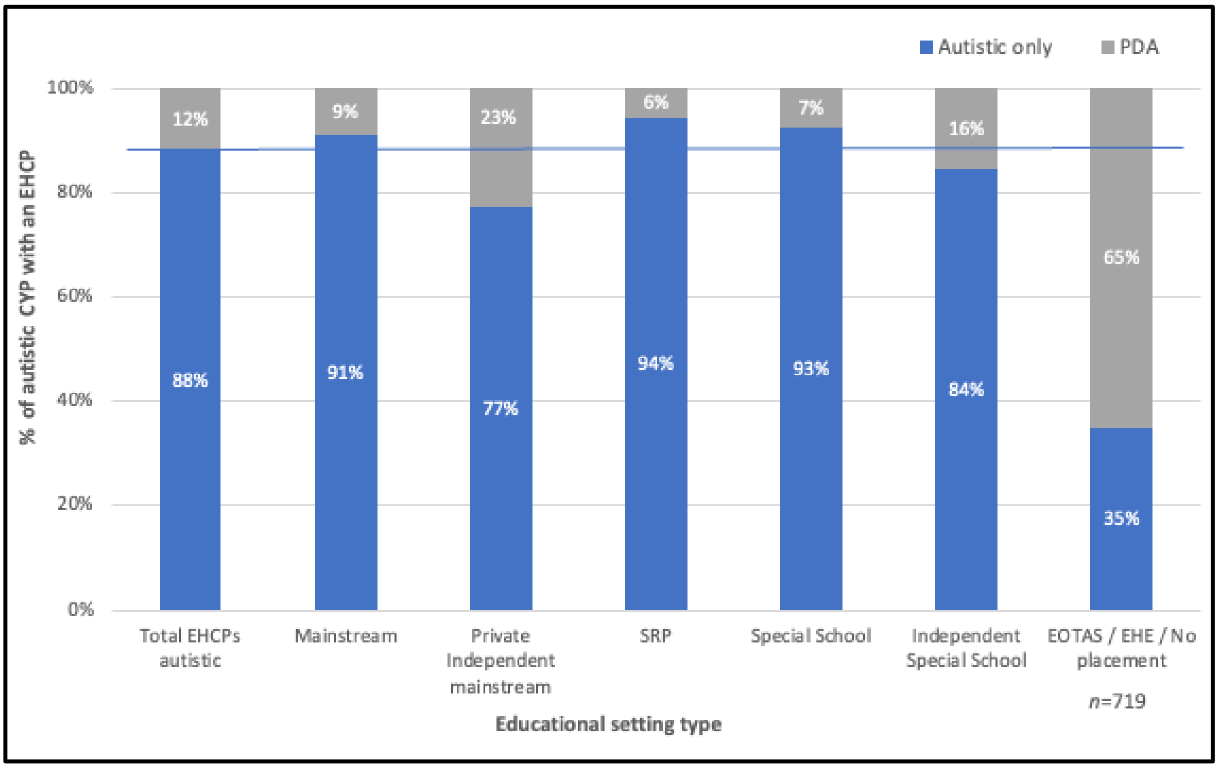


FIGURE 5.4: Percentage breakdown of setting types for autistic and PDA CYP with an EHCP

Figure 5.5 takes a closer look at this cohort of CYP by comparing the autistic CYP's placement types in this LA, with those of the PDA CYP (*n*=719). PDA CYP are educated more often in private independent mainstreams, independent special schools and outside of school settings, than their autistic only peers and are 5 times more likely to be out of a school setting than the autistic CYP.

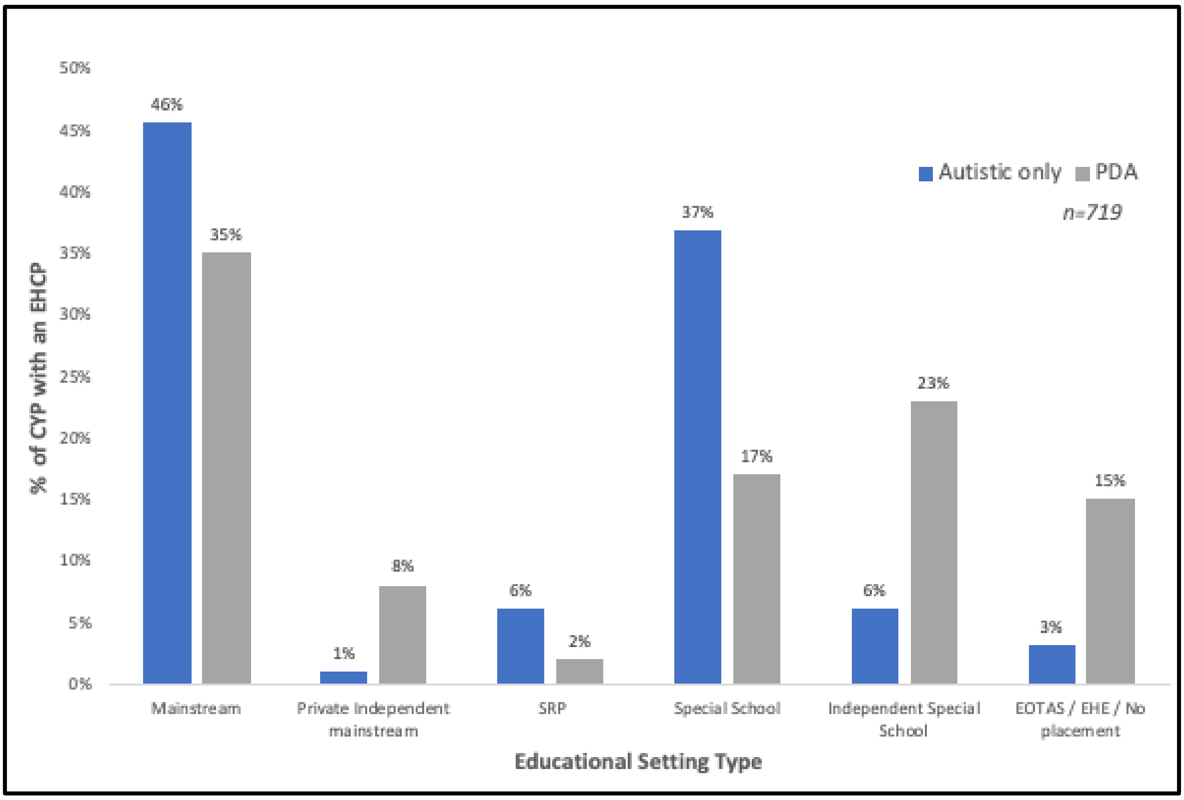


FIGURE 5.5: Percentage breakdown of educational settings for autistic and PDA children

Terminology

The final question asked in the FOI request was if the LA uses the terms, PDA or a demand avoidant profile of autism, in their EHCPs. 60% of LAs stated that they use the term in EHCPs, if stated in a professional's report, while 12% of LAs do not use the term, even when provided in a professional's report. 27% of LAs in the East of England use the term, while 73% do not, demonstrating inconsistency not only across England, but also within geographical areas (Figure 5.6). Only the West Midlands applied terminology consistently, using PDA, or a demand avoidant profile of autism, if provided in professional reports.

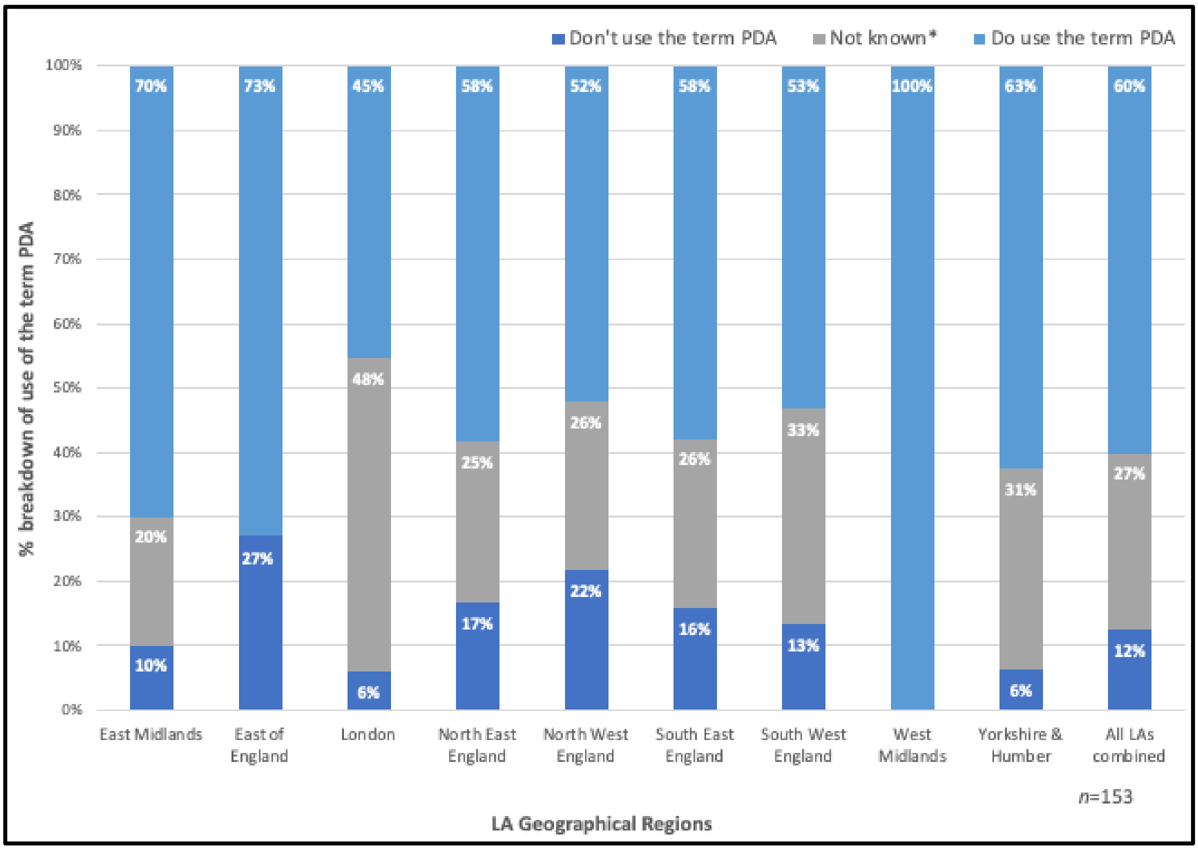


FIGURE 5.6: LA regions that use the term PDA, or demand avoidant profile of autism, in EHCPs

*Not known includes where a response was not provided, when a response was unclear, when a LA claimed section 12 exemption, and when the response was that the LA do not hold the data.

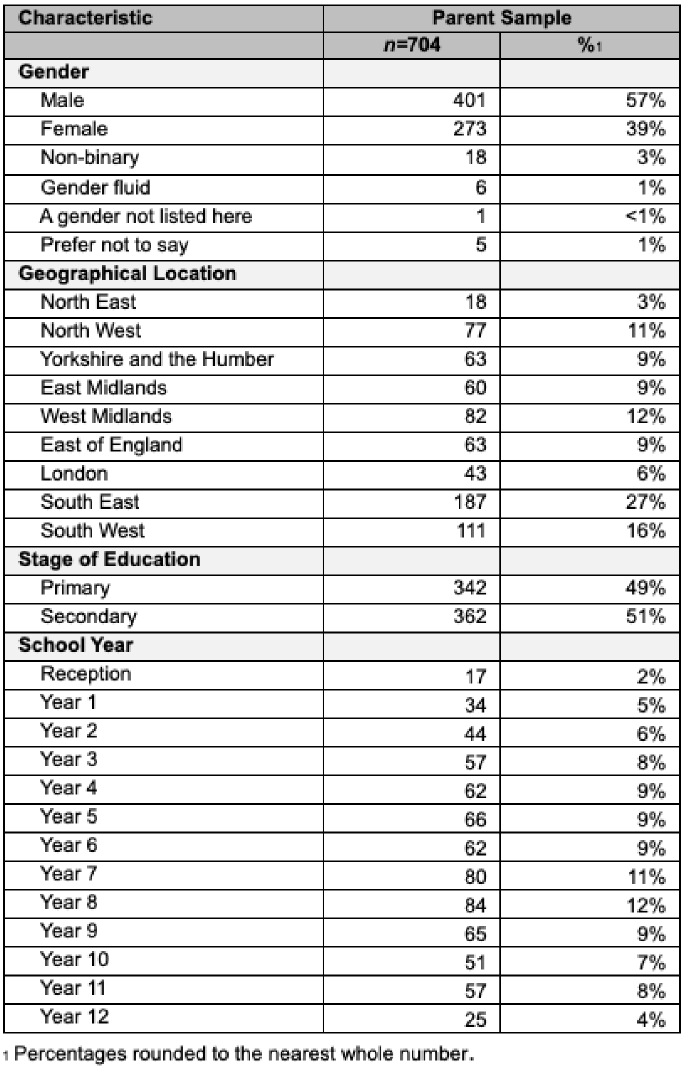
Parents of PDA CYP

The findings of the parent questionnaire that produced quantitative data are next presented.

Demographics

CYP from all geographical regions of England were represented (*n*=704). 57% of the CYP were male, 39% female and the remaining 4% were split between gender fluid, non-binary, a gender not listed, and the prefer not to say option. 49% of CYP were in primary education and 51% secondary (Table 5.2).

TABLE 5.2. Demographic characteristics of CYP in the parent sample



Characteristic	Parent Sample	
	n=704	%[1]
Gender		
Male	401	57%
Female	273	39%
Non-binary	18	3%
Gender fluid	6	1%
A gender not listed here	1	<1%
Prefer not to say	5	1%
Geographical Location		
North East	18	3%
North West	77	11%
Yorkshire and the Humber	63	9%
East Midlands	60	9%
West Midlands	82	12%
East of England	63	9%
London	43	6%
South East	187	27%
South West	111	16%
Stage of Education		
Primary	342	49%
Secondary	362	51%
School Year		
Reception	17	2%
Year 1	34	5%
Year 2	44	6%
Year 3	57	8%
Year 4	62	9%
Year 5	66	9%
Year 6	62	9%
Year 7	80	11%
Year 8	84	12%
Year 9	65	9%
Year 10	51	7%
Year 11	57	8%
Year 12	25	4%

[1] Percentages rounded to the nearest whole number.

All CYP in the sample group were either diagnosed autistic (77%), currently in the assessment process (18%) or suspected to be autistic (5%), and all were either diagnosed as PDA (50%) or identified as PDA (50%). The average number of co-occurring conditions over and above autism and PDA, was 3 (*M* = 3, *SD* = 1.79) ranging from 0 to 10. Anxiety was the most frequently occurring (63%), followed by ADHD/ADD (58%) (Figure 5.7).

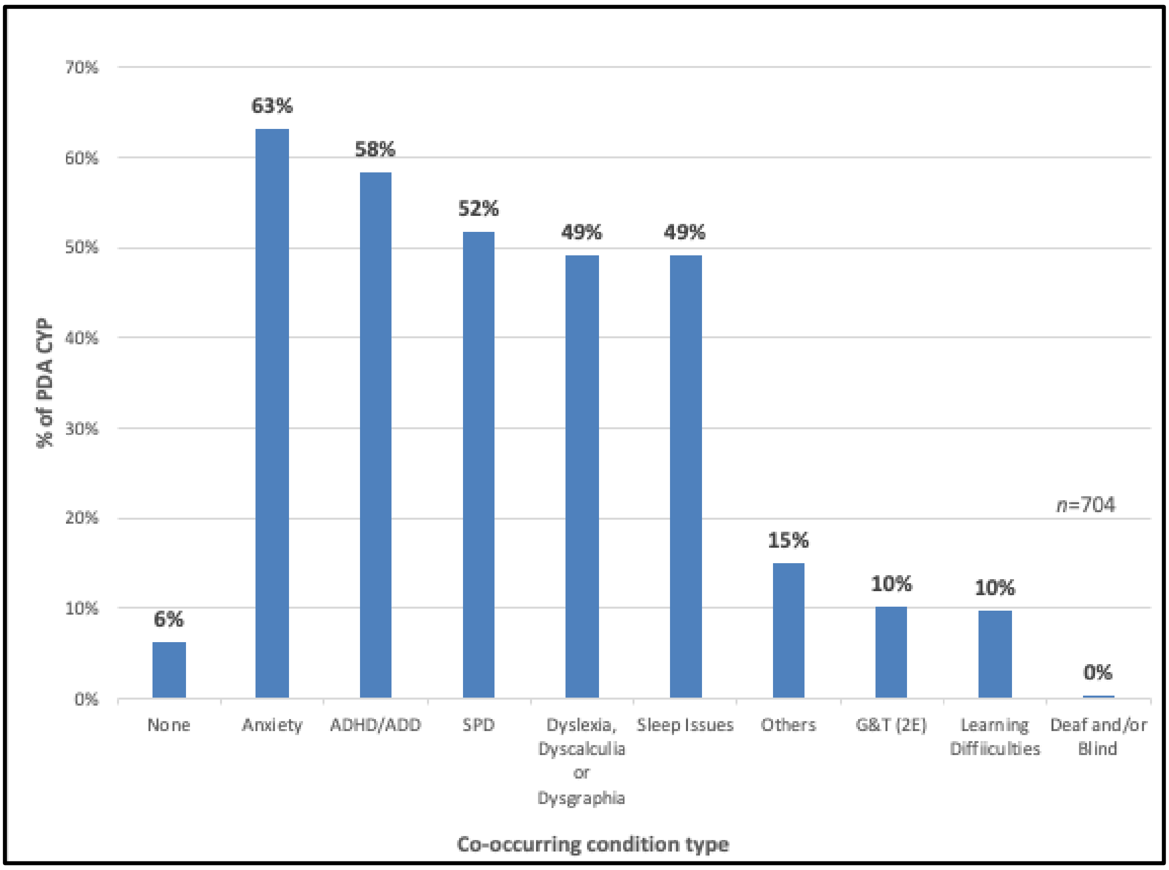


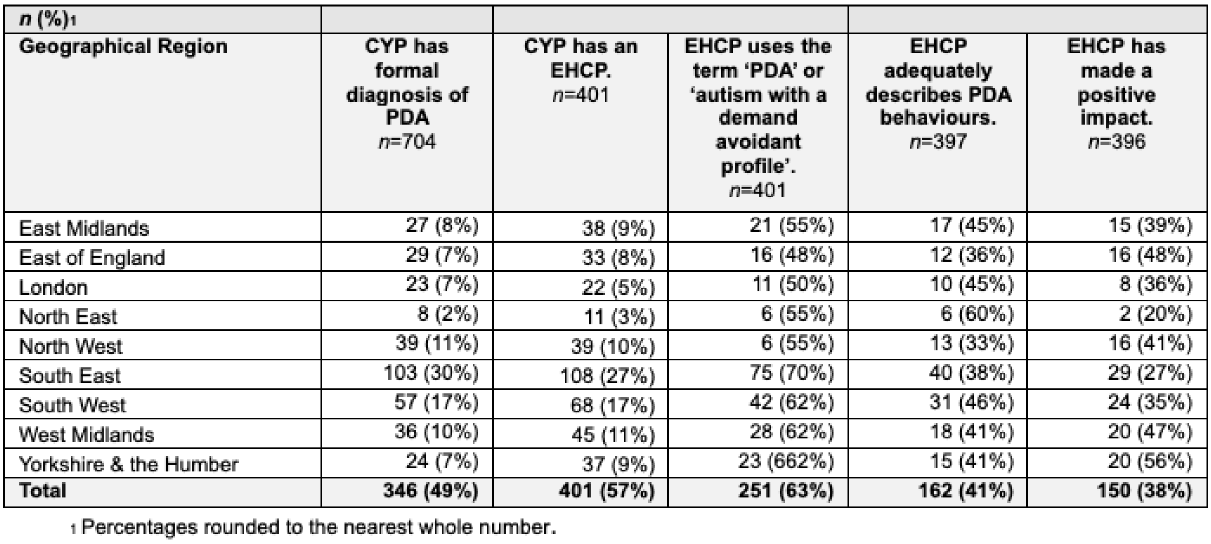
FIGURE 5.7: Percentage of CYP with other neurodivergences and co-occurring conditions

ADHD/ADD = Attention Deficit Hyperactivity Disorder / Attention Deficit Disorder. SPD = Sensory Processing Disorder. G&T = Gifted and Talented. 2E = Twice Exceptional Learner (Gifted and SEND).

Terminology

57% of the CYP had an EHCP, with 16% having applied for one, whereby it was currently in assessment or the LA decision not to assess the CYP or not to issue an EHCP was being appealed, and 27% of the CYP did not have an EHCP (*n*=692). 63% of the EHCPs issued used the term ‘PDA’, or ‘autism with a demand avoidant profile’. Table 5.3 shows a breakdown of EHCPs by geographical region and the parent responses to EHCP related questions.

TABLE 5.3: Diagnosis, EHCPs, their content and impact by geographical region



n (%)[1]					
Geographical Region	**CYP has formal diagnosis of PDA** *n*=704	**CYP has an EHCP.** *n*=401	**EHCP uses the term 'PDA' or 'autism with a demand avoidant profile'.** *n*=401	**EHCP adequately describes PDA behaviours.** *n*=397	**EHCP has made a positive impact.** *n*=396
East Midlands	27 (8%)	38 (9%)	21 (55%)	17 (45%)	15 (39%)
East of England	29 (7%)	33 (8%)	16 (48%)	12 (36%)	16 (48%)
London	23 (7%)	22 (5%)	11 (50%)	10 (45%)	8 (36%)
North East	8 (2%)	11 (3%)	6 (55%)	6 (60%)	2 (20%)
North West	39 (11%)	39 (10%)	6 (55%)	13 (33%)	16 (41%)
South East	103 (30%)	108 (27%)	75 (70%)	40 (38%)	29 (27%)
South West	57 (17%)	68 (17%)	42 (62%)	31 (46%)	24 (35%)
West Midlands	36 (10%)	45 (11%)	28 (62%)	18 (41%)	20 (47%)
Yorkshire & the Humber	24 (7%)	37 (9%)	23 (662%)	15 (41%)	20 (56%)
Total	**346 (49%)**	**401 (57%)**	**251 (63%)**	**162 (41%)**	**150 (38%)**

[1] Percentages rounded to the nearest whole number.

A chi-square test of independence was performed to examine if there was a relationship between formal diagnosis and the EHCP using the term PDA and found a significant relationship X^2 (1, N = 401) = 93.970, p <0.001, with the term more likely to be used if the CYP was formally diagnosed. It was also found that having a diagnosis meant that it was more likely that the EHCP would adequately describe the CYP's demand avoidant behaviours, X^2 (1, N = 397) = 31.066, p <0.001. However, having a diagnosis was not significantly related to the EHCP then having a positive impact on the CYP's education, X^2 (2, N = 396) = 5.721, p= 0.57. Also, whether the EHCP used the term PDA or not was not significantly related to the EHCP having a positive impact on the CYP's education, X^2 (2, N = 396) = 6.155, p= 0.46.

Geographical regions were also examined for relationships. There was no significant relationship found between geographic regions using the term PDA in an EHCP, X^2 (8, N = 401) = 9.968, p= .267, EHCPs adequately describing demand avoidant behaviours, X^2 (8, N = 397) = 7.195, p= .839, or if the EHCP then had a positive impact on the CYP's education, X^2 (16, N = 396) = 23.964, p= .090. Neither was there a significant relationship between geographic region and formal diagnosis X^2 (8, N = 704) = 8.042, p= .429.

Educational Settings

As not all the CYP have an EHCP, the educational settings for all the CYP in the sample were next explored. 91% of the CYP began their education in mainstream schools, 4% in independent mainstreams with only 2% educated outside of a school setting with the parents electing to home educate from the start of the CYP's education (*n*=693). 35% of parents cited the reason for leaving mainstream was the school not meeting their CYP's needs, 14% due to the child having attendance difficulties and 6% either excluded or having a managed move. 39% of the CYP either remained in this setting or left due to reaching a normal transition stage (*n*=603). Figure 5.8 shows the reasons for leaving the first mainstream educational setting.

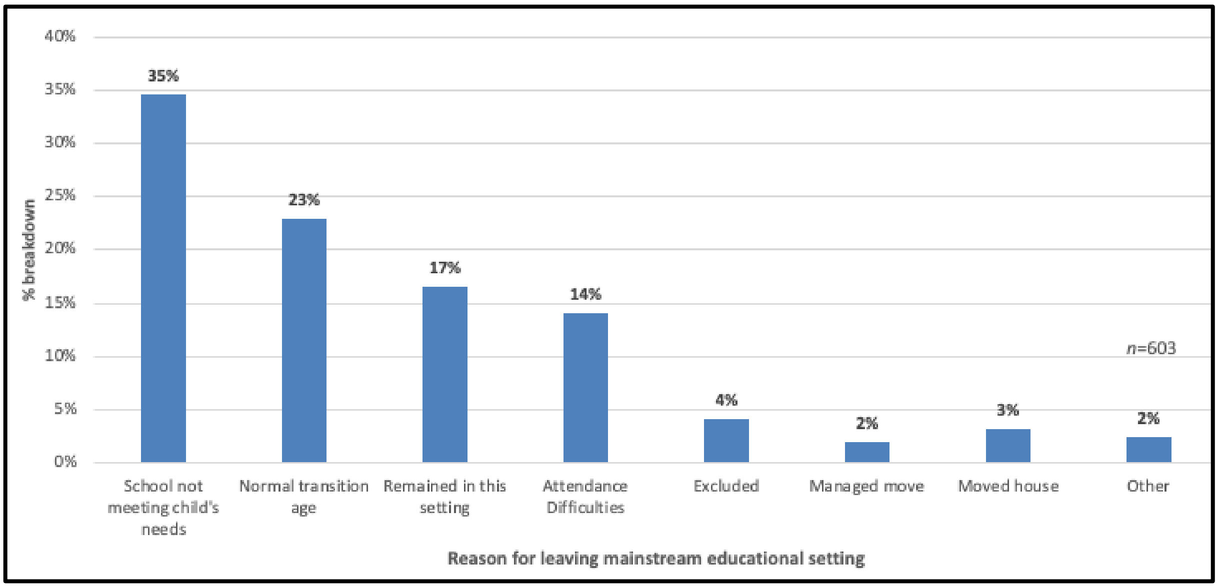


FIGURE 5.8: Percentage breakdown of reasons for leaving mainstream education

53% of the primary CYP are in mainstream educational settings which reduces to 34% for secondary aged children. 21% of primary CYP are educated outside of a school setting (EOTAS, AP and EHE), increasing to 31% for secondary aged CYP, so 26% of PDA CYP are educated outside of a school setting. 15% of primary CYP are in special schools (special, independent special and SRP), increasing to 22% in secondary demonstrating a marked movement from mainstream towards specialist provision and education outside of a school environment as the CYP moves from primary to secondary (Figure 5.9).

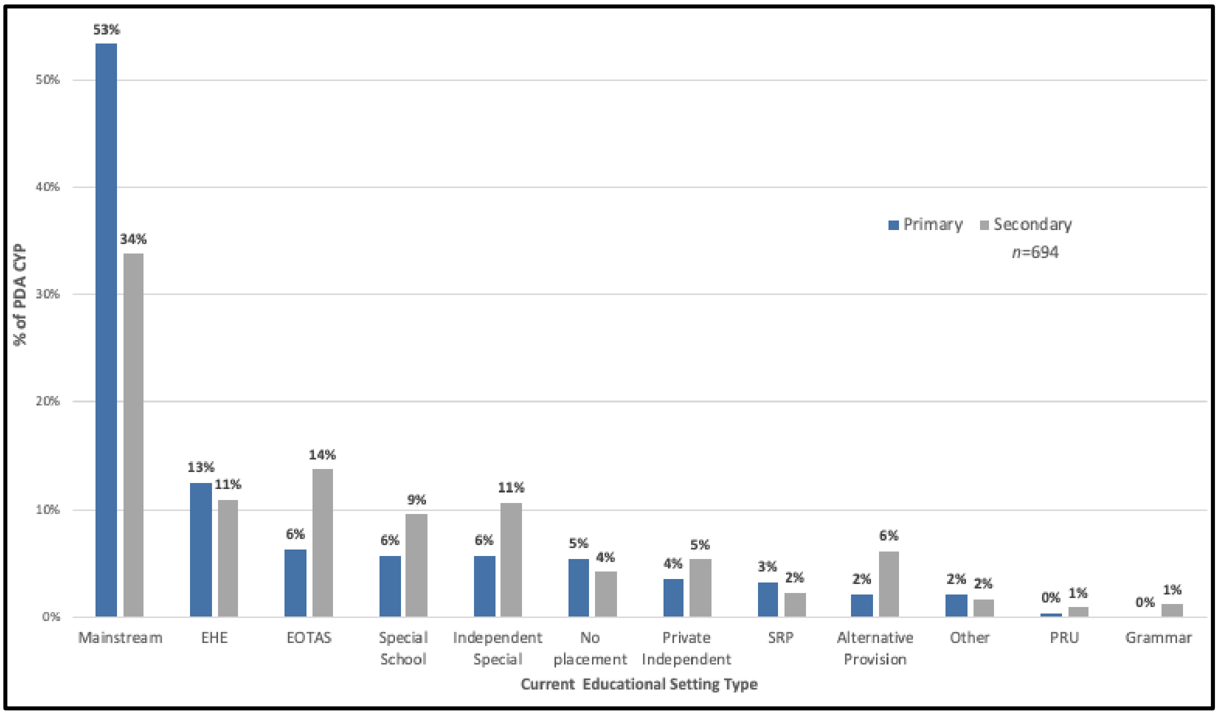


FIGURE 5.9: Current educational settings of CYP by Primary and Secondary

Of the 180 (26%) CYP educated outside of a school setting (EOTAS, AP and EHE), only 5 (3%) had electively chosen to do so. 55% were due to schools not meeting the CYP's needs, and 34% due to attendance difficulties. All reasons are shown in Figure 5.10 by current placement type.

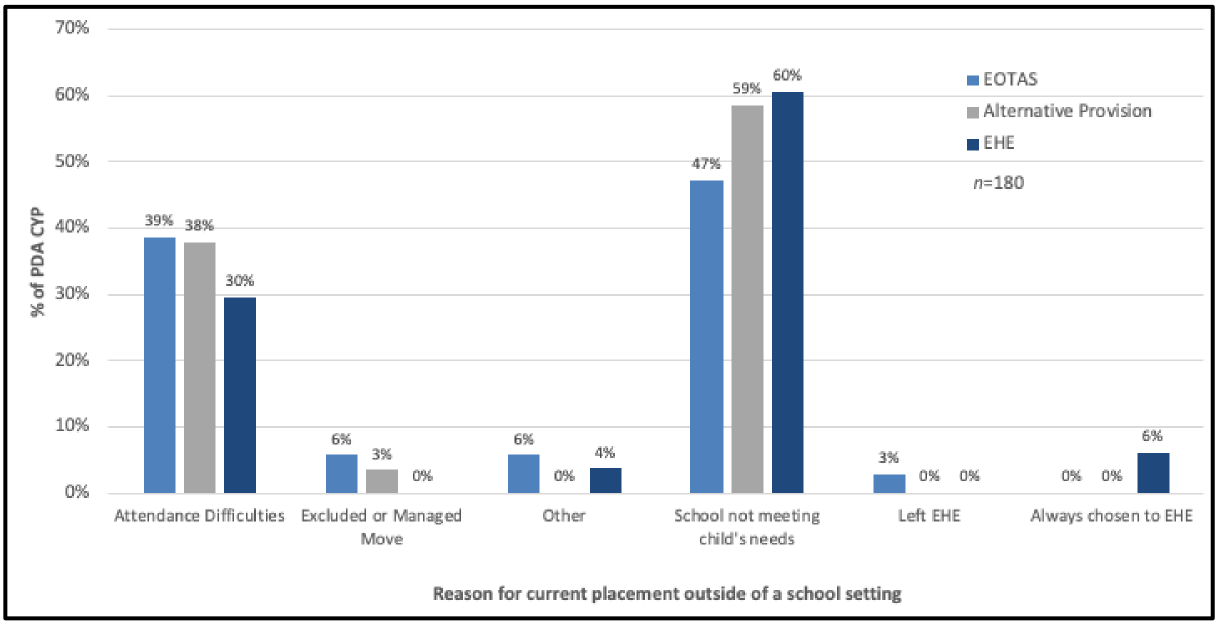


FIGURE 5.10: Reasons CYP are educated outside of a school setting by placement type

Educational Experiences

73% of parents reported their CYP had either negative or very negative educational experiences with only 10% reporting positive or very positive experiences (Figure 5.11).

