"I had no control over myself or my education": mainstream school refusal from the

perspectives of young people on the autism spectrum.

by

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Abstract

Young people on the autism spectrum are more likely to experience school refusal than their neurotypical peers. However, research is dominated by the neurotypical experience and where autism is directly addressed, it is done so from the perspective of parents or professionals. By hearing from young people on the autism spectrum about *their* school refusal, it is hoped that this study is an early step in redressing the imbalance seen so far. This qualitative study, built on a social constructivist and communitarian paradigm, which views participants as experts, utilised online conferencing software to record parent-child conversations about their school refusal experiences. Participants were four young people on the autism spectrum between the ages of 10-18, who have experienced school refusal in a mainstream setting in one Local Authority in the South of England. The heterogeneous nature of school refusal is widely accepted; however, the School Environment, Peer Relationships and Teacher Relationships have emerged as dominant themes for participants when explored through the lens of school based factors, which this thesis focussed upon. Conclusions show that the influencing factors for school refusal identified by students on the autism spectrum include student-teacher relationships, being both listened to and heard by staff and peers, the values of the school system and ultimately the overwhelming culmination of factors at play. Framed through personal anecdotes, emotional responses and mental health reactions (such as anxiety and depression), participants demonstrated the very personal nature of school refusal. Recommendations include further research with an emphasis on student voice and participation, teacher training which contains examples of effective and positive working relationships with students on the autism spectrum, the early identification of risk factors, and a call for changes to academic outcomes as the single measure of schools.

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Contents Page

Chapter 3 - Methodology

Chapter 4 – Participant Narratives

Chapter 5 – Discussion

Chapter 6 - Conclusion

List of Appendices

List of Tables

List of Figures

Chapter 1

Introduction

This chapter sets out the underlying context within which this research thesis sits. It addresses the prevalence rates of both autism and of school refusal, explores the importance of student voice in research and the education system, outlines my positionality within the research study and finally, identifies the contribution this thesis makes to the field of educational research for children on the autism spectrum.

1.1 Prevalence Rates of Autism and School Refusal

The current education system in England is one which advocates a philosophy of inclusion (United Nations, 1989; United Nations Educational, Scientific and Cultural Organisation (UNESCO), 1994; Great Britain, 2010; Great Britain, 2014). This philosophy has seen an increase in the prevalence of children and young people on the autism spectrum attending mainstream education (McConkey, 2020). The Special Educational Needs (SEN) register indicates that the prevalence rate of autism for all school age children in one Local Authority (LA) in the South of England is between 1% and 1.5% (Abraham and Gerrard, 2017).

Young people on the autism spectrum in mainstream education face barriers on a daily basis (Goodall, 2020; Morewood, Humphrey and Symes, 2011). They are supported through best practice guidance available for schools (Autism Education Trust (AET), 2021a), the wide array of online resources and books, and more recently Initial Teacher Training (ITT) courses emphasising autism training (Sackville-Jones, 2019). Despite this, data indicates that the

prevalence rate, and the change over time of that prevalence rate in absence among students on the autism spectrum in England, is higher than is seen among the general student population (Appendix 1). Furthermore, and of more relevance to this thesis, the prevalence rate, and the change over time of that prevalence rate, in absence among students on the autism spectrum in one LA in the South of England is higher than the national average (Appendix 2). Understanding possible causes of higher prevalence in absence rates is crucial to ensure that students on the autism spectrum are provided with an equal opportunity to develop and are not put at an unfair disadvantage comparatively to their peers (Department for Education (DfE) and Department of Health (DoH), 2015).

1.2 The Importance of Student Voice

The inclusive approach to education mandated by the Children's and Families Act (2014) stipulates that the "wishes, feelings and participation" of children be considered in decisions affecting their education (DfE and DoH, 2015, p. 19). Unfortunately, it is evident that when young people on the autism spectrum are included in research about their education, issues of being mis-understood are commonly highlighted (Goodall, 2020). It is also evident within literature regarding school refusal, that the voices of young people on the autism spectrum are significantly under-represented (Munkhaugen, 2019a; Totsika et al., 2020), resulting in a gap in our knowledge about how these young people view their school experiences, and what may have caused their school refusal. Understanding this to be the case, it was important to me for participant voice to be a key feature of the title of this thesis. As will be explored through Chapters 5 and 6, control is important to participants within this study. It therefore felt appropriate to include a quote from "James" (a pseudonym) as the first words

encountered by the reader of this study. The context of James' quote relates specifically to his dislike of the anger he began to display at school, however the lack of control he felt was clearly linked to not being listened to or heard by his school and his having no influence over the decisions affecting his education – something other participants expressed too.

1.3 My Position in Relation to this Research

The topic of school refusal is one which I am unfortunately familiar with in both a personal (through close family) and professional capacity and this will certainly affect my positionality throughout the study. Working as a Learning Support Assistant in a mainstream secondary school directly supporting young people on the autism spectrum who had experienced school refusal, I have seen first-hand how these experiences damage not only educational outcomes, but also social and emotional development too. Similarly, in my current role supporting young people on the autism spectrum with their life and social skills, I meet individuals who have complex and challenging relationships with the education system and are negatively affected as a result.

Furthermore, my experiences have shown me that much of the impact of school refusal can be seen to fall on wider family, e.g., emotional turmoil of having a young person in distress; missed workdays as a result of extra meetings with school; home based meetings with educational welfare officers; and increased medical appointments. It is therefore important that within my research parents/carers are afforded the position of participant too. Parent/Carers' understanding of the experience their child has lived through, and how to navigate the subject of school refusal with their child, is crucial in enabling young people to feel comfortable discussing what is likely to be a sensitive topic.

1.4 The Contribution of this Thesis

The key questions that address the research gap identified through the literature review (Chapter 2) and which this thesis attempts to answer are:

1. What school-based factors do young people on the autism spectrum relate to their school refusal?

2. How do young people on the autism spectrum frame these school-based factors?

This thesis contributes to existing literature on the absence from school of young people on the autism spectrum by focusing specifically on the topic of school refusal. Whilst the heterogeneity of school refusal is acknowledged and addressed, it is the school-based factors affecting school refusal which specifically form the focus of this thesis, as these represent the best chance of change toward preventing school-refusal (Wood et al., 2012). Furthermore, by taking an interpretive social constructivist stance toward the methodology, this thesis directly engages with children and young people to hear their perspectives, experiences, and stories. This approach has been taken due to the obvious gaps in existing literature, and because of my belief that only by listening and hearing young people can we hope to truly support them appropriately. In developing a methodology for this thesis, I have had to overcome several ethico-epistemological problems that led me to a unique approach involving a three-stage process (Figure 1). This consisted of a parent survey (stage one), a parent-child conversation (stage two) and a young person questionnaire (stage three). Each of these stages contributed to my understanding of separate participating families and their unique school refusal experience. However, it was the on-line recorded parent-child conversation (stage two) which formed most of the data collected. Once transcribed verbatim, parent-child conversations were analysed for multimodal data, combined with data from the stage three questionnaire

and then thematically analysed to reveal key findings. These findings and the subsequent critical discussion were used to draw out substantial conclusions and produce key recommendations to engage with.
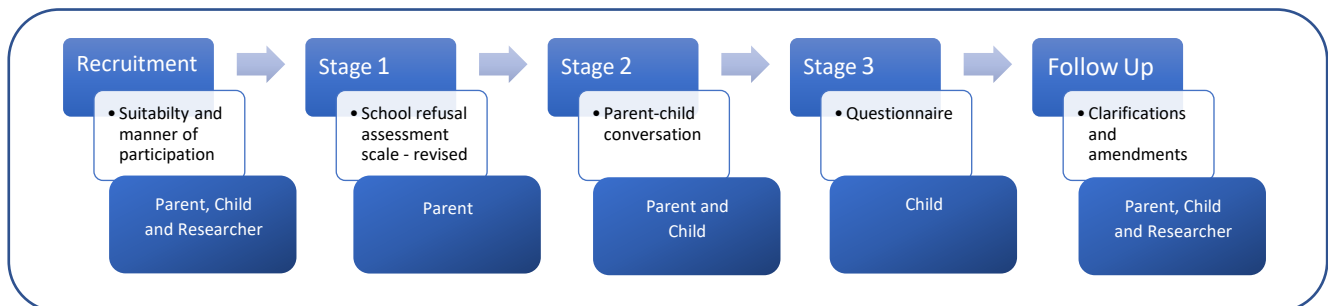
Figure 1 – A Visual Representation of the Data Collection Process.

1.5 Chapter Summary

The rationale and justification of research explained above is the first step in understanding the school-based factors affecting the school refusal of young people on the autism spectrum. The following chapter descriptions provide the next steps in this process by providing an overview of how I will answer the research questions identified above.

In chapter two, I analyse academic and educational literature associated with autism, inclusion, school refusal and best practice guidance.

In chapter three, I set out the rationale behind the qualitative interpretative approach I have taken, in addition to justifying the choices made in a developing a unique three-stage research design, including a parent-child conversation. I also outline the process of thematic data analysis I have undertaken.

In chapters four and five, I present participants narratives and critically discuss the findings of the research data.

Finally, in chapter six, I identify conclusions from the research process and participants data, answer the research questions set out above and provide recommendations for future educational practice and research.

Chapter 2

Literature Review

2.1 Introduction

Having established the context for this research thesis, the following literature review presents and critiques the current understanding of school refusal among students on the autism spectrum in mainstream education. By exploring the definitions of autism and school refusal, and how students with autism are included in mainstream schools, this review establishes the mainstream educational environment encountered by students who go on to school refuse. This chapter analyses the risk factors recognised as impacting a student's school refusal, acknowledging the heterogenous nature of school refusal, addressing both individual/within-child factors as well as familial factors at play, whilst maintaining a focus on the school-based factors through utilisation of the AET Good Practice Guidance as a framework (AET, 2021a). The final section reviews the specific but limited research carried out into school refusal and students on the autism spectrum, laying the conceptual and theoretical framework for the methodology and research design of this thesis. I first outline the method of literature collection and then move on to identify the key terms used in this study.

2.2 Approach to Systematic Review of Literature

To conduct a review of literature which was thorough, current and relevant to the field of study, I used databases including the British Education Index, Education Resources

Information Center, Canterbury Christ Church University Library Search, Google Scholar, ProQuest, JStor in addition to general internet searches. When using these databases, I included a variety of key terms (Table 1) in a mix and match style as can be seen in Table 2. Once key and prominent literature was found, I used their bibliographies to deepen and strengthen my research further.

Autism	Student (s)	School Refusal	School
Asperger	Children	Absence	Mainstream
Autistic Spectrum Disorder (ASD)	Young People	Attendance	Primary School
Autistic Spectrum Condition (ASC)	Adolescents	School Refusal Behaviour	Secondary School
		Inclusion	

Table 1: Key Terms Used in Literature Review Search

1	"Autism" + "Children" + "School Refusal" + "Mainstream"
2	"Asperger" + "Children" + "School Refusal" + "Mainstream"
3	"ASC" or "ASD" + "Children" + "School Refusal" + "Mainstream"
4	"Autism" + "Children" + "School Refusal"
5	"Autism" + "Children" + "School Refusal Behaviour" + "Mainstream"
6	"Autism" + "School Refusal" or "School Refusal Behaviour"
7	"Autism" + "Children" or "Young People" + "School Refusal"
8	"School Refusal" + "Inclusion"
9	"Autism" + "Primary School" or "Secondary School"
10	"Autism" + "Attendance" + "Mainstream"
11	"Asperger" + Attendance" + "Mainstream"
12	"Autism" + "School" + "Absence"
13	"ASC" or "ASD" + "School" + "Absence" or "Attendance"
14	"Asperger" + "School" + "Absence" or "Attendance"
15	"Autism" + "Adolescents" + "School Refusal"
16	"Autism" or "ASC" or "ASD" + "Young People" + "School Refusal"

Table 2: Literature Review Database Search Strings

2.3 Defining Autism

The 20th and 21st centuries have seen a shift in the diagnostic criteria for autism (Volkmar and McPartland, 2014), moving from schizophrenia specifically to individuals who demonstrate difficulties with "social interaction, communication, and restricted, stereotyped, repetitive behaviour" (World Health Organisation, 2016) and hyper/hypo reactivity to sensory inputs (Centres for Disease Control, 2020). This diagnostic definition is echoed by the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), with the addition of a third social difficulty, namely "developing, maintaining and understanding relationships" (Centres for Disease Control, 2020).

The alteration in clinical perspectives over the years, has overseen different terminologies used in reference to those on the autism spectrum (Volkmar and McPartland, 2014). Importantly Kenny et al., (2015) asserts that the language used to refer to members of the autism community matters – however there is no unifying term accepted by the United Kingdom's autism community. Many autistic adults and their family members felt that autism could not be separated from the person (advocating an identify first perspective – *autistic person*); that autism is a different way of viewing the world not a disorder or condition - it is society that disables (leaning towards a social model of disability); and that the notion of an autism *spectrum*, where the entire population sits somewhere upon it, risks trivialising the experiences of those with a diagnosis (Kenney et al., 2015). Conversely, and perhaps due to the disability rights movement advocating person-first language, professionals identified the use of "person with autism" as the most appropriate term (Kenney et al, 2015, p. 450). However, as one autistic participant highlighted this perspective reinforces opinions that

autism is "a thing that can be removed, something that may be unpleasant and unwanted" (Kenney et al., 2015, p. 448).

When presented with the stimulus phrase "student with Asperger diagnosis", teachers' spontaneous five-word responses overwhelmingly focused on student deficit and need, rather than strengths and abilities (Linton et al., 2013, p.398), suggesting that the "unpleasant and unwanted" argument is not without foundation (Kenney et al., 2015, p. 448). While many teachers are supportive of an inclusive environment for students on the autism spectrum, there are unfortunately still those whose sentiments are not "conducive to supporting difference" (Goodall, 2020, p. 46). This can be seen in comments from student teachers who state that "…I'm not comfortable (with children with autism) …I'm a little bit scared to approach them" and "I don't know about different needs…it's terrifying" (Ravet, 2018, p. 723). The correlation between teacher's knowledge, understanding, motivation and self-efficacy in teaching students on the autism spectrum, and the outcomes of these students, was made clear by Busby et al., (2012). Furthermore, research by Lindblom et al., (2019, p. 7) found that "greater quality of contact" was a predictor of more positive attitudes towards students on the autism spectrum. However, even among those teachers who demonstrate a positive attitude, the barriers to support can often be overlooked due to the invisibility of autism (Ravet, 2018. P. 715). This is concerning when we consider that students on the autism spectrum perceive the supportive attitude of teachers as more important than the training they have received (Goodall, 2020, p. 46).

It is understandable that a coalescing term has not been agreed upon as autism is "richly heterogeneous" in nature (Happe, Ronald and Plumin, (2006, p. 1218). Indeed, Anglim, Prendeville and Kinsella, (2018, p. 74) point to this heterogeneity as a reason to question the

"validity of ASD interventions in school settings". This can be seen through the lens of what Preece and Howley (2018, p. 470) refer to as "inappropriate provision unsuited to children's needs", identifying that an individualised approach is considered best practice when supporting young people on the autism spectrum to reintegrate into an inclusive education system after a period of absence.

2.4 Inclusion

Inclusive education demands that we adapt the educational environment in response to the diversity of all students (Pellicano, Bolte and Stahmer, 2018). Inclusion is the fundamental right of all students to receive an education in an environment that respects their individuality and responds to their personal requirements and preferences (United Nations, 2016). Salend (2011 cited in Hornby, 2015) posits four key principles of inclusion, which align with the four principles of good autism practice suggested by the AET (AET, 2021a) (See 2.6.3). The principles of inclusion are:

> '…firstly, providing all learners with challenging, engaging and flexible general education curricula; secondly, embracing diversity and responsiveness to individual strengths and challenges; thirdly, using reflective practices and differentiated instruction; and fourthly, establishing a community based on collaboration' (Salend, 2011, cited in Hornby 2015, p.235)

These principles were built upon an international framework of policy promoting inclusive practice across the globe (United Nations, 1989; United Nations, 2006a; UNESCO, 1994). Their influence on legislation in England can be seen most recently through the Equality Act (2010)

and the Children's and Families Act (Great Britain, 2014), both of which underpin educational inclusion in mainstream schools. Unfortunately, it appears that the original child-centred pedagogical vision of the Salamanca Statement (UNESCO, 1994), was not fully built into legislation in English educational provision until the Children's and Families Act (2014), which placed an emphasis on the "wishes, feelings and participation" of children and young people – a 20-year delay in implementation.

2.4.1 A Golden Ticket to Inclusion

For young people on the autism spectrum and their families, a diagnosis and/or an Education Health and Care plan (EHC plan) can be seen as a "golden ticket to better outcomes" (Care Quality Commission and Ofsted, 2017, p. 13), where their wishes and feelings will truly be taken into account. The EHC plan was established through the Children and Families Act (2014), replacing the existing Statement of Special Educational Needs and places a legal duty on schools to ensure appropriate support is provided for students. Weintraub (2011, p. 24) suggests that the increase in prevalence rates of autism, discussed in Chapter 1, can be explained by; diagnostic accretion (25%), greater awareness (15%), parental age (10%) and spatial clustering (4%), however the causes for the remaining 46% are unclear. Hollenweger (2014, cited in Goodall, 2020) provides some explanation by pointing to the importance of a diagnosis, and arguably gaining an EHC plan, in unlocking appropriate support and services.

However, the process of obtaining a diagnosis of autism and an ECH plan "focus[s'] heavily on a child's deficits", sitting squarely within the medical model of disability (Goodall, 2020 p. 21). Oliver and Barnes (2010) argue that the medical model sees disability as caused by an impairment within the individual, while the social model of disability breaks this link and shifts

the emphasis onto restrictions imposed on the individual by environmental and social barriers. The argument can be made that relying on the medical model (and the associated labels) to provide adequate support to students on the autism spectrum, will perpetuate teachers misunderstanding of the individual, leading to stereotyped interventions which may be unsuited to the student's needs (MacMaster, Donavan and MacIntyre, 2002). Additionally, the EHC plan is connected to the issue of economics, resulting in a legally enforceable financial burden on LA's, causing LA's to implement a number of complex and burdensome obstacles for families to overcome in their pursuit of appropriate support (Brown, 2018). Ultimately, there is a risk that the current system promotes a tokenistic type of inclusion (Merrick, 2020) which dilutes student and parent voice and limits educator's capacity to fully understand what is in the best interest of the child (Goodall, 2020).

2.4.2 Inclusion in one Local Authority in the South of England

The LA within which participants of this thesis live, regularly engages in strategic planning to support children and young people with SEND. The latest iteration of this strategy has been developed, in part, as a reaction to an inspection which found weaknesses in their response to the Children and Families Act (2014) and where it was noted that there was a lack of willingness to accommodate students with SEND in some schools. For confidentiality purposes references to specific reports linked to the LA in question have been omitted from this thesis.

Within their response to these findings the LA made clear a determination to ensure that pupils with an identified SEND are supported through a genuinely inclusive approach. This response has the potential to improve the educational experience and outcomes of students

with SEND in the South of England. However, it is worth noting that whilst the LA sought the opinions of children and young people in developing the new strategic plan, only 2% of respondents (n=6) identified as having a SEND, and the report does not state whether these individuals were children and young people. The inclusion commitments identified are therefore built primarily on the views of adults (parents and professionals) and on the existing legislative agenda which is still situated within the medical model of disability (Goodall, 2020). In short, students' opinions on this matter have not been afforded the "due weight" which Article 7 of the UNCRPD stipules all "parties shall ensure" (United Nations, 2006a). This is the reverse of the ideal, which would see children and young people guide experts, rather than them being guided by "ideological crusades alone" (Goodall, 2020, p. 27). The rights of students on the autism spectrum "to an inclusive education should not be ignored any longer" (Pellicano, Bolte and Stahmer, 2018, p. 387). If the LA's strategic plan stands any hope of enacting meaningful change and improving outcomes for young people, it needs to put students' best interests at the heart of all actions by proactively seeking the opinions of those students who will be affected by any decisions made.

2.4.3 Excluded by Inclusion

The result of this steady, but ultimately slow change to adopt a truly inclusive approach, which up to now could be considered more integration than inclusion (Goodall, 2020, pp. 14-15), is that students on the autism spectrum have been physically included, but emotionally, socially and academically excluded in schools. Goodall (2020, p. 13) argues that the concept of inclusion for all has failed and that students on the autism spectrum have become "collateral damage, excluded by inclusion". Warnock, (2007. P. xii) provided a clear warning that if

students on the autism spectrum are not included appropriately in school, there is a risk that they "may begin to refuse school". A warning which, according to the data in Appendix 1 and 2, can be seen to have been prophetic.

2.5 School Refusal Defined

Having analysed the inclusive educational environment which has been established in England and how this impacts young people on the autism spectrum, this next section will explore literature explaining attendance problems within this inclusive system. In educational literature, Tobias (2019, p. 18) sees the terminology used for school attendance problems as both "complex and contradictory", leading to a difficulty in piecing together the "disparate pieces of research across time and discipline". That being said, Kearney & Silverman (1999, p. 673), define school refusal behaviour to be a "child motivated refusal to attend school" or remain in class. The functional analysis model of school refusal behaviour (Table 3) expresses the motives behind the continuation of school refusal in young people. The School Refusal Assessment Scale-Revised (SRAS-R) (Kearney, 2002) (Appendix 12) was consequently constructed to assess these functional conceptualisations and to "develop prevention and intervention strategies adapted to [the child's] needs" (Gonzalvez et al, 2020, p.2).

The remit of this thesis is to focus on a young person's absence from school solely due to functions A and B of Kearney and Silverman's Functional Analysis Model (Table 3). This places an emphasis on factors within school which are causing escape or aversive reactions from students. Additionally, it is the child motivated aspect of Kearney and Silverman's' (1999) definition which distinguishes school refusal from either School Withdrawal (SW), which is dominated by parental influence; or School Exclusion (SE), which is imposed by the school

(Heyne *et al.,* 2019). Additionally, school refusal is distinguished from truancy by parental awareness of the student's behaviour (Totsika, 2020, p.5).

	Conceptualisation of Function	Youth Reference Type
A	Avoid school-related stimuli that provoke a general sense of negative affectivity (i.e., anxiety and depression).	Refusal for negative reinforcement, i.e., avoiding difficult situations.
B	Escape school-related aversive social and/or evaluative situations.	
C	Gain attention from significant others (e.g., parents).	Refusal for positive reinforcement, i.e., seeking more pleasurable activities.
D	Pursue tangible reinforcement outside of school (e.g., shopping, playing with friends, or drug use).	

Table 3: Conceptualisation of the Functional Analysis Model of School Refusal Behaviour (Kearney and Silverman, 1990)

Pellegrini, (2007, p.65) suggests that the term school refusal denotes a within-child explanation for the displayed behaviour which "deflect[s] attention from the school environment". However, Stroobant and Jones (2006, p. 221), in citing the work of Yoneyama (1999) on school refusal in Japan, stress that "*school refusal is not an always-ready negative phenomenon"* and can in fact be seen as a thoughtful response to a constraining institution*.* In light of the narrow focus of this thesis, and despite the risk of any potentially negative connotations perceived by participants, it would be a mistake to use the terms "extended school non-attendance" (Pellegrini, 2007, p.65), or "problematic absenteeism" which are both intended to "account for all aspects of non-attendance" (Kearny, 2008, p. 265). Yoneyama's (1999, cited in Stroobant and Jones, 2006, p. 221) framing of the school refusal

behaviour places the fault with the wider system, rather than within the child, and is the spirit within which this research study sits.

2.6 School Refusal Behaviour Risk Factors

The three domains of risk factors relating to school refusal can be summarised as; individual/within-child; familial; and school-based (Ingul et al*.,* 2012; Munkhaugen, 2019b). It is important to understand that rarely is there likely to be a single risk factor which acts as a trigger for school refusal, instead factors are likely to be based within more than one of the three main domains. Appendix 4 provides specific examples relating to the three domains; however, each are summarised below.

2.6.1 Individual/Within Child

Individual/within child factors are often attributed to mental health difficulties, primarily relating to anxiety and/or depression (Gren-Landell et al., 2015). Researchers have identified separation anxiety, school specific anxiety, school phobia and generalised social anxiety as factors relating to extended non-attendance (Baker and Bishop, 2015; Elliott and Place, 2019). Importantly, Wood et al*.,* (2012, p. 352) suggest that non-attendance and psychopathology may present a "reciprocal risk", where one exists, the likelihood of the other becoming emergent or worsening increases.

In addition to mental health difficulties, individual/within-child risk factors associated with school refusal include somatic complaints, explained as physical symptoms of pain or weakness (Robitz, 2018) such as headaches, stomach-ache and generally feeling unwell.

Furthermore, and in-line with the findings of the pilot study for this thesis, the subjective nature of somatic complaints can result in them being overstated in order to not attend school (Ingul et al*., 2019*). Stroobant and Jones (2006. P. 220) go so far as to suggest that students used somatic complaints to "manipulate the situation". The legitimacy of somatic symptoms should be treated carefully and paid close attention to by educators and parents alike, as this may be one of the only ways for students to articulate their distress with school (Munkhaugen et al*., 2017*). It could be suggested that language such as *manipulate* does nothing to promote feelings of understanding on either side of the table.

Finally, individual risk-factors include what Preece and Howley (2018, p.470) identify as "cognition and affect". Totsika et al*., (2020)* suggest that there may be a correlation between the social skills and communication of students with SEND and the increased incidence of their absence from school. Munkhaugen et al*., (2019a)* also note the connection between executive functioning and school refusal behaviour. Whilst the prevalence rates of absence for students on the autism spectrum (Appendix 1 and 2), indicate that they are at greater risk of school refusal than their peers, Tobias (2019, p. 23), asserts that autism may exacerbate, but does not cause persistent school non-attendance alone. This argument can be seen through section 2.6.3 of this chapter, which demonstrates that whilst difficulties with the sensory environment, and complex social relationships play a part in students school refusal, (and lean on the diagnostic criteria of autism established in Chapter 1), it must be acknowledged that relationships and communication are two way processes, and therefore some responsibility lies with professionals and school systems for the school refusal behaviour of students on the autism spectrum.

2.6.2 Familial Factors

The risk of school refusal behaviour linked to family can be placed in three more specific categories; parental psychopathy; unhealthy family functioning and socio-demographic;. These are explored in more detail below.

2.6.2.1 Parental Psychopathy

Parental psychopathy relates generally to mental health problems, most commonly anxiety and depression (Ingul et al., 2019; Baker and Bishop, 2015). For a parent experiencing anxiety or depression, stepping in to support their child may be more difficult than for a parent without these difficulties (Ingul et al., 2019).

2.6.2.2 Unhealthy Family Functioning

Factors relating to unhealthy family functioning and school refusal are: poor parental involvement; low expectations of the child/young person; alcohol and drug abuse; domestic violence; conflict, separation and divorce (Gren-Landell et al., 2015); an unsafe home; lack of parent support (Munkhaugen, 2019b); difficulty in family communication; over/under control of parents and lack of flexibility in response to children's behaviours (Ingul et al., 2019).

2.6.2.3 Socio-Demographic Factors

Despite Pellegrini (cited in Baker and Bishop, 2015) finding that there were no associations between socio-economic status and extended school non-attendance, other researchers

have considered socio-demographic features such as parental education, employment status and social deprivation, as important in understanding the phenomena of school refusal (Ingul, Havik and Heyne, 2019; Gren-Landell et al., 2015).

2.6.3 School Based Factors

Having explored both individual/within child and familial factors, I now turn to the school-based factors associated with school refusal. Wood et al., (2012) suggest that it is those risk factors which are able to be changed, which can act as preventative measures in reducing school non-attendance. The AET Good Practice Guidance, produced alongside the Autism Centre for Education and Research (ACER), identify four key themes underpinning best practice in schools (AET, 2021a), which provide a framework upon which schools can begin to make change. The themes are: Understanding the Individual, Positive and Effective Relationships, Enabling Environments, and Learning and Development. Each of these are explored in more detail below.

2.6.3.1 Theme One - Understanding the Individual

To understand an individual, it is fundamental to explore their strengths, interests and challenges, in a person-centred approach which seeks and enables the voice of that individual (AET, 2021a). This position is underpinned by the United Nations Convention on the Rights of the Child (United Nations, 1989), which mandates that all children should be listened to, and have their opinions taken seriously by decision makers. "Local Authorities **must** ensure that

children…and young people are involved in discussions and decisions about their individual support" (DfE and DoH, 2015, p. 20).

Goodall (2020, pp. 95-96) found that 11 of 12 participants on the autism spectrum, spoke about not being understood by their teachers, whilst also stating that "understanding is a fundamental attribute of a good teacher". Students felt judged, stereotyped and patronised by not only their teachers but also by the teaching assistants who were there to support them, which led to one student feeling "as if she was saying this poor wee child and her wee brain disability, she can't think for herself" (Goodall, 2020, p. 96). This student was evidently not provided with the support to "participate as fully as possible in decisions" nor given the "greater choice and control" the SEND code of practice (DfE and DoH, 2015, p. 19) stipulates she should have received.

Engaging in conversation gives teachers an insight into student's "needs, thoughts, feelings and priorities" (Merrick, 2020, p. 110). Morewood, Humphrey and Symes, (2011) identify the importance of student contributions to decisions regarding lessons which are not compatible to them and therefore need to be adjusted or removed from their timetable. Hay and Winn (2005, p. 148) recognize the two-way nature of communication by noting that students on the autism spectrum "displayed a lack of understanding of social conventions" in their interactions with teachers. However, by placing the lack of understanding on the student, Hay and Winn (2005) arguably understate the responsibility of teachers to understand the needs of their students and plan accordingly. This is demonstrated through the case study of 'Max' (Mower and Dowling, 2021, pp.91-92), who flipped a classroom table after his teacher "minimised or misunderstood" his growing anxiety to a delay in the pre-established routine.

For Mower and Dowling (2021) this became an issue of control, with the teacher needing to assert dominance, rather than communicating and understanding Max's needs.

The importance of these student-teacher relationships in providing an opportunity for understanding, can be seen too in the example of Amelia (a pseudonym), a year 10 student diagnosed with Asperger's Syndrome, from the South of England (Baker and Bishop, 2015). In speaking of the factors leading up to her school non-attendance Amelia felt scared of her teachers (Baker and Bishop, 2015). Despite this, during the research study, when no longer attending school, Amelia makes an insightful observation of one her teachers noting that "…he actually wasn't a scary man. He was just trying to keep the class under control" (Baker and Bishop, 2015, p. 361). This is an example of the difficult balancing act teachers need to demonstrate, namely the ability to maintain class order and deliver planned lessons to a group of 30 students, whilst also providing an individualised approach when needed.

Schools demonstrating good practice would offer regular opportunities for students on the autism spectrum to give feedback on their experiences, to discuss difficulties with teachers and to influence day to day decisions affecting them (AET, 2021a). It is promising that 84% of teachers would like students to be more involved in the planning process, however these same teachers also cited children's individual difficulties and the attitudes of staff as barriers to this process (Merrick, 2020).

