“It would help if others could live in my autism for a day”: Understandings of autism, autistic identities and pupils’, parents’ and staff experiences of support in mainstream secondary schools.

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Declaration

I declare that the work contained within this thesis has not been submitted for any other Degree at any other university. The content found within this thesis has been entirely composed by the candidate, Elizabeth-Anne Graham.

Abstract

Support for autistic pupils is increasingly recognised within educational establishments. However, little research exists which brings together the needs of pupils alongside those who are key to this support, parents and school staff. This sociological study explores the challenges and support that autistic pupils, parents and staff experience and the ways in which the relationships and communication plays out between all three groups. The data was gathered using a variety of methods, including task-based activities, informal discussions within the home, and semi-structured face-to-face, email and Skype interviews.

The findings reveal that autistic pupils face stigma, and numerous sensory, emotional and practical challenges that largely relate to the social environment of school life. These challenges are experienced at home and in the space between home and school. For parents, challenges stem from the pressure and responsibility of supporting their children, advocating on their behalf and protecting their well-being. Staff challenges consist of institutional constraints and meeting the needs of individual pupils. Pupils, parents and staff do receive some forms of support; however it fails to meet their emotional and practical needs and consequently impacts on the pupils' education. The qualitative data shows that positive relationships are typically built on acceptance and understanding. In contrast, negative relationships can lead to pupil victimisation, exclusion and masking, with devastating impacts on their wellbeing and education. The findings also reveal that relationships among and between all participant groups are key to successful support and effective communication, which ultimately bridges the gap between home and school. It emerged from the data that although parents and school staff have an understanding of autism, all participant groups acknowledge that more training and education is required. This thesis argues that understanding autism and autistic identities plays a significant role in the inclusion and support of autistic pupils in mainstream secondary school.

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Key Terminology

Identity-first

There is no universally accepted way of referring to or describing autistic people (Keating et al., 2022). Person-first language, such as person with autism, has negative connotations and infers that something is wrong with the individual (Kenny et al. 2016). Identity-first language is used throughout the thesis because I subscribe to the view that autism is an inherent part of a person's identity, as opposed to a disorder. Accordingly, the young people who participated in this research are referred to as autistic pupils or autistic young people. Moreover, I support Beardon's (2017: 8) claim that the term autism should be used to cover all individuals who are autistic because doing so places more focus on how autism affects people individually as opposed to making assumptions related to the term itself. E.g. – high functioning, Asperger Syndrome, or Autism Spectrum Disorder (ASD) (see also Keating et al., 2022). Thus, the term autism will be used throughout the thesis unless quoting the participants who may use different terminology.

Predominant Neurotype

Predominant Neurotype' is a term adopted by Beardon (2008) instead of the 'neurotypical' preferred by the neurodiversity movement (see also Jaarsma and Welin, 2012). He interprets 'typical' as being alike to 'normal' and favours the term predominant neurotype because it succinctly emphasises that non-autistic people are the majority. I use this term throughout my thesis unless quoting participants who use different terminology.

CHAPTER ONE
Introduction

Autistic people can make sense of the world, process information and relate to other people differently to those who are predominant neurotypes (PNTs) (Beardon, 2008). Autism is a neurological difference, which is typically defined as a pervasive developmental disorder discernible by social and communication difficulties (Chown, 2017; Robeyns, 2016). It is often referred to as a 'hidden disability' (MacDonald, 2009) and is described as a 'spectrum disorder' because it affects people in different ways and to different degrees. (Mertz, 2005). However, autistic people typically have common difficulties in three main areas: social interaction, communication, and imagination (Chown, 2017). This research is less concerned with the latter but on the challenges experienced with social interaction and communication in mainstream secondary school. In recent years there has been a significant drive to teach autistic pupils in mainstream schools (Humphrey, 2008) and due to the increasing numbers of children being diagnosed, support needs have been recognised within educational establishments (Charman et al., 2011). However, very little exists in the way of understanding how the pupils who receive this support experience it, or what helps them effectively utilise it.

I have an autistic daughter who has always struggled to cope with the social demands of school; which became more challenging in secondary school. As a result, she did not attend school from the beginning of her second year until fifth year. During this period she was offered an 'Interrupted Learners' service whereby she would meet with a tutor for two hours each week (10 weeks in total) to complete schoolwork. This enabled her to sit, and pass, her maths Intermediate. 1 and Intermediate. 2 exams. However, the remainder of her education was non-existent. It was only after the family moved to a smaller town, that she considered attending school again. This was made possible by the interaction between herself and one member of the pupil support team at the new school. My daughter had previously struggled to interact with pupil support, or teaching staff, finding the interactions to be 'patronising', 'fake' or 'unequal'. However, the interaction with this particular member of pupil support was 'real' and 'honest' and was positive to such an extent that she was able to return to school in fifth year on a part-time timetable and pass her standard grade exams. Due to ill

health, this particular member of pupil support did not return the following year and as a result my daughter left school without finishing her sixth year.

As a parent to an autistic child, therefore, I witnessed how my daughter struggled in the school environment, and how she was misunderstood. I experienced challenges as a parent and identified that things worked best when there were good relationships and communication with the school. Since my studies began in sociology in 2008, I became aware of inequalities and power struggles between adults and children and the social problems that are present in society. This gave me a fresh insight into autistic people and the challenges they experience within schools. Thus, the experiences of my daughter and myself as her mother navigating school support have motivated this research. Some empirical research exists that offers insight from autistic children into the occurrences that are most challenging to them in general, and within the school environment. However, most of these UK studies have been conducted in England; and are predominantly in the field of psychology or education (for example, Connor, 1999; Humphrey, 2008; Humphrey and Symes, 2010; Wainscot et al., 2008). No sociological research exists which explores the experiences of autistic pupils, their parents and school staff in secondary school. This study is concerned with the challenges that autistic pupils, their parents and school staff are faced with, and their experiences of support, relationships and communication in relation to secondary mainstream education in Scotland. In doing so, it seeks to understand the experiences of autistic people and contributes to the growing body of participatory research *with* autistic people[1].

Autistic pupils are at an increased risk of school failure compared to those of PNTs (Totsika et al., 2020). Therefore it is worth considering if the circumstances in which they are placed determine whether or not their individualities are a cause of difficulty (Avramidis et al., 2000; Beardon, 2017). It is compulsory for children and young people (5-16yrs.) in the UK to receive an education (https://www.gov.uk/know-when-you-can-leave-school). Education can be delivered in an educational establishment or at home. However, it is a minority of parents who choose to home-school (Donnelley, 2007). The majority of young people aged 11-18 years old are educated in secondary school, a less structured environment than primary school and one in which the complexities of social groups intensifies (Tobias, 2009). Hence,

[1] There is especially a need for more participatory research with autistic people who make valuable contributions to the field as opposed to being passive participants.

the secondary school environment is a particularly important area of focus as it creates a host of social issues and anxieties that has the potential to impact on the educational and future prospects of autistic pupils. During adolescence, there can be an increasing awareness of a lack of social success, and greater insight into being different to other people (Willey, 2003). These differences can often lead to autistic pupils feeling unaccepted and misunderstood, isolated and at greater risk of being bullied (Cappadocia et al., 2012; Humphrey, 2008). Communicating with fellow pupils and teachers due to issues surrounding the typical rules of conversation add to these difficulties (Freedman, 2010). When one considers the difficulties autistic people experience in social situations, they are susceptible to stress, anxiety, frustration and emotional exhaustion (Bailey and Montgomery, 2012). Furthermore, experiencing intense anxiety is likely to deplete the pupils' energy, making it difficult to focus on learning. Thus, it is clear that secondary school is rife with social challenges and problematic interactions that are difficult for most pupils but particularly difficult for those who are autistic.

The central focus of this doctoral study is the way in which understandings of autism and autistic identities influence the support that autistic pupils experience in mainstream secondary schools in Scotland. According to McIntosh and Wright (2019, p.20) lived experience "can be associated with an empathetic immersion in the lives and concerns of people affected by and involved in policy processes and outcomes". The young people's lived experiences are the key focus of this thesis; however, parent and staff experiences are important in order to gain a deeper insight into these understandings and experiences and the ways in which they impact on support for all participant groups in the wider school context. Based on task-based activities with the young people, and face-to-face and email interviews with all participant groups, this thesis contributes to understandings of potential barriers, difficulties and challenges and highlights the tensions between school, pupil and parent and how these might be addressed in order to move forward.

Parents and school staff are at the centre of educating and supporting autistic pupils in mainstream secondary schools. This thesis finds that understanding their needs and experiences are imperative to better improve the quality of inclusive organisations and practices. Parents and teachers are expected to protect, guide, support, respect, encourage, and include children and young people. This it is believed will create confident individuals,

effective contributors, successful learners and responsible citizens[2]. However, these aims may be contradictory and unrealistic because a parent's priority is essentially to nurture their child whereas it is the priority of school staff to ensure that children and young people receive an education. Thus, these expectations may come with pressures that go against these instincts. For example, sending an autistic child to school knowing that they are dealing with challenges and difficulties does not necessarily keep them safe from harm, or mentally healthy. This may create additional challenges and pressures for parents of autistic children, potentially impacting on their own mental health and wellbeing. On the other hand, school staff are responsible for implementing education, however, teachers report that they do not have the necessary training to support autistic children in mainstream schools (House of Commons Education and Skills Committee, 2006). Two recent reviews have identified that teaching strategies and approaches for autistic pupils in mainstream schools need to be revised (Davis and Florian, 2004; Humphrey and Parkinson, 2006). Therefore, this research contributes to the knowledge base in this area.

This research draws upon literature in the field of autism, education and disabilities and applies a sociological lens because teaching, support, relationships and communication are relational. Thus the study adds to autism research, the sociology of childhood, the sociology of education and inclusion, and the sociology of disabilities literature. Giving the pupils, parents and school staff a voice provides a valuable insight into how support is received and experienced within an educational system which claims to be inclusive; which in turn may impact upon future developments of support for autistic pupils in secondary school. The main research question of this thesis is:

- What is the relation between understandings of autism and autistic identities and the support available to pupils, their parents and staff within mainstream secondary schools?

In order to answer this question it explores the following key sub-questions:

- What challenges are pupils, parents and staff faced with in relation to school?
- What support is available to autistic pupils, their parents and school staff?

[2] In Scotland, GIRFEC – Getting it Right for Every Child is a policy committed to ensuring all children and young people are able to flourish in an equal society. Within this are the SHANARRI wellbeing principles that children should be: Safe, healthy, Achieving, Nurtured, Active, Respected, Responsible, and Included.

- In what ways do relationships and communication between pupils, parents and staff impact on using or implementing support?

This thesis begins with a review of the literature in relation to the research topic and is divided into four themes that are centred on the above sub-questions; *Challenges*; *Support*, *Relationships*, and *Communication*. The following chapter provides a detailed account of the methods employed in this study and includes an insight into the benefits and challenges of conducting research with autistic pupils, parents, and staff who are time limited. The subsequent chapters are made up of four chapters which provide the key findings for each of the themes in turn, followed by a discussion chapter. A discussion chapter lends itself well to this thesis due to the three participant groups, pupils, parents and staff, to avoid jumping back and forth. It enables the reader to view and analyse the complete study in one combined section as opposed to reading results in between chapters. Thus it provides continuity in the discussion and allows the opportunity for results to be explained in a thorough and coherent manner. Finally, the concluding chapter summarises key findings, emphasises the main arguments, offers suggestions for future research and identifies the key contributions that this research has made to the existing literature.

CHAPTER TWO
Literature Review

In this chapter I present literature that underpins the key concepts and theoretical framework of the study. Firstly, I review writings that is concerned with autistic identities and autism theories. I then move on to explore literature relating to models of disability and discuss how the social relational model of disability is the best fit for the current study. Next, contributions in the field of the sociology of childhood and disabled childhoods are put forth. Following this, I consider research on education and inclusion and specifically that relating to the inclusion of autistic pupils in education. Thereafter, I put forward existing work relating to the challenges that autistic pupils experience in school. Finally, the writings surrounding intragenerational and intergenerational relationships and communication are presented.

2.1 Autistic Identity, Labelling and Stigma

Increased awareness of autism, a greater availability of services and a change in the diagnostic criteria are used by social constructionists to explain the rise in the number of those formally identified as autistic (Eyal, 2013). Other opinions have been put forth to explain the 'autism epidemic' relating to vaccinations (Bernard, 2004) or watching television (Waldman et al., 2006). Beardon (2019) asserts that if one were to simplify an explanation of autism it would be that autism is "…a *different* cognitive and *sensory* state" (p.11). The medical application of labels of autism adds to the confusing and ambiguous social constructions of identity (Bumiller, 2008; Nadeson, 2007). This process of labelling occurs despite a lack of scientific uncertainty as well as autism not being a treatable medical condition. However, a 'diagnosis' is required in order to qualify for services and to exercise rights (Beardon, 2019; Whitehouse, 2013). To be formally identified as autistic is typically based on behaviours that display challenges with social communication, social interpretation and social interaction (Beardon, 2019), alongside restricted, repetitive patterns of behaviour, interests and activities (Robeyns, 2016).

Social interaction could be described as, at minimum, an exchange between two or more individuals and is a central concept to understanding the nature of social life (Argyle, 2009; Dennis, 2010; Martin and Roberts, 2006; Turner, 1988). Classically, during social interaction,

two or more people take another into account when building up their actions (Beck et al., 2004). However, the solitary activity of prayer is also considered to be a legitimate social interaction with “imagined others” (Sharp, 2012). The social challenges of autism are linked to difficulty understanding bodily communication, understanding humour (although this is contested, see Beardon, 2019), picking up social cues, and challenges in maintaining eye contact. Thus understanding social context, expectations and social norms are thought to be taxing and problematic for the autistic person.

Intense and in-depth focus that is afforded to special interests is otherwise known as monotropism (Wood, 2019). Monotropism in autism refers to an all or nothing way of thinking, or a ‘narrow focus’ (Murray, 2018). The challenges that are experienced by autistic people are often perceived to be ‘deficits’ (Robeyns, 2016). Many are thought to have co-occurring conditions, including ADHD, gastrointestinal problems, anxiety, and depression (Trajkovski, 2019). Sensory sensitivities are also known to impact on the daily life activities of autistic people (Ashburner et al., 2013; Jones et al., 2020; Schaff et al., 2011). However, some claim that there is a lack of focus in this area (Beardon, 2019; Robeyns, 2016).

Autism is often considered to be a ‘spectrum’, and autistic individuals are categorised as being low or high functioning, with high functioning typically associated with Asperger Syndrome (Robeyns, 2016). This distinction is problematic as it does not recognise the multiple dimensions of autistic people’s lives or loses sight of the impact that autism has on each individual (Beardon, 2019; Robeyns, 2016; Whitehouse, 2013). According to Arnold (2012), each autistic individual will experience a collection of traits, or challenges, to varying degrees. Beardon (2019) asserts that the issue with viewing autism as a spectrum is that it comes with connotations of situating people in terms of their abilities and behaviours as opposed to the impact that it has on their individual lives.

The term neurodivergence is used to describe autism as a neurological difference as opposed to a cognitive disability and is now affixed to other neurological differences such as dyslexia, dyspraxia, and ADHD (Armstrong 2017). In more recent years, the neurodiversity movement has promoted positive understandings of autism (Bumiller, 2008), and there is now more recognition of the strengths that autistic people possess (Beardon, 2019; Grundwag et al., 2017). One term “diffabilities’, meaning different abilities, used in the context of autism describes how different abilities does not necessarily equate to lesser potential or decreased wellbeing (Brignell et al., 2014). Grundwag et al. (2017) suggest the term ‘coolabilities’ as a

way of naming enhanced abilities in conditions that are thought to be disabling, such as attention to detail, intense focus, being creative in specific areas of interest and original thinkers (see also Nordfors and Yirmi, 2017). For Beardon (2019), the list of qualities found in the autistic population is long and includes sense of humour, honesty, loyalty, fairness, determination, creativity, and imagination. Despite these growing positive narratives around autism, autistic people continue to encounter negative reactions in various social spheres (home, school, work).

Social identity describes a process that happens between people and takes into account similarity and differences between selves and others (Burkitt, 2008; Reynolds Whyte, 2009; Williams, 2000). Hall (2004, p.51) states that "an individual's self-consciousness never exists in isolation… it exists in relation to an 'other' or 'others' who validate its existence". Intersubjectivity occurs between the individual and society through shared meanings, understandings and connections (Crossley, 1996). Consequently, identities are socially negotiated constructs that are formed through a process of difference and similarity (Benwell and Stokoe, 2006). Hence, "identities are never unified" and "emerge within the play of specific modalities of power, and thus are the product of the marking of difference" (Hall, 2004, p.17). This suggests that identity can be understood as a process through which a group or individual establishes itself by observing the boundaries of otherness. Milton (2012) asserts that different dispositional outlooks and personal conceptual understandings that occur during social interactions between autistic and non-autistic actors can be considered a double-empathy problem. This he explains is because both parties experience a breach in communication and is therefore not a one-sided problem.

According to Goffman (1963), society uses collective characteristics about social groups to distinguish how one interacts with members of those groups. This social identity is made up of personal and structural characteristics which are received in the context of social settings. When an individual, or group member, is bestowed with failings or shortcomings, Goffman refers to that attribute as a stigma:

> The area of stigma management, then, might be seen as something that pertains mainly to public life, to contact between strangers or mere acquaintances, to one end of a continuum whose other pole is intimacy (Goffman, 1963, p.51).

The stereotypical label of autism and the behaviours related to it are predominantly portrayed in the media as negative and as a result are stigmatised (Botha et al., 2020). Such stereotypes can contribute to perceptions of autistic people being anti-social or odd, which can lead to avoidance of interactions and exclusion (Bumiller, 2008). These negative portrayals and perceptions of autism can often lead to autistic individuals attempting to manage feelings of unworthiness and rejection (Hodge et al., 2019).

A qualitative study with 20 autistic participants designed to understand how autistic people make sense of their autism and their experience of the stigma attached to it revealed that participants felt that autism was value-neutral like race, and sexuality (Botha et al., 2020). However, because autism is often treated negatively, attempts were made to fit in by concealing their autism and employing strategic disclosure. 'Passing' (Goffman, 1963) is a performance in which some individuals construct and enact a social interactional strategy to pass as someone they are not, by concealing their identity or playing it down. This is also known as masking, or camouflaging (Beardon, 2019; Kanuha,1999). Goffman defines it as "the management of undisclosed discrediting information about self" (1963, p.42). Impression management (Goffman, 1959) and stigma management is employed primarily for self-protection from societal prejudice (Goffman, 1963; Kanuha, 1999). Masking can present as a solution as it enables autistic people to feel included, however, it is problematic as it can mean that symptoms may be missed due to a seeming ability to cope (Cook et al., 2018).

Autistic children's social development is often measured in relation to their progress in gaining 'normal' social skills (Elliot and Gresham, 1987; Gross, 2003). As a way to 'fit' with societal expectations, children can imitate behaviour that is deemed the 'norm' (Bumiller, 2008). The concept of fit refers to the degree of conformity to a social stereotype (Kanuha, 1999). For the autistic participants in Botha et al.'s (2020) study, they recognised that they were caught in a double bind because both disclosure and failure to disclose resulted in negative consequences. Moreover, some of the participants continued to camouflage their autistic identity despite the negative impact that this was having on their mental health (see also Brownlow et al., 2021). This thesis brings together the experiences of pupils, parents and school staff and to what end all three participant groups understand or contribute to constructions of autistic identities and the impact that this has on support.

2.2 Theories of Autism

The three most prominent theories to explain the ways in which autistic people understand and think about the world around them, in addition to specific behaviours associated with autism, are Theory of Mind, Central (Dys)functioning, and Central Coherence (Chown, 2017; Beardon, 2019). Chown (2017) argues that good theory should contribute to breaking down negative stereotypes and barriers that keep autistic people from realising their potential. Theory of mind relates to an individual's ability to assign mental states to themselves and others (Beardon, 2019; Chown, 2017). This is a process that allows people to make sense of other people's actions by theorising about what leads to these behaviours; using sensory stimuli to guess the mental state of others (Chown, 2017). Baron-Cohen et al. (1985) claimed that autism involves a deficit in theory of mind. However, in 1989, Baron-Cohen repositioned autism as having a delay in theory of mind as opposed to a deficit. Beardon (2019, p. 42) argues that applying theory of mind to autistic people is somewhat inaccurate and that the term 'cross-neurological theory of mind' is more appropriate given that predominantly neurotypical people may lack an understanding of the autistic brain and vice-versa. Executive (dys)functioning relates to the several abilities that are used for preparing and engaging in complex organised behaviour. The main elements of executive functioning incorporate the formulation of abstract concepts, planning, focusing and sustaining attention, shifting focus and working memory (Chown, 2017).

Thus, executive (dys)functioning theory is concerned with the ways in which mental control processes can enable physical, cognitive and emotional self-control (Chown, 2017). It is believed that for some autistic people there are executive function problems. Critical coherence theory originated by Uta Frith and Francesca Happé (1994) and aimed to rationalise why autistic people possess specific strengths and weaknesses. The general position is that central coherence provides people with the ability to see the meaning in something as opposed to just the details involved. It was originally advised that autistic people have weak and central coherence (Chown, 2017). Central coherence relates to the inclination to focus on detail at the expense of being able to generalise. However, Happé and Frith (2006) now refer to it as being a preference for local processing, a different processing style, and not a weakness or impairment.

Although these cognitive theories of autism provide a framework for researchers to work from, they primarily focus on static cognitive impairments (Rajendran and Mitchell, 2007). This thesis highlights the frailties in these dominant conceptions by applying a sociological

lens. For instance, by adopting the dominant cognitive theories within the school context, autistic pupils are likely to be perceived as abnormal, someone who needs fixed. Without challenging these understandings, little progress can be made in terms of inclusion. A sociological lens shifts away from the individual and moves toward the social contexts that turn neurodivergence into disability.

2.3 Critical Autism Studies

Critical autism studies is the interdisciplinary study of autism (Woods et al., 2018). A key component of critical autism studies is that research should be participatory in nature involving autistic people as much and where possible. Houting et al. (2022) interviewed 20 stakeholders, including autistic people and their family members in relation to their experiences of community engagement in Australian autism research. Participants' perceptions of academia is that it was an "ivory tower" that was disconnected from the lives and priorities of community members. The standpoint of this thesis supports Beardon's (2019) view that it is autism and the environment that equates to the outcome. Therefore, this is a sociological study that is primarily concerned with the experiences of autistic pupils in the environment of mainstream secondary school. Thus, although the thesis draws upon psychology and medical literature, it is less concerned with a psychological viewpoint of autism and more so with the social world in which autistic pupils and those around them inhabit. A sociological approach to autism adds value to the field as social theory and analysis is beneficial in responding to the complex nature of autism and in addressing persistent patterns of inequality. Moreover, it brings to light the reproduction and transformation of social practices and the institutions associated with them (Shrove et al., 2012). For this reason, the following sections outline sociological theories and concepts and their significance in autism research that includes children.

2.4 Models of Disability

2.4.1 The Medical Model and Personal Tragedy

Disability is a term that has historically been used to refer to people with 'impairments' and 'deficits', who are perceived to be 'incapable' and 'abnormal' (Barnes et al., 2002; Brown et al., 2006; Thomas, 2007). Thus, disability signals a group of people who cannot engage in 'normal' activities because of their 'abnormal' bodily or intellectual 'deficit' or 'incapacity'. The origin of the medical model of disability views disabled people, or rather, 'people with

disabilities' as requiring a cure, with a 'find it and fix it' healthcare approach (Ayers et al., 2007; Beith et al., 2008). Terminology used within the medical model include 'prescription', 'affliction', 'defect', 'rehabilitation', 'prevention' and 'cure' (Devlieger et al., 2007). As a result, this approach treats and labels people as patients (Beith et al., 2008; Christie and Mersah-Coker, 1999). The individualising nature of the model fails to see society as the problem, for example, by not designing accommodations for all. Instead it views disabled people as the problem themselves and society is seen as *having* to provide 'special facilities' to assist them (Barnes, 1998; Moore, 2002; Rapley, 2004; Swain et al., 2004).

It should be noted that the medical approach has been responsible for the detection and treatment of acute health problems; initiatives to address issues of improved care, survival and quality of life; determining eligibility for legal and occupational purposes and for financial assistance (Ayers et al., 2007). Nonetheless, with language such as 'incurable', 'suffering', and 'wheelchair bound' the medical model attaches a 'personal tragedy' label to disabled people who are seen as victims, long-suffering and with ruined lives (Beith et al., 2008; Christie et al., 1999; Chui and Wilson, 2006). This conveys the message that disabled people cannot be happy or enjoy a fulfilling life (Ghai, 2006; Greenwood et al., 2003; Slee, 2011). Thus, the 'personal tragedy theory of disability' represents disabled people as victims of some tragic occurrence or circumstance and leave social and economic structures untouched (Barton, 2006; Slee, 2011; Swain et al., 2004).

2.4.2 The Social and Social Relational Model

Mainstream policy and practice has incorporated the social model, which seeks to remedy systemic institutional inadequacies that have occurred across various social and economic spheres, to include disabled people (Smith, 2011). The social model of disability argues that impairment is rarely the cause of disability but rather it is the failure of society to make appropriate provisions for the diversity of its citizens (Moore, 2002). Thus a disabling society is one that discriminates, disadvantages and excludes people with impairments by not making appropriate accommodations and in the process, favours those without impairment (Anastasiou and Kauffman, 2013). The main argument of the social model is that there is too much investment in individually based interventions, which are under resourced as opposed to creating a barrier-free environment for all (Oliver, 1999). Thus, the social model differs

from the medical model in that the focus, or fault, does not lie with the individual but with the barriers and attitudes found in society (Davis, 2013).

Despite the positive impact of the social model of disability, there are some weaknesses. Davis (2013) asserts that its authorship by a small group of activists, who for the most part were white, heterosexual males with a spinal injury failed to acknowledge non-physical or complex impairments. The result of this was a narrow understanding of disability which raises the question of its applicability to the circumstances of people across the range of impairments, particularly those with learning difficulties (Chappell, 1998). Disabled people have diverse sexualities and gender identities with different interests and characteristics including age, economic status, aspirations and different life experiences (Abu-Habib, 1997). Moreover, neglecting the impairment does not paint a holistic picture of all aspects of a disabled individual's life (Barnes and Mercer, 2010). For instance, denying, or overlooking, the existence of a physical impairment presents an argument that almost suggests that people are empty of biological factors (Anastasiou and Kauffman, 2013). There is a strong argument that the meaning of disability lies in both the impairment (whatever its nature), society and the interaction between the two.

The social relational model includes all impairments and not just the physical. Within this model, disability is seen as a form of social oppression which operates at both the public and personal levels (Reeve, 2004). Thus, the social relational model recognises that disability is a social relationship that restricts people with impairment's activity as well as undermines their psychological and subjective well-being (Schinke et al., 2016). For example, whilst someone with a hidden impairment is less likely to be stared at by others, their 'disability' status may be revealed and the reaction from others, just as with physical impairments, can affect their psycho-emotional well-being and indirectly restrict activity (Reeve, 2004). Thus, disability is rooted in an unequal social relationship whereby the activities of 'impaired people' are restricted by non-impaired people (Barnes and Mercer, 2010). Ultimately, the social relational model acknowledges that structural barriers and cultural/experiential barriers cannot exist one without the other (Shakespeare, 2015). Given the progress that has been made in disability studies, the term 'disability' now acknowledges it as a form of social oppression, and disablism enters the vocabulary alongside sexism, racism, and other discriminatory practices (Barnes et al., 2002).

2.4.3 Autism and the Social Model

A fundamental influence in the development of disability studies has been the resolve by disabled people that their experiences be appropriately incorporated (Barnes et al., 2002). These efforts are reflected in the neurodivergent movement, a political force associated with the autistic self-advocacy or 'autism rights' movements (Bertilsdotter-Rosqvist et al., 2020; Milton, 2020; Singer, 2017). While the social model of disability applies to physical and sensory impairment, neurodivergent labels have been left behind (Woods, 2017). The acknowledgement of neurological difference does not suggest that neurodivergent traits are desirable but that there are characteristics that are good and not so good just as with all humans (Bertilsdotter-Rosqvist et al., 2020). However, as aforementioned, the autism discourse is dominated by concepts of autism being a disorder and a deficit, allowing PNTs to treat autistic people as lesser than the 'norm'. Thus, applying a social model of disability to autism studies allows for a greater discussion of the barriers experienced by autistic people. This thesis explores the social barriers and challenges that autistic pupils experience at secondary school.

2.5 Sociology of Childhood

Children live in an adult-dominated society (Punch, 2002). The 'permanence' of childhood situates the child in a social structural category in opposition to the adult (Chisolm et al., 2005; van Blerk and Kesby, 2009; Wyness, 2006). Children are regulated in terms of their age in ways that adults are not (Watson et al., 2012; Wyness, 2006). A relational, generational, focus addresses the processes through which adults and children are socially positioned (Hutchby and Moran-Ellis, 1998; Wyness, 2006). Within a Western context, the regulation of children occurs via mass *compulsory* schooling, where, by contrast, despite tighter access to state income, adults can *choose* not to work (Wyness, 2006). Power has different meaning in different contexts, and it is linked to both agency and structure (Punch, 2007). Foucault argued that power is not something that is exchanged, given or taken back, but rather is exercised and exists only in and through forms of action:

> Power is everywhere and comes from everywhere, so in this sense, it is neither an agency nor a structure. Instead, it is a kind of 'metapower' or 'regime of truth' that pervades society, and which is in constant flux and negotiation. (Foucault, 1998, p.63)

Thus, according to Foucault, power is something that is embedded in social relations and is exercised in all social situations regardless of the form it takes (Anderson and Grinberg, 1998). In this sense, educational practices that may appear democratic, participatory or progressive may constitute forms of disciplinary power, resulting in effective technologies of control (Anderson and Grinberg, 1998). In terms of the school or home settings, norms, rules and laws are internalised in ways that do not need external control. The disciplinary gaze is personal but also institutional as pupils, or offspring, know that they can get into trouble if they are caught conducting or presenting undisciplined behaviour (Marshall, 1996). Moran-Ellis (2013, p.325) argues that children face specific hurdles due to three factors:

> … one is the nature of the institutionalisation of their lives; the second is the dominance of intergenerational relationships which positions them as developmental actors and hence repositions their actions as material for learning and correcting; the third is their limited access to resources they can mobilise in support of their own intentions.

Despite cultural differences in childhood from across the globe, it has universal characteristics in terms of limitations and needs. Young children especially are dependent on adults for their physical care; food, shelter, hygiene and safety (Wells, 2009). Thus, the child is seen as a becoming rather than an active agent in their own right (Leonard, 2015). For instance, children are often described as belonging to the next generation, reinforcing their status of future social actors and agents (Qvortrup, 2005). Childhood, therefore, is viewed as a transitional phase that the child passes through on route to becoming an adult (Corsaro, 2005). The (not so) 'new' sociology of childhood argued for the social construction of childhood rather than normalised development and for the recognition of children as active agents rather than passive dependents (Tisdall and Punch, 2012). What transpired from this was an increase in research which sought to explore children's realities as beings rather than becomings and adopted various methodologies in order to do so (Punch, 2002). Stainton Rogers (2009) proposes that in place of the discourses of needs and rights that produces an unhelpful dualism of objectifying and separating children, we should turn our attention to what she calls the 'quality of life' discourse with its capacity to not only recognise the diversity of children's lives, but also their embeddedness in social networks; and the very obvious resilience that many are required to show in navigating everyday life and shaping

their futures. This thesis places focus on the young people's individual realities and situates them as active agents in their own lives.

2.6 Disabled Childhoods

Social studies of childhood and disability studies share some common themes in that they are both motivated by a desire to turn those they work with from objects of study to active agents (Tisdall and Punch, 2012; Watson, 2012). Early research into disability in childhood tended to focus on the parents/ carers and professionals' views and in doing so failed to take into account the children's personal experiences (Davis et al., 2003). This resulted in children being seen as passive and vulnerable as opposed to the experts in their own lives (James et al., 1998; McLaughlin et al., 2016). Research suggests that disabled children and their families are subject to persistent discrimination and disadvantage, which are largely a result of social barriers (Emerson and Hatton, 2007).

For Hodge and Runswick-Cole (2013), the problem does not originate from the disabled person but rather 'normalcy' is constructed, creating the 'problem' of the disabled person, and in doing so reinforces ableist norms (see also Corker and Davis, 2002). Disabled children's experiences differ and thus they cannot be categorised as a homogenous group. Disability is an extremely complex variable, which is multi-dimensional and cuts across a range of political, social and cultural experiences (Callus and Farrugia, 2016; Watson, 2012). Economically disadvantaged children will experience disability different to those from an affluent background, just as ethnicity will affect the experience of childhood disability. Therefore, social differences, separations, boundaries and barriers that are encountered in everyday life are significant, as are the inequalities in power, conflicts, and injustices that may result from them (Blundell, 2016). Thus, it is clear that a 'one-size-fits-all' model is not the answer (Watson, 2012).

2.7 Education

In addition to formal academic lessons, schools are designed to achieve the condition that Foucault describes as governmentality through hidden lessons concerning the self, such as 'proper' morals, emotions and healthy development (Anderson and Grinberg, 1998). The institution of the school follows the template of the idealised child, which is constructed around a checklist of needs that require to be achieved for children to evolve into balanced, intelligent, adults (Alldred et al., 2002; Blundell, 2016). The timetable represents the lessons,

or classes, that are deemed appropriate or essential during a pupil's time in secondary school (Meighan and Siraj-Blatchford, 1997). For Harden (2012) the classroom is not solely a passive vessel for learning, but its form, layout and the associated practices are revealing about dominant constructions of childhood and the normative characteristics that children are expected to develop and internalise. The classroom is a space of regulation for children's bodies and emotions, and one that reinstates children's subordination to adults (Blundell, 2016; Harden, 2012). Moreover, the institutionalisation of children and young people separate children from the adults that they are working towards 'becoming' (Blundell, 2016).

Secondary school is a stark contrast to primary school. In primary school, the environment is less daunting, and pupils remain with the same group of children throughout. Moreover, the relationship that can be formed with a classroom teacher is more in-depth given that they are likely to be taught by one, or in some cases, a few teachers for each year of school (Rogers, 2007). In a single day, a pupil may have seven different classes, each with a different teacher and a different group of fellow pupils (Hedges et al., 2014). In secondary school, more focus is placed on forming friendships, of being accepted into a group, and relationships with fellow pupils and teachers can become diluted (Humphrey et al., 2004; Rogers, 2007). Thus, mainstream secondary schools in the UK are typically larger and more complex environments than primary school.

It has been proposed that the macro-nature of transitions from primary to secondary school should be managed through strategies such as additional visits to the new school, transition planning meetings, and information for students and parents (Carter et al., 2013; Hannah and Topping, 2012). This is because heightened levels of anxiety can be experienced following the transition from primary school as a result of the change in the school environment (size, noise, teachers, pupils), which can impact on a pupil's psychological response and social functioning. Thus, secondary school can prove to be a significant adjustment for pupils, which for most can be temporary (Humphrey and Ainscow, 2006). There is evidence to suggest that these levels will decrease for the majority of students during their first year at secondary school (Graham and Hill, 2003; Tobbell, 2003). However, there are several groups of pupils who have 'special educational needs' for whom acclimatising to life in the secondary environment proves to be a more demanding and sustained process (Anderson et al., 2000).

2.8 Inclusion

Inclusive education goes further than integration, a practice which focuses on the placement of a pupil within education with the expectation that they will adapt to the environment (Humphrey and Symes, 2013). Inclusion involves the quality of support and a positive school experience and involves restructuring the curriculum to best suit the pupil. Thus, inclusive education is the process of developing educational practices, based on a set of core beliefs that facilitate the learning and participation of all pupils (Douglas, 2010; Fallon and Zhang, 2013; Humphrey and Ainscow, 2006). Inclusion requires positive working relationships based on mutual respect and understanding every person's needs and outlooks. A study by Vaughn et al. (1996) found that teachers who were not currently participating in inclusive programmes, had strong negative feelings about inclusion. The teachers identified several factors that would affect the success of inclusion, including lack of adequate teacher preparation, inadequate resources, and class size (see also Osborne and Reed, 2011).

Effects of class size tend to fall into two main categories. First, there are those concerned with teacher to pupil interactions. It seems likely that bigger classes will decrease the amount of time that can be spent on instruction and dealing with the individual child. This is consistent with teachers' views (Bennett, 1996). However, observational research by Shapson et al. (1980) and Slavin (1989) support the view that the effects of class size reductions on teaching are minimal. Finn et al. (2003) argue that the effects of class size on pupils' classroom engagement are more important than those on teaching. Most attention has been paid to whether smaller classes lead to better academic outcomes for pupils (Blatchford et al., 2009; Wilson, 2006). However, there is a need to know more about the effects of classroom processes such as interactions between teachers and pupils and pupil behaviour (Blatchford et al., 2011).

According to Avramidis et al. (2000), student teachers hold positive attitudes towards the general concept of inclusion but perceive that children with emotional and behavioural difficulties cause more concern and stress than those with other types of additional needs. The head teacher's role in inclusion is one of the major components that make up an effective inclusion programme (Graydon, 2006; Hipp and Huffman, 2000; Horrocks et al., 2008; Praisner, 2003). Teachers need the input, supervision, support, understanding and collaboration of the head teacher to do what is necessary, and to lead the way to best practices (Eldar et al., 2010; Graydon, 2006). Rogers (2007) asserts that despite whole school efforts being made to include many pupils within mainstream education, they are being

excluded practically (removed from class for one-to-one work), intellectually (are not able to access the curriculum in the same way as their fellow pupils) and emotionally (sustaining friendships can be difficult).

2.9 Autism and Inclusion

Historically, the education of autistic students has occurred independently in separate schools for disabled students (de Bruin et al., 2013). In current times, specialist provisions do not always equate to separate 'special schools' but can be found in specific areas or departments within mainstream schools. It has been found that when compared to mainstream placement, children in specialist provisions made greater improvements in areas of conduct and socialisation (Reed et al., 2012). Holt (2007) and Tomlinson (1982) emphasise the complexity of spaces being constituted as both segregate and separate. For instance, while these spaces may be enlightened and advanced, they also represent a social categorisation of weaker social groups that does little to turn the gaze or to expose pathologies of ableism. Nonetheless, such provisions do have value in that they provide an oasis of calm to heal and recover from the challenges experienced in an ableist world (Holt, 2010). This is especially important because children in 'special education' can be affected by the stigma attached to the negative emphasis of 'not normal', and the implications of *in*capacity, *in*ability, and *dis*ability (Tomlinson, 1982).

The global prevalence of autism is reported as being between 1% and 2% of the population (Roman-Urrestarazu et al., 2021). It has been suggested that this rise may result from increased reporting and that fewer symptoms are now required for a clinical diagnosis (Fombonne, 2018). Due to the rapidly increasing prevalence of children being formally identified as autistic, and who are being educated in mainstream schools, there is a need for an understanding of effective practices (de Bruin et al., 2013). There is much concern among parents and teachers about the effectiveness of inclusive education for autistic pupils (Adamowycz, 2008). Successful educational experiences and outcomes for autistic pupils in mainstream education is largely based on environmental factors such as the curriculum, class size, the support offered and how this support is applied (Aljunied et al., 2010; Humphrey and Ainscow, 2006; Osborne and Reed, 2011).

Ashburner et al.'s (2010) study compares teachers' perceptions of autistic students to PNTs regarding the ability to perform academically and regulate emotions and behaviour in

mainstream classrooms. Autistic students seemed to be underperforming (54% compared to 8% of PNT) and were struggling to maintain their attention and regulate their emotions and behaviours in mainstream classrooms, despite receiving a range of specialist support services in the classroom. A study by McGregor and Campbell (2001) was concerned with the views of 23 specialist and 49 mainstream teachers regarding the advantages and disadvantages of integrating autistic children into mainstream education. Mainstream teachers who had experience of autism demonstrated more confidence in dealing with the children than those who did not. Specialist teachers acknowledged possible disadvantages for both groups of children and stressed that the success of integration was dependent upon the individual child.

According to Dybvik (2004), when inclusion is suitable, both the included children and their PNT peers can benefit as it promotes acceptance and understanding of diverse individuals with varying abilities and allows friendships to develop that otherwise would be impossible if autistic pupils were to be educated separately. Eldar et al. (2010) have suggested that students with additional support needs, including those on the autism spectrum, who are fully included (1) exhibit higher levels of engagement and social interaction, (2) give and receive higher levels of social support, (3) have a wider social network and (4) have more advanced individual education goals than their counterparts in segregated placement. As with all children, included students have the chance to socialise with peers, meet positive role models and to become members of the same society that they will share as adults (Farlow 1996; Harrower and Dunlap, 2001; Humphrey and Symes, 2011). Thus, contact with PNT peers is thought to be crucial to assist autistic pupils develop social and communication skills (Eaves and Ho, 1997).