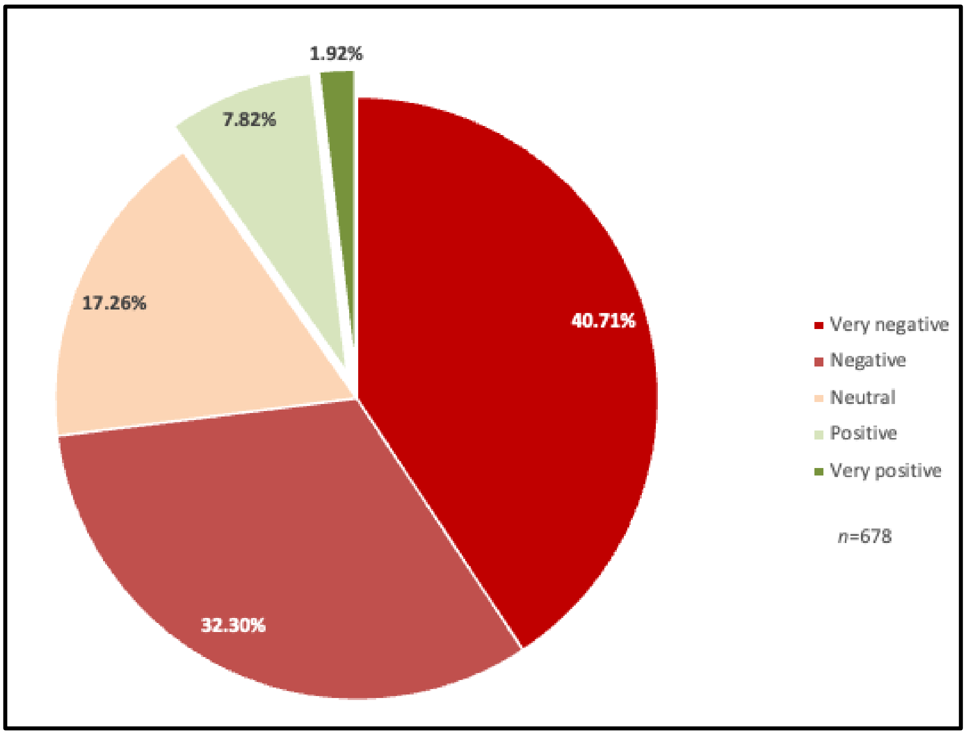


FIGURE 5.11: Overall educational experiences of CYP reported by parents

Of the 10% (*n*=678) who reported positive educational experiences (positive and very positive), 65% were in primary and 35% in secondary with males making up 64% of the positive experiences and females 36%. No other genders reported positive educational experiences. However, there was no significant correlation found between the child's gender and their educational experience (rs= -.002, *p*=.951), nor where they lived geographically (rs= .014, *p*=.720).

Whether the CYP had an EHCP or not correlated significantly with their overall educational experience (rs= -0.98, *p*<0.05). Overall, 63% of the EHCPs issued used the term 'PDA' or 'autism with a demand avoidant profile' and this increased to 70% when splitting the dataset to CYP with positive experiences. However, this was not of significance when related to their overall educational experience (rs= 0.93, *p*=0.67), nor was the child having a formal PDA diagnosis (rs= -0.12, *p*=.764). More important was that the EHCP described the demand avoidant behaviours of the CYP adequately as this significantly correlated with their overall educational experience (rs= .219, *p*<.001). Yet, 59% of parents felt that their child's EHCP did not adequately describe their CYP's demand avoidant behaviours, and only 38% of parents felt that the EHCP had made a positive impact on their CYP's educational experiences (Table 5.3).

CYP who struggled with school attendance was a significant factor in contributing to negative school experiences (rs= -.349, *p*<.001), as were formal exclusions (rs= 0.94, *p*<.005), informal exclusions (rs= 0.123, *p*<.001), and if the CYP had time with no educational provision (rs=.474, *p*<.001). So, the next section presents the findings of the CYP's experiences related to these specific factors.

School Attendance

86% of PDA CYP struggled with school attendance (*n*=694) in both primary (40% of CYP) and secondary (46%) settings (Figure 5.12).

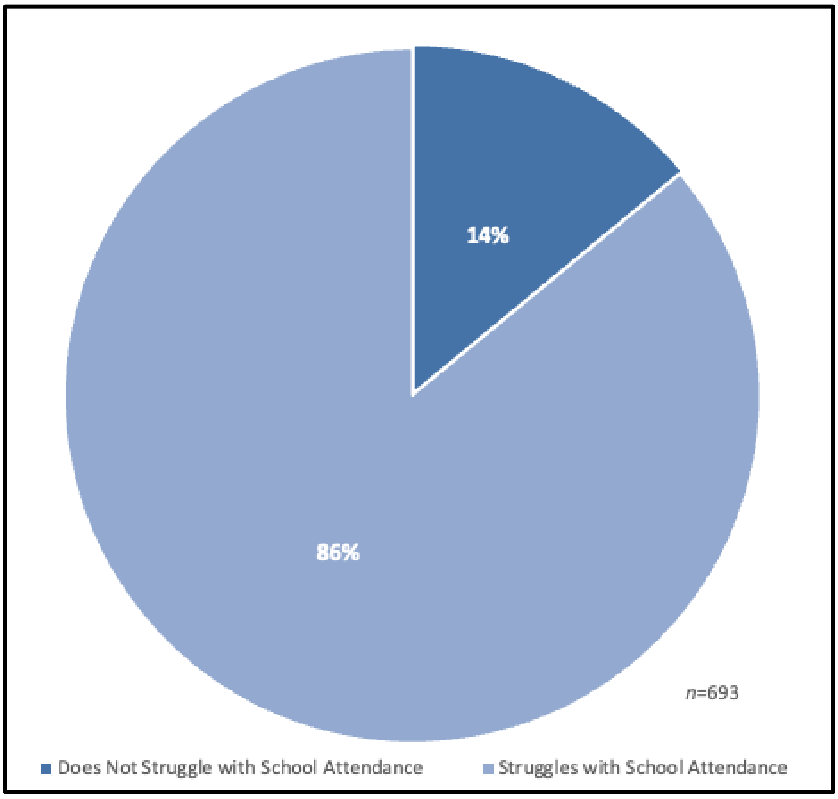


FIGURE 5.12: Percentage of CYP who struggle with school attendance

School attendance difficulties started from reception with 27% (*n*=594) of PDA CYP having attendance struggles from first joining school, with the onset of school attendance difficulties decreasing as they go through their education (Figure 5.13).

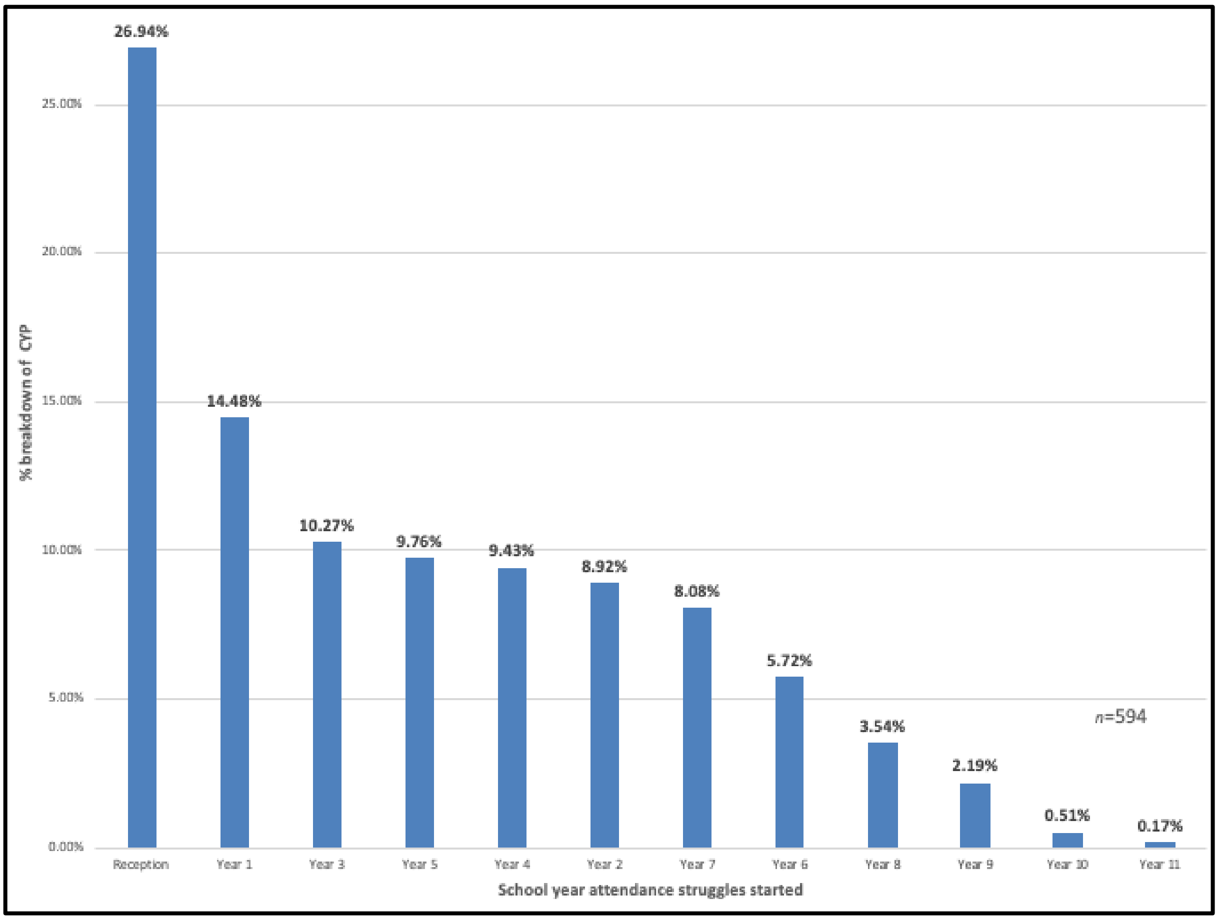


FIGURE 5.13: Percentage breakdown of the onset of school attendance struggles by school year

To discover if there was a gender difference in the onset of school attendance struggles, the data was split into male and female categories, with 'gender not listed', 'prefer not to say' and 'gender fluid' removed due to their low sample size. The % of male and female CYP were analysed separately as shown in Figure 5.14. Early school struggles were evident with male CYP, 31% in reception with school attendance difficulties, as opposed to 21% for females, which was consistent through the first three years of education. In year 3 both groups were balanced, but then after that girls predominantly started to struggle with school.

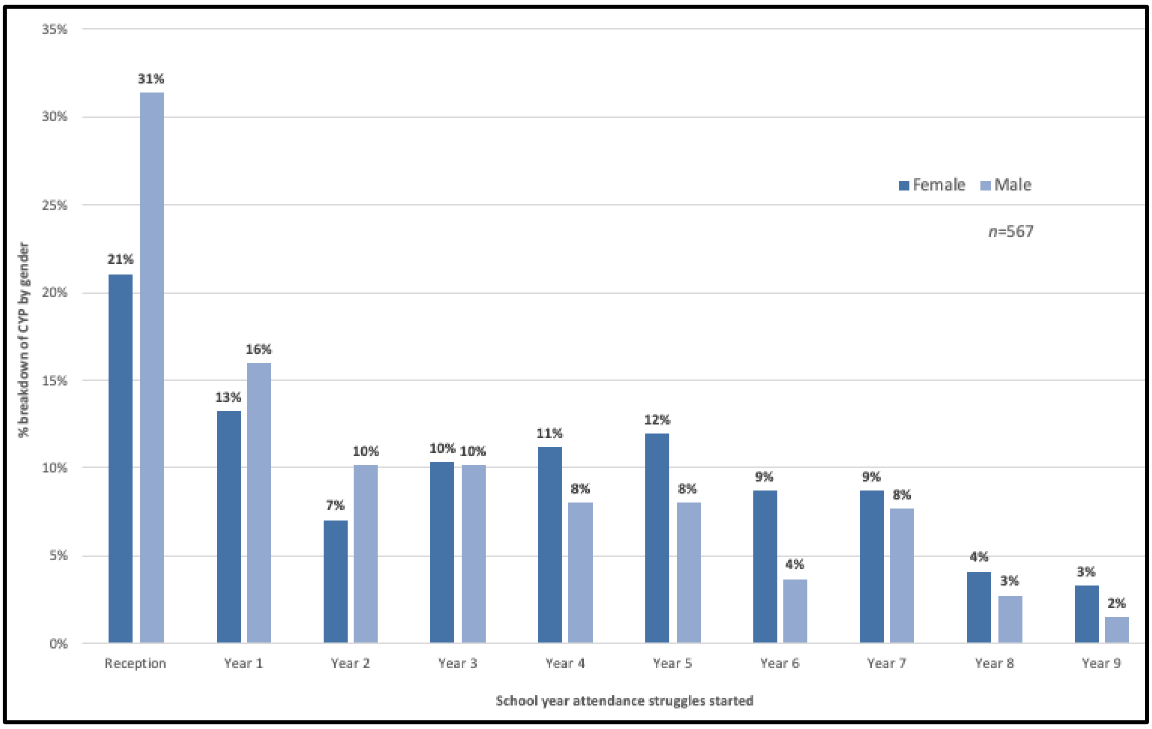


FIGURE 5.14: Percentage breakdown of the onset of school attendance struggles

On average CYP who struggled with school attendance had been doing so for 4 years, with some having attendance difficulties their entire school lives (Table 5.4).

TABLE 5.4: The number of months the CYP struggled with school attendance.

Responses	Mean	Range	Standard Deviation
n=588	48.25 months	1-140 months	31.93

Parents were asked to select what they felt were barriers to school attendance for their CYP. Only 4% (*n*=683) stated their child had no barriers to attending school, while demand avoidance (89%) and anxiety (86%) formed barriers to attendance, with sensory struggles (75%) and unmet SEND needs (73%), also being impactful (Figure 5.15). Of the 4% of CYP whose parents stated there were no barriers to school attendance, it was found that 14 had periods of time with attendance struggles, formal and informal exclusions, and time with no education and 36% of these parents still reported their CYP's educational experience as either neutral or negative. Only one of these CYP had anxiety reported as a co-occurring condition and their number of co-occurring conditions were lower that the sample mean (1.25).

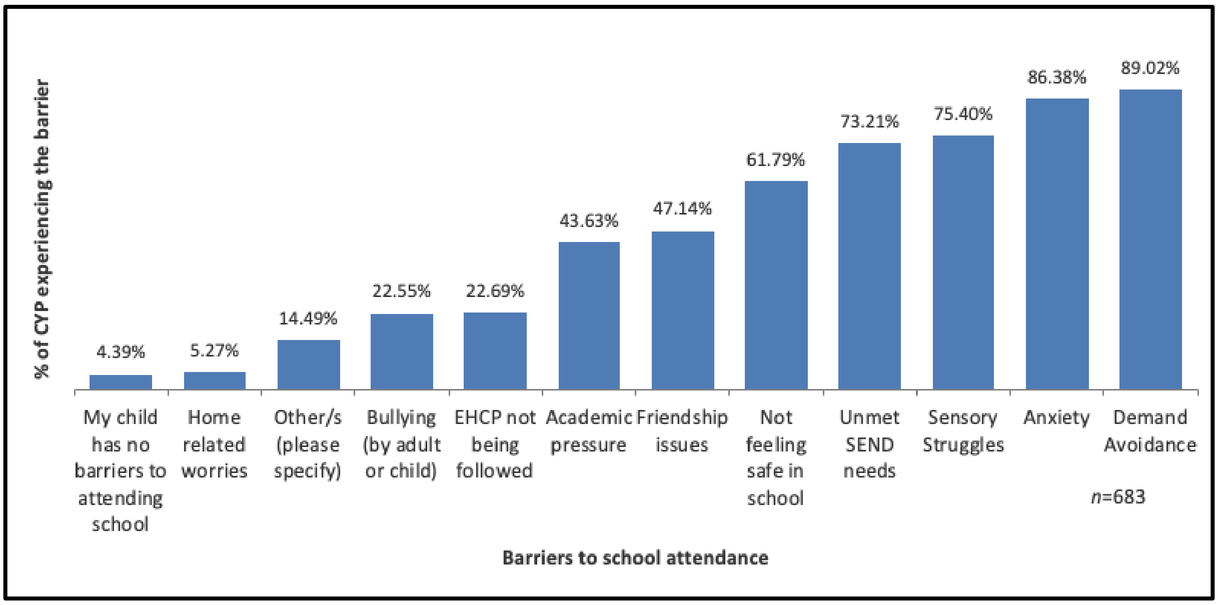


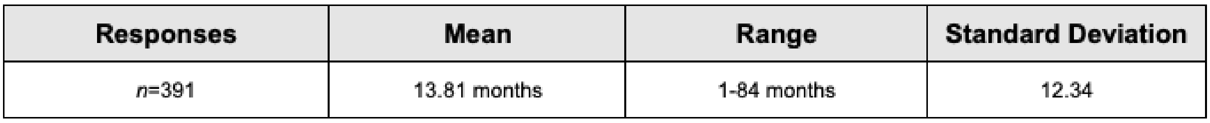
FIGURE 5.15: Parent identified barriers to school attendance for their CYP

Amongst the comments from parents for 'other' barriers to their child's attendance were EHCP's being badly written, not being followed, and not adequately describing their child's needs, as well as a lack of trusting relationships in school, and trauma caused by school. Masking in school leading to autistic burnout was also mentioned numerous times as well as a lack of understanding of PDA.

No Educational Provision

59% of CYP had time with no educational provision (*n*=686). Table 5.5 shows the number of months without provision.

TABLE 5.5: The number of months a CYP had no educational provision



Responses	Mean	Range	Standard Deviation
n=391	13.81 months	1-84 months	12.34

Exclusions

21% of CYP had received formal school exclusions (*n*=696). These ranged from occurring only once to 40 times for two of the CYP. The mean number of formal exclusions for this group of 148 children was 5.84 and 60% were for secondary ages. Informal exclusions, defined as when the parent has been asked to collect their child for reasons other than illness or were discouraged from sending them in, were more frequent with 36% of the CYP having informal exclusions, with a mean of 10 and ranging from 30 children experiencing this on one occasion to nine children having 100 informal inclusions. 60% again occurred in secondary education with majority of exclusions, both formal and informal, for males (Figure 5.16).

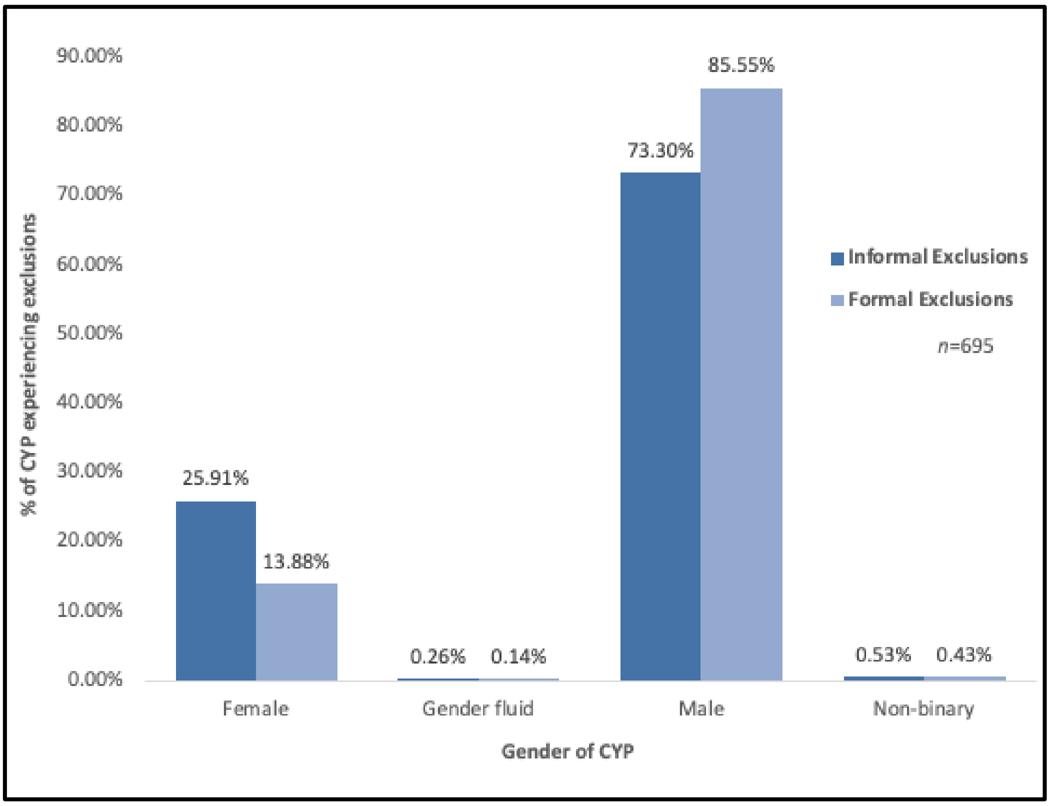


FIGURE 5.16: Percentage of CYP experiencing school exclusions by gender

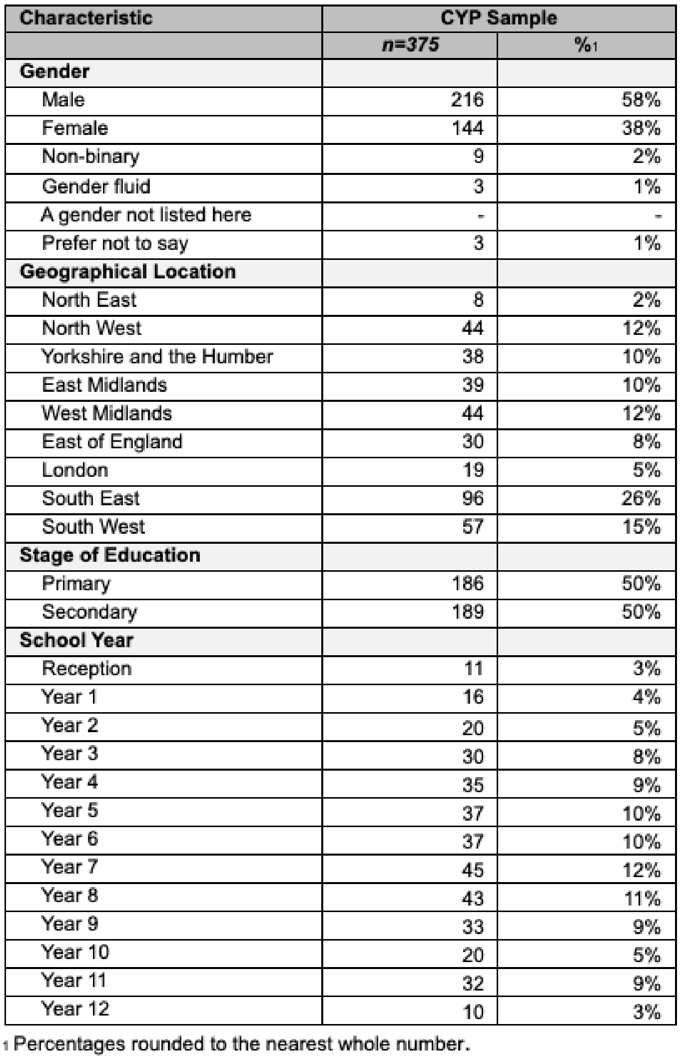
PDA CYP

To further understand the CYP's educational experiences from their own viewpoint, 53% of the parent participants' CYP continued with the CYP section of the survey, so 375 CYP participated.

Demographics

All genders and primary and secondary school ages from all geographical regions were represented as shown in Table 5.6.

TABLE 5.6: Demographic characteristics of CYP in the CYP sample.



Characteristic	CYP Sample	
	n=375	%[1]
Gender		
Male	216	58%
Female	144	38%
Non-binary	9	2%
Gender fluid	3	1%
A gender not listed here	-	-
Prefer not to say	3	1%
Geographical Location		
North East	8	2%
North West	44	12%
Yorkshire and the Humber	38	10%
East Midlands	39	10%
West Midlands	44	12%
East of England	30	8%
London	19	5%
South East	96	26%
South West	57	15%
Stage of Education		
Primary	186	50%
Secondary	189	50%
School Year		
Reception	11	3%
Year 1	16	4%
Year 2	20	5%
Year 3	30	8%
Year 4	35	9%
Year 5	37	10%
Year 6	37	10%
Year 7	45	12%
Year 8	43	11%
Year 9	33	9%
Year 10	20	5%
Year 11	32	9%
Year 12	10	3%

[1] Percentages rounded to the nearest whole number.

Educational Experiences

After conducting the thematic data analysis of the 6 open-ended questions presented to the CYP, 22 codes were generated to categorise their responses that were assigned to six key themes to summarise the CYP's views of their educational experiences (Figure 5.17).

FIGURE 5.17: The six themes identified from CYP's questionnaire responses

Table 5.7 shows the generated codes, the theme they were allocated to, and the number of responses that referenced each theme, with disengagement from the school education system being the most referenced theme, closely followed by poor relationships. The exported codebook from NVivo is shown in Appendix H.

TABLE 5.7: Generated codes for each theme and number of responses that referenced the theme

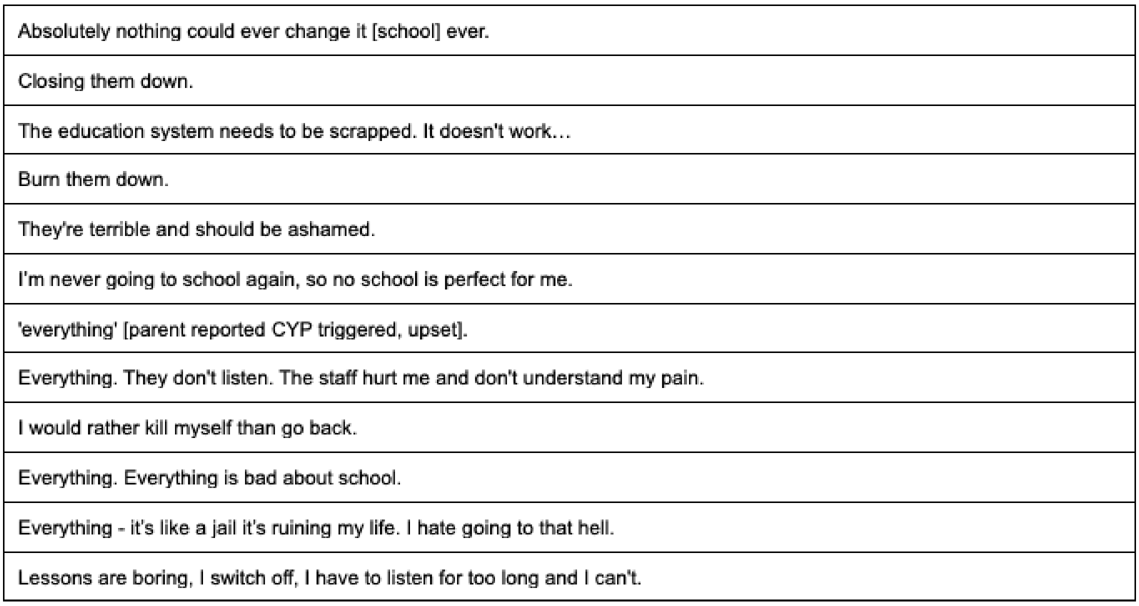
Themes	Codes	No. of Responses
Disengaged	Bored, disengaged, everything is bad, nothing is good, gaining engagement	740
Poor Relationships	Bullying, friendships, misunderstood, poor relationships.	701
Environmental Struggles	Physical restrictions, scared & unsafe, sensory struggles, uniform struggles, work difficulties.	629
Disempowered	Autonomy & choice, loss of autonomy, pressure & demands, rules & punishment, gaining support.	369
Excluded	Excluded & isolated, lack of support, underestimated.	233
Poor Mental Health	Exhausted, failing, stress & worries.	140

Findings from each theme are next presented, with some examples of direct quotations from the CYP. The CYP's views and experiences were corroborated by the parent's responses to open-ended questions, so examples of these are included.

Disengaged

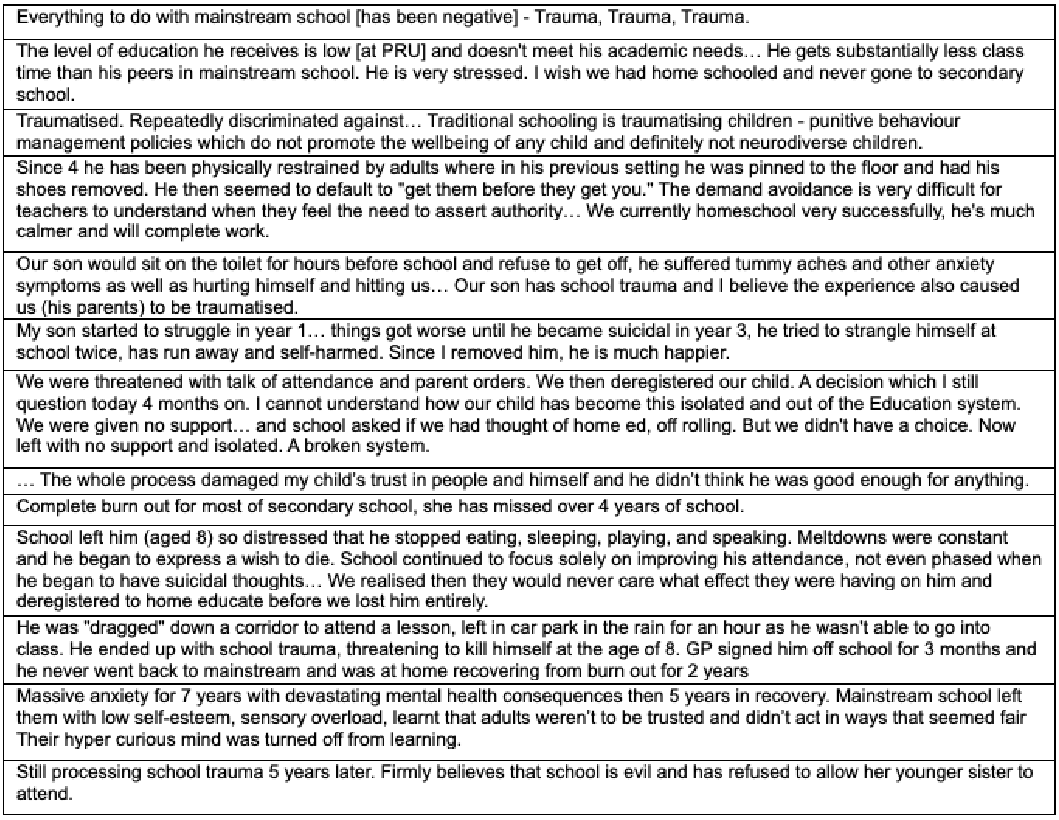
740 responses from the CYP were assigned to the theme 'Disengaged'. Examples of their responses are shown in Table 5.8 with parent comments in Table 5.9.

TABLE 5.8: Examples of CYP's responses within the theme 'Disengaged'



Absolutely nothing could ever change it [school] ever.
Closing them down.
The education system needs to be scrapped. It doesn't work…
Burn them down.
They're terrible and should be ashamed.
I'm never going to school again, so no school is perfect for me.
'everything' [parent reported CYP triggered, upset].
Everything. They don't listen. The staff hurt me and don't understand my pain.
I would rather kill myself than go back.
Everything. Everything is bad about school.
Everything - it's like a jail it's ruining my life. I hate going to that hell.
Lessons are boring, I switch off, I have to listen for too long and I can't.

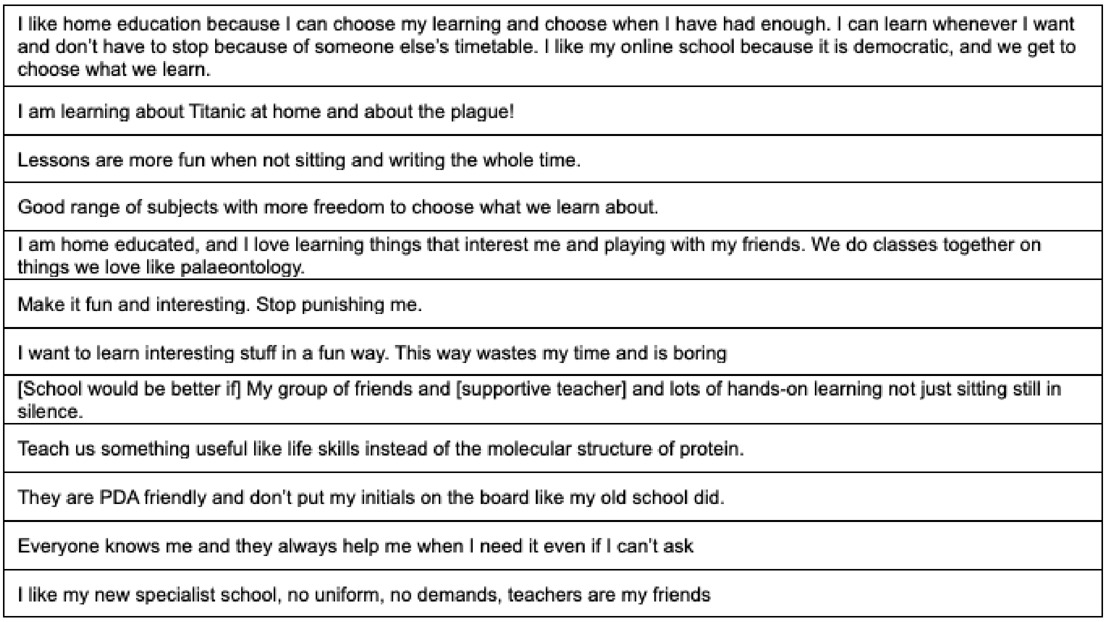
TABLE 5.9: Examples of parent responses within the theme ‘Disengaged’



Everything to do with mainstream school [has been negative] - Trauma, Trauma, Trauma.
The level of education he receives is low [at PRU] and doesn't meet his academic needs… He gets substantially less class time than his peers in mainstream school. He is very stressed. I wish we had home schooled and never gone to secondary school.
Traumatised. Repeatedly discriminated against… Traditional schooling is traumatising children - punitive behaviour management policies which do not promote the wellbeing of any child and definitely not neurodiverse children.
Since 4 he has been physically restrained by adults where in his previous setting he was pinned to the floor and had his shoes removed. He then seemed to default to "get them before they get you." The demand avoidance is very difficult for teachers to understand when they feel the need to assert authority… We currently homeschool very successfully, he's much calmer and will complete work.
Our son would sit on the toilet for hours before school and refuse to get off, he suffered tummy aches and other anxiety symptoms as well as hurting himself and hitting us… Our son has school trauma and I believe the experience also caused us (his parents) to be traumatised.
My son started to struggle in year 1… things got worse until he became suicidal in year 3, he tried to strangle himself at school twice, has run away and self-harmed. Since I removed him, he is much happier.
We were threatened with talk of attendance and parent orders. We then deregistered our child. A decision which I still question today 4 months on. I cannot understand how our child has become this isolated and out of the Education system. We were given no support… and school asked if we had thought of home ed, off rolling. But we didn't have a choice. Now left with no support and isolated. A broken system.
… The whole process damaged my child's trust in people and himself and he didn't think he was good enough for anything.
Complete burn out for most of secondary school, she has missed over 4 years of school.
School left him (aged 8) so distressed that he stopped eating, sleeping, playing, and speaking. Meltdowns were constant and he began to express a wish to die. School continued to focus solely on improving his attendance, not even phased when he began to have suicidal thoughts… We realised then they would never care what effect they were having on him and deregistered to home educate before we lost him entirely.
He was "dragged" down a corridor to attend a lesson, left in car park in the rain for an hour as he wasn't able to go into class. He ended up with school trauma, threatening to kill himself at the age of 8. GP signed him off school for 3 months and he never went back to mainstream and was at home recovering from burn out for 2 years
Massive anxiety for 7 years with devastating mental health consequences then 5 years in recovery. Mainstream school left them with low self-esteem, sensory overload, learnt that adults weren't to be trusted and didn't act in ways that seemed fair Their hyper curious mind was turned off from learning.
Still processing school trauma 5 years later. Firmly believes that school is evil and has refused to allow her younger sister to attend.