2.6.3.2 Theme Two - Positive and Effective Relationships

Taking time to understand an individual not only positively impacts the key decisions affecting a student's education, but it is also fundamental in building effective working relationships

between teachers and students. The development of these relationships cannot be the sole responsibility of students, nor of individual teachers and members of support staff. Rather it is the responsibility of the whole school and education system at large to promote and develop training and an understanding of autism (AET, 2021a) among the school community.

In considering the effectiveness of these relationships, both the National Autistic Society (NAS) (Sackville-Jones, 2019) and the AET (2021a) highlight the recent review of the Initial Teacher Training (ITT) Framework (Department for Education, 2021), which resulted in the inclusion of compulsory autism content, as a positive step forward. Effective ITT can improve the "attitudes, knowledge and skills" required to support students on the autism spectrum (Hornby, 2015, p. 244). This development by the Department for Education is therefore welcome and appears to be well founded, as the All-Party Parliamentary Group for Autism found that 51% of students felt that their teacher did not know how to support them (Great Britain, 2017). This is corroborated by Goodall's (2018) research participants, who felt that teachers did not have sufficient time or training to support them.

It should be noted that whilst ITT is crucial to develop effective practice and in providing appropriate strategies for support, teachers should use this knowledge flexibly and avoid a "one size fits all approach" (Goodall, 2018, p. 13). The SEND code of practice stipulates teachers should not rely on interventions alone to support students on the autism spectrum, rather they must rely on their own high-quality teaching and ability to differentiate (DfE and DoH, 2015). The ability to differentiate appropriately is not just a practical obstacle however, as the attitudes of teaching staff will impact the manner in which differentiation is created and delivered. Therefore, for ITT to be successful it needs to reduce the number of teaching staff whose approaches result in students feeling stereotyped and patronised (Goodall, 2020).

Dillon, Underwood and Freemantle (2016) suggest that the development of a bad student-teacher relationship can impact a student's conceptualisation of their school experience and result in school refusal. Saggers (2015, p.14), in research exploring adolescent students on the autism spectrums' views of education, found they expressed appreciation of staff who "recognised, responded to and supported their individual needs" and related to them. Connecting with a student is arguably much easier to achieve if you have first listened to and heard them – a characteristic which students on the autism spectrum sought in their teachers (Goodall, 2018). Stephen (a pseudonym), spoke of his experience of a mainstream school Principal who was not hearing what Stephen was expressing, when he articulated his difficulty in the classroom:

> *'So, I told them, I can't do the work, so I'm not coming to school. There's no sense to be in school if that's how it is. I called the Principal and I explained to him, 'I'm not going to come to school in that kind of environment' and he said, 'I don't care, then you'll fail'. And that's why I just stayed home.'* (Wilkins, 2008, p. 18)

Research exploring school from the perspective of students on the autism spectrum, found that all twelve participants expressed the importance of "caring and supportive" teachers (Hummerstone and Parsons, 2020, p.7). It is interesting to note that within this same study, teachers themselves were unable to articulate any instances of offering a caring or supportive action which could be deemed emotional support (Hummerstone and Parsons, 2020); instead, their priority and focus was on the academic nature of their role. Research by Tingskull et al., (2015) into potential traumatic events (of which school refusal could be included) highlighted the need for practitioners to listen to and hear students, to gain a true and full picture of their life experience, rather than relying on parents as a source of

information. An example of this reliance on parental input can be seen through the formalised EHC plan's annual review process, which risks decision makers behaving in a tokenistic manner to students (Merrick, 2020), rather than fully engaging the young person in decision making processes on a day-to-day basis (Palikara et al., 2018).

Building a deeper understanding of students should "pervade all aspects of school life" (Dillon, Underwood and Freemantle, 2016, p. 228). Indeed, Anderson (2020, p. 4359) suggests that relationships between students on the autism spectrum and their teachers and peers "appear[s] to exert the strongest influence on actions, norms and values, social interactions and learning processes". In considering the role of the professional specifically, research has demonstrated that a positive relationship with one caring adult, who is not a child's parent, is one of the single most protective factors for young people with multiple risk factors in their lives (Scales and Gibbons, 1996, cited in Rishel, Sales and Koeske, 2005).

2.6.3.3 Theme Three - Enabling Environments

When considering how to define an enabling environment, it is worth looking to the duties required of schools under the Equality Act (2010) cited in the SEND code of practice (DfE and Doh, 2015, p.17), schools **must;**

> *'…make reasonable adjustments to procedures, criteria and practices…and physical alterations…to ensure that disabled CYP are not at a substantial disadvantage to their peers… [they must] have regard to the need to eliminate discrimination, promote equality of opportunity and foster good relations between disabled and non-disabled CYP'.*

Ultimately leadership teams and governing bodies of schools enacting these requirements, set the agenda, the attitude, and the ethos toward autism for the whole school to follow (AET, 2021).

The risk of not establishing a positive ethos and attitude toward autism in school can be seen through the simple act of teachers shouting in the classroom, which is mentioned repeatedly in research by students on the autism spectrum (Hummerstone and Parsons, 2020; Goodall, 2018; Dillon, Underwood and Freemantle, 2016). In their study into the student-teacher relationship, Ibrahim and El Zaatari, (2019) state that schools should prioritise the psychological needs of their students, alongside any academic teaching – this they suggest, cannot be done when teachers shout at their pupils. The effect of shouting in the classroom can be seen in the statements of two separate students on the autism spectrum: *"[The teacher] is always shouting and stuff. It makes you [clenches fists and hunches over, teeth gritted] …I'm always on edge." (*Hummerstone and Parsons, 2020, p. 7) *And "Cos…when we're in [lesson], most of the teachers just shout at me, and I don't like it…and I just get…upset" (*Hummerstone and Parsons, 2020, p. 7)

Given the difficulty young people on the autism spectrum have in "developing, maintaining and understanding relationships" (Centres for Disease Control, 2020), the potential sensory, physical and emotional damage experienced by the two students above due to teachers shouting in the classroom, is clear. When relating this to the SEND code of practice (DfE and DoH, 2015), it could be argued that these schools have not successfully adjusted their practices and have not created or fostered an ethos of understanding toward students on the autism spectrum. A student who is "always on edge" (Hummerstone and Parsons, 2020, p.7) is at a substantial disadvantage than their peers. Creating a truly inclusive ethos in schools

should be encouraged not only to support students on the autism spectrum, but because it benefits all students (Dillon, Underwood and Freemantle, 2016).

The impact of a school ethos which, even inadvertently, diminishes or belittles the contribution students on the autism spectrum can make to a school, can be seen through the attitude of their peers towards them. 46%-94% of students on the autism spectrum are victims of bullying, compared to around 33% of their non-autistic peers (McClemont et al*.,* 2020). Research on what causes this disparity is ongoing, with three articles in 2020 addressing the issue with mixed results. Bitsika, Heyne and Sharpley (2020) found an association with restricted and repetitive behaviours and frequency of being bullied, but did not find any connection with socialisation and communication. However, Ochi et al*.,* (2020) suggest that the communication difficulties experienced by students on the autism spectrum may contribute to a misinterpretation of when they have been bullied, leading to either an over or under-reporting of incidences. This is reinforced by McClemont et al*.,* (2020) who suggest that the under reporting of bullying, by students on the autism spectrum, may account for the disparity in the connection between bullying and autism, and bullying in ADHD, where the frequency is higher in ADHD. It is of interest, and concern, that none of the three research papers address the attitude and ethos of the educational setting as a possible cause for bullying and school refusal. Rather, it could be argued they lean toward a medical model view of disability, seeing the "fault" as within the student, cross-refencing as they do, the incidence rates of bullying with diagnostic criteria of autism, or the prevalence of the student's anxiety and depression.

2.6.3.4 Theme Four - Learning and Development

Primary and secondary schools in England are required under the Education Act (2002), to provide;

> *"A balanced and broadly based curriculum, which…promotes the spiritual, moral, cultural, mental and physical development of pupils at the school and of society, and prepares pupils at the school for the opportunities, responsibilities and experiences of later life" (Department for Education, 2014, p. 4).*

The challenge for educators, is to take this direction for a broad and balanced curriculum, and apply it to individual students whose spiritual, moral, cultural, mental and physical abilities and values differ from one another. It is an interesting curiosity that schools (and ultimately students) are measured as successful or not by league tables, progress 8 scores and the proportion of GCSE 9-4/A*-C's (Department for Education, 2020b). However, the Department for Educations requirements above, do not mention academic ability or competence, they speak of personal development and preparedness for adulthood (Department for Education, 2014).

Having engaged with this National Curriculum (2014), the life-long outcomes for students on the autism spectrum, are starkly different to those of their non-autistic peers. Concerning mental health, individuals on the autism spectrum are almost three times as likely to experience anxiety, and over twice as likely to experience depression compared to the general population (Lai et al.*,* 2019). Just 21.7% of individuals on the autism spectrum are in work, in comparison to 81.3% of the general population (Office for National Statistics, 2020). And finally, in terms of academic outcomes, in 2019 just 33.5% of students on the autism spectrum received a grade 4/C in their English and Maths GCSE, compared to 64.6% of the total student

population (Department for Education 2020d). This calls into question the effectiveness of this national curriculum and the manner of its delivery for students on the autism spectrum. Indeed, Wittemeyer et al*., (2011) in discussing outcome measures for students on the autism spectrum, suggest that outcome data should be collected on social communication, independent living skills and sensory processing.

In their review of an educational provision for students who had experienced prolonged non-attendance, Preece and Howley (2018) identified the development of an appropriate learning environment as crucial. Participants in the study, both professionals and families, reflected on the smaller class size, a more nurturing and quieter environment and the low stimulus décor as positives in maintaining attendance (Preece and Howley, 2018). Additionally, student participants highlighted the physical organisation of the environment, which they said helped them to "concentrate and learn" (Preece and Howley, 2018, p. 475).

In a quantitative study exploring the school absence of students on the autism spectrum from the perspective of their parents, Anderson (2020) found that 54.4% of students received an adapted pedagogy, 38.7% adapted teaching materials and 29.7% an adapted study programme. The starkest findings concern the gender imbalance in support provided, where no matter the measure, boys were in receipt of more support than girls (e.g., adapted classroom teaching was seen by 74.4% of boys and 25.6% of girls). This is perhaps reflective of findings that girls on the autism spectrum may be more vulnerable and more susceptible to short term school absenteeism than boys (Anderson, 2020).

Providing a conducive learning environment also links to the atypical sensory processing often experienced by students on the autism spectrum (Zazzi and Faragher, 2018). Unfortunately, classrooms and school environments often contribute to an aversive response in students on

the autism spectrum, which is linked to hyper (rather than hypo) sensitivity (Zazzi and Faragher, 2018). Butera et al., (2020) provide an overview of key sensory considerations, along with suggestions on what adaptations can be made in school. These adaptations align with the three areas of sensory support suggested by Mills and Chapparo, (2018) who point to the modification of the environment (noise and lighting), task modification (help/exit cards) and finally additional sensory inputs (sensory circuits) as beneficial in promoting classroom performance.

The AET's Progression Framework, which was designed as a consequence of the work conducted by Wittemeyer et al., (2011), provides a clear overview of the key area's schools should focus on when supporting students on the autism spectrum (AET, 2021b). The areas addressed within the progression framework are social communication; social interaction; social imagination/flexibility; sensory processing; emotional understanding and self-awareness; learning; and independence and community participation (AET, 2021b). Furthermore, innumerable books are available with titles such as "The Essential Manual for Asperger Syndrome (ASD) in the Classroom" (Hoopmann, 2015), or "Autism Spectrum Disorder in the Inclusive Classroom" (Boroson, 2016), designed to guide teachers in providing the most appropriate support for students on the autism spectrum.

And yet, notwithstanding this wealth of literature and guidance, absence rates (Chapter 1.1.) and exclusion rates (Gray, 2018) of students on the autism spectrum are still much higher than the national average, suggesting that there is still more to be done. Leifler et al., (2020) may provide some insight into the disparity between the ambition of teachers to provide support and the outcomes of their students, by highlighting the historic predominance of

attempting to adapt the child to the environment (medical model of disability) rather than the environment to the child (social model of disability).

2.7 Autism and School Refusal Research

School refusal in the general student population is a subject which has received much greater attention from the research community, and as such the number of studies involving students who have experienced school refusal are significantly greater than those focused on autism (Appendix 4). Even in the general population however the voices of children and young people on their experiences of school refusal are "barely represented" (Baker and Bishop, 2015, p. 356). To date, the only research I have been able to locate (see Tables 1 and 2 for search details) specifically concerning the school refusal of students on the autism spectrum consists of; Bitsika, Heyne and Sharpley, (2020) in Australia; Ochi et al*.,* (2020) in Japan; and McClemont et al*.,* (2020) in the USA, all of whom explored the association between autism, school refusal and experiences of bullying; Kurita, (1991 cited in Totsika, 2020; Munkhaugen, 2019a) studied the prevalence of school refusal among those with Pervasive Developmental Disorders in Japan; Totsika et al*.,* (2020, p.1) investigated the "types and correlates of school non-attendance" for students on the autism spectrum in England, including school refusal; and finally Munkhaugen (2017; 2019a; 2019b), through a PhD thesis and with colleagues, explored both the frequency and the factors associated with school refusal behaviour among students on the autism spectrum in Norway.

The only study above to have sought information directly from children and young people on the autism spectrum was Bitsika, Heyne and Sharpley (2020), who gathered self-assessment data on anxiety and depression. Each of the other studies utilised parent and/or professional

questionnaires, or in the case of Ochi et al*.,* (2020, p. 2) a "retrospective chart review…of psychiatric outpatients". There are a lack of children and young people participating in this research field, which Munkhaugen (2019b) acknowledged resulted in a less than complete set of results. Munkhaugen (2019b, p. 52) goes on to explain that "descriptive studies…including students themselves" would enhance the understanding of school refusal behaviour of those on the autism spectrum.

Despite the limitations of both Totsika et al*.,* (2020) and Munkhaugen et al., (2017; 2019a; 2019b), in not including students in their research, it still bears significant relevance to this thesis due to their focus on school refusal, the age range of participants and the focus on mainstream education. Table 4 outlines key demographic information and findings from both studies.

	Totsika et al., (2020)	Munkhaugen et al., (2017; 2019a; 2019b)
Participants	486 Caregivers of students on the autism spectrum.	Parents and Teachers of 208 Students (n-78 Diagnosed with Autism, n-138 Typically Developing (TD) peers)
Student Gender	69% Male	86% Male
Student Age	Mean age = 11 Years	9-16 Years
School Type	Mainstream (n-392) and Specialist (n-94) Settings	Mainstream Settings (n-208)
Key Absence Statistics	On average students missed five days in 23 60 % of students missing 1 day in 23 43% of students missing 10% of all sessions	60 % of students on the autism spectrum missing four or more days in 20, compared to none of the TD students. 42% of students on the autism spectrum experienced school refusal compared to 7% of TD students.
Possible Correlates/Risks to Attendance Problems	Attending Mainstream School Older Age of Students	Lower Social Motivation Increased Symptoms of Depression

	Single parent household	Impaired ability to initiate actions and problem solve
	Unemployed caregiver	
		Illness in other family members
		Severity of school refusal increases with age.
Absence Type	43% School Refusal	Focussed on both school refusal and truancy therefore the distinction between the two is unclear.
	9% School Exclusion	
	9% School Withdrawal	
	32% Non-Problematic (Illness)	
	Truancy almost non-existent.	

Table 4: Totsika et al., and Munkhaugen et al., Comparison

The aim of Totsika et al., (2020, p. 7) was to better describe the school non-attendance of students on the autism spectrum and to investigate the variety of "potential correlates", whereas Munkhaugen et al., (2017; 2019a; 2019b) focused on individual characteristics of students and the risks linked to school refusal behaviour. Regardless of this difference in aims, it is striking how both studies found similar outcomes regarding the prevalence of school refusal (Table 4). Whilst the prevalence identified is significantly higher than that reported in national and local data (Appendix 1 and 2), this can be explained through caregivers and teachers with experience of children's absence being more inclined to participate in research of this kind, than those without. Of particular concern is the significant difference between the prevalence of school refusal reported by parents of children on the autism spectrum (42%) and those of typically developing children (7%) (Munkhaugen, 2019b). Again, these two statistics are greater than that seen through local and national data (Appendix 1 and 2) but adds weight to the argument that school refusal is experienced by significantly more children on the autism spectrum than their typically developing peers.

Given the difference in the aims of both studies, it is unsurprising that different correlates and risks were found (Table 4). However, it should be noted that Munkhaugen's (2019b) research focused on students attending mainstream schools, which links to Totsika et al., (2020) who found that the prevalence of school refusal increases for those attending mainstream settings. Additionally, both studies highlighted the link between school refusal and students increasing age. Combined, these findings could suggest that the transition from primary school to secondary school, and secondary school settings themselves are risks for children on the autism spectrum.

Furthermore, both studies highlight the likelihood of anxiety and depression as contributing factors to school refusal for students on the autism spectrum (Totsika, 2020; Munkhaugen, 2019a,), mirroring findings from studies concerning school refusal in the general student population (Kearney, 2008). It is important to note that whilst the current thesis does not explore *within-child* causes for school refusal behaviour, the social, emotional and executive functioning abilities of children and young people, will directly affect interventions, strategies and practices implemented by schools. Therefore, findings by Munkhaugen et al*.,* (2019a) concerning social motivation, executive functioning and mental health, and the link to school refusal behaviour, do bear relevance in understanding the classroom practices that are chosen to support students on the autism spectrum.

In their concluding statements, Totsika et al., (2020, p.22) assert the need to implement interventions which are based on our knowledge of "non-attendance drivers in ASD". It is important that the identification of these drivers is established through the narratives, feelings and lived experiences of young people on the autism spectrum (Goodall, 2020). An argument echoed by Munkhaugen (2019b) who points to the incompleteness of her study

due to the lack of student participation. Despite the absence of student voice, both Totsika et al., (2020) and Munkhaugen et al., (2017, 2019a, 2019b) have reignited the importance of addressing school refusal as a particular concern for students on the autism spectrum, and by doing so, have opened the door to more in depth studies in the future.

2.8 The 2020 Global Coronavirus Pandemic

The research explored in 2.7 was conducted when Covid-19 was not present in society and the school were operating in normal conditions. However, the impact of school closures and adjustments due to Covid-19, on the lives of children and young people on the autism spectrum cannot be underestimated. For some there was worsening of "behavioural, social and developmental domains" at home, whilst for others the reduction in demands from a school environment was seen as "positive and even beneficial" (Tokatly-Latzer et al., 2021, p. 1057). Either way, it has been suggested that between a third and three quarters of vulnerable children were not in receipt of any formal education during enforced school lockdowns (Pellicano and Stears, 2020), this would include those on the autism spectrum. The short- and long-term effects of this distance from education, will not be understood for some time to come. Whilst this study did not specifically investigate the effects of Covid-19 on the school refusal of participants, it is important to acknowledge that they are engaging with this study during a highly unusual period in history which will have impacted upon their attendance at school, and therefore their current relationship with it.

2.9 Chapter Summary

This literature review has provided a critical overview of key literature relating to the educational environment young people on the autism spectrum are required to engage with. This has included defining inclusion, autism and school refusal, analysing best practice guidance in mainstream schools and contextualising this alongside up-to-date research on school refusal among the general and autistic student community. It is evident from this review that despite the philosophy of inclusion advocated within both national legislation (Great Britain, 2014) and Local Authorities, young people on the autism spectrum still do not feel listened to by those leading their education (Goodall, 2020). Furthermore, whilst Munkhaugen (2019b) recognised that research into school refusal would be more complete with input from young people on the autism spectrum, it is a step that has yet to be taken in any meaningful way. It is for these reasons that I borrow from the concepts of inclusion and person-centred practice in my approach to the methodology and research design for this thesis. Put simply, engaging directly with young people on the autism spectrum is fundamental to the way in which I explore this research study. In taking this approach, I have developed the following research questions, which have not yet been asked of students on the autism spectrum:

1. What school-based factors do young people on the autism spectrum relate to their school refusal?

2. How do young people on the autism spectrum frame these school-based factors?

In summary, I have looked to address what I see as the over reliance on quantitative data and the homogenisation of students experiences in research related to school refusal for young people on the autism spectrum to this point. The following chapter on methodology explores

this person-centred approach through the epistemological paradigm adopted, the data collection processes, ethical considerations and finally extending to data analysis.

Chapter 3

Methodology

3.1 Introduction

Having set out the academic and educational literature underpinning this thesis, this chapter sets out the ontological and epistemological framework within which this research study has been carried out. The research design will be explained (Figure 1) and data collection and analysis choices will be scrutinised with reference to why they were considered most appropriate in answering the research questions identified in response to the literature review. Furthermore, whilst specific ethical concerns are addressed within this methodology, construction and delivery of an ethical study has been at the heart of every decision made across research design, collection, and analysis.

Within the field of autism research, much weight has been placed on the voices of parents and professionals over those of individuals on the autism spectrum (Goodall, 2020). Indeed Milton, (2014) suggests that the voices of those on the autism spectrum have been silenced in research, pointing to the examination, inspection, and interpretation of the autistic community by those of a "non-autistic disposition" (Milton, 2014, p. 796). Many reasons for an unwillingness to involve young people on the autism spectrum in research have been identified (Goodall, 2020). However, it can be explained quite simply as autism having historically been viewed as a deficit, which sees the individual as impaired and therefore the cause of difficulties engaging with others and the environment (Oliver and Barnes, 2010). Both Goodall (2020) and Milton (2014) argue strongly for inclusive improvements to research participation methods, to ensure that not only are the rights of the autistic community met,

but also to improve the quality and validity of data produced in research. The methodological design outlined herein is an attempt to answer this call.

3.2 The Impact of Covid-19 on the Research Process

The global coronavirus pandemic had a substantial impact on the design and implementation of this research project. The primary effect being on the manner of engagement with participants – moving from a face-to-face construction of knowledge to an online one. As a researcher I had to overcome ethico-episotmological challenges and create a unique approach to data collection utilising technology and understanding better the benefits of doing so.

3.3 Research Design

In keeping with the interpretivist ontological paradigm and the communitarian epistemology set out in more detail below, this research design is based within a qualitative methodology which can be defined as a research method adopted to investigate the "way in which people make sense of their…experiences" (Savin-Baden and Howell Major, 2013, p 11).

Figure 1 sets out the stages of this research process, the actions taken within each stage, and who the primary contributors were during each stage.

3.4 Ontological and Epistemological Perspective

To understand the multifaceted and ever-changing nature of human relationships, a subjective approach to research has been selected as it is recognised as the only way to examine the complex social phenomena under investigation. To perceive the world from an objective, realist perspective one would need to understand the human social experience as "independent of individuals perceptions of it" (Waring, 2017, p. 16). My ontological approach is that "meaning is not discovered; it is constructed through the interaction between consciousness and the world" (Crotty, 1998, p. 44). It is, I believe, the reflectiveness of human nature (Ormiston et al., 2014, cited in Al-Saadi, 2014), which continually develops understanding of the world around us, demonstrating that knowledge is socially constructed.

This perspective aligns well with an interpretivist epistemological paradigm. Thanh and Thanh (2015, p. 24) explain this as researchers viewing the world "through the perceptions and experiences of the participants" and as a paradigm which understands context as being crucial to the interpretation of data. Within the scope of this thesis, there are several contexts which must be acknowledged to enable a depth and validity to the research process. This includes the education system (explored in Chapter 2) impacting the first-hand information available for participants to reflect upon and share during data collection. Furthermore, my own interpretation of the social construction of data between participants, between participants and myself as researcher, and the positionality of all in relation to the research study are fundamental contexts of this research study. I therefore see the interpretive paradigm as one which perceives the exploration of situations and peoples as a coming together of complex and unpredictable factors, giving rise to events which cannot simply be quantified based on a set of static and fixed truths, but instead can be perceptively interpreted by researchers (Al-

Saadi, 2014). In agreement with Thanh and Thanh (2015), I believe an interpretive methodology provides an opportunity for contextual reflection to deeply examine and analyse participants perspectives on their experiences.

3.4.1 The influence of Social Constructivism on this research

Social constructivism posits that before individuals can internalise meaning, they first create it by interacting with other people and with their environment (Amineh and Asl, 2015). Throughout this research study participants continually reflected upon the interactions and utterances they saw and heard (including their own) and were influenced by their environment, leading to a unique set of circumstances within which meaning, and knowledge was created. These are circumstances which cannot be identically replicated again in future studies. To think of this another way, the dialogic nature of the parent-child conversation is a demonstration of "speaking consciousness" (Cazden, 1993 as cited in Daniels 2014); firstly, participants are acting within a given time and place with a known and unknown other; secondly participants are expressing a particular point of view framed within a personal set of values; and thirdly participants are taking account of who they are speaking with (or for the benefit of) (Daniels, 2014). A speaker's utterances should always be considered as a "link in the chain of speech communication" which are influenced by innumerable social and environmental factors including the previous speaker's utterances and those that are assumed to follow (Daniels, 2014, p.24).

Viewed through a lens of "distributed intelligence" (Bruner, 1991, p. 4), our experiences and memories, both as a collective species and as individuals, are organised predominately in narrative form expressed through story or reason. Narratives can only ever be considered to

present the appearance of truth which cannot be empirically verified. Whether verifiable or not however, participant utterances are the truth which they choose to share in each moment and are therefore their truth in that time and place. Furthermore, the narrative of participants is likely to be more coherent and meaningful when the speaker and listener share a linguistic, socio-cultural and historic understanding of each other and their environment (Werstch 1998 cited by Daniels, 2014). In this regard, the relationship between a young person and their parent is likely to represent one of the best opportunities for the coinciding of these "codes" (Werstch 1998 cited by Daniels, 2014, p. 24).

3.4.2 Conversations Between Parents and their Children

No matter how closely aligned the codified language is, relationships between parents/carers and children are often complicated, as they navigate their roles in relation to one another. This undoubtedly affected the dynamic and narrative of the parent-child conversation. Wainryb and Recchia (2014), in their exploration of moral development, identify a variety of motivations for parents and children to hold conversations including rule making, discipline, consequences of actions, encouragement, praise, admission of fault, boasting of good deeds and complaining about others behaviour, all of which they tend to do through conversation.

Two features stand out which relate directly to the methodology of this thesis. Firstly, a young person's experience of parental support and discipline, through conversational methods, potentially impacted upon their willingness to engage in a meaningful conversation. Secondly, participants in this study will have a complicated and likely uncomfortable history of experiences with their school refusal behaviour, which will already have been expressed to their parents. The way these expressions of discomfort were received during previous

conversations, could have impacted upon the young persons' willingness to discuss them again.

An exploratory study into the perspectives of parents living with adolescents with autism, found that there was a particularly strong bond between adolescents and their mothers (Mount and Dillon, 2014). A strong relationship of this kind can arguably increase a parents' ability to interpret a child's body language for signs of distress or pleasure (Mount and Dillon, 2014). This potentially improved the efficacy of the parent-child conversation, as parents may have been able to manoeuvre more adeptly through sensitive topics than a researcher could have done. This ultimately results in a more ethical study and a more rewarding experience for participants.

Furthermore, Wainryb and Recchia (2014, pp. 6-7) consider conversations as opportunities to continually discover and produce new facts which can be seen in a "new light", resulting in refreshed conclusions and "new-trains of thought" which is a perspective based within the socio-constructivist paradigm. This process, it could be argued, cannot be followed through an internalised monologue within one's own head, such as when completing questionnaires (Wainryb and Recchia, 2014). Therefore, to create new meaning and draw out salient points for analysis, in addition to promoting reflection and growth for participants, a conversational approach to methodological design can be seen as highly beneficial.

3.4.3 Communitarian Epistemology

When seeking participants perspectives, it is important to acknowledge the dependency on community as a resource, which Schostak and Schostak (2008, p. 44) refer to as a

"communitarian epistemology". Under this paradigm view, the researcher must come to "accept the authority of the other as expert" and to understand that determination of truth is not possible by objective deductions alone (Schostak and Schostak, 2008, p. 44).

Throughout this research study, both child and parent are considered experts – all be it in differing regards. Whilst it is acknowledged that the relationship between parent and child is instrumental in creating new knowledge (Wainryb and Recchia, 2014), parents did not attend school with their child and were not present during interactions experienced by their child, therefore they cannot be considered experts in this regard. It is in these matters, and others like them, that the label of *expert* is placed on the child. Parents however are very much the expert on their child. School refusal, as defined in Chapter 2, is a phenomenon which parents are aware is happening. They are therefore aware of their child's difficulties at school, have likely supported their child socially and emotionally to cope with their individual situations, and have advocated for their child in difficult circumstances. I see this distinction between two types of experts, and the connection between them, as crucial in revealing a deeper understanding of the child's school refusal experience. In light of these positions of both children and their parents as experts in differing areas, it is important to acknowledge that the narrative of the parent-child conversation, and the topics addressed throughout the research, could come from either party and still be considered valid.

3.5 Participation and Collaboration

In accepting that participants are experts in their own regard, I am intentionally engaging with a participatory research method (Bergold and Thomas, 2012). This paradigm enables participants to collaborate on crucial elements of research design (Bergold and Thomas,

2012), and to participate in research in a manner which suits them, both physically and cognitively (McGarry, 2015). Ideologically, participatory methods shift participants from being seen as an object to be studied, to a fellow researcher (Gallacher and Gallagher, 2008) - from unempowered to empowered, as can be seen in Figure 2.

| UNEMPOWERED | OBJECT | SUBJECT | | PARTICIPANT | RESEARCHER | EMPOWERED |

A visual interpretation of Gallacher and Gallagher (2008)
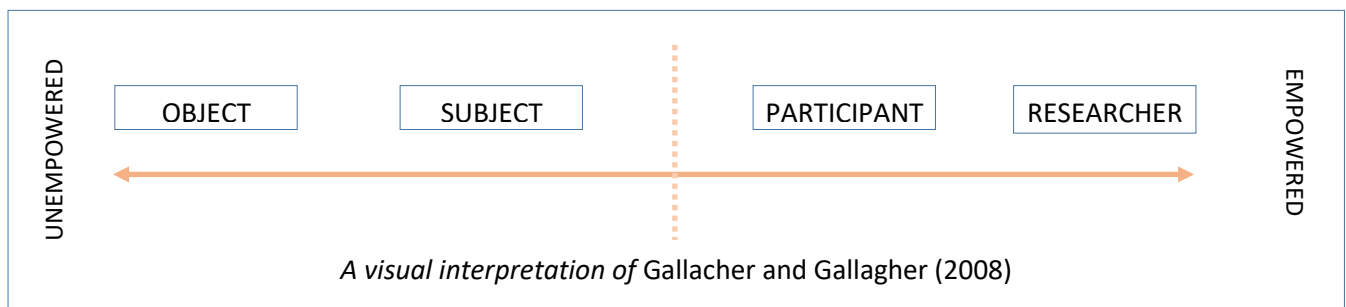
Figure 2: A Continuum of Participation in Research.

Aldridge, (2016) suggests that participatory research considers the needs of participants and addresses power imbalances by providing an inclusive methodological design. The needs of participants have been a fundamental feature of this research design which can be seen through the recruitment, consent forms, participation information letters and ethical risk assessments (Appendix 11). However, it still cannot be said that my research design is fully participatory in nature as is evidenced by the Hart's Ladder of Participation (Hart, 2008). Instead, I suggest that my research is situated between levels 5 and 6, designated 5.5 - Researcher initiated; participant collaboration (Table 5).