Eldar et al.'s (2010) study involving inclusion coordinators found that successful inclusion in the social domain mainly involved good relations with peers, but relations with individual friends and adults were also noted. However, it is worth noting that social interactions are instances of success that reflect the high expectations that PNTs place on the progression of autistic pupils (Harrower and Dunlap, 2001). Nonetheless, it is this rather than any academic difficulties that leads to the high non-attendance rates from mainstream schools (Bernard et al., 2000). School refusal impacts on attendance rates for autistic pupils and can negatively impact on their academic skills (Hancock et al., 2013; Totsika et al., 2020) and their mental health (Epstein et al., 2020). In a cross-sectional study of 216 students, 78 autistic and 138 PNT, school refusal behaviour was significantly higher in autistic students (Munkhaugen et

al., 2017). Barnard et al. (2000) claim that without a shift in the whole organisation's attitude and approach, autistic children will be failed in mainstream school.

Given the social and behavioural challenges of autistic pupils, teachers often face considerable obstacles in managing their needs (Bowe, 2004; Lindsay et al., 2014). One of the most important challenges in working with autistic students in integrated classrooms is inadequate knowledge about autism (De Boer and Simpson, 2009). A common finding conveyed in the international research literature on teacher attitudes towards inclusive education is that teachers do not receive the specialist teaching that they need to provide support to pupils with additional needs (Avramidis et al., 2000; Campbell et al., 2003; Florian and Black-Hawkins, 2010; Hinton et al., 2008; Lambe and Bones, 2006; Marshall et al., 2002; Sharma et al., 2008; Smith and Green, 2004; Symes and Humphrey, 2010). For example, one UK study found that only 5% of teachers received training about autism even though most teachers had an autistic child in their class (McGregor and Campbell, 2001). Such gaps in training can leave teachers feeling discouraged while pupils on the autism spectrum may miss opportunities to reach their full potential (Allen and Cowdery, 2005). Parents of autistic pupils identify teacher training as the single most enabling factor in providing for their children in the mainstream setting (Jindal-Snape et al., 2005; McGregor and Campbell, 2001). Jordan and Jones (1997) claim that this specialist instruction should be a central part of teacher training if schools are to meet the needs of autistic pupils and that policies should be in place to ensure it is received (Booth and Ainscow, 2002). This thesis explores to what extent autistic pupils, their parents, and school staff are prepared for and are assisted in their role of supporting autistic pupils to be included within mainstreams schools.

2.10 Classroom Support

Autistic pupils can receive various types of support in the classroom. For example, some receive the help of one-on-one classroom assistants who shadow them, either always or part of the time (Eaves and Ho, 1997). However, the presence of a learning support teacher may limit the overall interaction that the classroom teacher has with included students (Adamowycz, 2008). This form of personal support is a major resource; nevertheless, limited budgets can mean that there is typically a minimal allocation of support hours awarded. Moreover, according to Leibowitz (2000), this type of assistance can be relatively low paid, which results in a shortage of helpers, and those who are hired often lack the essential educational preparation and skills. Another form of support may be that the young people can leave the classroom at

various times for breaks or private learning or support sessions (Eldar et al., 2010; Mesibov and Shea, 1996).

Sometimes the additional support to help autistic pupils comes in the form of visual supports (Hannah and Topping, 2012). Visual supports are objects that can be seen and/or held, which are used to visually enrich the comprehension of physical and social environments; actions, rules and expectations and abstract concepts such as time, a sequence of events or socially abstract concepts such as emotions or reason (Rutherford et al., 2020). Some of the most commonly used visual supports are visual timetables, sequence charts, social stories, home/school diaries and timers (Hannah and Topping; Rutherford et al., 2020). Rutherford et al.'s (2020) Scottish study disclosed that parents had positive experiences with using visual supports but highlighted that there was a need for more training and support to start, maintain and develop the use of them. Digital devices (Personal Digital Assistant) have also been found to be effective for decreasing pupil's dependence on adults to help complete tasks at home and at school (Ferguson et al., 2005).

A key focus of this doctoral research is to discover the extent of support offered to autistic pupils in mainstream secondary schools. It further aims to add to the gap in the literature in relation to the support that is available to school staff and parents who are key providers of support to autistic pupils.

2.11 Challenges Experienced by Autistic Pupils

2.11.1 Stigma

Dealing with stigma and social rejection can make autistic people feel that they are strange and unworthy (Hodge et al., 2019). Autistic pupils can find disclosing their 'diagnosis' of autism challenging, making them feel 'marked' and difficult for them to fit in (Calzada et al., 2012; Humphrey and Lewis, 2008; Jones et al., 2015). Although young people may be capable of managing their reputations (Cage et al., 2015), adolescence marks many social changes that might lead to increased concerns for their reputation (Sebastian et al., 2008). Research by Cage et al. (2016) conducted in the UK with 12 autistic young people aged 12-15 years found that reputation was sometimes a concern for them. However, many expressed that they would rather be true to themselves than be 'cool'. Milton (2013) observes that the social experiences of autistic individuals are different to that of PNTs, in that they may pretend to know how social

situations work to hide their social difficulties. Thus, it is plausible that autistic individuals would be to some degree concerned about what others think of them.

White et al.'s (2020) study of stigmatising attitudes with adolescents (aged 11-12 and 14-16 yrs. N= 250) in a UK school revealed that disclosing autism to other pupils did not make young people more willing to interact or feel more positively towards the autistic pupil. However, it did reduce the extent to which others thought that the autistic pupil was responsible for their own behaviour. According to Mogensen and Mason (2015), having a formal label of autism is important in constructing a positive sense of self, by legitimising differences and providing a sense of common identity with other autistic people. This supports Hodge et al.'s (2019) claim that it may be beneficial to some autistic people to view themselves more positively if school staff facilitate them to have more contact with autistic people.

2.11.2 Creating and Maintaining Friendships

The school environment provides many young people with both formal and informal opportunities for building interpersonal relationships; for instance, within the classroom and in social areas occupied by pupils during lunch and interval (Hassrick et al., 2020).
It is within these latter spaces that the trickier aspects of social life for autistic pupils such as making friends and developing relationships may go unnoticed by school staff (Hedges et al., 2014). From a study that observed children's spontaneous social initiations during interval, autistic pupils were lonelier, but reported having at least one friend, and only spent half the time in social interactions compared to PNTs (Bauminger et al., 2000). However, the quality of the friendships were poorer in terms of companionship, security and help (Bauminger and Kasari, 2000). Autistic pupils are reported as least likely to frequently see friends outside of school, exchange telephone calls with friends or be invited to social events (Wagner et al., 2005; Winchell et al., 2018). Many mothers express that invitations to take part in social events diminish over the years for their autistic children (Winchell et al., 2018). A study by Cook et al. (2018) revealed that autistic girls in particular were motivated to form friendships but were also often the target of bullies. Thus, given that autistic pupils often lack friendships with fellow pupils, they may rely more heavily on parents and school staff for support, particularly to help them combat bullying (Whitaker, et al., 2003; Zablotsky et al., 2012).

2.11.3 Victimisation and Bullying

The prime cause of bullying of autistic pupils is considered to be their difficulties with social communication and interaction (Bauminger et al., 2003; Cook et al., 2018; Zablotsky et al., 2012). This it is thought can impact directly on friendship development and victimisation, with bullying occurring in part by the lack of protective friends, and more time spent in solitary activities at school (Winchell et al., 2018). There are numerous features of bullying: a fundamental imbalance of power between the perpetrator and the victim; the intent to cause harm; is repeated over time; it takes place in a social setting (e.g. with peers present) and it is unprovoked (Haynie et al., 2001; Humphrey and Hebron, 2015). According to Card et al. (2008), boys tend to use more overt aggressive forms of bullying, whereas girls are more subtle, for instance, spreading rumours, gossiping, excluding, or ignoring. Autistic pupil's victimisation and bullying is a major problem in adolescence and can often lead to absenteeism (Cook et al., 2018; Kloosterman et al., 2013; Winchell et al., 2018).

Victimisation has been linked to an array of internalising problems, including loneliness, anxiety, depression, and low self-esteem (Winchell et al., 2018). According to Macneil et al. (2009), autistic young people experience greater levels of anxiety than community populations, and similar levels to clinically anxious groups. During adolescence there is a growing self-awareness of social difficulties and negative experiences with peers that may exacerbate social anxiety (Hedges et al., 2014). Additionally, anxieties that are experienced in secondary school by autistic pupils can occur as a result of the chaotic school environment that can be at odds with the preference for routine and consistency (Hedges et al., 2014). On the other hand, anxieties that are already experienced by the individual separate from education (for example, social anxiety or social phobia), may negatively impact on school life and can be carried forward to life after school making it challenging to establish social network connections (Hassrick et al., 2020; Lei et el., 2020).

2.11.4 Negotiating Transitions

Transitioning from secondary education into adulthood can be particularly challenging and less straightforward for autistic pupils than PNTs (see Bertilsdotter Rosqvist et al., 2014). It has been proposed that pupils with better social skills demonstrate greater persistence and ability to navigate the demands of post-secondary education compared to those with lesser social skills (Dymnicki et al., 2013; Nasamran et al., 2017). Moreover, social skills have been

shown to be an important predictor of postsecondary success and those with greater social skills may be more desirable to employers (Hein and Smerdon, 2013; Nasamran et al., 2017). Bell et al. (2017) assert that encouraging the development of these important skills needs to begin in secondary school.

Participating in post-secondary activities such as education and employment can increase an individual's independence, contribution to society and quality of life (Nasamran et al., 2017). However, Nasamran et al. (2017) suggest that autistic pupils engage in these activities less than PNTs do. According to Bell et al. (2017), there is limited evidence that transition planning from secondary to post-secondary education is initiated as a formal process. For some pupils, accessing support in higher education can be a complex process requiring sustained input from parents (Bell et al., 2017). Moreover, periods of transition are a frequent source of intense stress levels for parents of autistic children and pupils (Lee et al., 2014). Parents often restart the planning process over at each new transition, which results in a vast amount of continued work and stress (Newsome, 2001)[3]. A key aim of this thesis is to widen the knowledge of the challenges experienced by autistic pupils within mainstream secondary schools. In doing so, it hopes to shed light on how these challenges impact on pupils, parents and school staff, and the ways in which they navigate these challenges in their formal and informal relationships.

2.12 Relationships and Communication

According to Blundell (2016) children in England are unhappier with their school experience than those in thirteen other countries. Amongst the highlighted concerns was a widespread fear of bullying and poor relationships with teachers. For instance the young people who took part in this study expressed that there was lack of opportunity to speak with other pupils and that teachers did not interact or listen to them. Similarly, eight 12 year olds expressed that bullying and ineffective communication were amongst the factors that contributed to a 'non-ideal school'; and that being listened to and friendship were among the qualities of an 'ideal school' (Fraser-Smith et al., 2021). What this highlights is that relationships and communication are important factors for pupils attending school. This section presents

[3] One study in progress worth following is Smyth et al. (2021) - Autism specific transition resources (T-Res) which aims to develop a flexible resource package to support autistic children and young people with a diagnosis of ASD, as well as their families and educators during the covid-19 transitions.

literature in relation to intragenerational and intergenerational relationships and communication among pupils, parents and staff.

2.13 Intragenerational Relations

2.13.1 Interactions Between Pupils

Intra-generagency represents the heterogeneity of children's everyday lives that is located within childhood and the recognition that there are structural boundaries between adulthood and childhood (Leonard, 2016; Punch and Vanderbeck, 2018). However, when thinking about agency it is important to understand that differences do not occur only between adults and children but between children too. Although children share similarities, it is important to understand how differences between children are constructed, reproduced, challenged and reformed (Leonard, 2016; Punch and Vanderbeck, 2018). Differences between autistic pupils and PNTs can create barriers to interaction attempts and communicating meaning. This is something that Milton (2012) describes as a 'double-empathy problem' because the different outlook or way of communicating is something that both parties experience and is thus not a singular problem to any one person. There has been research that has explored the gender differences in friendships between autistic young people (Hull et al., 2017; Kuo et al., 2013). Hull et al. (2017) found that autistic girls, and women, develop compensatory techniques to 'camouflage', or mask, their social difficulties with the purpose of being socially included. It is assumed that autistic people are not socially motivated and struggle with friendships (Chevallier, 2012; Long et al. 2018). However, the friendship difficulties used in research employ a model of 'typical' friendship, in particular 'best friendship', against which autistic participants experiences are compared (Long et al., 2018).

In Lindsay et al.'s (2013) study, ten teachers mentioned the challenges in creating an atmosphere of understanding for autistic pupils. Children often realise there may be something different about an autistic child but are unaware of the official diagnosis or of how these differences exhibit as behaviours. Consequently, autistic pupils are often excluded. Nowicki (2006) investigated the effects of the visibility of disability on the attitudes of 100 PNT peers using pictures of hypothetical children with or without a visible physical disability. The results highlighted that attitudes toward hypothetical children with a visible physical disability alone did not differ from attitudes towards children without a disability, but that negative attitudes were found towards individuals with an invisible disability alone, or an invisible disability combined with a visible physical disability. This suggests that the visibility of disability as such

does not have a negative effect on peer attitudes. However, visibility in this study is confounded by type of disability, physical or intellectual. Manetti et al. (2001) suggest that children with severe disabilities may be accepted differently and be treated more positively than their peers with mild invisible disabilities due to having an obvious need for help with daily living skills.

2.13.2 Home and School Relations

In earlier years of education, cultural reproduction was assumed and the division of labour between home and school was evident (Ericsson and Larsen, 2000). It was expected from teachers that parents would deliver children ready for formal education and parents in return expected teachers to educate their children in preparation for life beyond school (Ericsson and Larson, 2000). It could be considered that in recent years these boundaries have become somewhat blurred with policies[4] that aim to integrate home and school (Alldred et al., 2002). Barriers to poor communication between parents and teachers can relate to engaging parents and maintaining an open communication system (Lekli and Kaloti, 2015; Lindsay et al., 2013; Vickers and Minke, 1995). Mostly, parents enter into 'informal' conversations with teachers to discuss their concerns, such as telephoning the school, or speaking to a teacher at parents evening. Sometimes parents act more formally by writing to the school or requesting a meeting. Despite home-school relationships being considered central to the education of school pupils, very little research exists that explores the encounters between parents and teachers and as a result there is little understanding of how these relationships are sustained (MacLure and Walker, 2000). Traditionally in UK education, parents attend a parents' evening once a year to receive updates of their child's progress (Baker and Keogh, 1995; Ranson et al., 2010). From this perspective, parents' evenings are occasions where the institutions of home and school are made visible and thus parents and teachers are morally accountable to one another (Bilton et al., 2017; Maclure and Walker, 2000). During these encounters, the issue of good and bad parenting and teaching may arise. Therefore, teachers do not indisputably have the upper hand and issues of power, identity, competence and moral conduct are at stake for all involved (Maclure and Walker, 2000).

There have been few studies of parents' evenings at secondary level, and almost none which examine in detail the encounters during parent-teacher consultations. MaClure and Walker (2000) studied parents' evenings in five UK secondary schools (11-18-year olds) and was

[4] Getting it Right for Every Child (GIRFEC) in Scotland, and Every Child Matters in England and Wales.

informed by a Foucauldian perspective (for example, Foucault, 1977) on the workings of power and knowledge in parent-teacher consultations, and in home-school relationships more generally. For the authors, home-school relations is a practice through which parents, teachers and students regulate themselves and one another in the interests of governmentality.

For families, having an autistic child can be demanding, more so if the child is unsettled at school (Hebron and Bond, 2017). Parents of autistic children consistently report higher levels of stress, depression, stigmatisation, anger, anxiety and overall lower well-being than parents of typically developing children (Benjak et al., 2011; Ekas et al., 2016; Mancil et al., 2009). Mothers of autistic children in particular typically report lower overall family functioning and worse mental health (Whitehead, 2017). Mothers are likely to have higher caring responsibilities because of cultural expectations of 'women's work' and as a result do not have the same 'respite' that some fathers may experience (Gray, 2003; Hastings et al., 2005; Lee et al., 2008). Moreover, these expectations that are placed on mothers can lead to feelings of inadequacy and parental guilt if the child is seen to be struggling (Waltz, 2015). It is typically the parent's responsibility to ensure that the proper impression of the family is sustained (Voysey, 1972). Thus, the representation of the family during a parent – teacher interaction can create great pressure on a parent, which may impact on the exchanges with school staff.

Within education, the notion that a child's welfare should be a matter for professional experts can make it difficult for parents to question this assumption. Parents who do express that they know best about their child's educational needs can be labelled as ungrateful or as a problem (Tomlinson, 1982). Moreover, parent's intervention into school life can create a great deal of anxiety in schools at the growing incidence of the 'angry parent' (Ranson et al., 2010). Ranson et al. (2010) argues that these occasions are reactions to events in school and because the integrity of the parents' personal domain and their sense of responsibility for their children is called into question (Sennett, 2003); particularly because at times the school can communicate judgements of implied parental inadequacy, thus demeaning their sense of self-esteem and respectability (Maclure and Walker, 2000). On the other hand, some parents can feel extremely troubled by a particular experience or aspect of school practice, yet remain silent, wanting to speak but unable to do so (Maclure and Walker, 2000). This emulates the passivity noted by Heath (1992), who argues that minimal response is characteristic of responses to expert-talk.

2.13.3 Co-operation and Communication Among School Staff

Many people, other than the classroom teacher are involved in inclusion: the head teacher, form teacher, support teachers, educational psychologists and school advisors, in addition to community support organisations (Dybvik, 2004). It has been argued that inclusion and positive outcomes cannot be achieved by just a few members of staff (Barnard et al., 2000). Collaboration among school staff includes delegated responsibilities and roles as well as mutual decision-making and forms of action, which reinforces the importance of a whole-school approach to inclusion (Booth and Ainscow, 2002). The failure of the inclusion framework (teachers, pupil support, head teachers) can be caused by faulty relations and poor communication among the parties involved, lack of agreement regarding the best course of action, or a negative attitude toward the pupil (Eldar et al., 2010).

2.14 Intergenerational Relations between Pupils and Parents

This thesis explores the socio-spatial (home and school) aspects of intergenerational relations between pupils, parents and staff in relation to support (Mannion, 2007; Mannion, 2012). Children's lives are rarely their own, and are the focus of parents, educators, health workers and politicians' efforts to do what is in their best interest (Blundell, 2016; Stainton Rogers, 2001). The exclusion of children from the labour market separated children from adults and state institutions became a way of regulating their everyday lives (Backe-Hansen, 2002; Leonard, 2016; Punch and Vanderbeck, 2018). Inter-generagency refers to the numerous ways in which childhood and adulthood are performed and played out. Generation helps to understand the relationship between childhood and adulthood. Thus, generagency recognises the structural positioning of childhood while also acknowledging children's active agency in generational relationships (Leonard, 2016; Mayall, 2002). Within adult-child relationships, children are not powerless and adopt, resist, challenge and negotiate their positioning and the positioning of the adult generation (Backe-Hansen, 2002; Bugental and Martorell, 1999; Leonard, 2016). Kuczynksi (2003) argues that a one dimensional concept of power pays little attention to the give and take reality of most adult-child relationships. Parent-child relationships in particular can be complex and multi-layered. Therefore, it is essential to understand these relationships to better comprehend the extent to which children practice agency and can be considered as agentic (Leonard, 2016).

Children first learn about legitimate power and authority in their relationships with their parents and their capacity as protectors, providers and disciplinarian (Beetham, 1991; Punch, 2005; Scott, 2001). The relative power that children attribute to themselves versus their parents has been found to predict their ways of responding to unrelated adults (Cortez and Bugental, 1994). Keogh (1996) argues that the pervasive concern with the policing of student's behaviour and demeanour in school and at home is one of the ways in which governmentality is effected, through the production and surveillance of docile bodies within time and space. Thus, there is a need for pupils to have some control over parents' involvement, highlighting the importance of negotiation rather than imposition of psychological control characterised by intrusive or manipulative controlling/surveillance measures (Baumrind, 2005; Crozier, 1999).

Relationships between parent and child can be extremely supportive, particularly with regards to educational needs (Brown et al., 1993; Crozier, 1999). Parents play a key role in their children's academic achievement and motivation and their involvement has been defined as the dedication of resources by the parents to the child (Desforges and Abouchar, 2003; Grolnick, 1997; Grolnick et al., 2002). However, Kim and Hill (2015) highlight that parenting literature is primarily focused on mothers. Fathers of children with and without disabilities are under-represented in education (Olley 2012). Pfitzner et al. (2015) refer to the general adoption of a 'gender-blind' approach where providers 'often conflate parent with mother without understanding the gendered aspects of engagement'. Ghate et al. (2000) argues that a 'gender-differentiated' strategy is needed where providers recognise and address potential differences between mothers and fathers in terms of service needs and support preferences. Such undermining approaches exist in relation to fathers of disabled children, where stereotypical beliefs concerning traditional parental roles have resulted in men having trouble in asserting their involvement with professionals working with their children (Carpenter, 2007). Research conducted with 139 parents of autistic children in a London school highlights that the parents feel unsupported, isolated and alienated (Galpin et al., 2017). Moreover, they expressed that there was a need for a family-centred approach to support that took into account the needs of the whole family.

2.14.2 Relationships between Pupils and Staff

According to Mannion and Adey (2011), school and home and intergenerational relations co-develop and are influenced by each other. There are various types of teacher-pupil interaction, including individual attention to pupils, active pupil involvement with the teacher and classroom control and management (Blatchford et al., 2011). In a Scottish study, Maitles and Cowan (2010) found that 87% of pupils felt they were learning better because the teacher was trying to involve them. The findings demonstrated that the participatory classroom style had a 'positive impact on pupils' citizenship values, dispositions, motivations and interest' (see also Brownlow et al., 2021; Deuchar, 2009). In a study by Brownlow et al. (2021), the importance of positive relationships was positioned as key to successful participation within educational contexts. Grandin (2006) discovered, through meetings and discussions with parents, teachers and specialists over a period of 20 years that autistic pupils who go on to successful careers had teachers who motivated them to succeed. The teacher's prediction of a pupil's behaviour is thought to be communicated to them in unintended ways and it has been proposed that pupils may perform as well or as badly as is expected of them (Meighan & Siraj-Blatchford, 1997). Thus, assumptions made by teachers concerning individual pupil's ability based on labels given can be particularly damaging (Brownlow et al., 2021).

Discussion about teaching styles is largely restricted to groups of teachers and does not include pupils (Fielding, 2001). Emam and Farrell (2009) reported that teachers of autistic pupils experience tension when dealing with their difficulties in social and emotional understanding. These tensions include the anxiety the teacher feels over their ability to meet the needs of all pupils in the class, and these tensions can determine the quality of teacher-pupil interactions (Lindsay et al., 2013; Robertson et al., 2003). These relationship difficulties can stem from the teacher being nervous about and having misperceptions about autistic pupil's needs (Lindsay et al., 2013). It should also be noted that the disengagement from the pupils may derive from the enormity of administrative tasks, as was highlighted by the teachers in the Farouk (2014) study**.** For instance, one teacher described how disengaged from the students her work had become.

Within the classroom, knowledge is mainly transmitted verbally, and most of the talk is delivered and monitored by the teacher (Edwards and Furlong, 1978; Meighan and Siraj-Blatchford, 1997). For instance, teachers typically tell pupils when to talk, what to talk about and when to stop talking (Edwards and Furlong, 1978; Young 1992). Young (1992, p. 36) found that pupils are often seen as 'individuals who must simply be made to reproduce the

point of view being advanced, by whatever means seem expedient and economical'. Thus, to a large extent, communication between classroom teachers and pupils is one-sided. Leatherland and Beardon (2016) propose that one way to help pupils communicate their needs to school staff is via an electronic system FAMe™. This system allows the teachers to access 'three facts about me' about the pupil with the hope of reducing secondary school stressors and anxieties experienced in the classroom. This thesis adds to the literature surrounding the relationships within and across the pupils, parents, and staff participant groups. Moreover, it enhances understandings of the ways in which relationships and communication impacts on the support available to autistic pupils in mainstream secondary school.

CHAPTER THREE
Methodology

This chapter outlines the approach taken for the research and discloses the researchers positionality. It provides information on the participants, the criteria for their inclusion, and how they were accessed. The tools used for data collection are outlined alongside the reasons why they were selected, followed by a discussion on the validity and reliability of these methods and how they were analysed. It details the ethical considerations that were followed including informed consent, confidentiality and the safekeeping of the data. Finally, the constraints on the research are discussed.

3.1 Qualitative Approach

There are some fundamental differences between qualitative and quantitative research paradigms, which lie primarily at the level of epistemological and ontological assumptions of research (Atieno, 2009). However, features of qualitative and quantitative research overlap to a great extent, including the research process, methods and philosophy (see Allwood, 2012). Thus, perpetuating stereotypical portrayals of qualitative and quantitative research can be unclear and problematic and thus should be avoided. Quantitative research rests on broadly positivist epistemological assumptions, whereas qualitative research is primarily interpretivist (Atieno, 2009). Thus, a qualitative approach to research is deemed to be much more fluid and flexible than quantitative research in that it emphasises discovering unanticipated findings and the possibility of altering research plans in response to unforeseen occurrences[5] (Bryman, 1984; Mays and Pope, 1995).

The ontological position of constructivism is adopted for this research as the realities of the participants are socially constructed and reflect historical and cultural norms that operate in their lives (Dieronitou, 2014). An interpretivist epistemological position is taken to understand and interpret the meanings that the participants have about their social worlds (Al-

[5] This approach was vital to answering the research questions of this thesis as the participants at the centre of the project, the pupils with a formal identification of autism, experience communication difficulties which it was assumed would (and did) require flexibility during data collection. Moreover, as a consequence of the time-consuming nature of parents experiences with their child's unique challenges, and school staffs' busy teaching schedules, a more flexible approach was key.

Ababneh, 2020). This fits with the central aim of qualitative research, which is to learn about how and why people behave, think and make meaning as they do (Hammersley, 2013). The underlying approach requires detailed observation and explanation, to understand phenomena deeply and in detail. This is something that cultural anthropologist Geertz (1973) describes as 'thick descriptions' of human actions and behaviour. It attempts to study as much of the whole situation as possible, to acknowledge the complexity and ensure that conclusion takes account of both unique and general factors. This approach was deemed essential for this project as autistic pupils, and their families, each have their own set of unique challenges and experiences that sets them apart from each other whilst also sharing some commonalities. Moreover, this approach also allows for a more detailed account of teachers individual experiences and a more general picture of a whole school approach across the different schools included in this study.

It could be argued that the main disadvantage of a qualitative approach is that findings cannot be extended to wider populations with the same degree of certainty that quantitative analyses can (Atieno, 2009). As classically stated, this is a difference between idiographic and nomothetic approaches (Hermans, 1988; Windelband, 1894/1998). Thus, while this research is not necessarily generalisable to the wider population (Bonds, 2007), the findings will be of interest to pupils, parents and staff in other schools and can be used to inform similar contexts and situations.

3.2 Researcher Positionality

The identities of both the researcher and the participants have the potential to impact on the research process (Bourke, 2014). Allum (1991) argues that entry to a group of participants begins long before the researcher physically arrives and that the relationships established between the observer and the observed is one of continuous negotiation. Negotiating the hidden dilemmas of entry, therefore, requires a hypersensitivity to one's own previous knowledge assumptions and the positional space one occupies during entry (Labaree, 2002). Positionality refers to the researcher's social position, such as age, gender and race, alongside their personal experiences and beliefs (Berger, 2013; Holmes, 2020). Being reflexive of these social positions is a major strategy for quality control in qualitative research (Berger, 2013). The researcher having an insider specialised knowledge of the group being studied raises issues of researcher bias and validity while undertaking a qualitative research project. Thus, in order to ensure trustworthiness in qualitative research, it is important for the researcher to

engage in critical self-reflection about potential biases and predispositions (Galdas, 2017; Holmes, 2020; Johnson, 1997; Shenton, 2004).

3.3 Personal Positionality: On Being an Insider *and* an Outsider

In qualitative studies, it is increasingly common for researchers to be part of the social group that they intend to study (Dwyer and Buckle, 2009). In the current study, the researcher is a native or 'insider' due to being a parent of an autistic child who required support in secondary school (Adler and Adler, 1994; Kennedy, 1999; Lofland and Lofland, 1995; Tom-Orme, 1991). Bonner and Tolhurst (2002) outline three key advantages of being an insider: a superior understanding of the group's culture; the ability to interact naturally with the group members and a previously established relational intimacy with the group. In addition, being an insider can reduce many problems associated with social research. These include, gaining access (Kidd, 1992), establishing rapport with participants (Platzer and James, 1997) and dealing with ethical concerns (Ryan, 1993). An insider may have an easier time being accepted by others and recognised as being "one of them" (Ruane, 2016). Vasquez (2011) conveys how during her study of Mexican American Families*,* her part-Mexican heritage provided her with an insider status, which allowed her to pass the first test of authenticity.

According to Burke (1991), the unintended consequence of insider status is working with epistemological tunnel vision. Lipson (1984) suggests that recognition of patterns of practice might be difficult to identify, and therefore missed, because the behaviour is familiar and taken for granted. Moreover, there is a risk that over-familiarisation with the setting may lead to making assumptions about what is being observed without seeking clarification of the underpinning rationale for actions (Gerrish, 1997). Other researchers also highlight the dilemma of developing too much rapport with research participants, asserting that if all possess an understanding then it may not be vocalised in the same way that it would to an outsider (Coffey, 1999; Hammersley and Atkinson, 1995; Merrian et al., 2010), and runs the risk of the researcher becoming a non-observing participant (Miles and Huberman, 1994). Additionally, insider research can be seen as problematic, in so much that the insider may depend too much on his/her own background, sentiments, and desires for what is good for his/her community (Jones, 1970). Responsibility to one's own community has the potential to be challenging because false representations of phenomena, either real or perceived, could lead to feelings of betrayal on the part of the participants (Labaree, 2002). The outsider's

advantage then, lies in curiosity with the unfamiliar, the ability to ask taboo questions and being unconnected with subgroups thus often acquiring more information (Merriam, 2010).

The above advantages of 'insiderness' found in the literature can be categorized into four broad values: the value of shared experiences; the value of greater access; the value of cultural interpretation; and the value of deeper understanding and clarity of thought for the researcher (Labaree, 2002). However, each of these advantages are linked to a disadvantage. For example, greater familiarity can lead to a loss of 'objectivity', particularly in terms of inadvertently making inaccurate assumptions based on the researcher's prior knowledge and/or experience (DeLyser 2001; Gerrish, 197; Hewitt-Taylor, 2002). From these categorisations, it becomes clear that the advantages of the researcher being an outsider is that they are detached from commitments of the group being studied, can more readily acquire objectivity and are unrestricted by prejudiced practice and theory. In contrast, the key disadvantage of being an outsider is that the researcher may enter the field with a set of unquestioned assumptions which lead to certain types of conclusions (Jones, 1970). The crucial point is that insiders and outsiders may be able to collect different data and differently interpret the same set of data (Jones, 1970).

Early discussions in anthropology and sociology of insider/outsider status assumed that the researcher was either an insider or an outsider. More recent discussions of insider/outsider status have acknowledged that the boundaries between the two positions are not all that clearly defined (Merriam et al., 2010). The insider as outsider status requires that one look both from the outside in and from the inside out and to understand both positions (Merton, 1972). Reflecting on my own positionality, as a parent to an autistic daughter, I can look from the inside out in relation to the group of parent participants in this research. However, there is also a space in between in which this group of participants present with various differences to me. For instance, they are made up of different ages, gender, both as parents and the gender of their child, the number of children they have, their children still being at school, and different parenting values. Moreover, in addition to being a parent of an autistic child, I am also a researcher asking questions. Therefore, this may impact on how participants respond to me. For example, during an interview with one of the parents, she mentioned on several occasions that she did not hold higher education or professional status in high regard, stating that everyone's work is just as important as the next. This may have been in relation to my researcher status. With regard to the two other participant groups, the pupils and staff, I am

an outsider looking in. Thus, my position in relation to pupils and staff are more objective and the research problems and questions used during data collection are largely informed by literature. However, I was aware of my status as a researcher and as a parent of an autistic child causing some school staff to be somewhat defensive. Consequently, this may have impacted on the data collected from this participant group.

3.4 Sampling and Access

This study uses purposive sampling due to its exploratory focus (Adler and Clark, 2008; Barbour, 2001). The sample is made up of six pupils (12-18 yrs.) who are formally identified as autistic (see Table 1), six parents (see Table 2), and fourteen school staff (see Table 3). Thus, the total sample size is twenty-six. The purpose for the age range of the pupils is because the study is concerned with the experiences of secondary school pupils. The parents and pupils were accessed by posting an advertisement via a charitable organisation (see Appendix 5) and via information that I presented at an autism conference. However, initial response was very low, therefore, I recruited some participants by posting on relevant Facebook groups (see Appendix 6).

Data was collected via task-based interviews (pupils), semi-structured interviews, face-to-face and one via Skype (parents, staff and pupils), email interviews (staff and pupils) and informal discussions (parents). Fieldwork took place within the pupil and their parent's home over multiple visits and therefore the study had ethnographic elements to it. Two of the young people were siblings, therefore five families were included in the research. For four of the families, the young people's mothers were interviewed and for one both mother and father were interviewed together, thus six parents took part in the research. Two of the families were single-parent households while the other three had both parents and/or step-parents. Two of the families could be considered middle-class and three as working class. All of the children live in and attend school across four local authorities in central Scotland, one of which is included in the research.

Staff from five schools were interviewed, mostly via email, with four face-to-face interviews taking place, one of which included two staff members. Staff interviewed face-to-face were four Head of Pupil Support and one Deputy Head teacher. Email interviews were made up of Support for Learning Assistants (SLA), Deputy Head Teacher, Principal Teacher of Pupil Support, and Pupil Support Workers. The schools that these interviews represented consisted

of two large, one small, one with an autism support unit attached, and one rural. However, taking into account the schools that the pupils who participated in this study attend, nine schools in total are represented (See Table 4).

According to Oates and Riaz (2016) securing participation in schools has the potential to sabotage projects. The reasons that both authors found for schools declining to participate in their individual projects were exam preparation, staff/resource shortages and the head teacher being on sick leave. Other reasons for low response rates can include timetable clashes, lost to follow-up, or religious beliefs (Testa et al., 2006). In contrast, high response rates can be attributed to professional connections that the researcher has with the schools and face-to-face meetings with key members of staff (Oates and Riaz, 2016; Testa et al., 2006). In the current study, schools were accessed by first approaching the local authorities about the research. A research request was submitted (see Appendix 7), and once approval was sought from the director of education the next stage was to contact the Schools directly requesting permission to interview staff (see Appendix 8).

This was achieved by sending out information leaflets in the post with recorded delivery. One school contacted me after three weeks and the principal Teacher from the Additional Support Needs Department/Team called to confirm that the school could help out and we could arrange a two-day period for me to conduct the interviews. After five weeks with no response from the other three schools that I had contacted within the same local authority, I followed up my request via email and that same day received a request for more information from one.

Another local authority I had contacted at the same time in early September 2017 did not acknowledge my request, despite three attempts to contact various people. Therefore I stopped my attempts and instead focused on a different local authority. The response was very quick, within a day, however, they informed that I should resubmit my request late February 2018 and expect to wait six weeks from then for a decision. This would be too late for my study therefore I contacted an additional six local authorities and received approval from two. Two schools participated from Local Authority One (LA1), two from Local Authority Two (LA2) and one from Local Authority Three (LA3). Thus, staff from a total of five schools participated in the research. Eight staff from the schools in LA1, five from LA2 and one from LA3. A further three local authorities are represented in the data solely due to the pupils who were interviewed attending school in them. Therefore, a total of six local

authorities in Central Scotland and nine schools are represented in this study (see Table 4). The researcher initially had intended for the schools to be used primarily for comparative purposes. However, it soon became clear that the main focus of the study should be on shared experiences of support and supporting autistic pupils.

Table 1:Pupils

Pupil	Age
Oliver Biggs	Age 12
Stephanie Morgan *	Age 16
Mark Morgan *	Age 14
Russel Griffith	Age 13
Christina Grant *	Age 18
Jason Gray	Age 17

The three pupils with an Asterix are in the same local authority – two of which are siblings in the same school

Table 2: Parents

Parents	Characteristics
Louisa Biggs	Married, middle class
Lawrence Morgan *	Step-parent, married, middle class
Gaynor Morgan *	Married, middle class
Rebecca Griffith	Married, working class
Debbie Grant	Single parent, working class
Susanna Gray	Single parent, working class

Those marked with an Asterix are married to each other

Table 3: Staff Roles and Experiences

Local Authority 1 School 1	
Role	**Experience**
SLA (Support for Learning Assistant)	8+ years, prior – SLA for five years
Autism Provision	5 weeks, prior – classroom teacher 15 years
Autism Provision	2 months, prior – 12 years primary base, learning & behavioural support in secondary school 5 years
Autism provision	2 months
Deputy head	4.5 years
SLA	7 years

Head of Autism Provision/Pupil Support	2 years, prior- 8 years autism provision same school, 8 years language and communication facility
Local Authority 1: School 2	
Role	**Experience**
Principal Teacher of Pupil Support	15 years Pupil Support
Local Authority 2: School 1	
Role	**Experience**
Pupil Support Worker	20+ Years
Principal Support Teacher	20+ Years
Deputy Head teacher	Current post 4 months
Local Authority 2: School 2	
Role	**Experience**
Deputy Head Teacher	Support for children 10+ years, previously guidance teacher
Principal Teacher of Pupil Support	2.5 years, previously guidance teacher 13 years
Local Authority 3: School 1	
Role	**Experience**
Principal Teacher for support	8 years, 3 of which specific to autism support

Table 4: Breakdown of Nine Schools

School 1 LA1	Large, Autism Support Base: 855	1 pupil / 1 parent / 7 staff
School 2 LA1	Rural, ASN Support: 591	0 pupils /0 parents/ 1 staff
School 3 LA2	Large, ASN support (additional support needs): 1450	0 pupils / 0 parents/ 3 staff
School 4 LA2	Small ASN support 200	0 pupils / 0 parents/ 2 staff
School 5 LA3	Large, ASN Support: 1049	0 pupils / 0 parents/ 1 staff
School 6 LA4	Special education unit within school to cater for range of needs: 760	2 pupils / 2 parents/ 0 staff
School 7 LA4	Large, ASN Support: 1000	1 pupil/ 1 parent / 0 staff

School 8 LA5	Large, SEN Support :761	1 pupil / 1 parent/ 0 staff
School 9 LA6	Large, ASN Support: 1560	1 pupil / 1 parent/ 0 staff

3.5 Mixed Methods of Data Collection

As Barbour (2001) states, if we succumb to the lure of "one size fits all" solutions, we risk being in a situation where the checklist is controlling the qualitative research. It was especially important to implement various methods of data collection for this research to take into account the different participant groups (pupils, parents, staff). Taking this approach enabled the young people to participate in the research in ways that were less intimidating than some traditional methods (e.g. focus groups). Moreover, offering the parents and school staff accessible options of participating allowed the researcher to work around the challenges of distance and time limitations.

3.6 Conducting Research with Children

When conducting research with children and young people it is important to recognise the power between adult researcher and child participant (Christensen, 2004; Davidson, 2017; Lane et al., 2019). Research with children and young people runs the risk of infantilising them, of treating them as immature and incompetent (Alderson, 2008; Punch, 2002). This can make adult researchers conscious of the language that they use when interacting with young participants (Alderson, 2008; Punch, 2002). I was conscious of the language that I used when designing the task-based activities and during the follow-up interviews with the young people. However, this was more in relation to an understanding that some autistic people can interpret words literally and less to do with competence. This was another instance where my position as an insider aided my research; for instance my daughter can interpret things literally, making me aware that this may be the case for some of the pupils in my study. Nonetheless, one of the young people in the study did take offense to the child-like presentation of the structured diary and as a result this had to be adapted in order for him to continue with his participation[6].

[6] All activities were collected with relative ease with the exception of one young person who was put off by the emoticons in the diary and for a while refused to answer the questions. This was rectified by emailing some of the statements/questions of the diary via his mother with the absence of the emoticons.

3.7 Task-based Interviews with Children/Young People

Task-based activities offers variety to engage young people's interests and to help lessen the unequal power relationships between the adult researcher and young participants (Punch, 2006). Utilising task-based activities can help to improve the understanding of the perspectives of children of all ages and can build on their strengths and competencies (Barriage, 2018). Given the difficulties that can be experienced by autistic pupils in relation to face-to-face communication, task-based activities were considered to be an appropriate method of data collection. The activities used, over multiple visits with the young people, were an 'About School' exercise and a structured diary.