A few CYP shared how engagement could be achieved through positive relationships and focussing on topics they were interested in, with some CYP explaining how to ‘get it right’, where they felt understood and supported (Table 5.10).

TABLE 5.10: Examples of CYP’s responses coded to ‘Gaining Engagement’

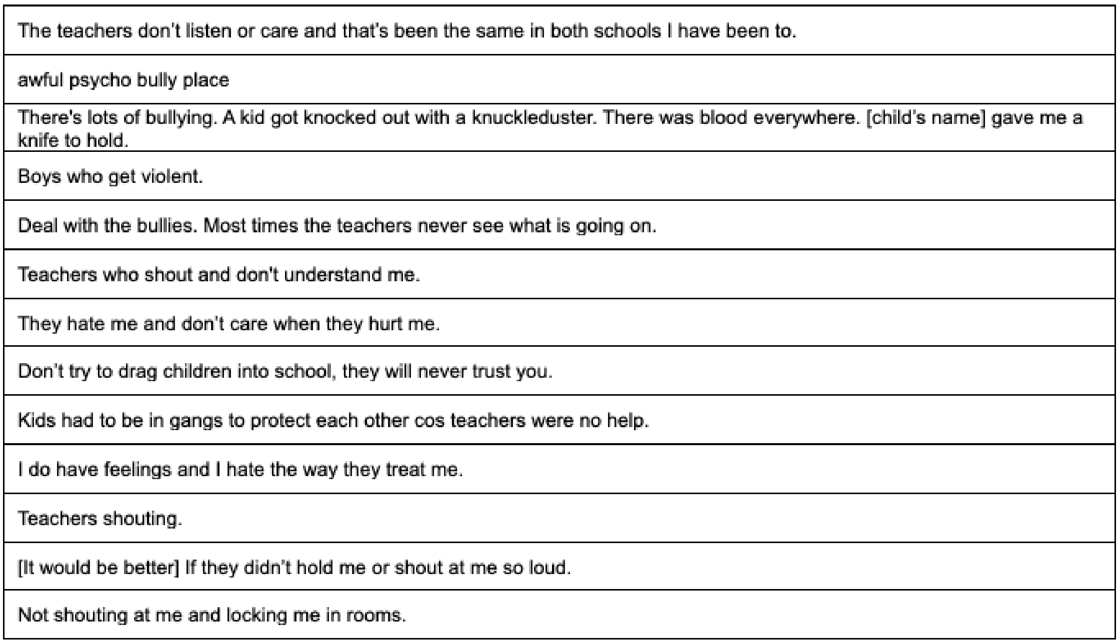


I like home education because I can choose my learning and choose when I have had enough. I can learn whenever I want and don't have to stop because of someone else's timetable. I like my online school because it is democratic, and we get to choose what we learn.
I am learning about Titanic at home and about the plague!
Lessons are more fun when not sitting and writing the whole time.
Good range of subjects with more freedom to choose what we learn about.
I am home educated, and I love learning things that interest me and playing with my friends. We do classes together on things we love like palaeontology.
Make it fun and interesting. Stop punishing me.
I want to learn interesting stuff in a fun way. This way wastes my time and is boring
[School would be better if] My group of friends and [supportive teacher] and lots of hands-on learning not just sitting still in silence.
Teach us something useful like life skills instead of the molecular structure of protein.
They are PDA friendly and don't put my initials on the board like my old school did.
Everyone knows me and they always help me when I need it even if I can't ask
I like my new specialist school, no uniform, no demands, teachers are my friends

Poor Relationships

CYP reported experiences of bullying, physical abuse and poor relationships with school staff and other children in 701 instances (Table 5.11).

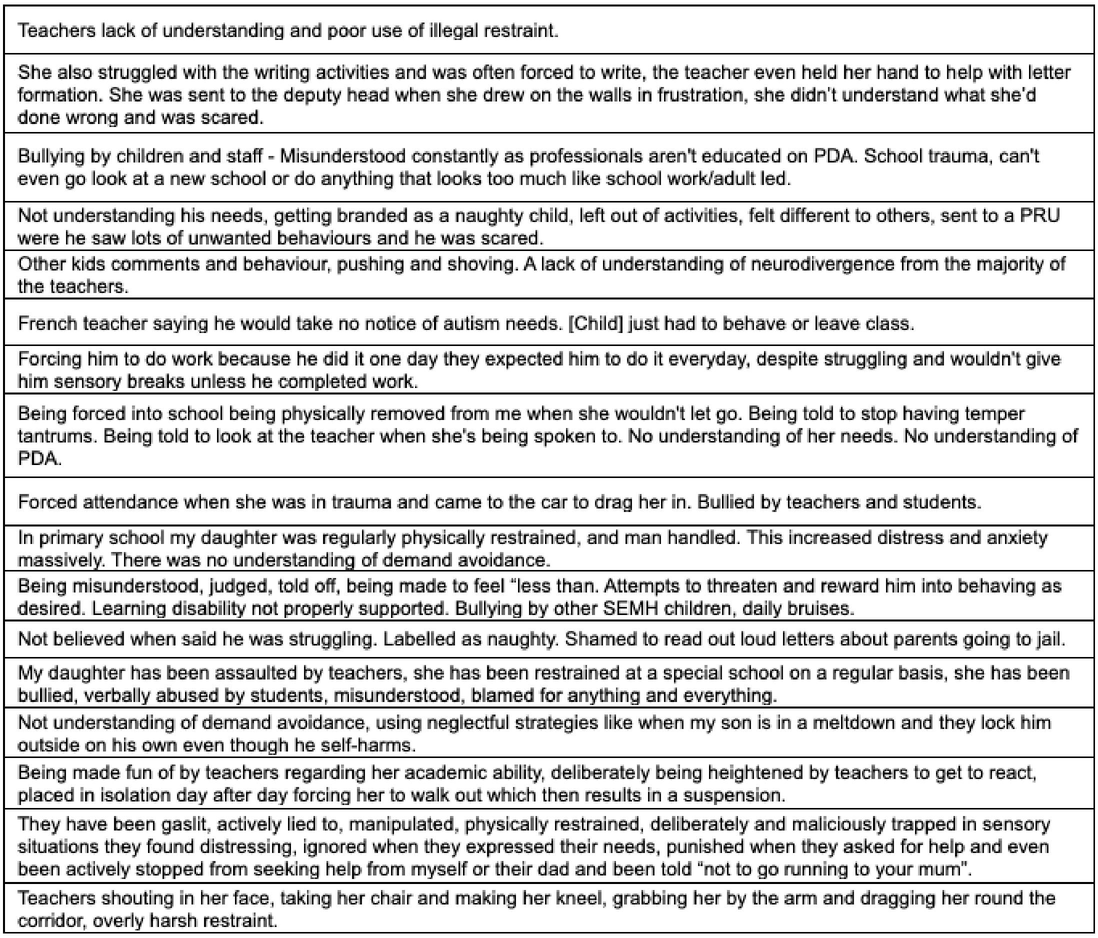
TABLE 5.11: Examples of CYP's responses coded to 'Bullying and 'Poor Relationships'



The teachers don't listen or care and that's been the same in both schools I have been to.
awful psycho bully place
There's lots of bullying. A kid got knocked out with a knuckleduster. There was blood everywhere. [child's name] gave me a knife to hold.
Boys who get violent.
Deal with the bullies. Most times the teachers never see what is going on.
Teachers who shout and don't understand me.
They hate me and don't care when they hurt me.
Don't try to drag children into school, they will never trust you.
Kids had to be in gangs to protect each other cos teachers were no help.
I do have feelings and I hate the way they treat me.
Teachers shouting.
[It would be better] If they didn't hold me or shout at me so loud.
Not shouting at me and locking me in rooms.

Parents corroborated the CYP's experiences, providing more detailed explanations (Table 5.12).

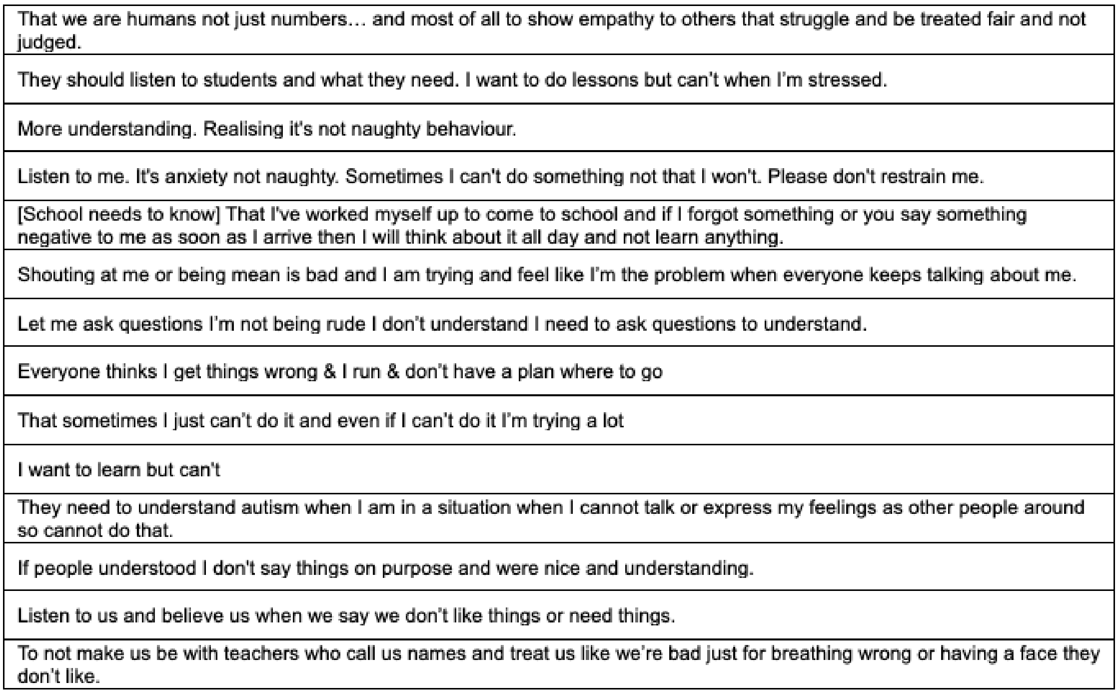
TABLE 5.12: Examples of parent responses within the theme ‘Poor Relationships’



Teachers lack of understanding and poor use of illegal restraint.
She also struggled with the writing activities and was often forced to write, the teacher even held her hand to help with letter formation. She was sent to the deputy head when she drew on the walls in frustration, she didn't understand what she'd done wrong and was scared.
Bullying by children and staff - Misunderstood constantly as professionals aren't educated on PDA. School trauma, can't even go look at a new school or do anything that looks too much like school work/adult led.
Not understanding his needs, getting branded as a naughty child, left out of activities, felt different to others, sent to a PRU were he saw lots of unwanted behaviours and he was scared.
Other kids comments and behaviour, pushing and shoving. A lack of understanding of neurodivergence from the majority of the teachers.
French teacher saying he would take no notice of autism needs. [Child] just had to behave or leave class.
Forcing him to do work because he did it one day they expected him to do it everyday, despite struggling and wouldn't give him sensory breaks unless he completed work.
Being forced into school being physically removed from me when she wouldn't let go. Being told to stop having temper tantrums. Being told to look at the teacher when she's being spoken to. No understanding of her needs. No understanding of PDA.
Forced attendance when she was in trauma and came to the car to drag her in. Bullied by teachers and students.
In primary school my daughter was regularly physically restrained, and man handled. This increased distress and anxiety massively. There was no understanding of demand avoidance.
Being misunderstood, judged, told off, being made to feel “less than. Attempts to threaten and reward him into behaving as desired. Learning disability not properly supported. Bullying by other SEMH children, daily bruises.
Not believed when said he was struggling. Labelled as naughty. Shamed to read out loud letters about parents going to jail.
My daughter has been assaulted by teachers, she has been restrained at a special school on a regular basis, she has been bullied, verbally abused by students, misunderstood, blamed for anything and everything.
Not understanding of demand avoidance, using neglectful strategies like when my son is in a meltdown and they lock him outside on his own even though he self-harms.
Being made fun of by teachers regarding her academic ability, deliberately being heightened by teachers to get to react, placed in isolation day after day forcing her to walk out which then results in a suspension.
They have been gaslit, actively lied to, manipulated, physically restrained, deliberately and maliciously trapped in sensory situations they found distressing, ignored when they expressed their needs, punished when they asked for help and even been actively stopped from seeking help from myself or their dad and been told “not to go running to your mum”.
Teachers shouting in her face, taking her chair and making her kneel, grabbing her by the arm and dragging her round the corridor, overly harsh restraint.

Feeling misunderstood was repeatedly mentioned and contributed to the theme of ‘poor relationships’ were CYP felt misunderstood, dehumanised and unheard (Table 5.13).

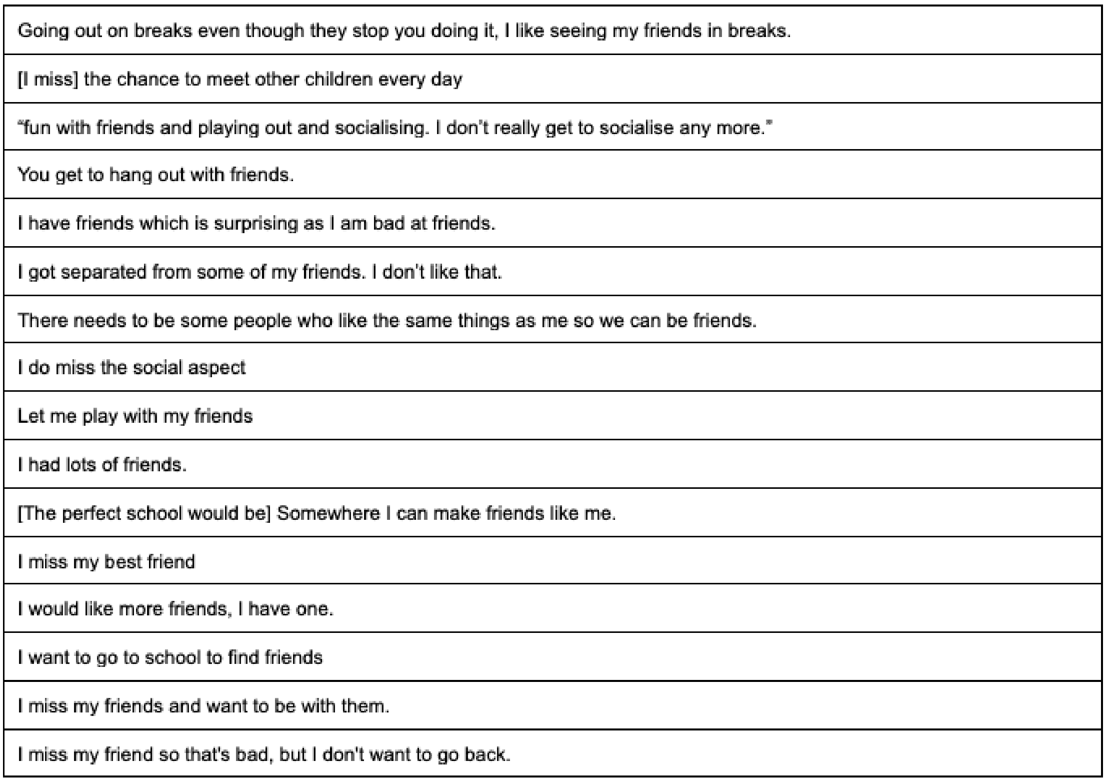
TABLE 5.13: Examples of CYP’s responses coded to ‘Misunderstood’



That we are humans not just numbers… and most of all to show empathy to others that struggle and be treated fair and not judged.
They should listen to students and what they need. I want to do lessons but can’t when I’m stressed.
More understanding. Realising it's not naughty behaviour.
Listen to me. It's anxiety not naughty. Sometimes I can't do something not that I won't. Please don't restrain me.
[School needs to know] That I've worked myself up to come to school and if I forgot something or you say something negative to me as soon as I arrive then I will think about it all day and not learn anything.
Shouting at me or being mean is bad and I am trying and feel like I’m the problem when everyone keeps talking about me.
Let me ask questions I’m not being rude I don’t understand I need to ask questions to understand.
Everyone thinks I get things wrong & I run & don’t have a plan where to go
That sometimes I just can’t do it and even if I can’t do it I’m trying a lot
I want to learn but can't
They need to understand autism when I am in a situation when I cannot talk or express my feelings as other people around so cannot do that.
If people understood I don't say things on purpose and were nice and understanding.
Listen to us and believe us when we say we don’t like things or need things.
To not make us be with teachers who call us names and treat us like we’re bad just for breathing wrong or having a face they don’t like.

Importantly, the CYP reported the value they place on friendships and how, when not in a school setting, it was friendships they missed the most about school (Table 5.14).

TABLE 5.14: Examples of CYP’s responses coded to ‘Friendships’

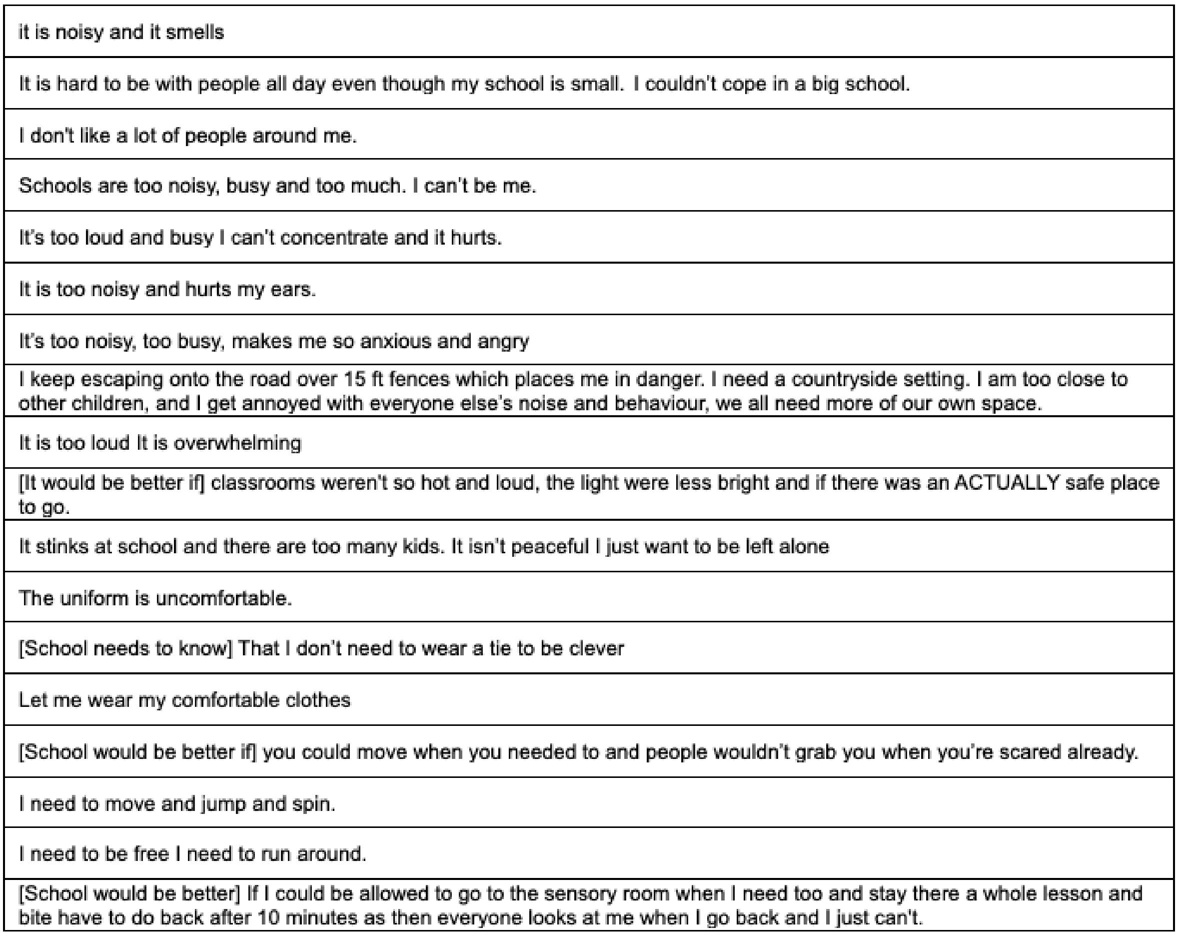


Going out on breaks even though they stop you doing it, I like seeing my friends in breaks.
[I miss] the chance to meet other children every day
"fun with friends and playing out and socialising. I don't really get to socialise any more."
You get to hang out with friends.
I have friends which is surprising as I am bad at friends.
I got separated from some of my friends. I don't like that.
There needs to be some people who like the same things as me so we can be friends.
I do miss the social aspect
Let me play with my friends
I had lots of friends.
[The perfect school would be] Somewhere I can make friends like me.
I miss my best friend
I would like more friends, I have one.
I want to go to school to find friends
I miss my friends and want to be with them.
I miss my friend so that's bad, but I don't want to go back.

Environmental Struggles

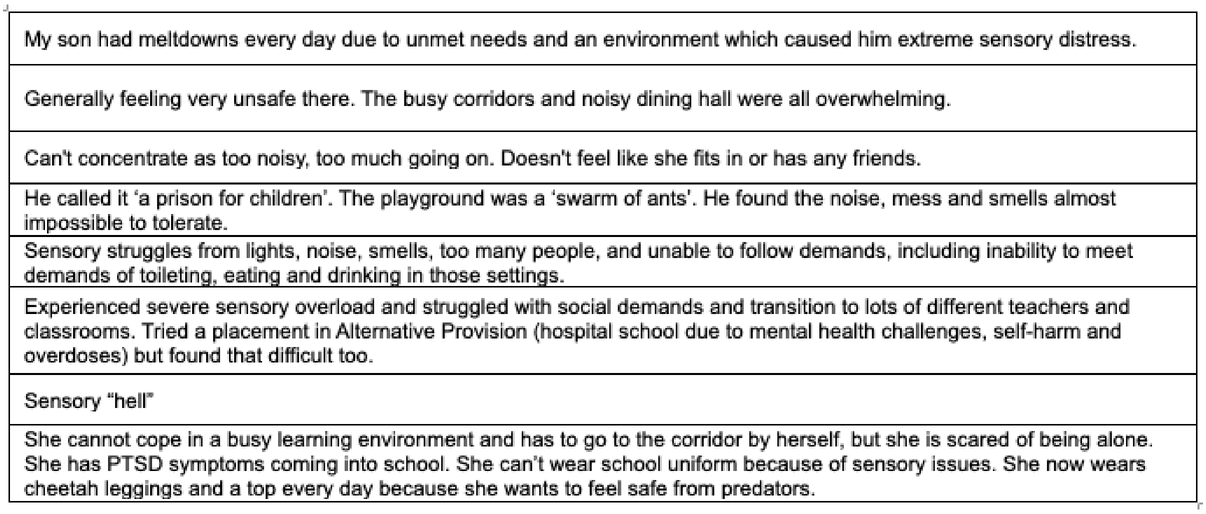
Environmental struggles were reported 629 times by the CYP. This included challenges with the busy environment, as well as noise, smells, food, school uniform and restrictions of movement (Table 5.15). Parents explained more about these struggles (Table 5.16).

TABLE 5.15: Examples of CYP's responses coded to 'Sensory Struggles'



it is noisy and it smells
It is hard to be with people all day even though my school is small. I couldn't cope in a big school.
I don't like a lot of people around me.
Schools are too noisy, busy and too much. I can't be me.
It's too loud and busy I can't concentrate and it hurts.
It is too noisy and hurts my ears.
It's too noisy, too busy, makes me so anxious and angry
I keep escaping onto the road over 15 ft fences which places me in danger. I need a countryside setting. I am too close to other children, and I get annoyed with everyone else's noise and behaviour, we all need more of our own space.
It is too loud It is overwhelming
[It would be better if] classrooms weren't so hot and loud, the light were less bright and if there was an ACTUALLY safe place to go.
It stinks at school and there are too many kids. It isn't peaceful I just want to be left alone
The uniform is uncomfortable.
[School needs to know] That I don't need to wear a tie to be clever
Let me wear my comfortable clothes
[School would be better if] you could move when you needed to and people wouldn't grab you when you're scared already.
I need to move and jump and spin.
I need to be free I need to run around.
[School would be better] If I could be allowed to go to the sensory room when I need too and stay there a whole lesson and bite have to do back after 10 minutes as then everyone looks at me when I go back and I just can't.

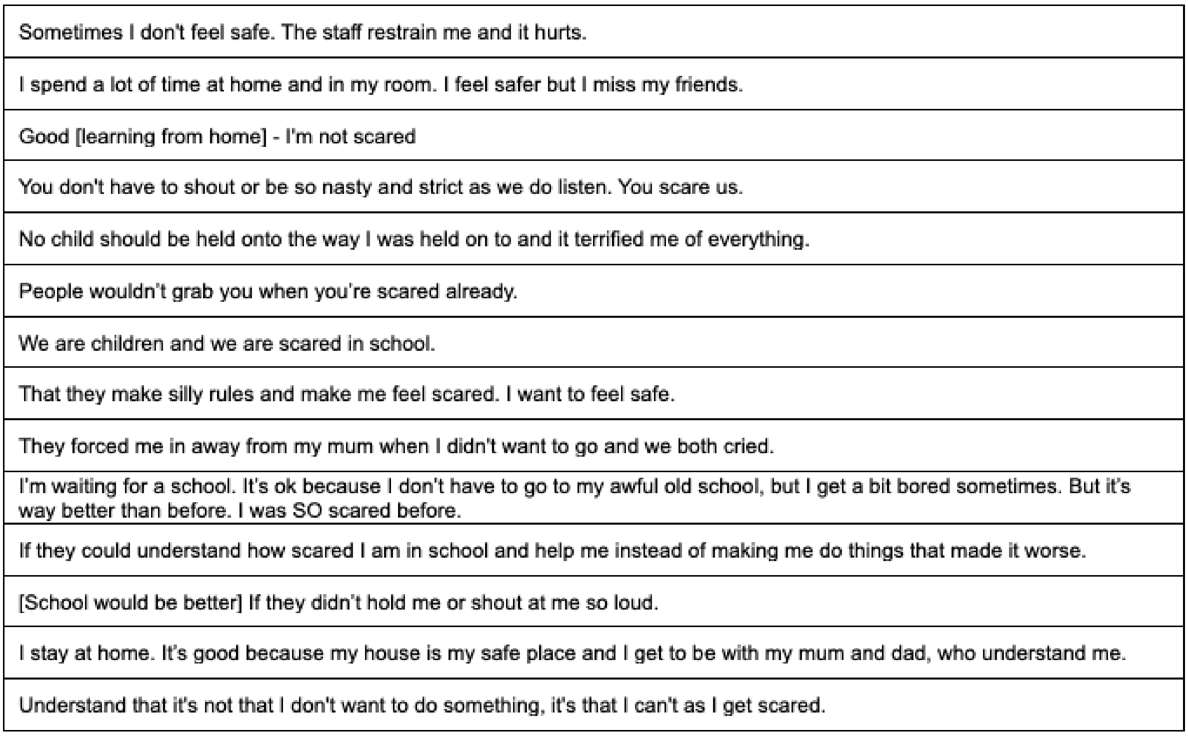
TABLE 5.16: Examples of parent responses within the theme 'Environmental Struggles'



My son had meltdowns every day due to unmet needs and an environment which caused him extreme sensory distress.
Generally feeling very unsafe there. The busy corridors and noisy dining hall were all overwhelming.
Can't concentrate as too noisy, too much going on. Doesn't feel like she fits in or has any friends.
He called it ‘a prison for children’. The playground was a ‘swarm of ants'. He found the noise, mess and smells almost impossible to tolerate.
Sensory struggles from lights, noise, smells, too many people, and unable to follow demands, including inability to meet demands of toileting, eating and drinking in those settings.
Experienced severe sensory overload and struggled with social demands and transition to lots of different teachers and classrooms. Tried a placement in Alternative Provision (hospital school due to mental health challenges, self-harm and overdoses) but found that difficult too.
Sensory “hell”
She cannot cope in a busy learning environment and has to go to the corridor by herself, but she is scared of being alone. She has PTSD symptoms coming into school. She can’t wear school uniform because of sensory issues. She now wears cheetah leggings and a top every day because she wants to feel safe from predators.

93 CYP reported feeling unsafe and scared in the school environment and safer at home (Table 5.17).

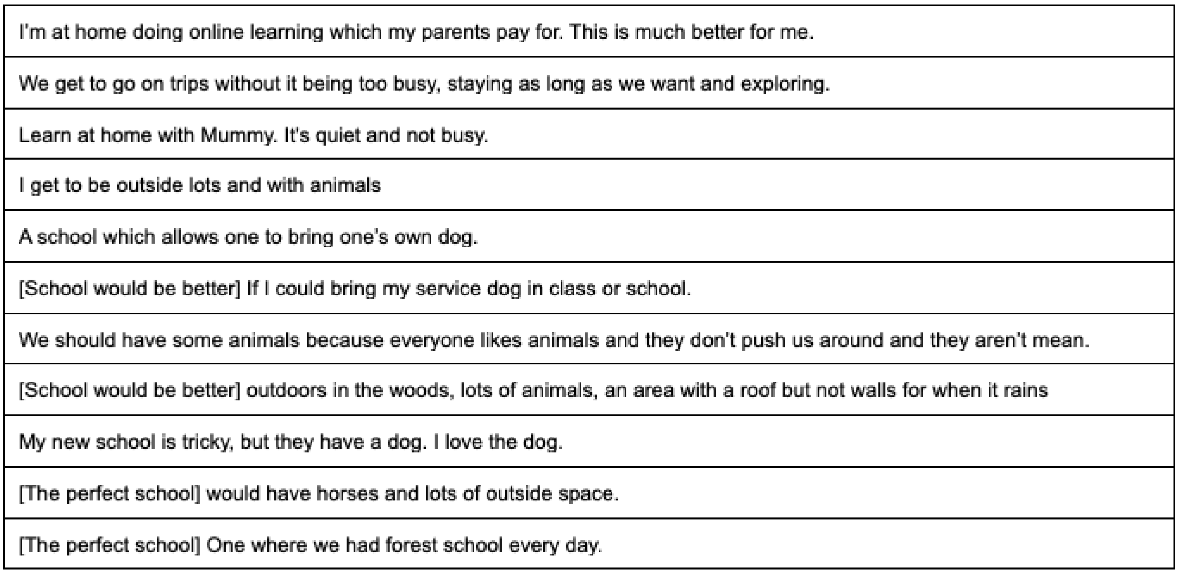
TABLE 5.17: Examples of CYP’s responses coded to ‘Scared and Unsafe’



Sometimes I don't feel safe. The staff restrain me and it hurts.
I spend a lot of time at home and in my room. I feel safer but I miss my friends.
Good [learning from home] - I'm not scared
You don't have to shout or be so nasty and strict as we do listen. You scare us.
No child should be held onto the way I was held on to and it terrified me of everything.
People wouldn’t grab you when you’re scared already.
We are children and we are scared in school.
That they make silly rules and make me feel scared. I want to feel safe.
They forced me in away from my mum when I didn't want to go and we both cried.
I'm waiting for a school. It's ok because I don't have to go to my awful old school, but I get a bit bored sometimes. But it’s way better than before. I was SO scared before.
If they could understand how scared I am in school and help me instead of making me do things that made it worse.
[School would be better] If they didn’t hold me or shout at me so loud.
I stay at home. It’s good because my house is my safe place and I get to be with my mum and dad, who understand me.
Understand that it's not that I don't want to do something, it's that I can't as I get scared.

Some of the CYP commented on how the home environment and outdoor education was more conducive to learning and how school would be better with animals (Table 5.18).