It should be acknowledged here that Roger Hart, the architect of the Ladder of Participation, reflected on his pivotal work stating that the schema he developed should not be used as a "comprehensive evaluative tool", as it was designed merely to bring a "critical perspective" to the subject matter (Hart, 2008, p. 21). It would not therefore be appropriate to say that my

research design is, or is not, participatory enough, rather the critical perspective I take is that my research is ultimately one of collaboration with my participants. As the researcher, I have supplied the raw material to work from, i.e., the research topic, questionnaires and the time and space for discussion, however it is my participants who collaborated to produce the research data. The story to be followed is theirs and they controlled the direction of the narrative entirely.

Level	Participatory Method	
8	Child initiated, shared decisions with adults.	
7	Child initiated and directed.	
6	Adult initiated, shared decisions with children.	Degrees of Participation
5.5	*Researcher initiated; participant collaboration*	
5	Consulted and informed.	
4	Assigned but informed.	
3	Tokenism.	
2	Decoration.	Non-Participation
1	Manipulation.	

Table 5: Research Design Vs the Ladder of Participation (Source: Hart, 2008)

3.5.1 Power in Participatory Methods

The indistinct nature of roles within this methodology deviates from the "pre-defined role expectations" of a structured approach to interview (Marvasti and Freie, 2017, p. 626). Anyan, (2013, p. 2) suggests that participatory methods should provide "an egalitarian status for both the interviewer and the interviewee". The roles of interviewer and interviewee, within my

study, cannot be easily identified due to the conversational nature of the methodology, and therefore designations of power are not simply assigned. Indeed, the complexities of the relationships between parents and their children compound this complication further. There is an argument that the conversational approach would appear to democratise the interview process through a realignment of what Anyan, (2003, p. 4) refers to as an "asymmetrical" distribution of power. This is because neither the parent/carer nor the child set the stage, controled the script or the location of interview, nor pose or respond to pre-determined questions and therefore neither has power over the other. A further effect of this methodology is that despite setting the agenda and the logistical features of the conversation, control over the direction of the narrative was not in the hands of the researcher either, which Anyan (2013) suggests it should be.

By taking a role aligned with passive participation (Savin-Badin and Howell Major, 2013) it could be argued that I have removed myself from the meaning making process (Marvasti and Freie, 2017). In stepping back from the interview and handing dominant control of the course and content of the parent-child conversation to participants, I attempted to take a "less powerful role" (Hoffman, 2007, p. 321). This is referred to as counter-control, where participants have power and control over what they say and how they say it (Brinkman and Kvale, 2006). However, as previously discussed in section 3.4.1, the socio-constructivist perspective suggests that my presence, no matter how small, will have impacted upon the utterances of participants. For example, conversation with participants during recruitment will have influenced their sense of me, resulting in either a more in-depth parent-child conversation due to a favourable impression or a more limited conversation due to a negative impression. No matter my intentions, participants may still have perceived me as holding

dominant power (Anyan, 2013) and therefore discussed topics which they felt I would like to have heard, rather than those they wished to discuss.

Whilst participatory methods appear to have become the modus operandi among youth researchers, there is a view that by focusing on empowerment as the end goal, rather than how that empowerment shapes youth experiences in society, researchers risk minimising power dynamics in the research process (McGarry, 2015). However, the issue of power, and the (mis)trust which arises from it, was fundamental to the design and ethical considerations of this research study.

3.6 Ethics

The British Educational Research Association (BERA, 2018) provide a set of ethical guidelines concerning participants, which the educational researcher should ensure are considered before, during and after any research study. In addition to compliance with these guidelines I also sought and obtained approval from the CCCU Faculty of Arts, Humanities and Education Ethics Panel. Appendices 7-11 demonstrate the ethical considerations made and the processes followed in relation to confidentiality and anonymity, data storage, the principle of beneficence, the right to withdrawal and finally mitigation of harm to participants. A key consideration to highlight was the informed consent of participants. To this end I produced two participant information letters and two consent forms, one version for parents and one for the young people (Appendices 7-10). This was due to the slightly different nature of their participation and the need to adapt the information accordingly. Additionally, I was mindful that both documents for the young person needed to be clear, concise and contained visual supports where appropriate, all of which contributed to ensuring participants were giving

their informed consent (Kumar, 2019). As these documents could potentially have been given to both a 9-year-old and an 18-year-old and I was eager to ensure they remained accessible to both, without being patronising to the older age group and alienating them in the recruitment process.

3.7 Research Design Process

The following section incorporates the ethical considerations above as it explains the research design process adopted for this thesis, moving from recruitment and participant information, to the three stages of data collection.

3.7.1 Recruitment

Establishing both inclusion and exclusion criteria (Appendix 6) helped to reach those participants who were best placed to enable the research questions identified in Chapter 2 to be answered, and to ensure validity to the research data (Patino and Ferreira, 2018).

Initial advertising (Appendix 5) took place through an autism charity which has a receivership of over 4000 individuals in their email bank. I then utilised local groups on Facebook (Bell and Waters, 2018), to advertise to over 25,000 individuals.

These methods resulted in 17 contacts expressing an interest in participation. After initial contact, assessment against the inclusion criteria and reading the participant information letters, five families remained, all of whom signed the appropriate consent and gatekeeper consent forms. One of the five families withdrew from the study prior to participation. Unfortunately, whilst many of the 17 families met several of the inclusion criteria most were

also still experiencing school refusal, which made them ineligible to proceed to stage one of

research.

3.7.2 Participants

Table 6 outlines key demographic data of those participants who took full part in the study.

All names are pseudonyms.

	Peter	Coen	Sara	James
Age	11	12	16	18
Gender	Male	Male	Female	Male
Diagnosis	Autism	Autism	Autism	Autism
Age received Autism diagnosis	7	9	13	14
Co-morbid diagnosis	None	None	ADHD	Dyspraxia ADHD Dyscalculia
EHCP?	Yes	No	No	Yes
School Year(s) school refusal took place in.	5-6	6-7	10-11	8-10
Previous School Type	Mainstream Primary	Mainstream Primary	Mainstream Grammar	Mainstream Secondary
Current School Type	Specialist	Mainstream Grammar	Mainstream College	Specialist College
Total Number of Schools since entering full time education	2	2	3	3
Parent Participant Name	Mary	Nell	Alice	Lucy
Relationship to Child	Mother	Mother	Mother	Mother
Two Parent Household?	Yes	Yes	Yes	Yes
Parents Employment Status:	One full time paid.	Both in paid employment	Both in paid employment	Both in paid employment
Number of Siblings	1	2	1	1

Table 6: Research Participants Demographic Details

3.7.3 Stage One - The School Refusal Assessment Scale – Parent (Revised)

As discussed in Chapter 2, school refusal is a heterogenous phenomenon (Ingul et al., 2012) making isolation of the particular cause of refusal for students extremely difficult, if not impossible. By focusing on the school-based factors affecting school refusal, it was important that only participants obviously affected by this were included in this study. To this end, the School Refusal Assessment Scale – Parent (revised) version (SRAS-P) was utilised as means of filtering suitable participants to proceed to stage two and three. The SRAS-P was devised by Kearney and Silverman (1990) to measure the maintaining functions influencing a student's school refusal (Table 3) and to support intervention and support.

After consent to participate had been given, parent participants completed the SRAS-P (revised) (Appendix 12). For the purposes of this thesis, either functions (a) or (b) were required to be identified as the primary maintaining function relating to the student's school refusal in order to proceed to stage two. The SRAS-P has not been designed to identify specific factors relating to a student's school refusal, rather it is used to identify the overarching function at play, therefore its purpose within this research study is twofold. Firstly, it provided a basis for inclusion/exclusion in stages two and three, and secondly it contributed to data analysis through identification of either function (a) or (b) as the primary source of school refusal from the parental perspective. Analysis of this survey was conducted using the established method outlined in Appendix 12.

3.7.4 Stage Two – The Parent-Child Conversation

Thomas (2017) notes that building rapport with children and young people can be extremely difficult and should be avoided, unless you have a pre-existing relationship with the child. As previously discussed, conducting an in-depth interview with a young person with autism as a relative stranger, and getting them to a point of feeling at ease and freely offering their perspectives on a potentially sensitive topic, during a global pandemic, was highly unlikely to be successful. In identifying an in-depth interview relationship as one which develops over time, based on trust and mutual respect, Goodson and Gill (2011) have described a relationship which may already exist between a parent/carer and their child. Parents and carers have the potential to scaffold their child's thinking, aiding them to articulate their inner thoughts (Wainryb and Recchia, 2014) in a way that an unfamiliar researcher would not be able to. Assuming that they have been consistent figures in a child's life, parents and carers are also likely to have a firm grasp on the history leading to key incidents which the young person may want to discuss (Wainryb and Recchia, 2014). This makes parents/carers invaluable in generating research data and, more importantly, helping the young person to reflect on their experiences both during data collection and retrospectively once the study has concluded.

In choosing to conduct parent-child conversations, rather than researcher led in-depth interviews, I accounted for several variables which could impact up on the quality of data (Table 7).

-	Lack of trust between young person and the researcher.
-	Awareness of young person's history with school refusal behaviour and how to safely navigate the topic with them, to ensure the least amount of harm possible.
-	Provide an opportunity for the young person to be able to articulate their thoughts fully with a supportive adult.
-	Conducting the conversations at home enable the young person to feel as comfortable as possible. This is important given that home, for a young person with autism is likely to be a safe space.
-	Parent's awareness of the topic might help the young person's recollections of key incidents.
-	Parent/carer is more likely to understand any colloquial language used by the young person and help to navigate this.
-	The impact of Covid-19 on conducting a research study under normal circumstance.
-	Any well-established power dynamics between the young person and their parent/carer are likely to be continued throughout the conversation. This has the potential to lead to the parent dominating the conversation or the young person being continually corrected.
-	The young person may not want to reveal details of their experience for fear of upsetting their parent/carer.

Table 7: The Factors Influencing Parent-Child Conversations as a Methodology Choice

3.7.4.1 Online Conferencing Software

The parent-child conversation was conducted using online conferencing platform Microsoft Teams to facilitate recording of both visual and audio data to support subsequent transcription. Recording participants using video aided me in interpreting the meanings of statements made when carrying out data analysis (see 3.8 for more detail).

3.7.4.2 Briefing and Recorded Conversation

By considering these influences and utilising a common framework (Figure 3), I was able to design a parent-child conversation which was appropriate to each participating family. I used a pre-set plan to brief participants (Appendix 15), which included explaining clearly the

purpose of the research and recording again, the process that would be followed throughout the recording, the protocols around safeguarding, and reiterated participants rights (see 3.6). At the outset of the recorded conversation, I asked key demographic questions outlined in Table 8. After this point I turned off my camera and microphone and left parent and child to engage in their conversation without interruption, until they came to a natural conclusion.

3.7.4.3 Conversation Scaffolding

Participants were provided with a narrative frame (Appendix 16) which provided scaffolding to support the parent-child conversation should it have been needed (Yang, 2019). Comprised of a list of sentence starters, featuring the phrase "I remember" and then a different feature of school life, the intention was to provide participants with a prompt should they find the conversation becoming difficult to navigate. Additionally, the sentence starters could have been used to support the conversation should participants have felt that they had substantially deviated from the topic (Thomas, 2017). However, it was also made clear to participants during the setup of the conversation, that the scaffolding device did not need to be used as a structure to follow and they were encouraged to discuss the topic as they saw fit.

1	How old are you?
2	How many brothers or sisters do you have?
3	In which town/village/city was the school where you experienced school refusal?
4	Do you currently attend a mainstream or specialist school?
5	Is this the school where you experienced your school refusal?
6	In which school year or years did you experience the school refusal that you will be discussing?
7	How many schools have you had since starting full time education, including your current school?
8	At what age did you receive your diagnosis of autism?
9	Do you have an Education, Health and Care Plan (EHC Plan)?
10	Did you have your diagnosis of autism during the period of your school refusal?
11	Did you have your EHC Plan during the period of your school refusal (if relevant)?
12	How many parents are in the household?
13	How many parents are in full time employment?

Table 8: Demographic Questions asked During Parent-Child Conversation

3.7.4.4 Contemporaneous Observations and Reflections

During the parent-child conversation I kept contemporaneous observations of the moments which felt to be particularly important to me at the time. These moments were based on my own subjective interpretations (Al-Saadi, 2014) of participants body-language, voice inflection and repetition/revisiting of subject matter. Further to this initial observation, I also wrote a reflective observation of each participating family's interaction with the research process, from the initial SRAS-P to the stage three questionnaire and everything in between (Appendix 19). Again, this was an entirely subjective reflective account to help me understand my participants more deeply. It also helped me to understand how they engaged with the research process and to identify the benefits and limitations of the research design.

Email with link to conferencing software sent. → Initial introductions and greetings → Briefing and reiteration of participant rights →

Explanation of conversation starter document. → Recording Starts → Demographic questions from researcher (table 8) →

Researcher turns off their camera and microphone → Participants engage in conversation - to conclusion → Researcher turns on their camera and microphone →

Initial follow up questions asked for missing information (due to internet interuption) → Debriefing - reiteraton of participant rights → Opportnity for questions from participants →

Explanation of stage three questionnaire requirments → Recording Ends → Thanks and Farewells

Figure 3: Parent-Child Conversation Framework

3.7.4.5 Multimodal Observations

Thomas (2017) highlights the benefit of behavioural cues such as fidgeting, sitting forward in a chair, or avoiding eye contact as useful in corroborating oral statements. Utilisation of multimodal analysis provided an opportunity to deepen the findings of this thesis by moving beyond a purely linguistic analysis (Jewitt, 2011), potentially highlighting crucial information participants expressed during their conversations. Participants may have verbally articulated a variety of school-based factors however it may be that only for a select few did they gesticulate, change their tone of voice, or engage/disengage eye contact from their conversational partner, providing added emphasis to their utterances that may be missed by linguistic analysis alone (Argyle, 2001). Within this study I recognise the importance multimodal observations can contribute to my understandings and analysis of participants experiences, however this is not a piece of multimodal research according to the overview provided by Jewitt (No Date). Significant occasions of these features of multimodal analysis have been identified and added to the transcript of the parent-child conversation to support my understanding of participants perspectives (Appendix 18).

3.7.4.6 Debriefing

Following the parent-child conversation, each participating family was debriefed whilst still on the Microsoft Teams session. This debriefing consisted of a reiteration of their right to withdraw from the research study, an opportunity to immediately have any particularly sensitive statements removed from the transcript and a reiteration of the confidentiality and anonymity of their data (BERA, 2018). Additionally, participants were invited to ask any questions they had about the research study.

3.7.5 Stage Three - Questionnaire

Following the parent-child conversation, a questionnaire was sent to participants for the young person to complete. The purpose of the questionnaire was to gather further insight on a variety of school-based factors from the children's perspective alone. To this end a Likert scale was utilised comprising a five-point categorical scale that is three-directional (Kumar, 2019). Furthermore, the questionnaire is divided across three areas; general school statements, school staff statements and intervention/support statements (Appendix 22). The visual design of the questionnaire and the simplicity of completion was a key consideration to ensure that participants across all ages could engage with it. However, some of the terminology used in the statements themselves may have been too complex for some of the younger participants, and therefore it was made clear that parents/carers could support the young person in understanding the statements.

Questionnaires were to be completed within 24 hours of the parent-child conversation to ensure that participants responses were more likely to be in sync with the narrative of their parent-child conversation, rather than disjointed and potentially irrelevant. Full detail on how this questionnaire was analysed can be found in 3.8.2.

3.7.6 Follow Up Email

Finally, email correspondence with participants afforded an opportunity to clarify information lost within the transcription process. Information was lost due to internet signal loss, unclear speech, unfinished speech, or participants talking over each other. Additionally, there were times during the conversation when participants expressed an opinion that is difficult to

understand or perhaps have used language that is coded in some way. Seeking clarification of these statements ensured that the full scope of participants experiences is gathered, allowing for as complete an analysis as possible. Any statements provided by participants in this way, have been added to the transcript to create a complete narrative.

3.7.7 Debriefing email

Once the final stage three questionnaire had been returned, participants were sent a final debriefing email which outlined my gratitude for their participation and a reiteration of their rights (Appendix 17). A further intention of this debriefing email was to provide families with a level of continuing support on their historic experiences of school refusal. As was shown in chapter 2, the cooccurrence of anxiety and depression with school refusal, led me to provide links to Mind (2021), Young Minds (2021), and the NHS (2021) to support participants in this regard should they require it. Additionally, on the topic of school refusal specifically, I signposted families to the Babcock LDP (2021) for current research and also to the Not Fine In School (2021) website which is a type of support group for families who have experienced school refusal.

3.8 Data Analysis

Having set out the data collection process, the following section sets out and rationalises the choices made in selecting both transcription and thematic analysis as tools to help answer the research questions. Even though the tables and figures incorporated within this section clearly identifying the step-by-step processes I followed, it is important to also recognise that

an immersive and reflexive approach to data analysis has been carried out, with revisiting of data at various points in the process.

3.8.1 Transcription

Transcription of parent-child conversations was undertaken to aid my immersion and familiarisation of data provided by participants (Oluwafemi et al., 2021). In choosing to transcribe each parent-child conversation verbatim, I aimed to ensure participant voice was heard in their entirety and that no data was lost. A key benefit to this transcription process is that reliance on intuition and individual biases is minimized (Azevedo et al., 2017) in the initial stage of processing data. Oluwafemi et al., (2021) assert that it is through transcription that the initial stages of interpretation begin and meanings within the data begin to form in the researcher's mind. In addition to the verbatim notation of utterances, transcriptions were developed to include key multimodal observations. In this regard, the transcriptions produced through this research process should be considered to sit between the naturalised and denaturalised processes described by Azevedo et al., (2017). Furthermore, as demonstrated by Figure 6, significant scores from the stage three questionnaires and follow up emails were merged with transcripts to ensure all data was in a single accessible location. The consistent structure and format of transcripts (Table 9) was developed to aid in data analysis, providing ease of reading and understanding complex data (Appendix 18).

FEATURE OF TRANSCRIPT	FORMATTING
POTENTIALLY RELEVANT DATA	<u>Underlined</u>
CODING	Placed in an adjacent column
MULTIMODAL OBSERVATIONS	**(bold in brackets)**
NEW SPEAKER	New Line
SPEAKERS NAME	**Highlighted in BOLD CAPS**

Table 9: Formatting Features of Transcripts

3.8.2 Thematic Analysis

In choosing an appropriate data analysis method, I carefully considered the theoretical paradigm under which this research study has been conducted (Kawulich, 2017). As a piece of qualitative research, framed within a social constructivist paradigm which views the community as an expert resource, it was important that the method of analysis provide opportunity for participant voice to be heard. It was equally important that the analysis method chosen facilitated interpretation of data, drawn from both my own subjective observations and from the direct views of my participants (Grbich, 2011).

It is for these reasons that I chose to engage in the process of thematic analysis to explore the data provided by participants. More specifically, I chose to work through a process which can be considered inductive, where codes emerge from the data, rather than assigning data points to pre-established codes (Miles, Huberman and Saldana, 2014). It should be noted that no matter my intentions, it is impossible to say that the codes and themes identified are without researcher bias (given the factors explored throughout the literature review) and therefore the coding process may unintentionally have a deductive influence (Kawulich, 2017). However, in producing an original piece of research which is among the first to specifically explore young people on the autism spectrums perspectives on the factors affecting their school refusal, it is crucial to me that codes were drawn from their perspectives

rather than applied to them. Further to this perspective, a combination of coding approaches have been utilised, which include descriptive, sub coding, simultaneous, and arguably most importantly In Vivo coding which is explained as using participants own words to create codes (Miles, Huberman and Saldana, 2014).

The process outlined through Figures 4-8 (explained in more detail below), demonstrate that the thematic analysis undertaken in this research study is not linear, instead it is intentionally reflective and cyclical. By re-engaging with data in a variety of methods, my intention was to explore participants perspectives from a range of angles to enable as fair a representation of their voices as possible (Wellington, 2015).

The first stage of thematic analysis had been completed prior to the parent-child conversation, through initial analysis of the SRAS-P (Revised) as part of the recruitment process. Once all data had been collated, I tabulated participants scores using a spreadsheet (Appendix 14). I then developed a Red, Amber, Green (RAG) system to denote highest and lowest functions affecting school refusal, allowing me to easily identify any similarities or differences in participants responses. This process can be seen in Figure 4.

Scores tallied to establish function of school refusal (A, B, C or D) (completed during stage one of research prior to Parent-Child Conversations)

All participants scores tabulated together (Appendix 14)

Red, Amber, Green system used to analyse tabulised scores for similarities and differences (Appendix 14)
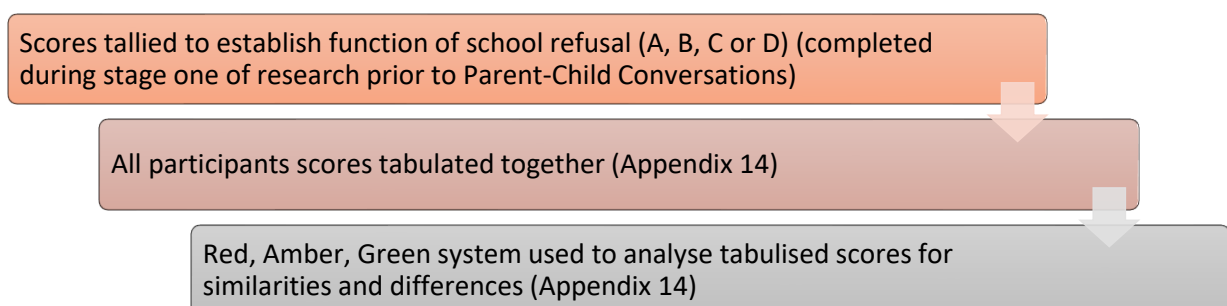
Figure 4: Process of Analysis of the School Refusal Assessment Scale (Stage One)

Having written contemporaneous reflections during the parent-child conversations, I added to these my initial reflections on participants responses to the SRAS-P and the stage three questionnaire, in addition to my thoughts about any technical issues involved in the parent child conversation (Appendix 19). In order to accurately present, compile and familiarise myself with data produced during the parent-child conversations, I undertook the following process (Figure 5). Firstly, I watched back the recorded parent-child conversation and transcribed verbatim the dialogue, producing an initial transcript. Then I re-watched each parent-conversation and annotated transcripts with key multimodal observations. After this, I read each transcript in full, ensuring that it made sense and that nothing was missing.

Contemporaneous reflections written during and after the parent-child conversation. (Appendix 19)

Initial transcription of parent-child recordings.

Second watch of recorded conversations with addition of multimodal observations to transcripts.

First full reading of parent-child conversation transcripts.
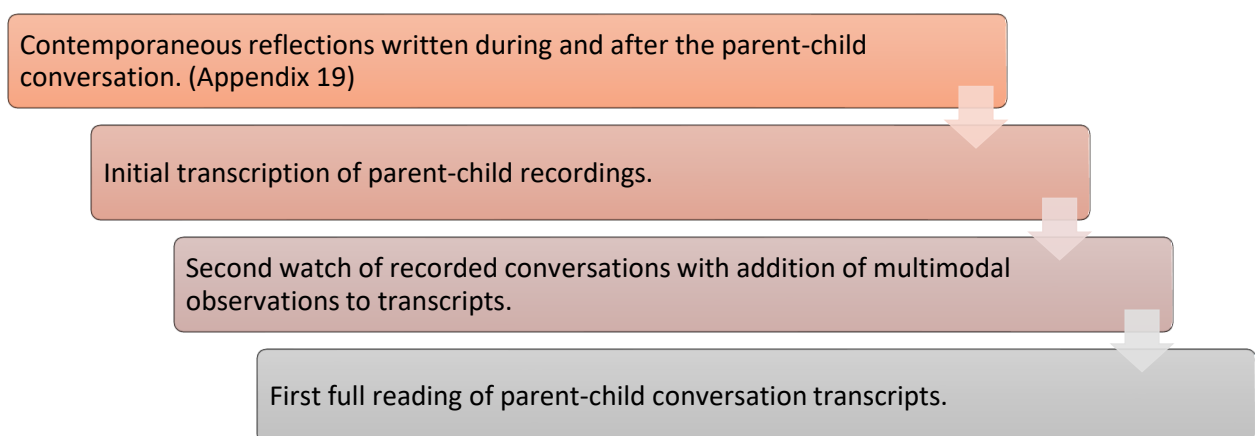
Figure 5: Process of Familiarisation with Parent-Child Conversation Data (Stage Two)

Once a full initial transcript had been produced, I moved onto the process of analysing the stage three questionnaire (Figure 6). Statements were scored based on positive or negative affinity, where the most positive receives a score of 5, and the most negative receives a score of 1 (Kumar, 2019; Appendix 23). This process helped to reaffirm data identified within the parent-child conversation, revealed information not previously identified, or helped to

expand upon a topic only touched upon during the conversation. Furthermore, those statements identified as either a 1 (most negative) or a 5 (most positive) were highlighted as significant. These have the potential to be the most influential on participants perception of, and behaviour at, school. These influential statements were cross referenced with the transcript of the parent-child conversation. Where there were matches in comments made and statements identified, the transcript was annotated accordingly. I then tabulated all participants scores together on a spreadsheet, adding together all scores for each statement. I then developed a RAG rating to identify those statements which consistently received the most negative response (6 or under = Red), those which were intermediate (7-10 = Amber), those which were less of a concern (10 or over = Green) (Appendix 23).

Individual questionaires scored and totaled.

Significant scores (1's or 5's) highlighted and added to transcripts.

All participants scores tabulated together (Appendix 23).

Scores across participants totaled for each statement (max score 20)

Total scores tallied and given Red, Amber, Green rating (>6, >10, <10) (Apendix 22)
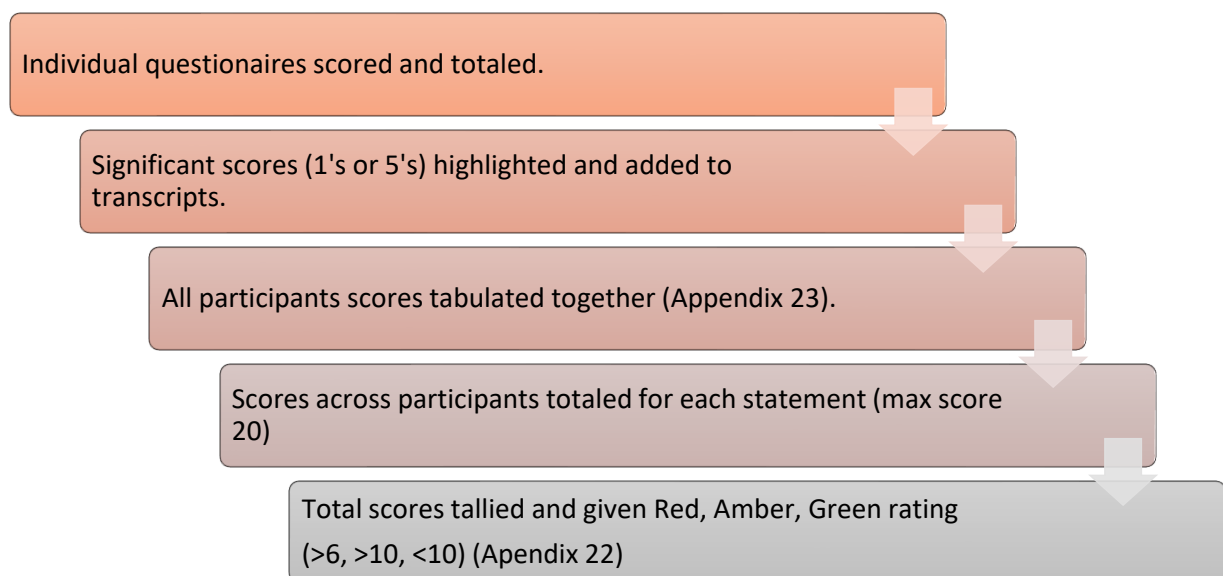
Figure 6: Process of Stage Three Questionnaire Analysis

Only once these phases of analysis had been completed did I move onto the full process of thematic analysis (Figure 7). I contacted participants via email to obtain any missing

information (see 3.7.6 for more detail), which was added to each transcript. Next, I read through each transcript and underlined each participant comment which I thought was relevant to help answer my research questions. These were determined by considering their direct relation to school, the weight of emphasis placed on the comment by multimodal communication, the length of time spent discussing the issue, or if it were an issue repeated again within the parent-child conversation. I then applied codes (descriptive, sub coding, simultaneous, and In Vivo coding) to each of these comments and created a spreadsheet listing each of the codes.

Having established initial codes present in the data, I moved to create a reflective narrative (Bruner, 1991) of each participant's experience, by following the process outlined in Figure 8. This approach helped me to further understand each of the participants as a whole person, to delve deeper into their story and to begin to understand how to present them to the reader of this thesis. Once these first drafts were completed, I printed and used physical versions of the transcript to cut and separate sections and codes, building separate mini transcripts which addressed a singular code/factor (Appendix 20). Where sections addressed more than code, elements were photocopied and compiled together. These mini transcripts were then used to generate themes within and across participants. This process produced the initial themes from which to work from. I was then able to cross reference these themes with the spreadsheet of codes to identify any outlying data. This was also important in helping to reveal what Delamont (1992, cited in Wellington, 2015, p. 272) describes as the "irregularities, paradoxes and contrasts" of participant data too. This revealed that not only were participants discussing factors affecting their school refusal, but also the manner in which they presented their difficulty with school (i.e., anxiety, depression, hiding), and also the more positive aspects of school life. Finally, I watched the

parent-child conversations for a third time and read each full transcript for a final time, again noting any surprising, outlining or new information I had not spotted before. This resulted in a final set of themes which were tabulated alongside coding (Appendix 21) to ensure clarity in answering my research questions.

Follow up emails used to add missing information to transcripts (Appendix 18) → Highlighting "important" comments on transcript. → Creation and application of initial codes to comments. ↓

Transcripts printed ← First draft of reflective narrative of each particiapnts experience. (figure 8) ← Creation of spreadsheet of codes. ↑

Transcripts cut and seperated in piles of similar codes. (Appendix 20) → Initial themes generated → Initial themes cross referenced with spreadheet of codes. ↓

Final themes established (Appendix 21) ← Re-read final transcripts ← Third watch of parent-child conversation recordings.