Visits to the pupil's homes were multiple, taking time to ensure that patience was practiced, and the data was collected in a way that was more comfortable for the pupil. This provided the pupil more time to become accustomed to the researcher's presence. Moreover, it allowed the researcher to answer any questions that the pupils may have regarding the tasks. Multiple visits also allowed me to build rapport with some of the participants and brought up new issues of school support over a longer time period. For example, on my first visit to a young person's home (Russell, age 13), he and his mother spoke of the support he received and how it was helping him. However, on the second visit to his home, approximately five months later, Russell and his mother communicated that all of the support had been removed.

From the six young people who took part in the study, I met five. Two I met with to explain the study to them and inform them of what their participation would involve; two I met for the first time during the follow-up interview to the activities that I had either sent out by post or left with their parents; one I met briefly when I visited the house to interview their parent and one I have never met or had no direct contact with and all activities for the latter two were passed on via their parent. This means that the activities were left with the young people or their parents for three families; and for two families, the activities were sent via post with instructions included within the envelope and supported with email. Four of the young people posted back their activities which I went through and created questions for the follow-up interview. One young person's follow-up questions were emailed to them and they completed the questions and emailed them back to me. This worked well and had the added advantage of not requiring transcription.

3.7.1 'About School' Exercise

An A4 sized paper template was given to the pupils to include what they like/dislike about school and things that they get/would like help with at school (see Appendix 1)[7]. It was believed that this activity would go some way to answering sub-questions one and three. Moreover, by completing this task, I was able to gauge an understanding of the young peoples' communication skills and develop a basic indication of their level of comfort with myself, whilst also conveying their initial experiences of school support. Once the young people completed the template, I contacted them to arrange a follow-up interview so that they could expand on their statements. One interview was conducted immediately after first reviewing activity 1 in a young person's home; however this did not leave enough time to thoroughly think through follow-up questions in the moment and therefore this was not repeated. Subsequent activities were collected from the young people, read through at the researcher's convenience and then followed up with an interview at a later time.

3.7.2 Structured Diary

The next phase of the research was to give the participants a structured diary with each page beginning with a statement relating to a part of their school day (see Appendix 2). The reason for this was because asking them to complete a more traditional style diary may have been too complex for some, if not all, of the young people in this study. A structured diary provides participants with some guidance and prompts (Bartlett and Milligan, 2015; Buchwald et al., 2009). Moreover, it offered a means for the young people's thoughts to be included in the research if they struggled to communicate verbally. Nonetheless, using a diary method requires literacy skills and had the potential to introduce a level of participant bias (Bartlett and Milligan, 2009), thus emoticons were used alongside each written statement of the diary to allow for this. Each page of the diary began with a statement relating to various points of the school day. Some pages were left blank in order to give the pupils the opportunity to include people and situations that they wished to or that they believed to be relevant or important to them (Milligan, et al., 2005). To account for the potential for participants to lack motivation in completing the diary (Lamsa et al., 2012), they were given a time-scale, for example, they were asked to have it ready for their follow-up interview in a

[7] It should be noted that at the time of designing the activities and information sheets, autistic pupils were referred to as those with Asperger Syndrome, with ASD, or on the autism spectrum. This changed as my viewpoint evolved on the matter.

few weeks. This research tool was designed with the purpose of it going some way towards answering all of the sub-questions. The data collected in the structured diaries offered more depth and detail to that collected in the about school exercise.

3.8 Pilot Study

It was the intention to recruit an advisory group made up of autistic young people to provide feedback on the research tools and to seek advice and guidance throughout the research (Malmqvist et al., 2019; Sampson, 2004; van Teijlingen and Hundley, 2002). It was hoped that this approach would be participatory in nature and respectful of the social values of the participants (Kilifi, 2011). A local charitable organisation that support autistic school-age children agreed to share this information with their young people and found that four were keen to contribute to the study as it progressed. However, the group lost funding and was unable to continue. Therefore I sought insight from two young people known to the researcher, both autistic, one male (15) and one female (19), to gauge their reactions to the about school exercise and the structured diary to help inform and improve it before distributing it to participants. I gave both activities to them in a folder on a Monday and asked if they could have them completed by the Friday that same week. I intentionally did not repeat my request each day because I wanted the circumstances to reflect other families where the goal of completing the activities might not be as important as it was to me as the researcher. This proved to be an effective exercise in terms of feedback (Malmqvist et al., 2019; Sampson, 2004).

Two days after being given the activities, the female had completed most of Activity 1 but with minimal input. She expressed that she needed even more structure to the diary because she struggled to think about some of what was asked of her. She also said she would prefer it in A4 because then each category is on one page and would feel like less work. She further advised that she would not complete this during the summer holidays because this is a time to not think about school, which was a very important insight. The male did not return Activity 1 and only ticked the emoticons in the diary. He similarly said that it was too hard to think. However, we then used one of the categories as an example and he opened up about a lot of really interesting things relating to his school experiences. This again reassured me that face-to-face follow-up interviews with the participants would be useful. Both diaries came back in bits and not in order, which gave me advance warning to ensure that diaries were stapled together when given to participants (Malmqvist, 2019; van Teijlingen and Hundley, 2002).

3.9 Informal Discussions with Parents

Informal conversations can complement a research project by producing more naturalistic data (Swain and King, 2022). The decision was made to include informal discussions as part of data collection with the awareness that participants were likely to be more relaxed in the times between the more formal methods of data collection. Participants were informed that informal discussions may be included in the research unless they specifically asked that something they mentioned to the researcher be excluded from the data. During the course of the visits to the pupil's homes, informal discussions took place with the young people's parents and the researcher. Moreover, conversations took place between some of the pupils and their parents during the young person's interview. For example, during one visit, before the young person's interview started, one mother had expressed to me that she thinks her son has never refused to go to school because it provides him with a routine. However, her son joined the conversation and explained that the reason he had never refused to go to school was because he felt he had to attend. Including informal discussions in the research allowed topics such as this that arose during these conversations to be explored in the semi-structured interviews. Being present in the parents' homes on multiple visits provided an opportunity to discuss anything in particular that may have arisen during the course of the research in relation to their child's schooling. The researcher's insider status helped with this a great deal in this regard as she was able to refer to personal experiences making her more relatable. However, great care was taken not to lead the participants' discussions. For example, care was taken to keep statements broad.

3.10 Face-to-Face Semi-Structured Interviews

The open-ended nature of semi-structured interviews allows for flexibility and is suited to exploratory research. This method of data collection allows the researcher to obtain in-depth information from the participant. At the same time, it provides reliable comparable qualitative data compared to that of unstructured interviews (Mashuri et al., 2022). During face-to-face interviews, rapport can be built with participants, that is perhaps not present with online interviews (Curasi, 2001). Moreover, the human touch allows the interviewer to encourage the participant to speak in more depth and detail and allows for adjustments to be made should the participant require a break (Schober, 2017). However, face-to-face interviews may also prove to be awkward for some participants who may be reluctant to express their thoughts and opinions freely (Schober, 2017). As the nature of the current study

is exploratory in nature, semi-structured interviews were deemed to be a desirable method of data collection. Semi-structured interviews were conducted with parents which allowed them to expand on topics already discussed during informal discussions or those that had not yet arisen (see Appendix 3). Three interviews were conducted individually and face-to-face, and another with two parents present (from the same family), one was conducted via Skype. Parent interviews ranged from 75 to 140 minutes.

Individual interviews were initially chosen as an appropriate method of data collection for school staff as it would allow each staff member the opportunity to freely and openly express their views without prejudice from colleagues (see Appendix 4). Furthermore, on a practical level, arranging individual interviews was deemed to be less problematic than attempting to arrange a group interview within the school environment, taking into account busy schedules and teaching commitments. It was initially thought that interviews would be one hour long so as not to disrupt the school day too much. However, after discussion with staff from one school it was suggested that 50 minutes would be a more appropriate time-scale as this is the length of each class and therefore would fit better with teachers in between teaching.

3.11 Email Interviews

Conducting interviews via email allows participants the freedom to express themselves without screening information that would typically occur during face-to-face interviews (Au, Yee Wei and Marks, 2013). A potential downside to this is that participants are able to reread and make changes to their answers which may make their responses less spontaneous (Curasi, 2001). Email interviews are more convenient for some participants in that they are less intrusive on people's homes and schedules (Schober, 2017). However, according to Cusari (2001), research participants found that email interviews required more effort. There is also the risk that only offering this method of data collection could have excluded 'hard to reach groups' for example, those with inadequate computer literacy or those without access to emails (Brooks-Wilson and Snell, 2012). This is why multiple options were made available to participants, with email interviews being one.

When I met with the Principal of Pupil Support at the first school, and two other members of staff, I was advised that the interview schedule was too long, and that teaching staff would not have time to answer them in their schedule. I suggested they complete the questions via email (were given a choice of face-to-face or via email) which gained their approval.

Following the interview, I adapted the questions, reducing them and emailed them with an invitation to arrange a face-to-face interview or send responses via email. Four days later I received my first set of responses via email and three weeks later I received seven responses in total via email with no requests for a face-to-face interview. Therefore, the decision was made to use this method with further schools with the intention of only conducting a face-to-face interview with Head of Pupil support in each school. This approach was believed to be more appropriate due to the lengthy delays from local authorities and schools, therefore it was more time effective in terms of collecting and analysing the data and for removing the need for transcription. All interviews with pupils, parents and school staff were transcribed by the researcher no later than one week after being recorded to avoid a build-up of audio data that had the potential to be overwhelming.

Another advantage to using emails as a data collection method is the ability to access hard to reach groups due to practical constraints of money, time, travel, disability and language (James, 2007). The research diary that I maintained during fieldwork offers personal insights into some of the challenges that I was faced with in relation to conducting face-to-face interviews (Browne, 2013; Punch, 2012). During my research, I began experiencing health issues that were making it increasingly difficult to travel to and from participants homes/place of work. The following extracts from my research diary convey these difficulties and confirm that conducting email interviews allowed me to continue with the research with as little impact on my health as possible:

> **Thursday 11th May -** Health issues extremely problematic now and I am scared this will impact on fieldwork. I meet my first participants on Monday, and I am really excited about that, but I am also worried that I am not meeting them until 4.15 pm and my symptoms gets worse as the day goes on. This will likely be an issue for a while considering it is school children I will be meeting and will have to wait until after school to speak to them.
>
> **Friday 16th June -** Was supposed to visit a family today but broke out in hives again (damn illness!). I emailed to explain that I am not keeping well at the moment… She said it was absolutely fine to postpone it until next week and was very understanding.
>
> **Friday 23rd June -** I was so nervous about meeting the new family today, not because of the family, I really looked forward to meeting them, but I feel so ill and tired and I hate driving to unfamiliar places. My daughter and her friend came for the

> drive in case I got ill on the way there or back and I left them in a café while I visited the family.

Using email interviews with staff meant that I could take the pressures off anxieties I was experiencing relating to cancelling meetings with participants who are extremely busy. However, a challenge of using emails as a data collection method is communicating meaning that normally occurs in a social space, such as non-verbal communication; for instance gesture, tone of voice and facial expression (James, 2007). This presented itself in one email as shown below:

> **"How important is it to you that a child or young person fits in at school?"**
> I would like all of my caseload pupils (Autistic or not) to be happy at school – am not really sure what this question is getting at? (LA2: Sch.1 Pupil Support Worker)

It is clear that there is some confusion to the meaning of my question. Thus, had this been a face-to-face interview, I would have been able to clarify my meaning to the participant. However, this was the only email interview that raised this concern and the advantages of this method were found to be many, including, convenience to both the participants and the researcher.

3.12 Triangulation

Qualitative research allows a research question to be examined from various angles. A multi-method approach allows the biases of any one method to be cancelled out by those of the others (Seale, 1999). Utilising different methods of data collection proved to be rewarding in this research in that it offered the participants choices that worked better for their preferred method of communication and also worked around busy and demanding schedules. This resulted in participants taking part who may not have done so if the options were not there and allowed some to open up in a way they were comfortable with. Email interviews with school staff were brief and to the point whereas the face-to-face interviews with staff were more in-depth. However, in contrast, email interviews with some of the young people were more in-depth than face-to-face interviews which highlights their preferred method of communication.

Additionally, the follow-up interviews with pupils allowed for clarification on some of the questions that were asked in the activities. The diaries added more depth and understanding

to the first ‘About School’ activity. Nonetheless, the first activity provided an overview of key concerns for the pupils regarding support in school and meant that their views were noted should they decide that they were unable to proceed with the structured diary or follow-up interview. Parents were able to converse both freely and informally as well as in a more structured way which helped with potential feelings of imposter syndrome or self-doubt in what could be considered a professional situation (Bothello and Roulet, 2018; Bravata et al., 2020). Having various choices of data collection allowed the research question to be examined from various angles and undoubtedly captured data that otherwise would have been lost.

3.13 Validity and Reliability

Research should demonstrate that valid research methods have been utilised that best suit the research and that accurately present the social issue being explored (Drost, 2011; Holmes, 2020; Shaw et al., 2019). Using the various multiple methods of data collection for each participant group helped to reduce research bias (Seale, 1999). It was considered that these methods would gather repeatable information should they be used in further research with future researchers. The methods used ensured reliability of the research (Cohen et al., 2017; Drost, 2011; Kimberlin and Winterstein, 2008). The research tools utilised in the study were also designed to ensure validity, in that the data that was gathered via the various methods answered the key research questions set out in Chapter 1 (Kimberlin and Winterstein, 2008).

Triangulation helps to facilitate the validity of the data through cross verification from two or more sources (Cohen et al., 2017). Consideration was given to the possibility of triangulating pupils, their parents and the staff at the pupil’s school. It could be suggested that this approach would offer a tighter set of data and that the findings could be more easily checked for validity and reliability. However, triangulating the data in the current study raised some ethical concerns. For instance, although every effort would be made to ensure the anonymity of participants, in smaller schools with fewer autistic pupils, staff may have been able to identify which pupil and their parent was taking part in the study. Parents conveyed to me that they were worried about taking part in the research if their child’s teachers/staff would be involved. Moreover, this approach would not have been practical due to the struggles getting

schools on board and the difficulties that this would have presented involving specific staff. One measure taken to address validity by way of triangulation was to include some of the issues that had arisen during pupil and parent interviews and present them to school staff as case studies during their interviews (Rowley, 2002) (see Appendix 4).

Respondent validation exercises, such as reading drafts, can place considerable demands on participant's time and depending on the research topic and content of transcripts, can prove to be exploitative or distressing (Atkinson, 1997). In contrast, it can be somewhat therapeutic in that participants can feel a sense of relief and validation that they are not alone (Harper and Cole, 2012). In the current study, school, for most of the pupils, and some of the parents, is a distressing topic. With this realisation, it was deemed that respondent validation would cause additional and unnecessary stress and was therefore not sought. With regards to the school staff, they struggled to find time for the interviews in the first instance and therefore asking for respondent validation would put additional pressures on their time.

3.14 Thematic Analysis

Thematic analysis is used to analyse classifications and present patterns within qualitative data (Alhojailan, 2012). The identification of these patterns are then reported as researcher generated themes (Lochmiller, 2021). All data was primarily coded and organised manually into emerging themes. The themes that were selected for the thesis were those that aligned with the research questions. Therefore, themes relating to challenges, support, relationships and communication were included. Additional themes were identified but rejected as they were outwith the scope of the research; for example, those relating to after-school clubs and weekend and holiday activities. According to Barbour (2001) some element of multiple coding can be a valuable strategy. Therefore, once initial coding was completed, it was a useful exercise to share these with my supervisors. This prompted discussions that provided valuable insight for refining the coding frames. Once the codes were created, the data was then uploaded onto NVivo for further coding and organisation before analysis began. It was decided that using NVivo would be useful for managing the multiple methods of data collection used in this study. NVivo is a computer-assisted qualitative data analysis software (CAQDAS) with multiple advantages that aids the researcher in the process of data analysis (Bryman and Bell, 2011). It is a particularly useful visual tool for managing and organising data and ideas (Bazeley and Jackson, 2013).

Using this software enabled me to organise the data for each participant group and arrange school staff data within the local authority and schools to which they belonged (see Appendix 9). Following this I created a thematic coding framework that was then printed off and each code was read over multiple times in order to identify further themes. The key themes that were identified were challenges, support, relationships and communication. These themes were deemed appropriate for this topic as they relate to the sub-questions. After arranging the themes into pupil, parent, and staff categories, they were cut and pasted into word documents which were then again read over multiple times to break down themes within them. For instance, within the theme pupil support, data relating to educational support, emotional support, and other forms of support were identified.

3.15 Ethical Considerations

Ethical principles underpin all stages of the research process from choosing a topic, design, data analysis and dissemination of the findings. Thus, ethics in social research is not limited to the point of contact with potential participants (Russell et al., 2013) and apply to all participants, adults and children alike (Farrell, 2005). In order to ensure this, ethical approval was sought from the University of Stirling's Research Ethics Committee. Ethical approval was also sought and obtained from relevant local authorities and head teachers before the research commenced. This study adheres to the guidelines set-forth by the British Sociological Association's (BSA) *Statement of Ethical Practice* (BSA, 2002).
Research with children does raise questions that require specific consideration, particularly due to the way childhood is constructed and understood within cultural contexts (Alderson and Morrow, 2020; Morrow, 2008). The researcher took measures to ensure that the children and young people participating, along with all participants, were as comfortable as possible with the process and respected throughout. This included respecting young people's wishes to not meet the researcher and offering parents the option of Skype interviews, which one parent chose. The researcher also made no attempts to interview the young people during the school summer holidays as this is a time where many autistic pupils can take a break from the stress and anxiety of attending school. This approach was informed by an insider status and the pilot exercise and was supported by the young people's parents.

3.16 Informed Consent

3.16.1 Pupil Consent

Typically, research with children or young people requires a two-step consent process: obtaining consent from a parent or guardian and obtaining assent from the child or young person (Freeman and Mathison, 2009). The reason for this process is because 16 to 18 year olds are seen as young adults who are entitled to make decisions for themselves, whereas research with younger children raises issues of competence and rights (Lewis and Lindsay, 2000). However, parental consent could restrict children's ability to participate voluntarily in research (Coyne, 2010). For instance, parents may consent to their child taking part in the research whether their child wishes to or not, or a child may wish to participate but cannot do so if parental consent is not obtained (Alderson and Morrow, 2004).

It was the researcher's intention to inform the pupils of what was involved in the research via a video recording (McSherry et al., 2008). It was thought that this way, the pupils could become familiar with how the researcher looks and speaks (Parsons et al., 2016). The video was to include the researcher discussing the nature of the study, what their participation would involve, how the findings may be used and would stress their right to withdraw at any stage. Great care would have been taken with regards to word choice to avoid literal interpretation. It was also believed that this method would remove the social anxiety of being told about the research face-to-face, allowing them to make fully informed, un-coerced and less pressured consent (Weiss, 2008). However, due to complications in relation to establishing an advisory group, which consequently impacted on timing, the video did not go ahead. Instead, an information booklet (see Appendix 10) was given to the young people which was based on the video script and included a photograph of the researcher.

The consent form included four questions for the young people to complete with the purpose of increasing the researcher's confidence that the young people fully understood what their participation involved before agreeing to take part and that they were doing so of their own free will (Perrault and Nazione, 2016). It also included an additional two questions based on why they were taking part and if they were nervous about doing so. Three of the young people circled that they were not nervous at all and two that they were very nervous. They were also asked to circle the reason why they were taking part ranging from because they wanted to and because their parents wanted them to. Two of the young people circled that they wanted to, three because they were asked to and one because their parents wanted them to. This information reassured me for the most part that the young people were not feeling pressured into participating and allowed me to reiterate that they were free to withdraw at any

time without prejudice (Mamotte and Wassenaar, 2015). Cocks (2007) emphasises that consent is not something that is obtained at the beginning of the research and then set aside. Thus, care was taken to ensure that the young people continued to be willing to participate by asking them at each stage of the research.

3.16.2 Adult Consent

Parents were fully informed of the research, both in terms of what their own and their child's involvement would entail. This was accomplished following their responses to an advert that was posted on charitable social media pages and websites. Posting an invite to participate on a public forum had potential for the parents to engage in private talk in a public space (Williams et al., 2017). To counter this, respondents were instructed to respond to me directly via private message to signal their interest in the study. I then sent them information leaflets, one for themselves (see Appendix 11) and one for their child to read through, either by post or email or went over them during a face-to-face meeting with the parent(s).

School staff were provided with information leaflets via email (see Appendix 12) and for those being interviewed face-to-face, information was explained verbally in addition to the leaflets detailing the aims of the study, the methods used, what their participation would involve and how the data would be stored analysed and disseminated. Written consent was obtained via an accompanying consent form, which clearly stated that they have the right to withdraw from participating at any stage without prejudice. The first point of contact for the school was the Head of Pupil support who offered to send my email to colleagues. It was made clear that any colleague wishing to participate via email should send their contributions directly to me to ensure confidentiality (McCoyd and Schwaber Kerson, 2006).

3.17 Confidentiality

The decision was made to use five schools that represent a variety of settings (small, large, one with an autism unit attached, one rural) and not those that are necessarily linked to the pupils and parents. This allows for anonymity and confidentiality and enables all of the participants to speak freely without fearing repercussions or having their participation impact on their relationship with each other. Including various local authorities in the study brings multiple approaches, policies and ways of doing things than limiting the research to just one or two. Moreover, as some schools in each local authority had an identifiable feature, such as an autism unit attached, this would potentially identify families who attended such a school.

It was anticipated that confidentiality may be tricky to manoeuvre within the home setting. As well as being disruptive and distracting to the interview process, interruptions in the home setting have implications for confidentiality insomuch that family members/guests may overhear the interview (Bassett et al., 2008). Moreover, it is questionable if it is ethical to leave the recording equipment running when others enter the home (MacDonald, 2009). Confidentiality can also be difficult to maintain as a consequence of parents' curiosity and concern for their child (Fargas-Malet et al., 2010). For example, parents may ask about the content of the interview, which can result in stress for everyone concerned (Bushin, 2007). During data collection in participant's homes, distractions were minimal. Occasionally, a cat would jump up on my knee or a dog that had been placed in another room for the interview to take place would bark for attention. During one joint interview in particular, one of the interviewees (parent) left to take one of their children to school. However, otherwise, interviews conducted in the home were straightforward and unproblematic. In terms of confidentiality, I ensured that all interviews with the young people were conducted while their siblings were not at home. This proved to be fairly straightforward as many of the young people being interviewed were often unable to attend school due to their anxiety and so I interviewed them during the day while siblings were at school. However, while conducting one parent interview, the young person arrived home from college and sat in the next room (kitchen) eating dinner. During this time the parent spoke quite loudly about how she has struggled with her child's diagnosis and the negative impact it has had on her life since. I was aware that her daughter may be overhearing this and felt extremely uncomfortable, but I struggled to find a gap in the conversation to suggest we wait. All future interviews with parents were conducted while the young people were not at home to avoid this situation reoccurring.

3.18 Recording Data

The data from the pupils was recorded in a variety of ways. For example, the 'About School' Exercise and the structured school diary was completed by hand and therefore produced written data. Moreover, some of the follow-up interviews with the pupils and interviews with school staff were conducted via email, again producing written data. Data sent via email was saved, anonymised and stored securely alongside the other data and then the emails were deleted (McCoyd and Schwaber Kerson, 2006). Face-to-face interviews with pupils, parents and school staff were audio recorded. Recorded audio data was transferred to a secure password protected computer and transcribed no later than one week after it was conducted.

The original recording was then deleted from the recording device (McCrae and Murray, 2008). The data collected from informal conversations with parents were typed up immediately after each visit to the field. All transcripts were stored in a locked cabinet.

3.19 Constraints on the research

In hindsight, the time-scale of this research was limiting due to the lengthy process of accessing schools and gaining approval. There was also some difficulty in recruiting school staff, classroom teachers in particular, whose perspectives would have benefitted the research a great deal. Additionally, following a leave of absence due to illness I returned to my research with the purpose of reconnecting and writing up, while also juggling chronic illness and the subsequent treatments. This got off to a good start, however shortly after returning from my leave of absence things were thrown into chaos with the Coronavirus situation. I was extremely fortunate that I had completed fieldwork prior to this outbreak, nonetheless, it had implications for analysing my data and writing up my thesis. For instance, as well as being distracted by the situation, lockdown meant being affected both practically and emotionally. Living in a middle flat between large families with children who were not at school due to the pandemic meant that noise levels impacted on my focus. Emotionally, being in the shielded group meant that I was unable to spend time with close family and had to mentally adjust to not leaving the home for a very long period of time. Thus, these external factors limited my motivation and progress.

The following four chapters demonstrate how the application of the methods used in this study produced findings in relation to the research topic. This is followed by a discussion chapter which explains the results of these findings in more depth.

CHAPTER FOUR
Findings: Pupil Challenges and Support

"I like learning but sometimes things get in the way".
(Oliver Biggs, Age 12, Diary)

This chapter presents data produced in response to research question 1: What challenges are pupils, parents and staff faced with in relation to school?; and research question 2: What support is available to autistic pupils, their parents and school staff? This chapter specifically presents the pupils' experience of challenges and support, however data from all participant groups are included.

4.1 Overall Experience of School Life

The pupils in this study are faced with the challenges of communicating with teachers and other pupils, both in the classroom and during social times such as interval and lunch. Moreover, the many changes throughout each day in secondary school differs greatly from the routine of primary school, and can be problematic for the young people, as one staff member conveys:

> *My biggest concern is that for some, the secondary environment can be very challenging and undo some of the great work that is done in the earlier educational experience.* (Deputy Head Teacher, LA2: Sch.2)

In secondary school, classes are not taught in the same room with the same people for the whole day, every day, but rather are divided into separate classrooms with different teachers and fellow pupils throughout the school week. It is clear in the findings that individual classes or the subjects taught within them, each teacher and/or group of fellow pupils has the power to impact negatively, or positively, on the pupils. For the autistic pupils in this study, the location of their seat, how they access the room, and the teaching style or personality of the teachers themselves all shape this experience:

> *For him we have had to look at things like who sits next to him in the class and he even picks up on teachers' voices and things and I think things like that make a big difference for the kids*. (Gaynor Morgan, Parent)

On the other hand, classes that are more enjoyable may make school more tolerable, if only for the time that is spent in them. For example, when asked what they liked about school, the following pupils highlight specific subjects or classes:

> *Computing science because it's something I like to do. I like the subject and time spent on computers.* (Jason Gray, Pupil: Age 17, Diary)

> *I enjoyed going to my favourite subjects (Art, English, and History).* (Christina Grant, Pupil: Age 18, About School Activity)

However, it could also be considered that problems arise when classes that are perceived to be both enjoyable and unpleasant to the pupils are delivered on the same day. This influences how the pupils in this study experience their school day, or how they anticipate that their school experience will be that day. For example, on a day that includes classes that are not enjoyed, or that some pupils particularly struggle with, this can affect how they experience, or perceive that they will feel for the remainder of that school day. This can create feelings of apprehension or anxiety which then negatively impacts on their school attendance:

> *When we've had meetings with parents it's about certain subjects. And that young lady[8] I was speaking about who has come out another class, that might be an issue for another few days or a week where she's maybe not in maths because of that incident. So, the anxiety in my experience here is that its more to do with individual classes as opposed to coming to school as a whole.* (Mr Fairns, Deputy Head Teacher, LA2: Sch.2)

The anxiety associated with the classes that the pupils dislike may mean missing out on the ones that they do value, if they choose not to attend school that day to avoid them. However, the above quotation does not necessarily resonate with the pupils views insomuch that coming to school as a whole does create most of the challenges that are experienced by the young people. Individual classes is only one of these challenges that may create anxiety. For all but one of the pupils, school is a place that they do not enjoy attending and one that instils feelings of fear and anxiety. When asked what they thought or felt about school, the pupils' overwhelming responses were of a negative nature:

> *Something to endure.* (Jason Gray, Age 17, Diary[9])

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[8] During the interview with Mr Fairns he received an email to say that a female pupil had walked out of class.

[9] An altered diary was created for Jason as he did not like the diary format in its original form – particularly the emoticons.

School is bad, like really bad. When I get to the school building overall I am sick (Mark Morgan, Age 14, Diary)

For Mark, school is an environment in which he feels overwhelmed by sensory issues in the classroom and in the school building, of standing out from others as being different and by being surrounded by other pupils during social times at school. Ultimately, he describes school, as do most of the participants in this study, as a place where he does not feel safe. When asked what he would want others to know about how school is for him, Russell (Age 13, Diary) wrote that he wishes others knew "How scary school is for me with all the kids and noise and info!". These quotations paint a sobering picture of how school is experienced for the young people in this study. The first half of this chapter unpacks these experiences in more detail before going on to explore the support that the pupils currently receive.

4.2 Need for Stability

It is clear from the data that there is a need for routine for the young people in relation to school. Stephanie (Age 16, Follow-up Interview) stated that "I've got a plan of the day, but like something different could happen and that worries me." The need for routine, particularly on school days, is so significant that the upset caused when routines are disrupted can create an immense amount of turmoil:

… a few weeks ago he was supposed to have food and health and he had his form ready to hand in. They decided that they were having a morning of technical work rather than food and health, so it threw him completely… So he was in a cracker of a mood that night… He doesn't like change. (Rebecca Griffith, Parent)

I have one wee boy who is very much a stickler for routines and rules and that has always been a way that he has coped with his anxiety. To know that his day will go in such a way and the rules will be followed by everyone. He gets very frustrated at times if other people don't follow those rules. (Mr Martin, Head of Pupil Support, LA3: Sch.1)

The parents convey that they tailor routines and preparations to suit their child and to better support them cope with the challenges and potential changes of school:

School days we've got both their timetables up and we'll talk about it the night before about what their next day ahead is going to look like. Neither of them handle change… and we have got our contingency plans. We normally have two so that if

> *that doesn't work they go to that and if that doesn't work this is their fallback. Which is normally, phone me and I'll come and get you.* (Gaynor Morgan, Parent)

It is important to demonstrate that this need for routine is consistent throughout the young people's lives and is not only related to school. The following quotation shows that while routine is still implemented at home on non-school days, they are somewhat more relaxed:

> *It's almost like it's a regimented day, the school day. I feel much more dominant as a parent on a school day as at the weekends cause he's a young man now, so you've got to let him have his own time and stay up to three o clock in the morning if that's what he wants to do.* (Susannah Gray, Parent)

The reason for less rigid routines at home is likely because there are less opportunities for 'unpredictable' changes to occur that could throw the young people's sense of stability as opposed to those at school. Moreover, they have their own space within the home to recover and recharge from anxieties surrounding change. Thus, weekends and holidays can be differentiated and slightly more laid-back for both pupils and parents. The observations regarding the stress that the pupils experience due to changes in routine were mostly articulated by the parents and staff, and not by the pupils themselves. This demonstrates the importance of educating staff on the needs of autistic pupils and also that communication is key between parents, staff and pupils so that these difficulties can be made known to the relevant person. It also supports the decision to include parents in the current research because it offers insight into particular struggles the pupils experience that may have been overlooked had the research relied solely on the pupils' data.

4.3 Adapting to Change: Transitions

Adapting to change was a challenge that was directly addressed by parents and staff but that also emerged in the pupil data. Transitions that arose within the data are returning to school after a period of absence. Being away from school removes various pressures from the young people and their families. However, losing the momentum of attending school can be problematic. Mark (Age 14) explained in his follow-up interview that he did not get much sleep on the Sunday before school on Monday. When asked if school is worse following a weekend he replied "Sometimes. If I've been to school on the Friday, then it's not so bad". Thus, having a more prolonged period of time away from school can impact a great deal on the pupils returning. This is worth considering for autistic pupils following a long weekend and term breaks. One parent (Gaynor) suggested that having meetings with her children

(Stephanie and Mark) and a key staff member prior to school beginning can help with transitioning to school after holidays. This illustrates how enabling autistic pupils to familiarise themselves with their surroundings is a key element of support. However, these micro-transitions do not appear to currently receive the same level of consideration that the transition from primary to secondary school does. Transitioning from primary to secondary school (macro-transitions) were discussed in all face-to-face interviews with school staff and conveyed similar measures of support as those of Mr Martin:

> *So my role is often to start meeting with young people and their families and the primary school staff as the P7 year goes on to organise additional visits. We know that for a lot of pupils on the autism spectrum the high school environment can be quite challenging in terms of its size, the sensory information that's going on, the new people, the change to routine so we do quite a lot through transition to get used to the high school routines…* (Mr Martin, Head of Pupil Support, LA3: Sch.1)

Transitions was also raised in staff email interviews. This indicates that staff recognise this as an area of need for the young people and the importance they place on supporting autistic pupils through their transitions. This support begins before the pupils even reach secondary school, which stresses the importance of being formally identified as autistic before or during primary school. Concerns around further transitions that occur for autistic pupils during secondary school were raised by school staff. For example, Mrs Couper (Head of Pupil Support, LA1: Sch.2) explained that support for autistic pupils who are continuing to struggle with secondary school life, particularly in their first year, can be extended. Mr Martin relays how some pupils require support as they transition from one year group to the next:

> *I've seen it around school in different contexts where we run nurture groups until the end of second year and not in S3. And some pupils have that experience, not necessarily kids with autism, but they felt a form of support they had come to rely on a little bit was taken away.* (Mr Martin, Head of Pupil Support, LA3: Sch. 1)

Mr Martin's quotation suggests that transitions from one year group to the next, is not as supported as the transition from primary to secondary school. It appears that there is more recognition of it now than perhaps was previously the case, but there is no solid approach as yet to help support the autistic pupils in this way. However, new approaches are being introduced to assess their effectiveness. Mr Martin (Head of Pupil Support, LA3: Sch.1) explained that the sixth year pupils who volunteer for the buddy scheme are trained to support pupils who may be struggling in secondary school. Thus, awareness of and concerns

about autistic pupils transitions within secondary school is on some of the staff agendas. Moreover, it draws attention to innovative forms of help that are being tried and tested to help support autistic pupils navigate their time throughout secondary school. However, this related to one school in particular and not across the remainder of the schools included in this research.

4.4 Sensory Overload

School presents more sensory challenges to autistic pupils than most other areas of their lives due to it being a large environment occupied by many people. This makes it more problematic to make allowances for the pupils than those that are made for them in the home environment (discussed later and in Chapter 5). For all of the young people, noise and crowds create the biggest challenges when attending school:

> *Things I don't like about school - People, it's very busy in the halls and classrooms.* (Stephanie Morgan, Age 16, About School Interview)

> *I don't like - groups of teenagers. The noise and the narrow spaces for walking about.* (Russell Griffith, Age 13, Diary)

Despite one of the participants (Oliver, Age 12) voicing that he generally enjoys attending school, and it is worth noting that he was the only pupil in this study who did feel this way, he still experiences issues with crowds and noise and unruly behaviour. He wrote in his about school activity that "It does get annoying sometimes because the queues just get claustrophobic. People cut in line". Stephanie (Age 16, Follow-up Interview) explained that being pushed around in busy halls and corridors made her feel "anxious and stuff". This is particularly problematic given that getting from class to class is an unavoidable element of secondary school. Moreover, some schools will be busier and noisier than others depending on size. Several staff expressed that school size can matter in terms of knowing the pupils' needs, including their sensory challenges:

> *Because we are such a small school everybody knows each other and if any child does have a particular difficulty, the children are very tolerant and support each other.* (Mrs Couper, Head of Pupil Support, LA1: Sch.2)

The above quotation underlines how important a smaller school is for pupils and staff to know, understand and help autistic pupils (Osborne and Reed, 2011). Mrs Rea (Head of Pupil

Support, LA2: Sch.1) identifies that parents can worry about how their autistic children will cope in larger settings. It could be argued that a smaller school would allow staff to be more aware of, and have a deeper understanding of, pupils' individual challenges with sensory experiences. Additionally, there would be less people around, which would perhaps lessen the sensory issues around noise. Many of the young people themselves mentioned that being able to attend a smaller school would improve their school experience. However, the option of attending a smaller school was not available to all:

> *It would probably be less busy, but I'm not allowed to go*. (Stephanie Morgan, Age 16, Follow-up Interview)

Interestingly, the option of transferring to another school was not available to Stephanie but is being considered for her brother Mark (Age 14). This is partly due to Stephanie reaching the end of her secondary school education and because she presents with different needs to her brother. Nonetheless, it is important to consider the tensions that this may cause at home between siblings and with parents in similar circumstances. However, all of the young people in this study who currently attend various sized schools communicate that noise, and busy enclosed corridors and classrooms present them with challenges. Smaller sized schools may possibly help with some sensory issues for some autistic pupils, but it will not remove the challenges altogether. For instance, the classroom is a space with fewer people than the shared public spaces, yet it still presents sensory problems:

> *There are kids that really struggle and just can't cope with the pressure of being in a classroom with other kids and sensory issues and stuff.* (Debbie Grant, Parent)

For the autistic pupils, the classroom is a space made up of many distractions and anxieties that prevent them from learning as effectively as their PNT classmates. Stephanie (Age 16, Follow-up Interview) expressed that she cannot concentrate if the classroom is too noisy and is unable to get any work done. Mark (Age 14) has a similar experience:

> *If it's noisy I can't really concentrate. Cause I'm just thinking about the noises that are in the class. If it's quite quiet, I normally zoom through my work… It just makes me a bit agitated.* (Mark Morgan, Age 14, Follow-up Interview)

The difficulties mentioned above represent some of the more obvious noises that can be challenging for the young people. However, sensory issues around sound are not always linked to volume. The sound and/or tone of specific teachers' voices as well as the volume at

which they speak can not only create sensory problems for the autistic pupils but can also instil feelings of fear:

> *Sometimes Mark, if the persons got a voice that grates on him he doesn't study as well...* (Gaynor Morgan, Parent)

> *English teacher - he's too shouty! I don't like people shouting or sudden loud noises.* (Russell Griffith, Age 13, Diary)

While some of these concerns[10] are not dissimilar to PNT pupils who may not always enjoy both the subject and the teacher or the other young people in their class, and while others with different needs could also benefit from smaller class sizes, autistic pupils have additional anxieties. For example, they have the added apprehensions of simply attending school, of not fitting in, and the various sensory challenges that have been previously outlined. Part of the predicament for autistic pupils experiencing sensory and other issues in class, is that they are not always obvious to the teacher. This is one of the areas where a parent's input is helpful for pointing out the issues that they know their child is experiencing that are perhaps not so obvious to staff:

> *Parents can give more information on the sensory difficulties that pupils have so plans can be made.* (Mrs Rea, Head of Pupil Support, LA2: Sch.1)

This assertion was supported during the parent interviews as they acknowledged that many areas of school life posed broad sensory issues for autistic pupils, with some detailing more specific challenges faced by their children. For example, some parents disclose that particular smells can be distracting, while for others the material of the school uniform can be unbearable:

> *Smells are another big thing that affects how Mark is going to learn. And I don't think they realise how much of these things do affect him.* (Gaynor Morgan, Parent)

> *... home economics... I mean probably he would pick up an orange and touch it but don't ask him to peel it cause when the smell comes out he'll be retching... He wears joggers to school instead of trousers because he can't handle the material... if he*

[10] PNT pupils could also experience many of the sensory issues mentioned in this chapter, however what differentiates them is the prolonged and sustained impact that they have on autistic pupils, in addition to the other challenges that they experience. Moreover, taking all of this into account, the recovery time for autistic pupils may take longer than it would PNTs.

> *touched them he'll have goose bumps and you can see him tense up.* (Rebecca Griffith, Parent)

The difficulties that Russell experiences in relation to his school uniform and smells were not raised directly by him during data collection, but via his parent's interview. This was the case with some of the other pupils' sensory issues, reinforcing the importance of the parents input into their child's school experience, their understanding of their child and their ability, and opportunity, to communicate this to school staff. Nonetheless, regardless of contacting the school, and making their child's concerns known, the parents express how they perceive that the classroom teachers in particular lack an understanding of sensory problems:

> *There's a teacher that keeps going on about him wearing jeans and won't let it go. The teacher doesn't really understand, to her just following the rules, to him, it's a huge big thing. (*Gaynor Morgan, Parent)

School staff knowing about an autistic pupil's sensory matters does not always equate to understanding them. Therefore, educating school staff about the experiences of autistic pupils in mainstream secondary school is key to their support. However, it is important to understand that even if some of these issues are prepared for, despite parents and staff's best efforts to identify them, and make exceptions for them, there are some challenges that it is not possible to eliminate in a mainstream school. For example the school bell can create stress and anxiety in itself, and more so because it then results in the corridors being filled with other pupils going to and from classes:

> *Mark was in at the meeting on Thursday and came out just as the bell went so he hid in at the door, and I stayed with him. There had been loads of folk at this meeting and everybody else just walks off. Whereas Mrs Harley stayed with us cause she knew Mark and it doesn't take Einstein to figure out that he's upset.* (Gaynor Morgan, Parent)

Communication and relationships are important for delivering effective support for autistic pupils (see Chapter 7) as evident by the quotation above where Mrs Harley, Head of Pupil Support, understood Mark and his challenges and how to respond in that moment. These findings highlight that sensory difficulties are a significant barrier to autistic pupils' education in a mainstream setting. They impact on the pupils' ability or desire to attend school and on their productivity levels while there. These challenges are not solely related to

the classroom and corridors but are particularly problematic in the shared social areas of school, especially those that are occupied during interval or lunch.