TABLE 5.18: Examples of CYP’s responses coded to ‘Animals to Support’ and ‘Sensory Struggles’

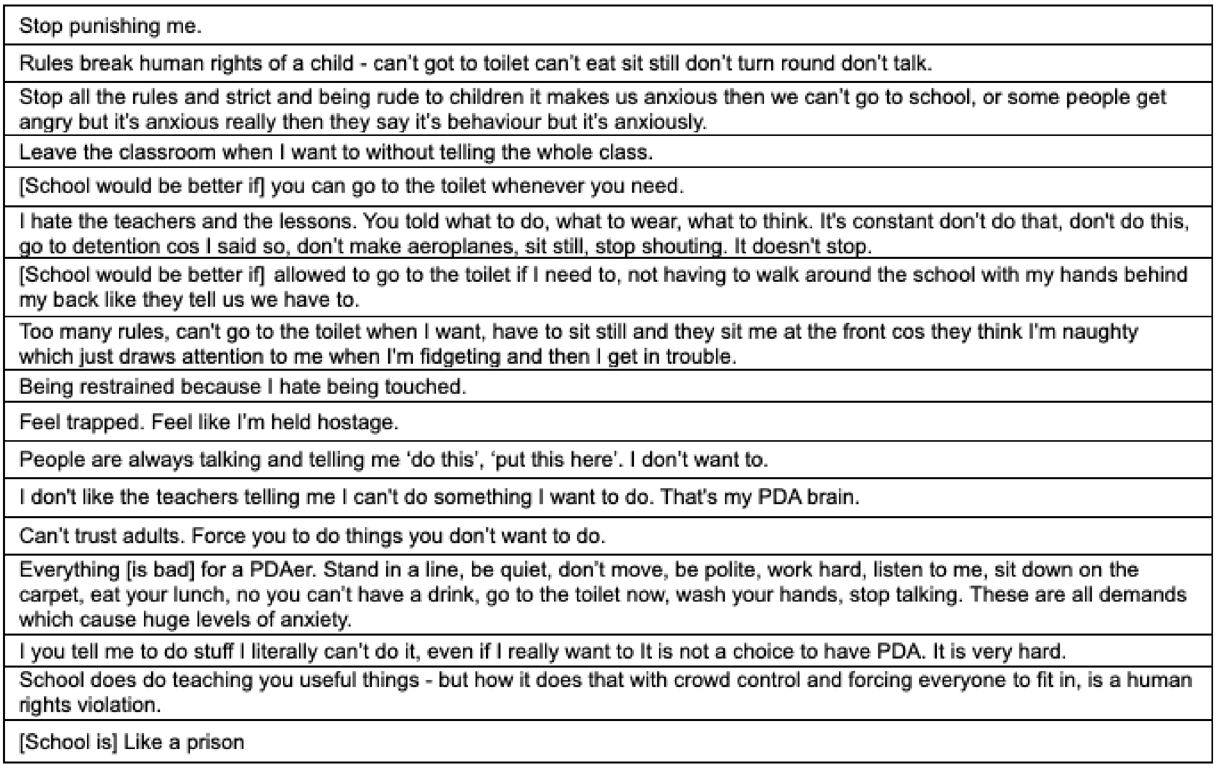


I'm at home doing online learning which my parents pay for. This is much better for me.
We get to go on trips without it being too busy, staying as long as we want and exploring.
Learn at home with Mummy. It's quiet and not busy.
I get to be outside lots and with animals
A school which allows one to bring one's own dog.
[School would be better] If I could bring my service dog in class or school.
We should have some animals because everyone likes animals and they don't push us around and they aren't mean.
[School would be better] outdoors in the woods, lots of animals, an area with a roof but not walls for when it rains
My new school is tricky, but they have a dog. I love the dog.
[The perfect school] would have horses and lots of outside space.
[The perfect school] One where we had forest school every day.

Disempowered

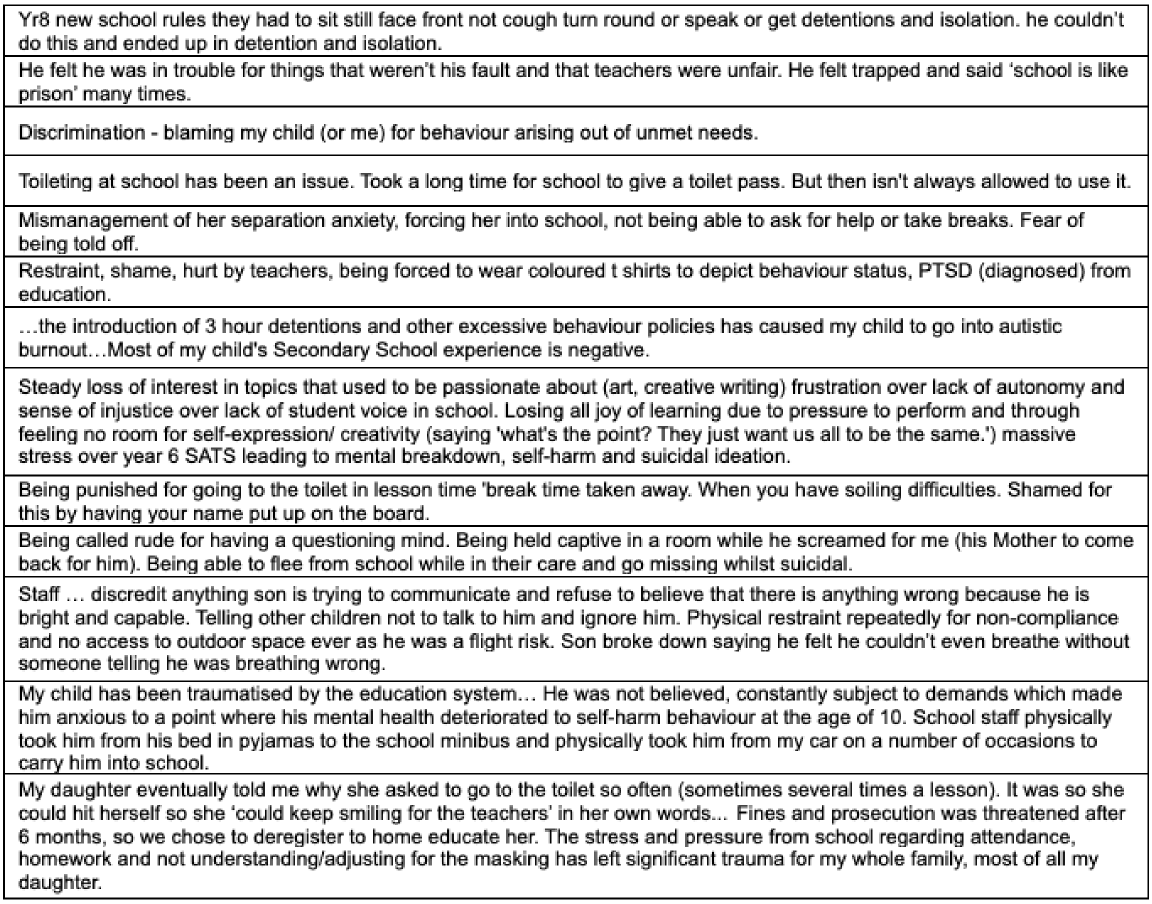
There were 369 responses from the CYP feeling disempowered by the education system, experiencing a loss of autonomy, struggling with pressure, demands and school rules and punishments (Table 5.19). Parents expanded on this (Table 5.20).

TABLE 5.19: Examples of CYP's responses within the theme 'Disengaged'



Stop punishing me.
Rules break human rights of a child - can't got to toilet can't eat sit still don't turn round don't talk.
Stop all the rules and strict and being rude to children it makes us anxious then we can't go to school, or some people get angry but it's anxious really then they say it's behaviour but it's anxiously.
Leave the classroom when I want to without telling the whole class.
[School would be better if] you can go to the toilet whenever you need.
I hate the teachers and the lessons. You told what to do, what to wear, what to think. It's constant don't do that, don't do this, go to detention cos I said so, don't make aeroplanes, sit still, stop shouting. It doesn't stop.
[School would be better if] allowed to go to the toilet if I need to, not having to walk around the school with my hands behind my back like they tell us we have to.
Too many rules, can't go to the toilet when I want, have to sit still and they sit me at the front cos they think I'm naughty which just draws attention to me when I'm fidgeting and then I get in trouble.
Being restrained because I hate being touched.
Feel trapped. Feel like I'm held hostage.
People are always talking and telling me 'do this', 'put this here'. I don't want to.
I don't like the teachers telling me I can't do something I want to do. That's my PDA brain.
Can't trust adults. Force you to do things you don't want to do.
Everything [is bad] for a PDAer. Stand in a line, be quiet, don't move, be polite, work hard, listen to me, sit down on the carpet, eat your lunch, no you can't have a drink, go to the toilet now, wash your hands, stop talking. These are all demands which cause huge levels of anxiety.
I you tell me to do stuff I literally can't do it, even if I really want to It is not a choice to have PDA. It is very hard.
School does do teaching you useful things - but how it does that with crowd control and forcing everyone to fit in, is a human rights violation.
[School is] Like a prison

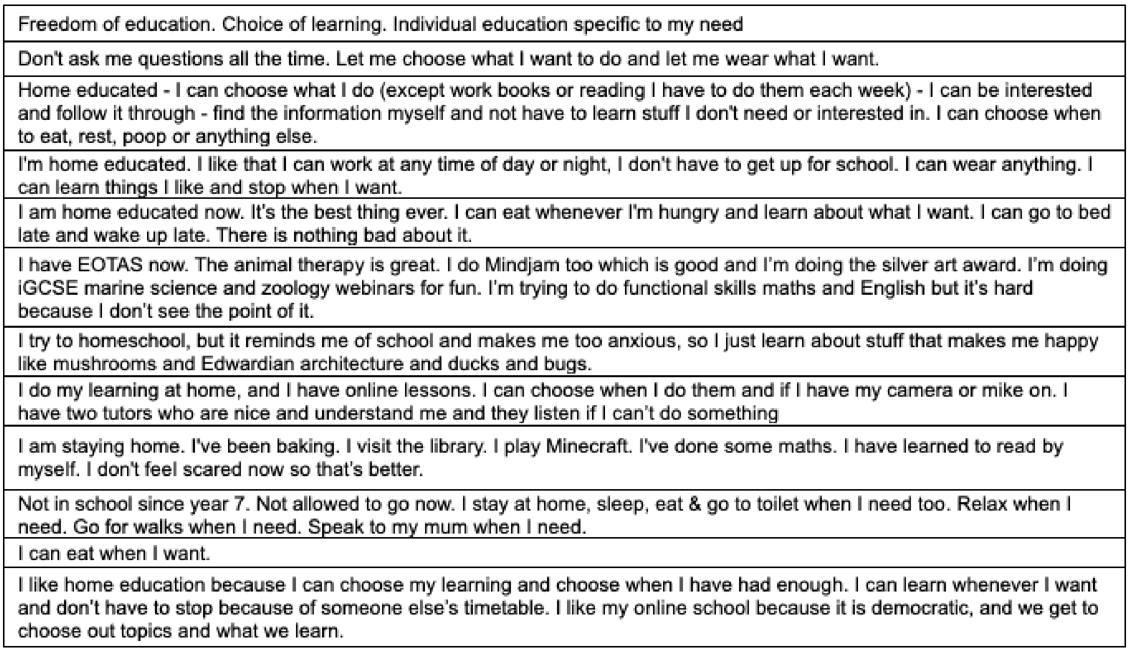
TABLE 5.20: Examples of parent responses within the theme 'Disempowered'



Yr8 new school rules they had to sit still face front not cough turn round or speak or get detentions and isolation. he couldn't do this and ended up in detention and isolation.
He felt he was in trouble for things that weren't his fault and that teachers were unfair. He felt trapped and said 'school is like prison' many times.
Discrimination - blaming my child (or me) for behaviour arising out of unmet needs.
Toileting at school has been an issue. Took a long time for school to give a toilet pass. But then isn't always allowed to use it.
Mismanagement of her separation anxiety, forcing her into school, not being able to ask for help or take breaks. Fear of being told off.
Restraint, shame, hurt by teachers, being forced to wear coloured t shirts to depict behaviour status, PTSD (diagnosed) from education.
…the introduction of 3 hour detentions and other excessive behaviour policies has caused my child to go into autistic burnout…Most of my child's Secondary School experience is negative.
Steady loss of interest in topics that used to be passionate about (art, creative writing) frustration over lack of autonomy and sense of injustice over lack of student voice in school. Losing all joy of learning due to pressure to perform and through feeling no room for self-expression/ creativity (saying 'what's the point? They just want us all to be the same.') massive stress over year 6 SATS leading to mental breakdown, self-harm and suicidal ideation.
Being punished for going to the toilet in lesson time 'break time taken away. When you have soiling difficulties. Shamed for this by having your name put up on the board.
Being called rude for having a questioning mind. Being held captive in a room while he screamed for me (his Mother to come back for him). Being able to flee from school while in their care and go missing whilst suicidal.
Staff … discredit anything son is trying to communicate and refuse to believe that there is anything wrong because he is bright and capable. Telling other children not to talk to him and ignore him. Physical restraint repeatedly for non-compliance and no access to outdoor space ever as he was a flight risk. Son broke down saying he felt he couldn't even breathe without someone telling he was breathing wrong.
My child has been traumatised by the education system… He was not believed, constantly subject to demands which made him anxious to a point where his mental health deteriorated to self-harm behaviour at the age of 10. School staff physically took him from his bed in pyjamas to the school minibus and physically took him from my car on a number of occasions to carry him into school.
My daughter eventually told me why she asked to go to the toilet so often (sometimes several times a lesson). It was so she could hit herself so she 'could keep smiling for the teachers' in her own words... Fines and prosecution was threatened after 6 months, so we chose to deregister to home educate her. The stress and pressure from school regarding attendance, homework and not understanding/adjusting for the masking has left significant trauma for my whole family, most of all my daughter.

The CYP felt that having autonomy and choice was better (Table 5.21).

TABLE 5.21: Examples of CYP's responses coded to 'Autonomy and Choice'

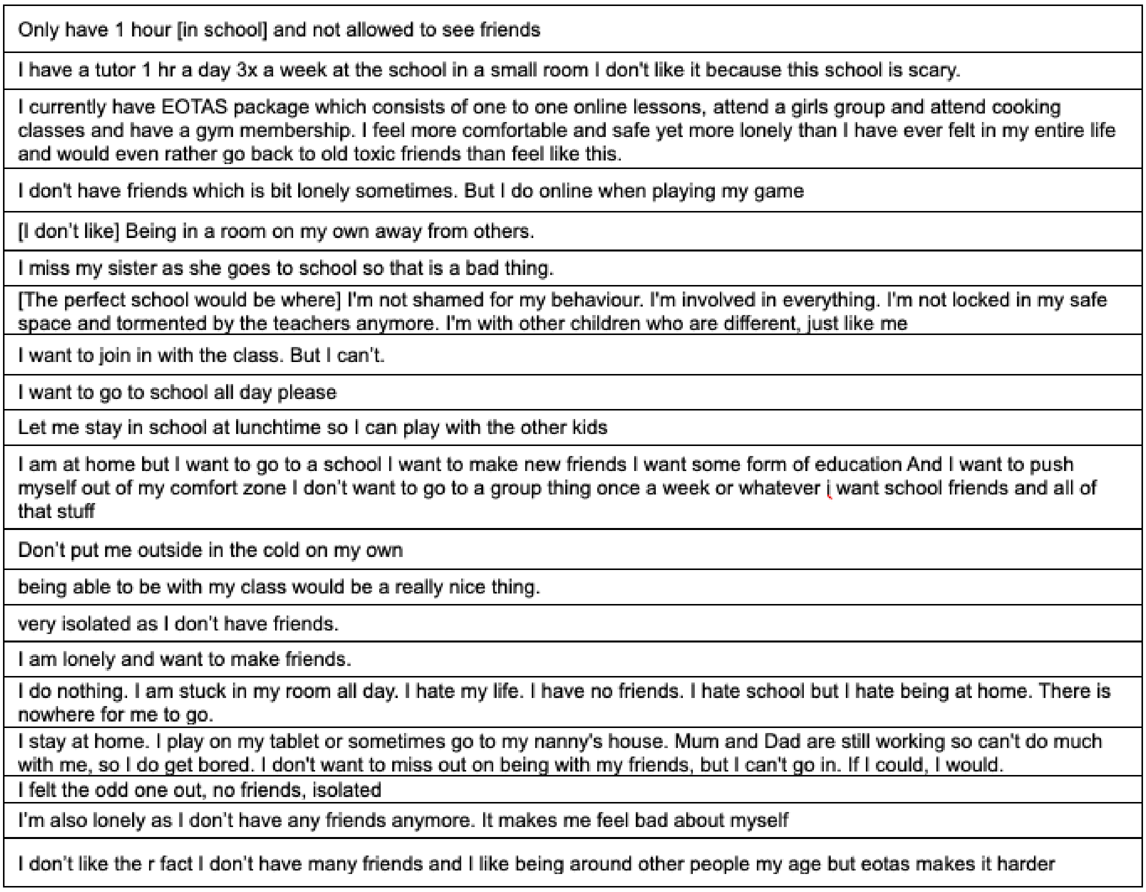


Freedom of education. Choice of learning. Individual education specific to my need
Don't ask me questions all the time. Let me choose what I want to do and let me wear what I want.
Home educated - I can choose what I do (except work books or reading I have to do them each week) - I can be interested and follow it through - find the information myself and not have to learn stuff I don't need or interested in. I can choose when to eat, rest, poop or anything else.
I'm home educated. I like that I can work at any time of day or night, I don't have to get up for school. I can wear anything. I can learn things I like and stop when I want.
I am home educated now. It's the best thing ever. I can eat whenever I'm hungry and learn about what I want. I can go to bed late and wake up late. There is nothing bad about it.
I have EOTAS now. The animal therapy is great. I do Mindjam too which is good and I'm doing the silver art award. I'm doing iGCSE marine science and zoology webinars for fun. I'm trying to do functional skills maths and English but it's hard because I don't see the point of it.
I try to homeschool, but it reminds me of school and makes me too anxious, so I just learn about stuff that makes me happy like mushrooms and Edwardian architecture and ducks and bugs.
I do my learning at home, and I have online lessons. I can choose when I do them and if I have my camera or mike on. I have two tutors who are nice and understand me and they listen if I can't do something
I am staying home. I've been baking. I visit the library. I play Minecraft. I've done some maths. I have learned to read by myself. I don't feel scared now so that's better.
Not in school since year 7. Not allowed to go now. I stay at home, sleep, eat & go to toilet when I need too. Relax when I need. Go for walks when I need. Speak to my mum when I need.
I can eat when I want.
I like home education because I can choose my learning and choose when I have had enough. I can learn whenever I want and don't have to stop because of someone else's timetable. I like my online school because it is democratic, and we get to choose out topics and what we learn.

Excluded

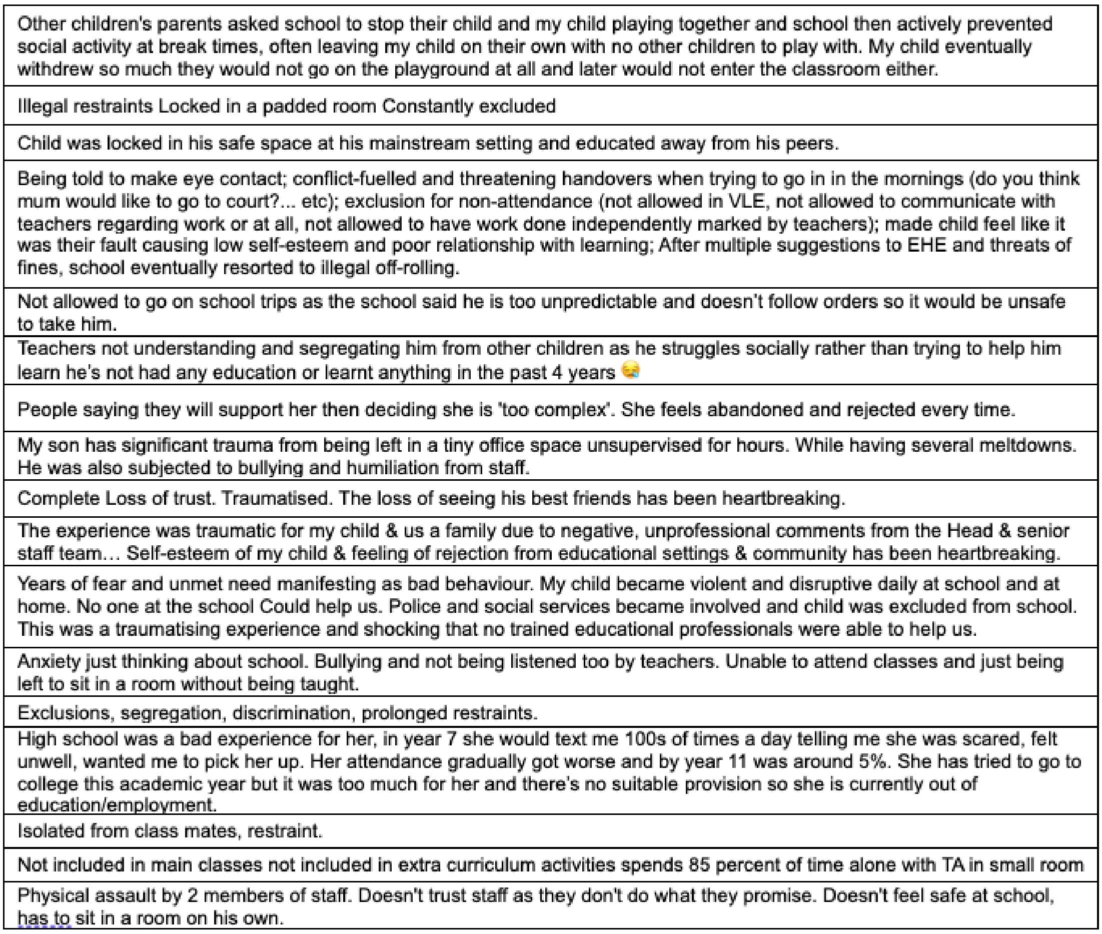
There were 127 reports from the CYP experiencing loneliness and isolation. They felt excluded from both education and friendships (Table 5.22). Parents explained these feelings further (Table 5.23).

TABLE 5.22: Examples of CYP's responses coded to 'Excluded and Isolated'



Only have 1 hour [in school] and not allowed to see friends
I have a tutor 1 hr a day 3x a week at the school in a small room I don't like it because this school is scary.
I currently have EOTAS package which consists of one to one online lessons, attend a girls group and attend cooking classes and have a gym membership. I feel more comfortable and safe yet more lonely than I have ever felt in my entire life and would even rather go back to old toxic friends than feel like this.
I don't have friends which is bit lonely sometimes. But I do online when playing my game
[I don't like] Being in a room on my own away from others.
I miss my sister as she goes to school so that is a bad thing.
[The perfect school would be where] I'm not shamed for my behaviour. I'm involved in everything. I'm not locked in my safe space and tormented by the teachers anymore. I'm with other children who are different, just like me
I want to join in with the class. But I can't.
I want to go to school all day please
Let me stay in school at lunchtime so I can play with the other kids
I am at home but I want to go to a school I want to make new friends I want some form of education And I want to push myself out of my comfort zone I don't want to go to a group thing once a week or whatever i want school friends and all of that stuff
Don't put me outside in the cold on my own
being able to be with my class would be a really nice thing.
very isolated as I don't have friends.
I am lonely and want to make friends.
I do nothing. I am stuck in my room all day. I hate my life. I have no friends. I hate school but I hate being at home. There is nowhere for me to go.
I stay at home. I play on my tablet or sometimes go to my nanny's house. Mum and Dad are still working so can't do much with me, so I do get bored. I don't want to miss out on being with my friends, but I can't go in. If I could, I would.
I felt the odd one out, no friends, isolated
I'm also lonely as I don't have any friends anymore. It makes me feel bad about myself
I don't like the r fact I don't have many friends and I like being around other people my age but eotas makes it harder

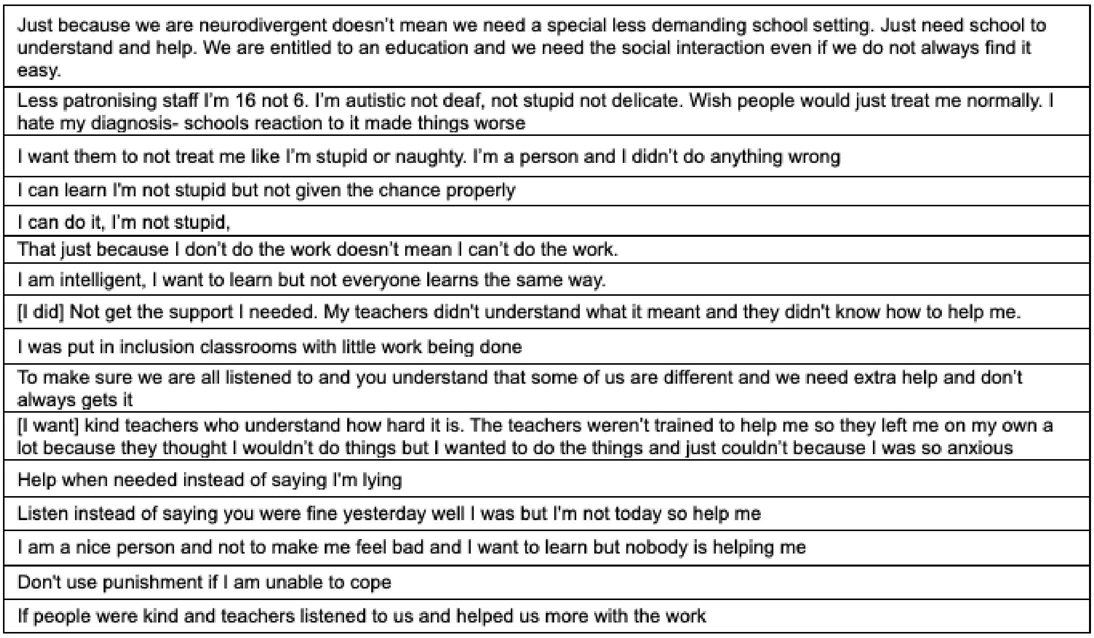
TABLE 5.23: Examples of parent responses within the theme 'Excluded'



Other children's parents asked school to stop their child and my child playing together and school then actively prevented social activity at break times, often leaving my child on their own with no other children to play with. My child eventually withdrew so much they would not go on the playground at all and later would not enter the classroom either.
Illegal restraints Locked in a padded room Constantly excluded
Child was locked in his safe space at his mainstream setting and educated away from his peers.
Being told to make eye contact; conflict-fuelled and threatening handovers when trying to go in in the mornings (do you think mum would like to go to court?... etc); exclusion for non-attendance (not allowed in VLE, not allowed to communicate with teachers regarding work or at all, not allowed to have work done independently marked by teachers); made child feel like it was their fault causing low self-esteem and poor relationship with learning; After multiple suggestions to EHE and threats of fines, school eventually resorted to illegal off-rolling.
Not allowed to go on school trips as the school said he is too unpredictable and doesn't follow orders so it would be unsafe to take him.
Teachers not understanding and segregating him from other children as he struggles socially rather than trying to help him learn he's not had any education or learnt anything in the past 4 years 😪
People saying they will support her then deciding she is 'too complex'. She feels abandoned and rejected every time.
My son has significant trauma from being left in a tiny office space unsupervised for hours. While having several meltdowns. He was also subjected to bullying and humiliation from staff.
Complete Loss of trust. Traumatised. The loss of seeing his best friends has been heartbreaking.
The experience was traumatic for my child & us a family due to negative, unprofessional comments from the Head & senior staff team… Self-esteem of my child & feeling of rejection from educational settings & community has been heartbreaking.
Years of fear and unmet need manifesting as bad behaviour. My child became violent and disruptive daily at school and at home. No one at the school Could help us. Police and social services became involved and child was excluded from school. This was a traumatising experience and shocking that no trained educational professionals were able to help us.
Anxiety just thinking about school. Bullying and not being listened too by teachers. Unable to attend classes and just being left to sit in a room without being taught.
Exclusions, segregation, discrimination, prolonged restraints.
High school was a bad experience for her, in year 7 she would text me 100s of times a day telling me she was scared, felt unwell, wanted me to pick her up. Her attendance gradually got worse and by year 11 was around 5%. She has tried to go to college this academic year but it was too much for her and there's no suitable provision so she is currently out of education/employment.
Isolated from class mates, restraint.
Not included in main classes not included in extra curriculum activities spends 85 percent of time alone with TA in small room
Physical assault by 2 members of staff. Doesn't trust staff as they don't do what they promise. Doesn't feel safe at school, has to sit in a room on his own.

The CYP's abilities were underestimated, and they wanted educators to understand they want to learn but feel unsupported to do so (Table 5.24).

TABLE 5.24: Examples of CYP's responses coded to 'Underestimated' and 'Lack of Support'

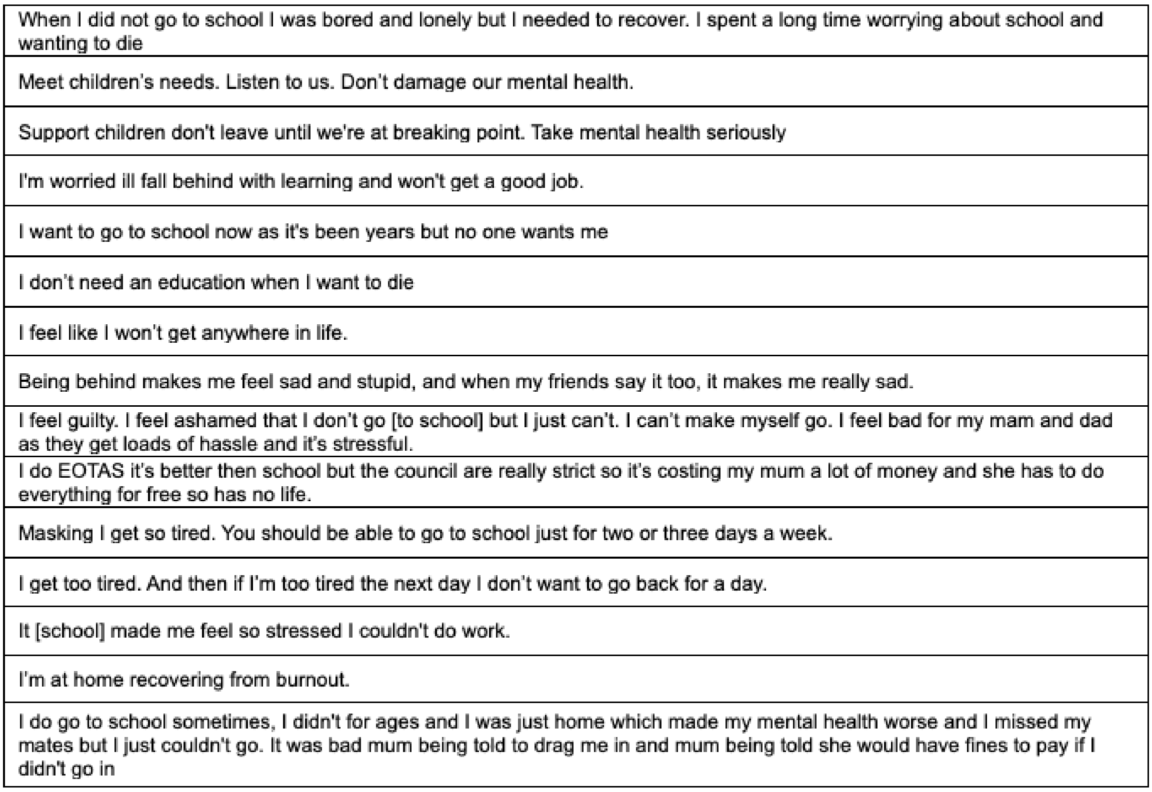


Just because we are neurodivergent doesn't mean we need a special less demanding school setting. Just need school to understand and help. We are entitled to an education and we need the social interaction even if we do not always find it easy.
Less patronising staff I'm 16 not 6. I'm autistic not deaf, not stupid not delicate. Wish people would just treat me normally. I hate my diagnosis- schools reaction to it made things worse
I want them to not treat me like I'm stupid or naughty. I'm a person and I didn't do anything wrong
I can learn I'm not stupid but not given the chance properly
I can do it, I'm not stupid,
That just because I don't do the work doesn't mean I can't do the work.
I am intelligent, I want to learn but not everyone learns the same way.
[I did] Not get the support I needed. My teachers didn't understand what it meant and they didn't know how to help me.
I was put in inclusion classrooms with little work being done
To make sure we are all listened to and you understand that some of us are different and we need extra help and don't always gets it
[I want] kind teachers who understand how hard it is. The teachers weren't trained to help me so they left me on my own a lot because they thought I wouldn't do things but I wanted to do the things and just couldn't because I was so anxious
Help when needed instead of saying I'm lying
Listen instead of saying you were fine yesterday well I was but I'm not today so help me
I am a nice person and not to make me feel bad and I want to learn but nobody is helping me
Don't use punishment if I am unable to cope
If people were kind and teachers listened to us and helped us more with the work

Poor mental health

CYP reported feelings of exhaustion contributing to poor mental health and burnout. They commented on how pressure and stress was reduced when not in school, but also the feelings of guilt and failure (Table 5.25).