Figure 7: Process of Thematic Analysis

Transcripts and codes for each participant analysed. (Appendix 21)

Contemporaneous reflections referenced for demographic data. (Appendix 19)

Follow up emails referenced for additional information

3-4 key themes identified

Examples within each theme utilised to illustrate key points in the narrative.
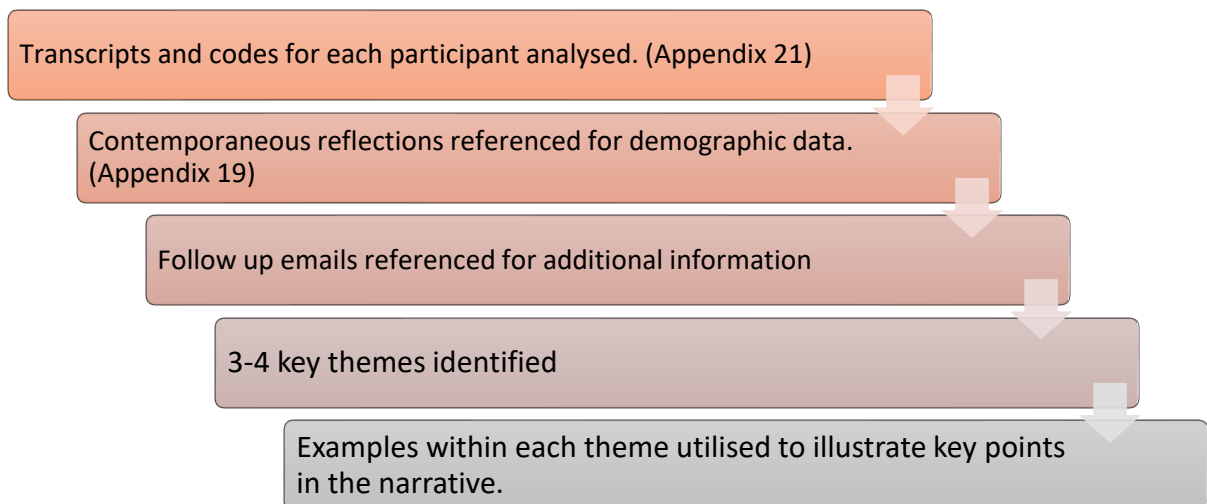
Figure 8: Process of Developing Individual Participant Narratives

3.9 Pilot Study

To prepare for the full-scale research process, I conducted a pilot study with two participant families. I was able to contact both families through my own professional and personal contacts. Table 10 outlines the demographic data of both pilot participants and Appendix 24-25 contains data from their stage one and stage three questionnaires.

Ostensibly, the pilot study was conducted to understand the viability of the planned research design, however there were in fact multiple purposes and benefits of conducting a pilot study which can be seen in Table 11 below. Conducting this pilot study provided me with clarity and confidence in my methodological design. Additionally, the pilot study also contributed to the validity of this research study, by demonstrating rigour in the research process (Ismail, Kinchin and Edwards, 2018).

	Olivia	David
Age	14	25
Gender	Non-Binary	Male
Diagnosis	Autism	Autism
Age received Autism diagnosis	12	13
Co-morbid diagnosis	ADHD	No
EHCP?	No	No
School Year(s) school refusal took place in.	7-8	8-11
Previous School Type	Mainstream Primary	Mainstream Primary and Secondary Grammar
Current School Type	Mainstream Secondary	N/A
Total Number of Schools since entering full time education	2	3
Parent Participant Name	**Zoe**	**Anna**
Relationship to Child	Mother	Mother
Two Parent Household?	No	No
Parents Employment Status:	Part Time Employment	Full Time Employment
Number of Siblings	0	1

Table 10: Pilot Study Participant Demographic Data

Reason for Pilot Study	**Changes Required? (Yes/No)**	**Notes**
Suitability of participant information and consent forms	YES	I gathered feedback from participants about the suitability of the information and consent forms. One participant felt that the young person information form may have been overly complicated. I adjusted the document accordingly.
Viability of using MS Teams as a conferencing software	NO	The use of this software worked very well, with no internet connectivity issues. The recording was saved to my CCCU drive correctly.
To become comfortable and familiar running the research process online.	NO	It may have been because I already knew the participants, however it felt very natural to run the research this way. I was able to have all my information to hand on my screen or in my notebook.
To find out if there were any other subjects needed to be added to the Conversation Starters crib sheet.	YES	I realised that I needed to add a couple more options to the crib sheet.

To find out if the subject matter was too sensitive for young people to discuss.	NO	All participants seemed comfortable discussing the subject of their school refusal.
To assess the viability of the stage three questionnaire	YES	Some changes to the phrases of statements and lay out of the questionnaire were required.
To practice transcription process	YES	I realised that I needed to create a clear and formulaic way of writing each transcript – which would aid in both the accuracy and speed of writing.

Table 11: Reasons for and Responses to Pilot Study

3.10 Chapter Summary

This methodology, built on an interpretivist ontological perspective, explored and analysed the rationale for the constructivist, communitarian, and participatory epistemological paradigms used to develop the research design. This chapter has explored the delicate navigation of issues such as ethical considerations, power dynamics of parent-child relationships and the influence of the researcher on the data collection process. Aligning with the person-centred approach outlined in Chapter 2, the research design has been crafted to enable young people on the autism spectrum to participate on their terms, as far as possible. Furthermore, the methodological design, including data collection and analysis, has been developed in a way which allows each participant to remain whole. Put simply, each participant's experience of school refusal can be explored and analysed independently of others – enabling a deep understanding of each unique experience. To this end, Chapter 4 presents each participant's experience of school refusal as a standalone narrative (Bruner, 1991), thereby keeping individuals at the heart of this thesis and underscoring the importance of listening carefully to each student voice. Finally, by engaging in a process of thematic

analysis across participants (Figure 7), individuals' narratives have been used to identify commonalities which are discussed in detail in Chapter 5.

Chapter 4

Participant Narratives

4.1 Introduction

Having set out the qualitative methodology and research design, this chapter draws out pertinent findings from each of the three stages of the research process for each individual participant. This will be done by firstly addressing the stage one SRAS-P and then by exploring participants experiences expressed during the stage two parent-child conversations, with links made to the stage three questionnaires. It was important to me to retain the unique identities of each participant, therefore, this section will be framed as a narrative of their singular stories which will inform the discussion in Chapter 5. This approach to wholeness of the participant, positively influenced the depth of analysis into each experience as there was a need to re-watch and re-read parent-child conversations to become familiar with them. All names used within the following chapters are pseudonyms. Additionally, unless specifically stated, comments made by children are their own and parents have supported them in telling their experiences.

4.2 Stage One -SRAS-P(Revised)

The stage one SRAS-P was used to identify suitable participants to proceed to stage two. All four parents/carers identified Function A as the dominant motive for school refusal, namely to "avoid school-related stimuli" (Appendix 14). Results indicate that James' parent believes Function B was also highly significant, whilst Sara's parent did not perceive any function other

than A as having any significant contribution to her school refusal. Notably for Peter and Coen, the two younger participants, their scores related to Function C (gaining attention from significant others) was not a great deal lower than Function A (Appendix 14).

4.3 Peters' Experience

Peter is an 11-year-old boy who received his autism diagnosis at the age of 7 (in year 2) and obtained an EHC plan at the end of year 5, which was "fought for" by Mary, Peter's mother. He currently attends a specialist school, having previously attended a mainstream primary school where he experienced his school refusal. Mary recalls that the school were unsupportive of the EHC Plan application and even after an Educational Psychologists' report, highlighting the degree to which Peter was masking in school, *"they (the school) did not want to hear it"*. Following the EHC PLAN, Peter moved to a specialist setting for young people on the autism spectrum which is *"working out fantastically"*.

However, the degree to which the negative educational experiences affected Peter, prior to his positive move, can be seen through his depression, self-harm and suicidal ideation.

Peter *"I was really depressed, so a lot of the time I couldn't go, so I hit my head with my fist, and I wanted to die"*

Mary *"That was really awful to see you like that wasn't it? (Peter nods). Can you remember why you wanted to hit your head and hurt yourself?"*

Peter – *(Peter shrugs)*

Mary *"you just felt a lot of anxiety in school?"*

Peter "Yeah"

Mary "And sometimes felt angry?"

Peter "Yeah"

There is no direct link mentioned here between any specific school-based factors and Peters emotions, however it could be argued that the accumulation of factors over a period of time potentially contributed to his depression and subsequently affected his refusal to attend school.

4.3.1 Peer Relationships

One of the primary driving forces behind Peter's negative experiences at school appeared to be related to the relationships with his peers which was addressed through three narrower topics, firstly his being bullied:

Peter "We had some bullies...I was bullied...remember when X pushed me against the fence?"

Then Peter spoke about his isolation from his peers when discussing lunch and break times:

Peter "That's because no-one looked at me or talked to me until lesson time. The whole time at school I was invisible"

And finally, Peter discussed how he felt his peers acted inappropriately during lessons and felt compelled to apologise on their behalf:

Peter "A lot of people were rude when we had guests, and a couple of them had to go out. So, I kept on saying sorry because I was embarrassed"

It was clear that Peter found these peer relationships complicated and difficult to navigate, however it was not mentioned during the conversation what support or interventions were put into place by the school to support Peter, and his peers, to improve their social relationships and understanding of each other. In fact, the stage three questionnaire completed by Peter in the final stage of this research indicates that he was not given appropriate support to help form friendships or to understand the perspectives of others. This is reflected further by his indication that he felt isolated, and that his thoughts and opinions were not valued by his peers.

4.3.2 Unstructured Time

An additional feature of Peters school refusal appears to be linked to periods in the day or during the course of the school year which are less structured or have the potential for unknown interactions. This is exemplified through the highlighting of Assemblies, Lunch Times and Sports Days as particularly troublesome.

4.3.3 No Voice

Both Peter and Mary indicated that Peter did not have a voice at school, that he was not visible and was not listened to:

Mary "I think for Peter at his last school, he didn't feel he had a voice"

Peter "The whole time I was at school I was invisible"

Additionally, it was indicated that Peter found it hard to speak with teachers to ask for help due to his anxiety. As with the lack of support for developing peer relationships, there is no indication that any support was in place to aid Peter in his anxiety or in building positive relationships with his teaching staff. Peters' responses to the stage three questionnaire indicate he was nervous about strict teachers. When asked during the conversation about his teachers, he said that *"some of them were good and some of them bad"*.

Furthermore, whilst not discussed during the parent-child conversation, Peter indicated in the stage three questionnaire that his school refusal was not understood or supported by the school, the teachers or the SENCo. In fact, the only member of staff who perhaps gave some support in this regard was the Teaching Assistant.

4.4 Coen's Experience

Coen is a 12-year-old student who attends a mainstream grammar school. He experienced school refusal during the final few months of year 6 and the first few months of year 7, this coincides with the transition stage from Primary to Secondary school. Coen received his autism diagnosis during year 4, whilst at primary school, which was then relayed to his peers by his class teacher, without his or his family's prior knowledge. Nell, Coen's mother, felt that this action by school staff had good intentions behind it, however it *"might have been good to talk to Coen about it before and checked that was what he wanted"*. Coen's school did support an application for an EHC Plan, however it was not given and Nell cites his doing *"well academically"* as a potential reason for this. Whilst Coen provided a large number of isolated factors relating to his dislike of school, there were some which appeared to be more pressing

for him than others, these included his relationships with peers, his relationships with teachers, and inappropriate support from the school.

4.4.1 Relationship with Peers

It is clear that the period of transition to secondary school has not been easy for Coen, and this can perhaps be explained by his moving from a small village primary school to a large secondary environment with more students, almost all of whom are physically bigger than him. Coen explained how his year group were treated by older students:

Coen "*Like people in year 10 would just trip year 7's over…they just swear and trip people over*"

Unfortunately, Coen's experiences with inappropriate behaviour from his peers is not limited to older students. During the conversation Coen spent a significant portion of time discussing students in his class and his relationships with them.

Coen *"I mean a lot of children in my class now are horrible people".*

He recalls how one student *"always says horrible stuff"* and that once he *"randomly pinched and called me bad at everything"*. On this occasion Coen's response to this bullying behaviour was to remove himself from the school grounds, which he said was simple because the school *"leave the gates open, so if someone's rude to you, it's just like inviting you to leave"* He went on to point out that peer relationships can be an issue during lessons too.

Coen *"With like 20 lessons and 30 people, if you think about it, that means there's like one or two people in your form that are rude to you, the chances are, you're most likely to be in a class with one of them, where you sit next to one of them".*

Although this clearly causes Coen some distress, he also points out that the reverse is also true and that he gets to sit with friends from time to time too.

4.4.2 Relationships with Teachers

Coen's relationship with teachers is an important feature of his feeling comfortable at school. Where the relationships are positive, Coen feels able to get involved with the lessons to a greater degree:

Coen *"because I'm used to the English teacher and I know, I like, (he's) the only teacher I can talk to about anything, once or twice, not about anything like different, just about the lesson, once or twice so I read in front once"*

This is further exemplified by the disparity in his relationship with his History and Geography teachers,

Coen *"well the History teacher's very kind and funny…if you get a question wrong in history, he says 'good job but you got it wrong'…and the geography teachers just rude…like say you get a question wrong he will just stare at you and go 'what', like that"*

Nell pointed out that the working relationship between Coen and his geography teacher got to a point where they had to have a meeting with his head of year to address it and attempt to resolve the issues.

4.4.3 Getting it Wrong

It was apparent throughout the parent-child conversation that Coen had a particular concern with getting things wrong or being seen to get things wrong. This resulted in avoidant behaviour where he would simply not take part in performative subjects such as music, drama, PE and even English. His fear seems to be based within two domains, the first being humiliation in front of his peers:

Coen *"That's why in sports day, if I had to race in front of everyone, I mean, what if you trip over or something. Then you'd never be able to go to that school again"*

And the second being fear of punishment from his teachers, which is exemplified in this example from his primary school:

Nell *"What was it about Mr A [that you didn't like]"*

Coen *"He just used to be really strict. That's pretty much it. You used to have to be really smart or he'd tell you off".*

Coen also referred to his PE teachers telling him off and shouting at him, his fear of getting detentions everyday if he is late to school, and his relief at the reassurance of Mrs G not telling him off for running away from a bully. This is further evidenced by Coen's strong agreement with the stage three questionnaire statement "I was nervous about strict teachers". This all feeds into the discussion later in Chapter 5, which identifies teachers as authority figures being a factor in participants school refusal.

4.5 Sara's Experience

Sara is a 16-year-old student who attends a mainstream sixth form setting having previously attended a mainstream grammar school where she experienced school refusal during years 10 and 11. Sara's mother Alice first suspected that she may be autistic toward the end of year 8 and she went on to gain her diagnosis at the end of year 9. Sara does not have an EHC PLAN but does have a co-morbid diagnosis of ADHD. Sara comes from two parent household, both of whom are in paid employment. She has one sibling and has attended a total of three schools since entering full time education.

Furthermore, though not mentioned in connection with a specific diagnosis, during the conversation Sara spoke about both her "anxiety" and periods of being "non-verbal". Sara revealed many individual factors relating to her school refusal and made it clear that there was not a single one alone which caused her to refuse, rather it was the combination of factors which influenced her actions:

Sara *"Like, by themselves they were all ones that I could probably manage…but once they're all together I just can't at all.*

This is perhaps linked to the incessant nature of the school day which Sara describes as:

Sara *"everything is going really fast in school anyway, even if it's not literally, everything seems to be going, I'm always going somewhere, I always have an eye on the clock, I always have something to do, and it just means that it's really difficult to take a step back"*

4.5.1 Academic Pressure

This pressure to be on the go and to be actively participating in school is reflected further through Sara's comments about the expectations placed on her by virtue of being at a grammar school.

Alice "can you put your finger on some of the things that made it hard to go to school"?

Sara "Obviously because it was a grammar school it was very academic based, and so there was a lot of academic pressures."

Within the stage three questionnaire, one of the few statements Sara strongly agreed with was that she 'felt a large amount of academic pressure at school'. Whilst this burden was felt by Sara throughout her education, she appeared to feel it most keenly during the period of her school refusal. This was due to the schools focus on ensuring that regardless of her absence, Sara continued to produce homework and keep up with her lessons.

Sara "And then suddenly, once I've missed the work, I have to try and do everything at once, and that just stressed me out, a lot, like, A LOT (original emphasis)"

Later in the conversation Sara spoke specifically about homework:

Sara "I wasn't able to do homework. And then if I hadn't done that, I couldn't go in. I felt like I couldn't go in because I was meant to have done it, I haven't, and being the only person who hasn't, the teacher will probably go on at me about it."

This concern about the teacher's response to homework is possibly founded in Sara's understanding that:

Sara "they were all very much focused on the grades rather than the person"

4.5.2 Unapproachable Authority Figures

By focusing on her academic achievement rather than Sara as an individual, Sara felt misunderstood by her teachers. Repeatedly during the conversation Sara spoke of the need to constantly explain her actions, or inactions, at school, which given her complex relationship with communication and anxiety was no easy feat. Sara explains that although finding gesture and sign an easier method of communication she doesn't…

Sara "feel comfortable communicating that way with them (teachers) because they were an authority figure and in a professional environment"

During times of high anxiety and stress in the classroom, when Sara would feel the need to step away to the AEN office, she would find that she still had to explain to the teacher where she was going:

Sara "which would involve some sort of communication…so if I wanted to go there, I'd have to explain it…and then I'd have to communicate that in front of the class"

Removing the need to communicate and being given a free pass to take herself from the classroom at any point, is no solution however as Sara notes:

Sara "Teachers are always gonna forget, teachers are always gonna ask me, people are gonna ask, students, it was just, I couldn't".

Interestingly, this is not just an issue focussed on anxiety and stress, but even having to ask to go to the toilet can be an unnecessarily complicated interaction:

Sara "Because I would always have to ask to go to the toilet. And if they said no, I wouldn't push it further, I'd just sit there and bottle it up. Which, umm, would usually make it worse because I would assume that would happen again" or "they always do that weird thing when

they go 'do you really need to go' and then you have to awkwardly say yes. Yeah, and they'd be like "just don't take too long".

4.5.3 Staff Understanding and Relationships

The stage three questionnaire shows that Sara did not feel that her thoughts and opinions were valued by the school staff, and that teachers did not take the time to listen to her. School staff being unapproachable and not appearing to prioritise Sara as an individual, is reflected in how she perceived their understanding of her and the subsequent relationship she had with them.

Sara *"They knew that I had anxiety, that I was autistic, that I had ADHD, they knew those things, but they didn't necessarily know the things that came along with those. And they assumed that because I was always kind of there, I was quiet, I didn't necessarily interrupt, I was always in the background, I didn't ask for help, I think they assumed I didn't need help".*

The presence of a diagnosis does not mandate a particular set of interventions for a student, rather it should highlight to teaching staff that there needs to be a discussion and a strategy put in place to support them. However, it would appear that Sara's experience was of teachers who did not see it as their job to help her engage with the school environment and curriculum.

Sara *"I remember…when I asked…for things I could do to catch up…one time they said, 'that's not my job'".*

Alice, Sara's mother, received a similar response from a teacher who she recalls as saying *"This is the way I teach; this is the way I've taught for the last 30 years, and I'm not going to*

change". This, Alice goes on to explain was a feeling she received from a number of teachers, although they were not quite as explicit.

Sara - *"So they wouldn't change it in any way to make it easier for the students and then they'd get frustrated when I struggled…and just a lot of them, they weren't willing to change because I was the minority in that sense."*

The stage three questionnaire demonstrates that the only interventions and supports Sara felt positive about related to her organisation in school and helping to understand herself. Aside from the SENCo however, she felt that no members of staff supported her during her period of school refusal. Even here, Sara does not seem to think that the SENCo really understood what was happening.

4.6 James' Experience

James is an 18-year-old student who attends a specialist sixth form setting, having previously attended a mainstream comprehensive school until the end of year 10. James was diagnosed as being on the autism spectrum when he was 14 years old (end of year 9 into 10). He had an Education Health and Care plan in place when entering secondary education for diagnoses of Dyspraxia, ADHD and Dyscalculia. James began school refusing toward the end of year 7, however the primary period of school refusal began in year 9, which James related to the increase in academic pressure. He describes his move to his current specialist school as him being *"in heaven. More than that. I can't even explain, I was calmer, I was better, my work improved, I had an end in sight, I had a future planned".*

It was clear throughout the parent-child conversation that James felt passionate about the experience of his mainstream school, using phrases such as *"being tortured", "it was awful" and "it was cruel".* This has led James to experience what Lucy described as *"trauma induced anxiety"* which *"will still flicker up sometimes".* Whilst James and Lucy touched on a wide variety of specific factors during their discussion (including peer relationships, class sizes, academic pressures etc.), it was clear that the overarching factor involved in James' school refusal related to the school staff.

4.6.1 Teacher Understanding of Support Needs

James indicated in the stage three questionnaire that his teachers did not take the time to listen to what he needed in school and that his thoughts and opinions were not valued by school staff. James went so far as to state that he felt *"very robotic and very controlled…I have no control, I'm not going to have my say".* This is exemplified by the insistence of staff that James use a blue overlay to support his reading in exams, in spite of him saying that it would not be beneficial.

James *"I said no miss, this is not helping me cos this is just changing the colour of the page, what I need is the information on the page (changed), unless you can make this overlay scatter the words out, this is not going to help. They just ignored me. They completely ignored me. Nothing. They didn't care."*

When trying to explain his hyper-sensitivity to the SEN team (which was on his EHC PLAN), and his need for a quiet space to take his exams, James recalled an interaction with staff that left him feeling like an alien.

James "Literally I went in and I remember saying, look Miss, I can't handle this, I can't do this I'm feeling ill and, but it was more than that. It was a plead, it was like an I CAN'T do this. PLEASE! And they just looked at me…and one of the staff turned to the Deputy SENCo and this is genuinely quoted, they went 'what should we do about James?', It was, it was really poorly done…they crumbled at the slightest request."

Reflecting again on the stage three questionnaire, it can be seen that James felt totally unsupported by the school during the period of his school refusal.

4.6.2 Teacher Training

Perhaps this lack of understanding of James's support needs, has a basis in a lack of appropriate training. Multiple times during the parent-child conversation James and Lucy mentioned insufficient training and a lack of understanding on how to support individuals on the autism spectrum.

Lucy "It was about the teachers…not having specialist training…they didn't have the training to know what to do with you".

In another exchange James and Lucy stated that:

James "there was no help"

Lucy "they had no idea"

James "It was a one-track road, no turning back, no junctions, no other routes round, nothing.

For James, another issue linked to this was the overstated expertise of staff. Lucy explained that they chose school X because it was a small setting with a resourced provision for Special

Educational Needs and Disabilities, and she was told by staff that they had *"a lot of expertise in house that could help"* to which James replied, *"They didn't"*.

Furthermore, later in the conversation Lucy stated that,

Lucy *"From a parent point of view it was because the staff didn't have the training to know"*

James *"And also claiming that they had, a lot of them, but they didn't"*.

4.6.3 Inappropriate or Insufficient Interventions

Linked to both teacher training and the lack of understanding of James, is the interventions put in place to support him during his time at the school. The stage three questionnaire is clear in indicating that James felt the support he was given was unsuited to his needs, and that he was not given the help he needed across a range of school areas such as sensory difficulties, peer relationships, homework and even in understanding himself.

The lack of appropriate interventions can be seen through this example drawn out by James and Lucy.

James *"I said that it was like they were putting the work on a power point, printing it off, scrunching it into balls and literally pelting it at me with no direction, no means, no instructions and I just could not pick them up.*

Lucy *"it was like you're receiving that language. Ya know, we know there is a difficulty there don't we…in processing. How fast you could process that information and it really became intolerable for you…I remember saying to the SENCo at school, ya know, just give him a print*

out of the lesson and the lesson objective and he can make notes on that…she said she would ask the teachers and then it never ever got done".

It seems even when the difficulties and the ideal interventions were conceptualised by James and Lucy and handed to the teaching staff to put in place, they were still not followed through with. The consequences of this can be seen not only in James' academic decline but also in his growing frustration, anger and lack of trust in the school staff.

James *"I became angry"… "once I'd lost trust in the teachers, I lost trust in everyone. I lost trust in Mum. That was a big thing. I lost trust in anyone's advice, anyone's!".*

4.6.4 Non-Inclusive Environment

The combination of factors highlighted above points to a school which found it exceptionally difficult to understand and provide appropriate support for a student who needed help. One reason for this difficulty, may be seen through James's feeling that it was in fact two schools.

James *"The unit that was attached to the school, they claimed that they could integrate special needs into the mainstream school, and it felt very separate. I would genuinely plan my day around am I, it was like two different schools. It was like am I going to School X or am I going to the SEN unit".*

When speaking about his current specialist setting, James highlights that support structures are built into every aspect of his school day…

James *"Whereas now it fully integrated, it's the norm, there's no 'oh you need this extra help', it's integrated with everything".*

The expectation James and his family had, upon starting at school X was that the staff understood and had the expertise to support James within mainstream classrooms, using the expertise they had on hand from staff within the specialised unit. However, this never transpired, and James was left to make a choice between coping in the SEN unit, or not going to school at all.

James *"If I knew that I was going to be staying in the SEN Unit, I would (Long pause), I would just about be able to go in. If I knew I had a whole day in the (main) school, forget it, I would not go in."*

4.7 Chapter Summary

By engaging in a narrative approach and keeping each participant whole, this chapter has provided an opportunity to hear from each young person about the unique contexts and experiences they associate with their school refusal. As a result, it could be suggested that this study concurs with the current understanding of school refusal as a heterogeneous phenomenon (Ingul et al., 2012), as each participant's experiences are distinctive to them. However, it is also evident that whilst circumstances, individuals and actions taken are indeed unique to every participant, there are in fact commonalities to be seen throughout the four parent-child conversations which can help to answer the research questions. By critically evaluating these common factors alongside current literature, Chapter 5 will develop a fuller understanding of the school refusal experiences of young people on the autism spectrum, leading to a clear set of conclusions outlined in Chapter 6.

Chapter 5

DISCUSSION

5.1 Introduction

Having explored each individual participant's school refusal experiences in Chapter 4, this chapter will now analyse and discuss the findings of this research study as a whole. To begin, it is useful to reassert the two research questions which are to be answered:

1. What school-based factors do young people on the autism spectrum relate to their school refusal?

2. How do those same young people frame those school-based factors?

Following rigorous thematic analysis (Appendix 18-23; Figure 7) the following discussion is framed around three key themes identified by participants, these are the School Environment, Peer Relationships and Teacher Relationships.

5.2 School Environment

The school environment encompasses features such as the sensory environment, the general school curriculum (e.g., the subjects studied and the structure of the school day/year) and staff pedagogy. As previously mentioned in Chapter 2 school refusal is a heterogeneous phenomenon (Ingul et al., 2012), and the variety of factors within the school environment highlighted by participants are shown within Table 12.

Sensory Environment	Peter	Coen	Sara	James	School Curriculum	Peter	Coen	Sara	James
Cramped/Small Classrooms		■	■	■	Fast Pace of School/ Busy Environment	■		■	■
Distractions			■		Non-Uniform Days				
Bright Lights		■	■		Performance Subjects (Music, Drama, PE)		■	■	
Narrow Corridors		■	■	■	Sports Days	■	■		
Noisy/Loud	■		■		Unstructured Time	■			
No Safe Space		■	■		Exam Arrangements				■
Uniform		■	■		Academic Pressure			■	■
Transition between Classes		■	■						

Table 12: A summary of participants negative comments regarding the school environment and curriculum.

5.2.1 Sensory Environment

As discussed in Chapter 2, effective modification to the sensory environment is fundamental to providing a conducive learning space for young people on the autism spectrum (Mills and Chapparo, 2018; Zazzi and Faragher, 2018). The Mainstream Core Standards (2021c) have been provided to help schools understand how to support students in this context. Participants in this study mentioned a wide variety of environmental factors (Table 12) which negatively impacted their sensory processing and ultimately their ability to engage effectively and positively with school, this information was gathered from both stage two and three of the research process. This could suggest that even with the plethora of information and guidance available on how to develop an environment suitable to the sensory needs of individuals on the autism spectrum, schools are either unable or unwilling to adapt their physical spaces accordingly. Having said that, despite all participants highlighting the sensory environment as an issue at various times during the parent-child conversations, it was also dismissed as unimportant in the grand scheme of things: "*Well at School Y it stinks, but that*

doesn't matter" (Coen), *"It wouldn't have been a problem by itself, but it just added on"* (Sara – referring to her uniform)

5.2.2 School Curriculum

Similarly, to factors which had a sensory impact, participants highlighted a variety of factors which were influenced by the general (rather than specifically academic) school curriculum. Considering these as a collective, it could be said that they represent the *"unknown things that would happen"* highlighted by Sara as being of particular concern. Routines and structures have long been established as beneficial in best practice for young people on the autism spectrum and here again we see participants articulating a difficulty with breaktimes, lunch times, and alternative school days such as sports day and non-uniform days.

Participants also expressed a particular concern with the academic curriculum. This was expressed not so much around the content but rather how it was delivered and the importance of academia over social, emotional and mental health issues, or as Sara puts it *"they were all very much focussed on the grades rather as opposed to the person"*. This is perhaps not surprising given findings that just 54.4% of students were in receipt of an adapted pedagogy (Anderson, 2020). Coen signposted to this when explaining that a reflection area had been established at primary school for him to use as space to *"have a break"* – however he was only permitted to use it during lunchtime, *"so there was nothing you could do if you didn't like the lesson".* For James, the issue of academic pressure was linked to his performative ability in testing prior to attending secondary school, which then informed the expectations of teachers of his academic path, i.e. he should be entered for GCSE's rather than BTEC's – a key consequence of this expectation was that James was obliged to attend

lessons with larger class sizes, which were known to be a particular issue for him prior to attending secondary school. This appears to be an example of the contradiction between what the Education Act (2002) states is the requirement of schools and the manner in which schools measure their success (Department for Education, 2020b), suggesting that mainstream schools focus on academic outcome measures rather than the development and growth of individuals (see 2.6.3.4). Within the stage three questionnaire, Peter, Sara and James all indicated that they *strongly agreed* with the statement that they "felt a large amount of academic pressure".

5.2.3 Summary of School Environment

Participants within this study all highlighted a variety (Table 12) of environmental factors which affected their school experience, ranging from the smell of classrooms to the focus on academic results. However, the key finding from this study is that even with the physical environment and structure of the general curriculum being as issue for participants, it was also not the most pressing concern for any of them. Whilst an explanation for this was not offered by participants, I would argue that it is perhaps because both peer relationships and teacher relationships (and the individual factors therein) are more burdensome and harder to overcome.

5.3 Peer Relationships

Recent research into school refusal for young people on the autism spectrum and the link to peer relationships has tended to focus on the phenomenon of bullying (Bitiska, Heyne and

Sharpley, 2020; McClemont et al., 2020; Ochi et al., 2020). However, it is apparent from participants in this research study that whilst bullying is indeed a factor which must be considered (mentioned by Peter, Coen and James), it is just one element in a more complex social interaction that takes place within a mainstream school.

5.3.1 "I Was Trying My Best"

It is important to understand that participants in the study identify as students who wanted to work hard and learn. This can be seen through comments such as Coen not *"see[ing] the point in PE",* as it doesn't help academically and won't help him get a job; and this exchange between Lucy and James - "*You are a boy who really tried hard…who wants to learn…who wants to do his best*" to which James replied, "*I was trying my best*". The general behaviour of peers is echoed through Sara's observations that she *"would kinda dread"* on classroom where *"nobody else in the class wanted to do any work".* This has ramifications on the perceptions of these students on their less hard working, uncooperative peers. Peter recounted how he felt the need to apologise to teachers and visitors for the behaviour of his peers because he was "*embarrassed*". The weight of this apparent responsibility and the emotional distress Peter felt because of his peer's behaviour to others demonstrates the empathetic response he was having to others.