4.5 Sharing Social Spaces

Typically, young people learn how to do relationships in shared spaces, primarily with their families and then during nursery, primary and secondary school. The latter is a space in which they discover the groups they are more drawn toward or belong to more than others. This is something that can be particularly difficult for autistic pupils:

> *During break/interval I don't like… Feeling sad, alone and isolated all the time. Not being able to talk to people and make friends (segregated groups and being judged for trying).* (Christina Grant, Pupil: Age 18, Diary)

> *Break I don't like… it being busy. No friends to spend time with. I have no one. It's like I like to be alone, but I don't like to be lonely.* (Stephanie Morgan, Pupil: Age 16, Diary)

Christina mentions how she is judged or left out so often feels isolated. For Stephanie, who does not particularly want to spend time with others, she nonetheless dislikes feelings of loneliness; emphasising the complexity of social spaces and interacting with other pupils. For Russell (Age 13, Diary) during interval he likes "meeting up with friends and having a snack" but does not like "the large groups of teenagers. The noise and small spaces are too much". Mark's comments below can seem quite contradictory or confused:

> *Things I like about school, Break and lunch.* (About School Exercise)
> *Break time, I don't like… anything*. (Diary)
> *I like getting out with friends and seeing them at lunch and going for lunch with them and talking to them.* (Follow-up Interview) (Mark Morgan, Pupil: Age 14)

However, it could be suggested that in the wider context of school, interval and lunch time is perhaps more favourable to Mark than the time spent in classes. Individual friendships can be positive for the pupils. However, integrating with other pupils in general during social times can be problematic as some autistic pupils' struggle to form friendships. As the above quotations make clear, these difficulties may be due to challenges in talking to others or through being rejected by other pupils. Lunch time repeats the issues encountered during interval but are endured over a longer period of time. It can also present additional sensory

issues. Oliver (Age 12) wrote in his structured diary that he does not like standing in the big queues to get his food[11]. For Mark, the stress is so great that he is sometimes physically sick:

> *Sometimes at lunch I am properly sick after I have had my lunch and that because I am so stressed.* (Mark Morgan, Pupil: Age 14, Follow-up Interview)

Mark's quotation draws attention to how the stress of secondary school not only affects him mentally, but also physically. Autistic pupils can stim to help calm themselves down or concentrate. Mark's mum Gaynor explains that "he plays the tapping games for his stress and they said he can do that in class… he does tap on his leg". Some pupils are often unaware that they are stimming:

> *Jason came home 'mum, my teacher said that I've to stop doing this thing but I don't know what I'm doing'. Basically, he was stimming and the teacher went, 'stop that' and he went 'stop what' and the teacher went 'you know what you're doing' and of course he doesn't so you are like, do these teachers have any training about what that means.* (Susanna Gray, Parent)

As with Susanna, some of the other pupils and/or their parents mentioned stimming behaviours in their interviews. They also discussed that these behaviours can often be interpreted as not following the rules or can make the pupils stand out if they openly display them. Thus, a practice that helps to ease difficulties in school can also create further challenges for the pupils. When asked about the parents and pupils' concerns about the consequences of stimming, some staff responded that they had not experienced this, particularly not in the autism base. Other staff commented that how teaching staff respond to stimming can be down to the individual teacher. One Support for Learning Assistant (SLA) commented that teachers are understanding of stimming:

> *Teachers in this school are generally very understanding of pupils with Autism, as they are used to them coming into their classes.* (SLA, LA1: Sch.1)

Mrs Couper (Head of Pupil Support, LA1: Sch.2) expressed that she would be horrified to think of anyone experiencing negative consequences as a result of their stimming in

[11] Oliver's mum makes him a packed lunch to ensure he eats if hungry. However, Oliver has a particular preference for the hotdogs on offer at school and is disheartened after enduring the sensory issues surrounding the lunch queue to most often none being available.

class. However, many of the school staff, like Pupil Support Worker (LA2: Sch.1) conveyed that they had “definitely observed this in some classes”:

> *Imagine a teacher’s off, a cover teacher steps in at the last minute and doesn’t know the pupils. Things like that can happen and can be quite damaging, especially if it’s a kid who being back in that class has been a big deal for them and that’s a coping mechanism and then they are told off about it. So aye, I recognise that and that’s certainly happened here.* (Mr Martin, Head of Pupil Support, LA3: Sch.1)

The above quotation raises how difficult it can be to understand a pupil’s struggles if the pupil and teacher are not known to each other. In doing so it also reveals the importance of relationships for supporting autistic pupils (Chapter 7). The quotations from pupils, parents and staff indicate that social times heighten sensory issues and are extremely challenging for autistic pupils. They also reveal that there are misunderstandings around coping mechanisms, stimming, and that these can vary depending on the individual teacher. Such misunderstandings, however, are not solely linked to the pupils’ sensory issues but point to a need for a deeper understanding of other autistic ‘traits’, ‘behaviours’ and needs in order to better support autistic pupils in mainstream secondary schools.

4.6 Consequences of Misunderstanding ‘Autistic Behaviour’

The pupil/teacher relationship does not always play out positively in the classroom and it was relayed via parent interviews that some pupils find themselves in trouble for not understanding the rules. For example, some pupils ask for help understanding the work or speak out without putting up their hand or waiting their turn:

> *A teacher said to me he keeps shouting out in class, and he keeps saying the answer and not putting his hand up. I went that’s because he is desperate to tell you and he doesn’t have the processing to slow it down to think I’ve got to put my hand up and I’ve got to wait until he says my name.* (Louisa Biggs, Parent)

Louisa was referring to a classroom teacher in the quotation above. School staff interviewed in this study were predominantly made up of learning support staff. The views of classroom teachers are not included, despite attempting to include them in the research. Staff members, like SLA (LA1: Sch.1) convey that classroom teachers in particular need to have more understanding of autistic behaviours and appreciate “more that language or habits used by a pupil on the spectrum are not meant to be offensive - it's just how they communicate”. One

area identified by parents and staff that needs to be understood is that it is common for autistic pupils to interpret things literally:

> *They have to understand that they don't take jokes, they don't take sarcasm, they take it literally… hold your horses things like that. Cause they are thinking, what do you mean there's no a horse anywhere here.* (Louisa Biggs, Parent)

> *I remember a pupil was standing in the doorway and the teacher said can you move and then they didn't do it. We had the parent in, it's because the teacher didn't say please… they won't even pass the sauce to me at home unless it is 'can you please pass the sauce'.* (Mr Fairns, Deputy Head Teacher, LA2: Sch.1)

The above quotation also recognises the role that parents play in communicating between their children and school staff (see Chapter 7). Had the parent not being able to translate the difficulties of that particular situation it could have remained unresolved, causing difficulties for the pupil and the teacher. Mrs King (Principal of Pupil Support, LA1: Sch.1) explains during her face-to-face interview that due to the literal interpretations and different ways of processing, additional time is needed for some autistic pupils. Overall, being misunderstood has negative consequences for the autistic pupils and impacts on their education alongside their mental health and well-being.

4.7 Masking, Isolation and Victimisation

One of the consequences of school staff failing to understand autistic behaviour is that some pupils are having to mask, alter or supress their behaviours in an attempt to fit in. However, this can have the unintended consequence of not appearing to require support. This lack of understanding can mean that the pupils' needs are often overlooked or dismissed:

> *In school the teachers would always be there waiting hand and foot on those who were severely impacted by autism. However, when I would ask for extra help I was more often than not told to figure it out on my own. If you don't have an obvious mental or physical disability you're seen as a normal 'shy' person who doesn't need a lot of extra help.* (Christina Grant, Age 18, Follow-up Interview)

> *I think a lot of the thing is he wants to please. He's a good boy, he doesn't kick off, he doesnae throw chairs, so that's why they don't give him any support. What they don't understand is that it's taking out his uniqueness. It's taking out his… colours.* (Louisa Biggs, Parent)

Christina's quotation suggests that she is perceived to be 'not autistic enough' for support and Louisa is conveying that because her son is masking to fit in, he is not being his true self in the classroom. The real needs of the pupils, therefore, are not being recognised or identified by teaching staff and as a result are creating difficulties for the pupils and their education. PNTs can also experience feeling misunderstood and not included among pupils, however, autistic pupils often face stigma and are labelled as different which can make them vulnerable to being excluded:

> *Feeling isolated. Feeling as though I had "has autism" tattooed on my forehead and people would be judging me but not showing it… The vast majority of people at my school whom I would try to be friends with would shut me out as I wasn't the same as everyone else… And I felt like it was my fault that people didn't like me or accept me.* (Christina Grant, Age 18, Diary)

Mark (14) also indicated that he felt left out and different to other pupils and expressed in his diary that it would help him if he were normal. When asked to describe what he meant by someone normal in his follow-up interview he responded "Someone who gets along with everyone. Knows how to make friends and don't stress about everything*"*. This statement suggests that Mark relates the ability to form multiple friendships as 'being normal'. One staff member, Mrs Couper (Head of Pupil Support, LA1: Sch.2), explained during her interview that she observes how friendships that were developed at primary school between PNT pupils and autistic pupils fall apart at secondary school. She speaks of one boy in particular who is now noticing that friends no longer want to play with him and are distancing themselves because of his behaviour. Mrs King elaborates on the type of behaviours she has seen displayed by autistic pupils that may contribute to these fallouts:

> *Yesterday, one child had gone into the personal space of another, and the child whose space had been invaded, just sort of gently pushed them away, whereas the first child did it forcibly and said I will defend myself. No, you are not defending yourself because you were actually the person who invaded the space of the other person.* (Mrs King, Principal Pupil Support, LA1: Sch.1)

Despite staff awareness of the situations that can create these difficulties for autistic pupils, one pupil support worker expresses that there is no simple solution available to resolve these experiences:

We do not have a 'magic wand' that we can wave, to ensure that their school experience will be wonderful, and that they will make lots of genuine friends. Many of them have a really troubled and negative experience (in terms of fitting in with their peer group) and some become extremely socially isolated and very unhappy. Some are severely bullied by other pupils: others do not experience bullying at all. There is no simple solution to this problem. (Pupil Support Worker, LA2: Sch.1)

Nonetheless, this is an area of school life that parents and staff take extremely seriously. As one SLA (LA1: Sch.1) expresses "Fitting in and having friends can be a huge boost for self-esteem and have a negative impact if social inclusion is a problem." Christina shares how she enjoyed specific classes because she felt included:

I enjoyed social dancing in P.E. as I felt that I was a part of something with people I usually wouldn't talk to… no one was left out. (Christina Grant, Age 18, Follow-up Interview)

When Christina was asked to describe how she felt when other pupils did avoid her and isolate her she responded that she felt "Horrible, unwanted, ashamed of who I was." She went on to explain that if the pupils understood her better that it would have made her school experience "much more happy and enjoyable". Her mother speaks of the exclusion that Christina experienced:

Completely excluded, to me is just as bad… she walks to a building nearly every day with 300 people in it and not one of them speak to her, not one of them ask her if she's alright. (Debbie Grant, Parent)

One parent (Gaynor) explained during her interview how important it is for her son not to stand out and be seen as different and that he avoids it where possible. She conveyed that he also refused some forms of support, such as an amended timetable, because he did not want the stigma attached with it. Another mum, Susannah, asserts that certain areas of the school are associated with pupils with additional needs and that these have negative connotations that create a divide between PNT pupils and autistic pupils:

The way Jason's school is when the kids come up from the [support] wing, you don't even want to know the names they call that Wing. Straight away it's a joke and those kids are targeted… so Jason wouldn't even go anywhere near it because he already knew that association. (Susannah Gray, Parent)

Measures that are implemented and designed to support autistic pupils in secondary school, at times have the opposite effect of excluding them further. When asked how important it was that the pupils fit in at school, the overwhelming message, such as that from one Deputy Head Teacher (LA2: Sch.2) is that pupils should be able to "fit in as 'who they are' and with the relevant support". This view is supported by all parents in this sample and is summarised by Rebecca:

> *I think there is an element that is important that he fits in, but I also don't want him thinking that he has to be the same as everybody… The head teacher from his old school had always said that he is like a square peg trying to fit in a round hole… So there's an element that it is important that he fits but only for education. I don't want him to change, I wouldn't change him, not in the slightest.* (Rebecca Griffith, Parent)

One parent acknowledges that the value she places on her son's friendships is likely to mean more to her than it does to him:

> *Oh god don't get me crying. It's really important for me that Jason fits in at school, but, I don't think it's that important to Jason. As a neurotypical, I want him to make friends, I want him to be in clubs, I want him to not be bullied at school and I don't want him to be isolated and I don't want him to be the weirdo kid… Jason's not got any friends in school… And for me that's heart-breaking, but for Jason, not so much.* (Susanna Gray, Parent)

Susanna highlights the importance of friendships for PNTs and what being included typically looks like. The following quotation recognises that inclusion may look different for autistic pupils and all is sometimes not what it seems:

> *I think each young person is very individual. I think what my perception is of fitting in might not be their perception of fitting in and certainly… to the other adults round about them they might look as though they are isolating themselves socially but in actual fact they are perfectly happy and that's their method of calming themselves down if they are feeling agitated.* (Mrs Couper, Head of Pupil Support, LA1: Sch.2)

Stephanie (Age 16, Follow-up Interview) supports the above viewpoint and succinctly illustrates the complexities of friendships and fitting in when she says "I have no one. It's like I like to be alone, but I don't like to be lonely". It could be suggested that these misconceptions surrounding inclusion, alongside the communication difficulties that the autistic pupils may be experiencing can make it extremely difficult to gauge a pupils circumstances. The majority of the parents and staff believe that fitting in should not be about

changing who the pupils are. This is not how it has played out for the autistic pupils in this study. Moreover, measures designed to offer support to the pupils have made their differences stand out and has resulted in many of the pupils becoming the targets for bullies:

> *School is a lot better now but in the past it was hard, other kids weren't that nice, teachers didn't always help with 'situations' with kids.* (Jason Gray, Age 17, Diary)

> *I don't like - the bullies! They call me names and it makes me sad. It would help me if - bullying was stopped!* (Russell Griffith, Age 13, Diary)

Christina expresses below how bullying was dealt with quickly at school. However, this did not result in her being included in friendship groups or that bullying did not reoccur:

> *Bullying was dealt with quickly… There was no instances of physical bullying, however I was somewhat cyber bullied and accused of things that weren't true… Most of the time people have just been horrible to me wither that's directly or indirectly.* (Christina Grant, Age 18, Follow-up Interview)

Lawrence and Gaynor Morgan (parents) both discussed during their joint interview how their son Mark was a target for bullies which heightened during a P.E. class. During this lesson another pupil pushed him into the shower, fully clothed and with his school bag. Afterwards they made fun of him the throughout his class. This was particularly devastating for Mark because this was the one class that he enjoyed and was attending in the mainstream. Another parent shares her child's experiences of bullying:

> *… numerous vile names for him because you're autistic so you are different, he's had them all. He's forever coming home and saying am I gay? Shouldn't I go to that school because this boy said you shouldn't go here you should go somewhere else because you don't belong here… he finds that quite tough.* (Rebecca Griffith, Parent)

It can be taken from the above quotation that Rebecca's son (Russell) is being made to feel that he should be attending a 'special school' and that instances of bullying occurs often enough that he questions his own sexuality. One parent mistakenly thought that bullying would come to an end when her son started secondary school:

> *For Jason it was great because the people that had bothered him in primary were no longer there. He was a fresh start nobody knew him, then the bullying started and… you find out he's getting his bags ripped off him and at break and lunch people are jumping on top of his head.* (Susanna Gray, Parent)

Bullying within primary school is outwith the scope of this study, nonetheless, the above quotation raises that this is also a concern. Susanna's son, Jason, had experienced bullying for a long period of time, both in primary and secondary school. Therefore, this could have contributed to his retaliation; which was not only dangerous to the other pupil, but resulted in him being punished by the school:

> *At one point my son flung something at a boy, he nearly killed him… boys had been bullying him for years and he just lost it and his meltdown happened. He had a clamp in his hand, and he flung it and he got excluded from school.* (Susanna Gray, Parent)

It is without question that the above response to bullying warranted formal reprimand from the school. However, more understanding is needed of bullying and the consequences that this may present to autistic pupils and PNTs. This is especially the case because often bullies are underhand and less obvious with their attempts to harm, physically or otherwise. On the other hand, autistic pupils may respond more openly and as a result are attributed blame. One parent, Rebecca, disclosed to me during an informal discussion at her home that there was an incident in which pupils had been calling her son (Russell) names in the playground. Russell retaliated by telling one of the boys to 'go back to his own country'. There is no disputing that any of the behaviour that took part during this exchange is acceptable, however, it was only Russell who was reprimanded and was told that the other boys' behaviour was playground banter. Some staff members discussed that bullying is subjective and open to interpretation:

> *We've got a boy who feels like he is being bullied. It's their interpretation of it. Nobody should be bullied but, they have a very narrow view on it… Bullying, they can be the bullyer…* (Mrs King, Principal Pupil Support, LA1: Sch.1)

This appears to lessen or take away from the mistreatment that autistic pupils are subjected to by some other pupils. It suggests that some autistic pupils may believe that they are being bullied but are instead experiencing 'playground banter' or general disagreements with other pupils. However, as the findings show, bullying that repeatedly occurs due to the stigma of being different and as a result being excluded from friendships, is further reaching than individual incidents. Thus, the consequences of bullying to the autistic pupil are not only immediate but can have long lasting effects.

4.8 Impact of School Challenges on Pupils Mental Health and Wellbeing

Bullying, alongside the host of other challenges autistic pupils experience in relation to school, significantly impacts on their mental health and well-being. Many of the pupils expressed how attending school made them experience high levels of stress:

> *Sometimes I wake up and I'm just feeling way too ill and too stressed and the school know that, and they started sending work home.* (Mark Morgan, Age 14, Follow-up Interview)

Mark's sister Stephanie (Age 16) also conveyed that school was just 'too stressful' and that no amount of support would change that. Some of the other pupils spoke about being sad and depressed:

> *I didn't cope well, due to the segregation of my peers and limited help from teachers and at home no one knew how to help, which made me feel very depressed.* (Christina Grant, Age 18, Follow-up Interview)

During his follow-up interview, Russell (Age 13) confided in me that during school days he was "Scared. Upset a lot, angry, sad". All but one of the parents spoke about instances where their child had attempted, or discussed, suicide. Gaynor expressed that when her daughter (Stephanie) took an overdose, she knew that the support was not working. Susanna communicated during her Skype interview how distressing it was to hear her son speak of wanting to kill himself:

> *I've had my son say to me I just want to kill myself. And to have your child say that is shocking. There's not really anywhere, I feel, for Jason to have that help. You can go to your doctor, as an adult and understand these issues. Jason doesn't.* (Susanna Gray, Parent)

Another parent (Debbie) was visibly upset during her interview as she disclosed how she had found a box outside of her daughter's bedroom with a note inside telling how she did not want to be here anymore. What this reveals is that secondary school does not only impact on the autistic pupils who attend, but that the consequences on their mental health also impacts on their parents. Witnessing the pupils' struggles can also be upsetting for school staff. One pupil support worker (LA2: Sch.1) describes pupil anxiety which she claims, "can be *really* severe for some autistic pupils and is very upsetting to observe". The most significant impact of secondary school on the pupils in this study is the degree of anxiety that they all

experience. One parent believes that this is related to the challenges they experience around fitting in:

> *I think anxiety is the driver. Cause they know they don't fit in. They know they are a square peg. If you went somewhere where you knew they really don't get me? You would be in a state of high anxiety all day all the time. That's not good for them. That's not good for their system.* (Louisa Biggs, Parent)

Pupil anxiety is also something that most of the school staff have observed. Mrs Couper (Head of Pupil Support, LA1: Sch.2) asserts that "this is not just the case for autistic pupils, but for all pupils in secondary school". Pupil anxiety can also impact on autistic pupils' education, more so because it often leads to non-attendance:

> *I would say non-attendance definitely kind of affects our kids with autism and it is very often linked to anxiety.* (Mr Martin, Head of Pupil Support, LA3: Sch.1)

One SLA (LA1: Sch.1) expressed during her email interview that she has seen non-attendance occur as a result of anxiety and that changes have to be made to help support the pupil return to school. Modifications are mostly made up of an amended timetable and accessing a separate space within the school. Such modifications were implemented for many of the pupils, however, this did little to make school more appealing. Christina (Age 18) explains that she would rather have not attended school:

> *I would have preferred not going to school at all… I only ever stayed home from school when I was physically ill as if I'd said to my mum I was too sad to go to school she'd tell me to go anyway.* (Christina Grant, Age 18, Follow-up Interview)

Likewise, Russell (Age 13) expressed in his follow-up interview that he wants to stay home all the time but that his mum makes him go. Christina and Russell's views were similar to most of the pupils in this study who revealed that if they had the choice, they would rather stay home. The findings show that time spent in school creates anxiety and distress for most of the young people in this study. By contrast, home time signifies the end of the school day.

4.9 No Place Like Home

Home is a space where the pupils can de-stress from the noise, sensory issues and anxieties that they have experienced leading up to and during their attendance at school. It is where the pupils can reunite with their families and where all have articulated is a place of comfort, a

safe zone and their favourite place to be. This was repeated across all of the data collection methods and it was clear in the young people's body language. For instance, the pupils, with whom I conducted face-to-face interviews with, would smile and visibly relax when they mentioned home. Many describe home as a space where they can relax, feel safe and be themselves:

> *On the way home from school I like - Knowing I was going back to a place without fear, isolation or judgement is the best thing. Knowing I could be myself and people would understand me. Knowing I wouldn't have to deal with people at school for a bit felt great.* (Christina Grant, Age 18, Diary)

Russell (Age 13, Diary) wrote that he liked "being back home as I feel safe and happy". The importance of home is significant to such an extent that several of these pupils control, to some degree, who enters this space. This applied to me as a researcher entering the participants' homes, as Rebecca communicates below:

> *He is wary of people. If he doesn't know who they are then he can be very standoffish and no you are not coming into my world. But Dave [pupil advocate] is obviously cool because he has been allowed in and you're obviously cool cause you were allowed in.* (Rebecca Griffith, Parent)

As much as home is a safe place for the pupils, it is not stress free. The night before school, thoughts and apprehensions about school infiltrates into this space. For some of the young people, thinking about school the following day can impact on their sleep and wellbeing. Mark (Age 14, Diary) expressed that the night before school his thoughts are often "wishing school doesn't exist". This is similar for Christina:

> *At night thinking of school the next day, I don't like - Knowing I would need to deal with all the negativities again.* (Christina Grant, Pupil: Age 18, Diary)

Parents can feel pressured in this space as they attempt to prepare their children for the school day ahead. It is a space in which they take time to ease their children's fears, which is not without its own demands (see Chapter 5):

> *Mark, his worry time is always around 11 o'clock at night and he'll come through to me and we'll try and talk it through and try and give him understanding how he can move it forward. But it takes a long time to do that.* (Gaynor Morgan, Parent)

However, it is imperative to acknowledge the importance of home being a space where the young people feel able to unload the tension of their day at school on to their parents or by retreating into their own spaces within the home to decompress. Hence, despite some strains of the day unfolding in the home, home is not necessarily the cause of the stress but a space within which the pressures and challenges that stem from school are released:

> *Yesterday was just full on and we've not had that for a while. I mean screaming hysterically to the point where I couldn't even hear what he was saying.... he will generally go to a corner somewhere and just cuddle in and scream and cry and just be inconsolable… He will come looking for me and will want a hug. And still be crying and still be inconsolable for a while but then he is exhausted after.* (Rebecca Griffith, Parent)

The above quotation refers to an incident that had happened while Russell was at school the previous day. He had been disappointed to not be selected to attend a much anticipated school trip. This information was relayed to him in the class setting and therefore he could not vent his frustrations while at school[12]. Some of the young people, like Russell, vent their school frustrations to their parents or other family members in the shared family space within the home. Others choose to decompress in the privacy of their own bedroom:

> *Just straight up the stair and into her room and shut off and disnae speak to me. She's no really physical or violent… she would just sit and greet rather than act out and punch somebody. Very internal and emotive.* (Debbie Grant, Parent)

The bedroom is a safe retreat for the young people where talk of school does not occur. The data shows that the pupil's bedrooms are generally an extremely important safe space. Lawrence (Parent) discussed how his daughter (Stephanie) changes into her pyjamas and gets into bed within two minutes of returning from school. Stephanie explained during her follow-up interview that it was a good feeling to be in bed. One mother, below, describes how her son created his own safe space within his bedroom to decompress when he returned from school:

> *I would always know what kind of day he had at school because he would interact, or he wouldn't. He would go straight into the room and he would stay there underneath his bed covers for a good hour or so and then come out.* (Susannah Gray, Parent)

[12] I witnessed his frustrations unfold as I had attended his home that evening to collect the research activities that he had completed. Russell was extremely upset and inconsolable.

Susannah's son, Jason, created this safe space within his bedroom that he could retreat to and centre himself before feeling able to communicate with her for the rest of the evening[13]. It is evident from the data that the parents recognise the importance of the safety of home for their children. In doing so, many nurture and actively create these feelings of safety by constructing routines for when they return home:

> *I tend to have his milk ready and a snack, probably crusty bread, that's what he likes. Then he needs to decompress for a wee while, so he'll go on his iPad and watch a YouTube video for a wee while or whatever and then I'll say to him, right I'm going to give you your tea and then you've got homework to do.* (Louisa Biggs, Parent)

It is unsurprising given the feelings of safety and comfort at home that all but one of the young people expressed that they would prefer to be home-schooled[14]:

> *Night before school I like - chilling with my mum and dad. Thinking about seeing my friends again. I don't like - having to go again as I worry about bullying, noise, teenagers and that I may fall. It would help me if - I could be home schooled.* (Russell Griffith, Age 13, Diary)

Comments suggest that pupils are not necessarily adverse to completing schoolwork, but that the school environment is challenging and, in most cases, distressing. The findings have shown that being at home is a place in which the young people can vent their frustrations from the school day. It is a space for them to relax from the sensory issues experienced at school and where their needs are understood and catered to by their parents. However, school impinges on this time due to the nature of preparing for school the following day practically, mentally and emotionally, and whilst doing homework. Thoughts of school while at home can impact on their sleep, mental health and wellbeing.

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[13] It is noteworthy that I had initially met with a few other families in their homes, who later decided not to continue with the research. Nevertheless, while I visited the homes, I became aware of spaces that were created for the autistic pupils. For example, in one home, a whole area of the house was set aside for the autistic siblings to relax and unwind, which was separate from their bedrooms.

[14] While the pupils anticipate that they would learn better from home, the realities of what this may involve for both themselves and their parents did not feature much during the interviews. This may suggest a certain naivety on the part of the pupils or be indicative of the lack of these conversations between parent and child and perhaps school staff.

4.10 Space Between Home and School

The journey to and from school is a space in which the young people must occupy in order to attend school. This creates multiple anxieties and challenges for them before they even begin to attempt to learn. Getting from the safety of home to the school environment is one of upset and anxiety for most of the young people. It is a space that is very public and extremely frightening. The noise of the traffic and groups of teenagers can make it an exceptionally overwhelming journey. Mark (Age 14) wrote in his diary "On the way to school I am very stressed". Russell explained that for him:

> *It's just bad. I just couldn't walk properly cause it was hurting my ears and hurting my head.* (Russell Griffith, Age 13, Follow-up Interview)

Russell also explained that he feels intimidated by school pupils, particularly if they are in large groups because "they are just scary, and they look big". Just as some of the participants attempt to detach themselves from being in social spaces in school, by listening to music through headphones, this is also a method they utilise on the way to school. For example, Stephanie (Age 16, Follow-up Interview) shared that on the way to and from school "I try to distract myself, listen to music and stuff. And not even think about it". Many expressed that they would prefer it if they could always get a lift to school so that they could avoid having to deal with the fears and challenges they experience in this space:

> *I like - my grandpa giving me a lift, so I get there safely. It would help me if - I could zoom home or fly. If I didn't have to walk or if I had a buddy to walk with.* (Russell Griffith, Age 13, Diary)

Receiving a lift is the preferred method of getting to and from school for most of the pupils. This is because it takes away the angst surrounding the noise and the fear of other teenagers. Thus, their preference is more concerned with not having to be in a space that creates challenges as opposed to having to walk. Similar issues occur for those who take the bus to school, which is seen as an enclosed space within which other pupils display unruly behaviour. Stephanie (Age 16) described in her follow-up interview that "they throw things and then it's really noisy and all enclosed". Oliver's (Age 12) mum, Louisa, communicates how her son describes the bus as being noisy and that he does not like that pupils are not nice to each other or do not follow the rules. Following the rules can be important for some autistic people. Therefore, witnessing others not doing so can create feelings of distress and

anxiety. The issues experienced on the way to school are repeated on the way home. It could be suggested however, that some of the morning anxieties are removed in that the apprehension about what might occur during that particular school day is no longer relevant. In contrast, energy levels will be much lower at the end of the school day, making dealing with the journey back home mentally and physically exhausting. Thus these journeys at the beginning and the end of each school day could be considered micro-transitions.

4.11 Support Received

When asked to share their views on what they define as support for autistic pupils, staff, such as Autism Teacher (LA1: Sch.1) expressed that "Health and wellbeing and emotional support is of upmost importance". Another autism teacher from the same school includes in her email interview that supporting autistic pupils' individual needs is what would equate to successful support:

> *Support that meets the needs of the child. Opportunities to access mainstream at times with support when relevant. If appropriate encourage other interactions in playground, or lunch hall.* (Autism Teacher, LA1: Sch.1)

For parents, successful support means that their child is enabled to fit in and be included for who they are:

> *For them to be able to fulfil their full potential. For them to not feel as if they are an inconvenience. For them not to feel different and not to have it forced upon them that they need to conform to fit in.* (Louisa Biggs, Parent)

The data reveals that some, but not all, of the pupils needs in this study are being met by schools, to varying degrees of effectiveness. The three main areas that the pupils are supported in are: support from others (parents, key helpers, advocates and counsellors); support within a separate space within the school, typically known as the base; and support in the form of an amended timetable. Above all else, the support that the pupils receive in relation to school comes from their parents, particularly their mothers:

> *My mum did everything she could to try make school more enjoyable but obviously that would only go so far.* (Christina Grant, Age 18, Follow-up Interview)

As suggested by Christina, emotional and practical parental support cannot remove the challenges completely. One mother (Gaynor) explains, some of the pupils find support from fellow pupils who experience their own challenges:

> *Mark's friend has got dyslexia and they help each other, but they sourced each other out and they help each other through.* (Gaynor Morgan, Parent)

Gaynor highlights that her son is able to offer support to friends who are experiencing their own difficulties in school. In one school in particular (LA3: Sch.1) support from pupils comes in the form of a pupil buddy scheme. All of the young people and their families spoke of a specific member of staff, mostly support staff, that was particularly helpful to the pupil and the family as a whole (see Chapter 7). Beyond this, one pupil (Christina, Age 18) received support from a counsellor within her school. She began with weekly sessions, then monthly and as she was feeling better it was whenever needed. Christina expressed during her follow-up interview that "It was helpful as I felt I had an outlet where I could speak about whatever I wanted to". Some of the support that pupils receive comes from outside of the home or school, for example, Russell (Age 13) finds great value in his support from his current and previous advocate, as his mother discusses below:

> *I have said to numerous people, you need an advocate, you really need one, it makes such a difference. And it's nice for Russell to know that someone is believing him because sometimes I think he says things and doesn't think anybody believes him and that must be horrible.* (Rebecca Griffith, Parent)

The support from others stood out as being something that is vital for helping the pupils cope with school (see Chapter 7). The challenges that autistic pupils experience in mainstream classes can be overwhelming. For some, a separate area of the school, typically named the base, is an alternative. One parent describes that her daughter (Stephanie, Age 16) is *"...* happier going into the base, there are a few small groups that she wants to be included with and that's who she goes in and spends time with". Similarly, another parent describes how it has been a retreat for her son despite his initial reservations:

> *He was very reluctant, he didn't want to do it, but it's actually been a wee haven for him and he's meeting other kids and it has definitely helped.* (Susannah Gray, Parent)

Overall, most of the young people enjoy spending time in the base, and this is a space that is available to them not only for lessons but during different times of the school day:

> *There are a number of children with ASD diagnosis in the mainstream school setting. However, the school has opportunities to support these children – allowing them to come into base setting at morning break and lunchtimes.* (Autism Teacher, LA1: Sch.1)

Oliver (Age 12, Follow-up Interview) mentions when asked what he likes or dislikes about arriving at school "I like being able to go to the base or ASN room". Similarly, Jason (Age 17, Diary) feels the benefits of having this calm space to go to when he arrives at school. The base also gives the parents peace of mind knowing their child has a safe space to go to in school:

> *I like the fact that he at lunch time can go out of the busy hall and he goes to the ASN classroom. And I like the fact that he can go into the autism base and see some of his friends. That makes a huge difference to him because he can't cope with the busyness and the noisiness of having a thousand kids in the one place having their lunch. So, I think it's good that he gets to go and can chill a bit.* (Louisa Biggs, Parent)

Mr Martin (LA1: Sch.1) informs that within his school, there are two members of teaching staff and one pupil support worker who are dedicated to working closely with young people in the support base. Furthermore, the base is beneficial to autistic pupils as it is a smaller space with fewer people. Classes are made up of smaller groups, which makes it more comfortable for the pupils, and more manageable for the staff to teach them:

> *Putting 20 autistic pupils together is not always good… they all have their likes and their dislikes and all their little ups and downs, so you can't put them all together and expect them to get on okay cause they just don't.* (Mrs King, Principal of Pupil Support, LA1: Sch.1)

Sharing space can be particularly difficult for autistic pupils, therefore it is important that school adapts to their needs and creates more comfortable environments. All groups of participants identify that the base is an invaluable resource for support, whether it is accessed on a full-time or part-time basis. However, the need for own space can sometimes mean being allocated a separate room within the base:

> *If something gets too much, Mrs Harley puts me in another room, which is good. And I could just focus on what I was doing and not think about the things around me. When I'm doing my work I always think about my work but also the things around me.* (Stephanie Morgan, Age 16, Follow-up Interview)

We have got one boy, he's actually got a wee room all of his own, it's a teeny wee room but it's got a table, chair, a computer and a place to hang his jacket and put his laptop down. And if he feels stressed at any point of the day he goes down and accesses that room. (Mrs Couper, Head of Pupil Support, LA1: Sch.2)

The above quotation reiterate the sensory and other challenges that autistic pupils experience in the company of others in secondary school and that these challenges do not necessarily relate only to large busy areas. Nonetheless, several staff see the benefit of autistic pupils accessing both mainstream and the base:

Due to a base setting, the children 'mix' with others who may have similar needs. Strong personalities can lead to difficulties. However, some children interact positively and are relaxed in the company of one another. The opportunity to have mainstream peers access the base is positive as the children in the base can wider interactions and those in the mainstream setting can learn to understand the children in the base setting more. If there are any difficulties in interactions, staff can support these or revisit difficulties through a mediation conversation. (Autism Teacher, LA1: Sch.1)

This suggests that autistic pupils can test the waters with their interactions with fellow pupils in the mainstream setting and that these can be observed and supported in the base setting. It also points to the benefits that PNTs and autistic pupils can gain by observing each other's behaviours with the hope of learning from it; something that would otherwise be missing if kept apart in separate areas of the school. The base is a resource that is also available to some autistic pupils purely as a retreat during social times at school, and not a space in which they are necessarily taught lessons. Another way that autistic pupils are supported in secondary school is to be offered a flexible timetable. Several of the pupils in this study have an amended timetable to allow them to better cope with the demands of school. Shorter school days and/or attending less classes than is typically expected of secondary school pupils could suggest that autistic pupils will be missing out on education or are not on track. However, an amended timetable allow the pupils to focus on particular subjects rather than being spread too thin and being unable to cope with the demands of a full timetable, which ultimately could result in the pupil not learning across the board. One parent describes how even small tweaks to a timetable can make a significant difference:

... he now leaves early from school; he gets out five minutes early from class so he can get a seat in the bus and he needs a seat in the bus so that he is not crammed in

> *with other people. So the school gave him a pass and that made such a difference.* (Louisa Biggs, Parent)

An amended timetable can also mean that the pupil can occupy a space within the school that they feel safer in, such as the aforementioned base. However, this does not always translate to them working or receiving an education:

> *He's got his own room in the base and he's got his phone, he can game on the phone if that's what he wants to do and then he can pick up work cause he does want to learn. I dropped him off at 9, by 20 past 9 he was texting to say can you come and get me*. (Gaynor Morgan, Parent)

Gaynor highlights that despite Mark receiving a flexible timetable this does not always remove the urge to leave school. This came across strongly from all of the pupils in this study, no matter the forms of support that were implemented. One pupil (Oliver, Age 12) enjoys school for the most part, despite the many difficulties he faces. However, shorter days, or less days at school is much preferred by him and all the other pupils. Some of the parents and several of the school staff agree that shorter days or fewer days would work better for the young people as it would allow them to recover and recharge from the days that they do spend in school. Moreover, some staff conveyed that it would allow them to better prepare for the young people's education and needs in the school environment. One SLA (LA1: Sch.1) proposed that if the pupils ended the school week on Friday lunchtime, it would give staff the opportunity to have a weekly meeting.