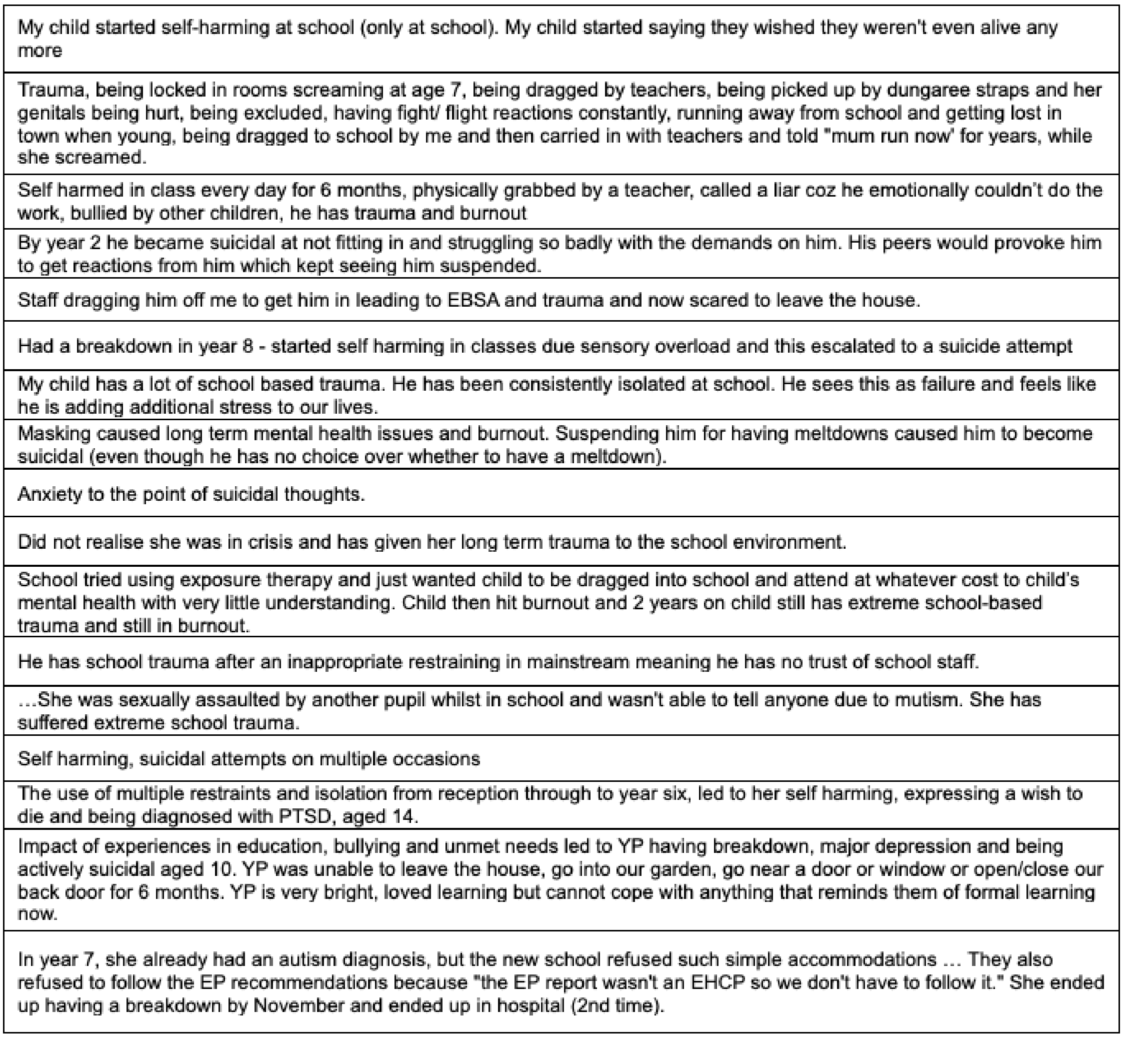
TABLE 5.25: Examples of CYP's responses within the theme 'Poor Mental Health'



When I did not go to school I was bored and lonely but I needed to recover. I spent a long time worrying about school and wanting to die
Meet children's needs. Listen to us. Don't damage our mental health.
Support children don't leave until we're at breaking point. Take mental health seriously
I'm worried ill fall behind with learning and won't get a good job.
I want to go to school now as it's been years but no one wants me
I don't need an education when I want to die
I feel like I won't get anywhere in life.
Being behind makes me feel sad and stupid, and when my friends say it too, it makes me really sad.
I feel guilty. I feel ashamed that I don't go [to school] but I just can't. I can't make myself go. I feel bad for my mam and dad as they get loads of hassle and it's stressful.
I do EOTAS it's better then school but the council are really strict so it's costing my mum a lot of money and she has to do everything for free so has no life.
Masking I get so tired. You should be able to go to school just for two or three days a week.
I get too tired. And then if I'm too tired the next day I don't want to go back for a day.
It [school] made me feel so stressed I couldn't do work.
I'm at home recovering from burnout.
I do go to school sometimes, I didn't for ages and I was just home which made my mental health worse and I missed my mates but I just couldn't go. It was bad mum being told to drag me in and mum being told she would have fines to pay if I didn't go in

The parent responses related to their child's mental health told the same story, expanding on the information the children provided, describing incidents of self-harm, trauma and suicidal ideation (Table 5.26).

TABLE 5.26: Examples of parent responses within the theme ‘Poor Mental Health’



My child started self-harming at school (only at school). My child started saying they wished they weren't even alive any more
Trauma, being locked in rooms screaming at age 7, being dragged by teachers, being picked up by dungaree straps and her genitals being hurt, being excluded, having fight/ flight reactions constantly, running away from school and getting lost in town when young, being dragged to school by me and then carried in with teachers and told "mum run now' for years, while she screamed.
Self harmed in class every day for 6 months, physically grabbed by a teacher, called a liar coz he emotionally couldn't do the work, bullied by other children, he has trauma and burnout
By year 2 he became suicidal at not fitting in and struggling so badly with the demands on him. His peers would provoke him to get reactions from him which kept seeing him suspended.
Staff dragging him off me to get him in leading to EBSA and trauma and now scared to leave the house.
Had a breakdown in year 8 - started self harming in classes due sensory overload and this escalated to a suicide attempt
My child has a lot of school based trauma. He has been consistently isolated at school. He sees this as failure and feels like he is adding additional stress to our lives.
Masking caused long term mental health issues and burnout. Suspending him for having meltdowns caused him to become suicidal (even though he has no choice over whether to have a meltdown).
Anxiety to the point of suicidal thoughts.
Did not realise she was in crisis and has given her long term trauma to the school environment.
School tried using exposure therapy and just wanted child to be dragged into school and attend at whatever cost to child's mental health with very little understanding. Child then hit burnout and 2 years on child still has extreme school-based trauma and still in burnout.
He has school trauma after an inappropriate restraining in mainstream meaning he has no trust of school staff.
…She was sexually assaulted by another pupil whilst in school and wasn't able to tell anyone due to mutism. She has suffered extreme school trauma.
Self harming, suicidal attempts on multiple occasions
The use of multiple restraints and isolation from reception through to year six, led to her self harming, expressing a wish to die and being diagnosed with PTSD, aged 14.
Impact of experiences in education, bullying and unmet needs led to YP having breakdown, major depression and being actively suicidal aged 10. YP was unable to leave the house, go into our garden, go near a door or window or open/close our back door for 6 months. YP is very bright, loved learning but cannot cope with anything that reminds them of formal learning now.
In year 7, she already had an autism diagnosis, but the new school refused such simple accommodations … They also refused to follow the EP recommendations because "the EP report wasn't an EHCP so we don't have to follow it." She ended up having a breakdown by November and ended up in hospital (2nd time).

How school feels for CYP

In response to the question ‘what 3 words would you use to describe how school makes you feel?’, 26% of the CYP used the word ‘sad’ and 24%, ‘angry’. The word cloud in Figure 5.18 shows all words used by the CYP with the size of the text representing the frequency of the word occurring. All words used by the CYP, with their frequency and weighted percentage of use are shown in Appendix I.

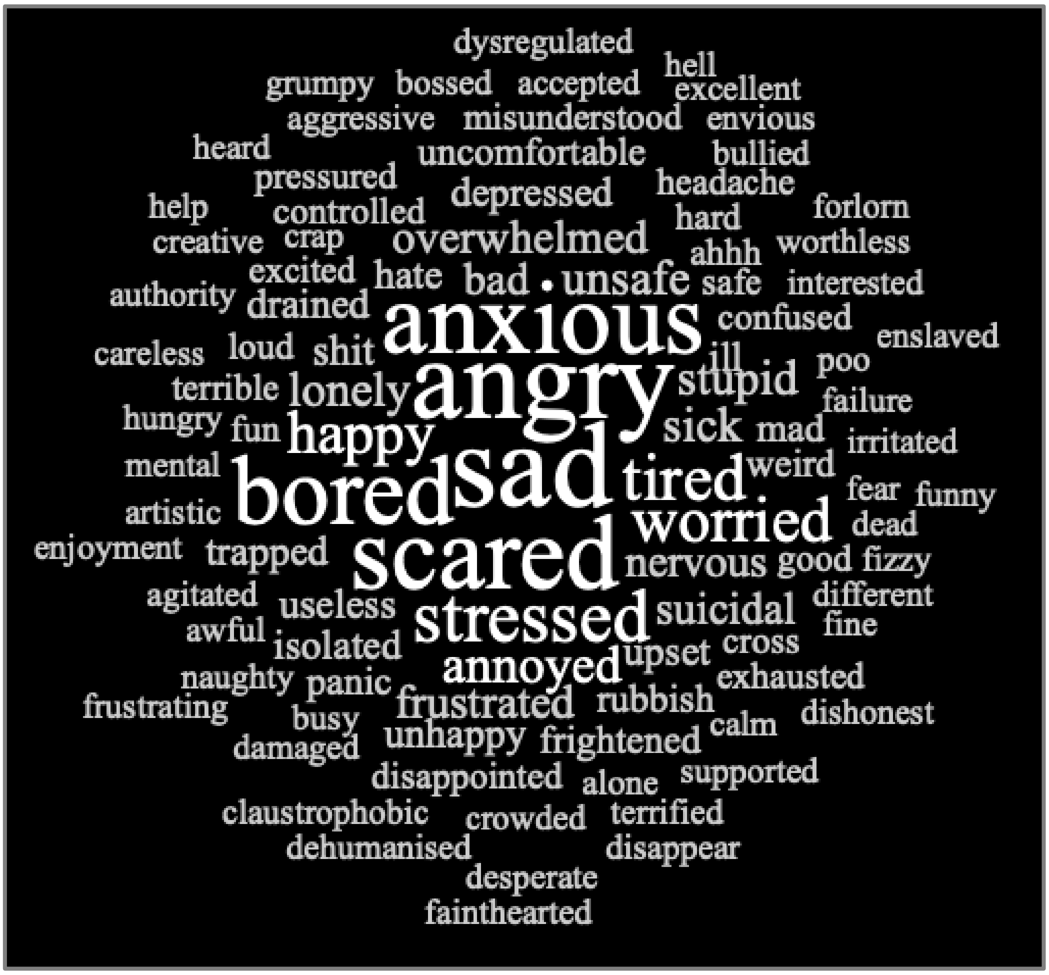


FIGURE 5.18: Frequency of words used to describe how school makes CYP feel

Having presented the findings of the study, the next chapter discusses these findings and their implications.

CHAPTER 6 – DISCUSSION

This study set out to shine a light on PDA CYP's educational experiences and address 3 research questions:

- What terminology regarding PDA is used and does a PDA diagnosis matter?
- Where are PDA children currently being educated?
- What are the experiences of PDA children with education?

Therefore, the intention of this chapter is to interpret and discuss the findings presented in the previous chapter and their implications.

The Prevalence of PDA

For the single LA who could identify their PDA CYP with an EHCP, 12% of them were PDA. This figure could suggest a lower prevalence of PDA in the autistic population than the 20% identified by Gillberg *et al.* (2015). However, 12% is only accounting for the autistic PDA children who have an EHCP, so it cannot be assumed that it is indicative of the prevalence of PDA. In the parent sample it was found that 57% of PDA CYP have an EHCP, so only just over half of PDA CYP were represented by the 12%. When taking this into account, this study has found that 21% of the autistic population are likely to be PDA, meaning that Gillberg *et al.*'s prevalence statistics are likely to be accurate. If PDA CYP are more likely to struggle with school attendance than both the PNT and autistic CYP and have more negative educational experiences than their autistic peers (Truman *et al.,* 2021), these statistics are relevant as it suggests there are 41,000 school aged PDA CYP in

England today. Understanding their educational experiences is essential if their experiences are to be improved.

The Importance of Terminology and Diagnosis

By including participants in this study whose parents identify their CYP as PDA, as opposed to only those with a formal diagnosis, I intended to support both autistics with high demand avoidance behaviours, as well as those identified as PDA, ensuring the wider autistic community is not marginalised and with the intention of avoiding the controversy surrounding PDA. However, this debate has impacted practice with LAs unable to identify their demand avoidant CYP, only their autistic children with an EHCP. The reason cited for this is that PDA is not recognised in the DSM-5 or by the DfE as a SEND category. It was also found that recognition of PDA across LAs in England varies, but there was no significant geographical variation of CYP with a PDA diagnosis, the use of the term PDA in EHCPs, the EHCP adequately describing demand avoidant behaviours or, of an EHCP having a positive impact on the CYP's education. So, Moore's (2020) observation that clinicians providing a PDA diagnosis varies across the country was corroborated, and this study confirms that this variation is not specific to geographical regions but applies country wide, with only one LA consistently using the term PDA or autism with a demand avoidant profile.

The literature review highlighted the importance of understanding reasons for a CYP's behaviours, and that support provided must meet the individual's needs, and a diagnosis is not required to access this support (*Children and Families Act 2014, s20*). The findings of this study revealed that although having a diagnosis, and using the term PDA within an EHCP, is not significantly related to the CYP's educational experience, the EHCP adequately describing the CYP's behaviour does significantly impact on their overall educational experience, and having a formal diagnosis meant that the EHCP was more likely to accurately describe behaviours. Therefore, these findings support the importance of EHCPs adequately describing CYP's demand avoidant behaviour by identifying their strengths and challenges (NAS, 2024). Gore Langton and Frederickson's (2018) and Truman *et al.'s* (2021) findings that parents consider a diagnosis important to enable support is further supported by this study as it was found that having a formal diagnosis meant that the CYP's demand avoidant behaviours were more likely to be accurately described in the EHCP, which in turn led to better overall educational experiences. So, until we have clinical and societal shifts, whereby a transdiagnostic and holistic approach could be adopted in line with Wood's aspirations (Woods, 2021), a PDA diagnosis is currently useful for parents who are striving to ensure their children's educational experiences are positive.

The Educational Settings of PDA CYP

LAs revealed that 1 in 3 (30%) of EHCPs issued in England are for autistic CYP, which aligns with the DfE's published numbers (DfE, 2023b). Despite the LAs knowing where these autistic children are educated, they were unable to identify which CYP were PDA, or where their PDA CYP are educated. By investigating the single LA who could identify their PDA CYP, it was found that the PDA CYP were 5 times more likely to be educated out of a school setting compared to their autistic only peers and they represented 65% of the autistic CYP who were not in school settings. Parents provided an explanation for this, as similar to Gore Langton and

Frederickson's (2016) study, 91% of PDA CYP had begun their education in mainstream school settings but had struggled with attendance and schools not meeting their needs, leading to multiple changes in setting types and the CYP being educated outside of school. This was evidenced by 26% of the sample of PDA CYP in the study being educated outside of a school setting, 31% by secondary school age, an increase of 173% between primary and secondary ages, with only 3% electively choosing this option. Although on the surface the figure of 26% of PDA CYP being educated outside of a school setting does not support the PDA findings that 70% of CYP are not in school, it only accounts for the setting type the children have named, not if they are able to then attend or access this setting. The types of educational setting attended were also varied for this cohort of CYP which could reflect the difficulty in understanding these children and their complex presentations to enable successful placements to be made. To understand more it is essential to explore the educational experiences of these children and not just the type of setting they are placed in.

The Educational Experiences of PDA CYP

When the experiences of these CYP are analysed, it tells a story of unmet need and overwhelming numbers of PDA CYP having either negative or very negative educational experiences across all regions of England. Factors contributing to negative experiences included long term struggles with school attendance, formal and informal school exclusions, and time spent without educational provision. Although there were no differences in overall educational experiences between genders, boys often exhibited school attendance struggles from first joining the education system, while girls started to struggle from year 3. This may be as girls desire to ‘fit in’ more than boys (O’Hagan *et al.,* 2022) and are able to camouflage their differences at a young age, which may become increasingly difficult as the complexities of social interactions increase. No studies were found that explored this difference in gender, so this may be a useful area for further research, to support understanding school attendance struggles.

86% of the PDA CYP struggled with school attendance over many years, a higher number than reported by Gore Langton and Frederickson (2016), and this significantly contributed to negative school experiences with parents quoting demand avoidance and anxiety, in over 86% of cases, as factors contributing to attendance struggles. This statistic of 86% supports the findings of the PDA Society that 70% of PDA CYP are not in school, suggesting that while many are educated outside of school, there are high numbers unable to access their named educational settings, which may be even greater than the 70% previously identified. As anxiety is related to demand avoidance behaviours (Johnson and Saunderson, 2023; White *et al.,* 2023) and emerging as a factor in recent studies that correlates with autistic pupil’s non-attendance (Adams, 2021; Totsika *et al.,* 2023) these findings suggest that this may be the case. However, it is not clear if it is anxiety causing the attendance struggles, with 63% of the children identified as having anxiety as a co-occurring condition, or if school creates anxiety for these children, leading to a vicious cycle of avoidance.

Another factor contributing to negative educational experiences included repeated school exclusions, both formal and informal. Findings were consistent with the limited earlier research with PDA CYP repeatedly experiencing exclusion from schools, with boys experiencing exclusions more often than girls, while girls' school exclusions tended to be more informal. This gender difference was not explored in this study, or the earlier studies, to find out if it is of significance, but a reason may be that girls may tend to camouflage behaviours and mask their difficulties in school more than boys (Hull *et al.,* 2020; O'Hagan *et al.,* 2022), so behaviours leading to formal exclusions are encountered more often for boys. Time with no educational provision was also a factor contributing to negative educational experiences and the findings of this study revealed that 59% of PDA CYP had time with no educational provision. This was significant in terms of how much education was missed, and the amount that this was happening to young people, whereby they are excluded and prevented from accessing their named educational setting.

The findings of this study, from data provided by the parents of the CYP, is consistent with the limited research into the educational experiences of PDA CYP. However, I set out with the intention of shining a light on these CYP's educational experiences and wanted to ensure their voices were heard, so while the parent views gave a powerful picture of what contributed to the CYP's negative experiences, the voices of the children are incredibly powerful in describing their feelings and the real-life implications of these experiences. By taking the approach of asking questions of both the parents and the children, the study identified the CYP's complete disengagement from the education system with comments such as "*I would rather kill myself than go back"* and *"The education system needs to be scrapped. It doesn't work…".* These views were enforced further with the parent comments such as *"[my child had] complete burn out for most of secondary school, she has missed over 4 years of school"* and *"[my child] firmly believes that school is* *evil and has refused to allow her younger sister to attend"*. The parent views build on those of the CYP and demonstrate their disenfranchisement and disappointment with the system, consistent with the findings of Truman *et al.* (2021). These CYP are significantly impacted by their school experiences and are feeling both guilt and shame as demonstrated by their comments; *"I feel guilty. I feel ashamed that I don't go [to school] but I just can't. I can't make myself go"*, "*I do go to school sometimes, I didn't for ages and I was just home which made my mental health worse and I missed my mates but I just couldn't go", "It was bad mum being told to drag me in and mum being told she would have fines to pay if I didn't go in"*, *"I do EOTAS it's better then school but the council are really strict so it's costing my mum a lot of money and she has to do everything for free so has no life"*. It is evident from the findings of this study that these CYP want to be in school and learning but are unable to do so.

The impact on their mental health was apparent with suicidal ideation often described by the children; "*When I did not go to school I was bored and lonely, but I needed to recover. I spent a long time worrying about school and wanting to die"* and *"I don't need an education when I want to die".* Parents further described the state of their children's mental health with accounts of self-harm and abuse; *"My child started self-harming at school (only at school). My child started saying they wished they weren't even alive any more"* and, *"The use of multiple restraints and isolation from reception through to year six, led to herself harming, expressing a wish to die and being diagnosed with PTSD, aged 14".*

Consistent with studies focussed on school non-attendance and the autistic pupil population, the children's struggles are contributed to by the school environment being challenging for the sensory differences, as identified in the DSM-5, of an autistic CYP (Brede *et al*., 2017), *"It's too loud and busy I can't concentrate and it hurts"*. The children describe environments that would be better suited; *"I get to be outside lots and with animals*" and *"[School would be better] outdoors in the woods, lots of animals, an area with a roof but not walls for when it rains"*. They explain the difficulties they have with sitting still in the classroom describing a need to move around; *"[School would be better if] you could move when you needed to and people wouldn't grab you when you're scared already"* and "*I need to be free I need to run around".* These classroom struggles may be better understood when consideration is given to co-occurring conditions, given the high numbers of PDA CYP in this study also having a diagnosis of Sensory Processing Disorder (SPD), as well as ADHD. This suggests that support strategies and classroom environments need to adopt a transactional approach, as recommended by Milton (2013) and Green *et al.* (2018), taking into consideration the environment and the impact it has on the child's ability to engage in school.

In direct contrast to the published advice for supporting PDA CYP, whereby the focus is on building strong and trusting relationships, and promoting a sense of safety (Christie, 2007; Kerbey, 2023), the CYP gave many accounts of feeling unsafe and scared. "*Sometimes I don't feel safe. The staff restrain me and it hurts"* and *"We are children and we are scared in school".* They also described poor relationships with school staff and wanted schools to understand their mistrust; "*Don't try to drag children into school, they will never trust you"* and *"[It would be* *better] If they didn't hold me or shout at me so loud."* These poor relationships were further contributed to by the children feeling misunderstood and staff not understanding autism or PDA; *"sometimes I just can't do it and even if I can't do it I'm trying a lot"* and "*I want them to not treat me like I'm stupid or naughty. I'm a person and I didn't do anything wrong."*

Relationships were not only poor with staff, but also the children. The research highlighted that autistic children are more at risk of bullying than the PNT (O'Hagan *et al.,* 2022), and that bullying and poor relationships may contribute to school attendance difficulties (Ochi *et al.,* 2020; Amundsen *et al.,* 2022). The findings from the CYP sharing their views supported this, bringing the reality of the impact of bullying to life with their accounts; *"There's lots of bullying. A kid got knocked out with a knuckleduster. There was blood everywhere. [child's name] gave me a knife to hold"* and *"Kids had to be in gangs to protect each other cos teachers were no help".* Yet, these children wanted friendships and it was friendships that they missed most when not going to school; *"I miss my friends and want to be with them"*, *"I want to go to school to find friends".*

The CYP described positive experiences as when they have autonomy and choice in their learning; *"I am staying home. I've been baking. I visit the library. I play Minecraft. I've done some maths. I have learned to read by myself. I don't feel scared now so that's better"* and *"I like home education because I can choose my learning and choose when I have had enough. I can learn whenever I want and don't have to stop because of someone else's timetable. I like my online school because it is democratic, and we get to choose out topics and what we learn".* This is consistent with the description of PDA whereby the PDAer has a '*need for control'* (Newson *et al.*, 2003) and suggests that specific PDA strategies are required to support these children in education with parents consistently sharing the message that schools are not meeting the needs of these children. The children's suggestions are also significant as they support the two case studies found, where PDA strategies of allowing the child autonomy and choice and building trusting relationships, meant the CYP could re-engage with education.

Despite this study not having a control group of autistic pupils to compare the PDA CYP's experiences with, the findings from the children support those of Truman *et al.* (2021), which relied on parent accounts, and the themes that emerged as described in the findings chapter, were closely aligned. The voices of these 375 CYP are powerful and demonstrate a cohort of children who are predominantly educated outside of schools and feel rejected, isolated and lonely. The three words they used to describe how school makes them feel were negative, with sad, angry, anxious, scared and stressed, powerful descriptors of their feelings about school. They long to be with friends which raises the question of how inclusive our education system really is and if these children are receiving an education that meets legal requirements or the support they are entitled to. The CYP's suggestions for good practice and engagement with learning, also support the PDA Society's recommended approaches and those suggested by authors working with PDA children. The children's views support adoption of the term 'School Distress' in relation to school non-attendance, as proposed by Connolly *et al.* (2023), as these CYP's experiences describe extreme distress related to school and demonstrate the real-life impact of the school attendance crisis raised by the government. So, while this study did not address if PDA CYP have more difficulties with school attendance than autistic children or the PNT, when set in the context of the published research this seems likely, and this study reveals what the negative experiences identified in the limited earlier research looks like in the real world, through raising the voices of the children themselves and demonstrating that appropriate support strategies for PDA CYP are not being implemented in schools today.

CHAPTER 7 - CONCLUSION

The government is focused on driving up school attendance as children missing education are more likely to have poorer academic and adulthood achievements (Pellegrini, 2007; John *et al*., 2022). It is known that autistic children are more likely to struggle with school attendance than the PNT and the PDA Society identified that 70% of PDA children are not in school (PDA Society, 2018). The literature review found that there is emerging evidence that PDA children are more likely than their autistic peers to struggle with school attendance and endure negative educational experiences, but there was limited research focussed on this cohort of children, and none that raised the voice of the children themselves. The controversy surrounding PDA was found to have impacted the views of leading autism organisations such as the National Autistic Society, yet parents are seeking diagnosis and recognition of PDA to support their CYP (Gore Langton and Frederickson, 2018). This study set out to address this gap in research by exploring the educational experiences of PDA CYP, and ensuring the viewpoints of the children were captured. It shines a light on the children's experiences and addressed the following research questions:

- What terminology regarding PDA is used and does a PDA diagnosis matter?
- Where are PDA children currently being educated?
- What are the experiences of PDA children with education?

It was found that many PDA CYP are educated outside of school and as evidenced by their personal accounts, experience significant distress related to school. These CYP struggle with attendance, due to schools not meeting their needs, struggles with the school environment, poor relationships with staff and bullying from both staff and other students. Their negative experiences were contributed to by exclusions from school, attendance struggles and time with no educational provision leading to disengagement from the education system and poor mental health. CYP with EHCPs that accurately describe their needs were more likely to have more positive experiences, and having a formal diagnosis meant that EHCPs were more likely to accurately describe their needs. This means that parents seeking diagnosis for their children have a valid reason to do so, if it means their needs are then adequately described, and the appropriate provision is then implemented to support their children in education.

The CYPs' accounts were often shocking and described feelings of being scared, of feeling like a failure and feeling isolated, with many accounts of worthlessness and suicidal ideation. Their suggestions to make improvements and their descriptions of what is good in education support the PDA Society's recommendations for educators to support PDA CYP, yet these approaches are not being applied in educational practice, leading to children describing their feelings towards school with negative adjectives, such as sad, stressed and anxious.

Limitations of this Study

There are several limitations of this study to be considered. Firstly, although groups that supported parents of children with school attendance struggles were avoided, participants were self-selecting from online PDA support groups, and via the PDA Society's page, so it is likely they represented parents who are active in the PDA online communities and those that are seeking support for their children. Therefore, consideration must be given as to if this sample was truly representative of all PDA children’s experiences, or if those with more negative experiences would be more motivated to take part in the questionnaire. Although rare, there were parents who stated that their children had positive experiences, and potential participants were actively encouraged to take part if they had positive experiences to report. Secondly, participants whose CYP were formally identified as PDA, and those that were identified by parents, were included in the study. This may have led to overrepresentation of those that accept PDA as a formal construct and presentation of behaviours that align to the PDA Society’s interpretation of PDA. In addition, using a questionnaire to gather the views of the parents and CYP meant that the questions were fixed. Care was taken to ensure the questions were neither leading or introduced bias, however interviews would have allowed the researcher to delve deeper into responses, or ask follow-up questions, and may have led to further insight into the CYP’s experiences. The positionality of the researcher can also not be ignored as the CYP’s responses were subject to interpretation of their meaning, although steps were taken in the analysis of the data to remain open-minded and mindful of this. It should also be recognised that the co-occurring conditions, identified by the parent, did not require formal diagnosis, so the information provided was not clinically proven data. Finally, by delegating the questions to the parents to ask the children, may have meant that parent bias was introduced with the parent interpreting the CYP’s response on their behalf. To mitigate this, parents were asked to provide their child’s responses verbatim, but this instruction may not have always been followed or children may have given a response they felt the parent would approve. It must also be accepted that the self-selecting sample may have over represented those who are able to communicate well enough to advocate, meaning that the voices of those less able, may not have been represented in the study.

Recommendations for Future Research

Although some participants stated their CYP had positive experiences with education, and a few stated their CYP had no barriers to education, future research should explore this further to identify the factors that differentiate positive and negative experiences in education. The literature review also raised that investigation of co-occurring conditions with PDA warrants further investigation. Despite the data on these conditions being gathered during this study, it was not possible to analyse this further due to timescale limitations so this remains an area that would benefit from research. Throughout this study, gender differences were looked at and it was found that PDA males tended to struggle with school attendance from first joining the education system, whereas females tended to have school attendance struggles from year 3 onwards. It was also found that males experienced more formal exclusions. Although it was hypothesised that this could be due to girls masking their struggles, this finding warrants further investigation to support understanding attendance struggles and anticipate problems before they arise. Future research also needs to consider how a wide range of autistic children, with differing abilities, can be facilitated to work in a collaborative, participatory and accessible way, to ensure those less able are represented in research.

Despite these many limitations, this study is of significance as, not only does it add evidence to the limited research on PDA CYP’s educational experiences, but it focussed on raising the voices of the children to understand their educational experiences first hand through their detailed accounts. It also went beyond the aims of the study by contributing to understanding the prevalence of PDA and provided some guidance from the children for educational strategies to support them. Autonomy and choice, along with a feeling of safety and trust were key, as were establishing positive and trusting relationships, suggesting that the advice of the PDA Society is well founded and provides a good starting point for educators.

The findings of this study are also consistent with the Children’s Commission report that these CYP want to be in school but find themselves without the support and environment suitable for their neurodivergences to learn (Children’s Commissioner’s Office, 2023). Implementing systematic SEND reform focussed on providing inclusive learning environments and understanding of the struggles that PDA CYP face is not only essential, but urgent to meet the CYP’s educational needs and alleviate the significant distress these CYP are experiencing. However, until a child-centred holistic approach is truly adopted, and educational staff are trained to understand and meet the unique set of needs of a PDAer, it is unlikely that this will be achieved. Instead, the arguments surrounding PDA will continue to be a distraction, impacting the implementation of the right support for these children and their futures.

REFERENCES

Adams, D. (2021) 'Child and Parental Mental Health as Correlates of School Non-Attendance and School Refusal in Children on the Autism Spectrum'*, Journal of Autism and Developmental Disorders*, 52 (8), pp. 3353–3365.

Amundsen, M-L., Kielland, A. and Møller, G. (2022) 'School refusal and school-related differences among students with and without diagnoses', *Nordisk tidsskrift for pedagogikk og kritikk,* 8, pp. 34-48.

Arnold, C. D. (2019) 'Flipping the script: Prioritising the autistic voice in the understanding of scripting as "key to autistic identity"', *Doctoral Dissertations*, 499. Available at: https://repository.usfca.edu/diss/499 (Accessed: 23 December 2023).

Autistic Self Advocacy Network [ASAN] (2023) *What We Believe.* Available at: https://autisticadvocacy.org/about-asan/what-we-believe/ (Accessed: 23 December 2023).

Autism Education Trust [AET] (2024) *What is Autism?* Available at: https://www.autismeducationtrust.org.uk/about/what-is-autism (Accessed: 7 March 2024).

Beardon, L. (2019) *Autism and Asperger Syndrome in Children*. London: Sheldon Press.

Bell, J. and Waters, S. (2018) *Doing your research project: A guide for first-time researchers*. London: Open University Press.

Berg, I., Nichols, K. and Pritchard, C. (1969) 'School Phobia – Its classification and relationship to dependency', *The Journal of Child Psychology and Psychiatry*, 10 (2), pp. 123-141.

Botha, M., Chapman, R., Giwa Onaiwu, M., Kapp, S., Stannard Ashley, A. and Walker, N. (2024) 'The neurodiversity concept was developed collectively: An overdue correction on the origins of neurodiversity theory', *Autism*, 0 (0). Available at: https://doi.org/10.1177/13623613241237871 (Accessed: 9 April 2024).

Bottema-Beutell, K., Kapp, S., Lester, J., Sasson, N. and Hand, B. (2021) 'Avoiding Ableist Language: Suggestions for Autism Researchers', *Autism in Adulthood*, 3 (1), pp. 18-29.

Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3, pp. 7-101.

Brede, J., Remington, A., Kenny, L., Warren, K. and Pellicano, E. (2017) 'Excluded from school: Autistic students' experiences of school exclusion and subsequent re-integration into school', *Autism and Developmental Language Impairments*, 2, pp.1–20.

British Educational Research Association [BERA] (2024) *Ethical Guidelines for Educational Research, fifth edition.* Available at:

https://www.bera.ac.uk/publication/ethical-guidelines-for-educational-research-fifth-edition-2024 (Accessed: 12 April 2024).

Broadwin, I. (1932) ‘A contribution to the study of truancy’. *American Journal of Orthopsychiatry*, 2 (3), pp. 253-259.

Bryman, A. (2016) *Social Research Methods*. 5th edn. Oxford: Oxford University Press.

Cat, S. (2019) ‘”Pathological demand avoidance” or needing to be free?’, *Sally Cat PDA,* 2 December. Available at: http://www.sallycatpda.co.uk/2019/12/pathological-demand-avoidance-or.html (Accessed: 8 March 2024).