Despite the difficulties identified here by participants, within the stage three questionnaire regarding the statements "I was given the help I needed to understand the perspectives of others" and "I was given the help I needed to form friendships", only Coen gave a response indicating he received support, while the remaining participants either disagreed or strongly disagreed with these statements. This is a damning indictment of school's responses to the

SEND code of practice (DfE and DoH, 2015, pp.16-17) which states that schools **must** "promote equality of opportunity and foster good relations between disabled and non-disabled CYP".

5.3.2 Bullying

Notwithstanding the findings above, it is important to note that bullying was mentioned by participants, and therefore whilst recent research (Bitiska, Heyne and Sharpley, 2020; McClemont et al., 2020; Ochi et al., 2020) does not paint the whole picture, it is important in understanding this crucial aspect of the school experience and its effects on school refusal. Peter and Coen both discuss bullying with regards to its physicality – *"X pushed me against a fence"* (Peter) and *"he randomly pinched me" (Coen)*. However, it was emotional bullying which was given more weight by participants, either though the amount of attention it received, or by their non-verbal behaviour when discussing it in the parent-child conversations. Peter spoke about others not *"look[ing] at me or talk[ing] to me until lesson time....I was invisible to them"*. Which is echoed in Lucy's observation of James' peers where she asserts that *"nobody included you",* leading James to state that *"I'd think, huh, they think I'm a weirdo, I must be the different one, I must be the wrong one here, what have I done wrong"*. Coen too discusses the constant verbal bullying he received, where he was told that he was *"bad at everything and told [sic] to kill myself"*. Meanwhile, Sara explained that her relationship with peers was framed around her being shy and a *"bit more withdrawn then"* and her difficulty in the classroom was in part *"because of people I wasn't comfortable around in lessons"*. This suggests that despite the complex nature of the diagnostic profile of autism

(see 2.3), students have an awareness of peer relationship breakdown and require support to navigate this.

Both Sara and Coen point to the importance of strong friendships and finding those who you can be comfortable around as a positive aspect of school life. Sara explains that unstructured times during the school day were not a big issue for her as she had an established group of friends whom she trusted and could rely on to support her. Coen too suggests that even through the bullying he experienced, the positive relationships made with peers can act as a counterbalance, *"now at secondary school I have like ten best friends, but like ten people who are rude to me, so yeah".*

5.3.3 Summary of Peer Relationships

Even with these positive aspects of peer relationships, all four participants disagreed or strongly disagreed with the statement that their "thoughts and opinions were valued by their peers" within the stage three questionnaire, suggesting that negative relationships far outweighed the positive. However, it is important to note the distinction found within this research between negative experiences resulting from bullying and those negative experiences resulting from a clash in values towards education and respecting others. This could suggest that schools need to refocus the way they view peer relationships and develop proactive measures to develop better understanding among students.

5.4 Teacher Relationships

The theme of Teacher Relationships is arguably the most complex of the three to be addressed within this discussion. Teachers were, by quite some margin, mentioned more frequently than any other factor participants related to their school refusal (Appendix 21). The manner in which participants identified and linked their difficulties at school with teachers came in a variety of forms, and the process of thematic analysis (Figure 7) led me to two secondary themes which will be used to explore and analyse Teacher Relationships below. These secondary themes are Teacher Understanding and Teachers as Authority Figures.

5.4.1 Teacher Understanding

There are two key factors which participant comments suggest are intertwined in teachers developing an understanding of student needs; firstly, the importance of listening to students when they express their difficulties; and secondly ensuring that training and pedagogical practice relating to strategies and interventions are relevant.

5.4.1.1 Listening and Hearing

Coen explained that over time he had been given the opportunity to sit with "Mrs T" (his pastoral lead) for over three hours to discuss *"things to help"* and that *"she's very good at asking the right questions"*, providing a demonstration of Merrick's (2020, p.110) guidance that the "needs, thoughts, feelings and priorities" of students can be accessed through conversation. However, Coen goes on to say that *"I've never seen Mrs T do anything about*

it", suggesting that for Coen listening is about more than just hearing, it's about taking appropriate action as a consequence of what has been heard. The United Nations Convention on the Rights of the Child (United Nations, 1989) reinforces Coen's perspective as it mandates that teachers should take children's opinions seriously, something that Mrs T, through her inaction, does not appear to have done. James described occasions where he approached the school to explain his difficulties but felt ignored, stating that *"I literally went to all the members of staff, I even went to some cleaners, ya know, I went through everybody to try and get the message across, no one would listen. They just swept it under the [rug]"*. Here, James is attempting to keep his teaching staff informed about his needs on a regular basis, inadvertently doing the job Hughes-Lynch (2012, p.19) states is that of teaching staff.

It is equally vital to note that parent participants highlighted the importance of their being listened to and heard by staff when discussing their young people. Alice described a situation where she spoke with Sara's teacher about adapting the teaching style and differentiating to assist Sara and was told that *"this is the way I teach…I'm not going to change"*. This is despite the SEND code of practice (DfE and DoH, 2015) and Mainstream Core Standards (2021) making it clear that teachers are required to support learners through differentiated means. Alice went on to explain that whilst she was not able to directly quote others, this unwillingness to respond to the concerns of students and parents and adapt pedagogy in the classroom was something other teachers at the school had demonstrated. Sara perceived this as an example of teachers not *"care[ing] about the individual"*. Again, this apparent lack of care could be linked to the measures of success schools are judged by (see 2.6.3.4), or it could be explained by ineffective leadership in establishing an appropriate ethos (see 2.6.3.3) or even fatigued and over worked teaching staff. However, Mary, Peter's mother, explained that she *"fought for the EHC PLAN"* and that even once an Educational Psychologist was involved

in the process and described Peter's masking and anxiety to the school *"they didn't want to hear it",* suggesting that there is perhaps something more systemic at work than simple individual fatigue or pressure.

Communication is a two-way process of understanding (Hay and Winn, 2005) not limited to verbal conversation, something made clear by participants describing their non-verbal behaviours as indicative of difficulties being faced at school. For example, Coen's school refusal was often presented by his either running away or hiding during highly stressful moments. Whilst many of these incidents were observed and tracked by the school with appropriate follow up actions such as calling home, Coen observed that *"You can just hide the whole lesson, they don't really care".* Additionally, it was explained by Peters mother Mary, that Peter felt he had no voice at school and that he found it difficult to ask for help. Notably the feeling of not being able to ask for help has not gone away for Peter in spite of him moving to a specialist setting, suggesting this is a non-verbal characteristic of Peter's which should be considered by all members of staff within any setting. Similarly, Sara discussed the struggle she had in explaining her difficulties to teachers, *"I could barely work up the confidence to actually talk to them",* explaining further that *"they assumed that because I was always kind of there, I was quiet, I didn't necessarily interrupt, I was always in the background, I didn't ask for help…they assumed I didn't need help".* It is apparent from these examples that school staff need to be more proactive in their communication with young people on the autism spectrum, something which is reinforced by the Autism Education Trust (AET, 2021a).

Furthermore, James explained that after a long period of trying to articulate what he was finding difficult at school and how he needed to be supported, but finding he was "*completely ignored",* he finally resorted to anger, *"this was where they really made me leave lessons, be*

argumentative, answer back…this was me trying to get my message across". It would appear in this situation that James's reasonable and discursive attempts to resolve his difficulties were unresolved, however once *he* became difficult, the school responded by punishing him through detentions, which he described as *"really quite cruel to be honest".* This is perhaps a reflection of Merrick's (2020) findings that the attitudes of staff are a barrier to involving students in planning processes. Lucy stated that the school *"let you get to crisis point before they genuinely put enough help in for you",* which James perceived as his not being listened to, however Lucy, James' mother had another perspective, she felt that *"they were listening, but they just had no idea what to do with it",* suggesting a lack of appropriate training, which is addressed below.

5.4.1.2 Training, Strategies, and Interventions

It is clear then that listening, and hearing is important in understanding and supporting students on the autism spectrum through their school refusal experiences. However, Lucy's observation above suggests that it is as much about pedagogical practice, as it is about listening. As discussed in Chapter2, teachers themselves identified that they have insufficient training to support young people on the autism spectrum (Goodall, 2018, p. 12), which Hornby (2015, p.244) suggests would impact upon the "attitude, knowledge and skills" of teachers. The recent addition of compulsory autism specific training in Initial Teacher Training Programmes (Sackville-Jones, 2019), is a welcome step-change for new teachers, however it does not address the training needs of more experienced teaching staff. Therefore, it would be reasonable to suggest that schools should perhaps demonstrate an open and honest explanation around their capacity to support students on the autism spectrum - this would

be beneficial in establishing realistic expectations. However, James and Lucy describe the fallacy of the reassurance they received from school about the Specialist Resourced Provision, and the specialist training staff had to support James. It appears to have been an over-stating of expertise, which in this instance resulted in James and Lucy deciding this to be the best school to attend. However, it became apparent that *"this wasn't the right environment at all….it was awful…"* and *"they didn't have the training to know what to do with you, they weren't specialists"* (James and Lucy)*,* which is unfortunately the experience of 49% of students on the autism spectrum (Great Britain, 2017).

The effects of insufficient training and expertise for staff is that the strategies and interventions applied in school can be ineffective, as they are used in a manner which stereotypes the autism diagnosis rather than being applied to individuals (Goodall, 2018). Whilst no participant other than James directly referenced teacher training as an issue, there were multiple references of strategies and interventions as being unsuited to the needs of the participant (Appendix 18) and therefore lacking the differentiation cited as crucial by the SEND code of practice (DfE and DoH, 2015).

For instance, Peter was *"made to do assembly at his last school"* regardless of it being clear that he found these difficult. Just prior to his transition to a specialist setting the mainstream school acknowledged the difficulty, and Peter was told to *"read in silence instead"*. Furthermore, the school admitted around this time, that despite Mary being told Peter was taking part in sensory circuits each week (advocated by Mills and Chapparo, 2018), these had not been happening. These simple examples of inappropriate support for Peters hyper-sensitivity at school, demonstrates that staff did not have a full understanding of the

implications on both his immediate ability to process information, but also the impact on the physical and emotional drain this would cause for him throughout the school day.

Sara also explored the inappropriate strategies that had been adopted to support her during school, the most obvious of these was the use of a "time out card", which was established as a means for her to leave lesson when they became too much. However, as she stated during the parent-child conversation, *"I never felt confident enough to use it…I never knew how I would, how would be best to do it"*, this suggests a lack of appropriate individualised support to address her concerns and provide strategies for using the card. This is echoed in her use of a Five Point Scale (linked to her emotions and overload), which was devised by Sara and her family. These tools had promise in helping Sara to communicate her feelings with staff, however they were not pragmatic in the classroom because, *"Teacher[s] are gonna forget, teachers are always gonna ask me, people are gonna ask, students, it was just, I couldn't"*. Providing strategies such as these without wraparound support to aid Sara in understanding practical applications and to problem solve with them, potentially shows an attempt at a simple quick fix rather than a more nuanced and collaborative approach suggested by the Autism Education Trust (AET, 2021a, p.34). Effective training could have supported Sara's teaching staff to better comprehend the complex relationship Sara had with both her classroom, her teachers, her peers and her communication preferences, resulting in effective strategies and interventions underpinned by Sara's own contributions.

5.4.2 Teachers in Control

One of the more remarkable findings from this study was that all participants expressed a difficulty in their working relationships with teaching staff (Appendix 21 and 23). The individual reasons for a difficulty in student-teacher social relationships are wide ranging and arguably as heterogenous as school refusal itself. However, having heard from participants within this study I believe this issue can be refined down to being a preconceived notion of the *correct* power dynamic between teachers and student, i.e., the teacher is and *should be* in control.

An innocuous event perhaps exemplifies this dynamic in the clearest way. Both Sara and Coen mentioned the challenge of needing the toilet during lessons and the embarrassment and stress of having to ask to go. *"You can't go to the toilet in 80% of lessons, like if you ask, they just say no. You have to properly, it's quite embarrassing, cos say you're gonna wet yourself you have to tell the teacher in front of the whole class"* (Coen). Both participants mention *"holding it"* or *"bottling it up"* rather than asking to go, for fear of being told no and having to plead in front of their peers. Leaving aside the physical discomfort and effects on concentration in the classroom, Coen and Sara have explained through this example that teachers have control over a student's body and this clearly does not sit well with these two students. The effects of this control can be seen through Sara's explanation that in future lessons she wouldn't even try to ask to go for fear of hearing a no, which would *"usually make me [her anxiety] worse".* It could be argued that this is both a physical and mental health issue at risk of contravening Articles 3 and 28 of the UN Convention of the Rights of the Child, which point to not only the safety and health of children, but also their right to dignity when schools implement disciplinary practices (United Nations, 1989). In summarising his experience of

mainstream education James took the view that he *"had no control over* [himself] *or* [his] *education"*, he felt *"very robotic and controlled"*. An individual who is, or feels they are, being controlled cannot be said to be fully engaged with decision making processes on a day-to-day basis (Palikara et al., 2018). It could be argued that there are many pragmatic reasons why students need to keep teachers informed of their location during the school day, however for participants within this study, having to explain every action to teachers places a burden on them which is difficult to reconcile.

Coen's experience of his teachers as authority figures reflects findings of previous researchers who point to the detrimental effects of teachers shouting on the psychological needs of students (Hummerstone and Parsons, 2020; Goodall, 2018; Ibrahim and El Zaatari, 2019). However, Coen appears to move beyond shouting as an exclusive feature of harm, and sees the punitive actions of staff, i.e., being shamed for getting an answer wrong, or receiving a detention, as equally damaging and responds by running from these situations, placing him at a disadvantage to his peers (Hummerstone and Parsons, 2020). This could be linked to students understanding of fairness and justice in praise and punishment, where a fuller explanation of punitive action could be required to ensure students on the autism spectrum have fully grasped the rationale behind it.

As has been previously discussed, all participants described difficulties in relating to their teachers, corroborating Goodall's findings into the school experience of students on the autism spectrum (2018). However, on a more positive note, participants also expressed positive reactions to teachers who demonstrated being *"kind and funny"* and having a positive reaction to wrong answers (Coen), and by *"chunking everything, breaking it down and making sure you understood it"* (James). This suggests that school staff need to display a "caring and

supportive" attitude when working with young people on the autism spectrum (Hummerstone and Parsons, 2020, p.7), if they hope to promote a positive environment and keep students in school.

5.4.3 Summary of Teacher Relationships

Participants relationships with teaching staff were the most complex theme discussed during the parent-child conversations, and the nuances of these discussions cannot be fully explored within the scope of this thesis. However, it is important to draw attention to participants highlighting their need to be listened to, to be heard, to be supported through appropriate strategies and interventions, and to be treated in a manner which makes them feel valued and related to, rather than controlled.

5.5 Chapter Summary

This chapter has provided a critical reflection on findings from the thematic analysis, taking in turn the three overarching themes of School Environment, Peer Relationships and Teacher Relationships and analysing them alongside existing literature. It is evident that the sensory environment and general curriculum (day to day operation) of schools impacts on the ability of students to engage with their education. In line with existing research (Bitsika, Heyne and Sharpley, 2020), bullying was identified as a negative feature of peer relationships, however a surprising finding within this theme was participants positive desire to learn at school and their difficulty reconciling this with the sometimes-poor behaviour of their peers. Finally, it appears that the most pressing and complex concern of students on the autism spectrum who

school refuse, is the relationship they have with their teachers. More specifically, in the understanding teachers have of them as individuals and as students, the degree to which they understand autism and can provide appropriate interventions, and the balance of control of teachers have over students and how this is communicated to them. The next chapter will draw together the points raised within this discussion, along with Chapter 4's participant narratives, to provide clear conclusions of this research thesis and to answer the research questions.

Chapter 6

Conclusion

6.1 Introduction

Having established the findings of this research and critically discussed them in Chapter 5 above, the following chapter provides conclusions from this discussion. Firstly, it will explore the limitations of this research thesis, it then identifies specific conclusions drawn from Chapters 4 and 5 linking to key literature discussed in Chapters 1 and 2, helping to answer the research questions below. Finally, a summation of conclusions will be provided.

This research study sought to answer the following research questions:

1. What school-based factors do young people on the autism spectrum relate to their school refusal?

2. How do young people on the autism spectrum frame these school-based factors?

6.2 Limitations

Participants in this study have been articulate and forthcoming in discussing and explaining their experiences of school refusal and in identifying the factors they feel contributed to it. Despite this success, it is important to acknowledge that this study can only comment on the experiences of those children and parents who took part, and findings and conclusions can only be hesitantly generalised to a wider student population.

A particular limitation of this thesis is the shortage of relevant literature exploring the perspectives of young people on the autism spectrum and their school refusal. This has meant

my methodological choices have been influenced by an absence of existing frameworks. However, this same gap in research has given me a unique opportunity to develop a methodology appropriate to my participants. It is also worth reflecting that the methodology of recording the online parent-child conversations presents its own limitations, as it was a method dependent on access to (high quality) technology for both participants and myself.

Ultimately, even with these limitations, by conducting this research with parents and children through online recorded conversations in the participants home, my participants have felt comfortable discussing a potentially sensitive topic with me. This has meant that I have been successful in answering both research questions to a high degree by identifying key factors affecting participants school refusal in their own language, on their own terms. These are explored in more detail below.

6.3 A Culmination of Factors

This thesis corroborates previous research which identified school refusal as a heterogenous phenomenon (Ingul et al., 2012). Participants signalled a culmination of factors draining resilience over time as resulting in them having no alternative but to school refuse. It is important to note that somatic complaints and mental health concerns (such as anxiety, depression, trauma and suicidal ideation) were discussed by participants. Understanding the "reciprocal risk" (Wood et al., 2012, p.352) of these outward signs of difficulty is a crucial step for educators in understanding the framing of school refusal by students on the autism spectrum.

Student voice mattered a great deal to participants in this research, framed through their frustration at not feeling listened to or heard by both educators and peers. The SEND Code of Practice (DfE and DoH, 2015, p.19) stipulates that children should be afforded "greater choice and control" over the support they receive in school. However as indicated through the title of this thesis, a key factor affecting school refusal for participants was a lack of control over their own education, which they framed through an inability to make simple decisions without explaining their actions to members of staff. It is evident that the direction on schools to regard the "wishes, feelings and participation" (DfE and DoH, 215, p19) of students has not been carried out in a manner in which participants felt included and therefore reinforces Merrick's (2020) suggestion that inclusion in mainstream schools is at risk of being tokenistic. Furthermore, participants framed their frustrations with teachers who misunderstood them, or disregarded their needs, as connected to systemic limitations such as curriculum design (Preece and Howley, 2018; Wittemeyer et al., 2011) and insufficient or inadequate teacher training (Great Britain, 2017; Goodall, 2018). It is important to note here that educational research over the past three decades appears to have perpetuated this tokenistic approach to understanding the school refusal experiences of young people on the autism spectrum, by seeking parents and professional's views above those of students affected (Munkhaugen, 2019b, Totsika et al., 2020).

Within this research, participants identified a need for positive relationships with both teachers and peers, reinforcing Anderson's suggestion that these relationships "exert a strong influence on values" (2020, p. 4359), however it was teachers who received the most detrimental comments, suggesting that these relationships were the most contentious. Connections can be made to pedagogical practice, (such as discipline in the classroom (Ibrahim and El Zaatari, 2019; Baker and Bishop, 2015)), though it appears to be teacher

attitudes (Goodall, 2020) which have the most impact on participant's ability to maintain attendance at school. This reinforces the perspective that teachers who demonstrated a "caring and supportive" attitude (Hummerstone and Parsons, 2020, p. 7) and who "recognised…individual needs" (Saggers, 2015, p.14), were more appreciated by students on the autism spectrum that those focused on academic results. Unfortunately, as identified in Chapter 2, schools (and therefore educators) are measured as being successful through results linked to academic outcomes (Department for Education, 2020b) and therefore this drives many decisions and actions of staff in mainstream schools, clearly affecting the ability to focus on developing positive relationships with students.

6.4 Recommendations

The following recommendations are made to further develop our understanding of the experiences of school refusal for young people on the autism spectrum, and to provide them with appropriate support in schools.

1. Further research into the school refusal experiences of students on the autism spectrum needs to be carried out – prioritising students views above those of parents and professionals.

2. In addition to increased autism awareness and understanding in Initial Teacher Training (ITT), long term members of school staff (teachers and support staff) would benefit from autism specific training. Training should encompass:

    a. Developing positive and effective working relationships with young people on the autism spectrum. Including adaptations to disciplinary practices.

b. Supporting students to feel valued beyond their ability to cope with the academic curriculum.

c. How to effectively include students in day-to-day decision making.

d. Identifying the early warning signs of school refusal for young people on the autism spectrum and the reciprocal risk of mental health and school refusal.

3. New outcome measures need to be developed and deployed (as suggested by Wittemeyer et al., 2011), allowing positive and effective relationships to be the focus of student-teacher interactions.

6.5 Chapter Summary

School refusal for young people on the autism spectrum is a phenomenon with significant and detrimental short- and long-term effects, it is therefore important that students are listened to in order to understand and reduce the negative impact on them. The recommendations above can be seen, in part, as reinforcing the current *differentiate and personalise* approach of the SEND Code of Practice (DfE and DoH, 2015). However, individual schools can, and should, look to their own interpretation of the SEND Code of Practice (DfE and DoH, 2015) through policy and practice to develop a positive ethos and environment within which students on the autism spectrum feel valued and able to communicate their needs. That being said, to see a transformative change in the experiences of young people on the autism spectrum in mainstream schools, the Department for Education needs to reassess how it wants schools to deliver a "balanced and broadly based curriculum… which prepares pupils for the…experiences of later life" (Department for Education 2014). Perhaps by replacing the existing focus on academic outcome measures and exploring ways to measure personal

growth and development, the pressure on schools can be re-framed and staff can be given the necessary time and space to truly listen to and understand our students behind the grades.

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Absence and Persistent Absence Rates Nationally: Overall Student Population vs Students on the Autism Spectrum (2014/15-2018/19) (Department for Education, 2017; 2018; 2019a; 2020a)

	Overall Student Absence	Overall Absence (Students on the autism spectrum)	% Difference	Overall Student Persistent Absence (10% of more)	Overall Persistent Absence for students on the autism spectrum	% Difference
2014/15	4.6%	6.2%	+1.6%			
2015/16	4.6%	6.2%	+1.6%	10.5%	16.6%	+6.1%
2016/17	4.7%	6.5%	+1.8%	10.8%	17.3%	+6.5%
2017/18	4.8%	6.9%	+1.9%	11.2%	18.4%	+6.4%
2018/19	4.7%	7%	+2.3%	10.9%	18%	+7.1%
% Change over time	+0.1%	+0.8%	+1.6%	+0.4%	+1.4%	+1.0%

Absence and Persistent Absence Rates in South of England LA: Overall Student Population vs Students on the Autism Spectrum (2015/16-2018/19) (Department for Education, 2017; 2018; 2019a; 2020a)

	Overall Student Absence	Overall Absence (Students on the autism spectrum)	% Difference	Overall Student Persistent Absence (10% of more)	Overall Persistent Absence for students on the autism spectrum	% Difference
2015/16	4.7%	7.2%	+2.5%	11.3%	19.8%	+8.5%
2016/17	4.8%	7.8%	+3.0%	11.6%	21.6%	+10%
2017/18	5	8.1%	+3.1%	11.8%	21.8%	+10%
2018/19	5	8.4%	+3.4%	12.1%	22.6%	+10.5%
% Change over time	+0.3%	+1.2%	+0.9%	+0.8%	+2.8%	+2%

Appendix 2: Student Absence Rates: National vs South of England Local Authority

Overall Absence Rates of Students National vs South of England LA: 2015/16-2018/19 (Department for Education, 2017; 2018; 2019a; 2020a)

	Total Primary School Absence Percentage			Total Secondary School Absence Percentage		
	England	LA	% Diff	England	LA	% Diff
2015/16	4	4	0	5.2	5.5	+0.3
2016/17	4.	4.1	+0.1	5.4	5.6	+0.2
2017/18	4.2	4.2	0	5.5	5.8	+0.3
2018/19	4	4.2	+0.2	5.5	5.9	+0.4
% Change Over Time	0	+0.2	+0.2	+0.3	+0.4	+0.1

Overall Persistent Absence Rates of Students National vs South of England LA: 2015/16-2018/19 (Department for Education, 2017; 2018; 2019a; 2020a)

	Primary School Overall Persistent Absence Percentage			Secondary School Overall Persistent Absence Percentage		
	England	LA	% Diff	England	LA	% Diff
2015/16	8.2	8.7	+0.5	13.1	14.2	+1.1
2016/17	8.3	8.7	+0.4	13.5	14.6	+1.1
2017/18	8.7	9.1	+0.4	13.9	14.7	+0.8
2018/19	8.2	9.1	+0.9	13.7	15.1	+1.4
% Change Over Time	0	+0.4	+0.4	+0.6	+0.9	+0.3

Appendix 3: Definitions of School Attendance Problems

School Refusal	School refusal is said to occur when: (1) a young person is reluctant or refuses to attend school, in conjunction with emotional distress that is temporal and indicative of aversion to attendance…or emotional distress that is chronic and hindering attendance…usually manifest in absence; and (2) the young person does not try to hide associate absence from their parents…and if they previously hid absence then they stopped doing so once the absence was discovered; and (3) the young person does not display severe antisocial behaviour, beyond resistance to parental attempts to get them to school; and (4) the parents have made reasonable efforts, currently or at an earlier stage in the history of the problem, to secure attendance at school, and/or the parents express their intention for their child to attend school full-time. (Heyne et al., 2019, pp 22-23)
Truancy	Truancy is said to occur when: (1) a young person is absent from school for a whole day or part of the day, or they are at school but absent from the proper location…; and (2) the absence occurs without the permission of school authorities; and (3) the young person typically tries to conceal the absence from their parents. (Heyne et al., 2019, p. 23)
School Withdrawal	School withdrawal is said to occur when a young person's absence from school…is; (1) not concealed from the parent(s); and (2) attributable to parental effort to keep the young person at home, or attributable to there being little or no parental effort to get the young person to school. (Heyne et al, 2019, p. 23)
School Exclusion	School exclusion is said to occur when a young person is absent from school or specific school activities, for any period of time, caused by the school: (1) employing disciplinary exclusion in an inappropriate manner; or (2) being unable or unwilling to accommodate the physical, social-emotional, behavioural, or academic needs of the young person; or (3) discouraging a young person from attending, beyond the realm of legally acceptable school policy. (Heyne et al., 2019, p. 24)

Appendix 4: Individual, Environmental and Familial Factors Relating to Absence from School

Domain	Risk Factor	ASD	Primary Source	Secondary Source (mine)
Within-Child	Individual cognition and affect	N	Pellegrini 2007	Preece and Howley, 2018 p. 470
	Unconscious processes	N	Jung 1913,1961,	Baker and Bishop, 2015. P. 355
	Separation anxiety	N	Johnson et al., 1940	Baker and Bishop, 2015. P. 355
	School specific anxiety	N	Kearny, 2008b; Miller, 2008	Baker and Bishop, 2015. P. 355
	Generalised social anxiety	N	Francis, Last & Strauss, 1992	Baker and Bishop, 2015. P. 355
	The child's affronted sense of omnipotence	N	Berry, Injejikian & Tidwell, 1993	Baker and Bishop, 2015. P. 355
	Anxiety, nervousness, worry	N	Multiple	Baker and Bishop, 2015. P. 364; Gren Landell, et al 2015, p.413. p.418
	Depression	N	Mulitple from above	Baker and Bishop, 2015. P. 364, Gren Landell, et al 2015, p.413, p. 418
	Antisocial problems	N	Corville-Smith et al., 1998; Kearney & Albano, 2004)	Gren Landell, et al 2015, p.413
	Somatic complaints (headache, abdominal pain, chronic illness	N	Elliott, 1999; Breuner et al., 2004; Thornton et al., 2013	Gren Landell, et al 2015, p.413, p. 418
	Poor social competence	N	Corville-Smith et al., 1998; McShane et al., 2001	Gren Landell, et al 2015, p.413
	Low self esteem	N	Reid, 2007	Gren Landell, et al 2015, p.414
	Low expectations among students	N	Reid, 2007	Gren Landell, et al 2015, p.414
	Students perceived level of education	N		Gren Landell, et al 2015, p.418

Domain	Risk Factor	ASD	Primary Source	Secondary Source (mine)
School Environment	Avoiding specific academic subjects at school	Y		Munkhagen et al., 2017, p. 35
	Conflicts with peers and teachers	Y		Munkhagen et al., 2017, p. 35
	Conflict with non-autistic peers	Y	Goodall, 2018	Bitsika, Heyne and Sharpley, 2020, p. 1
	Insufficient information concerning the subjects or activities in school	Y		Munkhagen et al., 2017, p. 35
	Stressful emotional events	Y		Munkhagen et al., 2017, p. 35
	School environment and structure	N	Archer et al., 2003; Pellegrini 2007	Preece and Howley, 2018 p. 470
	Complexity of secondary schools	N	Archer et al., 2003; Pellegrini 2007	Preece and Howley, 2018 p. 470
	Relationships with teachers and peers	N	Archer et al., 2003; Pellegrini 2007	Preece and Howley, 2018 p. 470
	Social isolation	N	Archer et al., 2003; Pellegrini 2007	Preece and Howley, 2018 p. 470

	Transition	N	Archer et al., 2003; Pellegrini 2007	Preece and Howley, 2018 p. 470; Baker & Bishop, 2015, p. 355
	Fear of Subjects and academic pressures	N	Archer et al., 2003; Pellegrini 2007	Preece and Howley, 2018 p. 470
	Inappropriate provision unsuited to students needs	N	Archer et al., 2003; Pellegrini 2007; Thornton et al., 2013	Preece and Howley, 2018 p. 470; Gren Landell, et al, 2015, p.413, p. 418
	School Demands	N	Pellegrini 2007	Preece and Howley, 2018 p. 470
	Bullying; Teasing	N	Kearney & Beasley, 1994; Lauchlan, 2003; Lyon & Cotler, 2007; Astor et al., 2002; Havik et al., 2014; Eggar et al.,; Reid, 2007	Baker and Bishop, 2015. P. 355; Gren Landell, et al, 2015, p.413; Bitsika, Heyne and Sharpley, 2020, p.2
	Nervous about strict teachers	N	Kearney & Beasley, 1994; Lauchlan, 2003; Lyon & Cotler, 2007	Baker and Bishop, 2015. P. 355
	Fear of unmonitored school areas	N	Kearney & Beasley, 1994; Lauchlan, 2003; Lyon & Cotler, 2007	Baker and Bishop, 2015. P. 355
	Frequent teacher absences	N	Malcolm et al., 2003; Bridgeland et al., 2006; National Centre for Education Statistic, 2006	Gren Landell, et al 2015, p.413
	Lack of attention and appropriate contingences for handling absenteeism	N	Malcolm et al., 2003; Bridgeland et al., 2006; National Centre for Education Statistic, 2006	Gren Landell, et al 2015, p.413
	Irrelevant or tedious curricula	N	Malcolm et al., 2003; Bridgeland et al., 2006; National Centre for Education Statistic, 2006; Reid, 2007	Gren Landell, et al 2015, p.413, p. 414
	A negative relationship between student and teacher	N	Lee & Burham, 2003	Gren Landell, et al 2015, p.413
	Large classes	N	Brookmeyer et al, 2006	Gren Landell, et al 2015, p.413
	Lack of attention and registration of absenteeism	N	Reid, 2007	Gren Landell, et al 2015, p.414
	Lack of attention to presence and few or no consequences of absenteeism	N		Gren Landell, et al 2015, p.418
	School organisational deficiencies	N		Gren Landell, et al 2015, p.418

Domain	Risk Factor	ASD	Primary Source	Secondary Source (mine)
Family	Physical or psychiatric disease in other family members; Parents mental health difficulties; Parental psychopathology	N	Multiple + Hersov, 1977, Thornton et al., 2013; McShane et al., 2001	Munkhagen et al., 2017, p. 32; Baker and Bishop, 2015. P. 355; Gren Landell, et al 2015, p.413; Gren Landell, et al 2015, p.414
	Parental unemployment	N	Multiple	Munkhagen et al., 2017 p. 32; Gren Landell, et al 2015, p.414
	Low educational level of mothers/parents	N	Multiple; Henry, 2007	Munkhagen et al., 2017 p. 32; Gren Landell, et al 2015, p.414
	Disorganised and unsafe home environments with poor adult support and attendance	N	Multiple	Munkhagen et al., 2017 p. 32
	Holiday or illness related absence from school	N	Berg, 1996; Miller, 2008	Baker and Bishop, 2015. P. 355

History of attending multiple schools	N	Campbell, 2001	Baker and Bishop, 2015. P. 355
Poor parental involvement and supervision; lack of support/involvement in school-work from parents	N	Reid, 2008; Thornton et al., 2013	Gren Landell, et al 2015, p.414, p. 418
Low expectations of school performance/attendance/parents keeping child at home; parental attitudes; parental permissive style; absence being partially condoned by parents	N	Reid, 2000; Baker et al., 2001; Reid, 2007; Malcolm et al, 2003	Gren Landell, et al 2015, p.414, p. 418
Alcohol abuse	N	Baker et al., 2001	Gren Landell, et al 2015, p.414
Poor economic conditions	N	Eggar et al., 2003	Gren Landell, et al 2015, p.414
Poor cohesion in the family	N	Corville-Smith et al., 1998	Gren Landell, et al 2015, p.414
Domestic violence	N	Baker et al., 2001	Gren Landell, et al 2015, p.414
Conflicts and separations	N	Reid, 2000; McShane et al., 2001	Gren Landell, et al 2015, p.414

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Research Participants Advert

We are looking for research participants to help us better understand _**school refusal behaviour in young people on the autistic spectrum**_. More specifically, we would like to hear from young people (and their parents/carers) about their experiences and what at school might have affected their difficulty in attending.