4.12 The Need for Tailor Made Support

The four key areas identified as support needed for the autistic pupils, by themselves, their parents and staff are: support with grades and schoolwork; support understanding social situations and life skills; helping others to understand autism; and emotional support. One Principal Teacher of Pupil Support (LA2. Sch. 2) is happy with the support provided to their pupils but also recognises the need for more family support. From the pupil and parent data it was revealed that some, but not all of the pupils, received support specifically with their schoolwork and/or help working towards achieving good grades:

> *He has the ability to work, he knows the answers, he doesn't have the confidence and we can't get from his head to his hand, so last year he had a scribe. He had to answer the questions verbally and she would scribe. This made such a difference to him. (*Rebecca Griffith, Parent)

However, Rebecca also disclosed during an informal discussion that this support, alongside the support her son (Russell) received in maths, was discontinued when he returned to his second year of secondary school. This was something that Russell himself was especially frustrated by and communicated this to me during his follow-up interview. Delays in support was a common frustration that was expressed by the parents:

> *I was told in February he was getting a Chromebook, and this is what, August. He's finished first year.* (Louisa Biggs, Parent)

Delays create stress and irritation for the parents, which has sometimes led to them offering to pay for things to help their child. For instance, one parent (Louisa) offered to buy her son's bus pass because there was a delay in the local authority providing him with one; she also paid for private speech and language therapy. Another mother explains how it would have been less frustrating to buy the supplies her son needed rather than wait for school to put things in place:

> *Tell me how many subjects he needs the jotters for, and I'll go buy enough jotters. I don't grudge the money. I just want to make life easier for him. But then to be told oh we'll see what funding we have, but they are quite dear.* (Rebecca Griffith, Parent)

Some parents do not however have access to resources. For those on a smaller income, support for their child will be reliant on that which the school can provide. This means that delays will impact on the support that their child receives; particularly in the classroom which is an area that was identified as needing more support by the following pupils:

> *More time to complete tasks. Check list to help me with steps to complete.* (Oliver Biggs, Age 12, Follow-up Interview)

> *Grades and how to cope in classes.* (Mark Morgan, Age 14, About School Activity)

Oliver and his mum (Louisa) spoke about the checklists that are created for him at home to help organise his schoolwork. This is something that was common for most of the families in this study as it offered the young people structure. For Mark, as well as help with his subjects, some guidance on how to cope within the social classroom setting is also important to him. Mark's mum (Gaynor) agrees that this is an area that both her son and daughter (Stephanie) struggle with. Staff typically agreed with this, but many expressed that each child

is individual, and some need more support with social skills than others. For example, Mrs King (Principal Pupil Support (LA1: Sch.1) replied when asked what support autistic pupils need in secondary school "That would vary… some of them will need it with socialisation, some of them will need it with communication, some of it is behavioural, it varies according to the child". Some forms of help that the pupils did receive but were found to be negative was that the support put in place would make them stand out. For instance attending the base, having a toilet pass, and leaving early from class:

> *Not everyone wants to let other people know they are different and struggling, help us without others knowing.* (Jason Gray, Age 17, Diary)

Some offers of support were also deemed as unrealistic. For example, one parent (Gaynor) discussed that her son (Mark) was offered mindfulness during one of his school meetings. She explained that her son would be unable to use his imagination to mentally place himself on a beach. This indicates that a better understanding of each individual pupil would be helpful so that suggestions are better tailored to their needs. Most of the young people and their parents conveyed that more support is required to help others understand autism, and difference. Christina believes that this is particularly important when it comes to other pupils:

> *Do more class time devoted to it and make it mandatory for people to learn more in school about the differences around them. Educate us more on various mental illnesses so everyone can be more tolerant.* (Christina Grant, Age 18, Follow-up Interview)

Her mum, Debbie, agrees and also adds that this information would best be delivered via consulting with autism experts:

> *Get kids, parents, or like Scottish Autism or the National Autistic Society, but get it from people who know, that live with it every day, because you know it inside and out.* (Debbie Grant, Parent)

Many think that educating teachers is especially important because they require a level of understanding to be able to best educate and understand their children at school:

> *I think the teachers should have some training and understanding around it. I just feel that a lot of them just do not get it. I don't think people understand what autism is at all.* (Gaynor Morgan, Parent)

One pupil Russell (Age 13, Follow-up Interview) explains that it would help if other people could live in his autism for a day. When asked what he thought other people would feel if they could live in his autism for a day, he replied "they would feel sad as well". Therefore, educating others, both pupils and staff, would provide autistic pupils with a better understanding of the challenges that are experienced at school. As discussed, the many challenges that the young people experience while in school and in relation to school can have a significant impact on their mental health. Thus emotional support is an area of need identified in the data:

> *If I had someone to talk to when I struggle (Mrs Harley helps a lot of people), a smaller school.* (Stephanie Morgan, Age 16, About School Activity)

> *If I had more support to make me feel less isolated within school and to make me want to go to school.* (Christina Grant, Age 18, Diary)

Stephanie's quotation suggests that she benefits from being able to talk to Mrs Harley, a key person for her at school (see Chapter 7), but that she would ideally like to be able to access this support more than she can at the moment due to the demand from other pupils. Christina's quotation highlights how adequate emotional support would impact on her desire to attend school. Receiving emotional support in school, it could be suggested, would reinforce the support provided by parents at home and positively impact on the pupils' school experience. In addition to the above areas of support needed, many staff members assert that what is needed is spaces available in all schools to best support and educate autistic pupils, for instance the aforementioned school base, as well as more staff available to the pupils. Many of the school staff, like Mr Martin (LA3: Sch.1), expressed that they would like to "offer more learning and experiences outside of school for the young people", and a curriculum better suited to autistic pupils needs. However, limited resources make this extremely difficult, if not impossible (see Chapter 6). The findings have shown that support for autistic pupils is complex and that there is no one size fits all approach to helping autistic pupils cope with the challenges that they experience in mainstream secondary schools.

CHAPTER FIVE
Findings: Parent Challenges and Support

"And they wonder why parents of additional support needs, especially autism, have the same stress as soldiers, cause they go into battle every day".
(Louisa Biggs, Parent)

This chapter presents the findings relating to the parents' challenges and experiences of support in response to research question 1 and 2. The chapter is primarily concerned with data collected via interviews with parents, however contributions from support staff during face-to-face interviews are included.

5.1 Guilt, Tears, and Fears

Parents' mental health is impacted by the challenges, pressures and worries that can accompany having an autistic child. Some of these pressures begin before the child starts secondary school and following a formal identification of autism. Thus, these challenges are all encompassing and not separate from those experienced in relation to secondary school. Formal identification can be an emotional time for parents as they come to terms with a different life from the one in which they had envisioned:

> *I dinnae really think that they took on board the impact that it had… but to go for 15 years and think they have got a teenager who is going to sit exams and then going to college and then going to do whatever. For someone to say to them, no stop, wait a minute, this wain is on the autistic spectrum and this is not going to be your path. I don't think they got it just totally blew me away.* (Debbie Grant, Parent)

For Debbie, the life that she had envisioned for her daughter changed significantly when she received a formal identification of autism. This is something that she felt intensely and perceived that others could not understand how her life had changed. Her quotation also highlights the difficulties that can result from late diagnosis, which is particularly the case for autistic girls more so than boys (see D'Mello et al., 2022). She explained that there was little support available to help her come to terms with the situation. Not receiving the support following their child being formally identified as autistic is particularly challenging for the parents who do not fully understand autism:

> *I still don't fully understand autism. I don't quite get it. Some days they amaze me because I think why would you even know that. I mean reciting the alphabet backwards at a hundred miles an hour… And other days they are frustrating as hell and I think his dad still finds it really difficult... And he'll say to me, do you understand? And I say no I don't. Every day is a learning day.* (Rebecca Griffith, Parent)

Rebecca also disclosed that she received no support following her son (Russell) being formally identified as autistic. This underlines the struggles that she and her husband, and other parents, can experience attempting to support an autistic child when they do not fully understand autism and how it may impact on their child's life. For some parents, having an autistic child and watching them struggle can create feelings of guilt:

> *You just feel a failure as a parent. You also feel the guilt that you're not a good parent and I think that impacts your mental health. If you're not a strong person, if you're not looking after yourself you can't look after your child.* (Susanna Gray, Parent)

Thus, parenting an autistic child can negatively impact on mental health. These difficulties are associated with supporting the child in addition to processing the formal identification and the emotions that this evokes. All of the parents in this study revealed that secondary school has been a significant challenge for their child and their family. Susannah and Rebecca both raised that it is mentally draining caring for an autistic child and that it can often require a great degree of mental strength. Rebecca describes how at times her son can have meltdowns when he returns from school, which takes great effort as a parent to try and console him (see Chapter 4). Gaynor supports this view stating "You think I just can't do this. It's hard enough trying to get the kids through the day without having to keep knocking at everybody else's door". Gaynor is referring to the difficulties of supporting her children with daily life, and the effort it takes to have her children attend school, which are increased with having to pursue support for them while there. Parents also have to cope with their child's distress in relation to school, which can impact on their own mental health. As presented in Chapter 4, autistic pupils distress is not solely associated with education but the social challenges of school:

> *What does upset me is that they get so upset because they feel they don't fit in… I hate it when they come home, and they are so distressed, and you think why am I sending them there to do that. Its rubbish.* (Gaynor Morgan, Parent)

Gaynor emphasises the dilemma that parents of autistic pupils are faced with on a daily basis. School is compulsory for young people in the UK[15] and policies have been designed to reinforce not only the benefits[16] of a secondary education but also the punitive measures placed on parents if they fail to comply. For example, local councils and schools can enforce a Parenting Order (parent has to attend parenting classes); an Education Supervision Order (supervisor appointed to family to hep child attend school); a School Attendance Order (if not registered child with school or acknowledge home-schooling, parent can be issued with a fine); and a fine, or penalty notice (parent can be fined £60, which can then be raised to £120 and if not paid within 28 days parent can be prosecuted which may result in a fine of £2,500, a community order, or a jail sentence of up to 3 months). However, a parent's instinct is typically to protect their children from harm. Thus, insisting that they attend a place that instils them with fear can negatively impact on their own mental health and wellbeing. The fears that the young people express go beyond what might be considered typical for PNTs who dislike attending school[17]. All but one of the parents expressed that their child had either spoken or written about suicide, one of which had made an attempt, because life was too difficult. It is worth noting that these all occurred while they were of secondary school age. During a face-to-face meeting with one mother in her home, she became visibly upset as she recounted the day in which it became clear to her that her daughter's (Christina) mental health was suffering:

> *I was passing her bedroom door one morning and I spotted the box that these necklaces had been in, but there was something else inside it. I went and opened the box, and it was a note, it was like a big map thing like why am I here, and then it would be a bubble like I have no friends, nobody talks to me. I think she had said I don't want to be here… So, rushed her along to the GP, floods of tears, tripping myself with tears…See when you've actually saw in black and white that your wain doesn't want to be here [crying].* (Debbie Grant, Parent)

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[15] In 1988 the Education Reform Act introduced the national curriculum and defined four stages of compulsory education based on age groups: 5-7, 8-11, 12-14, 15-16.

[16] In Scotland, GIRFEC – Getting it Right for Every Child emphasises that all children have the right to an education to ensure the most positive outcomes for them later in life and the potential to succeed and play a part in society.

[17]This thesis acknowledges that any individual pupil may experience fear and distress in relation to secondary school. Thus it is not the intention to belittle or lessen these difficulties. Rather it focuses on the challenges that many autistic pupils in this study have in common.

Debbie was clearly distressed that her daughter had implied that she did not want to be alive. Another parent speaks about taking medication for depression because she cannot fully trust that her child will be cared for and supported in school. She worries about the impact that this will have on her son's mental health:

> *I'm on anti-depressants. I'm not on anti-depressants because I can't cope with Oliver. I'm on them because I don't fully trust that they won't hurt him. I'm not saying physically. I'm saying emotionally, you know his confidence, they could take it away in a heartbeat and they don't get that… That's why we are on anti-depressants because we feel the world isn't listening.* (Louisa Biggs, Parent)

Having a child with a diagnosis of autism, especially if there is a lack of support to the parent following this, is a significantly challenging time for the parents. This not only relates to the impact that it has on their emotions and mental health, but also practically with the continued daily support that they provide for their children (discussed later in this chapter). However, the findings also indicate that parents demonstrate a great deal of strength in the face of these challenges as their child navigates secondary school.

5.2 Unequal Opportunities

Parents worry that their child(ren) will be unable to progress and have the same opportunities to PNT pupils and that these will impact on their lives post-secondary school. Many of the school staff, like Mrs Rea (Head of Pupil Support, LA2: Sch.1) believe that "the school syllabus does not suit all pupils with ASD". During her face-to-face interview she went on to say, "We have seen pupils not attain at the levels that may have been anticipated and this may be due to time management, organisation, literal interpretation". Some of the parents agree that the current curriculum is not suitable for autistic pupils:

> *The system is set up for our kids to fail… Oliver loves maths, but they are complicating it by using English. There was a crocodile and he got stuck in this net, so Oliver's thinking poor wee crocodile, that's terrible and why would he not be able to bite out of it because they have teeth… It's not what they are expecting, the examinations are not autism friendly.* (Louisa Biggs, Parent)

Mrs Rea understands the difficulties that autistic pupils may face in relation to learning. However, her role in the school is concerned with pupil support, and it could be considered that support staff have a deeper insight than that of classroom teachers. Louisa (parent) supports Mrs Rea's claim that not taking into account autistic pupil's ways of learning

impacts on their schoolwork and examinations. She explained during her face-to-face interview that many autistic pupils are literal thinkers and struggle with interpreting schoolwork. Her quotation underscores that despite her son enjoying maths, it is delivered in a format that is typically designed for PNTs. Thus, failing to understand autism and different ways of thinking puts the young people at a disadvantage. Mrs King explains that it is not only grades and qualifications that the staff are required to help the pupils progress with but life and social skills too:

> *We are now trying to get them ready for working, or life skills after work. So you are trying to give them work experience. Social skills too. Don't get me wrong we try to do qualifications for them as well, where and when possible, because I think if not only for them, well certainly for some of them, but for others it's their parents too, they have to feel that their child is actually making some sort of progress. (Mrs King, Principal Pupil Support, LA1: Sch.1)*

This suggests that despite the many different areas in which the staff help pupils progress, grades and qualifications are not always a top priority. Moreover, Mrs King appears to be suggesting that effort afforded to some of the pupils in this area is made to help ease the worries of the parents; as opposed to providing a robust education. This feeds into the parents worries that their children are not being treated fairly within the education system. For example, one parent (Susanna) expressed that her son (Jason) was encouraged to undertake his education in the base setting only and that the school had advised her "don't bother about your Highers cause you might not get them or don't bother about your national 5 cause I don't think you're going to get them either". This was particularly frustrating and upsetting for Susanna because she knows that her son is intelligent and capable. Parents' frustrations are also likely to be connected to the time and effort that they themselves put in to ensure that their children receive grades and qualifications. The dissatisfaction may come from a perspective that parents' efforts to work toward these goals are not being matched in school:

> *I think we are getting there; I think it's taking a long time and a lot of pushing. And that makes me sad as well because I'm pushing because I can see that they do have potential. But there is a lot of kids that go through school that aren't getting the help like that because their parents aren't pushing or because the school hasn't picked up.* (Gaynor Morgan, Parent)

Furthermore, parents are concerned that this approach can also instil feelings of worthlessness in the pupils:

> *How many kids are out there that feel they are rubbish and feel they are not worthy of anything because of the way the school system treated them. And if you get that instilled into you at a young age you can't recover from that. Cause that's with you your whole life and if you are basically told you are not good enough you start to believe that.* (Louisa Biggs, Parent)

During Louisa's face-to-face interview I observed her frustration when she spoke of her wish for her son to be given the same opportunities to progress in life as those of PNTs. For example, her raised voice, becoming animated and her facial expressions reflected how passionate she felt on the subject of her son's education. Frustrations were also observed in relation to support being delayed. Difficulties for the pupils and their parents are intensified when support is delayed. For instance, it impacts on the pupil's education and feeds into the parents fears that, time will run out and their children will leave school without receiving enough support to gain an adequate education. This is despite parents requesting support since the beginning of their children's secondary school journey. Lawrence indicates that although his daughter received support throughout secondary school, a *successful* support package has never been implemented:

> *I think everything just takes so long. And you don't have a lot of time when they're coming up to nearly leaving, since first year there has been problems. It has just come right through high school; it has taken that long and she's just about to leave.* (Lawrence Morgan, Parent)

Time running out on support can create increasing pressure for the parents as they fear what is next for their child. This is likely because autistic young people can experience a loss of services upon leaving secondary education, also known as the "service cliff" (Laxman et al., 2019). One parent explains the worry she experiences about her son leaving the education system and what this might mean for his life:

> *I am absolutely dreading him leaving school to go to something that's not supported as much. I don't know what he's going to do for a job. I am stressed out my box about it. Once they fall out the education system that's it. From talking to people, there's no support, absolutely nothing… If you want to sit in the house all day well, that'll be that. You'll have to sign on, you won't get any money and then he'll just get more isolated. I worry for the future. School has been hard enough, but for me, once he leaves education it's going to be even more difficult.* (Susannah, Parent)

Susanna is not only expressing her fears regarding her son's education and future job prospects but also the social element of school life. For example, she highlights that once the momentum of attending school and interacting with staff and pupils is gone that he may become increasingly isolated. These fears are confirmed by one Head of Pupil Support who explains that she sometimes hears of former pupils who were once successful in school now struggling due to the lack of routine and support that was provided there:

> *We have got some autistic children who do fantastically well, doing Highers, advanced Highers. But we sometimes hear that something has gone wrong when they have moved on to the next step cause here we are governed by bells; they wear the same uniform every day they come to school and then when that bit is gone it can sometimes be tricky.* (Mrs Rea, Head of Pupil Support, LA2: Sch.1)

The challenges that parents experience in relation to their child's education are made up of fears regarding their child not receiving a fair and equal education to PNTs, how this may impact on their feelings of worth, and how this might impact in their future prospects. It should also be considered that the parents' concern is not only that their child will leave school with no support and qualifications, but that this will also have significant consequences on themselves who may have to provide financial and practical support. One way of addressing some of these issues with school staff is by attending meetings. However, doing so is not without challenges for the parents.

5.2 Intimidating and Emotional Meetings

Meetings can be daunting and intimidating for the parents, who are faced with multiple professionals. Susanna disclosed that she feels like she is a pupil again when attending meetings and that "you don't feel like you are going in there as an equal*"*. Another parent (Louisa) has strong feelings about the bad experiences she has had at school meetings:

> *I've had bad experiences with school meetings where I have been ambushed by head teachers and stuff like that and it was them and us… sometimes it's like the lynch mob is ready for you.* (Louisa Biggs, Parent)
> (Louisa Biggs, Parent)

Susanna and Louisa emphasise that it is challenging when it can seem at times that the parents and school staff are not working together towards the same goal of supporting the child/pupil. One staff member understands that parents may feel unequal and intimidated

during meetings and explains that this could be as a result of the number of professionals around the table:

> *They can feel intimidated but that's partly because you invite the team around the child and at the most you've got two parents. But you might have four or five professionals. It shouldn't be that they feel bullied. Their views should count as much as anybody else's and should certainly be taken into account.* (Mrs King, Principal Pupil Support, LA1: Sch.1)

Mr Martin agrees that being faced with a team of professionals can understandably be daunting for a parent. He adds that this was something that only came to his attention following feedback from a family learning worker:

> *It was only through working with the family learning worker that it opened my eyes that sometimes working with schools can be quite intimidating or daunting or threatening for people, and I think to come into quite formal meetings sometimes with a team of professionals can be quite tricky.* (Mr Martin, Head of Pupil Support, LA3: Sch.1)

For Rebecca, speaking during the meeting is no less intimidating than speaking in front of others in general. When attending school meetings she feels less intimidated and more emotional:

> *I don't feel intimidated by them, I'm not afraid. I don't feel oh you are highly educated, and you are in a better job and I'm just Russell's mum. That's not how they make me feel at all. But it's just certain things they say, and I think that's my baby. He's 13 I know, but he needs me to protect him and if you're not going to fecking listen to me, what can I do. So I now go in prepared with my tissues in my pocket ready.* (Rebecca Griffith, Parent)

Rebecca's emotions are linked to feelings of protection for her son. She goes on to explain that being emotional at meetings is something that she dreads when a meeting is arranged. She also knows that she will "go in there and fall apart" as she says she always does. For another parent, the emotions she experiences while attending school meetings is anger:

> *… when I get angry I cry. So it's no always sometimes that I'm feeling emotional and weepy, its sometimes I'm like I need to greet or I'll murder you… when they ask Christina questions and she gets upset trying to explain things that gets me upset.* (Debbie Grant, Parent)

Debbie becomes emotional in response to seeing her daughter being upset rather than as a direct reaction to school staff or the content of the meeting. Rebecca and Debbie's quotations reveal that whichever form their emotions take, they derive from protective feelings towards their children. Susanna gets upset at meetings because she believes that the school staff find dealing with her son too difficult and do not make his needs top priority:

> *There was a point when I went into one of the meetings and they're like he's doodling, he's drawing guns, he doesn't talk to anybody, we think he should be in the base. And I was really upset, and I thought you just want to get rid of the problem for you. Just because you can't deal with it, put it off to somebody else. I just think that's not right.* (Susanna Gray, Parent)

This is something that Susanna felt very strongly about and it arose at various times throughout her Skype interview. It is one of the areas regarding her son's support that she felt was not taken seriously, despite her attempts to communicate this to school staff. For example she stated, "I sometimes think that I just repeat the same old things all the time". Some of the other parents also felt frustrated at not being listened to in meetings:

> *It's frustration more than anything else. I wish they would just listen to me. Do what I'm asking you to do. I'm not asking you to spend all your time and attention and money on my child, but at the same time notice he is there and see that he needs something cause there is a pattern forming.* (Rebecca Griffith, Parent)

Rebecca suggests that her views are not taken as seriously as she would like them to be. She is attempting to assert her position as her son's parent who has a good knowledge of his struggles in school and the ways in which these could be helped. Susannah, despite her challenges during meetings, claims that these are not solely down to individual staff members, but that lack of staffing is part of the problem:

> *Teachers aren't always there. Jason's had stand in teachers this week and I don't know what's going on. So if you have a meeting and then maybe there's a holiday or you have a meeting and the teachers off, nothing gets done.* (Susanna Gray, Parent)

Therefore, it is not necessarily that parents' views are being dismissed but rather staff shortages, and school holidays can impact on school meetings. Another parent (Louisa) expressed that "it's hard to get your views across when there's limited time and this is just to be 45 minutes only". Debbie's viewpoint supports that of Louisa's in that she agrees that

there are limitations placed upon school staff that impacts on what they can implement for the pupils. However, she asserts that she did feel listened to in meetings:

> *I didn't feel that they were patronising. I felt that they listened to me. I got to say everything that I wanted to say and how I felt. Their measures for helping support Christina were limited with budgets and whatever else they've got to do and I think they did as much as they could, but I felt that they were quite honest.* (Debbie Grant, Parent)

Debbie communicates that she always felt the school staff during meetings were being honest with her and doing everything that they possibly could. However, she does go on to say that at times some staff "try to placate you and just tell you what you want to hear". Louisa agrees:

> *Politeness, lip service. Telling you what you want to hear but as soon as you go out the door it's like aye right, she's no getting a Chromebook. Or who does she think she is asking for that.* (Louisa Biggs, Parent)

Louisa would not have been privy to the conversations that took place after leaving the meeting, however, the above quotations suggest that for some of the parents, there is a lack of confidence in the school staffs' intentions to implement the support required for their child. The findings have shown that parents experience many challenges in relation to school meetings. Attending meetings can be overwhelming and daunting. It can evoke emotions due to feelings of intimidation and also in response to observing their child being upset. Some parents who do not feel intimidated can nonetheless become overwhelmed with emotions relating to frustration and anger. However, many of the parents accept that the school staff are limited in what they can realistically offer their children due to time and staffing constraints. It could be considered that because some measures of support suggested at meetings do not materialise, that the parents have to continually press the school for progress, which leads them to feeling as though they are being nuisance parents.

5.3 'Neurotic' Mothers

All of the mothers in this study have experienced feelings of being perceived to be a bother to school staff, as opposed to an assertive, caring parent. Rebecca (Parent) explains that she is made to feel this way because nothing seems to be being implemented for her son, so she feels it is her parental duty to keep on pressing the school for support to be put in place. This puts her in a position that she does not welcome:

> *I just feel like sometimes I am banging my head off a wall. Why am I bothering? But no one else is going to fix it so I have to be the annoying mum who constantly phones and says it's me again, anybody helping? Somebody? I just have to keep being a pest. It's horrid because I don't want to have to do it, I don't want to be that pain in the backside, but I also don't want to see my son not have an education… It's very difficult.* (Rebecca Griffith, Parent)

Rebecca is demonstrating that she is an assertive parent striving to achieve the best outcome for her son (Russell). It is evident in her quotation that she is extremely resilient as she continues to push for this support in spite of how it makes her feel. Another parent (Louisa) describes how being an assertive parent made her feel like she is labelled as a neurotic mother:

> *I've told them you need to tell me things, but you are just seen as a neurotic mother. You're just seen as the one that's making it worse and oh god what is she wanting now, is she thinking the whole school just revolves around her son.* (Louisa Biggs, Parent)

This suggests that parents believe that they are labelled as being demanding of school staff, which can be perceived as requesting special treatment for their child. Following the parent interviews, these concerns were presented to school staff either in face-to-face or email interviews. Many staff, like Deputy Head Teacher (LA1: Sch.1), confirms that these concerns of being labelled as neurotic have been reported by parents during meetings or interactions with parents. Mrs Couper conveys that she understands the difficulty parents are faced with when trying to ensure that their child is receiving help in school:

> *I do understand it must be pretty challenging. I would hate to think that anyone felt they had to fight their corner because that's what our responsibility is, to provide support. It must be really tough.* (Mrs Couper, Head of Pupil Support, LA1: Sch.2)

Mrs Couper acknowledges that it is challenging for the parents despite staff efforts to be reassuring. Similarly, Mr Martin, although expressing his opinion that some parents do contact the school more often than others, acknowledges that it comes from a place of genuine concern:

> *I think some parents do feel they need to make contact quite frequently. I think from a school point of view that's not a bad thing. Obviously, we probably do have some neurotic parents and some who get in touch too much, but I wouldn't say with the pupils with autism that's the case, it tends to be genuine concerns, a genuine spirit of*

> *wanting to work together to make things better for their kid.* (Mr Martin, Head of Pupil Support, LA3: Sch.1)

Overall, staff members appear to be understanding of the parents' dilemma of being perceived as a nuisance, or a neurotic mother. Nothing directly arose in the data that indicated that the parents had been directly or outright labelled as such, which suggests that this is perhaps a perception that the parents have, or something that has been relayed to them with tone of voice or the body language of school staff. Nonetheless, being perceived to be labelled as such, is a challenge for parents who are doing what they believe to be in the best interests of the child.

5.4 The Impact of Providing Support

Parents of autistic pupils are key to their child's support and invest a lot of time and effort to assist their children in secondary school. In the morning, in the home environment, parents schedule a substantial amount of preparation to ready their children for the school day ahead. For example, Susanna tells how the routine of the morning is essential for her son (Jason) to keep him calm and to make it to school on time. She recognises the downfall of not implementing routine stating, "Because if any of those were out of the way, then he was obviously like factor ten if you like, before he went in to school and the day wasn't very well, that's it, it was just downhill from there". Although this practice is not necessarily specific to autistic children as parents typically organise their children's school equipment, it is perhaps not so common to do so for those of secondary school age. The parents also revealed that they go above and beyond what could be deemed typical preparation for their autistic children. For example, time is invested into making the timetable more understandable for their children and by explaining the day ahead and what changes might take place:

> *I've got a poster on the wall. It's Monday to Friday and its colour coded and blocked. So, he knows to go and get the red one [folder] for maths, the blue one for English and the yellow one for science. I did that to make it easier for him. Without that he'd be looking through all the folders he's got, and he would get frustrated.* (Louisa Biggs, Parent)

Similarly, preparations are put in place by parents on their children's return from school in preparation for the following day:

> *The night before we will set up his school bag and read through his timetable, and just make sure everything is in the right place and in the right order in his bag, it has got to be in order.* (Rebecca Griffith, Parent)

This can mean that parents' lives are ruled by their dedication to creating and maintaining the routine and structure that their children require. While routine and rules almost dictate the school week, there is a need from the parents to not have routine during non-school days, which they more often as not do not receive:

> *Some days I don't want to have a routine today. How about we just wing it for a day. If it's just me and him that will work. But if his big sister was to suddenly turn up with the little one and the dog and throw his day completely that can sometimes mess things about.* (Rebecca Griffith, Parent)

Routine is not solely reserved for school days but the need for stability impacts on the daily life of the family as a whole. As well as the efforts put in by parents in preparing their children for school before and after each day, they are often required to attend school meetings, GP appointments and sessions with agencies such as speech and language therapists. This often impacts on time that could otherwise be spent at work or at home. Debbie explains that she was lucky that her manager also has a daughter with additional needs and so was very understanding of the many appointments she had to attend. This is extremely important to Debbie who as a single parent had no one else to accompany her daughter (Christina) to appointments, stating "she's my priority... If she needs to go to the doctors I take her, if she needs to go to the hospital I take her". Gaynor explains below that she is also fortunate to be able to work flexible hours but that this is not without consequences:

> *I was full-time and I had to go part-time cause I couldn't fit it all in and that has financial implications as well. Even now, I work 25 hours and I'm really lucky with my job and I can do it flexibly and not a lot of people have that, but I have to juggle it all together so because of that I end up working most days and hours. If I didn't do that they wouldn't go in.* (Gaynor Morgan, Parent)

The findings have shown that much of the parents' time and energy is required of them to support their child and does not end once their child attends school each day or begin when they return home. It is an all-consuming effort during work hours and time that would otherwise be spent at home with other family members or conducting household tasks. Debbie and Gaynor are fortunate in that they express that they both have understanding

bosses who allow them to attend to their child's needs if called for during working hours. However, some parents of autistic children may not have this luxury and therefore supporting their child during school hours has implications for employment and socialisation. Much of the parents' time is also spent contacting the school and various other services to help support their child. Thus, not only does the parent attend meetings, but also often has to arrange them and communicate with the school.

Constant contact with the staff throughout the school day/week impacts on parents' time away from their child. For instance, when a child attends school, it is typically a time for a parent to relax or to have a break from parenting. It would ordinarily provide them time to go about their day without the added responsibility of supervising their child. A parent's life, most often the mother's, is almost consumed with the time spent providing support to their autistic child; more so in relation to education but also in most other areas of their lives. This leaves very little opportunities for the parents to pursue their own interests and unwind, which is an immense amount of responsibility for someone to be coping with, unaided, on a daily basis.

5.5 Forms of Support

What emerged in the findings is that the parents who do have some form of support, have sourced this themselves or via referrals from outside agencies and not through the school. When asked about support groups for parents, school staff appeared to have little awareness of what was available to parents of autistic pupils. One autism teacher (LA1: Sch.1) said that she did not know of any support groups. Similarly, another support for learning assistant (LA1: Sch.1) stated in her email interview that "*I am not really aware of this".* During the face-to-face interviews, some staff did mention that they knew that there were local support groups but did not have specific details about them:

> *I can never really remember these things of the top of my head but there are kind of support groups and there are yearly meetings with particular groups. When it comes around I will get an email to say can you send this information out to parents.* (Mrs Couper, Head of Pupil Support, LA1: Sch.2)

However, it became clear that most of the support groups that the school staff were referring to where those for parents in general, or parents of children of additional needs and were not specific to autism. Gaynor pulled back from attending such groups as she felt it was not a

good fit for her circumstances. For example, during her interview she explained, "My problem is a lot of the people who are at the parent groups are all glowing about how wonderful their kids are and that's not helpful. If it was specifically around kids who were struggling, that might be a bit more useful". Moreover, the groups mentioned were not something that was arranged or offered by the school, but rather groups in the local community. For example, Mr Martin (Head of Pupil Support, LA3: Sch.1) responded when asked about support groups available to parents "Not necessarily in house through the school. I know that there's a number of parents attend different groups outside the school either specifically through things like the Autistic society or more generally for kids with additional support needs". Mrs Couper expresses that there is support for parents associated with schools available if they should require it:

> *Our ASD outreach worker will provide support for parents if they need it and also if there are significant needs then the social services might offer support. So there is definitely support out there for parents, if they need it.* (Mrs Couper, Head of Pupil Support, LA1: Sch.2)

However, it became clear when speaking to the parents, that any support they did find was not signposted to them by the school but by outside agencies. This suggests that this form of support is not readily offered to the parents, but is perhaps there if the parents seek it out:

> *I got the carers support group from the speech and language lassie. The online one I found myself and it was through the carers group I learned about the befriending thing through the social work and the school had to fill that form in for her to get a place.* (Debbie Grant, Parent)

Despite not being a direct source of support from the school, at times, the school are required to complete a form for the support to be put in place for the parent. Many of the staff appeared to have more information regarding larger autism charities and organisations that are available and that offer support to parents, as opposed to less formal parent support groups. These were specific charities to the area local to the participant as well as more national charities such as The National Autistic Society (NAS). For one parent who discovered NAS for herself, she found it was extremely helpful in aiding her understanding of autism and how to best support her son:

> *National Autistic Scotland was the best thing that ever happened to me because at that point they had lottery funding and they actually ran 3 workshops and they talked*

you through all different aspects and all the things you can do to help your child, coping mechanisms. They were brilliant. (Susanna Gray, Parent)

Susanna went on to say that since losing the lottery funding, some of the events that she had attended through NAS were now too expensive to attend, costing around £300- £400. One of the many positives she took from attending such sessions was being able to talk to other parents and learning important information from them. This suggests that it is beneficial for parents of autistic children to speak to other parents who have already gone through, or are going through, some of the situations they may be experiencing.

5.6 Support Needed

Support is needed for the parents of autistic pupils in the following three areas: support after a formal identification of autism; support with school meetings; and support with their child transitioning from secondary school. As aforementioned, being a parent of a child receiving a formal identification of autism can be overwhelming and daunting. The parents revealed that there is a lack of support following a diagnosis, which can leave them feeling alone and unsupported:

> *I think once he was diagnosed we were basically pushed away, it was like there you go that's his label, off you go. And I don't feel the support is there after it...* (Rebecca Griffith, Parent)

Rebecca discussed how she mistakenly thought a 'diagnosis' would bring with it support for her child and her family. This highlights that getting a diagnosis of autism can seem like the resolution the family were seeking, but instead it is just a starting point. Susannah adds:

> *Basically when Jason got his diagnosis, we got a leaflet like that [demonstrates the width of a big booklet] there you go. That makes or breaks a parent. It was just there you go read up about it. End of. You've got a diagnosis, what else do you need. There wasn't any support. If you don't have the knowledge and you don't know what your rights are and you don't know where the support is, it's just right over your head and you'll be left like a wee squashed mess and your kids not getting any help.* (Susanna Gray, Parent)

This signals that support is needed to help the parents come to terms with their child being autistic, and what this might mean for everyday life, future prospects and navigating the education system. This might include what difficulties to expect for their child and their family and strategies for managing these challenges. Another area of support identified that

the parents would benefit from is help with school meetings. The findings reveal that attending meetings is often a daunting, emotional and intimidating experience. Hence, support in this area is needed to help the parents make the most out of the time allocated during a meeting to discuss their child's school needs. Some parents mention how they felt more supported when their partner could attend with them:

> *It used to be great cause his dad worked locally so I used to say to him you need that day off cause you need to come and be my voice. He was good at being quite, not aggressive, but enough to make them realise that actually we are not going to be pushed around. And now he works all over and so he's not available, so I have to go it alone.* (Rebecca Griffith, Parent)

Being accompanied by her husband provided Rebecca with a sense of security and the knowledge that their concerns would be heard. She discussed during her interview that because she gets emotional during meetings she sometimes cannot get across what she wants to say. At times, Rebecca's mother accompanied her, who she describes as also being more forthright, like her husband. Another parent (Louisa) pays to have a speech and language therapist accompany her:

> *The team around the child should be everybody that's in your team. So I pay for my speech and language therapist to give up her time and go. I did used to have a social worker but she's no longer in the position.* (Louisa Biggs, Parent)

Louisa demonstrates that she is aware of who should be included in team around the child (TAC) meetings, but that perhaps are not always present. By having her speech and language therapist accompany her, it could be considered that she is attempting to balance out the 'us and them' inequality mentioned previously in this chapter and not solely rely on the school professionals. In this sense, she is including a professional of her choice who has had more involvement with the family outwith school and who can provide an additional insight. However, not all parents can access these resources due to financial restraints. Likewise, not all parents have their own support systems in place, for example, single parents or those with small/no friendship or family groups. Parents being supported before, during and after meetings would help with feelings of intimidation, allow them to get their points across clearly and would enable them to be supported emotionally. Furthermore, this would in turn benefit their child in that meetings would be more effective, and the time would be best used to identify and implement areas of support. Knowing how best to support their child once they leave secondary school is another area where support would be beneficial to the parent.

This is because parents will be faced with new or intensified challenges and pressures due to changes to their child's current school routine. The findings revealed how this might impact on the parents own mental health as they worry about the wellbeing and future prospects of their child. Susannah feared that the support she currently has will cease once her child leaves the education system, which may have practical and financial implications for both herself and her son. If a young person leaves school with little or no qualifications, parents need to know what support may be available for college, employment, or benefits that they may be entitled to. Thus, signposting the parents to relevant organisations that help support young autistic school leavers, leading up to this transition, would be beneficial for the family.

The key issues that have emerged from the findings presented in this chapter are that parents of autistic pupils experience a high degree of stress, guilt and fears that are not solely linked to the demands of coping with an autistic child but are associated with the worries that they have regarding their child's school experiences, wellbeing and future prospects. It pinpointed that meetings for some of the parents were intimidating, and for most were emotional, and that parents perceived that they were labelled as 'neurotic' mothers. The findings also revealed that support to help parents cope with these challenges is inaccessible or non-existent.

CHAPTER SIX
Findings: Staff Challenges and Support

"It can be challenging to meet the needs of so many 'individual' pupils".
(Deputy Head Teacher, LA1: Sch.1, Email Interview)

This chapter presents the findings from interviews with school staff and parents. It stresses that staff are faced with structured barriers that prevent them from implementing measures they deem necessary to successfully educate and support autistic pupils in mainstream secondary school.

6.1 Not Enough Time and Resources

Staff explained that they do not have enough time to teach or support the pupils as they would like to. Mr Martin voices that this constrains the potential for more innovative ways of teaching:

> *I would like to offer more learning and experiences outside of school. Outdoor education, doing some of the life skills and social skills stuff that we talk about in the department. Take it out the building if money and time and transport was no barrier to these things.* (Mr Martin, LA3: Sch.1)

The above quotation reflects many of the staff and parents' beliefs that autistic pupils would respond better to a different curriculum. This is based on the pupils' different learning styles and their struggles with literal thinking. Thus, staff are aware of the needs of autistic pupils and can identify innovative ways to help support them, but they do not have the time or authority to act on them. Parents also view time constraints as an obstacle to their children getting the assistance that they need in school. It could be considered that the parents may take what they see at face value and not recognise the efforts, or obstacles, that occur behind the scenes from school staff in relation to supporting their children. This may prove to be challenging or frustrating to staff in that their individual efforts do not translate or are recognised by the parents (see Chapter 7). For instance, some parents believe that this is down to individual teachers:

> *… there's some teachers out there that really don't want to see children that learn differently. That's too much hassle. I've not got time to change this lesson into 13 different bits. Even though it says in my contract I have to and I have to be*

accommodating. Nothing really in law that says I have to really enforce it. (Louisa Biggs, Parent)

However, Mrs King (Principal Pupil Support, LA1: Sch.1) is confident that parents are aware of the lack of time and resources the school staff have, stating "I think most of them are aware that many of the constraints that we have are financial and outwith our control". This viewpoint is supported in some of the parent data whereby parents identified that wider constraints can impact on how support is distributed to pupils. For example, during their joint interview, Stephanie's parents (Gaynor and Lawrence) discussed how one of her support teachers spent time at home with her on schoolwork for two hours, once a week for four weeks. They explained that this support was really beneficial for Stephanie but that the funding was pulled, and as a result the support was stopped. It is clear that this support was welcomed by both Stephanie and her parents. However, this support was short-lived due to a lack of funding. Financial constraint is something that Mrs Couper identifies as being a national issue:

> *I think we like all the high schools in Scotland feel like our resources and our support staff are being reduced all the time… I think we are all very well aware of the difficulties that our kids have but if we had more resources that would be fantastic.* (Mrs Couper, Head of Pupil Support, LA1: Sch.2)

One suggestion that arose in an email interview for making the most of the time that is available to best support autistic pupils is a shorter school week. One Support for Learning Assistant (SLA, LA1: Sch.1) proposed that "The pupils would go home at lunchtime on a Friday so the staff could have a weekly meeting". This approach, alongside allowing the pupils to recharge from attending school, would enable staff time to better prepare for the pupils' lessons and discuss ways to support them. When specifically asked how they would best support an autistic pupil without the limits of time and resources, staff responded with many suggestions for improvement:

> *I would alter the accommodation so that a greater number of small classrooms was available to give greater flexibility for teaching in ones, twos, threes etc. according to need. This would also allow for "chill out" areas. We would have our own swimming pool and fitness equipment. We would have subject specialists in all areas coming into the Base to teach. I would also have regular craft activities taking place. I would reinstate Music Therapy which many of our pupils used to enjoy but we no longer have.* (Email Interview, Deputy Head Teacher, LA1: Sch.1)

Similarly, Mrs Couper (Head of Pupil Support, LA1: Sch.2) stated that if she "had a magic wand" that she would like to see more creative subjects made available to autistic pupils. She also suggested that focus on socialisation would be beneficial, such as "small targeted groups where we would build a sort of social network round a couple of kids that were maybe having difficulty". For one deputy Head Teacher (LA2: Sch.2) the need for more support staff with the appropriate skills is needed. As aforementioned, Mr Martin (Head of Pupil Support) revealed his desire to offer more learning outside of the school building and in the community. He went on to recommend how things might be improved within the support department if funds were limitless:

> *I'd like to develop our base further… I visited one school and they had a very nice sensory area attached to their base, there was lots of nice lights going on. And I read about some kind of effective apps and digital technology that are interesting. We don't do an awful lot of that at the moment. But a wee sort of a suite of iPad for the guys and the right sort of apps that would help autistic kids. Oh aye if funds were limitless, it would be great.* (Mr Martin, Head of Pupil Support, LA3: Sch.1)

Mr Martin underlines that mainstream secondary schools do not receive the same resources and therefore do not offer the same level of support. However, the sensory area that is mentioned above is not without its challenges. For instance, while I was visiting one of the schools to conduct an interview with a member of staff, I was shown around the facilities that they had in the base. The sensory room there was fitted out with various lamps. The school had received funding to create this room. However, one of the bulbs had broken on the lamp, which was no longer in use because replacement bulbs cost £70. This is important to recognise and highlights that the resources needed are ongoing. The findings demonstrate that school staff have an understanding of what is needed, and the motivation to improve autistic pupils' experiences in secondary school. However, they do not have enough time and resources to best educate, support and meet the needs of the pupils.