Children and Families Act 2014, s.20. Available at: https://www.legislation.gov.uk/ukpga/2014/6/section/20 (Accessed: 5 July 2024).

Children’s Commissioner’s Office (2023) *Written evidence submitted by the Children’s Commissioner: PA0148.* Available at: https://committees.parliament.uk/writtenevidence/118322/html/ (Accessed: 20 December 2023).

Chown N., Robinson J., Beardon L., Downing J., Hughes L., Leatherland J., Fox K., Hickman L. and MacGregor D (2017) ‘Improving research about us, with us: a draft framework for inclusive autism research’, *Disability & Society*, 32 (5), pp. 720-734.

Christie, P. (2007) ‘The distinctive clinical and educational needs of children with Pathological Demand Avoidance syndrome: guidelines for good practice’, *Good Autism Practice*, 8 (1), pp. 3-11.

Cohen, L., Manion, L. and Morrison, K. (2018) *Research Methods in Education*. 8th edn. Oxon: Routledge.

Connolly, S., Constable, H. and Mullally, S. (2023) ‘School distress and the school attendance crisis: a story dominated by neurodivergence and unmet need’, *Frontiers in Psychiatry*, 14, pp. 1-24.

Davidson, J. and Orsini, M. (2013) “Critical Autism Studies: Notes on an Emerging Field.” In Worlds of Autism: Across the Spectrum of Neurological Difference, edited by J. Davidson and M. Orsini, 1–28. Minneapolis, MN: University of Minnesota Press.

Denscombe, M. (2021) *The Good Research Guide*. 7th edn. London: Open University Press.

Department for Education [DfE] (2023a) *Pupil absence in schools in England.* Available at: https://explore-education-statistics.service.gov.uk/find-statistics/pupil-absence-in-schools-in-england (Accessed: 20 December 2023).

Department for Education [DfE] (2023b) *Academic year 2022/23 Special educational needs in England.* Available at: https://explore-education-statistics.service.gov.uk/find-statistics/special-educational-needs-in-england/2022-23 (Accessed: 20 December 2023).

Department for Education [DfE] (2023c) *SEND and Alternative Provision Improvement Plan: Right Support, Right Place, Right Time.* Available at: https://www.gov.uk/government/publications/send-and-alternative-provision-improvement-plan (Accessed: 20 December 2023).

Department for Education [DfE] (2024a) *Major national drive to improve school attendance* Available at: https://www.gov.uk/government/news/major-national-drive-to-improve-school-attendance (Accessed: 24 April 2024).

Department for Education [DfE] (2024b) *Special educational needs in England Academic year 2022/23* Available at: https://explore-education-statistics.service.gov.uk/data-tables/permalink/2d19155f-bc3f-4069-52d1-08dc3ae70a0c (Accessed: 8 March 2024).

Doyle, A. and Kenny, N. (2023) ‘Mapping experiences of pathological demand avoidance in Ireland’, *Journal of Research in Special Educational Needs*, 23 (1), pp. 52-61.

Dwyer, P. (2022) The Neurodiversity Approach(es): What are they and what do they mean for researchers?’, *Human Development*, 66 (2), pp. 73-92.

Eaton, J., Duncan, K. and Hesketh, E. (2018) ‘Modification of the Coventry Grid Interview (Flackhill et al, 2017) to include the Pathological Demand Avoidant Profile’, GAP, 19 (2), pp. 12-24.

Education Act 1996, s.444. Available at: https://www.legislation.gov.uk/ukpga/1996/56/section/444 (Accessed: 15 August 2022).

Egan, V., Bull, E. and Trundle, G. (2020) ‘Individual differences, ADHD, adult pathological demand avoidance, and delinquency’, *Research in Developmental Disabilities*, 105, pp. 1-10.

Epstein, R., Brown, G. and O’Flynn, S. (2019) Prosecuting Parents for Truancy: who pays the price? Coventry University. Coventry. Available at: https://covrj.uk/prosecuting-parents/ (Accessed: 17 April 2024).

Fidler, R. and Christie. (2019) *Collaborative Approaches to Learning for Pupils with PDA: Strategies for Education Professionals.* London: Jessica Kingsley.

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R. and Pellicano, E. (2019) 'Making the future together: Shaping autism research through meaningful participation', *Autism,* 23 (4), pp. 943-953.

Freedom of Information Act 2000. Available at: https://www.legislation.gov.uk/ukpga/2000/36/contents (Accessed: 1 December 2023).

Get Information about Schools (2023) *Local authority name and associated codes*. Available at: https://www.get-information-schools.service.gov.uk/Guidance/LaNameCodes (Accessed: 1 December 2023).

Gillberg, C. (2014) ‘Commentary: PDA– public display of affection or pathological demand avoidance? – reflections on O’Nions et al. (2014)’, *Journal of Child Psychology and Psychiatry*, 55 (7), pp. 769-770.

Gillberg, C., Gillberg, I., Thompson, L., Biskupsto, R. and Billstedt, E. (2015) ‘Extreme (“pathological”) demand avoidance in autism: a general populations study in the Faroe Islands’, *European Child and Adolescent Psychiatry,* 24, pp. 979–984.

Gillespie-Lynch, K., Kapp, S., Shane-Simpson, C., Smith, D. and Hutman, T. (2014) ‘Intersections Between the Autism Spectrum and the Internet: Perceived Benefits and Preferred Functions of Computer-Mediated Communication’, *Intellectual and Developmental Disabilities*, 52 (6), pp. 456-469.

Gore Langton, E. and Frederickson, N. (2016) ‘Mapping the educational experiences of children with pathological demand avoidance’, *International Journal of Research in Special Educational Needs*, 64 (4), pp. 254-263.

Gore Langton, E. and Frederickson, N. (2018) ‘Parents’ experiences of professionals’ involvement for children with extreme demand avoidance’, *International Journal of Developmental Disorders,* 64 (1), pp. 16-24.

Green, A. (2022) *What can we learn from parents and caregivers of school-aged autistic children to inform current Emotionally Based School Attendance (EBSA) intervention approaches in England?* Available at: https://www.pdasociety.org.uk/resources/what-can-be-learnt-from-parents-about-school-avoidance-in-autistic-pupils/ (Accessed: 23 December 2023).

Green, J., Absoud, M. Grahame, V., Malik, O. Simonoff, E. Lee Couteur, A. and Baird, G. (2018) ‘Pathological Demand Avoidance: symptom not a syndrome’, *The Lancet Child & Adolescent Health*, 2 (6), pp. 455-464.

Green, J. (2020) ‘Commentary: Anxiety and behaviour in and beyond ASD; Does the idea of ‘PDA’ really help? A commentary on Stuart et al. (2020)’, *Child and Adolescent Mental Health*, 25 (2), pp. 74–76.

House of Commons Education Committee (2023*) Persistent absence and support for disadvantaged children*. Available at: https://committees.parliament.uk/work/7179/persistent-absence-and-support-for-disadvantaged-pupils/ (Accessed: 21 December 2023).

Hull, L., Lai, M-C., Baron-Cohen, S., Allison, C., Smith, P., Petrides, KV and William, M. (2020) ‘Gender differences in self-reported camouflaging in autistic and non-autistic adults’, *Autism*, 24 (2), pp. 352-363.

IBM (2024) *IBM SPSS Statistics*. Available at: https://www.ibm.com/products/spss-statistics (Accessed: 13 May 2024).

John, A., Friedmann, Y., DelPozo-Banos, M., Frizzati, A., Ford, T. and Thapar, A. (2022) ‘Association of school absence and exclusion with recorded neurodevelopmental disorders, mental disorders, or self-harm: a nationwide, retrospective, electronic cohort study of children and young people in Wales, UK’, *The Lancet Psychiatry*, 9 (1), pp. 23–34.

Johnson, A.M., Falstein, E.I., Szurek, S.A. and Svendsen, M. (1941) ‘School Phobia’. *American Journal of Orthopsychiatry*, 11 (4), pp. 702-711

Johnson, L. and Rutherford, M. (2020) *NAIT Anxiety Related Absence: A guide for practice.* Available at: https://www.frontiersin.org/articles/10.3389/feduc.2024.1358354/full#supplementary-material (Accessed: 15 April 2024).

Johnson, M. and Saunderson, H. (2023) ‘Examining the relationship between anxiety and pathological demand avoidance in adults: a mixed methods approach’, *Frontiers in Education*, 8, pp. 702-711.

Kearney, C.A. (2008) ‘School absenteeism and school refusal behavior in youth: a contemporary review’, *Clinical Psychology Review*, 28 (3), pp. 451-471.

Kearney, C.A. and Silverman, W.K. (1990) ‘A Preliminary Analysis of a Functional Model of Assessment and Treatment for School Refusal Behavior’, *Behavior Modification*, 14 (3), pp. 340-366.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C. and Pellicano, E. (2016) ‘Which terms should be used to describe autism? Perspectives from the UK autism community’, *Autism*, 20 (4), pp.442-462.

Kerbey, L. (2023) *The Educator’s Experience of Pathological Demand Avoidance: An Illustrated Guide to Pathological Demand Avoidance and Learning.* London: Jessica Kingsley.

Kildahl, A., Helverschou, S., Rysstad, A., Wigaard, E., Hellerud, J., Ludvigen, L. and Howlin, P. (2021) ‘Pathological demand avoidance in children and adolescents: A systematic review’, *Autism*, 25 (8), pp. 2162-2176.

Lawson, W. (2020) *PDA (Pathological Demand Avoidance) or Persistent Drive for Autonomy.* 16 December. Available at: https://www.youtube.com/watch?v=Pw9fNf9jShw (Accessed: 7 March 2024).

Lewis, A. and Porter, J. (2004) ‘Interviewing children and young people with learning disabilities: guidelines for researchers and multi-professional practice’, *British Journal of Learning Disabilities*, 32 (4), pp. 191–197.

Lumivero (2024) *Nvivo: Nvivo 14 – Leading Qualitative Data Analysis Software*. Available at: https://lumivero.com/products/nvivo/ (Accessed: 4 May 2024).

Malik, O. and Baird, G. (2018) ‘Commentary: PDA-what's in a name? Dimensions of difficulty in children reported to have an ASD and features of extreme/pathological demand avoidance: A commentary on O'Nions et al. (2017)', *Child and Adolescent Mental Health*, 23 (4), pp. 387–388.

Maynard, B. R., Brendel, K. E., Bulanda, J. J., Heyne, D., Thompson, A. M. and Pigott, T. D. (2015) 'Psychosocial interventions for school refusal with primary and secondary school students: A systematic review', *Campbell Systematic Reviews*, 11, pp. 12.

Milton, D. (2013) *Natures answer to over-conformity: Deconstructing pathological demand avoidance*. Available at: https://kar.kent.ac.uk/62694/431/Natures%20answer%20to%20over%20conformity.pdf (Accessed: 9 February 2024).

Milton, D. (2014) 'Autistic expertise: A critical reflection on the production of knowledge in autism studies', *Autism*, *18* (7), pp. 794-802.

Moore, A. (2020) 'Pathological demand avoidance: What and who are being pathologised and in whose interests?', *Global Studies of Childhood,* 10 (1), pp. 39-52.

Munkhaugen, E.K., Gjevik, E., Pripp, A.H., Sponheim, E. and Diseth, T. H. (2017) 'School refusal behaviour: Are children and adolescents with autism spectrum disorder at a higher risk?', *Research in Autism Spectrum Disorders*, 41-42, pp. 31–38.

mySociety (2023) *What Do They Know*. Available at: https://www.whatdotheyknow.com/ (Accessed: 15 December 2023).

National Autistic Society [NAS] 2023 *Demand avoidance*. Available at: https://www.autism.org.uk/advice-and-guidance/topics/behaviour/demand-avoidance (Accessed: 23 December 2023).

National Institute for Health and Care Excellence [NICE] (2011) *Autism: recognition, referral and diagnosis of children and young people on the autism spectrum*. CG128. Available at: https://www.nice.org.uk/guidance/cg128/evidence (Accessed: 8 February 2024).

Newson, E., K. Le Maréchal and David, C. (2003) 'Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders', *Archives of Disease in Childhood*, 88 (7), pp**.** 595-600.

Nind, M. (2017) 'The practical wisdom of inclusive research', *Qualitative Research*, 17 (3), pp. 278-288.

Nind, M. and Vinha, H. (2014) 'Doing research inclusively: bridges to multiple possibilities in inclusive research', *British Journal of Learning Disabilities*, 42 (2), pp. 102-109.

Ochi, M., Kawabe, K., Ochi, S., Miyama, T., Horiuchi, F. and Ueno, S. (2020) 'School refusal and bullying in children with autism spectrum disorder', *Child and Adolescent Mental Health*, 14 (1), pp. 1-7.

O'Hagan, S., Bond, C. and Hebron, J. (2022) 'Autistic girls and emotionally based school avoidance: supportive factors for successful reengagement in mainstream high school', *International Journal of Inclusive Education,* 28 (9), pp. 1919-1935.

O'Nions, E. and Eaton, J. (2020) 'Extreme/'pathological' demand avoidance: an overview', *Paediatrics and Child Health*, 30 (12), pp. 411-415.

O'Nions, E., Viding, E., Greven, C., Ronald, A. and Happé, F (2014a) 'Pathological demand avoidance: Exploring the behavioural profile', *Autism*, 18 (5), pp. 538–544.

O'Nions, E., Christie, P., Gould, J., Viding, E. and Happé, F. (2014b) '*Development of the 'Extreme Demand Avoidance Questionnaire' (EDA-Q): preliminary observations on a trait measure for Pathological Demand Avoidance*', *Journal of Child Psychology and Psychiatry*, 55 (7), pp. 758-768.

O'Nions, E., Viding, E., Floyd, C., Quinlan, E., Pidgeon, C., Gould, J., and Happé, F. (2018) 'Dimensions of difficulty in children reported to have an autism spectrum diagnosis and features of extreme/pathological' demand avoidance', *Child and Adolescent Mental Health*, 23 (3), pp. 220-227.

Opie, C. (2004) *Doing Educational Research*. London: Sage Publications.

Ozsivadjian, A. (2020) 'Editorial: Demand avoidance — pathological, extreme or oppositional?', *Child and Adolescent Mental Health*, 25 (2), pp. 57–58.

PDA Society (2018) *Being Misunderstood: Experiences of the Pathological Demand Avoidance Profile of ASD*. Available at: https://www.pdasociety.org.uk/resources/2018-summary/ (Accessed: 24 July 2023).

PDA Society (2021) *Helpful approaches for a PDA profile of autism.* Available at: https://www.pdasociety.org.uk/life-with-pda-menu/family-life-intro/helpful-approaches-children/ (Accessed: 14 April 2024).

PDA Society (2022) *Identifying & Assessing a PDA profile – Practice Guidance* Available at: https://www.pdasociety.org.uk/resources/identifying-assessing-a-pda-profile-practice-guidance/ (Accessed: 9 February 2024).

PDA Society (2023) *PDA Research Priority Setting* Available at: https://www.pdasociety.org.uk/research-priorities-project-update/ (Accessed: 23 December 2023).

PDA Society (2024) *PDA About autism & PDA* Available at: https://www.pdasociety.org.uk/what-is-pda-menu/about-autism-and-pda/ (Accessed: 6 March 2024).

Pearson, A. and Rose, K. (2023) *Autistic Masking and Autistic Burnout.* UK: Pavilion Publishing & Media Limited.

Pellegrini, D. (2007) 'School Non-attendance: Definitions, meanings, responses, interventions', *Educational Psychology in Practice*, 23 (1), pp. 63–77.

Pellicano, E., Crane, L. and Gaudion, K. and the Shaping Autism Research team (2017) Participatory autism research: A starter pack. London: UCL Institute of Education.

Roman-Urrestarazu, A., van Kessel, R., Allison, C., Matthews, F., Brayne, C. and Baron-Cohen, S. (2021) ‘Association of Race/Ethnicity and Social Disadvantage With Autism Prevalence in 7 Million School Children in England’, *JAMA Pediatrics,* 175 (6), pp. 1-11.

School Home Support (2023) *Filling the gaps in family support to improve school attendance: School-Home Support. Briefing Paper.* Available at: chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.schoolhomesupport.org.uk/wp-content/uploads/2023/03/Briefing-Paper-March-2023.pdf (Accessed: 20 December 2023).

Shore, S.M. (2003) *Beyond the wall: Personal experiences with autism and Asperger syndrome*. Shawnee Mission, KS: Autism Asperger Publishing Company.

Stuart, L., Grahame, V., Honey, E. and Freeston, M. (2020) ‘Intolerance of uncertainty and anxiety as explanatory frameworks for extreme demand avoidance in children and adolescents’, *Child and Adolescent Mental Health*, 25 (2), pp. 59–67.

Summerhill, L. and Collett, K. (2018) ‘Developing a multi-agency assessment pathway for children and young people thought to have a Pathological Demand Avoidance profile’, GAP, 19 (2), pp. 25-32.

SurveyMonkey (2023) *SurveyMonkey.* Available at: https://www.surveymonkey.co.uk (Accessed: 18 August 2023).

Thomas, G. (2017) *How to do your research project: A guide for students*. 3rd edn. London: SAGE Publications.

Totsika, V., Kouroupa, A., Timmerman, A., Allard, A., Gray, K., Hastings, P., Heyne, D. Melvin, G. and Tonge, B. (2023) ‘School Attendance Problems Among Children with Neurodevelopmental Conditions One year Following the Start of the COVID-19 Pandemic’, *Journal of Autism and Developmental Disorders*.

Truman, C. (2021) *The Teacher's Introduction to Pathological Demand Avoidance: Essential Strategies for the Classroom.* London: Jessica Kingsley.

Truman, C., Crane, L., Howlin, P. and Pellicano, E. (2021) ‘The educational experiences of autistic children with and without extreme demand avoidance behaviours’, *International Journal of Inclusive Education*, ahead-of-print (ahead-of-print), pp. 1-21.

University of Birmingham (2018) *The University of Birmingham Code of Ethics*. Available at: https://www.birmingham.ac.uk/Documents/university/governance/Code-of-Ethics/Code-of-Ethics-Approved-by-Council-April-2018.pdf (Accessed: 12 August 2023).

Web Content Accessibility Guidelines Working Group (WCAG WG) (2023) *How to meet WCAG (Quick Reference).* Available at: https://www.w3.org/WAI/WCAG22/quickref/?versions=2.1 (Accessed 26 February 2024).

West Sussex County Council (2020) *What is Emotionally Based School Avoidance?* Available at: https://www.westsussex.gov.uk/local-offer/information/education/emotionally-based-school-avoidance-ebsa/ (Accessed: 01 July 2024).

White, R., Livingston, L., Taylor, E., Close, S., Shah, P. and Callan, M. (2023) ‘Understanding the Contributions of Trait Autism and Anxiety to Extreme Demand Avoidance in the Adult General Population’, *Journal of Autism and Developmental Disorders*, 53 (7), pp. 2680-2688.

Wilding, T. (2020) ‘Changing The name PDA’, *Tom Wilding Neuropsychology specialist,* 4 April. Available at: http://tomlinwilding.com/changing-the-name-pda/ (Accessed: 7 March 2024).

Wing, L., Gould, J. and Gillberg, C. (2011) ‘Autism spectrum disorders in the DSM-V: Better or worse than the DSM-IV?’, *Research in Developmental Disabilities*, 32, pp.768-773.

Wing, L., Leekam, S., Libby, S., Gould, J. and Larcombe, M. (2002) ‘The Diagnostic Interview for Social and Communication Disorders: Background, inter-rater reliability and clinical use’, *Journal of Child Psychology and Psychiatry*, 43, pp. 307–325.

Woods, R. (2017) ‘Pathological demand avoidance: my thoughts on looping effects and commodification of autism’, *Disability & Society*, 32 (5), pp. 753-758.

Woods, R. (2018) ‘Rational (Pathological) Demand Avoidance: what it is not, what it could be & what it does’, *PARC Critical Perspectives on Pathological Demand Avoidance (PDA):* London South Bank University, May 2018. Available at: https://www.researchgate.net/publication/325181432_Rational_Pathological_Demand_Avoidance_what_it_is_not_what_it_could_be_what_it_does (Accessed: 8 March 2024).

Woods, R. (2020) ‘Commentary: Demand Avoidance Phenomena, a manifold issue? Intolerance of uncertainty and anxiety as explanatory frameworks for extreme demand avoidance in children and adolescents – a commentary on Stuart et al. (2020)’, *Child and Adolescent Mental Health*, 25 (2), pp. 68-70.

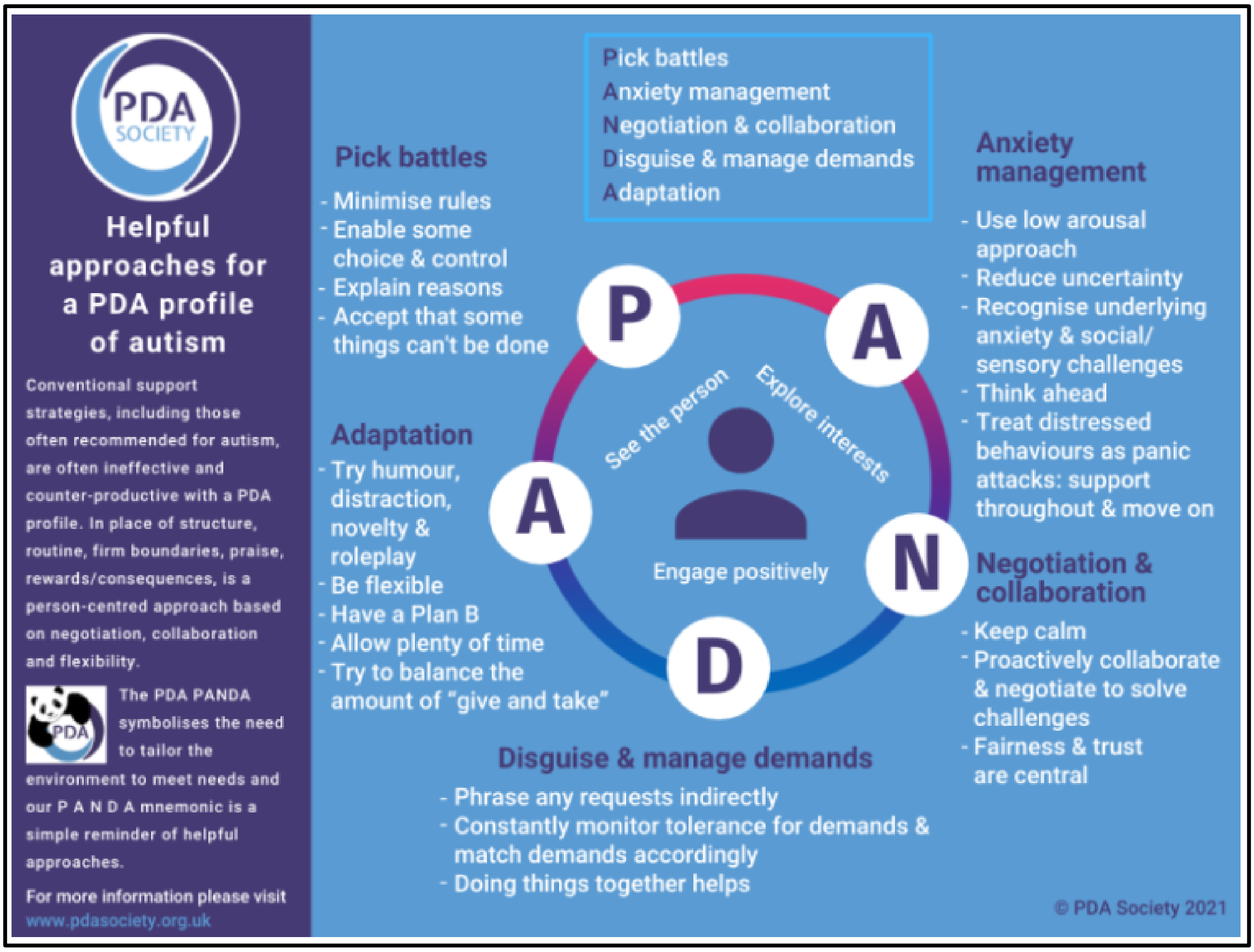
Woods, R. (2021) ‘Demand-Avoidance Phenomena (“Pathological”/”Extreme” Demand Avoidance): As a biopower identity?’, *PARC Critical Autism Studies: Autumn Workshop,* London South Bank University, October 2021. Available at: https://www.researchgate.net/publication/355427579_Demand-Avoidance_Phenomena_Pathological_Extreme_Demand_Avoidance_As_a_biopower_identity (Accessed: 8 March 2024).

World Health Organization (WHO) (2019) *International Classification of Diseases (ICD-11).* Geneva: WHO.

APPENDICES

APPENDIX A: PDA Society – PANDA Infographic

The below graphic (Figure AA.1) is published by the PDA Society to support parents, caregivers, educators and clinicians to understand and support PDA children. This leaflet is available from the following web link: https://www.pdasociety.org.uk/life-with-pda-menu/family-life-intro/helpful-approaches-children/



PDA SOCIETY

Helpful approaches for a PDA profile of autism

Conventional support strategies, including those often recommended for autism, are often ineffective and counter-productive with a PDA profile. In place of structure, routine, firm boundaries, praise, rewards/consequences, is a person-centred approach based on negotiation, collaboration and flexibility.

The PDA PANDA symbolises the need to tailor the environment to meet needs and our P A N D A mnemonic is a simple reminder of helpful approaches.

For more information please visit www.pdasociety.org.uk

Pick battles
Anxiety management
Negotiation & collaboration
Disguise & manage demands
Adaptation

Pick battles

- Minimise rules
- Enable some choice & control
- Explain reasons
- Accept that some things can't be done

Anxiety management

- Use low arousal approach
- Reduce uncertainty
- Recognise underlying anxiety & social/ sensory challenges
- Think ahead
- Treat distressed behaviours as panic attacks: support throughout & move on

Adaptation

- Try humour, distraction, novelty & roleplay
- Be flexible
- Have a Plan B
- Allow plenty of time
- Try to balance the amount of "give and take"

Negotiation & collaboration

- Keep calm
- Proactively collaborate & negotiate to solve challenges
- Fairness & trust are central

Disguise & manage demands

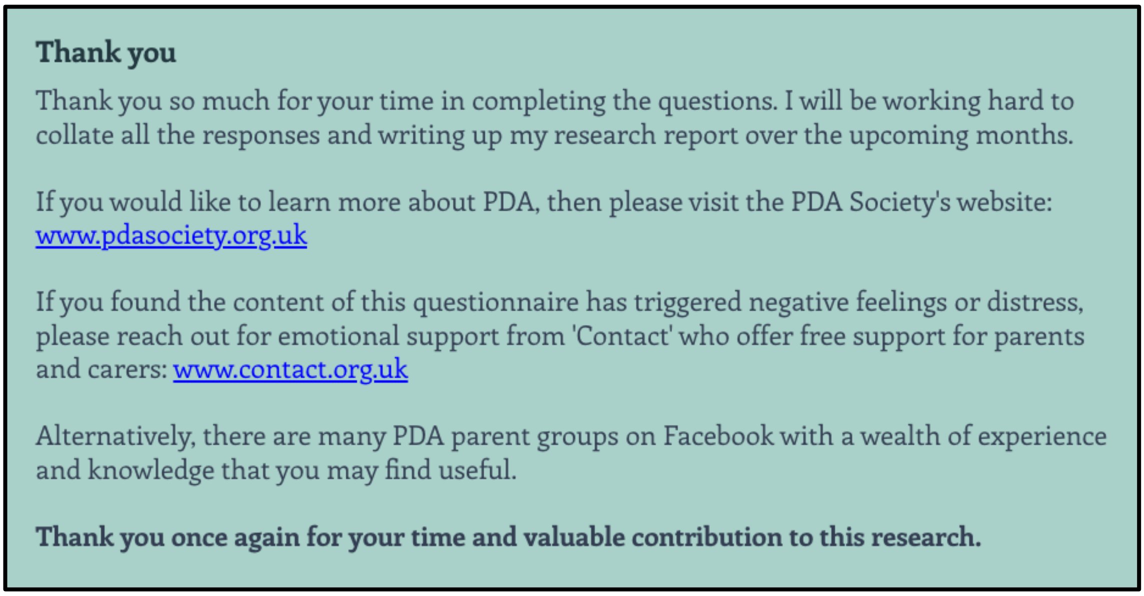
- Phrase any requests indirectly
- Constantly monitor tolerance for demands & match demands accordingly
- Doing things together helps

© PDA Society 2021

FIGURE AA.1: PDA Society's PANDA infographic (2021)

APPENDIX B: Signposting for Parent Support

Figure AB.1 shows the final screen presented to parents who took part in the online questionnaire, signposting them to free emotional support and guidance.



Thank you

Thank you so much for your time in completing the questions. I will be working hard to collate all the responses and writing up my research report over the upcoming months.

If you would like to learn more about PDA, then please visit the PDA Society's website: www.pdasociety.org.uk

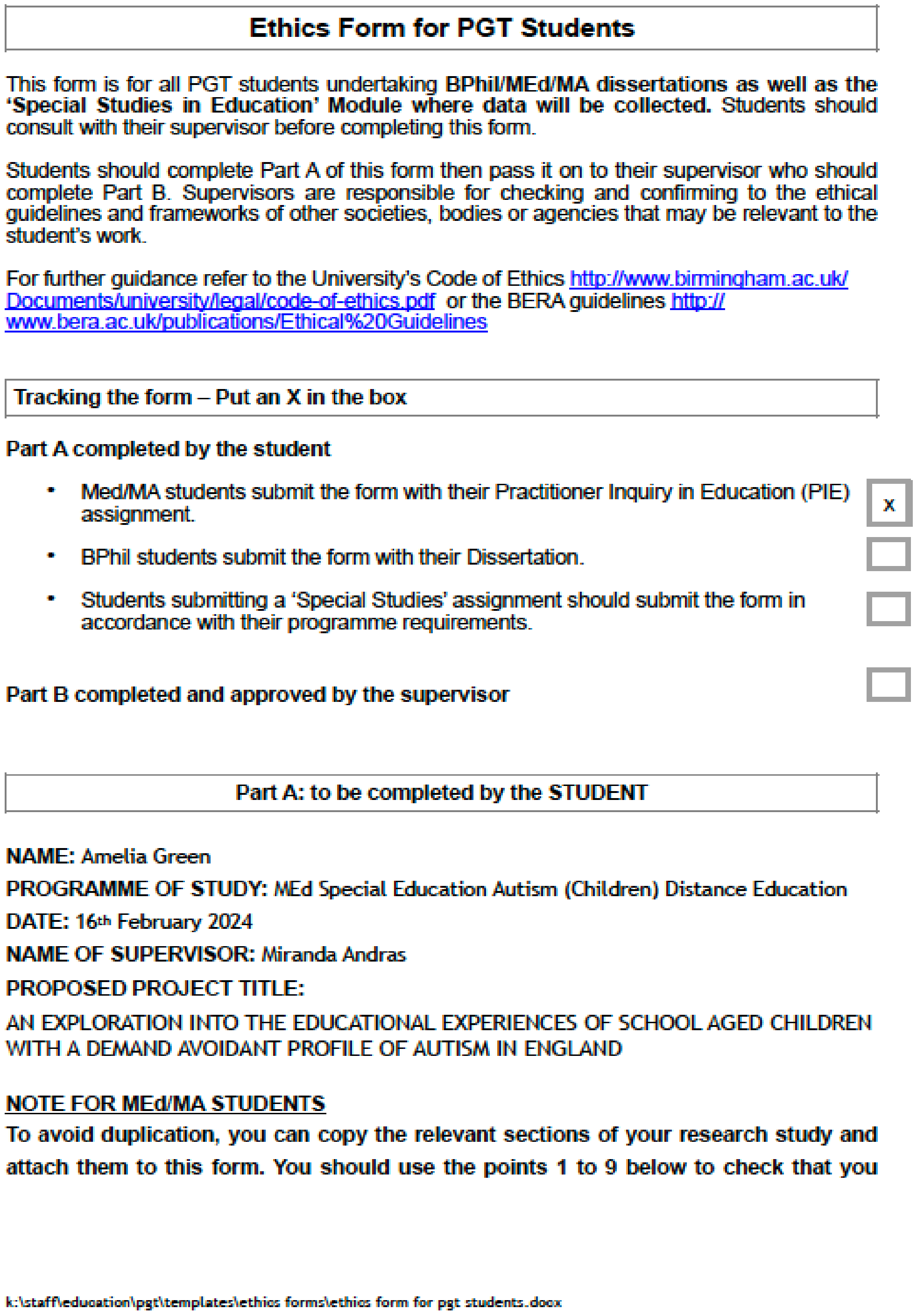
If you found the content of this questionnaire has triggered negative feelings or distress, please reach out for emotional support from 'Contact' who offer free support for parents and carers: www.contact.org.uk

Alternatively, there are many PDA parent groups on Facebook with a wealth of experience and knowledge that you may find useful.

Thank you once again for your time and valuable contribution to this research.

FIGURE AB.1: Final screen presented to participants on completion of the questionnaire

APPENDIX C: Ethics Approval



Ethics Form for PGT Students

This form is for all PGT students undertaking **BPhil/MEd/MA dissertations as well as the 'Special Studies in Education' Module where data will be collected.** Students should consult with their supervisor before completing this form.

Students should complete Part A of this form then pass it on to their supervisor who should complete Part B. Supervisors are responsible for checking and confirming to the ethical guidelines and frameworks of other societies, bodies or agencies that may be relevant to the student's work.