What is School Refusal Behaviour?

School Refusal Behaviour means that you have refused to attend school and/or stay in class and your parents/carer were aware of your refusal to go.

The period of refusal could be as short as a couple of days or as long as a few years.

If your child...

✔ Is aged 9-18,

✔ Has a diagnosis of autism,

✔ Has experienced School Refusal Behaviour,

✔ Is **NOT** currently experiencing School Refusal Behaviour,

✔ Attended a mainstream school during their experience of school refusal behaviour,

...then it would be great to hear from you.

If this sounds like something you might be interested in, or if you have any questions about this research study please contact Paul Reed by email: pr172@canterbury.ac.uk

Research Study Supervisor is Dr Kate Smith: kate.smith@canterbury.ac.uk

This research has been approved

by the Canterbury Christ Church University Ethics Panel.

participate in RESEARCH

Appendix 6: Inclusion and Exclusion Criteria Rationale

(Inclusion) Participants must...	Rationale
Have a diagnosis of autism	This research study is focused entirely on the experiences of those students on the autism spectrum. Co-morbid diagnosis are not of particular concern and therefore are not addressed within these criteria.
Have experienced school refusal behaviour	Participants need to be able to explain why they were unable to attend school so must have had a period of school refusal. The duration and time period of that refusal is not important.
Be between the ages of 9 and 18 at the time of participation.	This age bracket was chosen for two reasons. Firstly, participants needed to be of an age to engage in a meaningful conversation with their parents about an experience they remember.

Secondly, this age bracket is similar to that used by other researchers investigating school refusal, such as Munkhaughen (2019), and Bitiska, Heyne and Sharpley (2020), therefore it is relatable to their research. |
Have attended a mainstream school during the period of their school refusal.	Whilst participants may currently attend a specialist setting, it is not the purpose of this research to investigate the factors affecting school refusal of these establishments.
(Exclusion) Participants must not…	Rationale
currently be experiencing school refusal	This is crucial to the ethical considerations of this research study as explained through Section??.

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ADULT CONSENT FORM AND GATEKEEPER CONSENT FORM

(Two Copies – one for participant and one for researcher – please sign both copies)

Title of Project: Mainstream school refusal from the perspectives of young people on the autism spectrum.

Name of Researcher: Paul Reed

Contact details:

Address:	Faculty of Education Canterbury Christ Church University N Holmes Rd, Canterbury CT1 1QU
Tel:	01227 927700
Email:	PR172@canterbury.ac.uk

My Participation

Please initial box

1. I confirm that I have read and understand the participant information for the above project and have had the opportunity to ask questions.

2. I confirm that I agree to any audio and/or visual recordings.

3. I understand that any personal information that I provide to the researchers will be kept strictly confidential and in line with the University Research Privacy Notice

4. I understand that my participation is voluntary and that I am free to withdraw my participation at any time, without giving a reason.

5. I agree to take part in the above project.

My Gatekeeper Consent

1. I confirm that I have read the participant information for the above project, had the opportunity to ask questions and understand what my child/young person is being asked to do.

2. I confirm that I agree to my child/young person being included in audio and/or visual recordings.

3. I understand that my child's/young person's participation is voluntary and that they are free to withdraw their participation at any time, without giving a reason. I understand that this will end my participation in the research project too.

5. I agree for my child/young person to take part in the above project.

Name of Participant/Gatekeeper:	Date:	Signature:
Researcher:	Date:	Signature:

Copies: 1 for participant

             1 for researcher

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YOUNG PERSON CONSENT FORM

Mainstream school refusal from the perspectives of young people on the autism spectrum.

Name of Researcher: Paul Reed
Address: Faculty of Education, Canterbury Christ Church University, N Holmes Rd, Canterbury, CT1 1QU. **Telephone:** 01227 927700 **Email:** PR172@canterbury.ac.uk

Please read this carefully. You might want to talk about it with your parent/carer too. When you are ready, complete the information in the box below on both pages.

I have read and understand the **participant information sheet** sent to me.

I agree to visual and/or audio recordings of my conversation with my parent/carer.

I understand that any personal information that I provide to the researcher will be kept strictly confidential.

I understand that taking part is voluntary and that I am free to stop taking part at any time, without having to give a reason.

I agree to take part in the above project.

My Name………………………………………………………………………………………

Today's Date…………………………………………………………..

Researchers Name……………………………………………………………………….

Today's Date …………………………………………………………

Mainstream school refusal from the perspectives of young people on the autism spectrum.

ADULT PARTICIPANT INFORMATION

A research study is being conducted at Canterbury Christ Church University (CCCU) by Paul Reed

Please refer to our Research Privacy Notice for more information on how we will use and store your personal data.

Background

This research study aims to develop an understanding of the school- based factors affecting school refusal behaviour of young people on the autism spectrum attending mainstream schools. Importantly, this research aims to develop this understanding by seeking the perspectives of young people themselves. It is hoped that this research will give a voice to those young people who have experienced school refusal behaviour and to enable a deeper understanding of the factors contributing to their experiences.

What will you be required to do?

- Consent to your participation in this research.
- Consent to the researcher seeking consent from your child to participate in this research (the young person's participant information form is also attached).
- Complete the School Refusal Assessment Scale to assess the reasons for your child's school refusal behaviour.
- Take part in a recorded conversation with your child about the school-based factors which have historically affected their school refusal behaviour.
- Keep in regular contact with the researcher to share information, exchange documents and arrange a date and time for the parent-child conversation.

To participate in this research, you must:

- Be the parent/carer:
  o of a young person who fulfils the **criteria below**:
- Be a young person who:
  o Is aged between 9 and 18 years of age,
  o Has a diagnosis of autism,
  o Has experienced school refusal behaviour in the past (as defined below)
  o Is **not** currently experiencing School Refusal Behaviour,
  o Attended a mainstream school during the period of their school refusal behaviour.

School Refusal Behaviour is considered to have been present if your child has refused to attend school and/or remain in class and you were aware of this refusal.

Procedures

The procedures which will be carried out within each stage are as follows:

Stage 1
You will be asked to complete a questionnaire called the School Refusal Assessment Scale which looks at the possible reasons for your child's school refusal behaviour. This will be emailed to you as a pdf document, along with instructions on how to complete it and will need to be sent back before we are able to proceed to stage two. This research study is looking to explore specific factors within this questionnaire and therefore if your responses at this stage do not match the research focus, you will not be invited to proceed to the next stage of research. Additionally, this research is looking to explore the experiences of just five young people, therefore if this number is met before your questionnaire is returned to us, you will unfortunately not be able to proceed to stage 2. You will be contacted by the researcher in either of these scenarios. Your contact details will be deleted from our records on the 24th July 2021 if this happens.

Stage 2

The young person, for whom the questionnaire was completed, along with a single parent/carer will be asked to have a conversation about the school-based factors which they feel affected their school refusal behaviour. The parent-child conversation will take place at your home and will be recorded using online conferencing software Microsoft Teams (an audio recording device (Dictaphone) will also be used to record the conversation). It is important therefore that you have access to a computer/tablet/smartphone which has both a camera and microphone. A date and time for the parent-child conversation will be arranged once stage 1 has been completed.

The researcher will remain "virtually present" for the duration of the parent-conversation, though once the initial set up has been completed, the researcher's camera will be turned off. Should you, or your young person, feel at any stage during the conversation that you are feeling distressed, you are urged to request for the recording to be paused. Additionally, should the researcher notice either of the participants becoming unduly distressed, they will step in and pause the recording to support you.

As this research is taking place in your own home, it is important that you choose a location in which you feel comfortable and are happy to have on camera. It is also important that participants are dressed and behave in a manner which is appropriate for a recording. Unfortunately, if this is not the case, the recording and participation may have to either be paused or cancelled all together.

Stage 3

Immediately following the parent-child conversation you will be emailed a final questionnaire which is required to be completed by your young person independently. This needs to be completed and returned to the researcher within 24 hours of the parent-child conversation. It is crucial that the answers within this questionnaire are the young persons, however if they need support in understanding the questions or some of the words, please do help them in this way.

Feedback

Should you request it, you will be provided with a one-page document outlining the summary findings of this research enquiry. This will be provided to you, by email, no later than the 31st of January 2022

Confidentiality and Data Protection

The following categories of personal data (as defined by the General Data Protection Regulation (GDPR)) will be processed:

- Your First Name and Surname
- Your Email Address
- Your experiences, feelings and opinions on the given topic of this research study.

We have identified that the public interest in processing the personal data is:

- To enable appropriate contact to be made between the researcher and yourself to carry out the research as outlined above. Personal data will be used to contact you by email, to exchange documents and to provide you with an invite to the parent-child conversation recording. Your experiences, feelings and opinions will be analysed to draw out any relevant findings from this research study and to inform recommendations arising from this analysis.

Data can only be accessed by, or shared with:

- The principle researcher.

The identified period for the retention of personal data for this project:

- Is four years. This is to enable clarification of responses should it be needed and also to contact you regarding participation in future research studies by this researcher within this period.

If you would like to obtain further information related to how your personal data is processed for this project please contact Paul Reed at pr172@canterbury.ac.uk.

You can read further information regarding how the University processes your personal data for research purposes at the following link: Research Privacy Notice - https://www.canterbury.ac.uk/university-solicitors-office/data-protection/privacy-notices/privacy-notices.aspx

Dissemination of results

This research study will be published in the CCCU library which can be found here: https://www.canterbury.ac.uk/library/library-services.aspx

Process for withdrawing consent to participate

You are free to withdraw your consent to participate in this research project up to the 24th July 2021 without having to give a reason. To do this please email pr172@canterbury.ac.uk and state that you would like to withdraw from this research study.

You may read further information on your rights relating to your personal data at the following link: Research Privacy Notice - https://www.canterbury.ac.uk/university-solicitors-office/data-protection/privacy-notices/privacy-notices.aspx

Any questions?

Please contact Paul Reed at pr172@canterbury.ac.uk or Kate Smith at kate.smith@canterbury.ac.uk. Faculty of Education Canterbury Christ Church University N Holmes Rd, Canterbury CT1 1QU.

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Mainstream school refusal from the perspectives of young people on the autism spectrum.

YOUNG PERSON PARTICIPANT INFORMATION

A research study is being conducted at Canterbury Christ Church University (CCCU) by Paul Reed

Please refer to our Research Privacy Notice for more information on how we will use and store your personal data.

Background

My research aims to gather the views of young people on the autism spectrum on the things at school which affected their school refusal. It hoped that this research will give a voice to those young people who have experienced school refusal behaviour and to enable a deeper understanding of the factors contributing to their experiences.

What will you be required to do?

- Consent to take part in this research.
- Take part in a recorded conversation with your parent/carer about the things at school that affected your school refusal behaviour in the past.
- Complete a questionnaire about the things at school that affected your school refusal behaviour in the past.

To participate in this research, you must:

o Be between 9 and 18 years of age,
o Have a diagnosis of autism,
o Have experienced school refusal behaviour in the past (this is explained in detail below)
o **Not** currently be experiencing School Refusal Behaviour,
o Have attended a mainstream school during the period of your school refusal behaviour.

SCHOOL REFUSAL BEHAVIOUR DEFINITION

School Refusal Behaviour means that you have refused to attend school and/or stay in class and your parents/carer were aware of your refusal to go.

What will happen?

Stage 1

Your parents/carers will be asked to complete a questionnaire called the School Refusal Assessment Scale. ***You do not need to take part in this stage of the research***. There are a couple of reasons that you might not end up taking part in the rest of the research even though you have given your consent. Firstly, because we are looking to research a specific thing, it might be that your parents/carers answers on this assessment are not quite what we are looking for. Secondly, because we are only looking to record five people having a conversation with their parent/carer, it might be that we just found these five people already. We will email your parents/carers to let them know if either of these happen.

Stage 2

During this stage, you will be asked to have a conversation with your parent/carer about the things at school which you feel affected your school refusal behaviour. This conversation will take place at your home and will be recorded online using Microsoft Teams (the researcher will also use an audio recording device in case the online recording does not work).

The researcher will remain "virtually present" all the way through your conversation, though once the initial set up and debrief has been completed, the researcher's camera will be turned off. Should you feel at any stage during your conversation that you are feeling upset, please let your parent/carer know, or just ask for the recording to be paused. Also, if the researcher notices either you or your parent/carer becoming upset, they will step in and pause the recording to support you.

As this research is taking place in your own home, it is important that you choose a location in which you feel comfortable and are happy to have on camera. It is also important that you are dressed and behave in a manner which is appropriate for a recording. Unfortunately, if this is not the case, the recording and your participation may have to either be paused or cancelled all together.

Stage 3

Straight after your conversation, you will be emailed a final questionnaire which is required to be completed by you. It is really important that the answers to this questionnaire are yours and yours alone, but if you need help reading or understanding the questions, please ask your parent/carer to help you. This needs to be emailed back within 24 hours of receiving it.

Feedback
☹ ☺ 😀

Should you ask to see it, you can be provided with a one-page document outlining the summary findings of this research enquiry. This will be provided to your parents, by email, no later than the 31st of January 2022

Confidentiality and Data Protection

So that the researcher can talk to you using your name during the recorded conversation we do need your First Name and Surname in our records. We also need to record your experiences, feelings and opinions on the topic of this research study so that we can study the information, explain our findings and make any recommendations that might be appropriate.

The only person who will be able to see and use this information is the researcher.

Your name will be kept in our records for four years, so that we can contact you to clarify what you said if we need to. Also we might contact you to see if you would like to participate in future research by this researcher.

If you would like to obtain further information related to how your personal data is processed for this project, you can email pr172@canterbury.ac.uk

You can read further information regarding how the University processes your personal data for research purposes at the following link: Research Privacy Notice - https://www.canterbury.ac.uk/university-solicitors-office/data-protection/privacy-notices/privacy-notices.aspx

Where will the research be published?

This research study will be published in the CCCU library which can be found here: https://www.canterbury.ac.uk/library/library-services.aspx

How can I take back my consent to participate?

You are free to take back your consent to take part in this research project up to the 24th July 2021 without having to give a reason. To do this please ask your parents to email pr172@canterbury.ac.uk and state that you would like to withdraw from this research study.

You may read further information on your rights relating to your personal data at the following link: Research Privacy Notice - https://www.canterbury.ac.uk/university-solicitors-office/data-protection/privacy-notices/privacy-notices.aspx

Any questions?

Please contact Paul Reed at pr172@canterbury.ac.uk or Kate Smith at kate.smith@canterbury.ac.uk. Faculty of Education Canterbury Christ Church University N Holmes Rd, Canterbury CT1 1QU.

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DATE of Assessment:	25/2/2021	RD ETHICS APPLICATION REFERENCE No:	
Assessed by :	Mr Paul Reed (Principle Investigator)	SCHOOL/DEPARTMENT:	Faculty of Education
NATURE OF ACTIVITY:	Research Project: **Mainstream school refusal from the perspectives of young people on the autism spectrum.**		DATE OF ACTIVITY: Feb17th to July 31st
LOCATION:	Data will be collected online	NEXT H&S RISK REVIEW DATE:	19th March 2021
REVIEWED BY*: (for students only)	Dr Kate Smith	REVIEW DATE*: (for students only)	
APPROVED BY**:	*Stefania Ciocia*	APPROVAL DATE:	3rd March 2021

*For students: Your Academic Supervisor should review this form with you before it is sent for approval

**Heads of School/Departments are ultimately responsible for Health and Safety Risk Assessments within their area, however, they may nominate senior members of staff (such as a manager or senior lecturer) who have undertaken the University Health & Safety Risk Assessment training to support them by approving risk assessments under their control.

RESEARCH

HEALTH AND SAFETY - RISK ASSESSMENT

Hazard/Risk	Persons at Risk & Nature of harm	Current Control Measures	Risk Rating (High /Medium /Low)	Additional Control Measures Required	Revised Risk Rating (High/ Medium/L ow)	Action by who	Action by when
Breach of confidentiality of participants personal data arising from mishandled, misplaced or unprotected software/hardware.	Participants	Personal data will be limited to essential information (namely the participants name and contact email address). All personal data collected from participants will be placed onto a password protected memory stick and a password protected external hard drive as a back-up in case of hardware malfunction. Both devices will	Low		Low	Paul Reed	June 2021

Hazard/Risk	Persons at Risk & Nature of harm	Current Control Measures	Risk Rating (High /Medium /Low)	Additional Control Measures Required	Revised Risk Rating (High/ Medium/L ow)	Action by who	Action by when
		remain be located within my home and will not be removed at any time. This information will never be downloaded onto a computer, laptop of tablet. Email correspondence with participants will include their personal data (name and email address). I will only use my CCCU Outlook email account to contact participants. This email account is password protected.					
Participants identities being revealed within the final publication of research.	Participants	Participants will be provided with a pseudonym. This will be used in all written documents pertaining to the research (including drafts, notebooks, and the final thesis). The document denoting participants pseudonyms will be kept within my CCCU One Drive Cloud Storage. Importantly, this is a separate location to the documents with participants real identities and personal data. Access to the One Drive account can only me bade through my personal devices, or a CCCU computer, all of which are password protected.	*Low*		*Low*	*Paul Reed*	*June 2021*
Emotional harm and/or distress arising from	Participants	The research methodology has been designed to reduce the level of harm arising to the young people participating in this	Medium	As a professional with experience supporting young people autism and their families, I will remain online for the	Medium	Paul Reed	June 2021

Hazard/Risk	Persons at Risk & Nature of harm	Current Control Measures	Risk Rating (High /Medium /Low)	Additional Control Measures Required	Revised Risk Rating (High/ Medium/L ow)	Action by who	Action by when
discussing topics of a sensitive nature.		research, by utilising a trusted adult (their parent/carer) to discuss the topic with. It will be made clear to participants within the participant information form that should they begin to feel distressed by the topic they are discussing, they have the absolute right to stop the conversation at any point. Should this happen I will discuss with the family how they would like to proceed, whether they are withdrawn from the research or whether they would like to try and have the parent-child conversation at another point. Participants will be signposted to external support services if required.		duration of the parent-child conversation in order to step in and support, pause or even stop the conversation, should it become clear that participants (both young people and parents/carers) are becoming distressed.			
Personal Identities of third parties (such as teachers and other students) being revealed by participants during the parent-child conversations.	Members of the public.	I will ensure that any comments made by participants during the parent-child conversations which name third party individuals, are altered and anonymised during the transcription process. This will involve assigning a descriptor such as "teacher X" or "student X".	Low		Low	Paul Reed	June 2021
Participant over-sharing private information.	Participant, third parties.	Participants will be advised within the participant information sheet, and during the set up of the parent-child conversation that they have the right to request elements	Low		Low	Paul Reed	June 2021

Hazard/Risk	Persons at Risk & Nature of harm	Current Control Measures	Risk Rating (High /Medium /Low)	Additional Control Measures Required	Revised Risk Rating (High/ Medium/L ow)	Action by who	Action by when
		of their conversation be removed from the transcript. Participants will also be made aware that they have the right to withdraw from the research up to the 24th July 2021.					
The nature of the methodology involves participants being recorded within their own home and has the risk that they will behave in a way that they may not in public.	Participants and researcher.	It will be made clear to the participants both within the participant information form that if the researcher feels that there is inappropriate behaviour being observed, such as bullying or abusive behaviour of any kind between participants, the conversation will be stopped. Additionally, it is noted within the participant information sheet that participants are requested to dress appropriately for the recording. This is to avoid any chance of participants wearing in-appropriate clothing for a recording, which may occur from them being in their own home.	Medium	Participants will be reminded, during the set up and briefing of the recording for the need for appropriate behaviour during the course of the parent-child conversation. They will be reminded that the researcher may step in and pause or stop the recording if it is felt that inappropriate behaviour is being observed. Additionally, participants will be reminded that they have the right to pause of stop the recording if they feel distressed at any point.	Medium	Paul Reed	June 2021

All members of staff and where relevant students affected by this risk assessment are to sign and date to confirm they have read and understood it and will abide by it.

NAME	SIGNATURE	DATE
Paul Reed	*PREED.*	25/2/2021

School Refusal Assessment Scale-Revised (P)

Name:_____

Date: _____

Please select the answer that best fits the following questions:

1. How often does your child have bad feelings about going to school because he/she is afraid of something related to school (for example, tests, school bus, teacher, fire alarm)?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○	○	○	○	○	○	○

2. How often does your child stay away from school because it is hard for him/her to speak with the other kids at school?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○	○	○	○	○	○	○

3. How often does your child feel he/she would rather be with you or your spouse than go to school?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○	○	○	○	○	○	○

4. When your child is not in school during the week (Monday to Friday), how often does he/she leave the house and do something fun?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○	○	○	○	○	○	○

5. How often does your child stay away from school because he/she will feel sad or depressed if he/she goes?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○	○	○	○	○	○	○

6. How often does your child stay away from school because he/she feels embarrassed in front of other people at school?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○	○	○	○	○	○	○

7. How often does your child think about you or your spouse or family when in school?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○	○	○	○	○	○	○

1. When your child is not in school during the week (Monday to Friday), how often does he/she talk to or see other people (other than his/her family)?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○	○	○	○	○	○	○

2. How often does your child feel worse at school (for example, scared, nervous, or sad) compared to how he/she feels at home with friends?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○	○	○	○	○	○	○

3. How often does your child stay away from school because he/she does not have many friends there?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○	○	○	○	○	○	○

4. How much would your child rather be with his/her family than go to school?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○	○	○	○	○	○	○

5. When your child is not in school during the week (Monday to Friday), how much does he/she enjoy doing different things (for example, being with friends, going places)?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○	○	○	○	○	○	○

6. How often does your child have bad feelings about school (for example, scared, nervous, or sad) when he/she thinks about school on Saturday and Sunday?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○	○	○	○	○	○	○

7. How often does your child stay away from certain places in school (e.g., hallways, places where certain groups of people are) where he/she would have to talk to someone?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○	○	○	○	○	○	○

□□. How much would your child rather be taught by you or your spouse at home than by his/her teacher at school?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○ □	○ □	○ □	○ □	○ □	○ □	○ □

□□. How often does your child refuse to go to school because he/she wants to have fun outside of school?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○ □	○ □	○ □	○ □	○ □	○ □	○ □

□□. If your child had less bad feelings (for example, scared, nervous, sad) about school, would it be easier for him/her to go to school?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○ □	○ □	○ □	○ □	○ □	○ □	○ □

□□. If it were easier for your child to make new friends, would it be easier for him/her to go to school?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○ □	○ □	○ □	○ □	○ □	○ □	○ □

□□. Would it be easier for your child to go to school if you or your spouse went with him/her?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○ □	○ □	○ □	○ □	○ □	○ □	○ □

□□. Would it be easier for your child to go to school if he/she could do more things he/she likes to do after school hours (for example, being with friends)?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○ □	○ □	○ □	○ □	○ □	○ □	○ □

□□. How much more does your child have bad feelings about school (for example, scared, nervous, or sad) compared to other kids his/her age?

Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
○ □	○ □	○ □	○ □	○ □	○ □	○ □

□□. How much would your child rather be taught by you or your spouse at home than by his/her teacher at school?

☐☐. How often does your child stay away from people at school compared to other kids his/her age?

	Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
	O ☐	O ☐	O ☐	O ☐	O ☐	O ☐	O ☐

☐☐. Would your child like to be home with <u>you</u> or your spouse more than other kids his/her age would?

	Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
	O ☐	O ☐	O ☐	O ☐	O ☐	O ☐	O ☐

☐☐. Would your child rather be doing fun things outside of school more than most kids his/her age?

	Never	Seldom	Sometimes	Half the Time	Usually	Almost Always	Always
	O ☐	O ☐	O ☐	O ☐	O ☐	O ☐	O ☐

Do not write below this line

_____

☐. _____   ☐. _____   ☐. _____   ☐. _____

☐. _____   ☐. _____   ☐._____   ☐. _____

☐. _____   ☐☐. _____   ☐☐. _____   ☐☐. _____

☐☐. _____   ☐☐. _____   ☐☐. _____   ☐☐. _____

☐☐. _____   ☐☐. _____   ☐☐. _____   ☐☐. _____

☐☐. _____   ☐☐. _____   ☐☐. _____   ☐☐. _____

Total Score =   _____   _____   _____   _____

Mean Score =   _____   _____   _____   _____

Relative Ranking =   _____   _____   _____   _____

<u>Appendix 13: School Refusal Assessment Scale- Parent Instructions</u>

> **Important Note:** Please **do not** include your name or date on the form you complete.

Children sometimes have different reasons for not going to school. Some children feel badly at school, some have trouble with other people, some just want to be with their family, and others like to do things that are more fun outside of school.

The accompanying form asks questions about why you think your child did not want to go to school. For each question, think back to the time when your child was not going to school and then pick one number (statement) that best describes the situation. After you answer one question, go on to the next one. Don't skip any questions.

There are no right or wrong answers. Just pick the number that best fits the way you think your child felt about going to school and select the relevant statement/number.

Here is an example of how it looks.

> **Example:**
>
> How often do you like to go shopping?
>
> | Never | Seldom | Sometimes | Half the time | Usually | Almost Always | Always |
> |---|---|---|---|---|---|---|
> | 0 | 1 | 2 | 3 | 4 | 5 | 6 |

Appendix 14: School Refusal Assessment Scale – Revised (P) Participant Responses and Scores

Name	Mean- Function A	Mean - Function B	Mean - Function C	Mean - Function D
Mary (Peter)	5.3	3.5	4.6	0.8
Lucy (James)	6	5.1	4.1	0.6
Alice (Sara)	5.2	0.8	0.3	0.8
Nell (Coen)	5.3	4	4.5	0.3

Appendix 15: Parent-Child Conversation Briefing

1. **Initial greeting**
2. **Check**
   … that everyone read and understood the participation information letter and the consent forms. Particularly note:
   a. Safeguarding – If anyone feels distressed, I will step in and pause/stop the recording.
   b. Right to Withdraw – You can stop the recording at any point and stop taking part at any point up until the 23rd July.
   c. Recording- that you give consent to recording the conversation.
3. **Explain**
   …that I will start recording once everyone is ready and once I have explained how everything is going to work.
   Would you like to get yourself a drink before we start?

4. **Explain**
   … that the purpose of this conversation is to talk about a time when the young person experienced school refusal – meaning they did not want to be at school and their parents were aware of this. The conversation can either be considering a specific time or a reflection of the young person's entire experience – whichever is the easiest for them to discuss.

5. **Explain the process of the conversation**
   a. Firstly, I am going to ask you a few specific questions so that I can build a picture and get a little bit of context about you and your school. Don't worry, there will not be any names, places or anything that can be used to identify you in the final report. Any names you mention will be given a different name.
   b. Then I will turn my camera and microphone off so that you can have your conversation without me in the background.
   c. You might like to begin your conversation using one of the sentence starters to get the conversation going, but you do not have to do this.
   d. If at any point during the conversation either or you, or I, feel as though you are becoming upset, we can pause the recording – or stop altogether if need be.
   e. Your conversation might last anywhere between 15 minutes to an hour. I will step in at the one-hour mark and stop the conversation if it is still going. Whenever you feel as though your conversation on the subject has come to a natural end just let me know and we will stop recording.

Do you have any questions before we start?

OK, I will start recording now.

Appendix 16: Parent-Child Conversation Sentence Starters

The purpose of the parent-child conversation is to explore the young person's perspective of the school-based factors which affected their school refusal.

This means that your conversation should focus on the things in school that might have affected going to school or not.

Below is a list of **"I remember" sentence starters** which you might find useful to help you start your conversation, or if you think you might have drifted off topic. You can use these by reading the beginning of the sentence aloud and then finishing the sentence in your own words. **You do not have to use them**; they are just here to help should you feel that you need them. You might find it useful to look at these sometime before the conversation.

> I remember that my classroom was…
>
> I remember that my teacher…
>
> I remember that my teaching assistant…
>
> I remember that other teachers…
>
> I remember that other members of staff…
>
> I remember that the other children in my class…
>
> I remember that the other children in school…
>
> I remember that my lessons….
>
> I remember that at breaktimes…
>
> I remember that at lunch times…
>
> I remember that at the start of the school day…

<u>Appendix 17: Participant Debriefing Emails</u>

<u>Stage 1 Debriefing Email (A)</u>

Dear

Thank you for your time in completing the first stage of our research study into the school-based factors affecting school refusal behaviour for young people on the autism spectrum. As was mentioned in the participant information letter, the School Refusal Assessment Scale you completed is used to understand the possible factors relating to a young person's school refusal behaviour and this research study is looking for a specific set of factors to investigate further in stage 2. It appears, based upon the responses you have provided, that the factors relating to your young person's school refusal behaviour, do not meet these criteria and therefore we will not be asking you to continue forward into Stage 2 of this research.