6.2 Witnessing the Struggles and Vulnerabilities of Individual Pupils

The staff discuss how challenging, and unpredictable, it can be to support autistic pupils. This is because despite sharing some common difficulties, each autistic pupil has their own individual needs and behaviours. Moreover, as pupils are supported in different environments

within the schools, finding a balance is challenging for staff. One deputy head teacher explains:

> *You've got to get it right for every single pupil within the context that we can deliver it in terms of number of staff, size of classes, within what the government provide us with and tell us to do. So there's a lot more work or support goes into different young people who has autism or other needs and it's about us trying to balance that to get it right.* (Mr Fairns, Deputy Head Teacher, LA2: Sch.1)

Thus, staff do not only have autistic pupils to support within secondary school but also PNTs and non-autistic pupils who have additional support needs. Mrs Rea (Head of Pupil Support, LA2: Sch.1) underlines the difficulty of catering to autistic pupils needs within mainstream classes, particularly large classes "because they have also got 30 other kids in the class, they have got to be aware of their needs." This suggests that in larger mainstream classes the needs of autistic pupils may become lost. On the other hand, there are also challenges with supporting multiple autistic pupils together in a smaller setting:

> *Frustration with on-going behaviour of individual pupils, which interrupts the learning programmes of other autistic children within the autism base.* (Autism Teacher, LA1: Sch.1)

Smaller settings such as the base where autistic pupils are supported often have pupils being supported alongside them with their own individual needs. Not only do pupil behaviours impact on each other, the way that their moods and behaviours can change, due to their own rising stress levels and frustrations, can also impact on staff. One autism teacher (LA1: Sch. 1) explains that "planned lessons do not go according to plan and take much longer than expected due to the fact that the mood of the pupils can vary hugely from one day to the next". Other staff members discuss that the pupils moods can sometimes be intimidating:

> *On occasions some pupils are so stressed they become physically violent, and this can be a frightening experience.* (SLA, LA1: Sch.1)

> *… second and third year for boys can be very hormonal and sometimes violent. So its intimidating. Not always nice to be at the end of that.* (Mrs King, Principal Pupil Support, LA1: Sch.1)

The above quotations uncover that staff can experience disruption to their teaching, making it difficult to provide both education and support to the pupils. They also illustrate that, at times, staff can have fears for their own safety and wellbeing. It could be suggested that being subjected to unpleasant and aggressive behaviour, particularly on a regular basis could

take its toll on their own wellbeing and mental health. Staff also expressed difficulty in witnessing some of the pupils struggles. Mrs Couper (Head of Pupil Support, LA1: Sch.2) explains how one pupil had significant challenges with his transition from primary to secondary school. She explains that initially he seemed to make progress and settle in. However as time has gone on, the pupil is struggling more than she expected him to. She expresses "But that's your difficulties, when you see youngsters struggling, what can we do to support them." Another head of pupil support explains how disheartening it is to witness pupils presenting with harmful behaviours and vulnerabilities:

> *When you see pupils that are totally disengaging and then they go into the self-harming or they become very vulnerable in the community… So you have girls who become very promiscuous… and it becomes unsafe and they don't realise the risk… and there was one girl a couple of years ago now and she was so distraught at her higher results she shaved her head and went into complete meltdown.* (Mrs Rea, Head of Pupil Support, LA2: Sch.1)

Supporting autistic pupils is challenging for staff. Being able to support them with limited time and resources is testing, impacting on the quality of education the pupils receive. It is challenging for staff to balance education and support both in mainstream and smaller settings, both practically in terms of catering to individual needs and mentally as they deal with pupil frustrations and behaviours, which at times can be violent. Moreover, staff can be impacted emotionally as they witness pupils they have come to know become vulnerable and distressed. However, it is important to present the many positives that staff expressed in relation to supporting autistic pupils.

6.3 The Rewards of Working with Autistic Pupils

One of the positives mentioned by staff about supporting autistic pupils in secondary school is witnessing the pupils overcome difficulties. A Principal Teacher of Pupil Support (LA1: Sch. 2) conveyed in her email interview that she enjoys "Seeing how the young people develop through secondary school and the strategies that they employ that allows them to function within the setting". Mrs Couper supports this view:

> *… a situation that I've enjoyed watching will be this young person. In first and second year he had blanket support across every single period, breaks, lunchtimes and now he totters off to class himself and he'll say whether he needs support or not… We've got another young person that just left last year that is at college and just doing fantastically. And he was non-verbal halfway through primary school. And I've got a young lad that's in sixth year who has got an unconditional to university.* (Mrs Couper, Head of Pupil Support, LA1: Sch.2)

It is evident from the above quotation that this staff member's interest in the pupils that she supports does not end when they leave secondary school. Moreover, this interest is not simply concerned with if the pupil receives an offer of college or not but in how they are progressing while there. Staff also conveyed positive experiences of building relationships and engaging pupils. For instance, one SLA (LA1: Sch.1) stated that "One of the most positive experiences is to succeed in building a relationship with a pupil who is initially unresponsive. Seeing a pupil's anxiety levels decrease sufficiently to enable them to engage with learning". When the pupils do feel less anxious, staff explain that autistic pupils have much to offer:

> *... pupils who have taught themselves to read… I've seen pupils who have very little language actually become really quite talented musicians… And we just heard that one of our former pupils is away down to Oxford to a job in cyber technology.* (Mrs King, Principal Pupil Support, LA1: Sch.1)

Working with autistic pupils also gives some staff an awareness that diversity is good. One SLA (LA1: Sch. 1) wrote in her email interview that "Autism does not always have to be a disability - it can make someone's behaviours appear different, but diversity is good!" She went on to say that autism affects each person differently and that it was important to get to know the pupil first before deciding on what strategies would work best. Similarly, for one Autism teacher, working with autistic pupils provides an appreciation of how different people have different outlooks on life and the importance of understanding these differences:

> *It makes me see the world in a different way and I have come to appreciate how hard it is for any people to truly understand each other.* (Autism Teacher, LA1: Sch.1)

Overall, staff agree that it is rewarding to see autistic pupils take part in school activities and are appreciative of the various opportunities that they receive through their work with them. For example, Deputy Head Teacher (LA1: Sch.1) states that she has been provided with "Numerous volunteering experiences and work experience" and that it is rewarding "seeing pupils perform in school shows, seeing pupils happy to attend". Thus, despite the many challenges associated with supporting autistic pupils in mainstream classes and support bases in secondary school, there are also various positive and rewarding experiences.

6.4 Support Provided by Staff

The various forms of support provided by school staff for autistic pupils include pastoral care, such as listening to pupils, showing an interest, and supporting and understanding behaviours. It includes teaching and demonstrating tolerance and encouragement in addition to anticipating needs rather than reacting. This support is provided on a bespoke level, where staff can meet pupils weekly, or more often if required, both during class times and at social times, such as during break and lunch. One SLA (LA1: Sch.1) states "I support pupils individually and in small groups in activities within the Base, and also support pupils, usually on a one-to-one basis, in mainstream classes". A Pupil Support Worker (LA2: Sch.1) informs that she provides "Whatever type of support they need at the time (curricular, emotional, organisational, 'a listening ear')". Curricular support involves helping pupils cope with transitions, study support periods, assessment arrangements, supported work experience, and creating a flexible curriculum. Staff roles also include managing and coordinating pupil support, including setting targets, attending Team Around the Child (TAC) meetings, liaising with professionals, and making referrals to relevant agencies:

> *I coordinate the support package and so it would be my responsibility to organise the stage intervention reviews and get all the professionals round the table… and if I'm key worker for a young pupil with ASD then I'll meet with them once a week, once every couple of weeks, that kind of thing just again depending on their needs.* (Mrs Couper, Head of Pupil Support, LA1: Sch.2)

Communicating with colleagues and parents is also a key role in supporting autistic pupils, alongside liaising with the young person and their family, which assists with home and school communication. For instance, a Principal Teacher of Pupil Support (LA2: Sch.2) explains "I am responsible for liaising with the young people and their family. I address any concerns that they have. I create Pupil Profiles to give to staff to make them aware of the young people's strengths and how best to support them". Mr Martin has similar responsibilities and differentiates the duties of different members of staff:

> *A lot of what I do is liaising with families, with the staff who look after the autism base and the children themselves to plan their support… So my role is a bit more strategic. And then the actual day to day support in terms of teaching and learning, creating additional resources, differentiating activities and things is more the role of the teachers in the base.* (Mr Martin, Head of Pupil Support, LA3: Sch.1)

Some of the formal duties of support staff is delivered behind the scenes, in terms of planning and coordinating support with the pupils' families and relevant agencies. The responsibilities of supporting autistic pupils in secondary schools are many and are delivered both in

mainstream classes and in smaller groups, in social areas and on a one-to-one basis. This support is typically designed to cater to pupils individual needs and distinctive circumstances. In order to provide this support, staff receive support in the form of training, education and on the job experience.

6.5 Opportunities and Constraints of Receiving Support

Support for staff is provided in two main ways; one to educate and train staff on how best to support autistic pupils, and two, support that is provided to the staff in their role. Some staff acknowledge that most of their learning regarding supporting autistic pupils comes from work experience and learning from colleagues. One Autism Teacher (LA1: Sch.1) states in her email interview that she learns from "More experienced members of staff, senior management staff within the school". Another Autism Teacher from the same school agrees that much of her learning has come from "On-the-job training. Excellent support from colleagues, particularly from my fellow teachers, but also from the SLAs". Some staff training is provided for by the school, either financially or practically. For instance, one Support for Learning Assistant (LA1: Sch.1) stated "I completed an Open University course on autism, funded by the school". Staff also mentioned that they attend conferences or training sessions within the school to help them better support autistic pupils:

> *Part of my role is to coordinate the CPD and Calendar and certainly we would be looking for Mrs Rea's team to maybe run some sessions for staff to opt in on after school just for an hour's twilight.* (Mr Fairns, Deputy Head Teacher, LA2: Sch.1)

Mr Fairns is referring to Mrs Rea, Head of Pupil Support at the same school and suggests that training for support staff is one of her roles within the school. From a face-to-face interview with Mrs Rea, it is suggested that she is able to provide staff training sessions by attending training provided by local authorities:

> *This LA do their own courses that are run for support staff, or any staff actually. They have a part on the council website where they post all their CPD stuff. So the PowerPoints and stuff from training is all there. I was on a training course last night with five colleagues from here and on girls with autism.* (Mrs Rea, Head of Pupil Support, LA2: Sch.1)

An Autism Teacher (LA1; Sch.1) commented that there are a "range of courses offered through the council that you can opt into". This is reiterated by Mr Martin (Head of Pupil Support, LA3: Sch.1) who describes how some of the training sessions "Covers a lot of the

additional support needs but sessions specifically petered towards learning about autism". A Deputy Head Teacher (LA2: Sch.2) revealed through her email interview that there is a variety of local authority training available to school staff and that she is "able to call on advice from the outreach team in order to support the children and staff*"*. Staff from other schools also depend on external agencies for support:

> *We have to rely quite heavily on our external agencies… I have a small caseload, so my specialism if you like is pupils who have kind of complex needs and difficulties. I kind of have the network of people round about me, so I know who to contact. More often than not it's our ASD outreach person… And they are pretty fantastic at supporting, they know their stuff.* (Mrs Couper, Head of Pupil Support, LA1: Sch.2)

This highlights that there are outreach teams available with more autism expertise. Mrs King points out that there are additional forms of external support available to staff, and parents, in the form of larger conferences or training programmes. However, she indicated that these are more expensive to attend:

> *There are training days put on, but training is expensive. To go to one of these big conferences in Glasgow, you are talking £200/£300 pounds. Now parents get it cheaper but that's a lot of money… autism is so huge you have different factions within it, you have got PDA[18], ADHD[19], Fragile X[20], Asperger's[21], pupils with high anxiety. No one is an expert in any of these things, it's about trying to just work their way through some of them.* (Mrs King, Principal Pupil Support, LA1: Sch.1)

During my interview with Mrs King, and other staff members, it was revealed that due to the limited funding available to attend larger conferences, only one or two members of staff would attend and then report back to the department. The above quotation shows the complexities of supporting autistic pupils with their different needs. For instance, Mrs King, who has been in her role for almost twenty years, still suggests that staff are not experts and have to learn as they go with no clear or fixed guidelines to work from. At a later point in her interview she expressed her frustrations associated with this lack of guidance:

> *We are totally frustrated, because we find that the services are being streamlined, not to suit the individual pupils, but to suit the services that they are providing… to get individual speech and language sessions is very difficult. They each come in and say we will come in and talk to your staff, to give them an idea of what to do. But the reality is it's difficult to get that.* (Mrs King, Principal Pupil Support, LA1: Sch.1)

[18] Pathological Demand Avoidance – avoiding everyday demands.
[19] Attention Deficit Hyperactivity Disorder.
[20] A genetic disorder characterised by mild-to-moderate intellectual disability.
[21] Often characterised as high-functioning autism.

The findings emphasize that there are a variety of opportunities for training available to staff supporting autistic pupils. However, these opportunities are sporadic and not all modes of support are available to all staff in each local authority or school. For example, one pupil support worker (LA2: sch.1) claims that they receive regular autism training, while Mrs Rea (Head of Pupil Support, LA2: Sch.1) feels that further support and training is required in relation to "Staff awareness of ASN and strategies to support, in class particularly in group working, discussion etc.". Nonetheless, the data has revealed that staff utilise what is available to them via on the job training, through colleagues, and with local authority and external agencies.

CHAPTER SEVEN
Findings: Relationships and Communication

"I've found that it really begins with a person. Someone that you can communicate with and they can communicate back. So if you have that point of contact in school, that knows you and your son, I think you're cooking with gas".
(Susanna Gray, Parent)

There are many people involved in supporting an autistic pupil in secondary school. This chapter presents data produced in response to research question 3: In what ways do relationships and communication between pupils, parents and staff impact on using or implementing support? It details the intragenerational and intergenerational relationships of the people that the pupils, parents and staff express are key to this support. Moreover, it offers an insight into the ways in which all three groups communicate with each other.

7.1 Intragenerational Relationships

7.1.1 Organic and Formal Relations Among Pupils

Most of the staff conveyed that pupil relationships in school differ depending on the child. For example, when asked if they could speak about the relationships that autistic pupils have with other pupils, one Deputy Head Teacher (LA1: Sch.1) replied "It very much depends on the situation and how comfortable the child feels". Similarly, a Deputy Head Teacher from another school (LA2: Sch.2) responded "I don't think it's possible to answer this succinctly as this very much depends on too many variables particularly the needs of the individual". These insights are important because they underscore that relationships are individual to each pupil, autistic or PNTs, and should not be generalised. The following quotation identifies a common observation of autistic pupils spending time alone, while at the same time acknowledging that friendships occur between different groups within the school:

> *Most of them keep themselves to themselves. Although, there are some friendships which develop, particularly among the pupils who work together… Some pupils who access the mainstream school will have good interactions with mainstream pupils and develop friendships.* (Autism Teacher, LA1: Sch.1)

This reflects the experiences of the young people in this study, who all have differing experiences of relationships with other pupils. For Oliver (Age 12), friends are a positive

feature of his secondary school experiences. He particularly enjoys break because he can meet up with friends in the base and ASN room and have a snack together. Russell (Age 13) enjoys relationships with friends who he has known for three years, who he also pointed out knew about 'his autism'. This suggests that Russell has a sense of acceptance with his friend group. This is not the reality for Christina, whose experience differs from Russell's and Oliver's:

> *Even those who knew about my diagnosis would still continue to isolate me and made me feel as though no one would want to be friends with me. No one really cared enough to want to get to know me.* (Christina Grant, Age 18, Diary)

Christina demonstrates that disclosing herself as autistic did not produce positive results. Thus, while friendships can occur in mainstream school, for some, these relationships can be negative. The base has consistently been identified throughout the qualitative data with all participant groups as being a safe space for autistic pupils. However, negative relationships can also occur in this smaller setting within the school, which can cause tension:

> *Some of them manage to form small friendship groups within the Base, which works really well. Others interact very little with other pupils. Sometimes problems occur when one pupil is seriously wound up by another pupil and cannot stand being in the same room.* (SLA, LA1: Sch.1)

Therefore, friendships between pupils in various spaces within mainstream secondary school "Can be positive or negative – it depends on the make-up of the classes that they are placed in, and on the personalities of the pupils involved" (Pupil Support Worker, LA2: Sch.1). One particular concern that is more likely to be experienced with autistic pupils as opposed to PNTs, is that it can be difficult to judge whether someone is a friend or not:

> *I'll never forget him coming home one day and saying to me 'Mum, some people pretend to be your friend but they're not really your friend. They're just being your friend so they can hurt you'… So, he has isolated himself because he doesn't want to be hurt.* (Susannah Gray, Parent)

Susannah raises an important concern regarding the difficulties in interactions with others that are not simply attributed to difficulties in speaking to others but in interpreting others' intentions and behaviours. Other school staff highlight that some autistic pupils tend to gravitate towards each other, perhaps without being aware that the other is autistic, but they do so because they share an interest, such as roleplay games or anime:

> *Sometimes they gravitate together without probably ever realising they all have autism. We have a group that play with the role play card games every lunch time. It's very routine in the same room and there is probably about five or six of them that are on the autistic spectrum.* (Mrs Rea, Head of Pupil Support and Mr Fairns, Deputy Head Teacher, LA2: Sch.1)

Here we can see an important distinction between smaller shared spaces that are attended through necessity or by choice. For example, on the one hand in the smaller space of the base or support units in school, there can be tension between pupils who attend. On the other, pupils who attend groups such as those mentioned above, do so because of a shared interest, and through their own choosing. It is important to highlight that autistic pupils are not just recipients of friendship but can be instrumental in building supportive relationships for other autistic pupils or pupils with additional support needs:

> *Stephanie is great with stuff like that, she's great with the younger [pupils] and she's been put into this youth club, through social work… there was one girl who started the same time who is eleven with ASD and really struggling. Stephanie has been texting her. I see Stephanie when Mark [brother] is really struggling with things, and I mean Stephanie still struggles, but she will give Mark coping mechanisms to talk round.* (Gaynor Morgan, Parent)

Stephanie, who has considerable difficulties in school and in other areas of her life, is a great support to other autistic young people, including her brother. Thus, sibling relationships can also be positive and supportive. Some schools adopt a buddy system, whereby pupils are trained to help support autistic pupils. One school in this study has implemented such a scheme for the first time and believe the results to be promising:

> *So that team of 6th year buddies assist in the autism base, they are also mentors and buddies around school. They are people that young people can come to if they have any worries. They are also helping with that process of managing the transition back to mainstream for some people where if they are maybe a wee bit anxious going into certain classes, the buddies can go in with them for a wee while and help them to settle and get into the routine of that class.* (Mr Martin, Head of Pupil Support, LA3: Sch.1)

Of interest, no other school in this study mentioned this form of pupil support. Relationships with other pupils can alter the experience of school for autistic pupils, whether it be through organic friendships, groups, or more formally through buddying schemes. Typically, young people learn how to do relationships in shared spaces, whether it be primarily with their families and during nursery, primary and secondary school. The latter is a space in which

they discover which groups they are more drawn toward or that they belong to. This is something that can be particularly difficult for autistic pupils and as such having a base setting in which they can feel more comfortable around others and perhaps learn to develop these relationships is extremely beneficial. It could also be considered that for those who access both the base and the mainstream setting, the former allows them to learn how to form relationships in a safe environment that can then be tested in the latter. The base setting, as disclosed, also allows a separate area for pupils who cannot cope with shared space no matter the size of the group.

7.1.2 Complexities of Parent and Staff Relationships

Some of the parents expressed that relationships with school staff can be frustrating. There was a particular member of staff that one parent (Debbie) had negative interactions with. One example of this was when she contacted the school to discuss her daughter failing to turn up for volunteer work at the school support base, and was frustrated with the response she received:

> *I phoned her to see what was happening. She said, 'I think she's just a belligerent teenager, she just ignores things if she doesn't want to do them' and I'm like oh you are so far off the mark it isnae real.* (Debbie Grant, Parent)

Debbie's frustrations derive from the staff members lack of understanding of her daughter's challenges. This is something she felt strongly about and prior to a subsequent meeting she requested that this member of staff did not attend. She told the school "that woman does not see that Christina needs support or has any special needs, she is refusing from the day and hour I spoke to her. She just isnae listening to me". However, despite the negative relationship with this particular staff member, Debbie goes on to say that for the most part she had a good relationship with other school staff who listened and took her views into account. Other parents also spoke of positive connections with school staff:

> *I think the fact we have got Mrs Murray. I don't know where I would be without Mrs Murray.* (Gaynor Morgan, Parent)

Both Gaynor and her husband Lawrence agreed that their relationship with their children's Head of Pupil Support was a positive and important one. They added that they had good rapport with other staff members, including the secretary who calls daily due to

an issue with group call texts that they have been unable to receive. Rebecca mentions that while the interactions with her son's guidance teacher are good, this does not necessarily equate to the best support for her son:

> *She's lovely, she's very scatter-brained. I think her heart is in the right place, and she is very approachable and very easy to talk to and she does listen. But I just think she is so airy fairy and disorganised.* (Rebecca Griffith, Parent)

While there appears to be pleasantries between Rebecca's and her son's guidance teacher, there is no sense of trust in her abilities to support her son while at school. Susanna is unsure of her relationship with the school, with some associations with staff members being more positive than others:

> *I don't know if I have a good relationship with the school. I feel that there are certain members of staff that I can talk to, but whether the school go oh Jesus God here she comes again, I have no idea. You know, like oh here she's up moaning about her boy, all of those things go through your head.* (Susanna Gray, Parent)

Thus, for the parents, relationships can be positive and/or negative depending on which member/s of school staff the parents interact with. Louisa described her experiences with the school as a "rollercoaster ride" with some experiences being more positive than others. However she also worries that her interactions with school staff will impact on the support her son receives in school or on his relationships with staff:

> *I try to step back a bit because I don't want them to then take it out on him… That's my biggest fear, cause people say oh you have to stand up for your child… but what if that person then took a vendetta against your child and made it difficult for them…* (Louisa Biggs, Parent)

Similarly, Susanna reflects how relations with staff can have a positive and negative effect on her son, emotionally, socially, and educationally:

> *When he was younger, when he was going through the bullying stage, he actually got to a point where he would stop telling me things because he was like it makes it worse. As far as educationally, if I hadn't been fighting the way that I've been fighting, just things like his exams, he is now allowed to sit in a separate room with a prompter and more time and I know if I hadn't been on and on, that wouldn't have happened and he couldn't have coped with a room full of people… so things like that have come about because of fighting for Jason.* (Susanna Gray, Parent)

Christina's mother (Debbie) affirms that there were a few key people at school who her daughter had a positive relationship with, even one staff member who she herself had a

negative relationship with. As aforementioned, there was one member of staff that Debbie had experienced specific problems with in relation to her daughter's diagnosis; in that she did not understand the gravity of the support that Christina required. In her quotation below, she is able to put aside these differences and recognise that this member of staff did support Christina:

> *So while she wasnae a person that I would have lifted the phone to or emailed about an issue with Christina, I knew that she was there supporting Christina, doing things roundabout art and focusing on her strengths and that gave Christina a lot of confidence.* (Debbie Grant, Parent)

This suggests that not all poor relationships between parent and staff impact negatively on the pupils as some of the parents fear. The findings have shown that for parents, the relationships with staff can be complex. Not only do they have to navigate them with multiple staff members, they also have the added worry of how these relations will impact on the education and/or support their child receives in school. In contrast, for staff, the overall views on their interactions with parents are that they are largely positive. They convey an understanding of the parents' challenges and discuss how relationships can differ and evolve. One staff member, below, is confident in her good bond with parents:

> *I have a good relationship with the parents. I have an open line of communication with them. They are happy to contact me with their concerns and trust me.* (Principal Teacher of Pupil Support, LA2: Sch.2)

A Deputy Head Teacher from the same school communicated "I hope it is a positive one although there are always pressures that can make that relationship more difficult. My aim is to assure them that we are all wanting the best for their child". Staff seem to understand that distrust appears to derive from the parents' fear that staff will not care or support their child as they would themselves, given that there are multiple pupils to care for in school:

> *I felt sometimes they were a bit like trying to get me to understand that they did have other kids in the school, and they couldn't work their whole school just to suit Christina. I wasn't interested because that's your job, you go and manage that. I've got one and I want you to do the best job for her that you can.* (Debbie Grant, Parent)

For Debbie, she understands that her daughter is not the only child in school that staff will be supporting. She does expect that her daughter is given the best support available to her and that her wellbeing and education is valued as it is at home. Mrs Rea expressed that 'building

good relationships with parents is very important' and goes on to say that she believes the staff in her school do just that:

> *We have pretty good relationships with parents… the guidance staff are obviously a key part in it as well, so we do try and have that kind of open conversation with parents. I mean we are never going to get it right all the time, but I think we do a pretty good job. We have very few parents that are complaining.* (Mrs Rea, Head of Pupil Support, LA2: Sch.1)

For Mrs King (Principal Pupil support, LA1: Sch.1), relationships with parents are different, and some are easier to build than others because all parents have different experiences and "it just depends on where the parents are and how they are able to cope with their child, or their children". Parents of autistic children may share similarities in terms of parenting and supporting an autistic child, but these will not be experienced the same within each household. This is because autism presents differently in every child and because household circumstances are not the same for everyone, for example, some may be lone-parent families, with or without siblings, some may be more affluent:

> *The parents are protective, yet vulnerable as they can sometimes be coping with a very difficult home life, so I try to keep this in mind… I would like parents to feel they don't have to "fight" - sometimes relationships start of negatively because they assume they're going to have to fight.* (SLA, LA1: Sch.1)

Regardless of the family circumstances, Mrs King states that the relationship between home and school has "got to be a two-way partnership. There's no point us doing something at school if it's not going to be followed up at home". Mrs Couper **(**Head of Pupil Support, LA1: Sch.2) supports this view and stresses that relationships with parents are important for navigating some key challenges:

> *I personally find most of our parents very supportive and we work together. One of our biggest challenges is homework. Children with ASD… homes not for work, schools for work so that can be quite a challenge. So I would work with parents and say look we're going to change the terminology a little bit.* (Mrs Couper, Head of Pupil Support, LA1: Sch.2)

Irrespective of the tone of the relationships, these are evolving and are always "developing and ongoing" (Autism Teacher, LA1: Sch.1). At times these relationships can be frustrating and complex, but also positive. The findings have shown that for both parents and staff, the relationship between home and school is an important one for supporting autistic pupils in school.

7.2 Intergenerational Relationships

7.2.1 Multi-layered Pupil/Parent Relations

Parents in this study are key to supporting autistic pupils in school. They demonstrate insight into the needs of their children and the problems that they encounter in relation to school. Louisa understands that her son will have experienced many challenges during his school day, and she prepares for him coming home in ways that will make him feel better and help him to unwind:

> *Usually at school he has not been to the toilet all day, so the first thing he does is comes running in and nearly breaks down the door because he is desperate for the toilet. I tend to have his milk ready and a snack. Then he needs to decompress for a wee while, so he'll go on his iPad and watch a YouTube video for a wee while or whatever and then I'll say to him, right I'm going to give you your tea and then you've got homework to do.* (Louisa Biggs, Parent)

Despite the loving and nurturing nature of the parent-child relationship, there can sometimes be misunderstandings that could be related to both the parent and child divide as well as the autistic/neurotypical differences:

> *So I didn't cope well, due to the segregation of my peers and limited help from teachers and at home no one knew how to help so I was just to get on with it which made me feel very depressed.* (Christina Grant, Age 18, Follow-up Interview)

Christina suggests that she is aware that her mother is unable to help her emotionally cope with the difficulties that she experiences at school. It could be suggested that this stems from a lack of understanding from a neurotypical parent towards an autistic child[22]. However, some tensions arise due to the parent-child boundaries that are typical of this relationship. For instance, parents have a duty to send their child to school, despite knowing that their child suffers in this environment. This can go against the parent's instinct to nurture and can make their child believe that their parent does not understand their situation: For instance, one pupil (Christina, Age 18) conveyed in her diary activity that "I would have preferred not going to school at all. I only ever stayed home from school when I was physically ill as if I'd said to my mum I was too sad to go to school she'd tell me to go anyway". Christina's quotation also indicates that her parent's authority is a position that she understands, accepts and adheres to

[22] It is important to note that some of the parents did recognise that they too may be autistic, although none had sought or received a formal identification.

as a child. Thus, tensions within the relationship can to some extent be a result of the ways in which childhood and adulthood is constructed. For some parents, these rules and boundaries can be tougher than they typically would be so that the child is not given special treatment and is not defined by autism:

> *I'm not one that lets him off with 'I'm autistic I can't do that'. So maybe I am harder on him but I'm trying to instil into him that life doesn't owe you anything… and yeah, you want to play your video games all day, but we cant. We have to do things. So, I will say to him, can you hoover for me please and he won't give me any backchat.* (Louisa Biggs, Parent)

While Louisa takes this approach, for Debbie, below, unless she knows that her daughter needs support in relation to school or more formal matters, she tends to give her daughter more space. Debbie goes as far as to say that without school, she would not interact much with her daughter:

> *I'd probably say more during the week just because she had something to say or something that had to be organised for school or something had happened. Whereas at the weekends or holidays, she was here with me so there wasn't really anything upsetting the applecart, so probably more when she was at school than at weekends… I dinnae need to be grilling her about every aspect of her life.* (Debbie Grant, Parent)

However, it should be noted that Debbie's daughter is 18 years old and is thus older than Louisa's son who is 12 therefore Christina is at an age where she is experiencing more independence. Nonetheless, what the parents in this study have in common is that school plays an important part in their relationship with their child/children. This is somewhat attributed to the fact that school attendance is compulsory for their children and is therefore something that they cannot avoid, in addition to the frequency of attendance. Moreover, the parents commit a significant amount of time preparing for and supporting their child before, during and after school.

7.2.2 Evolving Relationships Between Pupil and Staff

One pupil in this study, Oliver (Age 12), expressed that he was lucky because all of his teachers were good. He particularly had a valuable relationship with one, stating in his diary that "She listens and understands me". Oliver is the only pupil who liked all of his teachers. For the other pupils, some relationships were positive, while others were not. Some pupils

articulated that they would enjoy a class if they felt comfortable because they were understood by their teacher:

> *I enjoyed my classes in sixth year as they were the three classes I was confident in and also the teachers within the classes, particularly art, were nice to me, as in very patient and understanding.* (Christina Grant, Age 18, Follow-up Interview)

As Christina demonstrates, some relationships that pupils have with their teachers can positively influence their school experience. Most families had one key worker at school that devoted time to the pupil (and the parents) and provided them with practical and emotional support. This not only emerged from the diaries and interview transcripts but was visibly witnessed in the participants' body language whereby they became more relaxed and smiled while speaking. Russell (Age 13) wrote in his diary that what he likes about his guidance teacher is that "she listens to me even if she's busy". For Stephanie, her relationship with one member of staff was valuable to her school experience in many ways:

> *Mrs Murray, she is my go to person if something happens at school. She helps me a lot… she's really kind, she's an easy person to talk to. And she's funny. If I'm upset she takes me into the room and calms me down.* (Stephanie Morgan, Age 16, Follow-up Interview)

Stephanie's relationship with Mrs Murray plays a vital role in her education. Without the support of Mrs Murray, it is unlikely that she would have attended school at all. During an interview with Stephanie's parents (Lawrence and Gaynor), they stated that if Mrs Murray was not at the school that Stephanie "wouldn't go. She absolutely wouldn't". Thus, the relationship with this particular member of staff had quite a significant impact on the family. Susanna agrees that some teachers stand out above the rest:

> *Mrs Cassidy, she is probably more insightful with Jason than the rest of the teachers because she sees him, and she sees how he is reacting in a day… Jason always seems to get on better with females. It's a single unit family so I don't know if that's why, but she really is a lovely teacher and she just knows Jason.* (Susanna Gray, Parent)

This raises an important point regarding how pupils may respond to teachers depending on their gender. This could be down to single-parent households as suggested or could be related to the belief that females are typically perceived to be more caring and nurturing than males. Susanna identifies that relationships between pupils and staff can also negatively impact on how the pupil learns:

> *I know instantly within a few weeks of Jason going to school whether he will pass that subject and that's down to the teacher… if he doesn't trust that teacher or just doesn't click with that teacher, that's it. I went up last year and said he's going to fail his English this year, this teacher is not going to be right for my son… He failed miserably. He gave up halfway through the year.* (Susanna Gray, Parent)

As Susanna highlights, a poor relationship between the pupil and the teacher can create barriers to learning as they both coexist in the classroom space. As Mark (Age 14) expresses, some relationships with teachers, specifically his registration teacher, is very poor "She gets on at me for anything I do. She's not very nice to me". This can be typical of any pupil-teacher relationship; however autistic pupils have additional challenges when in school. For example, as mentioned in Chapter 4, Mark experienced difficulties with this teacher because she did not understand that for him school uniform created sensory challenges. Mark's experience suggests that for some autistic pupils the structure of secondary school is better suited. For instance, it allows them to experience different teacher-pupil relationships that are more favourable than others. It could be considered that having the same teacher every day in primary school may bring a sense of stability, particularly if the relationship is a positive one. However, the variety of teachers in secondary school removes the potential to be solely taught by one member of staff that the pupil may have a negative experience with:

> *I don't know, he seems to really enjoy secondary, whether it's because he maybe gets a teacher that doesn't get him, but he's only got him for 40 minutes. Whereas in primary, you had that teacher all the time so if they really didn't get you, you had a really hard time. Equally, if they did get you, you had a good time. Cause you felt accepted.* (Louisa Biggs, Parent)

School staff expressed that relationships with pupils can be enjoyable and positive, sometimes difficult, and always evolving. Some stated that these will differ depending on the child, with their own challenges and behaviours that are specific to them. Mrs King (Principal Pupil Support, LA1: Sch.1) communicated "Well again that will be entirely dependent on the pupil and they are all different personalities". Another staff member from the same school supported this view in her email interview:

> *I have different kinds of relationships with different pupils. With some pupils I have built a relationship of trust whereby we have conversations about things that are bothering them, or we may have a laugh and a joke as this makes it easier for them to do some work if the atmosphere is light. It always takes time to build a relationship.* (SLA, LA1: Sch.1)

It could be suggested that smaller schools in which the pupils are well known by staff or those who are supported in smaller groups within the base setting also impacts on the nature of relationships. For example, a Deputy Head Teacher (LA1: Sch.1) stated in her email interview "when I know the child, relationships are usually good'. The majority of staff did report that interactions with pupils were largely positive:

> *I feel that I have a good relationship with our autistic pupils. They are happy to talk to me about issues within school. I would like to think that they are trusting of me.* (Principal Teacher of Pupil Support, LA2: Sch.2)

It is well known that many autistic people will have specific interests. Mr Martin (Head of Pupil Support, LA3: Sch.1) discussed how good relationships are formed through staff taking an interest in the special interests of the pupil. This is supported by an Autism Teacher:

> *I find that showing an interest in what they are interested in is hugely beneficial. Rather than just rushing straight into a lesson – a short chat about what they are interested in works really well… Key to engaging pupils is often hooking into their interests/hobbies and where possible using this as a means to make a connection with them and also teach them using their interest.* (Autism Teacher, LA1: Sch.1)

This brings to light a positive element of monotropism, which at times can be portrayed negatively. For some of the teachers in this study, it has been a positive tool for building relationships and assisting in learning. However, despite efforts to build positive relationships with the pupils, not all of these relationships come easily and have to be worked on. One SLA (LA1: Sch.1) stated that "I formed good relationships with some of the pupils, but it is not easy to achieve this". The above quotations make important observations about autistic pupils and why they should not be classed as a homogenous group. For instance, autistic pupils may share some commonalities with the challenges they experience in school, however, they are also individuals with their own personalities. Just as the young people differ from each other, the relationships that they experience can also change throughout the school years:

> *Your relationship changes as they get older. The relationship that I have with a lad that is in 6th year is very different from in first year... so it changes as they mature and go through their stages*. (Mrs Couper, Head of Pupil Support, LA1: Sch.2)

Relationships are not fixed but can change and be built upon throughout the years as one Autism Teacher (LA1: Sch.1) describes in her email interview as "They are still developing. We are moving towards trust". One point of view on staff pupil relationships stood out as an

exception to the rule by a Pupil Support Worker (LA2: Sch.1) who classified them as "Fine, professional, not overly 'friendly', just calm and matter-of-fact". For the most part, staff are reflective about their relationships with pupils and identify positive modes of engaging with them. Moreover, they recognise areas of difficulty, which often comes down to communication between the the two groups.

7.3 Communication: Modes and Effectiveness

7.3.1 Barriers and Opportunities of Interactions Between Pupils

As aforementioned, those on the autism spectrum can struggle in social situations, making communicating with others difficult. The data revealed that all participant groups recognise the difficulties that the pupils may experience in engaging with other pupils:

> *It's probably true to say that social communication and social interaction tends to be an area that is more difficult for pupils on the autism spectrum. They sometimes need a bit of support to understand the more nuanced aspects of communications, for example, taking things literally or misinterpreting things that are maybe intended as humour.* (Mr Martin, Head of Pupil Support, LA3: Sch.1)

These difficulties can contribute to pupils lacking motivation to interact with fellow pupils. For example, Stephanie (Age 16) stated in her follow-up interview that "I don't really like talking to anybody". Her mother explains that despite living in close proximity to her friend, Stephanie very rarely communicates with her:

> *She has got one that she has been friends with since first year. They text each other infrequently, but they maybe meet up together twice a year. She only stays up the road, but they are good friends.* (Gaynor Morgan, Parent)

This underlines that friendship and communication are not one and the same. For instance, it indicates that Stephanie does have friendships but that she chooses to communicate and participate in this friendship less frequently that might typically be considered the 'norm' and her preference is by using technology. Technology offers ways for pupils to communicate with each other. Communicating via online forums, such as Xbox can be both positive and negative for autistic pupils because it is a way for them to communicate without the face-to-face interaction that many struggle with. One pupil (Oliver, Age 12) expressed in his follow-up interview "You hear a lot of bad things about Xbox and how it is bad because it stops kids going out as much, but I suppose it is a good thing too for communicating. As long as you

don't overuse it". Oliver refers to debates surrounding the use of technology and the impact it may have on young people's social lives (see Ruzic and Debeljuh, 2015).

However, for young people who struggle with interacting outside of the home, such as with some of the pupils in this study, or those who are physically unable to do so, technology offers an important line of communication (Bengtsson et al., 2021). Nonetheless, it could be argued that it also makes it easier for others to ignore them, and as aforementioned (see Chapter 4), it is another mode for taunting or bullying autistic pupils:

> *The whole summer nobody has contacted him. He used to play Xbox live with them, but he's not been in that for a long time because they were ganging up on him sometimes. Easy target. Vulnerable.* (Louisa Biggs, Parent)

The findings have shown that the barriers for autistic pupils communicating with other pupils stem from the difficulties that they experience in general with communication and social interaction. They have shown that technology offers a mode of communication with other pupils that they are more comfortable with. However, this method can also lead to further isolation should other pupils choose not to participate.

7.3.2 Open Line of Communication between Pupils and Their Parent(s)

During face-to-face interviews and informal discussions with the parents, it was evident that it was important for them to listen to their children and to create opportunities for them to communicate. Susanna (Parent) underlines that listening to her son is important because it could indirectly reveal something to her about his school experience that might not have otherwise been communicated to her:

> *As far as school is concerned, if he was saying anything to me about it, like listening, trying to listen. Obviously he goes into his room and he takes some time to get his head together but even like picking him up in the car. I've recognised that that's the best time for him to talk. So listening when he's talking more cause he could just say something offhand that's the important thing in the day.* (Susanna Gray, Parent)

Thus it is clear that listening is especially important given the communication difficulties that some of the pupils experience. For instance, it became clear from the pupil and parents that the pupils prefer to avoid conversations focused on school (see Chapter 4). Thus, respecting their child's boundaries while at the same time being receptive to hearing their concerns is an

important line of communication between autistic pupils and their parents. This is often the case when pupils vent their frustrations and emotions to their parents, more commonly known as autistic meltdowns (Phung et al., 2021). In doing so, they are communicating to their parent that their day has been challenging. Rebecca described how her son Russell would have a ‘meltdown’, crying and shouting if things had been overwhelming for him that day. By receiving this outpouring, parents are communicating that they understand or that they are in a safe space to do so. This thesis does not suggest that this is the reality for all autistic pupils and their interactions with their parents, but that this reflects the experiences of the families in the current study.