For further guidance refer to the University's Code of Ethics http://www.birmingham.ac.uk/Documents/university/legal/code-of-ethics.pdf or the BERA guidelines http://www.bera.ac.uk/publications/Ethical%20Guidelines

Tracking the form – Put an X in the box

Part A completed by the student

- Med/MA students submit the form with their Practitioner Inquiry in Education (PIE) assignment. ☒
- BPhil students submit the form with their Dissertation. ☐
- Students submitting a 'Special Studies' assignment should submit the form in accordance with their programme requirements. ☐

Part B completed and approved by the supervisor ☐

Part A: to be completed by the STUDENT

NAME: Amelia Green

PROGRAMME OF STUDY: MEd Special Education Autism (Children) Distance Education

DATE: 16th February 2024

NAME OF SUPERVISOR: Miranda Andras

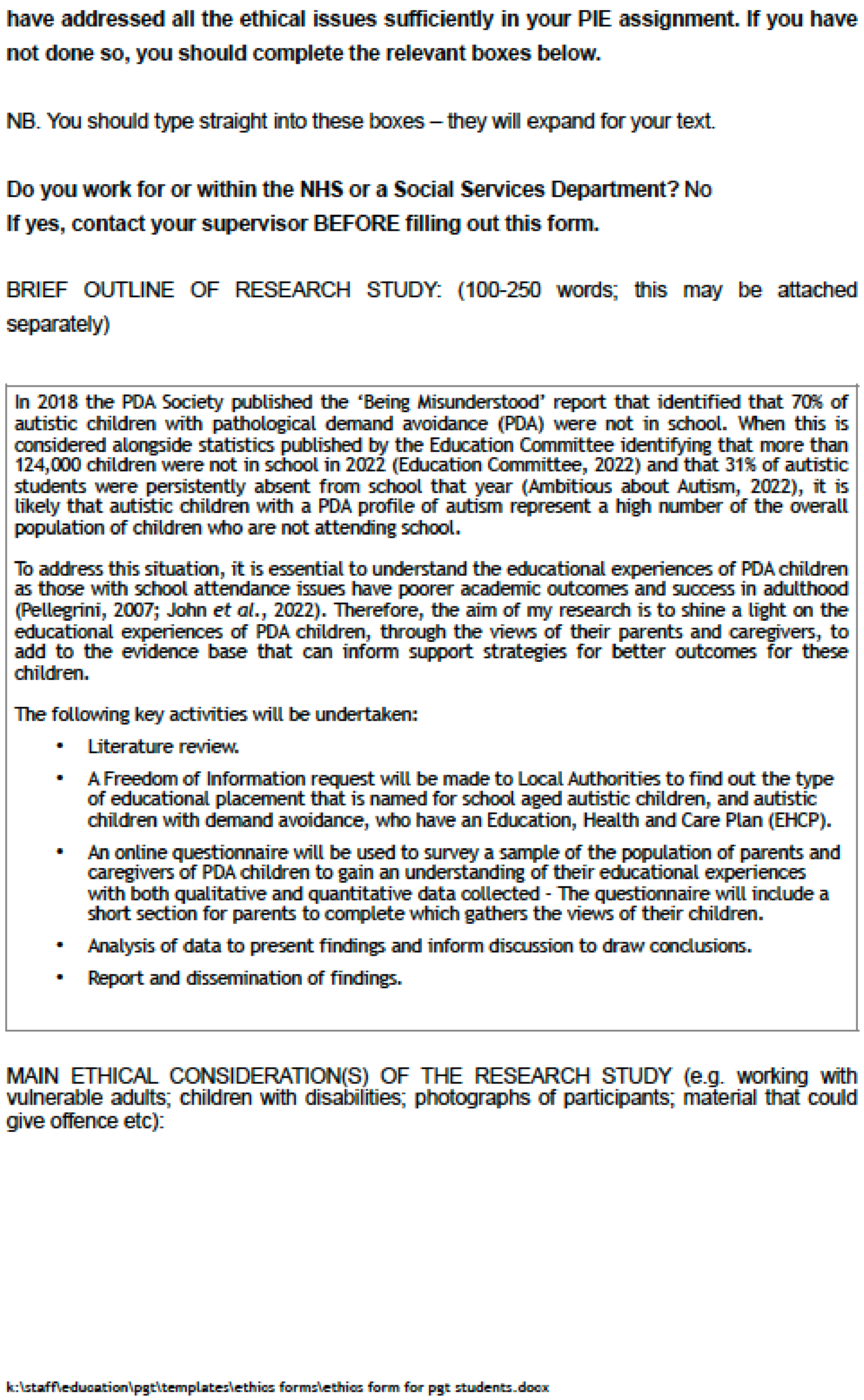
PROPOSED PROJECT TITLE:

AN EXPLORATION INTO THE EDUCATIONAL EXPERIENCES OF SCHOOL AGED CHILDREN WITH A DEMAND AVOIDANT PROFILE OF AUTISM IN ENGLAND

NOTE FOR MEd/MA STUDENTS

To avoid duplication, you can copy the relevant sections of your research study and attach them to this form. You should use the points 1 to 9 below to check that you

k:\staff\education\pgt\templates\ethics forms\ethics form for pgt students.docx



have addressed all the ethical issues sufficiently in your PIE assignment. If you have not done so, you should complete the relevant boxes below.

NB. You should type straight into these boxes – they will expand for your text.

Do you work for or within the NHS or a Social Services Department? No
If yes, contact your supervisor BEFORE filling out this form.

BRIEF OUTLINE OF RESEARCH STUDY: (100-250 words; this may be attached separately)

In 2018 the PDA Society published the 'Being Misunderstood' report that identified that 70% of autistic children with pathological demand avoidance (PDA) were not in school. When this is considered alongside statistics published by the Education Committee identifying that more than 124,000 children were not in school in 2022 (Education Committee, 2022) and that 31% of autistic students were persistently absent from school that year (Ambitious about Autism, 2022), it is likely that autistic children with a PDA profile of autism represent a high number of the overall population of children who are not attending school.

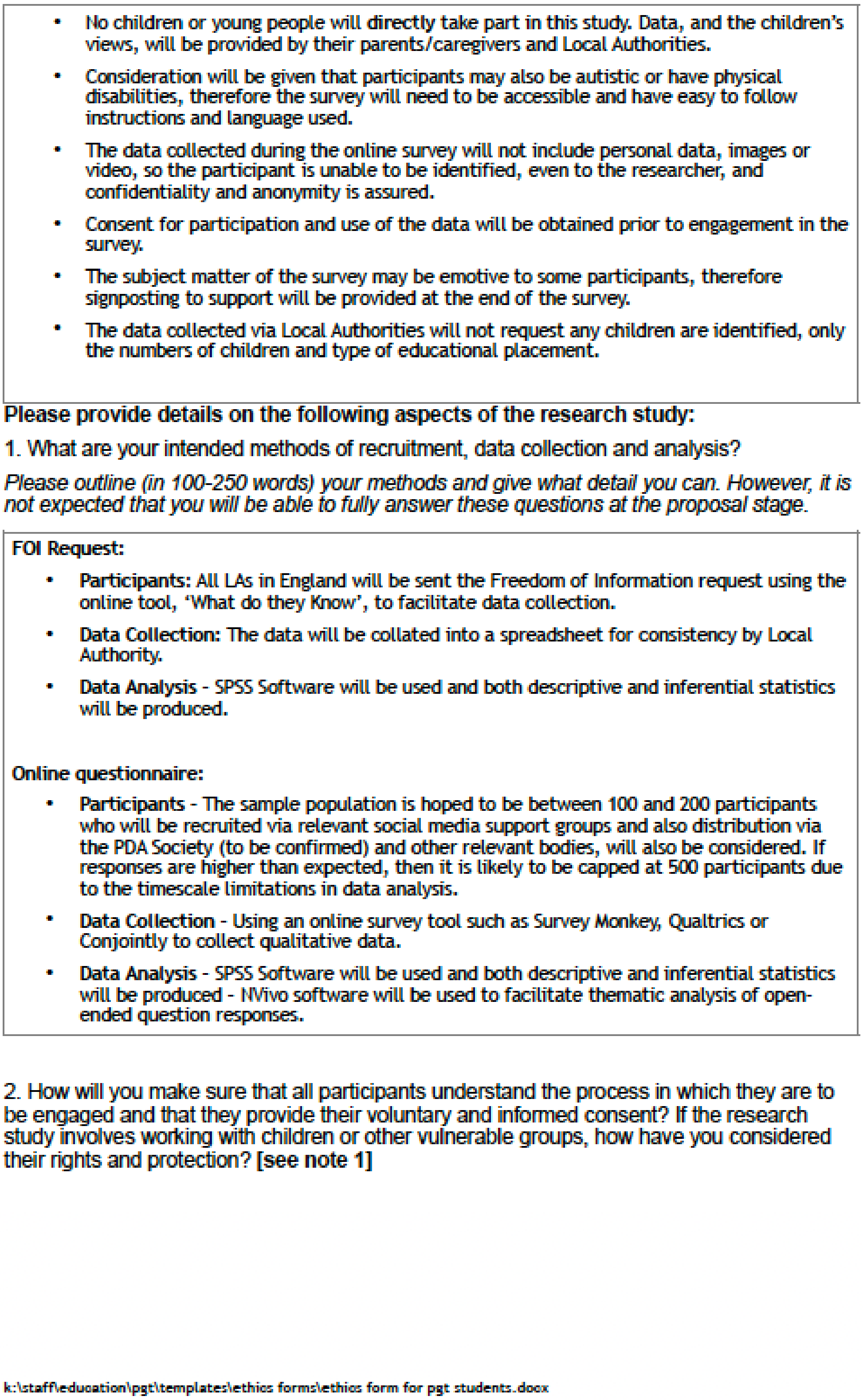
To address this situation, it is essential to understand the educational experiences of PDA children as those with school attendance issues have poorer academic outcomes and success in adulthood (Pellegrini, 2007; John *et al.*, 2022). Therefore, the aim of my research is to shine a light on the educational experiences of PDA children, through the views of their parents and caregivers, to add to the evidence base that can inform support strategies for better outcomes for these children.

The following key activities will be undertaken:

- Literature review.
- A Freedom of Information request will be made to Local Authorities to find out the type of educational placement that is named for school aged autistic children, and autistic children with demand avoidance, who have an Education, Health and Care Plan (EHCP).
- An online questionnaire will be used to survey a sample of the population of parents and caregivers of PDA children to gain an understanding of their educational experiences with both qualitative and quantitative data collected - The questionnaire will include a short section for parents to complete which gathers the views of their children.
- Analysis of data to present findings and inform discussion to draw conclusions.
- Report and dissemination of findings.

MAIN ETHICAL CONSIDERATION(S) OF THE RESEARCH STUDY (e.g. working with vulnerable adults; children with disabilities; photographs of participants; material that could give offence etc):

k:\staff\education\pgt\templates\ethics forms\ethics form for pgt students.docx



- No children or young people will directly take part in this study. Data, and the children's views, will be provided by their parents/caregivers and Local Authorities.
- Consideration will be given that participants may also be autistic or have physical disabilities, therefore the survey will need to be accessible and have easy to follow instructions and language used.
- The data collected during the online survey will not include personal data, images or video, so the participant is unable to be identified, even to the researcher, and confidentiality and anonymity is assured.
- Consent for participation and use of the data will be obtained prior to engagement in the survey.
- The subject matter of the survey may be emotive to some participants, therefore signposting to support will be provided at the end of the survey.
- The data collected via Local Authorities will not request any children are identified, only the numbers of children and type of educational placement.

Please provide details on the following aspects of the research study:

1. What are your intended methods of recruitment, data collection and analysis?

Please outline (in 100-250 words) your methods and give what detail you can. However, it is not expected that you will be able to fully answer these questions at the proposal stage.

FOI Request:

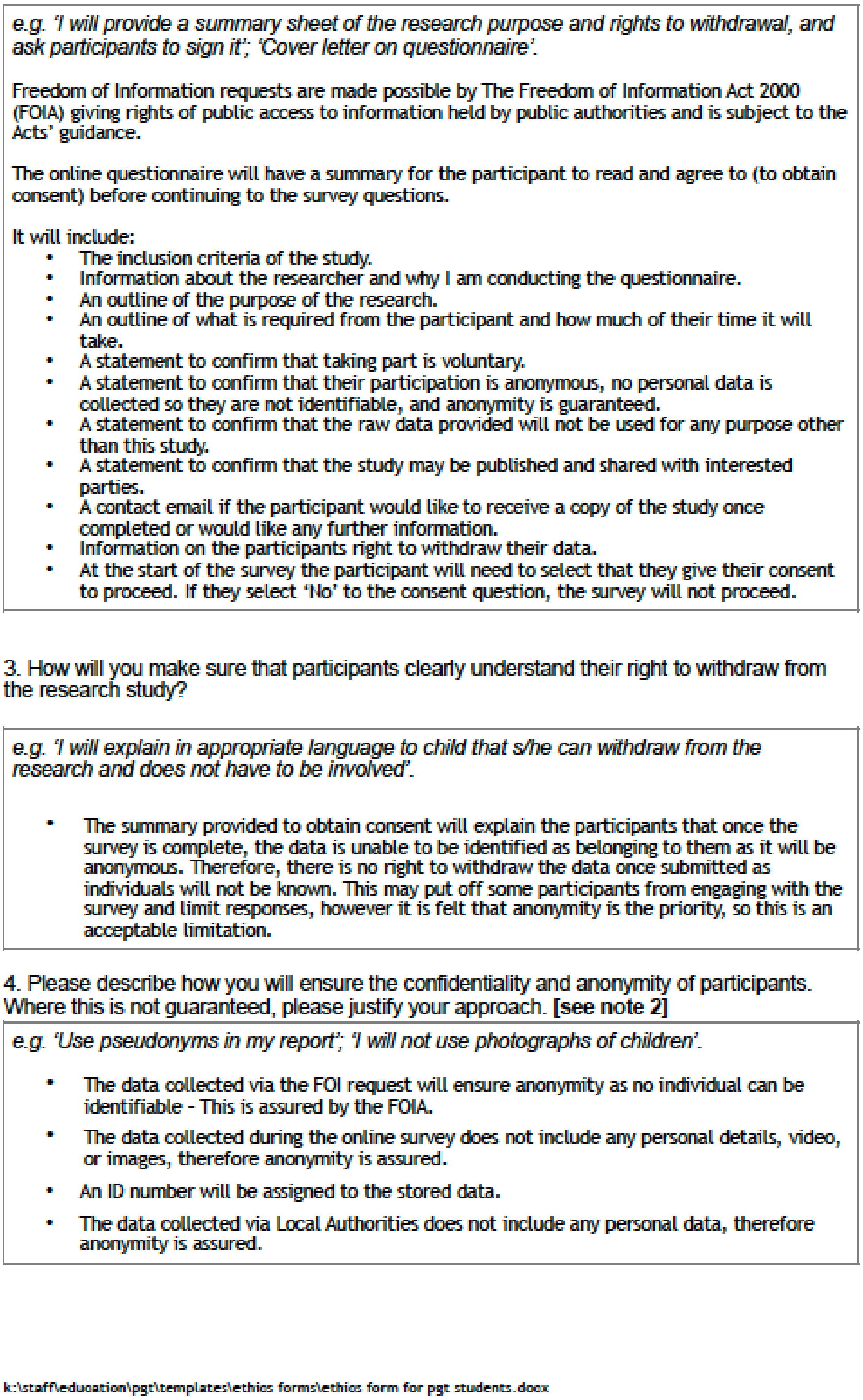
- **Participants:** All LAs in England will be sent the Freedom of Information request using the online tool, 'What do they Know', to facilitate data collection.
- **Data Collection:** The data will be collated into a spreadsheet for consistency by Local Authority.
- **Data Analysis** - SPSS Software will be used and both descriptive and inferential statistics will be produced.

Online questionnaire:

- **Participants** - The sample population is hoped to be between 100 and 200 participants who will be recruited via relevant social media support groups and also distribution via the PDA Society (to be confirmed) and other relevant bodies, will also be considered. If responses are higher than expected, then it is likely to be capped at 500 participants due to the timescale limitations in data analysis.
- **Data Collection** - Using an online survey tool such as Survey Monkey, Qualtrics or Conjointly to collect qualitative data.
- **Data Analysis** - SPSS Software will be used and both descriptive and inferential statistics will be produced - NVivo software will be used to facilitate thematic analysis of open-ended question responses.

2. How will you make sure that all participants understand the process in which they are to be engaged and that they provide their voluntary and informed consent? If the research study involves working with children or other vulnerable groups, how have you considered their rights and protection? **[see note 1]**

k:\staff\education\pgt\templates\ethics forms\ethics form for pgt students.docx



e.g. 'I will provide a summary sheet of the research purpose and rights to withdrawal, and ask participants to sign it'; 'Cover letter on questionnaire'.

Freedom of Information requests are made possible by The Freedom of Information Act 2000 (FOIA) giving rights of public access to information held by public authorities and is subject to the Acts' guidance.

The online questionnaire will have a summary for the participant to read and agree to (to obtain consent) before continuing to the survey questions.

It will include:

- The inclusion criteria of the study.
- Information about the researcher and why I am conducting the questionnaire.
- An outline of the purpose of the research.
- An outline of what is required from the participant and how much of their time it will take.
- A statement to confirm that taking part is voluntary.
- A statement to confirm that their participation is anonymous, no personal data is collected so they are not identifiable, and anonymity is guaranteed.
- A statement to confirm that the raw data provided will not be used for any purpose other than this study.
- A statement to confirm that the study may be published and shared with interested parties.
- A contact email if the participant would like to receive a copy of the study once completed or would like any further information.
- Information on the participants right to withdraw their data.
- At the start of the survey the participant will need to select that they give their consent to proceed. If they select 'No' to the consent question, the survey will not proceed.

3. How will you make sure that participants clearly understand their right to withdraw from the research study?

e.g. 'I will explain in appropriate language to child that s/he can withdraw from the research and does not have to be involved'.

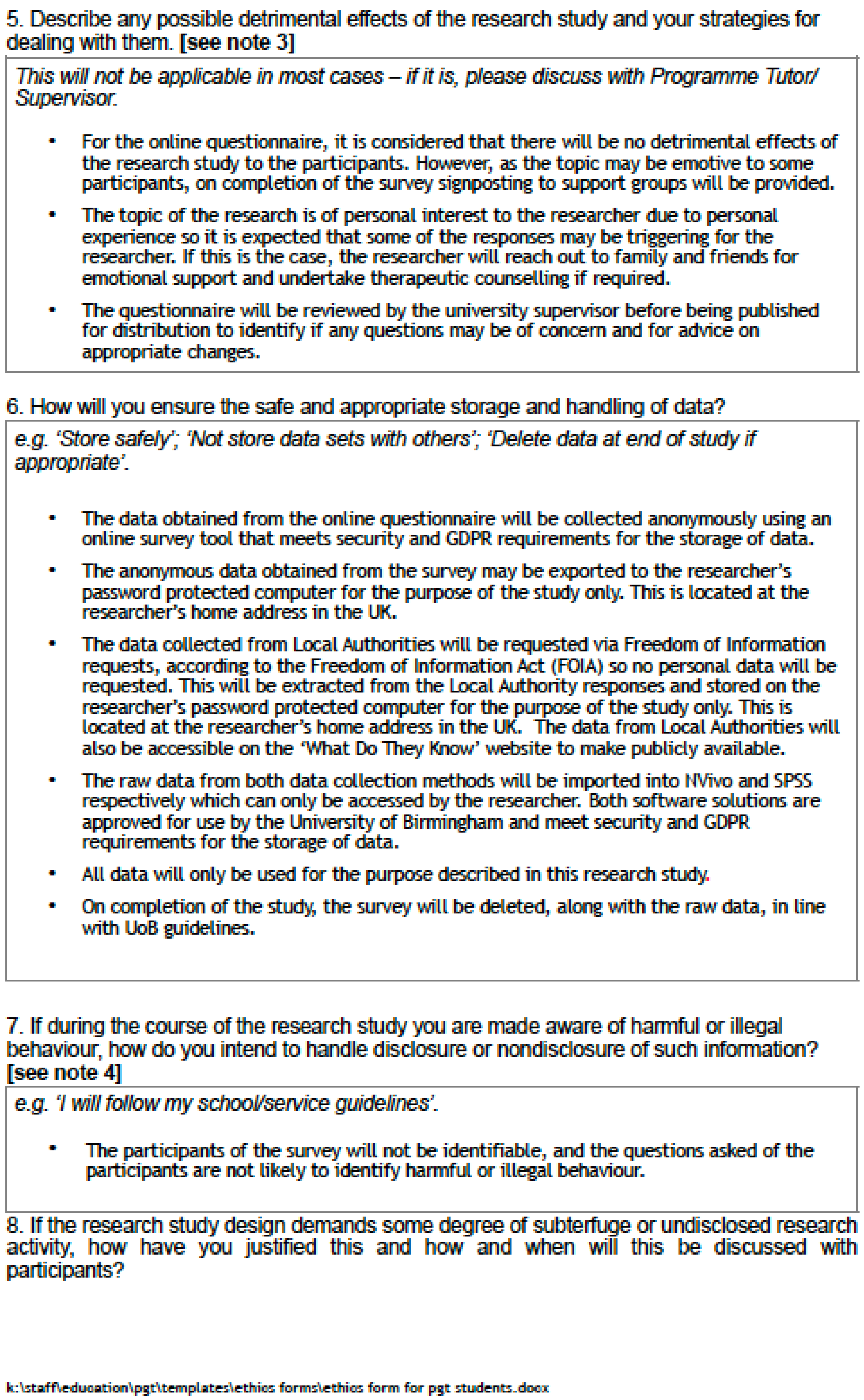
- The summary provided to obtain consent will explain the participants that once the survey is complete, the data is unable to be identified as belonging to them as it will be anonymous. Therefore, there is no right to withdraw the data once submitted as individuals will not be known. This may put off some participants from engaging with the survey and limit responses, however it is felt that anonymity is the priority, so this is an acceptable limitation.

4. Please describe how you will ensure the confidentiality and anonymity of participants. Where this is not guaranteed, please justify your approach. **[see note 2]**

e.g. 'Use pseudonyms in my report'; 'I will not use photographs of children'.

- The data collected via the FOI request will ensure anonymity as no individual can be identifiable - This is assured by the FOIA.
- The data collected during the online survey does not include any personal details, video, or images, therefore anonymity is assured.
- An ID number will be assigned to the stored data.
- The data collected via Local Authorities does not include any personal data, therefore anonymity is assured.

k:\staff\education\pgt\templates\ethics forms\ethics form for pgt students.docx



5. Describe any possible detrimental effects of the research study and your strategies for dealing with them. **[see note 3]**

This will not be applicable in most cases – if it is, please discuss with Programme Tutor/ Supervisor.

- For the online questionnaire, it is considered that there will be no detrimental effects of the research study to the participants. However, as the topic may be emotive to some participants, on completion of the survey signposting to support groups will be provided.
- The topic of the research is of personal interest to the researcher due to personal experience so it is expected that some of the responses may be triggering for the researcher. If this is the case, the researcher will reach out to family and friends for emotional support and undertake therapeutic counselling if required.
- The questionnaire will be reviewed by the university supervisor before being published for distribution to identify if any questions may be of concern and for advice on appropriate changes.

6. How will you ensure the safe and appropriate storage and handling of data?

e.g. 'Store safely'; 'Not store data sets with others'; 'Delete data at end of study if appropriate'.

- The data obtained from the online questionnaire will be collected anonymously using an online survey tool that meets security and GDPR requirements for the storage of data.
- The anonymous data obtained from the survey may be exported to the researcher's password protected computer for the purpose of the study only. This is located at the researcher's home address in the UK.
- The data collected from Local Authorities will be requested via Freedom of Information requests, according to the Freedom of Information Act (FOIA) so no personal data will be requested. This will be extracted from the Local Authority responses and stored on the researcher's password protected computer for the purpose of the study only. This is located at the researcher's home address in the UK. The data from Local Authorities will also be accessible on the 'What Do They Know' website to make publicly available.
- The raw data from both data collection methods will be imported into NVivo and SPSS respectively which can only be accessed by the researcher. Both software solutions are approved for use by the University of Birmingham and meet security and GDPR requirements for the storage of data.
- All data will only be used for the purpose described in this research study.
- On completion of the study, the survey will be deleted, along with the raw data, in line with UoB guidelines.

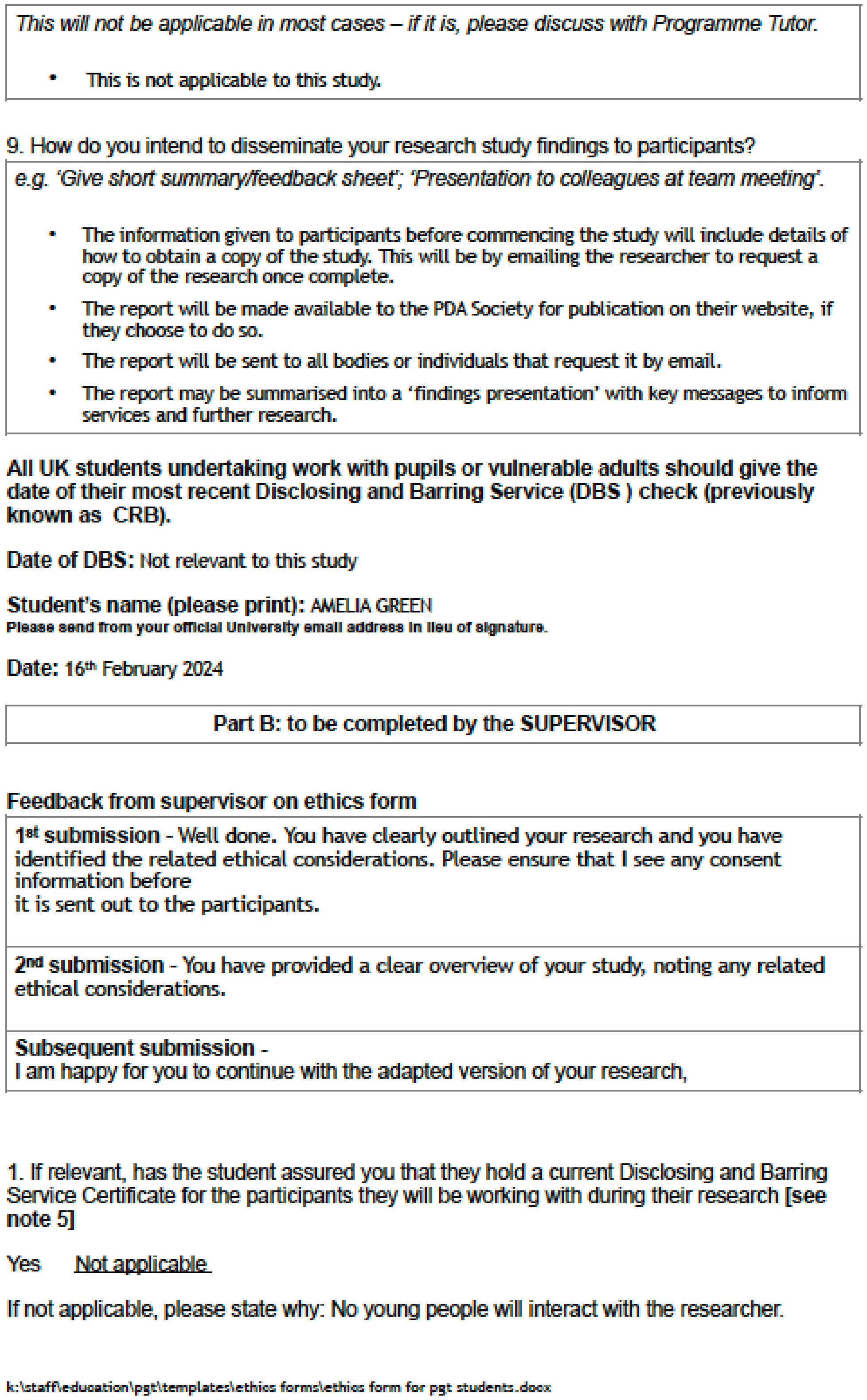
7. If during the course of the research study you are made aware of harmful or illegal behaviour, how do you intend to handle disclosure or nondisclosure of such information? **[see note 4]**

e.g. 'I will follow my school/service guidelines'.

- The participants of the survey will not be identifiable, and the questions asked of the participants are not likely to identify harmful or illegal behaviour.

8. If the research study design demands some degree of subterfuge or undisclosed research activity, how have you justified this and how and when will this be discussed with participants?

k:\staff\education\pgt\templates\ethics forms\ethics form for pgt students.docx



This will not be applicable in most cases – if it is, please discuss with Programme Tutor. - This is not applicable to this study.

9. How do you intend to disseminate your research study findings to participants?

e.g. 'Give short summary/feedback sheet'; 'Presentation to colleagues at team meeting'. - The information given to participants before commencing the study will include details of how to obtain a copy of the study. This will be by emailing the researcher to request a copy of the research once complete. - The report will be made available to the PDA Society for publication on their website, if they choose to do so. - The report will be sent to all bodies or individuals that request it by email. - The report may be summarised into a 'findings presentation' with key messages to inform services and further research.

All UK students undertaking work with pupils or vulnerable adults should give the date of their most recent Disclosing and Barring Service (DBS) check (previously known as CRB).

Date of DBS: Not relevant to this study

Student's name (please print): AMELIA GREEN

Please send from your official University email address in lieu of signature.

Date: 16th February 2024

Part B: to be completed by the SUPERVISOR

Feedback from supervisor on ethics form

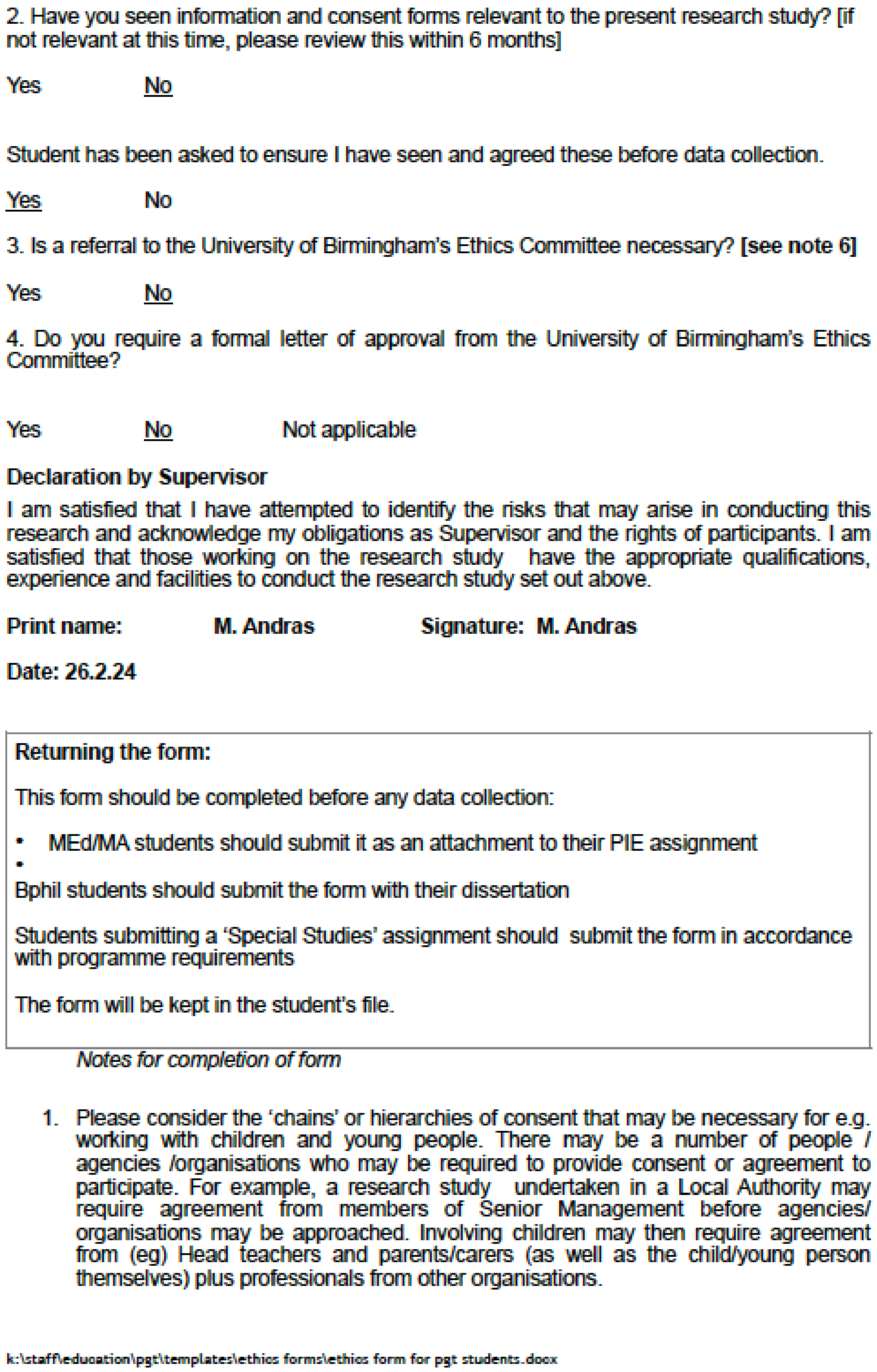
1st submission - Well done. You have clearly outlined your research and you have identified the related ethical considerations. Please ensure that I see any consent information before it is sent out to the participants.
2nd submission - You have provided a clear overview of your study, noting any related ethical considerations.
Subsequent submission - I am happy for you to continue with the adapted version of your research,

1. If relevant, has the student assured you that they hold a current Disclosing and Barring Service Certificate for the participants they will be working with during their research **[see note 5]**

Yes [✓ Not applicable]

If not applicable, please state why: No young people will interact with the researcher.

k:\staff\education\pgt\templates\ethics forms\ethics form for pgt students.docx



2. Have you seen information and consent forms relevant to the present research study? [if not relevant at this time, please review this within 6 months]

Yes [✓ No]

Student has been asked to ensure I have seen and agreed these before data collection.