Please do let me know if you would like to be provided with a summary of the findings from this research. If this is something you would like, you can expect to receive the summary in January 2022.

I would like to take this opportunity to highlight to you two useful websites which might be of interest to you on this subject.

1. https://www.babcockldp.co.uk/inclusion-and-ehwb/anxiety-based-school-avoidance/what-the-research-says

2. https://notfineinschool.co.uk/

Thank you again for your time up to this point.

<u>Stage 1 Debriefing Email (B)</u>

Dear

Thank you for your time in completing the first stage of our research study into the school-based factors affecting school refusal behaviour for young people on the autism spectrum. As was mentioned in the participant information letter, the School Refusal Assessment Scale you completed is used to understand the possible factors relating to a young person's school refusal behaviour and this research study is looking for a specific set of factors to investigate further in Stage 2.

Five participant families, who responded corresponding to those factors, have now been randomly chosen to move forward to Stage 2 of our research. I am sorry to say that at this

time you have not been chosen to move forward. However, because your responses also match what is being investigated further, I would like to keep your contact details on file in case I am unable to move forward with other participants. You do of course have the right to request your contact details are removed my records at any point before this.

Please do let me know if you would like to be provided with a summary of the findings from this research. If this is something you would like, you can expect to receive the summary in January 2022.

I would like to take this opportunity to highlight to you two useful websites which might be of interest to you on this subject.

1. https://www.babcockldp.co.uk/inclusion-and-ehwb/anxiety-based-school-avoidance/what-the-research-says

2. https://notfineinschool.co.uk/

Thank you again for your time up to this point.

Stage 2/3 Debriefing Email

Dear

Thank you for your time in taking part in this research study exploring the school-based factors affecting school refusal behaviour for young people on the autism spectrum. I hope that you have found this to be a valuable experience.

It is imperative at this stage that I reiterate your rights regarding the information you have provided to me so far.

Firstly, you have the right to ask for any specific comments made during the parent-child conversation to be removed from the research. This means that it will be deleted from the transcription and cannot be used within my analysis or findings.

Please do let me know if you would like to be provided with a summary of the findings from this research. If this is something you would like, you can expect to receive the summary in January 2022.

I would also like to take this opportunity to highlight to you some useful websites which might be of interest to you. I understand that school refusal can be a difficult and uncomfortable subject to talk about, therefore I have listed a few organisations which might be able to support you should you find that this is the case.

https://www.mind.org.uk/

https://youngminds.org.uk/

https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/

Finally, to find out more information on the subject of school refusal, and to speak with others who might have similar experiences these websites might be useful.

1. https://www.babcockldp.co.uk/inclusion-and-ehwb/anxiety-based-school-avoidance/what-the-research-says

2. https://notfineinschool.co.uk/

Thank you again for your time up to this point.

Appendix 18: Sara and Alice Full Annotated and Coded Transcript

Note: QS# = Stage Three Questionnaire Number

Transcript	Descriptive Code
Sara – Where to start	
Alice – So, where to start. So in my head I was mostly thinking about, as you said, year 10.	
Sara – And 11	
Alice – And 11, which were both pretty grim.	
Sara – Yeah. I'd say before that it was more, <u>I didn't actually realise why I was missing so much school.</u>	YP "didn't realise why"
Alice – No.	
Sara – Cos in the early years I didn't really know. I knew it was vaguely *(eyebrow raised and inflection of voice)* <u>anxiety</u> in year 9.	"anxiety"
Alice – Mhmm	
Sara – But that was it I think.	
Alice – I don't think either of us knew what was going on, from the start did we.	
Sara – I mean I still remember when you first told me you thought I might be autistic.	
Alice – Yea.	
Sara – When we were in Italy.	
Alice – Were we?	
Sara – Yeah,	
Alice – Ok. I don't remember that.	
Sara – We were sitting on the wall outside Granny's house.	

Alice – oh, yea. So I don't remember what year that was.	
Sara – me either.	
Alice – But, umm, when you think about, maybe if we focus on year 10 and 11 to start with.	
Sara – yeah.	
Alice – So what. I was obviously aware that you found it really difficult to go to school…	
Sara – Yea.	
Alice – but can you put your finger on some of the things that made it hard to go to school?	
Sara – I guess it's just the…the <u>school environment wasn't the best</u>. Obviously because it was a grammar school it was very academic based, and so there was a lot of <u>academic… pressure</u> *(pressure drawn out with inflection).*	"school environment" "Academic Pressure" (QS4)
Alice – So a high-pressure environment	
Sara – Yeah. And because I'd already missed so much school, I was already a bit behind so its like the teachers had a bit of a, a bit of a previous thing, idea about…	
Alice- Yeah, so you felt like teachers…because you'd missed a lot of school…and you were behind do you think <u>the teachers had an idea about you that wasn't correct</u>?	Teacher Understanding of YP (QS20)
Sara – Yeah	
Alice – Like you were*…(deep sigh*)… not trying hard…	
Sara – Yeah	

Alice – Or, lazy is not a word I would use, but do you think they thought that? Did you have that impression?	
Sara – Yep. Yep. **(nodding head).** Cos I remember a couple times, umm, when I asked, a few times I actually got the confidence to speak to my teachers and ask for like things I could do to catch up	YP Confidence
Alice – Mhmm	
Sara - Umm, and basically being like, there's nothing we can do. *(sara's voice gets quieter)* A couple of times. One time they said "that's not my job". *(said with a smile)*	Teacher perception of Role (QS26)
Alice – to show you…	
Sara – Yep.	
Alice – To help you catch up on what you'd missed.	
Sara. Yeah, and, I, cos it's not like I could properly explain to them, at that point I couldn't properly explain to them why I'd missed school and why I'd struggled with it, because I could barely work up the confidence to actually talk to them. Cos, they were all **(inflection on 'all')** very much focused on the grades rather as opposed to the person.	YP Confidence Academic Pressure (QS4)
Alice – Yeap	
Sara – Sooo, yeah, it just wasn't, I didn't feel as comfortable explaining it to them.	
Alice – And do you think they weren't, do you feel like they weren't treating you like an individual…	Teacher Understanding of YP (QS20)
Sara – Mmm, yea, yep.	

Alice – So they had an idea of what a "School X" girl looks like,	
Sara – Yeah. **(big smile and raised eyebrows)** And I didn't fit into it.	
Alice – You didn't fit into that.	
Sara – Yea. And so if I was in the classroom and I was struggling with something, I didn't actually feel confident enough **(quieter voice)** to ask for help.	YP Confidence
Alice - Mhmm.	
Sara – Aswell. And usually I'd be really overwhelmed in classrooms anyway *(looking down at the floor)*. It's just…there weren't that many classrooms that I felt comfortable in.	School Environment
Alice – You want to talk about what the classrooms were like, the actuall…	
Sara – Mmm	
Alice – The actual physical setting?	
Sara – yea. Just they were never. Sometimes they were like cramped. I remember one time, they were one of the ones in maths, it was the bottom of the music building, umm, with "Mrs X" and I was in a bit that was really really, I was put in a corner that was, and usually I like corners, umm but it was kind of in a corner between tables and it was really cramped **(gestures with hands)**, it was, yeah, really cramped and like small. And I think I was put there so the teacher could be near me, which, in theory **(higher pitch)** was good, but it was really cramped and then I was in front of the class and it was all just very…….uncomfortable.	"cramped" (QS18) "really cramped" (QS18) inappropriate support
Alice – yea	

Sara – it was just, I couldn't get out if I needed to. Because I had like a time out card.	trapped
Alice – yeah, yeah.	
Sara – But I still couldn't, I never felt confident enough to actually use it. Cos I don't know how I would. Cos I always had it in my blazer pocket, but I never knew how I would…how would be best to do it. Because I would always have to ask to go to the toilet. And then if they said no, I wouldn't push it further I'd just like sit there and bottle it up. Which, umm would usually make me worse because I would assume that would happen again.	Inappropriate support Toilet and Rigid system of control.
Alice – So do you feel like you didn't know for sure that the teachers knew what they were supposed to do in that situation?	Teacher Understanding of YP (QS20)
Sara – Yeah, I feel like because then I was obviously doing my GCSE's, a lot more subjects, a lot more teachers, I felt like, umm, not all of them were entirely aware of what needed to be done. Because at that point even I didn't really know what I needed to help **(elevated pitch)**, so it was a bit more difficult to identify that and then pass it on to the people in AEN and they could pass it on. And also they were quite busy with other students and sometimes it just was a bit….	YP "didn't really know what I needed to help" Teachers too busy to help
Alice – Yea	
Sara – And even with my student support manager, "Teacher X", I felt that I couldn't, uhh, explain it to her and she wouldn't be able to pass it on. ***PROPERLY*** pass it on.	Teacher Understanding of YP (QS20)

Alice – <u>So it, at that stage, you were having problems really, sort of, uhh, articulating what it was, you didn't know yourself what would help</u>.	YP "didn't know"
Sara – (nodding) Yeah. Yeah exactly.	
Alice – So you just had to keep going into that environment	
Sara – Yeah.	
Alice – Yeah. I remember you telling me about Maths.	
Sara – Mmm, Yeah **(eyebrow raise)**.	
Alice – That maths in particular was an issue because of the class?	
Sara – Yeah. Yeah because I was in bottom set. And, they kind of did a thing where…they'd kind of give the slightly laid back teacher to the bottom class **(inflection)**.	
Alice – Yeah	
Sara – And the <u>teachers we had couldn't really control the class as well</u>. And because, they were quite talkative **(inflection)**	School environment
Alice – the class was?	
Sara – The class was quite talkative. So most of the time no work would get done. It was really difficult for me to focus on things. <u>I felt like I couldn't focus on my, on getting any of my work done</u>. Because I had missed stuff anyway, so I was already struggling a bit and…so nothing really got done, and because the <u>classroom was really loud</u> **(inflection)** and there was always a lot happening **(inflection)**, <u>around people that I was a bit uncomfortable around</u> **(inflection)** and just not really my sort of….and yeah…umm a bit more withdrawn then. I was a bit shyer, so, umm, so, yeah I don't know, so…	YP trying hard to work

Loud

Peer relationships |

Alice – So the noise, it was noisy <u>cos it was chatty</u>	School environment
Sara – Yeah.	
Alice – so that was distracting, but also <u>you didn't like the fact that nobody else in the class wanted to do any work</u>?	Peer relationships + YP trying hard to work
Sara – Yeah, yeah, and it just made it a bit more difficult. It was <u>one of the classrooms that I would kinda dread</u>, it was one of the classes that I'd dread going to because the classroom environment was a really difficult thing to learn and it was even more <u>difficult for me to catch up on work and actually improve stuff</u>, I guess. And…yeah. *(Looking down at the floor throughout this comment)*	School environment
Alice – Umm, thinking about those days when you couldn't go to school. Were there like…….specific things, or…	YP trying hard to work.
Sara – I don't know. It was kind of a general…repulsion. Is that the word?	
Alice – Repul…	
Sara – I just, physic, I couldn't, I couldn't…drag myself,	
Alice – You couldn't physically force yourself in?	
Sara – No. (**shakes head)** I couldn't at all because I just, I dreaded it so much, and because there were <u>unknown things that would happen</u>, there were…no proper ways, <u>there were no proper places</u> I could go to if I got overwhelmed.	"unknown things" "no proper places"
Alice – Okay.	
Sara – Because obviously there was the AEN office. But, at that point I didn't have my scale (**gestures with hands)**, implemented.	
Alice – Yeah.	
Sara – So if I wanted to go there.	

Alice – Your five point scale?	
Sara – Yeah. So if I wanted to go there, I'd have to explain it, but they were always really busy so there was no where I, so I couldn't. So wherever I would go, wherever I could go, I would have to like explain to someone. So there was nowhere I could go, I could go sit without having to interact with anyone. Because that's what I kind of, would've been better for me.	"have to explain" No safe space
Alice – So, in those moments when you were feeling, you were in school and you were feeling overwhelmed…when you feel, just to give background, when you feel overwhelmed you find it really difficult to communicate…*(Sara nods head)…*and interact with people and all you want to do it, really sit quietly and not have to try and explain yourself and explain what's going on, you just need to sit quietly.	
Sara – Yeah. Because at that point I hadn't really, I didn't really go non-verbal **(voice gets quieter here)** at that point, still I struggled to communicate and struggled to communicate my feelings across, usually I'd just have to say separate words and kind of like gesture **(gestures with hands)**. Umm, and that was always more difficult for teachers because one, I don't feel comfortable communicating that way with them because they were an authority figure and a professional environment and kind of, that sort of, yeah. And also you don't know if they understood **(inflection)** entirely what I meant when I tried to communicate that across, so I kind of had to force myself to…verbalise things…which was one of things I would kind of have to, some of the things	Teachers as "authority figures"

weren't entirely true. Like because I was forcing myself to verbalise something that…	
Alice – that couldn't be verbalised.	
Sara – Yeah. So there were bits that were always like missed out. I couldn't actually get them out. <u>And then it's just, that would stress me out more. Cos I thought that I couldn't explain *everything (original emphasis)*</u>.	"explain everything"
Alice – No. So do you feel like, do you feel like if you had known, or if there had been, because actually at the school there wasn't like a <u>time out *room (sara shakes her head)*</u> or there wasn't just a <u>quiet space</u> that you could just go to and just be. Do you feel if there had been something like that in school that would have helped alleviate	Need for a quiet space
Sara – Yeah or maybe somewhere outside.	
Alice – Somewhere outside. <u>You like going outside</u>, that really helps you to ground yourself.	Being outside
Sara – yeah. So if there was something like that, it would just. So obviously with <u>schools I would have to let them know I was there **(rushes saying this)**</u>, kind of stuff. But just letting them know I'm there as opposed to explaining why I'm there and how long I would need. <u>So obviously once you made the five-point scale, I would be able to explain how I'm feeling without having to verbalise it</u>.	Explain everything
Alice – you could just point to where you are on the scale.	Five point Scale useful.
Sara – yeah and automatically the teachers would know, or like the AEN people would know	

Alice – But the AEN people, but that sort of hits the nail on the head because you would, <u>first of all you would have to get out of the classroom.</u> *__(Sara laughs a little)__*	Explain everything
Sara – <u>Which would involve some sort of communication.</u> Because <u>even if I did have a card and the teachers had been told to let me out. And I've been told that I can just walk out. I wasn't gonna do that</u> **(smiling)**<u>.</u> <u>That was never gonna happen, I was never gonna just walk out. Teachers are always gonna forget, teachers are always gonna ask me, people are gonna ask, students, it was just, I couldn't.</u> Even if I needed to go to the toilet, I didn't like standing up, and going and leaving the classroom.	Inappropriate interventions
Alice – you never wanted to draw attention to yourself.	
Sara – No. And just by getting up and walking out, it would draw attention from, yeah. So I felt like I couldn't do that, so that was the first barrier and then when I got to <u>AEN I had to actually be around people…before…</u>	
Alice – <u>Yeah, and that was a small setting, with lots of people, busy people.</u>	Inappropriate intervention
Sara – <u>And sometimes the space wouldn't even be free because they were having meetings, or other students would be using it, umm</u> **(voice gets quieter towards the end)**	
Alice – So once you got to AEN, even after the five point scale was in place…	
Sara – there was no guarantee	
Alice – There was <u>no guarantee</u>, and so that wasn't really there as a back up	"No guarantee"
Sara – Yea, yeah exactly. And once, I just felt, once, that would happen again, it seemed like a perfectly reasonable thing that would happen, because it was, it	

was something that could happen and that just kind of….if I'm ever gonna get stressed, then I might as well be at home.	
Alice – Because your safer at home.	
Sara – Because I'm safer at home. I have a comfortable space I can go to, I can communicate with someone and if I did have to communicate with someone, in you, I could communicate more comfortably with you because you'd understand without me having to properly verbalise it. So it's just more that I'd rather be here dealing with…	
Alice – Anxiety	"Anxiety"
Sara – Yeah. Than at school having to deal with it. Cos obviously a lot of the anxiety is caused by the fact that teachers don't necessarily, that in school I cant deal with things I need **(gets quieter)**, like in terms of arrangements. SO my anxiety is caused by, is, a lot of anxiety is because of that **(hesitant speech here)**.	Teacher Understanding of YP (QS26) + Anxiety
Alice – SO going back to those things, so we sort of talked about what happened in school when you felt anxious, and if you started to feel anxious and overwhelmed you didn't actually feel that there was anything you could do to help alleviate that anxiety, there wasn't anywhere you could go, it was a big performance..	No safe space + Anxiety
Sara – Yeah.	
Alice – and the biggest barrier was actually getting out of the classroom at all, but even then.	"getting out of the classroom"

Sara – It's not necessarily once I'm out of the classroom, it's not like it's a clean run to be, there are loads of other obstacles to deal with.	
Alice – Yeah, but maybe, so lets go back a step again to those things that might make you feel overwhelmed, so I remember you saying about umm **(sara shifts body position on chair)**, about the hallways for example and the change over of lessons, can you talk about that a bit.	
Sara – Yeah. Cos they were really <u>narrow and crowded</u>, so they were always quite small because its an old school, and so there were always like students lining up and teachers trying to get through, people were always trying to get to their lockers there were always two lines of people and so you were always pretty much <u>shoulder to shoulder</u>, umm, so its just, usually it meant it was <u>loud, and people were usually yelling and generally just being, being loud</u>. And because I was obviously, pretty much shoulder to shoulder trying to get through, it was people…<u>trapping</u> me in **(gestures with closed fists into body)**. And I just…	"narrow and crowded" School environment
Alice – sort of claustrophobic, or..	
Sara – yeah. I could just kind of feel…everything. It didn't help that the uniform wasn't the most comfortable thing. *(laughing)*	
Alice – yeah, so <u>the uniform was a problem</u> as well	"uniform was a problem"
Sara – It was added. <u>It wouldn't have been a problem by itself *(gesticulating)* but it just added it on. And its when everything is put together that it gets too much to deal with. Like by themselves they were all ones that I could probably manage *(inflection)*….</u>im not sure I could then, but yea, but once they're all	Build up of factors + Overwhelmed

together I just can't at all and that means that trying to calm down from that there are different things I need to do to help calm, to help deal with all the different factors, there's just…*(gesticulating)* a lot going on. Usually it means the lines moving really fast, it's difficult to take a step back, especially in school because everything is going really fast in school anyway, even if it's not literally **(gesturing)**, everything seems to be going, I'm always going somewhere, I always have an eye on the clock, I always have something to do and it just means that it's really difficult to take a step back because I know I should probably go to my next lesson **(raised eyebrows)**, because if I don't go to my next lesson then I'll have to walk in the middle of it. Which is another thing.	Fast pace of school
Alice – So you couldn't take time out between lessons and take 5 minutes and be late to lessons because then you had anxiety about arriving at the next lesson late.	No safe space
Sara – Which would then draw attention to me, and just generally that's another thing **(smiling)**.	
Alice – And then you would have to communicate with the teacher *why* you were late.	Explain everything
Sara – Yeah, which usually, and then I'd have to communicate that in front of a class. Because you'd have to walk over to their desk, everyone is already sitting down and looking at you, you usually walk in in the middle of teaching and umm, another thing that stressed me out is when I'm sitting and like I'm in the centre, I like to have my back to a wall, I like to be, not necessarily at the back of the class but umm, just not in the middle, that stressed me out cos I cant keep	Explain everything
	Seating Plan + School Environment

an, I cant see **(drawn out 'see')** what's going on. I need to see everything that's going on.	
Alice – you sort of want to be on the edge of the room so you can look in and see what's going on.	
Sara – yeah. It makes it easier for me to manage (gesticulating). I can notice all of the different factors. I can notice them, I can see them, that's fine. It's like I'm sitting, and I know there are <u>unknown things</u> happening behind me. And then that stresses me out cos it feels like it's something that could affect me, but I wouldn't know, cos I can't turn around and check, cos I can't keep spinning around. So…yeah. And then it also doesn't help in general in classes, so usually its <u>cramped, a bit loud</u>, your usually shoulder to shoulder with someone at the table, trying to organise all of your books on the table, especially in English. Umm, cos obviously those classrooms are quite small, and quite stuffy as well, obviously there's no air conditioning. So, they're all quite small, low ceilings, a bit <u>hot, stuffy, like 30 kids</u>, sitting in one, people sitting like on the edge of tables. Like in English we have big folders, so you have loads of bits of paper spread out but then umm, cos I need to have things in a place but I can't do that cos I have to be careful of other people. Cos obviously I can't put my folder to spread out, it becomes a large bit of the table, so I kind of have to be wary of that, umm, and that's another thing that stresses me out if things aren't where I want them to be. Umm, and, just, yeah. <u>It's obviously always quite *bright* **(emphasis)** in there</u>, sometimes there's a light flickering and also if there's stuff happening outside that I can hear **(inflection)**, if there's like a PE lesson	"Unknown things" Cramped and Loud (QS18) "Hot, stufy" "quite bright"

happening outside, that distracts me a lot, because I can hear people screaming or because it's on the main road as well, there's always like sirens and stuff like that umm, people walking out in the corridor I can't, I'm focussing on other people's conversations and I'm also trying to focus on the lesson and get the work done but I'm also more stressed out because I missed the work…	
Alice – because you've been distracted or have been focussing on something else.	
Sara – yeah. <u>And then suddenly once I've missed the work I have to try and do everything at once. And that just stresses me out, a lot. Like…a lot **(emphasis)**</u>. So, it's like I have to run to catch up but then things aren't neat in my book or my paper and then that also stresses me out. And then, it's <u>just everything at once</u>, is slowly rising up and it's just, there's no way of getting out. <u>The best thing to do would be to ask to go to the toilet,</u> but I can only do that when the teachers not teaching…	Academic pressure (QS4) Compounded factors Toilet as a break
Alice – Yeah, you don't want to interrupt.	
Sara – Yea exactly, so if once we get, once they say "go do this work", then I would go ask to do that because, and then usually what I would do then <u>is I would take a slightly longer route to a toilet **(inflection)** even if there was one right</u>, just because usually the corridors were clear and quiet and everyone was in the classrooms **(inflection)**, so it was a bit quieter and not as cramped so, and then it was easier for me to calm down a bit, for me to collect myself before going back in. But that's not always possible because there are just some teachers, I feel I just can't do that for<u>. Because then, because then they always</u>	Toilet as a break

do that weird thing when they "do you really need to go" and then you have to awkwardly say yes **(gets quieter)**. Yeah, and then they'd be like "just don't take too long"	Explain every action
Alice – and then in the back of your head you're thinking "I can't take too long".	
Sara – Yeah, when that's the whole point of this.	
Alice – Is to take time.	
Sara – Yeah exactly. Because that's what I do if I need to get out of the class, just go to the toilet. That's still what I do now. Cos otherwise I would have to explain that I am feeling stressed in front of a class of 30 teenage girls. Which **(tilts head)**, for obvious reasons, is not ideal, no matter how many of them I'm comfortable around. It's just an added thing. And….yeah **(shakes hands wide)**.	Toilet as a break

Explain every action |
Alice – Yeah.	
Sara – So classrooms were always difficult.	School environment
Alice – Classrooms were always difficult.	
Sara – There was only one that I felt was a bit better. Umm and that was Computer Science, because we were in rows, it was air conditioned, so it wasn't really stuffy and I sat next to people that I was comfortable around and I also sat on the edge of a row. And the person I sat next to on the other side was someone who I was comfortable with and kind of knew that I could get overwhelmed and so I wasn't…so I didn't have my back to a wall, but the only two people behind me are people I kind of knew…	Positive environment + Comfortable with peers.
Alice – and you trusted	Positive Peer relationships

Sara – and I trusted. And cos we were in rows and the computers facing that…yeah…and so, cos I was also at the front it meant I could easily ask the teacher "Mrs X" because I was also right by the door…and if I needed to stretch my legs, which I do need to do under the table sometimes. That's something when we're sitting at a square table, I'd obviously kick someone, so I need to sit at the edge, which is difficult. **Alice –** but it's really important for you to be able to stretch your legs out isn't it? **Sara –** because yea, I kind of just get a bit bees in my knees, that's what it feels like, buzzing bees in my knees and I need to stretch them out otherwise that just stresses me out. Oh yeah, so computer science was a bit better, it wasn't, it was a slightly smaller class because it was computer science, so the teacher I was with I was sort of comfortable, ish, around, I wasn't uncomfortable around him. I knew people that were near who can tell when I'm anxious and need to leave me alone **(waves hand)**. Who knew when I was overwhelmed, umm, and I wasn't as trapped as well. In general it was something that was a bit more enjoyable. And I don't feel, even though I was at the front I didn't feel forced to put my hand up so that was another thing. Cos it's when teachers pick on me **Alice –** Yep. So another thing is those, thinking about other things, those unknowns in school. Can you talk a bit about unknowns? **Sara –** Yeah. The unknowns are like if we go into a class and they say oh yea we're doing a mini test or something like that, which I need to know about before hand. I need to know about that at least a few days before hand	School environment (QS18) + Teacher Relationships (QS20) + Peer relationships The unknowns

(Scrunches up face). I need to be aware of it. Umm, because if I get surprised by that then the next time I'm going to automatically assume something's going to happen that I don't know about. <u>Or, so if the teacher picks on me and I'm not ready for it, umm cos sometimes when I'm, I'm mostly picturing English,</u> so if I'm tryna work at my own pace in a way that helps me understand it, or sort of catching up on past work, or asking other people what we've done, then the teacher calls on me, and I haven't necessarily done the current task because I've been too busy doing the other task and then you can have an awkward bit where I don't know <u>and the teachers like "well take a guess" and you just don't… you can't take a guess. And that's really stressful.</u> Usually, I would just go silent until they picked someone else because I couldn't answer it. So, the best thing is to just, I found what was easier with the teachers who wouldn't leave me alone unless I put my hand up, because I only put my hand up when I felt confident enough and comfortable enough to answer a question in front of the class, and things like that and so,**(gets quieter and hesitant)** <u>unknowns were always a bit stressful</u>.	Teacher Understanding of YP (QS20) Teacher Understanding of YP (QS20) Unknowns
Alice – Yeah, and what about unknowns when you miss, like a few days or even a couple of days and then you were coming back into school. Or trying to get back into school.	
Sara – Yeah, I remember <u>non-school uniform days</u>.	Non-school uniform days
Alice – Non-school uniform days	
Sara – Mmm yeah **(wide eyes and smiling – nods head too)**.	
Alice – why were they bad?	

Sara – I mean one cos it was a sort of unknown. Two, I don't, it's difficult to choose what to wear when there's no dress code. So obviously now I'm in the sixth form there's no uniform but there is a dress code, so it's easier for me to do that because I have a thing that's easy, sort of t-shirt, skirt, tights, shoes. But then it's kind of, you don't know if you're meant to be slightly smart, if you can come in in like a hoody, like I don't know, it's always, it was always an unknown and again just because it was an all-girls school **(leans towards mum)**, just…	
Alice – Girls conscious of what everyone else is wearing.	
Sara – And I remember one time somebody, like in year 8, made a comment or something, I can't remember much about it…	
Alice – I remember you telling me that you wore, <u>you always wore, she said that you always wore the same thing on non-uniform day</u>	Peer relationships
Sara – Which was black trousers and a t-shirt that I was comfortable in, my hoodie and my black boots, so yeah, but that just then…	
Alice – But you wore that because that's what you were comfortable in.	
Sara – Yeah and that's what made me feel comfortable <u>sensory wise</u>. Which is always something I need to…	Sensory
Alice – think about	
Sara – think about, yea. The good thing about the uniform is that that's one less thing for me to think about	
Alice – I was gonna say about the morning, about the impact of your morning routine. If you haven't got the uniform to wear, on a non-school uniform day that…	

Sara – It's really stressful cos having to choose something that I think looks nice and also, I feel comfortable in like fabric, like one thing is tucking in shirts, like when it rolls up and it, yeah, and its directly against your skin, it's not nice. It's easier to have an automatic thing to go to that everyone's going to be wearing and I can just blend in. And cos like, obviously the uniform wasn't ideal, the fabric was kind of like…, but it was still something that I wore every day for five years. So, I got used to it. It still felt a little bit uncomfortable than what non-school uniform would be and so which I why I never actually, most non-school uniform days I wasn't actually able to go in. Unless I was having an amazing day. Which didn't happen often **(shakes head slightly)**. Everything was slightly different, and it didn't feel right.	Sensory "uniform wasn't ideal"
Alice – yeah. Because also sometimes on non-school uniform days there were different activities.	Unknowns
Sara – oh yeah because they were for charity. So there would be, if it was a non-school uniform day run by my community, my house, then that would be, I would have to help out the stalls, selling stuff in the halls and umm, which wasn't ideal **(inflection)**. Cos, its people. And sometimes they would make us go around in different base rooms, selling sweets in our case, cos we did pick'n'mix, so, and it was always just something that could be different that could happen, so I struggled really badly to get in on those, so I never did. And there was always a bit of dread when I realised, oh no tomorrows a non-school uniform day. I also remember one time that I forgot there was a non-school uniform day.	unknowns
Alice – I remember that too.	

Sara – We drove into the car park, everyone was in non-school uniform, I was in my uniform and I just told you to turn around and go back. **Alice** – Yes, but you did get changed and go in. **Sara** – I did actually go in that day. That had always been, every Friday I will have a moment of **Alice** – Is it a non-school uniform day. **Sara** – At the end of term I will have to check, and I will be like, and even if it says there isn't, I would be really really worried about it. So, on those days I would ask you to take me in, just because it's easier to turn around and go home if you're in a car. If you're on foot you've just gotta kinda spin around and leave cos once you're in school, just…yeah. They weren't good. So, I didn't get in….so I didn't get in for most of them. **Alice** – What about lunch hours? **Sara** – Lunch hours were never actually a problem. Cos I have a set group of friends, <u>I have the four girls who I've been friends with since the first year, who I was comfortable around</u>. Sometimes I was a bit stressed when I didn't know where they were sitting at lunch. And I'd have to go to the toilets and message them. And I'd get really, that would always stress me out a little bit, but otherwise they weren't, lunch hours weren't bad. Especially in summer when we would all wit outside. Umm so yeah, lunch hours were never so much of a problem, when I knew where I was going. Umm and what I'd do to make sure I always knew where I was going, in the morning umm, I would ask where are we having lunch, or where am I meeting you and just to make sure or just like on	Positive Peer relationships

the chat the day before and ask about where they're going and if anything is different, and stuff like that and because everyone liked to eat outside, its just one less thing. And I was more comfortable around them and I still am.	
Alice – <u>So that was something that was more predictable and within your</u> <u>control</u>	Positive Predictability
<u>**Sara –** Yeah exactly</u>	
Alice – and that helps?	
Sara – because also my friends, <u>like "Friend X" she's basically really good at</u> <u>helping me with this sort of thing, so I knew that if I needed to I could go to her</u> <u>and she would help and just be a bit of a console, and yeah, cos she always</u> <u>understood it quite well so.</u> Lunches were never so much of a problem. Umm, yeah, there was no, because <u>it was mostly because of people I wasn't</u> <u>comfortable around in lessons, in quite small spaces and cramped classrooms,</u> <u>so hallways as well and like unknowns in lessons and exams, things like that</u> <u>were the main things that were the reasons behind it so</u> **(voice gets quieter)**, lunch never really came into it.	Positive Peer relationships School environment (QS18) +Unknowns +peer relationships
Alice – Umm, so, going back to teachers and things like that. I was thinking about like catch up work, but I was also just thinking about the fact that just before you started taking your ADHD meds how much that stressed you out in	
Sara – Yeah, cos I wasn't able to do my school work<u>, I wasn't able to do</u> <u>homework. And then If I hadn't done that, I couldn't go in</u>./ <u>I felt like I couldn't</u> <u>go in because I was meant to have done it, I haven't and being the only person</u> <u>who hasn't, the teacher will probably go on at me about it</u> and for good, not	Homework + Academic Pressure (QS4) + Teacher Understanding

cause but obviously its homework that I was meant to do, so it makes sense that they would question me about it. Umm so usually I wouldn't actually explain the reason why, which was that I felt too stressed to do it, usually I'd say oh I left it at home can I bring it in tomorrow. Which would then give me another stressful deadline (**scrunches face)** and then I wouldn't usually come in tomorrow and then I'd just avoid the teacher, until I felt, until I felt that it had been long enough. So my usual tactic was avoid.	
Alice – <u>So do you feel like teachers, school, didn't actually make sort of, enough adjustments and accommodations</u> **(Sara rests her chin in her hands)**<u>to allow for that and they had, so, umm understanding that actually having, if you did manage to spend a day in school that then coming home and doing homework</u>	Teacher Understanding of YP (QS26)
Sara – was difficult and not gonna happen.	
Alice - …was yeah, was unrealistic probably. <u>But they didn't understand that, or didn't acknowledge that.</u>	Teacher Understanding of YP (QS25)
Sara – They didn't really under…	
Alice – or respect it.	
Sara – <u>They knew that obviously, they knew that I had anxiety, that I was autistic, that I had ADHD, they knew those things, but they didn't necessarily know the things that came along with those</u>. And they assumed that because I was always kind of there, I was quiet, I didn't necessarily interrupt, I was always in the background, I didn't ask for help, I think they assumed I didn't need help.	Teacher Understanding of YP (QS20)
Alice – Do you think they had a picture in their head of what an autistic child, student with ADHD would like, and you didn't fit that?	