Using technology is another means of contact that can mean that the pupil can communicate with their parents at all times. Parents expressed that their children would contact them frequently throughout the school day either by text messaging, direct phone calls, or via school staff which interfered with their work and leisure time (see Chapter 5). This points to the frequent and consisting challenges that the pupils experience throughout the school day (see Chapter 4). Moreover, it pinpoints that this method of communication is a valuable and accessible form of support for the pupils. However, it indicates that this can put a strain on the parent who is ultimately always on call. This suggests that while parents respect the boundaries of their children, this is not always reciprocated. It could be considered that this is typical of most parent/ PNT child communication, especially during the young person’s teenage years. The data has shown that communication between autistic pupils and their parents can be face-to-face, via text messaging and phone calls and is not always verbal. It indicates that relationships of understanding and trust form the basis of effective communication.

7.3.3 Confusion, Fear and the Role of Technology in Pupil- Staff Communication

What emerged from the pupil’s ‘About School’ activities, their diaries and follow-up interviews is that interactions with school staff, more specifically classroom teachers, can be frightening. Mark expresses that he does not understand his teacher’s approach and as a result seeks support from fellow pupils:

> *Depending on what teachers, some of them are quite loud and do rude things that I don’t really understand. They don’t really explain things the way that I understand, that’s why I ask my peers.* (Mark Morgan, Age 14, Follow-up Interview)

Russell (Age 13) also wrote in his diary that his new P.E. teacher shouts a lot when communicating with him “She’s a bit strict. She shouts too much. It would help me if… Everything was explained properly”. When asked how it makes him feel when his teacher shouts at him, he responded that he was scared. This suggests that this method of communication negatively impacts on his education. For instance, if he is scared he is unlikely to be retaining information and will instead be focusing on the fear. He is also unlikely to ask his teacher for help if she is unapproachable. In contrast, he goes on to describe in his follow-up interview his interactions with a former P.E. teacher who communicated in a way that was helpful to him “He helped me a lot. When I ever asked a question and if I needed help he would just come over and help”. Thus, teaching staff being approachable is significant for autistic pupils who may be struggling with communication and anxiety (see Chapter 4). Some communication seemed lost between Stephanie and staff. When she was discussing her enjoyment of home economics. She was asked why she did not attend this class if she enjoyed it. Her response suggests that this was a result of poor communication:

> *I haven’t been in a while. Cause we didn’t know that I had that class until a couple of weeks ago, cause they told me that it wasn’t happening. It was all confusing.*
> (Stephanie Morgan, Age 16, Follow-up Interview)

Stephanie repeatedly mentioned in her about school exercise, her diary and interview that she did not like speaking to anyone. Therefore, she would have been unable to speak with staff regarding this class; which explains why the confusion lasted so long. It is also possible that due to her frequent absences from school there was a lack of clarity, or opportunity, to update Stephanie on the changes to the class schedule. Therefore, it is also possible that this information had not been passed on to her parents for them to relay it to her at home. For all of the young people in this study, parents play a vital role in the communication between themselves and staff. When specifically asked what support he received in class, one pupil (Jason, Age 17) replied “teacher and mum liaise a lot and I have a tutor”. Thus for Jason, he views his mum liaising with his teacher on his behalf as a form of support. In an interview with Mark Morgan’s (Age 14) parents, they discussed how by communicating the challenges that Mark had experienced in relation to bullying to the school, they were able to act on this and put measures in place:

GM: they didn't know until we came home, because he'd carried on, so I sent them an email…
LM: Cause Mark won't say anything. Or grass.
GM: No but you would think they would pick up that somebody was upset, however they didn't, so I emailed the school and they spoke to the boy, whoever he was and made a plan. He's got a separate place to change which is really difficult because Mark doesn't want to be somewhere different to change but for his safety he needs to be. (Lawrence and Gaynor Morgan, Parents)

This interview extract pinpoints the importance of the parents' communication with school staff to support pupils who are unable or unwilling to raise issues with staff themselves. However, Christina (Age 18) explained in her follow-up interview that "I asked the teachers within the department for help myself in person and that didn't help so my mum tried and still got nowhere". Although Christina conveyed her needs directly to school staff and despite her mother also communicating these needs, support is not always forthcoming. Oliver's mum (Louisa) expresses that there are benefits to her son using technology in the classroom and adds that new software[23] that she is currently waiting on will enable effective communication between home and school:

GLOW is supposed to be communication between his teachers and him and it's a software basically, but a lot of teachers hasn't embraced it, so they don't use it. Oliver uses his iPad in class to write things down, so he has to bring his iPad home. I download it to a server then I have to upload it to them. But I don't get any notification from them to say thanks I got it. Whereas I think GLOW should be used for internal conversations and also to make communication better. (Louisa Biggs, Parent)

Louisa's son Oliver (Age 12) described how his favourite teacher is one who "lets me use my chrome book and explains things well". Therefore, just as technology can play a significant role in pupils communicating with other pupils, parents and friends, the data has found that it is also a favoured form of communication for some pupils to communicate with staff and to enable their parents to communicate with school on their behalf. The findings also indicate that communication between pupils and staff has the potential to impact both positively and negatively on their school experiences and the education that they receive.

7.3.4 General and Specific Forms of Communication Between Parents and Staff

[23] Glow is Scotland's national digital learning platform provided by Scottish Government and managed by Education Scotland. It provides learners and educators across Scotland an environment that can support learning across the whole curriculum: https://glowconnect.org.uk

The parents' email interviews and informal discussions revealed that it is difficult for parents to convey their child's needs if there is little or no avenues of communication available with the school. In order for the parents to share information with the school on behalf of their child, they believe good communication with staff is necessary:

> *It should be that you have someone that you can call or email straight away and say just to let you know Oliver really didn't have a good time, he didn't sleep well at all last night and he is going to be on edge today. You email them and they don't get back to you for three days. Sorry, I wasn't at my email, or I was out of school or I asked the teachers and they said he was fine.* (Louisa Biggs, Parent)

The above quotation also highlights the time delays that can occur between school and home. It also underlines in what manner the difficulties that are perhaps considered to be more personal to the pupil has the ability to significantly impact on their experience of school. Similarly, it is important for incidents that may have occurred at school to be communicated to the parents:

> *They need communication with parents because she would have all these things happening at school, they would deal with them and I wouldn't know anything about them. So the next meeting you would go to they would say oh aye and after that happened… I was oblivious. I didn't know it had happened. So even just a text or an email to say this happened the day so you can say to her tonight are you alright or what happened and what can we do so it doesn't happen again.* (Debbie Grant, Parent)

Meetings are one way of parents communicating their child's needs to school staff, and vice versa. School meetings take place for pupils who require support. Attendees include parents, multiple staff members and may include outside agencies such as social workers, speech and language therapists and educational psychologists. As outlined in Chapter 5, meetings can be daunting and overwhelming for parents. However, Mr Fairns (Deputy Head Teacher, LA2: Sch.1) discloses "we've had some feedback recently from surveys that said we need to improve our communication as a school. But none of the complaints have centred around individual child planning meetings". Regardless of the effectiveness of meetings, they are often spaced out with months apart. As presented in Chapter 4, autistic pupils face challenges and difficulties that can arise more frequently, thus the parents deem it necessary to contact the school more regularly. Phoning the school is one method the parents use to communicate their child's needs:

> *If it was something that had to be sorted there and then I would phone them. I couldn't always phone them cos I wasn't aware of it until at night when I came in [from work] and the school was shut… and then if you were phoning the school it would be oh they're teaching, or they are at a meeting.* (Debbie Grant, Parent)

Debbie thus further indicates the difficulties with delays in contacting the school. The time delay can not only be frustrating for parents but also for their children who may have expected faster results in relation to their problem, or as Rebecca states, it can lead to her son not trusting that she did in fact call to speak to someone at school:

> *His guidance teacher is not always available during the day because obviously she teaches as well. So generally just leave a message with the office in the hope that they will get her to call back at some point. It is often the next day. So Russell will have left for school thinking that I am going to phone and speak to her this day, so he will then come in from school and say what did the teacher say, well she hasn't phoned me back. So then you can see his frustration, did you really phone her? Yes I did, I just haven't spoken to her yet though. So yeah it can take a few days to get any kind of response.* (Rebecca Griffith, Parent)

This underscores the difficulty in the young people speaking directly to school staff and the importance of their parents communicating on their behalf. Moreover, it indicates the stress that is placed on parents to resolve issues for their children, which may impact on the parent and child relationship. Rebecca also mentions above that Russell's guidance teacher, teaches mainstream classes, which highlights that communicating via phone calls or text messaging, is not always suitable for some staff:

> *I've got one lady who texts, that's not always brilliant for me because I'm not always good at looking at my phone all the time. I don't carry it with me when I'm working, it sits on the desk… Others are not so happy doing telephone conversations. We do telephone conversations as well and Emails.* (Mrs King, Principal Pupil Support, LA1: Sch.1)

As Mrs King emphasises, due to the dissatisfaction surrounding delays communicating via phone, some parents have settled on email communication. Mrs Rea (Head of Pupil Support) and Mr Fairns (Deputy Head Teacher, LA2: Sch.1) both discussed during their joint interview that following a survey completed by parents it emerged that parents are preferring email communication. This preference for communication also arose during interviews with the parents. For example, Susanna (Parent) stated "Emails. A lot of emails. Now. It used to be more face-to-face. But I've got contacts that I know I can chat with and then every so often I will demand a meeting [laughs]". It can be taken from Susanna's quotation that she thinks emails is a more accessible mode of communication between herself and school. Her choice

of the word 'chat' also indicates the relatively informal relationship she has with some staff members. This suggests that more frequent issues that she has to discuss with the school are relayed in this way and that more serious matters are reserved for formal school meetings. Another parent highlights the positives and downsides to communicating via email, but particularly appreciates the benefits of the 'paper-trail' that is created:

> *I find if I phone it gets lost. Friday was a perfect example, I phoned to say I was coming for Mark and it didn't go anywhere? So I email. But obviously that has got a bit of a time delay. At least that way I can go back and see what's all been said.* (Gaynor Morgan, Parent)

One parent chose to write a letter to her son's P.E. teacher to communicate that Russell is unable to participate in gymnastics. Participating in gymnastics evokes anxiety and stress for Russell. His mother wrote that he would willingly take part in other sports and activities and that it was important not to alienate Russell but to make him feel included. She also explained that by trying to make him take part, he would feign illness on the two days of the week that P.E. took place. However, despite her efforts to communicate these concerns to staff, she felt they were ignored:

> *I'm not doing it for the sake of my health, I've sat here and written you an A4 sheet of paper explaining what will happen and I know you will be phoning me or the office will be phoning me saying Russell is ill can you come and collect him, or he will get in trouble because he will just pretend he hasn't got his PE kit or something like that… the teacher didn't get back to me at all but said to Russell well we'll work on your confidence and flexibility so that hopefully in a few weeks' time you will be able to join in. So, he then came home and fell apart because he said he is still going to make me do it.* (Rebecca Griffith, Parent)

This less formal mode of communication is not taken as seriously as others may be. For example, face-to-face methods such as those during formal meetings or one-to-one are confronting and hold others accountable. Similarly, as aforementioned, email communication provides evidence of conversations and requires a response. Thus written notes to individual teachers does not necessitate a reply and is disposable. Rebecca indicates that miscommunication with staff can lead to frustration for the pupil because they do not have a solution to an issue that they might be experiencing. This can create stress or tension at home, as Rebecca describes as her son falling apart. Other forms of communication were diaries that are shared between home and school, newsletters, and information shared via online sites:

We have a wee kind of home/school diary that some of the kids in the base use and they take it home very night, we can give a wee bit of feedback or pass on notes. But equally mums and dads and parents and carers can send in any wee worries they have or things that the kids mention at home, we keep the lines of communication quite open…. It's been quite useful. I don't know if maybe an online thing would be better for that in the future but at the moment we are just using wee school diaries and its going okay. (Mr Martin, Head of Pupil Support, LA3: Sch.1)

Mr Fairns, mentions that his school does utilise online modes of communication, which he claims are good methods for reporting to parents:

The school's quite good, the head teacher puts out newsletters every term, and the school library can facilitate the Twitter and the departments themselves have twitter and the bulletin every day. The school bulletin is put on the website, so parents can see it. I think the communication bit is pretty good. (Mr Fairns, Deputy Head Teacher, LA2: Sch.1)

However, online forms of communication is not accessible to all parents who do not have access to the internet. Thus, there are various forms of communication between staff and parents, some which are general school information and some specific to their child. While face-to-face methods of communication was once a preferred method, it does not occur as often as frequently as is needed to communicate pupils often daily changing needs. Moreover, it could be considered that face-to-face communication is off-putting to some parents who feel like 'neurotic parents'. Parents time is often dominated by communicating with the school in relation to their child's immediate needs, and in some cases in relation to their longer term needs but is also taken up while waiting on a response. For some parents, communication *from* the school can be seen as too frequent:

Every week I am getting a phone call to say Russell is not feeling well. Can you come and pick him up. Or will we send him home. Yes, send him home [in a resigned voice] but he's not ill. Last week I said no he can stay he is absolutely fine, tell him to try a wee bit longer… Three times they phoned me and eventually I went fine I'll come and get him. (Rebecca Griffith, Parent)

Parents' time can be interrupted on a regular basis by the school to collect their children. As it appears to be almost expected that this will happen, it could be considered that the parents time is also obstructed, with the potential to impact on plans they may have made. This constant contact with the staff throughout the school day/week impacts on parents' time away from their child. When a child attends school, it is typically a time for a parent to relax or to have a break from parenting. It would ordinarily provide them time to focus on doing things around the home, socialising with others, pursuing leisure activities or attending work

without the added responsibility of supervising their child. Moreover, while the parents have stressed that their time is taken up a great deal by communicating with staff, this works both ways. Staff time can also be taken up with parents contacting them or them communicating back to the parents about their child's time in school that day/week. It is worth bearing in mind that they will be communicating with many parents given that they support multiple pupils in any one day. It could be suggested that this can impact on their time that would otherwise be spent supporting and educating the pupils. The staff appeared to be happy with the overall communication with the parents and certainly did not appear to be as frustrated by it as the parents did. This likely derives from the emotional attachment the parent has to the child and their child being their only focus; whereas the staff have multiple children to support on an almost daily basis.

7.3.5 Systems of Communication Among Staff

The staff data from their email and face-to-face interviews regarding the effectiveness of communication between colleagues produced mixed responses. One Deputy Head Teacher (LA1: Sch.1) describes communication between staff in her school as "*generally good - available in written format or orally through consultation".* The data reveals that communication within the base, or support department, in particular, is regarded by staff as being extremely good:

> *Excellent – working in a Base setting there is a lot of sharing communication. For example if a pupil has had challenging behaviour in one lesson this is passed on to whoever has that pupil next. More formal communication comes in the form of paperwork – e.g. targets for each pupil.* (Autism Teacher, LA1: Sch.1)

As aforementioned, no mainstream classroom teachers participated in this study, thus communication between these staff members are not included. Nonetheless it is positive that communication within a base setting appears to be effective. Moreover, some staff deem that the communication between the base and mainstream school is excellent. For example, one Pupil Support Worker (LA2: Sch.1) stated in her email interview that "this department excels at communicating ASN information to other mainstream staff within the school". For some parents, however, the base department in school can seem separate from the mainstream setting. One parent describes how this can mean teachers not being up to date with issues regarding the pupils needs:

> *For me it seems they are separate. I don't know the system they use, but if they are teaching a class, they should know about who they've got in the class.* (Gaynor Morgan, Parents)

Communicating among mainstream support and teaching staff can be more problematic because of the many teachers that a pupil will see at secondary school. For instance, one SLA (LA1: Sch.1) discusses that "often a pupil will be supported by several different staff members in one subject which means none of them is fully up-to-date with what is being taught". She continues by saying that "as many pupils need constant supervision, there is no time available when all staff can meet together to discuss pupils or other issues." This raises the issue of the time required for staff to effectively communicate across departments and reiterates the challenges that staff experience in relation to lack of time (see Chapter 6). Various systems of communication between school staff were put forth from the staff interviews. One method is meetings between key members of staff being held who then pass on information and outcomes to relevant departments:

> *What tends to happen is there is a school leadership meeting once a month. I would go to that on a Monday night; key focus areas are discussed. I would feed that back to the teaching staff. On a Tuesday we have a departmental meeting, so if I was at that kind of meeting I would say well we talked about this, this and this. So this affects us or doesn't affect us… Then on a Wednesday morning I tend to speak with the SLA staff.* (Mrs King, Principal Pupil Support, LA1: Sch.1)

Other face-to-face modes of communication were highlighted by a Deputy Head Teacher (LA2: Sch.2) "we communicate individually with staff and also highlight issues at staff meetings. We have an open door policy for any staff who wish to discuss a pupil". The above quotations indicate that efforts are made in attempts to inform and update different staff members within different departments across the school. It could be considered that these forms of in-person communication is time consuming, given the scope of teaching and support staff in mainstream secondary schools. Less time-consuming modes of staff communication with further reach are information being fed through a tannoy system and a daily information sheet being sent electronically to staff.

It emerged from the data that many schools have their own electronic system of flagging up pupils' needs across the school. These differ in name and style but essentially all have the same goal. Mr Martin believes that this form of communication is positive but identifies areas for improvement:

> *We use something called a passport to success, which has key things about a young person on them… so it's about flagging up what specific traits they might have and what they might find tricky… They see it electronically, so on our class register pupils might have beside their name a little green flag. It's just a wee prompt to teachers that you need to know something about this pupil and if they then click on it, it brings up a wee hyperlink to the passport to success.* (Mr Martin, Head of Pupil Support, LA3: Sch.1)

He clarifies that as well as using the link to the passport to success, some teachers like to have hard copies, which they keep in folders. He believes this to be positive because it means that teachers can easily access the information without barriers. A Deputy Head Teacher from Local Authority 2 explains that they too use learner profiles as well as other forms of communication between staff. He goes on to say that learner profile systems are good, when they are adhered to, but that this in itself can be problematic due to the workload of staff:

> *So there are certainly systems in the school. It's just going back to the staff and getting them to use them with some consistency. And we do have to keep reminding staff, this is this child's needs that is in the book and you are not meeting them because you've just not looked.* (Mr Fairns, Deputy Head Teacher, LA2: Sch.1)

The consequence of learner profiles, or similar electronic systems, not being utilised is that it can create problems for pupils:

> *There didn't seem to be a lot of communication across subjects. They said their system was all electronic so they were telling her teachers her diagnosis and things that had to be put in place from her speech and language therapists report and then she would go into history or whatever and her seat would be changed. And she'd be moved, and she would be like no I want to sit here, I feel comfortable sitting here… I think well if that History teacher had known Christina's diagnosis, she wouldnae have changed her seat.* (Debbie Grant, Parent)

A further incident occurred when Christina had telephoned her mother upset because a tutor was not aware that she was to receive extra time for an assessment. When Debbie called the school, she was disappointed that they were unaware that this had been put in place for Christina and as a result her daughter was anxious and upset. Overall, there are mixed messages about staff-staff communication. Parents do not feel that the communication between staff is as effective as it could be, and that important information is being lost along the way. At times, they feel that things are having to be repeated about their child's needs. Whereas staff for the most part, and particularly in the base setting, feel that their communication is excellent. Many of the schools have systems in place to encourage and prompt communication, such as face-to-face meetings and electronic profiles. Although,

some do acknowledge that work needs to be done, mostly in keeping classroom teachers updated with the pupil's situation.

CHAPTER EIGHT
Discussion

This chapter discusses the findings that were presented in the previous four chapters in more depth. These discussions are structured around the central themes of this thesis: Challenges; Support; Relationships; and Communication.

8.1 Pupil, Parent and Staff Challenges

8.1.1 The Practical, Sensory and Socio-Emotional Challenges of Autistic Pupils

The findings have shown that the pupils experience sensory challenges that are amplified due to the busy school environment (see Chapter 4). The difficulties they experience relate to sight, touch, smell, sound and taste (Larkey, 2007). Sensory issues were reported as being problematic in busy corridors and social areas (Ashburner et al., 2013). However, smaller environments, such as the classrooms, were also found to create sensory issues in relation to noise associated with voices, equipment, and smells (Jones et al., 2020; Schaff et al., 2011). Unavoidable day to day practices within the secondary school environment created further difficulties, for example, the volume and sound of the school bell and the discomfort of wearing school uniforms. Despite some schools in this study being smaller than others, sensory issues were raised by all of the young people. However, it was identified that a smaller school would perhaps be more beneficial to autistic pupils because this allows staff to be more aware of each pupil and their struggles; in turn being able to support them better (Osborne and Reed, 2011). This builds on Blatchford et al.'s (2011) study, in which observations were carried out on 686 pupils in 49 schools to examine relationships between class size and observation measures. At primary and secondary levels, smaller classes led to pupils receiving more individual attention from teachers and having more interactions with them than those in larger classrooms.

The data collected via the task-based activities and follow-up interviews revealed that for the pupils the social element of secondary school is complex. For the girls, one expressed feeling lonely and isolated (Christina) while the other (Stephanie) revealed that although she did not wish to form friendships, she did not want to be lonely. For the boys, most expressed enjoying time with friends, nevertheless some struggled with larger groups of teenagers and

preferred to socialise in smaller settings within the base. The findings revealed that attending the base setting also created feelings of being judged by PNT pupils. From their observations of 18 autistic children and 17 PNT children, Bauminger et al. (2000) uncovered that autistic children reported higher degrees of loneliness. While others have found that autistic girls have more friends (Dean et al., 2014) and are more interested in forming and sustaining friendships than autistic boys (Calder et al., 2013; Cook et al., 2018; Sedgewick et al., 2016), it was the girls in the current research that found greater difficulty in forming and maintaining friendships[24]. The boys in this study all had friendships but these friendships rarely existed outside of school, which brings into question the quality of these relationships (Bauminger and Kasari, 2000). For many of the young people in this study, interacting with other pupils via technology was preferred. Nonetheless it was disclosed during pupil and parent interviews that some of the young people were excluded from online gaming, which may have added to their feelings of rejection and loneliness.

As data from several studies have identified, reputation can be important to autistic pupils (Calzada et al., 2012; Humphrey and Lewis, 2008; Jones et al., 2015). This is evident in the pupil data as it discovered that disclosing for some of the young people made them feel judged and some made attempts to appear like the PNTs. For example, some of the pupils refused help that would make their challenges more visible such as using a toilet pass. This supports Humphrey and Lewis' (2008) assertion that disclosing can lead to feeling marked and difficulties fitting in. One of the young people (Russell) appeared to have no issue disclosing his autism and despite being bullied because of it did not attempt to change his behaviour. This supports Cage and Pellicano (2016) who argue that some autistic people prefer to be true to themselves and accepted for who they are as opposed to altering their behaviour.

As the qualitative data from all participant groups revealed, bullying was a challenge for the autistic pupils, which ranged from being excluded from friendship groups to name calling to physical assault (Card et al., 2008). Autistic pupils' victimisation is a major problem for young people as research has suggested that individuals on the autism spectrum may experience higher rates of bullying than their PNT peers (see Humphrey and Hebron, 2015; Zablotsky et al., 2012). A comparative study by Kloosterman et al. (2013) designed to examine percentage

[24] It should be noted that only two female pupils participated in the current study.

rates across different types of bullying behaviour in autistic adolescents (n = 24), adolescents with additional support needs (n = 22), and a group of PNT peers (n = 24) determined that more autistic adolescents reported victimisation than adolescents in the other two groups. In addition, those on the autism spectrum reported more social bullying in comparison to the other two groups, and more physical bullying than the PNT group. An important issue emerging from the data is that bullying also occurred via online social media sites, such as Facebook, and instant messaging services such as Snapchat (Canty et al., 2014; Cassidy et al., 2009; Fredstrom et al., 2011; Vandebosch and Cleeput, 2009). In Chapter 4, one of the pupils (Christina) discusses how she is cyber bullied. There has been relatively little literature published that focuses on children and young people with learning and developmental disabilities and their experiences of cyber bullying (Didden et al., 2009), or specifically on autistic pupils being bullied online (Kowalski and Fedina, 2011). However, the findings in this study raise concerns regarding autistic pupils being victimised at an attainable distance, for example, being targeted whether they attend school or not. Moreover, it could be considered that this form of bullying is less visible to others, such as parents and staff, and as a result may mean less intervention.

Transitioning from primary to secondary school is reported as frequently creating significant stress for autistic pupils (Hannah and Topping, 2012; Lee et al., 2014). This is a time where relationships can change, and become diluted, both those with other pupils and with teachers (Rogers, 2007). Despite these challenges, transitioning from primary school to secondary school was not specifically mentioned by the pupils. The staff spoke in great detail about the measures that are put in place to help support young autistic pupils transitioning from primary school to secondary education. However, it was highlighted that more could be done to support pupils transitioning from one year group to the next. For the general population, the stress associated with transitioning to secondary school is short lived (Tobbell, 2003). It has been argued that this is attributed to the relaxing effects of the summer holiday (Lohaus et al., 2004). What the findings have shown is that micro-transitions for the autistic pupils in this study were particularly challenging for the pupils. For example, returning to school following a break such as holidays, weekends, or following a period of absence.

Overwhelmingly, a challenge that the pupils experience is a heightened state of anxiety (see Chapter 4). Some staff did reveal in their face-to-face and email interviews that anxiety is a common issue for pupils across the board regardless of being autistic or not. However all pupils experienced anxiety in this current study as disclosed by themselves, parents and staff.

This supports MacNeil et al.'s (2009) claim that young autistic people experience greater levels of anxiety than community populations and similar levels to clinically anxious people. Experiencing anxiety will also impact on the pupils' ability to form social networks and navigate social resources in higher education (see Lei et al., 2020). Some of the young people described in their follow-up interviews and diary entries that being in a heightened state of anxiety can make it extremely difficult, if not impossible, to focus on what is being taught. Therefore, these difficulties alongside the other challenges that have been outlined in this study that the young people experience in relation to secondary school affects the education that they receive.

Moreover, education is negatively impacted because school refusal is more common in autistic pupils (Munkhaugen et al., 2017). Staff showed in their email and face-to-face interviews that due to anxiety, autistic pupils often refuse to attend school. This was supported with the data from the task-based activities and follow-up interviews with the pupils, in that all but one of the pupils expressed their desire to be home-schooled. Some did attend school at their parents request, which could be associated with the legitimate power and authority of their parents (Beetham, 1991; Hindess, 1996; Punch, 2005; Scott, 2001), while others refused or frequently returned home soon after arriving at school. As some of the parents emphasised, their children's education is also impacted by time spent being taught in support areas of the school, typically referred to as the base, and not in mainstream classes. Nevertheless, this is also a complex area given the pupils challenges within mainstream spaces. This has implications for the pupils' future education/career prospects but also for their experiences during secondary school and the implications for their mental health.

All of the young people described feeling a range of emotions; sad, angry, stressed and upset. For one pupil (Mark), the stress of school invoked intense reactions and at times made him physically sick. The findings have shown that most of the challenges that the pupils experience, and that negatively impact on their mental health, are associated with the social environment of school (Cook et al., 2018; Hodge et al., 2019; Humphrey et al., 2015; Reed et al., 2012; White et al., 2020). For example, Christina spoke at great length about her feelings of low self-esteem because of not being accepted or understood by her peers and teachers (Goffman, 1963). This supports Hodge et al. (2019) who assert that dealing with stigma can make autistic people feel unworthy. According to Winchell et al. (2018) alongside low self-esteem, victimisation can lead to loneliness and depression. All but one parent disclosed that

their child had mentioned, or attempted, suicide. There is a high rate of death by suicide in autistic young people (South et al., 2021). In a study conducted in Denmark (Kolves et al., 2021), it was found that autistic individuals are three times more likely to attempt suicide than those who are not autistic. For the young people in the current study, victimisation was not specifically underlined as being the root cause of this; however, as all had experiences of victimisation to varying degrees it is not unrealistic to point to this as being one of the contributing factors.

It has been argued that routine can simplify everyday life and provide a sense of normality and predictability (Marshall, 2005). However, as Alldred et al. (2002) assert, the regime of school life does not equate to feelings of safety. This is the case for the pupils in the current study in that despite autistic pupils favouring routine for the stability that it brings (Beardon, 2019; Hedges et al., 2014), the challenges that they experience within the routine of school life threatens this. While attending school, the pupils are challenged with overwhelming sensory issues (see Chapter 4), including for some (Russell and Mark) the uniform they are expected to wear. They also have to cope with the complexities of social relationships and shared social spaces. However, what is of particular importance is that the data found that these challenges are not isolated to the school building. Similar to the findings in Alldred et al.'s (2002) study, home is a place in which the pupils could relax from the constraints and challenges of being in school. However, preparing for and thinking about school in the home environment also creates stress and anxiety for the pupils. Moreover, the space between home and school creates sensory, social, and emotional challenges for the pupils. Hence the challenges experienced by pupils in relation to school are relentless and sustained in both the public and private spheres of their lives with little time to relax and decompress.

8.1.2 Labelling, Worries, and the Impact on Parents Mental Health and Wellbeing

Parents revealed through interviews and informal discussions that they are concerned with the level of education that their child is receiving in mainstream secondary school. This is particularly a worry for some of the parents whose children have been removed from mainstream classes and taught in the base or learning support area; or who switch between mainstream and base. These concerns develop into future worries about how their child will be equipped for life after school if they do not have the required grades or qualifications. These concerns feed into a national US study (Shattuck et al., 2012) on long term outcomes

for students with disabilities which revealed that autistic students were among the poorest of any disability category (see also Ivey, 2007). Moreover, the parental concerns speak to Bell et al. (2017) who claim that developing self-determination skills in secondary school is a key predictor of success in higher education. Parents also worry that their child will not have gained important skills during their time at secondary school, which have been found to be an important predictor of post-secondary success for autistic pupils (see Nasamran et al., 2017).

In addition to worries about their child's education and future prospects, parents are concerned with their child's wellbeing. The findings revealed that parents worry that their child is not, and they understand, cannot, be afforded the same attention to their difficulties as they do at home. Therefore they fear that their child is not coping or is feeling sad, excluded or bullied while at school. These findings highlight that parents of autistic pupils are faced with the dilemma of their child being educated but also with protecting their child's mental health. This thesis argues that such dilemmas are born from clashes between the value systems of home and school that are integrated within policy aims (Alldred et al., 2002), such as Getting it Right for Every Child (GIRFEC) in Scotland, and Every Child Matters in England and Wales.

The parents' views on how the school dealt with bullying varied. For two parents (Rebecca and Susanna) their child was punished after responding to bullying behaviour. Rebecca also mentions how she raised concerns of bullying at school meetings and questioned why these discussions did not appear on the minutes of the meeting. She disclosed during her interview that the response that she received from the school[25] impacted on the trust that she invested in school staff. This supports Zablotsky et al. (2012) who argue that parents are unlikely to view the school positively if their child has been bullied. For another parent (Debbie), however, she believed that the school managed the bullying of her daughter Christina extremely well.

Meetings for the parents are daunting and intimidating. Parents expressed that there is a divide between the school and other professionals attending, such as speech and language therapists, and the parents. For some this is no more intimidating than speaking in front of others in any setting. However the added pressure of securing support for their child can create tension and make it an emotional experience. Feelings of anxiety and frustration

[25] The school disclosed to her that they did not like to add instances of bullying to the minutes as it reflects badly on the school.

occurred not only during the meeting but also in the apprehension leading up to the meeting. There was frustration attached for some parents who felt that they were not being listened to and were discussing the same issues at subsequent meetings with no sign of progress. For some this felt like empty promises, which impacted on the trust they have in school staff. There are some studies which look at parent evenings (for example, MaClure and Walker, 2000; Ranson et al., 2010). The findings from the current study will contribute to the little research that exists in relation to the communication between parents of autistic parents and school staff during meetings.

The constant need to contact the school makes parents feel as though they are neurotic mothers. Most believed that they were being perceived as a nuisance to the school, although they had not necessarily been outwardly named as such. Thus, they felt that they were being labelled as an irrational mother as opposed to a caring parent. This raises awareness to the difficulties that parents are faced with in finding the 'right' balance to their level of input into school matters. For instance, parents who are not so vocal or assertive in their child's school journey, or who do not attend meetings may be labelled as neglectful by school staff (Ericsson and Larson, 2000). Having to regularly battle for their child's support impacts negatively on the parents' mental health and wellbeing. So too does not knowing if their child is being treated well in school. According to Mancil et al. (2009) parents of autistic children consistently report more stress than those of PNT children. Studies have shown that mothers in particular report poor mental health (Hayes and Watson, 2013; Khana et al., 2011; Whitehead, 2017). The findings support these claims as they highlight that mothers take on the majority of the responsibilities of supporting their autistic child through secondary school. Mothers have little respite from these responsibilities due to cultural expectations of childcare and women's work (Gray, 2003). The data shows that supporting their children impacts a great deal on parents' time before, during and after school. As a result, this leaves little time for leisure activities and impacts on employment.

The findings revealed that some of the parents experienced poor mental health and wellbeing and one parent (Louisa) disclosed that she takes medication for depression. Parents expressed how they experienced feelings of guilt following a formal identification of autism. For Debbie, this was a profound milestone for her daughter and her family, and it changed the course of how she perceived that their lives would look (Crane et al., 2018). Some felt that they were to blame and worry that they have failed their child. For some, these challenges derived from not

being given enough support or information following diagnosis and as a result feeling that they did not understand autism. These findings confirm Galpin et al.'s (2017) outcomes that parents of autistic pupils feel unsupported. The research to date has tended to focus on the impact that coping with the caring responsibilities and the behaviour of an autistic child has on the parents mental health and wellbeing (Qian Ping Ang and Ru Loh, 2019; Sivberg, 2002; Zablotsky et al., 2012). An important finding from the current study is that witnessing their child's mental health issues and stress and anxiety also impacts on the parents' mental health. For example, the findings in Chapter 4, revealed that parents experienced distress in sending their children to a place that brings them anxiety and the emotional impact of their children discussing or attempting suicide.

8.1.3 Institutional Constraints and Behavioural Hurdles

Although some staff were happy with the support they delivered, many explained that they do not have the time or resources to best provide the support to autistic pupils (Kucharczyk et al., 2015). Many considered that the current curriculum is not suited to autistic pupils and that they would benefit more from a different approach to learning. Thus, they believe that they are limited when it comes to supporting them in the way they would like to. Time was also taken up teaching and supporting pupils across a range of settings, leaving little time to prepare as effectively as they would have liked. They suggested that this could perhaps be resolved somewhat by reducing the amount of time autistic pupils spent in school giving them time to meet and communicate about the best steps. Teachers in a London study (see Farouk, 2014) expressed that being promoted to a desired senior position which focused on individual pupils with support needs, came with additional administrative tasks that monopolised their time.

Staff discussed how autistic pupils have varying degrees of behaviour that can be challenging to the teaching and support staff, for example, violent or aggressive behaviour which can be intimidating. It is challenging for staff when there are groups of autistic pupils and/or pupils with additional support needs being taught or supported together, which can create tensions among the group (see Humphrey and Symes, 2013). One study (Lindsay et al., 2013), which explored educator's challenges of including autistic pupils in mainstream classes, found that understanding and managing student behaviour was challenging. Moreover, it revealed that teachers felt they lacked adequate information about autism and how to appropriately manage

a child when a behavioural outburst occurs (Kucharczyk et al., 2015). Some teachers find it difficult to engage autistic students in lessons, noting that they often have specific interests and become frustrated when asked to do something different (Lindsay et al., 2013). Contrary to these findings, the data for this thesis revealed that staff used these special interests as a means to form relationships with the pupils. For some staff, challenges derived from witnessing a vulnerable autistic pupil struggling in school.

8.2 Support for Pupils, Parents and Staff

8.2.1 Emotional and Practical Support for Pupils

The parents in this study play a key role in their children's academic achievement and motivation. This supports existing literature which acknowledges parents as having a significant and positive impact on children's educational achievement (Desforges and Abouchar, 2003; Grolnick et al., 2002). It was shown from the pupil and parent data (see Chapters 4 and 5) that pupils receive the majority of their support from their parents, and more specifically, their mother. In this study, the mothers took on most of the responsibility of supporting their child. Although it should be noted that of the five families who took part, two were single-parent households. Nonetheless, it was the mothers from all families who contacted the school, attended meetings, prepared their child for the school day and collected them from school, during school hours, when needed. One father did attend meetings in the past until his employment changed and he had to work further from home. Another father helps with driving his children to and from school when they struggle to make their own way there. He also attends meetings with his wife, although they both acknowledge that it is his wife who takes the lead role in matters concerning their children and their education. These findings support Kim and Hill (2015), and Olley (2012) who stress that the parenting literature is still largely focused on mothers. Others argue that the adoption of a 'gender-blind' (Pfitzner et al., 2018) and undermining approach (Carpenter, 2007; Ghate et al., 2000) leads to men struggling to assert their involvement with professionals working with their children.

The data confirms that a key source of support that the parents provided was creating visual charts and timetables for their children. This is similar to a Scottish study (Rutherford et al., 2020) that found that timetables, sequence charts for daily routines, social stories, home/school diaries and timers were the most commonly used visual supports for autistic people. The pupils

in the current study responded well to this support and some mentioned that they would like to have something similar in school to help them with their classes.

In addition to the support received from parents, two of the pupils (Mark and Russell) discussed that they receive support from other pupils, especially those who also have their own support needs. It was shown that for each of the families, one particular member of staff stood out as being an invaluable source of support. These staff members typically provided emotional support alongside practical and educational assistance to the pupil and their parents. These findings fill a gap in the research regarding support that autistic pupils receive from other pupils and key members of staff.

Building on the work of others, the base was underlined as being a space that helps the students receive the support in secondary school. It is a smaller space, allowing for less sensory issues than mainstream classes. Many young people on the autism spectrum rely on one-to-one teaching, at least for part of the day, and find it challenging to work cooperatively with others. They may also require more direct input from teachers to help them progress (Adamowycz, 2008). Smaller groups are taught within the base meaning there is more attention for the pupils and makes it easier for the staff to teach them. Being supported in the base allows for some autistic pupils to switch between base and mainstream classes (Eldar et al., 2010; Mesibov and Shea, 1996). It also enables the pupils to interact with other pupils with similar needs. However, staff members highlighted that this can sometimes be problematic as behaviours and needs can clash (see Chapter 6). The base is also available to autistic pupils during social times, given them a space to retreat to. Knowing that this space is available to the pupils also gives their parents peace of mind.

The qualitative data has shown that amended timetables are a form of support available to the young people. An amended timetable helps to ease the pressure of attending classes or school full-time. It might mean that some pupils do not have to attend all classes but can sit out some classes in the base, or only attend school for a few subjects each day or spread across the week, easing the pressure. It can also mean starting the school day later than normal or finishing earlier which helps with some of the challenges pupils experience in relation to large crowds. Staff agree that a reduced timetable for all autistic pupils would allow them to recover from the days that they do attend. However, a flexible timetable does not remove the many challenges that will still be experienced while attending school. Lawrence (2012)

argues that a ‘flexischooling’ approach for autistic pupils, that is, the flexibility between mainstream school and home-schooling, would be beneficial. While there are many benefits raised by Lawrence, the parents in the current study discussed how they did not feel equipped to educate their children at home. Others stated they could not afford to do so because this would mean being unable to work. Thus, home-schooling or flexi-schooling is not an option available to all parents.

The data confirms that the pupils receive various types of classroom support. For example, some received the help of one-on-one classroom assistants, or one-on-one help at home with their schoolwork. However, due to limited funding and resources, this support was only offered for a short time or was removed with little notice. According to Leibowitz (2000) classroom assistants can be in short supply due to funding issues. The pupil data illustrated that they require lessons to be taught to them in a way that they understand, which may not always occur from the classroom teacher. Some pupils did receive support for their subject classes but not all. It was expressed by parents and pupils that some teachers provided more support to pupils who had more obvious support needs. This is an important finding given that autistic pupils can often mask to fit in, and as a result they appear to be coping and are overlooked (Cook et al., 2018; Goffman, 1963; Kanuha, 1999). Most expressed wanting more time to complete tasks, (see Chapter 4) likely due to processing issues relating to autism and taking into account the heightened level of anxiety experienced in the classroom. The issues associated with classroom, and other forms of support, for the young people is that it makes them stand out as different from the PNT pupils. Pupils can feel ‘marked’ by their diagnosis and worry that others knowing will alter how they are treated (see White et al., 2020).

The support that the young people felt was needed was for staff and pupils to be educated about autism. Parents of autistic pupils identify teacher training as the single most enabling factor in providing for their children in the mainstream setting (Jindal-Snape et al., 2005). This is because teachers play a key role in their successful inclusion in school (McGregor and Campbell, 2001). However a common finding conveyed in the international research literature on teacher attitudes towards inclusive education is that teachers do not receive the specialist teaching that they need to provide support to pupils with additional needs (Avramidis et al., 2000; Campbell et al., 2003; Florian and Black-Hawkins, 2010; Lambe and Bones, 2006; Marshall et al., 2002; Sharma et al., 2008). Avramidis et al. (2000) assert that

the SEN (Special Educational Needs) element of teacher training courses are very difficult to implement and monitor in practice.