[✓ Yes] No

3. Is a referral to the University of Birmingham's Ethics Committee necessary? **[see note 6]**

Yes [✓ No]

4. Do you require a formal letter of approval from the University of Birmingham's Ethics Committee?

Yes [✓ No] Not applicable

Declaration by Supervisor

I am satisfied that I have attempted to identify the risks that may arise in conducting this research and acknowledge my obligations as Supervisor and the rights of participants. I am satisfied that those working on the research study have the appropriate qualifications, experience and facilities to conduct the research study set out above.

Print name: **M. Andras** **Signature: M. Andras**

Date: 26.2.24

Returning the form:

This form should be completed before any data collection:

- MEd/MA students should submit it as an attachment to their PIE assignment
-

Bphil students should submit the form with their dissertation

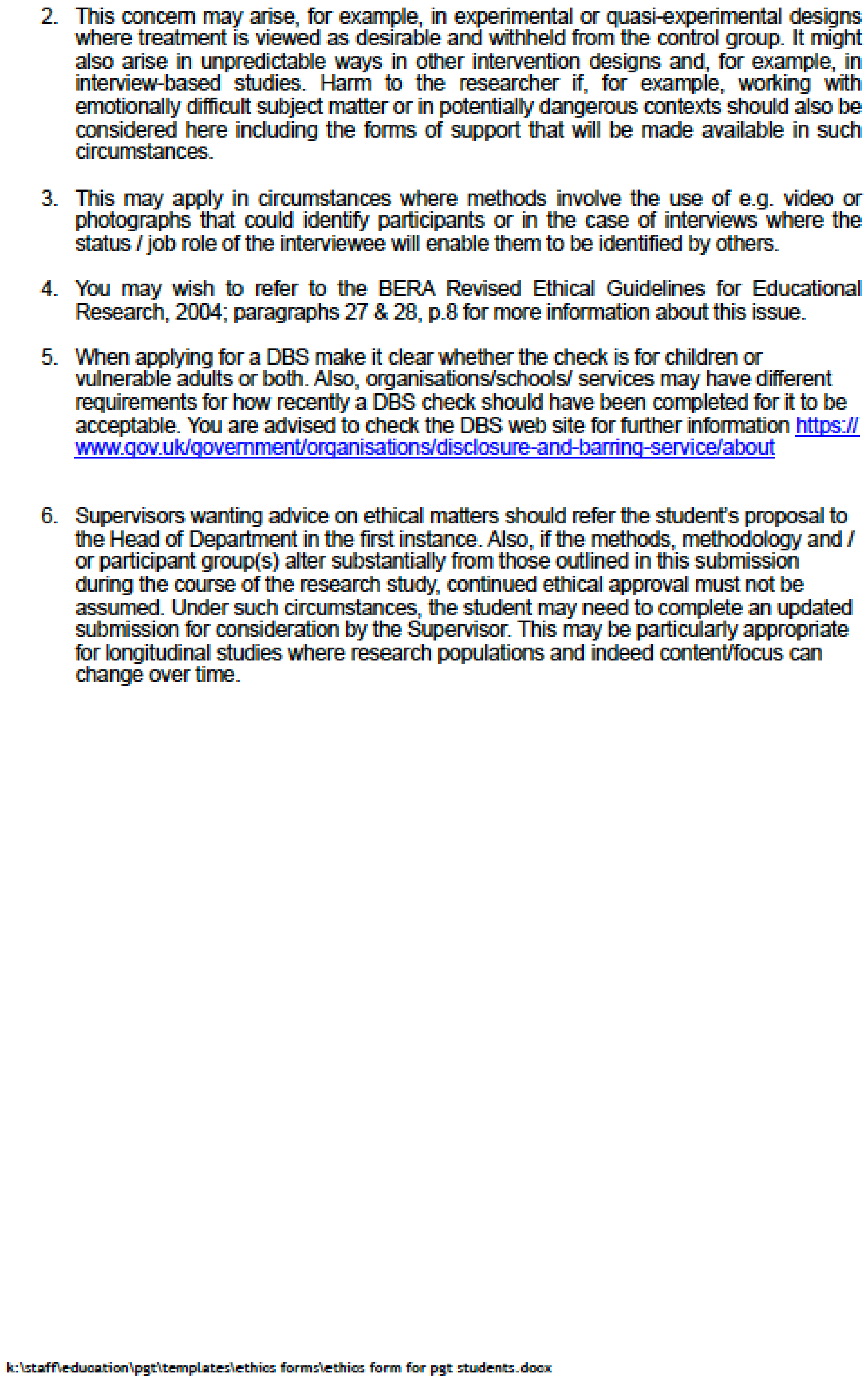
Students submitting a 'Special Studies' assignment should submit the form in accordance with programme requirements

The form will be kept in the student's file.

Notes for completion of form

1. Please consider the 'chains' or hierarchies of consent that may be necessary for e.g. working with children and young people. There may be a number of people / agencies /organisations who may be required to provide consent or agreement to participate. For example, a research study undertaken in a Local Authority may require agreement from members of Senior Management before agencies/ organisations may be approached. Involving children may then require agreement from (eg) Head teachers and parents/carers (as well as the child/young person themselves) plus professionals from other organisations.

k:\staff\education\pgt\templates\ethics forms\ethics form for pgt students.docx



2. This concern may arise, for example, in experimental or quasi-experimental designs where treatment is viewed as desirable and withheld from the control group. It might also arise in unpredictable ways in other intervention designs and, for example, in interview-based studies. Harm to the researcher if, for example, working with emotionally difficult subject matter or in potentially dangerous contexts should also be considered here including the forms of support that will be made available in such circumstances.

3. This may apply in circumstances where methods involve the use of e.g. video or photographs that could identify participants or in the case of interviews where the status / job role of the interviewee will enable them to be identified by others.

4. You may wish to refer to the BERA Revised Ethical Guidelines for Educational Research, 2004; paragraphs 27 & 28, p.8 for more information about this issue.

5. When applying for a DBS make it clear whether the check is for children or vulnerable adults or both. Also, organisations/schools/ services may have different requirements for how recently a DBS check should have been completed for it to be acceptable. You are advised to check the DBS web site for further information https://www.gov.uk/government/organisations/disclosure-and-barring-service/about

6. Supervisors wanting advice on ethical matters should refer the student's proposal to the Head of Department in the first instance. Also, if the methods, methodology and / or participant group(s) alter substantially from those outlined in this submission during the course of the research study, continued ethical approval must not be assumed. Under such circumstances, the student may need to complete an updated submission for consideration by the Supervisor. This may be particularly appropriate for longitudinal studies where research populations and indeed content/focus can change over time.

APPENDIX D: FOI Request made to Local Authorities in England

The Freedom of Information Request sent to Local Authorities in England:

Subject: Autistic children and school placement type

Dear [Local Authority],

Can you please provide me with the data for school aged children in the year 2023 to answer the questions below broken down by ages:

- 5-10 (Primary)
- 11-15/16 years (Secondary)

For questions 4 and 6, please use the below list to categorise the setting type:

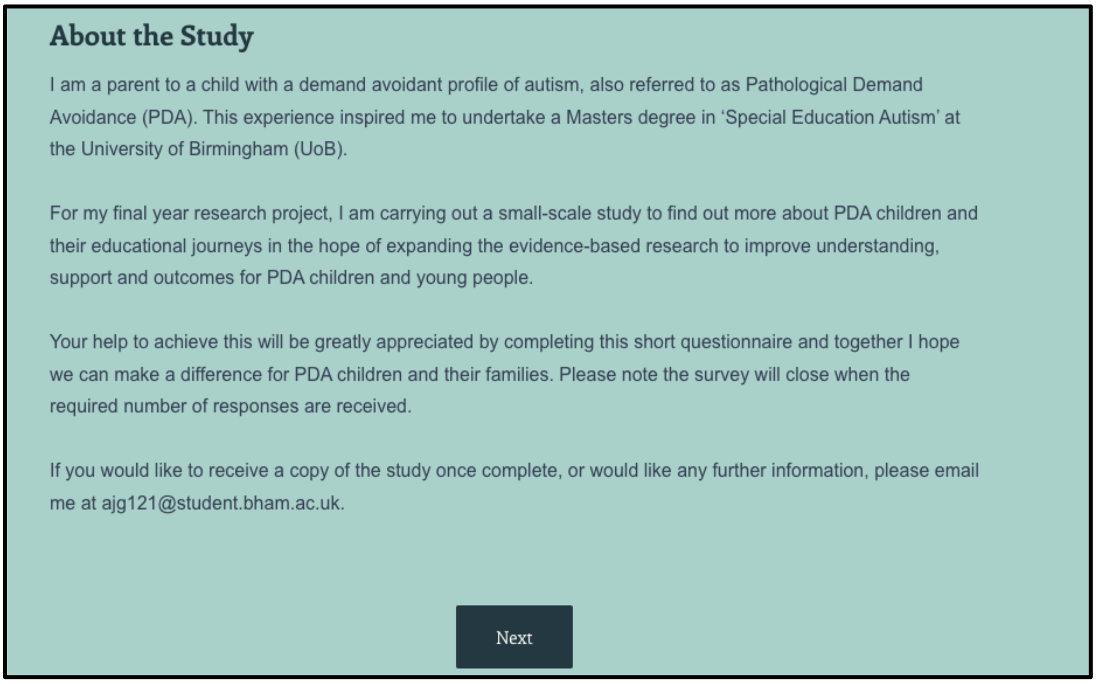
- Mainstream (This can be academy, Free or LA maintained)
- Grammar School
- Private Independent Mainstream (not special)
- Specialist Resource Base/Provision or SEN unit - If so, what is the primary need?
- Special School (Academy, Free, LA maintained)
- Independent Special School (maintained or non-maintained)
- Pupil Referral Unit (PRU)
- Alternative Provision
- Educated Otherwise than At School (EOTAS) - Section I is blank.
- Electively Home Educated (EHE)
- No placement available
- Other
- Don't know.

Please provide the data as detailed above for the following 8 questions:

- How many children have an EHCP?
- How many children identified as autistic do not have an EHCP?
- How many of these EHCPs identify ASD, ASC or Autism as a need or diagnosis?
- For the EHCPs that have Autism (ASD/ASC) identified, what is the type of educational setting they attend (type of school named in Section I).
- For the EHCPs that have Autism (ASD/ASC) identified, how many mention that a child has demand avoidance, identifiable by any of the following terms being used in any section of the EHCP:
- Demand Avoidance
- Pathological Demand Avoidance
- PDA
- Extreme demand avoidance.
- Avoids everyday demands or activities.
-
- For these EHCPs that have demand avoidance mentioned, what is the type of educational setting they attend (type of school named in Section I). Please use the above list to categorise setting type.
- Does your LA use the term 'Pathological Demand Avoidance' or 'PDA' or 'autism with a demand avoidant profile' in EHCPs if provided in a professional report?
- If these terms in question 7 are not used, what is the reason for this?

Yours faithfully,
Amelia Green

APPENDIX E: Screens presented to Participants of the Online Questionnaire



About the Study

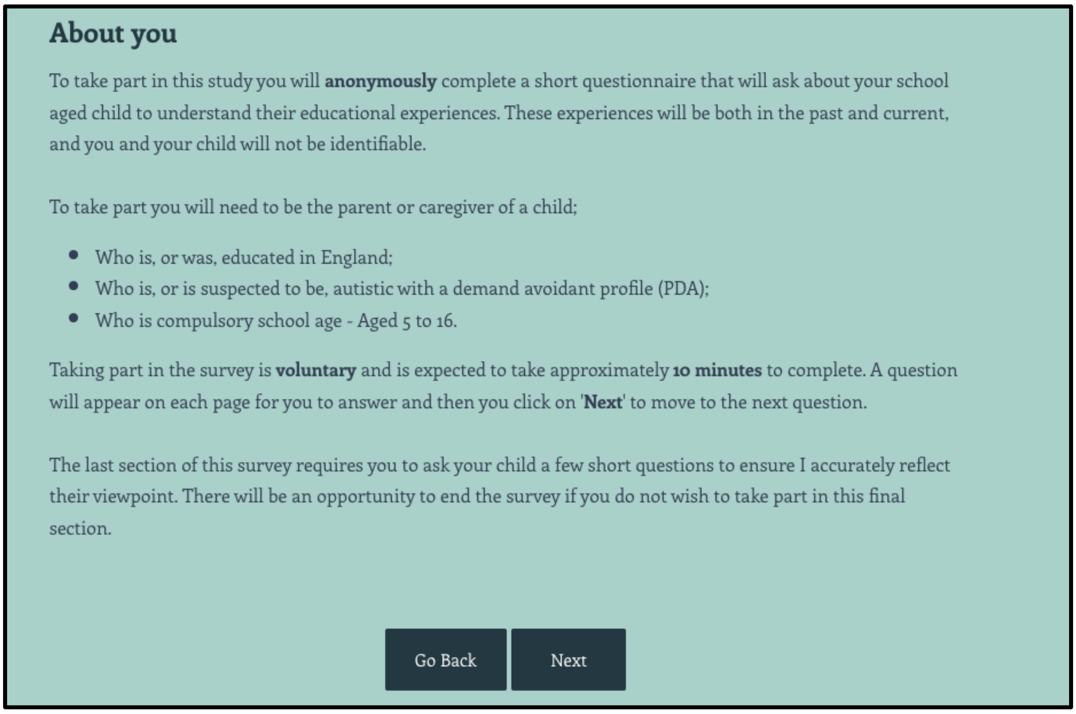
I am a parent to a child with a demand avoidant profile of autism, also referred to as Pathological Demand Avoidance (PDA). This experience inspired me to undertake a Masters degree in ‘Special Education Autism’ at the University of Birmingham (UoB).

For my final year research project, I am carrying out a small-scale study to find out more about PDA children and their educational journeys in the hope of expanding the evidence-based research to improve understanding, support and outcomes for PDA children and young people.

Your help to achieve this will be greatly appreciated by completing this short questionnaire and together I hope we can make a difference for PDA children and their families. Please note the survey will close when the required number of responses are received.

If you would like to receive a copy of the study once complete, or would like any further information, please email me at ajg121@student.bham.ac.uk.

FIGURE AE.1: First screen presented outlining the purpose of the study



About you

To take part in this study you will **anonymously** complete a short questionnaire that will ask about your school aged child to understand their educational experiences. These experiences will be both in the past and current, and you and your child will not be identifiable.

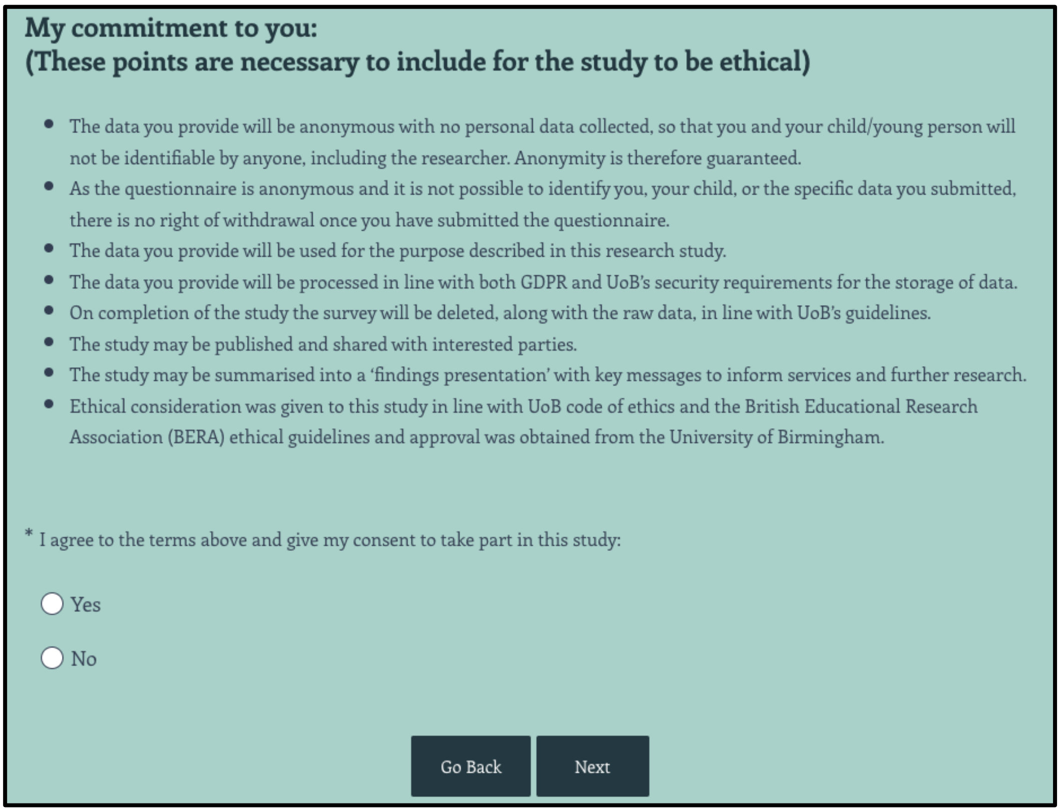
To take part you will need to be the parent or caregiver of a child;

- Who is, or was, educated in England;
- Who is, or is suspected to be, autistic with a demand avoidant profile (PDA);
- Who is compulsory school age - Aged 5 to 16.

Taking part in the survey is **voluntary** and is expected to take approximately **10 minutes** to complete. A question will appear on each page for you to answer and then you click on '**Next**' to move to the next question.

The last section of this survey requires you to ask your child a few short questions to ensure I accurately reflect their viewpoint. There will be an opportunity to end the survey if you do not wish to take part in this final section.

FIGURE AE.2: Second screen presented detailing inclusion criteria



My commitment to you:
(These points are necessary to include for the study to be ethical)

- The data you provide will be anonymous with no personal data collected, so that you and your child/young person will not be identifiable by anyone, including the researcher. Anonymity is therefore guaranteed.
- As the questionnaire is anonymous and it is not possible to identify you, your child, or the specific data you submitted, there is no right of withdrawal once you have submitted the questionnaire.
- The data you provide will be used for the purpose described in this research study.
- The data you provide will be processed in line with both GDPR and UoB's security requirements for the storage of data.
- On completion of the study the survey will be deleted, along with the raw data, in line with UoB's guidelines.
- The study may be published and shared with interested parties.
- The study may be summarised into a 'findings presentation' with key messages to inform services and further research.
- Ethical consideration was given to this study in line with UoB code of ethics and the British Educational Research Association (BERA) ethical guidelines and approval was obtained from the University of Birmingham.

* I agree to the terms above and give my consent to take part in this study:

○ Yes

○ No

FIGURE AE.3: Third screen presented to gain participant consent

APPENDIX F: Questions presented to Parent Participants of the Online Questionnaire

Part 1: Inclusion Criteria

The first set of questions are to ensure you meet the criteria for inclusion in this study so that the research makes a valuable contribution to the educational experiences of PDA children.

Q1. *Are you the parent or caregiver of a child or young person who is educated in England?

○ Yes
○ No

Q2. *Is your child or young person of compulsory school age (5 to 16 years old)?

○ Yes
○ No

Q3. *Does your child or young person have an autism diagnosis?

○ Yes
○ Not yet, but we are in the assessment process
○ I suspect autism, but we are not under assessment
○ No and I don't suspect they are autistic

Q4. *Do you consider that your child or young person has PDA (a demand avoidant profile of autism)?

○ Yes, and has formal diagnosis/identification by a professional
○ Yes, but does not have a formal diagnosis/identification
○ No

If the response to any of the above 4 questions is 'No', the survey will be ended early, and the participant will receive a message explaining that they are not eligible to be included in the study and thanked for their time.

Part 2: Demographics

This next set of questions is to find out a little more about you and your child to compare responses and identify if there is a difference in educational experience.

Q1. *Which geographical area of England do you live in?

If you are unsure of which geographical area you live in, then click on this link to see a map of all Local Authorities and the geographical area you are in:

- ○ North East
- ○ North West
- ○ Yorkshire and the Humber
- ○ East Midlands
- ○ West Midlands
- ○ East of England
- ○ London
- ○ South East
- ○ South West

Q2. *Which school year is your child in?

- ○ Reception
- ○ Year 1
- ○ Year 2
- ○ Year 3
- ○ Year 4
- ○ Year 5
- ○ Year 6
- ○ Year 7
- ○ Year 8
- ○ Year 9
- ○ Year 10
- ○ Year 11
- ○ Year 12

Q3. *What gender does your child identify as?

- ○ Male
- ○ Female
- ○ Non-binary
- ○ Gender fluid
- ○ A gender not listed here.
- ○ Prefer not to say.

Q4. *Does your child have, or do you suspect any of the below?

(Please select all that apply)

- ○ No
- ○ Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder (ADD/ADHD)
- ○ Anxiety (any type)
- ○ Sensory Processing Disorder (SPD)
- ○ Dyslexia, Dyscalculia or Dysgraphia
- ○ Dyspraxia, Developmental Coordination Disorder (DCD), motor skills difficulties
- ○ Sleep Issues
- ○ Gifted & Talented, Twice Exceptional (2E)
- ○ Learning Difficulties
- ○ Deaf and/or Blind
- ○ Other, not listed (free text field)

Part 3: Educational Experiences – Parent Responses

This section of the questionnaire is to understand the educational experiences of your PDA child. All questions should be answered by yourself**.**

Q1. Does your child have an Education Health & Care Plan (EHCP)?

- ○ Yes
- ○ No
- ○ Applied for, Assessment in progress or currently in appeal
- ○ I don't know

If 'no or applied for' or I don't know is answered, participant will be taken directly to Q5.

Q2. Does your child's EHCP specifically use the terms either 'PDA' or 'autism with a demand avoidant profile'?

- ○ Yes
- ○ No

Q3. Do your feel your child's EHCP adequately describes their demand avoidance behaviours as needs?

- ○ Yes
- ○ No

Q4. Has the EHCP made a positive impact on your child's educational experience?

- ○ Yes
- ○ No
- ○ Not sure

Educational Settings (Schools)

Q5. What type of school has your child attended in the order they attended:

This question is important to understand your child's educational journey.

Please provide the types of educational settings your child has attended, **in the order in which they were attended**. Please then select the **reason for leaving** each setting as this will help to understand your child's educational journey.

The options include Elective Home Education (EHE) and Educated Otherwise Than At School (EOTAS).

- ○ 1st School Type – dropdown selection
- ○ Reason for leaving – dropdown selection

- ○ 2nd School Type – dropdown selection
- ○ Reason for leaving – dropdown selection

- 3rd School Type – dropdown selection
- Reason for leaving – dropdown selection

- 4th School Type -— dropdown selection
- Reason for leaving – dropdown selection

- 5th School Type -— dropdown selection
- Reason for leaving – dropdown selection

- 6th School Type -— dropdown selection
- Reason for leaving – dropdown selection

- 7th School Type -— dropdown selection
- Reason for leaving – dropdown selection

- 8th School Type -— dropdown selection
- Reason for leaving – dropdown selection

- Free text box to enter if more than 8 educational settings

Educational setting drop down options:

- Mainstream - (This can be academy, Free or LA maintained)
- Grammar School
- Private Independent Mainstream (NOT special)
- Specialist Resource Base/Provision or SEN unit
- Special School (Academy, Free or LA maintained)
- Independent Special School (maintained or non-maintained)
- Pupil Referral Unit (PRU)
- Alternative Provision (while on role at a school)
- Educated Otherwise than At School (EOTAS) - Section I is blank or states EOTAS
- Electively Home Educated (EHE)
- No placement available
- Other

Reason for move drop down options

- Normal transition age
- Excluded
- Managed move
- Moved house
- Attendance difficulties
- School not meeting child's needs
- Other
- Remained in this setting
- Free text box provided to expand on 'other'

Q6. Has your child had any fixed term exclusions from school (exclusions that are formally recorded)?

- Yes
- No

If yes, how many?

○ Free text field *(restricted to a number)*

Q7. Has your child had any informal exclusions from school (such as being asked to collect your child from school for reasons other than illness)?

○ Yes
○ No

If yes, how many?

○ Free text field *(restricted to a number)*

Q8. Does, or has, your child struggled with school attendance?

○ Yes
○ No
If 'no' answered, the participant will be taken directly to Q12.

Q9. In which setting types did (or does) your child struggle with attendance?

Please select all that apply.

○ Mainstream
○ Grammar School
○ Private Independent Mainstream (NOT special)
○ Specialist Resource Base/Provision or SEN unit
○ Special School
○ Independent Special School
○ Pupil Referral Unit (PRU)
○ Alternative Provision
○ Educated Otherwise than At School (EOTAS) - Section I is blank or states EOTAS
○ Electively Home Educated (EHE)

Q10. In which school year did your child first struggle with attendance?

○ Reception
○ Year 1
○ Year 2
○ Year 3
○ Year 4
○ Year 5
○ Year 6
○ Year 7
○ Year 8
○ Year 9
○ Year 10
○ Year 11
○ Year 12

Q11. How long has your child struggled with attendance?

(please answer in terms of years and months)

- ○ Free text field

Q12. What, if anything, do you believe are the barriers to your child attending school?

(please select all that apply)

- ○ My child has no barriers to attending school
- ○ Unmet SEND needs
- ○ Anxiety
- ○ Demand Avoidance
- ○ Bulling (by adult or child)
- ○ EHCP not being followed
- ○ Sensory struggles
- ○ Friendship issues
- ○ Academic pressure
- ○ Not feeling safe in school
- ○ Home related worries
- ○ Other, please specify (free text field)

Q13. Has your child had any periods of time with no educational provision?

- ○ Yes
- ○ No (survey to go directly to question 11

Q14. How many months has your child had with no educational provision?

(If this is multiple times, please state the total amount of time in month)

- ○ Free text field

Q15. Which of the below would you describe your child's educational experience as:

- ○ Very positive
- ○ Positive
- ○ Neutral
- ○ Negative
- ○ Very Negative

The next four questions are to find out a little more in your own words about your child's educational experiences. You can choose to add a single word, multiple sentences or skip the question using the 'next' button.

Q16. Please tell me about positive experiences your child has had with education.

- ○ Free text field

Q17. Please tell me about any negative experiences your child has had with education.

- Free text field

Q18. What type of educational setting do you think is most suitable for your PDA child?

- Free text field

Q19. Please use this space to say anything you believe schools and Local Authorities need to know to improve the educational experiences of PDA children.

- Free text field

APPENDIX G: Questions presented to CYP Participants of the Online Questionnaire

Part 4: Educational Experiences – Child View

This section is optional, but it is very important for my research to capture your child's views of their educational experiences, so this section has been devised by my 2 child research helpers.

Please could you ask your child the questions in this section and provide their responses verbatim (using the words, sentences that your child said).

Can you please also tell your child what this survey is about and ensure they are happy for their answers to be used in this study.

If your child is not happy to take part, then that is also fine, and your responses have been incredibly valuable. Below you have the option to continue or to end the survey without completing the child view section.

*Please confirm you are happy to continue, and your child has agreed to provide you with their view for this survey:

- ○ Yes, I will continue
- ○ No, I would like to end the survey now and not provide my child's views

Selecting 'No' will take the participant to the end of the survey with a thank you for taking part.

Q1. What is good about school?

- ○ Free text field

Q2. What is bad about school?

- ○ Free text field

Q3. What 3 words would you use to describe how school makes you feel?

- ○ Free text field
- ○ Free text field
- ○ Free text field

Q4. What would make school better?

- ○ Free text field

Q5. What would be the perfect school?

- ○ Free text field

Q6. If you don’t go to school anymore, please tell me what you do now and what is good and bad about it?

- ○ Free text field

Q7. What would you like schools to know that would make school better for you?

- ○ Free text field

APPENDIX H: Codebook exported from NVivo representing the Educational Experiences of CYP

THEMES AND CODES	NUMBER OF TIMES REFERENCED
Theme - DISEMPOWERED	**369**
Autonomy & Choice	125
Loss of Autonomy	128
Pressure & Demands	39
Rules & Punishment	77
Theme - DISENGAGED	**740**
Bored	36
Disengaged	159
Everything is Bad	140
Nothing is Good	193
Gaining Engagement	212
Theme - ENVIRONMENTAL STRUGGLES	**629**
Physical restrictions	25
Scared & Unsafe	93
Sensory Struggles	324
Uniform Struggles	41
Work Difficulties	99
Animals to Support	47
Theme - EXCLUDED	**233**
Excluded & Isolated	127
Lack of Support	65
Underestimated	24
Gaining Support	17
Theme – POOR RELATIONSHIPS	**701**
Bullying	37
Friendships	183
Misunderstood	277
Poor Relationships	204
Theme – POOR MENTAL HEALTH	**140**
Exhausted	76
Failing	29
Stress & Worries	35

APPENDIX I: Words used by CYP when asked ‘what 3 words would you use to describe how school makes you feel?’

Word	Count	Weighted	Word	Count	Weighted
sad	91	9.63%	**headache**	3	0.32%
angry	85	8.99%	**terrible**	3	0.32%
scared	75	7.94%	**exhausted**	3	0.32%
anxious	73	7.72%	**pressured**	3	0.32%
bored	66	6.98%	**controlled**	3	0.32%
stressed	42	4.44%	**disappointed**	3	0.32%
tired	34	3.60%	**misunderstood**	3	0.32%
worried	32	3.39%	**poo**	2	0.21%
happy	27	2.86%	**busy**	2	0.21%
annoyed	19	2.01%	**calm**	2	0.21%
sick	15	1.59%	**crap**	2	0.21%
lonely	15	1.59%	**fear**	2	0.21%
stupid	15	1.59%	**alone**	2	0.21%
unsafe	15	1.59%	**hungry**	2	0.21%
overwhelmed	14	1.48%	**mental**	2	0.21%
frustrated	13	1.48%	**crowded**	2	0.21%
bad	11	1.16%	**failure**	2	0.21%
nervous	11	1.16%	**naughty**	2	0.21%
suicidal	11	1.16%	**agitated**	2	0.21%
shit	9	0.95%	**different**	2	0.21%
hate	8	0.85%	**irritated**	2	0.21%
trapped	8	0.85%	**supported**	2	0.21%
useless	8	0.85%	**terrified**	2	0.21%
depressed	8	0.85%	**worthless**	2	0.21%
ill	7	0.74%	**interested**	2	0.21%
upset	7	0.74%	**meh**	1	0.21%
drained	7	0.74%	**dead**	1	0.11%
unhappy	7	0.74%	**fine**	1	0.11%
isolated	7	0.74%	**hell**	1	0.11%
weird	6	0.63%	**help**	1	0.11%
frightened	6	0.63%	**hurt**	1	0.11%
mad	5	0.53%	**love**	1	0.11%
panic	5	0.53%	**mean**	1	0.11%
rubbish	5	0.53%	**nope**	1	0.11%
uncomfortable	5	0.53%	**okay**	1	0.11%
good	4	0.42%	**pain**	1	0.11%
safe	4	0.42%	**poop**	1	0.11%
cross	4	0.42%	**stop**	1	0.11%
confused	4	0.42%	**awful**	1	0.11%
fun	3	0.32%	**fizzy**	1	0.11%
ahhh	3	0.32%	**aggressive**	1	0.11%
hard	3	0.32%	**imprisoned**	1	0.11%
loud	3	0.32%	**idiot**	1	0.11%

excited	3	0.32%	**liked**	1	0.11%
Word	**Count**	**Weighted**	**Word**	**Count**	**Weighted**
maxed	1	0.11%	**hopeless**	1	0.11%
noisy	1	0.11%	**horrible**	1	0.11%
quiet	1	0.11%	**included**	1	0.11%
smart	1	0.11%	**shutdown**	1	0.11%
stuck	1	0.11%	**sociable**	1	0.11%
bossed	1	0.11%	**uuurgghh**	1	0.11%
grumpy	1	0.11%	**authority**	1	0.11%
pissed	1	0.11%	**desperate**	1	0.11%
prison	1	0.11%	**disappear**	1	0.11%
social	1	0.11%	**dishonest**	1	0.11%
tricky	1	0.11%	**enjoyment**	1	0.11%
valued	1	0.11%	**excellent**	1	0.11%
wiggly	1	0.11%	**pointless**	1	0.11%
bullied	1	0.11%	**reassured**	1	0.11%
damaged	1	0.11%	**patronised**	1	0.11%
envious	1	0.11%	**propaganda**	1	0.11%
forlorn	1	0.11%	**rebellious**	1	0.11%
helpful	1	0.11%	**understood**	1	0.11%
ignored	1	0.11%	**unhygienic**	1	0.11%
jittery	1	0.11%	**dehumanised**	1	0.11%
pleased	1	0.11%	**frustrating**	1	0.11%
shivery	1	0.11%	**intimidated**	1	0.11%
talking	1	0.11%	**unimportant**	1	0.11%
tearful	1	0.11%	**dysregulated**	1	0.11%
unheard	1	0.11%	**fainthearted**	1	0.11%
accepted	1	0.11%	**hyperaroused**	1	0.11%
artistic	1	0.11%	**claustrophobic**	1	0.11%
careless	1	0.11%	**overstimulated**	1	0.11%
creative	1	0.11%	**funny**	1	0.11%
enslaved	1	0.11%	**heard**	1	0.11%
helpless	1	0.11%			