Sara – I didn't fit that. And obviously I was at a grammar school and I was quiet, and I didn't get bad grades but I didn't get good ones either, so I was just kind of…there. Sort of, I did the work in class at least, most of the time. <u>So, they didn't really understand what sort of troubles came along with it</u>. Umm and they never really did. Even as it got late one, even in year 11 like right towards the end of it, they never understood it entirely. <u>Though only managed to understand recently at my new school</u> **(raises eyebrows)**. <u>And obviously that's because I've finally been able to understand what I need help with.</u>	Teacher Understanding of YP (SQS20) YP understanding of self + Teacher Understanding of YP (QS20)
Alice – We know better what you need now.	
Sara – <u>I didn't then, so I didn't know what to tell them, but still, I knew the basics and they didn't really understand that at the very least</u>.	Teachers Responsibilities (QS26)
Alice – So I feel like <u>they didn't make the effort ot understand</u>. I don't think. I remember having a conversation with one of your teachers, umm, who basically said <u>"this is the way I teach; this is the way I've taught for the last 30 years, and umm, I'm not going to change".</u> And that was the impression I had from not just her but from a lot of teachers that they didn't feel the need to change the way they taught or the way they gave you information to adjust for the way you learn.	Teacher Responsibilities (QS26)
Sara – Yeah, because I was the minority **(looking down)**, and <u>umm at the end of the day they just wanted us to get the grades, they didn't necessarily care about the individual</u> they just wanted us to get good grades. So, it would look good on them **(inflection)**. So, they wouldn't want, <u>they wouldn't change it any way to make it easier for the students and then they'd get frustrated when I struggled</u>	Academic Pressure (QS4) + Teacher Understanding of YP (QS20) Inappropriate support

(frowning). Which wasn't helpful. And just a lot of them, <u>they weren't willing to change</u> because I was the minority in that sense. Everyone else was fine, so they thought oh its just one student, why should I change.	Teacher responsibility (QS26)
Alice – Everyone else appeared to be fine.	
Sara – Which in all likelihood they probably weren't. And now later on, a lot of people I know actually did struggle with things like that but because of the environment **(inflection)**, didn't outwardly express it and just kind of put up with it.	
Alice -So, <u>PE was another thing I was thinking about</u>. I know you didn't, you didn't go to PE but, for the last couple of years at all **(sara rubs her neck)**, but during those earlier years at secondary school PE was definitely a lesson, like if you had PE in a day, there was a good chance you weren't going in.	PE
Sara – It was just, it was too much. I mean I wasn't overly sporty, like one thing my hand eye co-ordination was never good like I could never catch a ball. And then people in class who were very sporty would then kind of then get mad at me, because I wasn't good enough, umm…yeah.	
Alice – It's just another thing.	
Sara – It's just another thing and then there was the whole thing about <u>getting changed and going outside and not knowing what we were doing</u>. And the <u>teachers were even less likely to understand it because they weren't on my regular timetable, so they weren't usually kept in the loop because most of the time they assumed it was academic subjects and that environment that I struggled with, so they discarded PE as an actual issue</u> **(inflection)**, so…	Unknowns Teacher Understanding of YP (QS27)

Alice – So another case of that <u>unpredictability and not knowing</u>, and the teachers not really understanding what was an issue and what they could do, to help.	Unknowns
Sara – Yeah, yea yea yea **(looking down)**.	
Alice – Umm, so, umm, going back to that time in year 10 and 11 when you were hardly going to school, do you feel like, like all those things that we've just talked about basically it got to a stage…**(sara puts her chin in her hands)**what happened to basically get to the stage where you just weren't going to school?	
Sara – (talking with chin in hands) I missed school once and found that it was a, it would allow me not to have to deal with those issues and then it built up, I missed work, I wasn't performing as well in classes, <u>it just built up</u> and and it got to a point where there just was no point in me going in cos I would get so stressed. The only time I would be able to go in was when I did half days. Cos it was just not as long for me to have to…cos it feels like I have to **(gestures with hands)**, like when you tense your body up, that's what it feels like going around school, I kind of have to keep myself very much…together. I cant express myself in the same way. I have to bottle everything up, I just feel like, its like being tensed up but…emotionally **(inflection)**. I guess. I just have to very much keep that in. And then, just the idea of having to do that for 6 hours <u>around other people. In an environment, in an uncomfortable environment, in an overwhelming environment, was just a lot</u>. And difficult, and I didn't want to have to do that, to go through 6 hours of an uncomfortable environment, having to just hold everything in. So, just, the fact that it was <u>easier for me to</u>	Compounded issues Relationships School environment

just not go in **(looking down)**, and then the more work I missed, if I went in, I didn't know what was going on in class. <u>Teachers would ask if I've done catch up work and I would have to say no. Cos I couldn't manage that cos I was barely managing to keep myself together at home.</u> And just because I'm at home doesn't mean I can still do the work. Because doing the school work makes me think about school, and that's just another thing, but yea.	"Easier for me to just not go in" Teacher understanding of YP
Alice – So it was a vicious circle as well because <u>school made you feel stressed</u>, that then made it difficult for you to work at home, pretty much impossible during that time to do work at home, but then that's another thing that makes it more difficult for you to go back into school **(Sara looking down while Alice is talking)**. But to start with, Im just thinking about sort of, looking at, it, it was a lot about the school environment…	"School made you feel stressed"
Sara – <u>and the work.</u>	
Alice – <u>and the work, and teachers and things like that,</u> that then built up to the stage where you sort of dreaded it…	Academic Pressure (QS4) Teacher Relationships
Sara – Yeah basically	
Alice – and then it just snowballed.	
FOLLOW UP EMAIL INFORMATION	
I've had a chat with Sara about your question and after a bit of thought this was her response - I'm paraphrasing:	

Sara's coping mechanism throughout primary school was to 'zone out' and daydream. So, whenever she started feeling overwhelmed she would just block out whatever was going on around her. Because she has always been academically able, she could do this and still easily keep up with whatever was being taught. It was only when she started at grammar school that this strategy started to fail her.

She also said that always being in one classroom for most of the time made things easier to manage, as did the fact that the days were much more predictable.

Sara also pointed out that because she was a quiet, well-behaved and capable pupil, the teachers never really paid her much attention. So it was easy for her to blend into the background, and she's always been happiest and most comfortable when she can avoid drawing attention to herself.

I hope that all makes sense. I believe that Sara's experience is quite common among autistic girls - they can go through primary school with no problems at all and it's only when they get to secondary school that the wheels fall off! We had absolutely no inkling that Sara could be autistic until well into year 8, though in retrospect she was struggling almost from day one.

We were a bit vague on Saturday about when Sara was diagnosed as autistic, but I've now checked and it was in August 2018, the summer between year 9 and 10 when she had just turned 14. She was diagnosed with ADHD in December that year. Do let me know if you need any more information - we're happy to help in any way we can.	194

Appendix 19: Example of Contemporaneous Reflections of Research

*The names referred to in this reflection are Pseudonyms.

My first research participants were Peter and his mother Mary. Peter is 11 years old, currently attends a specialist setting and thoroughly enjoys his time there. He previously attended a mainstream primary school, and it was the experience there that he spoke about with Mary.

I have created a document which identifies each of the key pieces of information that I need to go through with the participants prior to beginning the recording, including consent, safeguarding and the process of the conversation. In addition to this, I have a set of contextual questions to ask the participants, which I direct towards the young person, to establish their age, the period of their school refusal etc. I found that Peter was able to answer most of these questions, and Mary helped him when he was unsure.

During the conversation, Mary took a dominant role, using the sentence starter crib sheet at times to direct the flow of the conversation. Peter answered her questions and agreed/disagreed with Mary's statements, but rarely did he freely offer extra information beyond what was asked. Despite this, I do feel that Mary was supporting Peter to express himself, rather than simply expressing and imposing her opinions. Her line of questioning used phrases such as "Do you remember when you told me". As we have discussed the experience of school refusal affects both child and parent and it seemed to me that Mary was re-living Peters experiences and asking him to join her in recounting those moments.

Peters body language from the beginning to the end of the process was quite revealing. To start, before the parent-child conversation began, he was sitting forward in his chair, paying

close attention to what I was explaining, looking around, shifting his body weight regularly. However, when the parent-child conversation started, he sat back in the chair and did not move much at all. He had a large water bottle on his lap which he appeared to use as something to fidget with. He made eye contact with Mary on a couple of occasions (during points of emphasis in his explanation). His tone was very matter of fact when discussing his previous school, however when discussing his new school his voice became more animated. During the de-briefing phase of the process Peter once again sat forward in his chair. He then disappeared and came back with this dog, which we chatted about for a moment – he was again much more expressive in both his body language and his verbal language.

There was a moment during the conversation in which I considered pausing the conversation. Peter mentioned an historic incident of self-harm (hitting himself in the head) and suicidal ideation (he wanted to die). However, there was no additional visible distress in either his body language or his voice, it appeared to me that he was simply recounting a historical event. Additionally, Mary's response to this statement, was one of acknowledgement and support, she was aware of this incident and therefore did not seem surprised about Peter mentioning it. Mary very naturally tried to explore the reasons behind this incident then moved the conversation on. At no point did either participant appear unduly distressed by this interaction and therefore I did not step in and pause the conversation.

In terms of findings from the conversation, the following appear to be the school based factors which Peter and Mary relate to Peters school refusal – The loudness of the classroom, bullying, assemblies, sports day and school events, finding it difficult to ask for

help, other naughty children, low staff to student ratio, false promises (sensory circuits) and feeling invisible/not being listened to.

Initially, Peters mention of feeling invisible was in relation to his peers, however at the end of the conversation, during the debriefing, Mary spoke of Peter's feeling that he did not have a voice during his time at the primary school. She felt that neither of them were listened to by the school. Mary instigated the EHCP process, despite being told by the school that Peter would not get one (which he did). Mary also made it clear that their motivation to engage with this research project was to enable Peter to have his thoughts heard on the subject and hopefully to help other students in the future avoid experiencing what Peter went through.

Mary's responses to the SRAS-P demonstrate the Peter was indeed refusing school due to avoidance of school related stimuli provoking a negative affectivity (Function A). However, this was closely followed by Function C, "garnering parental attention" and then Function B "escape from aversive social or evaluative situations". It was only D "positive tangible reinforcement" which was a very low contributor to school refusal. Mean scores were as follows A=5.3, B =3.5, C=4.6, D=0.8

Peters response to the stage three questionnaire appears to show that his teachers, teaching assistants, and the school in general did not understand or support him through his school refusal. He also notes that his thoughts and opinions were not valued by staff. Peter reports that he was given help in understanding classroom discipline, but not in forming friendships, sensory processing, homework, expressing himself in the classroom, incidences of bullying, adapting to change, organisation, and understanding others. Peter also reported feeling a large amount of academic pressure, being nervous of strict teachers, support being

unsuited to his needs and that his thoughts and opinions were not valued by his peers. Positively, Peter did report that in general he had a good relationship with his autistic peers.

The technical side of the conversation could have been smoother. Unfortunately, the internet connection on the participants end seemed to be slightly unstable at times, which meant that some of the comments were inaudible. Additionally, once the parent-child conversation began, Peter sat back in his chair, moving slightly further from the microphone, which added to the difficulty in hearing what he was saying. However, a new set of speakers for my PC has improved the sound quality and very little of what was said is missing from the original transcript. I have since been in touch with the participants via email to clarify the content of the missing statements. The use of a Dictaphone recording at my end of the conversation did nothing to aid in transcription, I have realised that if the internet is down or if audio quality is bad during the recording, the Dictaphone is not going to pick up any missing information. The only solution would be asking the participants to record the conversation at their end and then I collect the Dictaphone after the event, but I am not keen on asking participants to do this, as it adds a level of responsibility on them which seems unfair. Aside from this, the process of setting up, running, recording and reviewing the online conversation using MS Teams worked really well. The video replay system is easy to use, with a 10 second rewind button which helps to reply hard to hear comments without having to try and find the right place each time. Unfortunately, the university does not subscribe to the Microsoft Transcription service, so I have transcribed manually instead – though that being said the quality of the audio might not have worked with an automated system anyway.

significant anxiety all day. Even then they didn't want to hear it, sooo. X is

last school, he didn't feel he had a voice. He couldn't verbalise it and I was

constantly told by the SENCO he might be masking in school but we don't think

School not listening to need. (SFQ1)

amazing. The school had been telling me he was doing sensory circuits each

week but had to admit later that they had not been doing it. Peter now gets

Inappropriate support (SFQ1)

MARY – Can I just say when you were at your at your last school, how many

teachers or TA's were there with the children in the room.

Staff to Student Ratio support. (SFQ1)

silence instead. His current school doesn't do whole school assembly.

PETER – Yeah, I've made

PETER – Umm, I like to do sensory circuits and

MARY – And you've bought home mum some interesting things haven't you?

Sensory Positive

R – I was really depressed, so a lot of the time I couldn't go, so. (AUDIO

Y – And sometimes you felt angry?

– Yeah

MARY – Can you remember what else was difficult in the classroom?

MARY – And, what about your teacher?

PETER – umm some of them were good and some of them were bad.

MARY – And do you remember when we talked about this last time, you said to

me that you didn't feel that you could ask for help?

Teacher Relationship

Teacher Relations

e talk about what you remember about the classroom?

ARY – Both maybe, okay. And what about breaktimes and lunchtimes?

ARY – And that was even wearing your ear defenders wasn't it.

TER – (PETER nods)

Unstructured Time

Theme	Sensory Environment	School Curriculum	Peer Relationships	Teacher Relationships
Designation	A	B	C	D
Total Mentions	43	67	24	122

JAMES			Theme			
Codes			A	B	C	D
Small Classes Needed			▓			
Inappropriate Support						▓
No Personal Control				▓		▓
Academic Pressure				▓		
Teachers Understanding						▓
Class Size + "busy environment" + Inappropriate support			▓	▓		▓
Inappropriate Support						▓
Fast Pace				▓		
"physical and mental weight on my back"			▓			
Inappropriate Support						▓
YP Tries Hard						▓
Inappropriate Support						▓
Teacher Relationships						▓
Fast Pace + Inappropriate Support				▓		▓
No Follow Up						▓
Good Teachers						▓
Appropriate Support						▓
School Structures				▓		
Inappropriate Support + Teacher Training						▓
Peer Relationships					▓	
Bullying					▓	
No Control				▓		▓
Inappropriate Support						▓
Teacher Training + Peer Relationships						▓
Overstated Expertise						▓
Sensory Overload + Teacher Understanding + "they looked at me as if I was an alien"			▓			▓
"they crumbled at the slightest request"						▓
"I had no control"				▓		▓
Teacher Understanding						▓
Overstated expertise						▓
Teacher Training						▓
Non-Inclusive Environment			▓			▓
"It was like going to two different schools"			▓			▓
Unresponsive to diagnosis						▓
"no idea what to do with your diagnosis"						▓
Inappropriate Support						▓
Inappropriate Support						▓
Teacher Understanding						▓
Staff not listening + "they completely ignored me"						▓

	A	B	C	D
"I became angry				▓
"this was me trying to get my message across"				▓
Punishments		▓		▓
Not listening + Teacher training				▓
inappropriate Support + not listening				▓
Lost trust				▓
Busy environment		▓		
Homework		▓		
Inappropriate timing of support				▓
Teacher training				▓
Small class sizes	▓			
Academic Pressure		▓		
Academic Pressure		▓		
Teacher Training + Fast Pace				▓
Big Environment + Big Class Sizes	▓			

SARA	Theme			
Codes	A	B	C	D
YP "didn't realise why"				▓
"school environment"	▓			
"Academic Pressure"		▓		
Teacher Understanding of YP				▓
YP Confidence				▓
Teacher perception of Role				▓
YP Confidence				▓
Academic Pressure		▓		
Teacher Understanding of YP				▓
YP Confidence				▓
School Environment	▓			
"cramped"	▓			
"really cramped"	▓			
inappropriate support				▓
trapped	▓			
Inappropriate support				▓
Toilet and Rigid system of control.		▓		
Teacher Understanding of YP				▓
YP "didn't really know what I needed to help"				▓
Teachers too busy to help		▓		
Teacher Understanding of YP				▓
YP "didn't know"				▓
Loud	▓			
YP trying hard to work				▓
School environment		▓		
Peer relationships			▓	
School environment		▓		
Peer relationships +			▓	
YP trying hard to work				▓
School environment		▓		
YP trying hard to work.				▓

"unknown things"		■		
no proper places"	■			
"have to explain"				■
No safe space	■			
No safe space	■			
Teachers as "authority figures"				■
explain everything"				■
Need for a quiet space	■			
Being outside	■			
Explain everything				■
Five-point Scale useful				■
Explain everything				■
Inappropriate interventions				■
Inappropriate intervention				■
No guarantee"				■
Teacher Understanding of YP + Anxiety				■
No safe space + Anxiety	■			
"getting out of the classroom"	■			■
"narrow and crowded"	■			
Loud	■			
"uniform was a problem"	■			
Build up of factors + Overwhelmed	■	■	■	■
Fast pace of school		■		
Explain everything				■
Explain everything				■
Seating Plan + School Environment	■			
Unknown things"		■		
Cramped and Loud	■			
Hot and Stuffy	■			
Quite Bright	■			
Academic pressure		■		
Compounded factors	■			
Toilet as a break		■		
Toilet as a break		■		
Explain every action				■
Toilet as a break		■		
Explain every action				■
School environment		■		
Positive environment		■		
Positive Peer relationships			■	
School environment		■		
Teacher Relationships				■
Peer relationships				■
The unknowns		■		
Teacher Understanding of YP				■
Teacher Understanding of YP				■
Unknowns		■		
Non-school uniform days		■		
Peer relationships			■	
"uniform wasn't ideal"	■			

Codes	A	B	C	D
Unknowns		■		
Positive Peer relationships			■	
Positive Predictability		■		
Positive Peer relationships			■	
School environment		■		
Unknowns +peer relationships		■	■	
Homework		■		
Academic Pressure		■		
Teacher Understanding				■
Teacher Understanding of YP				■
Teacher Understanding of YP				■
Teacher Understanding of YP				■
Teacher Understanding of YP				■
YP understanding of self				■
YP understanding of self + Teacher Understanding of YP				■
Teachers Responsibilities				■
Teachers Responsibilities				■
Academic Pressure + Teacher Understanding of YP		■		■
Inappropriate support				■
Teacher responsibility				■
PE		■		
Unknowns		■		
Teacher Understanding of YP				■
unknowns		■		
Compounded issues	■	■	■	■
School environment		■		
Academic Pressure		■		
Teacher Relationships				■

PETER	Theme			
Codes	A	B	C	D
School environment	■			
Peer Relationships			■	
"I was bullied"			■	
Extracurricular activities		■		
Teacher Relationships				■
Teacher Relationships				■
Unstructured Time		■		
Bullying			■	
Peer Relationships			■	
Invisible in School				■
Invisible in school				■
Peer Relationships			■	
Food Tech		■		
Sensory Circuits as a Positive	■	■		
Food Tech		■		
Creative Lessons		■		
Staff to Student Ratio		■		
Outdoor Learning		■		

	A	B	C	D
Lack of Voice + "He couldn't verbalise it"				■
School not listening to need.				■
Inappropriate support				■
Inappropriate support.				■

COEN	Theme			
Codes	A	B	C	D
It Stinks	■			
Seating Plan	■			
Really bright	■			
Inappropriate Support				■
Focus on Academic rather than social support			■	
Transitions		■		
Classrooms always smell	■			
Teacher Relationships				■
Cover Teachers + teacher relationships				■
Teacher relationships				■
Punishments				■
Teaching assistants				■
Teacher Relationships				■
Peer Relationships			■	
PE		■		
Punishments + Peer Relationships			■	■
Peer relationships			■	
Peer Relationships			■	
Punishments				■
Punishments				■
Sports Day + Peer Relationships + Lessons		■	■	
Lessons				■
Peer Relationships + Seating Plan	■		■	
Peer Relationships			■	
Uniform	■			
PE		■		
PE Lessons + Punishment				■
Toilet		■		
Bullying			■	
Walk to School + Cars were loud	■			
"my ears got really sensitive"	■			
Transition to secondary		■		
Punishment				■
Teacher Supports				■
Class size + PE	■	■		
No Follow Up with Interventions				■
Unclear directions				■
Insufficient Support				■
Insufficient Support				■
Staff to talk with				■

YP unaware of need				■
Performance Subjects		■		
Performance Subjects		■		
Sports Day		■		
Teacher Relationships				■
Teacher Relationships				■

Appendix 22:

Stage Three - Questionnaire

Please take your time to read the statements below.

Then put an X in the box that matches how you feel about that statement. The top one has been completed by the researcher to demonstrate.

	Statement	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
0	Marvel is better than D.C Comics			X		
	General School Statements	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1	I avoided specific academic subjects at school					
2	I did not like the school environment					
3	I did not like the structure of the school day					
4	I felt a large amount of academic pressure from the school					
5	The support I was given at school was unsuited to my needs					
6	I was nervous about strict teachers					
7	My teachers were often absent					
8	I did not have enough information about my subjects in school					
9	I did not have enough information about the different activities in school					
10	I was afraid of unsupervised areas in school					
11	In general, I had a good relationship with my autistic peers					
12	In general, I had a good relationship with my non-autistic peers					
13	My thoughts and opinions were valued by my peers					
14	I was socially isolated at school					
15	I was bullied or teased at school					
16	I found secondary school more complicated than primary school					
17	I did not like changing between classes					

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
18	I had a large class size					

	School Staff Statements	**Strongly Disagree**	**Disagree**	**Neither Agree nor Disagree**	**Agree**	**Strongly Agree**
19	My teacher paid me lots of attention in class					
20	My teachers took the time to listen to me and what I needed in school.					
21	My thoughts and opinions were valued by school staff.					
22	In general, I had a good relationship with my teachers					
23	My school refusal was acknowledged by the school.					
24	The school supported me when I experienced school refusal					
25	I felt that the school understood my school refusal					
26	My teacher supported me when I experienced school refusal					
27	I felt that my teacher(s) understood my school refusal					
28	My Teaching Assistant supported me when I experienced school refusal					
29	I felt that my teaching assistant understood my school refusal					
30	The SENCo supported me when I experienced school refusal					
31	I felt that the SENCo understood my school refusal					

	Intervention/Support Statements	**Strongly Disagree**	**Disagree**	**Neither Agree nor Disagree**	**Agree**	**Strongly Agree**
32	I was given the help I needed to organise myself at school					
33	I was given the help I needed to adapt to changes at school					
34	I was given the help I needed to understand the perspectives of others					
35	I was given the help I needed to form friendships					
36	I was given the help I needed with any sensory difficulties I had					
37	I was given the help I needed doing my homework					
38	I was given the help I needed to understand classroom discipline					
39	I was given the help I needed to express myself in the classroom					
40	I was given the help I needed going on trips out of school					
41	I was given the help I needed to deal with bullying					
42	I was the given the help I needed to understand myself at school					

Thank you for taking the time to complete this questionnaire. Please return it to pr172@canterbury.ac.uk

Appendix 23: Stage Three Questionnaire Participant Responses and Data

Statement	Peter	Coen	Sara	James	Total
General School Statements					
I avoided specific academic subjects at school	3	2	2	1	8
I did not like the school environment	1	1	2	1	5
I did not like the structure of the school day	3	2	2	1	8
I felt a large amount of academic pressure from the school	1	3	1	1	6
The support I was given at school was unsuited to my needs	1	3	2	1	7
I was nervous about strict teachers	1	1	2	1	5
My teachers were often absent	4	2	4	2	12
I did not have enough information about my subjects in school	4	2	3	1	10
I did not have enough information about the different activities in school	2	2	3	2	9
I was afraid of unsupervised areas in school	2	3	4	1	10
In general, I had a good relationship with my autistic peers	2	2	3	3	10
In general, I had a good relationship with my non-autistic peers	2	3	4	1	10
My thoughts and opinions were valued by my peers	2	1	2	1	6
I was socially isolated at school	2	4	4	1	11
I was bullied or teased at school	1	2	4	1	8
I found secondary school more complicated than primary school	3	1	1	1	6
I did not like changing between classes	2	1	2	1	6
I had a large class size	3	3	1	1	8
SUB TOTAL A	57/90	38/90	46/90	22/90	163/360
School Staff Statements					
My teacher paid me lots of attention in class	2	2	2	2	8
My teachers took the time to listen to me and what I needed in school.	3	4	1	1	9
My thoughts and opinions were valued by school staff.	2	3	2	1	8
In general, I had a good relationship with my teachers	3	4	3	3	13
My school refusal was acknowledged by the school.	1	2	2	2	7
The school supported me when I experienced school refusal	1	3	2	2	8
I felt that the school understood my school refusal	1	1	1	1	4
My teacher supported me when I experienced school refusal	1	3	1	1	6
I felt that my teacher(s) understood my school refusal	1	2	1	1	5
My Teaching Assistant supported me when I experienced school refusal	2	3	2	3	10
I felt that my teaching assistant understood my school refusal	1	3	2	1	7
The SENCo supported me when I experienced school refusal	1	3	4	1	9
I felt that the SENCo understood my school refusal	1	4	2	1	8
SUB TOTAL B	20/65	37/65	25/65	20/65	102/260
Intervention/ Support Statements					
I was given the help I needed to organise myself at school	2	1	4	2	9
I was given the help I needed to adapt to changes at school	2	2	2	2	8
I was given the help I needed to understand the perspectives of others	2	3	3	1	9

I was given the help I needed to form friendships	1	4	2	1	8
I was given the help I needed with any sensory difficulties I had	1	1	2	1	5
I was given the help I needed doing my homework	1	2	2		1	6
I was given the help I needed to understand classroom discipline	4	2	3	3	12
I was given the help I needed to express myself in the classroom	1	1	3	2	7
I was given the help I needed going on trips out of school	3	2	3	4	12
I was given the help I needed to deal with bullying	1	2	3	1	7
I was the given the help I needed to understand myself at school	2	2	4	1	9
SUB TOTAL C	20/55	22/55	31/55	19/55	92/220
Total	97/210	61/210	102/210	97/210	357/840

Participant	General/90	%	Staff/65	%	Interventions/55	%	Total/210	%
Peter	57	63	20	30	20	36	97	46
Cohen	38	42	37	57	22	40	97	46
Sara	46	51	25	38	31	56	102	48
James	22	24	20	30	19	35	61	29

Appendix 24: Pilot Study SRAS-P Revised Data

SRAS-P Scores				
Participant	Mean- A	Mean - B	Mean -C	Mean -D
Anna	5.3	4.2	1.3	2.1
Zoe	4.5	2.8	3.8	2.7

Appendix 25: Pilot Study Stage Three Questionnaire Data

Statement	David	Olivia
General School Statements		
I avoided specific academic subjects at school	5	3
I did not like the school environment	1	1
I did not like the structure of the school day	1	3
I felt a large amount of academic pressure from the school	3	1
The support I was given at school was unsuited to my needs	1	3
I was nervous about strict teachers	4	1
My teachers were often absent	3	4
I did not have enough information about my subjects in school	3	3
I did not have enough information about the different activities in school	3	3
I was afraid of unsupervised areas in school	5	3
In general, I had a good relationship with my autistic peers	3	3
In general, I had a good relationship with my non-autistic peers	2	1
My thoughts and opinions were valued by my peers	1	1
I was socially isolated at school	2	2
I was bullied or teased at school	1	1
I found secondary school more complicated than primary school	5	1
I did not like changing between classes	4	3
I had a large class size	3	3
SUB TOTAL A	60/90	40/90
School Staff Statements		
My teacher paid me lots of attention in class	1	3
My teachers took the time to listen to me and what I needed in school.	1	3
My thoughts and opinions were valued by school staff.	1	4
In general, I had a good relationship with my teachers	1	5
My school refusal was acknowledged by the school.	3	1
The school supported me when I experienced school refusal	1	1
I felt that the school understood my school refusal	1	1
My teacher supported me when I experienced school refusal	1	1
I felt that my teacher(s) understood my school refusal	1	1
My Teaching Assistant supported me when I experienced school refusal	1	1
I felt that my teaching assistant understood my school refusal	1	1
The SENCo supported me when I experienced school refusal	1	1
I felt that the SENCo understood my school refusal	1	1
SUB TOTAL B	15/65	24/65
Intervention/Support Statements		
I was given the help I needed to organise myself at school	1	3
I was given the help I needed to adapt to changes at school	1	4
I was given the help I needed to understand the perspectives of others	1	3
I was given the help I needed to form friendships	1	2
I was given the help I needed with any sensory difficulties I had	1	1
I was given the help I needed doing my homework	2	5

I was given the help I needed to understand classroom discipline	3	1
I was given the help I needed to express myself in the classroom	1	3
I was given the help I needed going on trips out of school	3	4
I was given the help I needed to deal with bullying	1	2
I was the given the help I needed to understand myself at school	1	3
SUB TOTAL C	16/55	31/55
Total	84/210	95/210

School Factors Scores								
Participant	General/90	%	Staff/65	%	Interventions/55	%	Total/210	%
David	54	60	15	23	16	27	84	40
Olivia	40	44	24	36	31	56	95	45