A study by Morina and Melero (2020) found that from 20 educators who teach disabled students, the actions taken to meet the students' needs were as a result of their own willingness and the efforts of the students than any training they had received on disability. Parents in the current study expressed during their interviews that they would like to see more support available to their children that included social skills to best equip them for life. Moreover, many expressed that delays in receiving support were problematic and often was not put in place fully before it was time for their child to leave secondary school (see Chapter 5).

8.2.2 Inaccessible Support for Parents

The findings indicate that the parents did not feel supported following their child's formal autism diagnosis and that they were not armed with sufficient information about autism to help them process and cope (Pottie and Ingram, 2008). Specific and ongoing support following diagnosis, would help the parents to better understand autism (Bromley et al., 2004). Moreover, it would prepare them for navigating the education system. The parents did find some support within the school. As aforementioned, there is one key member of staff, typically, head of pupil support, that provides a great deal of support to parents (see Chapter 7). The support provided to their children means that the parents can be confident that the appropriate measures will be put in place. This in turn eases some level of stress and anxiety for them. Parents explained how having that someone at school who 'gets' their child and their needs in addition to the impact that parenting an autistic child can have on families is vital. It provides them with a point of contact that is more personable than frequent phone calls to reception.

With regard to more direct support for parents, and specifically to parents of autistic pupils, little was available within the school, or associated with the school. Most of the parents in this study sourced their own support outwith the school. For example, they were not aware of support groups or parent groups available to them. Of the few that did exist, these were found to be unsuitable; for example, they would not be specific to autism. This supports Galpin et al.'s (2017) findings that for parents of autistic children, being in touch with other parents who are, or have been, in a similar situation is a needed source of support. In a study

conducted in Saudi Arabia (Balubaid and Sahab, 2017), six out of eight participants who are parents to autistic children said that they found support groups to be extremely helpful. With regard to informal support in the current study, some of the parents felt supported at times, for example while attending meetings with a spouse or parent. Informal support plays an important role for parents of autistic children, particularly having someone to talk to (Heiman, 2002). However, it was the mothers who took on most of the caring and support responsibilities for their children. Bromley et al.'s (2004) research into mothers supporting autistic children found that mothers are more likely to experience psychological distress associated with low levels of family support, which is more so for lone parents.

For the parents who did attend conferences and external support groups, the experience was invaluable. One parent (Susanna) engaged well with external autism specific conferences and classes. This allowed her to mix with other parents of autistic children and share information on how best to approach particular challenges that might be faced in relation to school and other areas of their lives. The problem with these groups/conferences is that they are costly. Thus, autism specific support is not accessible to all parents, which may increase levels of stress (Pottie and Ingram, 2008).

As aforementioned, parents can find school meetings extremely daunting and intimidating. Support is needed to help speak on the parents' behalf, when they are unable to speak due to the emotion involved. Having an advocate would help the parents to feel less outnumbered. One parent (Louisa) paid for her speech and language therapist to attend meetings. However, not every parent can afford to do this and is therefore inaccessible to all. According to Dillenburger and Jordan (2014), 60% of mothers and 23% of fathers alter their work arrangements to meet the needs of their autistic child. Consequently, raising an autistic child can be financially challenging (Chamak and Bonniau, 2016).

Transitions is another area that parents need support with. Many felt overwhelmed at the thought of what would come next for their child following secondary school (see Chapter 5). Fears were linked to their child not having a job or education. They worry that their child will be restricted to the home with no friends and no quality of life. The consequences of these possibilities and the pressure it would place on them as parents, financially, emotionally and practically were also of great concern. Moreover, the parents expressed concern that the support that their child currently receives while in the education system would cease. This

thought was overwhelming to some parents and the apprehension was that they would have to deal with things on their own. Given the pressure that they currently feel while receiving support, transitions is a key area of needed support. These findings support Bell et al. (2017) who claim that there is limited evidence of transition planning from secondary to post-secondary education.

8.2.3 Educate the Educators

School staff provide a range of support and education for autistic pupils. Support tends to be on a bespoke level, whatever the pupil needs. This can range from listening and understanding behaviours, classroom support, arranging meetings, contacting parents, and communicating with colleagues. In order to fulfil their role, the findings have shown that staff are supported in two main ways. One way is to support the staff in their role, and many claimed that they felt that a lot of their support and learning came from colleagues. The other way is to educate and train staff so that they can provide the best support to pupils. Education and training is available to some of the support staff, with some expressing that they have completed autism training courses, conferences or university courses. Some of these courses are made available to them by their local authority. However, funding for these courses is an issue, which sometimes means that only a select number of staff can attend and then report back to the support team. Some staff highlighted that training is needed specifically for autism understanding. This builds on a growing body of literature that consistently shows that many teachers feel unprepared to support pupils on the autism spectrum socially, academically, and behaviourally (Hinton et al., 2008; Kucharczyk et al., 2015; Symes and Humphrey, 2010). For instance, the staff indicated via face to face and email interviews that they face considerable obstacles in managing pupils needs, partly due to the behavioural challenges of autistic pupils (see also Bowe, 2004; Lindsay et al., 2013).

All other participant groups also recognised that one of the most important challenges in working with autistic students in integrated classrooms is inadequate knowledge about autism (see De Boer and Simpson, 2009; Kucharczyk et al., 2015). One UK study (McGregor and Campbell, 2001) discovered that only 5% of teachers received training about autism even though most teachers had an autistic child in their class (see also Smith and Green, 2004). Parents in the current study expressed concerns that such gaps in training can result in their child and other autistic pupils missing opportunities to reach their full potential (Allen and

Cowdery, 2005). All participant groups proposed that more efforts should be focused on educating and training school staff. This speaks to the findings of a Spanish study (Morina and Carballo, 2017), in which teachers who took part in a training program on inclusive education and disability found that they felt more useful, better informed and more aware of student needs. The concerns that have been raised in the current study are not new. For example, Jordan and Jones (1997) recommended that specialist should be a central part of teacher training if schools are to meet the needs of autistic pupils and that policies should be in place to ensure it is received (see also Booth and Ainscow, 2002). The findings in the current study elevates the importance that the response to these challenges are prioritised and implemented. They are especially significant given that these were the concerns of pupils and parents and not solely those of staff.

8.3 Intragenerational and Intergenerational Socio-Spatial Relationships

8.3.1 Identity, Stigma, and Belonging

The findings indicate the relationships that autistic pupils have with other pupils can be complex. It is widely reported that autistic people commonly struggle to form and maintain friendships (Chevallier, 2012; Koster et al., 2009; Long et al., 2018), however this degree of difficulty differed for the young people in this study. For instance, for some of the pupils (Stephanie, Jason and Christina), relationships with other pupils were mostly negative and as a result they were often excluded and felt lonely (Card et al., 2008; Koster et al., 2009). Other pupils (Russell, Oliver and Mark) have small friendship groups, with pupils who they have known since primary school and who are aware that they are autistic.

Nonetheless, Oliver and Mark also experienced negative interactions with other pupils and were both subjected to name-calling and bullying (Humphrey and Hebron, 2015; Zablotsky et al., 2012). These findings add to the literature on friendships for autistic young people and underscore the complexities and grey area of relationships. For instance, many of the young people in this study were bullied but also had friendships (see Chapter 7). This speaks to Winchell et al.'s (2018) research that suggests those who are bullied typically do not have a large friendship group to support or protect them. One of the pupils (Stephanie) has a distant friendship insomuch that she texts one particular friend who lives close to her home but very rarely meets up with her in person. Thus, this form of friendship is less likely to be known to others and unlikely to ward off threats from other pupils who mean harm.

Mrs Rea (Head of Pupil Support) observed that many autistic pupils at her school attend clubs without knowing that each other are autistic. Thus, the pupils do not necessarily form close relationships or one-to-one friendships, but it could be suggested that they feel part of a group, and thus a sense of belonging. According to May (2011), belonging is essential for connecting individuals to the social and it is through this relational process that the sense of self is constructed.

A few of the parents mentioned that their child struggles to identify or judge if another pupil is a friend or not. One parent (Susanna) stated that her son (Jason) would tell her that he was unsure if someone was being genuine or if they were instead trying to hurt him. These challenges could be associated with theory of mind (Chown, 2017) or as Beardon (2019) terms, cross-neurological difference, and further supports the difficulties described for autistic people with communication and interaction (Beardon, 2019). There was only one set of siblings in this study, but this relationship was found to be positive, particularly for the younger brother (Mark) who received advice from his sister (Stephanie) about matters concerned with navigating secondary school. Current literature exists that discusses both the negative (Jones et al., 2019; Mascha and Boucher, 2006; Roeyer and Mycke, 1995) and positive (Macks and Reeve, 2007; Rossetti et al., 2018) aspects of sibling relationships between autistic and PNT siblings. For instance, Macks and Reeve (2007) disclose that there is increased empathy and prosocial behaviour of those with autistic siblings and Rossetti et al. (2018) underline the protection that autistic pupils experience from their PNT siblings. The current findings speak to the existing literature relating to the positive aspects of sibling relationships within families with one or more autistic family members.

The pupils indicated that being isolated or rejected by other pupils was due to their autism diagnosis being disclosed to others (Calzada et al., 2012; Humphrey and Lewis, 2008; Jones et al., 2015). Christina told how she felt as though she has autism stamped on her forehead. This suggests that for Christina, she believes that other pupils labelled her with autism and excluded her as a result (Goffman, 1963). Christina also spoke in great detail in her diary and follow-up interviews about how she was not perceived to be 'autistic enough' and as a result she did not present as having visible disabilities. Instead, Christina and other pupils in the study eluded to being perceived to be 'odd' or 'weird' and ultimately, different to PNT pupils. These findings relate to Manetti et al.'s (2001) research which contrasted different groups of children with

invisible disabilities and found that those with moderate invisible disabilities received higher social acceptance than those whose were mild. The authors concluded that children with severe disabilities may be accepted differently and be treated more positively than their peers with mild invisible disabilities due to having an obvious need for help with daily living skills.

One Head of Pupil Support (Mrs Couper) noted from her observations that typically friendships that were formed at primary school often break apart as the pupils' progress through secondary school. She believes that this is due to reputation and what some pupils might have once found quirky about their autistic friend no longer fits with the new friendship groups they are creating. Thus, as some literature suggests, it is not the diagnosis itself that creates negative relationships but rather the behaviour of the pupil (see Koster et al., 2009; Lindsay et al., 2013). For example, in Lindsay et al.'s (2013) study, ten teachers mentioned the challenges in creating an atmosphere of understanding for autistic pupils. They state that children often realise there may be something different about an autistic child but are unaware of the official diagnosis, or of how these differences exhibit as behaviours. This makes it difficult for teachers to create an understanding and empathetic environment within their class. Consequently, autistic pupils are often excluded which is similar to the findings of this thesis.

Some of the young people and their parents communicated in their interview data that they were aware how other pupils with additional support needs were treated by peers and thus they did not wish others to know about their diagnosis. Cage et al. (2015) suggest that young children may be capable of managing their reputations. However, secondary school is a time in young people's lives that marks many social changes that may lead to increased concern for reputation (Sebastian et al., 2008). Parents and pupils in the current study told how measures were put in place by the young people to protect their reputation and to avoid negative treatment from other pupils. These included attempting to attend regular mainstream classes and foregoing an amended timetable and refusing some offers of support, such as a bathroom pass, so that they would not stand out. This is similar to Milton's (2013) observations that the social experiences of autistic individuals are different to that of typical individuals, in that they may pretend to know how social situations work to hide their social difficulties from typical peers. Thus, it is plausible that autistic individuals would be to some degree concerned about what others think of them.

8.3.2 Formal and informal managed interactions between Parents and Staff

Many of the exchanges between the parents and staff members took place during school meetings. Parents describe these experiences as daunting and like being back at school due to the multiple professionals facing them. Thus relationships with staff during meetings can make parents feel that they have less professional input into their child's support despite knowing their own expertise regarding their child. There is little literature relating to school meetings. However these, typically one-to-one, interactions, to some extent reflect relationships that are formed during parents' evenings in school. Maclure and Walker (2000) studied parents' evenings in five UK secondary schools (11-18-year olds). For the authors, home-school relations is a complex practice of surveillance and negotiations whereby parents and staff are required to render themselves visible, exposing themselves to the risk of critical scrutiny (see also Keogh, 1992, p. 89).

The parents communicated during their one-to-one interviews and informal discussions that the relationships they have with school staff can be frustrating. These frustrations often arise due to staff perceptions of a pupil's support and educational needs in comparison to the parent's in-depth understanding of their child. One of the concerns that parents expressed was that their child was a priority to them but was only one of many pupils in school. They discussed that they knew their child, and their needs, best and became frustrated when they knew that some offers of support were not suitable for their child. For instance, Mark was offered mindfulness exercises and his mum Gaynor knew that he would not be able to visualise scenarios, such as sitting on a beach, to benefit from such an exercise. Jason was offered to seek out a member of staff if he had any issues or needed to talk, but his mum Susanna knew that he would not be able to approach the teacher himself.

Findings in the present study speak to Maclure and Walker's (2000) research on parent evenings which found that teachers are afforded the right to use professional and specialist vocabularies, while down-playing parents' distribution of their own privileged knowledge of the pupil. One way the authors maintain that parents attempt to increase or retrieve their share of power is to make use of opportunities for 'expertise trading'. For instance, parents might seek to offer privileged information that the teacher does not have access to. This is a means of staking a claim to the specialist knowledge utilised by the teacher to let them know that they too are experienced in matters concerning their child. In the current study, parents were not

without power in relation to their child's experiences at school and most parents would contact the school to implement changes. For example, Debbie insisted that her daughter Christina be moved back to a seat in one of her classrooms that she was comfortable with. Susanna persevered with her assertion that her son Jason be allowed to sit exams that she knew he was capable of.

Besides the more formal relationships that take place during school meetings, many of the parents spoke positively about staff. Positive relationships were considered to be made with one key member of staff in particular (see Chapter 7). These relationships are important to parents and provide them with someone approachable that can be trusted with their child's wellbeing. This relationship enables the parents to discuss their own concerns and are a point of contact more familiar and intimate than with other members of staff. However, as uncovered in the findings, good relationships between parents and staff do not always equate to adequate support for the child. This is because support is not delegated to one member of staff but is rather a whole school approach (Avramadis et al., 2000; Eldar et al., 2010; Graydon, 2006; Horrocks et al., 2008; Rogers, 2007).

During meetings, parents are faced with various members of school staff, who they will have varying degrees of familiarity and affiliation. Most one-to-one relationships with school staff in general were reported as being positive or agreeable. One parent (Debbie), however, had a particularly negative relationship with one staff member who she did not believe understood or acknowledged her daughter's diagnosis. This was particularly frustrating for Debbie, nonetheless it did not affect her relationships with other staff at the school. Some parents described feeling worried that the relationship they had with staff would impact negatively on their child in school. Louisa was concerned that she would come across as too pushy and that this would delay support available to Oliver. Therefore, it could be suggested that parents may employ a process of impression management (Goffman, 1959) to regulate their own behaviour and to alter their interactions with staff to avoid such repercussions. These findings are significant given the lack of research on parent-teacher relationships and goes some way to developing an understanding in this area within educational and sociological research.

The majority of staff claimed that they had good relationships with the parents. Although they acknowledge that there are some similar experiences of parenting an autistic child, they also recognise that family difficulties will differ with some having more pressures than others

(Mancil et al., 2009). This is evident in the study whereby one family has two autistic children in secondary school in addition to other younger children with additional needs. Two of the families are single parent households and thus take on the responsibilities alone. Another family household has two parents but experience tension due to different understandings of autism and ways of parenting their son. One family with two working parents are able to afford additional support services such as private speech and language therapists. Thus, this extra means of support is not accessible to all families in the study (Pottie and Ingram, 2008). Overall, the staff appear to accept that parents can be protective of their children and understand why they have concerns for their child's wellbeing at school. They appreciate the parents' views that their child is their top priority at home but not in school, given the number of pupils requiring support. In general, staff are happy with the relationships that they have with parents.

8.3.3 Supportive Colleagues

Relationships between staff members were only discussed at a formal level. Some staff did mention that they learned a lot and felt supported by their colleagues in their role in supporting autistic pupils.

8.3.4 Familial and Informal Relationships Among and Between Parents

Some parents touched upon the benefits of meeting with other parents of autistic children who attend external conferences (see Chapter 7). However, there was very little mention of relationships. For some parents who had attended local support groups, they did not bond or connect with other parents and ceased to attend due to differences among the group. For example, the groups were made up of parents of additional needs and were not specific to autism. This acknowledges the parents' need for support groups with parents of other autistic children (Balubaid and Sahab, 2017; Galpin et al., 2017).

Some mothers discussed their relationships with their husband. Two mentioned that their husband attends some meetings with them. For instance, one parent (Rebecca) explained that her husband had little understanding of autism and so most of the responsibility of their son's (Russell) schoolwork or dealing with the aftermath of school (meltdowns) fell to her. However, the informal support she received when he had attended meetings with her in the past was beneficial (Heiman, 2002). Another parent (Gaynor) expressed that her husband

(Lawrence) is becoming more understanding of the anxieties around school that their children (Stephanie and Mark) find challenging, but that this was not always the case. Two of the mothers are single parents and another did not discuss her and her husband's relationship in relation to supporting their son.

8.3.5 Informal Constraints

The relationship between the parents and pupils in this study are largely positive, with parents being nurturing and understanding of their child and their needs (Brown et al., 1993; Crozier 1999; Grolnick et al., 2002). Nonetheless, the data has also found that the challenges that the pupils and their parents experience in relation to school places stress and pressure on the relationship. It was evident from the pupil and parent data that parents put in a great deal of effort to help their children prepare for the school day, both practically and emotionally. They understand that the school day impacts on their child's mental wellbeing and stress levels and describe how they would put things in place for them returning from school. For instance, Louisa prepares snacks and allows her son (Oliver) to destress with his iPad. Another parent (Susanna) uses the time when she collects her son (Jason) from school to listen to him. The parents explained that their children would vent their frustrations to them when they returned from school. It could be suggested that the pupils have been holding in their frustrations and masking their emotions until they are in the safety of their home and their parents to release them. This finding adds to literature around the consequences of masking to autistic pupils. Moreover, it provides a new insight into the consequences that masking has on others, in this case the parents of autistic pupils.

The pupils voiced in their diaries and follow-up interviews that they appreciate the support that they receive from their parents. Education researchers have found that children in all age groups, including secondary school students, value their parents' help, interest and support (Brown et al., 1993; Crozier, 1999). However, some of the young people added that despite appreciating their parents support, there was a lack of understanding of the extent of their challenges in school. In their structured diaries the pupils were presented with the statement 'I want my parent/carer to know that for me school is…' Russell responded that he liked that his parents supported and encouraged him to learn and improve. He did not like that they did not see how scary school was for him with all the 'kids and noise and info' and claimed it would help him if they could live in his autism for one day.

Some of the tensions that arose in the pupil and parent data could be attributed to typical parent-child boundaries; for example the responsibility of the parent to ensure that the child attends school and receives an education (Blundell, 2016; Stainton Rogers, 2001). These responsibilities are conflicting because the parent must send their child to school knowing that this is not a good place for the child's wellbeing. The pupils typically have little control over the decision to attend school. Parents also had the power to make their children do homework, limit Xbox and Wi-Fi or reading time, which again is linked to their status as parent. In social psychology, researchers have given increasing attention to the notion of relationship schemas, and power schemas, that is, the extent to which individuals believe they have more or less power than the child (see Bugental and Martorell, 1999). However, some of the pupils in this study refused to follow adult instruction to attend school despite the parents' efforts and in doing so negotiated a degree of power (Baumrind, 2005; Crozier, 1999). In a similar vein, McIntosh et al. (2010) found in their research into food practices within residential care homes that at times the young people refused to eat the food that was provided and instead sourced their own 'unapproved' foods. Therefore refusal, for the pupils in the current study, could also be considered as a channel for the young people to acquire some control and demonstrate that children are active agents in their own lives (Tisdall and Punch, 2012).

The young people also exercised power by withholding information from their parents about some of their experiences at school. For example, Jason did not tell his mum (Susanna) about some instances of being bullied, with the intention of stopping her intervening. Pupils also had the power to control their surroundings when home from school by shutting down and not interacting with their parents (Jason, Christina, Stephanie). These findings adds to the literature on generagency (Mannion, 2012; Leonard, 2016; Mayall, 2002) and supports the assertion that the relationship between adults and children is multi-dimensional (Kuczynksi, 2003). One mother (Debbie) revealed that school was the thing that created most opportunities to connect with her daughter (Christina), as otherwise they both spend a lot of time in their own space and do not have a lot to say to each other. Thus the findings also underline the role of school between parents and autistic children as they demonstrate that while school can create difficulties in the relationship, it is also a medium to encourage interaction and communication for many of the families.

8.3.6 Formal Regulation

Some of the pupils described how they did not like specific teachers or that they did not look forward to their classes. For example, Russell did not like teachers who shouted too much or too loud. Mark had difficulty with a teacher who he claimed 'got on at him' for things that he did not see as being important (wearing the correct school trousers). Christina did not enjoy some of her subjects because her teachers did not understand her and explained that she felt more comfortable in school and in classes when they did. Maitles and Cowan (2010) found that 87% of pupils felt they were learning better because the teacher was trying to involve them (see also Deuchar, 2009; Fielding, 2001; Young, 1992). Thus, as with the findings in this thesis, it could be considered that feeling included, involved and understood is important for the pupils' wellbeing and their education (Mannion, 2007). Grandin (2006) observed from meetings and discussions with parents, teachers and specialists spanning 20 years that autistic students who go on to have successful careers had teachers who motivated them to succeed.

One pupil (Stephanie) stated that she would not have attended school at all if it was not for a key member of staff. Similarly, it was found in the qualitative data that parents support the view that there were key people at school who made a difference to their child's school life and education (see also Blatchford et al., 2011). However, it has been argued that positive outcomes cannot be achieved by just a few members of staff and that inclusion cannot rely on the interest, commitment and enthusiasm of one or two individuals (Barnard et al., 2000; Booth and Ainscow, 2002). This is relevant to the findings of this study because despite these strong relationships, it was often not enough for some of the pupils to attend school. For example, siblings Stephanie and Mark missed a lot of school due to the challenges and anxieties they experience. The one-to-one and email interviews with staff revealed that school staff do work together and have various tasks in their role of supporting autistic pupils. However, staff expressed that anyone can be key to supporting autistic pupils in secondary school, including cleaners, janitors, and lunch staff. Establishing a rapport with pupils has been noted by some teachers as being important. For instance, Mr Martin explained in his face-to-face interview that taking note of an autistic pupil's interests is a good way to connect and form a positive relationship (see Lindsay et al., 2013; Mannion, 2012).

For staff, relationships can also differ depending on the pupil. Some expressed that these relationships can be difficult due to the pupils' mood swings or violent behaviour. One

Student Learning Assistant (LA1: Sch.1) conveyed that dealing with such behaviours can be 'a frightening experience'. This coincides with Emam and Farrell (2009) who reported that teachers of autistic pupils experience tension when dealing with their difficulties in social and emotional understanding. These tensions include the anxiety the teacher feels over their ability to meet the needs of all pupils in the class, and these tensions can determine the quality of teacher-pupil interactions. Autistic pupils lack of interaction and behavioural problems that are sometimes displayed in the classroom can make it less likely for teachers to report having a positive relationship with them (Robertson et al., 2003). However, staff in the current study revealed that in addition to the challenges experienced in their role, there were also many positives of working with autistic pupils (see Chapter 6). For instance, one Head of Pupil Support (Mrs Couper) enjoys witnessing the personal progress that the pupils make, for example dealing with anxieties. Mrs King and Mrs Rea (also Head of Pupil Support) appreciated the skills that some of the autistic pupils held, which were witnessed both in the classroom and in school talent shows. Therefore, staff expressed that they enjoyed positive relationships with autistic pupils.

8.4 Communication

8.4.1 Benefits and Pitfalls for Pupils Communicating in Online and Offline Social Spheres

The data has shown that technology is a popular method of communication for the pupils. Technology offers pupils an alternative means of face-to-face communication with other young people and increases the scope for young people to form and sustain friendships (Punch and Vanderbeck, 2018). One pupil (Stephanie) texts her friend infrequently and has very little face-to-face contact with her; despite living in close proximity. This suggests that this is her preferred form of communication. These findings are particularly important when exploring friendships and relationships in school because even for someone who is considered a friend, there is still a lack of desire for autistic pupils to communicate regularly or in person. This highlights that interactions with people who are not considered close friends or trusted members of staff in school are unwelcome for some autistic pupils. Thus it supports the widely held contention that those on the autism spectrum face difficulties in relation to communicating with others (Beardon, 2019; Chown, 2017; Freedman, 2010; Robeyns, 2016).

Online gaming, such as via PlayStation, PC and Xbox also enables players to communicate with others using a headset and microphone. Xbox was mentioned by a few of the parents in relation to how their children communicated with other pupils. Bengtsson et al. (2021) found that during COVID-19 lockdown, online video games proved beneficial in maintaining a social life and provided a social space to maintain friendships. However, for the pupils in this study, online interactions were not always necessarily positive ones. For instance, Mark's parents (Lawrence and Gaynor) communicated that other pupils would taunt Mark online because they enjoyed his frustrated reactions. One mum (Louisa) explained that her son (Oliver) used to have fun playing online with his friends but recently has not been invited to interact. Social media platforms were a further means of exchange for some of the young people. However, these provided opportunities for bullying (Canty et al., 2014; Cassidy et al., 2009; Fredstrom et al., 2011; Vandebosch and Cleeput, 2009). One pupil (Christina) experienced harassment on Facebook, which led to her mum (Debbie) contacting the school to inform them of the issue. This suggests that technological methods of communication provide another avenue for others to exclude and target autistic pupils, who are susceptible to experiencing this at school.

Some pupils did communicate face-to-face with friends at school, mostly in smaller groups and in less busy settings such as the support base in school (Eldar et al., 2010; Mesibov and Shea,1996). These interactions were welcome during the school day. For example, some pupils (Russell and Oliver) enjoyed spending time with friends during break and lunch (Bauminger et al., 2000). Other pupils, such as Mark, expressed that walking to and from school with friends was something that they enjoyed. There seemed to be very little mention of face-to-face communication outside of school, with the exception of Russell who at the time of data collection had begun going on bike rides with a few friends on a Friday after school. It should be noted that some pupils attend after school clubs (Oliver) and groups during the weekend (Russell), however it is unclear how the pupils communicated with others while there. One parent (Susannah) did convey that her son (Jason) had previously attended various groups, for a short time, and he was more comfortable in the ones where he could communicate with adults as opposed to young people. Conversely, his level of comfort could also be attributed to his mum being in attendance at the same group. Exploring how relationships and communication preferences play out for autistic pupils outwith the pressures and challenges of school is an area worthy of future research.

8.4.2 Actions Speak Louder than Words

Face-to-face communication is the most common method between the pupils and parents in the current study. This form of interaction takes place in shared living spaces at home, and in the pupils' bedrooms and at times in the car on the way to and from school (see Chapter 7). Pupils often vent their frustrations to their parents, which can often present as meltdowns (Phung et al., 2021). In doing so, they communicate to their parents that their day has been particularly stressful. Interestingly, not talking and shutting down is another way that the young people communicate to their parents that they need space to decompress from the challenges that they have experienced at school that day. For example, Susanna explained how her son (Jason) would go into his room and put the bedcovers over his head for a while until he felt calm enough to join her in the shared spaces of the home. According to Punch and Vanderbeck (2018), open communication between parents and adults can create intergenerational power struggles. The authors assert that young people withholding information may safeguard privacy, power and identity.

Parents can react to their children's meltdowns or behaviours and respond with their own frustrations (see also Cantero-Garcia and Alonso-Tapia, 2017). During an informal discussion with Rebecca, she told how her husband would get frustrated at their son Russell because he did not understand his challenges or personality (Midence and O'Neill, 1999). Thus some forms of communication between parent and child are reactionary and stem from misunderstanding, stress and fear. However, some exchanges between parent and child can be deliberately firm (Zand et al., 2014). One parent (Louisa) is extremely supportive of her son (Oliver) but at the same time chooses to be somewhat firm because she wants to 'prepare him for life'. Most parents expressed that communication with their children on school days is more direct and firmer than it is on non-school days. This is because it can take repeated attempts to get the child to leave for school due to their reluctance given their anxieties associated with school. One mother (Susanna) describes interactions between herself and her son (Jason) as regimented. As with typical parent/child relationships, love is communicated via nonverbal communication (Sauter, 2017). One pupil (Russell) discussed his enjoyment of 'family time' where he would cuddle with his mum on the sofa.

Parents explained in their interviews and informal discussions that their children would message them via text messages many times throughout the school day. This was a popular method of communication to convey to their parents the struggles that they were

experiencing, and if they wished to be collected from school. According to one parent (Debbie), at times this method could be used for things that she considered to be trivial. Debbie recalls how years ago her daughter (Christina) had text her at work to say that she had the cold and she needed some handkerchiefs. She advised her daughter to go to the toilets to get some toilet paper and that she was not to contact her gran. This exchange motivated Debbie to create a chart for Christina to help her solve some issues on her own and to help her decide when things should be classified as an emergency or not. These findings underline the dependency that autistic pupils have on their parents which could be considered as being more urgent and frequent than it typically would for PNTs (Wells, 2009).

8.4.3 Advocacy, Technology and Ineffective Practices for Pupils and Staff Communication

It emerged from the findings that parents are key for communication between their children and staff and for advocating for their child's needs (Inglis, 2012). This was the preferred method for all pupils in this study. Pupils would relay struggles that they were experiencing at school to their parents and ask their parents to intervene. One parent (Rebecca) wrote to her son's (Russell) teacher at his request asking that he be exempt from one particular element of Physical Education. Most times, the pupils do not need to ask their parents to intervene, they do so driven by their role of acting in their child's best interests (Blundell, 2016; Grolnick, 1997). When one pupil's (Christina) chair was moved in one of her classes, her mum (Debbie) contacted the school to explain the difficulties that her daughter experiences with change and requested that the chair be moved back to its original location. However, such intervention can be seen as problematic by school staff (Tomlinson, 1982).

Depending on parents to communicate could be considered a common form of corresponding for young people and is not solely linked to school but also other areas of life where interactions with adults is required, for example, with doctors (Wells, 2009). However, autistic pupils have additional difficulties with communication, and they experience these difficulties more frequently than a PNT pupil (Beardon, 2019; Milton, 2012). Thus, it could be considered that parental involvement in their child's interactions with staff is more intensive and necessary.

Technology is another form of communicating that was mentioned by some staff, pupils and parents. One family (Biggs) in particular placed great value on using a Chromebook. Oliver's

mum (Louisa) spoke a great deal about the Chromebook and the benefits it would have for her son and herself with regards to communicating with staff. For Oliver, a Chromebook would allow Oliver to interact with his teacher while in his classroom from his Chromebook to her computer, taking away the need for face-to-face communication. Ferguson et al. (2005) also suggest that the use of technology is effective for decreasing the pupils' dependency on adults. For Louisa, it is her belief that this form of technology would allow her to communicate with staff regarding Oliver's needs more efficiently. However, this was also one of the areas of support that Louisa had underlined as being delayed. The findings indicate that technology favours a preference for non-face-to-face communication for the pupils and for the parents it reduces the need for numerous phone calls and emails.

Some forms of communication were regarded as ineffective. For example, one pupil (Russell) repeatedly spoke of his teachers shouting. This was mentioned in his 'about school' activity, his structured diary and his follow-up face-to-face interviews. Given the sensory challenges discussed in Chapter 4 and earlier in this chapter, this form of communication is frightening and anxiety inducing. At times the exchanges between staff and pupils is ineffective because lessons are being taught in a way that the pupils do not understand (Maitles and Cowan, 2010). This arose in many of the pupils interviews and was confirmed by their parents. Some of the parents had a good understanding of the difficulties their autistic child had in understanding concepts. They regularly mentioned how their child would take things literally and would need help to break this down to make it understandable (Hobson, 2012).

One of the ways that help autistic pupils understand what the teacher is attempting to teach them is via fellow pupils. Some staff members also recognised this as a particular challenge that the pupils would need help with. However, it should be noted that all staff in this study were all pupil support staff. Therefore, it could be considered classroom teachers may not have this level of awareness (see also McGregor and Campbell, 2001), particularly taking into account the findings that suggested that more education for school staff is required (Jindal-Snape et al., 2005). Some of the pupils mentioned that if their teacher was explaining something to them in a way that they could not understand that a fellow pupil would help break it down for them in a way that they could comprehend. This indicates the importance of pupils being understood, included and involved in interactions with teachers (Mannion,

2007). Moreover, it underlines the significance of the positive relationships that autistic pupils have with other pupils and peer-to-peer support.

8.4.4 Rules of Engagement between Parents and Staff

The findings have shown that, for some of the parents, better communication is needed between themselves and staff. It emerged from the interviews with parents that communication with school staff is much more frequent than the typical yearly updates. The challenges that some autistic pupils experience are frequent, at times daily, therefore parents engage in 'informal' conversations with teachers to discuss their concerns. Many of the parents telephone the school, write letters or notes to staff, send text messages, leave notes in their pupil's school diaries, and send emails. Flood-Grady (2015) claims that there has been an increase in parents preference for frequent email communication, text-messages and social media. For the parents in the current study, sometimes communication is more formal and traditional whereby parents will request a face-to-face meeting. School meetings provide an avenue to be able to discuss child's needs, but these are often few and far apart leaving daily issues unmet in the meantime.

The findings are relatable to the little research that exists on parents' evenings, as this thesis suggests that formal school meetings discussed by the parents and staff are to some extent similar arenas for communication between home and school. The dominant historical tradition in UK education is that parents attend a parents' evening to receive updates of their child's progress (Baker and Keogh, 1995; Ranson et al., 2010). From this perspective, parents' evenings are occasions where the institutions of home and school are made visible and morally accountable to one another. For instance, during the parent-teacher exchange, parents can confront teachers regarding how they are educating their child and helping them reach important targets. Similarly, teachers can confront parents regarding the ways in which they are helping their child to develop, for example keeping up with homework, that will assist them in helping the pupil reach these targets. Thus, parent's evenings are a domain in which parents and teachers hold one another accountable, both for students' problems and their progress (Bilton et al., 2017). It is also during these encounters that the issue of good and bad parenting and teaching arise. However for the parents in this study, their child's needs are more pressing and thus communication with school is much more frequent and at times, less formal.

The issue with these less formal methods of communication is the delay that can occur. For example, parents disclosed that some staff may be busy teaching and will not have the time to respond to their emails immediately, which may leave parents feeling pushed aside. This supports Lindsay et al. (2013) who found that a barrier to poor communication between parents and teachers related to engaging parents and maintaining an open system of exchange. One staff member, (Mr Martin), in the current study communicated in his face-to-face interview that he understood why some parents can contact the school on a regular basis because it derives from concern about their child.

It became clear from interviews and informal discussions with the parents that they value good relationships with staff to be able to communicate their child's needs. From the data it could be considered that good relationships for the parents were those in which they felt staff understood them and their family circumstances, acted on their concerns, and were approachable (see also Lekli and Kaloti, 2015; Vickers and Minke, 1995). Relationships of this kind provided the parents with a sense of safety. All of the staff in the study expressed that communication with the parents was good. Nonetheless, one school in particular took on board recent feedback from parents that this is an area that could be improved. Some of the ways that school staff communicate and involve all parents, is by providing newsletters and using social media, such as Twitter; although the latter may be inaccessible to some parents who do not have the means to utilise this method (Flood-Grady, 2015). While recognition of the need to involve parents in the life of the school grows in public policy, according to Ranson et al. (2010), their intervention can create a great deal of anxiety in schools at the growing incidence of the 'angry parent'. The authors note that at times when parents are particularly upset or angry at a situation, they may be vehement in their response (storming).

The above relates to one parent (Debbie) in the current study who was furious with one member of staff who did not accept her daughter's (Christina) diagnosis or seemed to belittle Christina's struggles. Debbie described during her interview how she responded to this particular member of staff 'I blew my lid. I was standing at my work screaming at her, just about doon the phone". 'These situations may occur because communication between staff and parents can potentially question the integrity of parents' personal domain, their sense of responsibility for their children and their well-being, and their need for respect and mutual understanding (Maclure and Walker, 2000; Ranson et al., 2010; Sennett, 2003). One mother

(Susanna) in particular believed that during meetings staff seemed to imply that the problems were not linked to their school but to home life. She found this particularly difficult because she believed that she did not have the knowledge or know her rights and that it left her feeling like "a wee squashed mess".

Some literature argues that at the other extreme, some parents can feel extremely troubled by a particular experience or aspect of school practice, yet remain silent, wanting to speak but unable to do so (Heath, 1992; Ranson et al., 2010). The argument is that this kind of minimal response is characteristic of responses to expert-talk. Parents passivity during exchanges with teachers, therefore, may seem surprising given that they concern a person whom parents know better than the teacher. However, the teachers' knowledge of the student is firmly located in domains to which the parents do not have direct access such as reading age, test scores and examination predictions (MaClure and Walker, 2000). Parents in the current study did not feel that the teachers, for the most part, knew best regarding their child's needs. They did express that at times they feel intimidated in the meeting setting being faced with multiple professionals; however, they were not passive. At times some parents struggled to say what they wished to due to their emotions. For example, some parents would cry during meetings because they were discussing a meaningful topic, their child and the support that they needed. For one parent (Debbie) she was clear that she would say what she had to say, despite sometimes crying out of anger and frustration: "I just think no I'm articulate enough to sit and get my point across and aye I'll get upset and I'll greet but dinnae talk down to me*"*.

Some of the parents did fear that negative communication with staff would result in consequences for their child, which caused them to alter their behaviour somewhat. For instance, one parent (Louisa) worried that at times by pressing for the Chromebook that was promised to help support her son (Oliver) that it would have negative consequences, stating that: "I don't want them to then take it out on him. I don't want them to go, you know what she's a pain in the butt… let's make sure he doesn't get one." Nonetheless, all parents did not hold back their interactions with staff in relation to their child's needs. Moreover, by 'fighting' and pushing for support they felt that they were being judged and labelled as a 'neurotic mother', however this did not deter them. Therefore, this thesis argues that parents are not passive during their exchanges with staff but that their agency is impacted by structural constraints (see also Dornbusch and Glasgow, 2009).

8.4.5 Use it or Lose it: Maintaining and Utilising Staff Communication Systems

The findings revealed that it is the view of some of the parents and staff that communication across departments, particularly between the base and mainstream departments, can be lacking. For example, staff in one department may not be aware of a pupil's challenges if this information is not relayed by staff in another (see Chapter 7). This is perhaps comprehensible given that there are many people, other than the classroom teacher involved in educating and supporting an autistic pupil including the head teacher, form teacher, classroom teachers and support teachers (Dybvik, 2004). Therefore, problems may occur when communication is unclear or ambiguous (Eldar et al., 2010; Kasa-Hendrickson, 2005).

Many staff claimed that communication across different areas of the school is good and that this is made possible by Learner Profiles. Learner profile systems were mentioned by all schools and involve electronic communication (sometimes with additional hard copies) between staff regarding the needs of the pupil. This system allows teaching staff to know what challenges the pupils may experience while in the classroom. Leatherland and Beardon (2016) discuss the positives of a similar system, namely, FAMe ™ (Facts About Me), whereby in addition to providing school staff with general information regarding the pupil, there are three facts about the pupil that would help make their experience in class less challenging. The authors report that the pupils who took part in the research experienced a reduction in levels of anxiety. What is particularly important about this research is that the pupils themselves provided the information that would be communicated to the teachers.

During face-to-face and email interviews with staff in the current study, it became clear that they believe that this is a type of system that works well. However, there there was no indication that the pupils had an input into the information on their learner profiles. Moreover, one parent (Debbie) in particular made specific mention of the electronic system stating that it was supposed to share information across her daughter's (Christina) classes, but failed to do so, causing disruption and anxiety. One staff (Mr Martin) asserted that although the system is good, it only works when it is used and often teaching staff need reminders to utilise the system. Therefore, this thesis suggests that electronic learner profiles have the potential to be an effective form of communication between school staff if all staff utilise it and if pupils have the opportunity to be included in creating their profile.

The following chapter summarises the key findings that have emerged from this study and are structured around the main research questions of this thesis.

CHAPTER NINE
Conclusion

This chapter provides the final reflections of the research, drawing out the key findings from the study. It also takes into consideration their implications for future policy and practice. Next, it discusses the contributions that this research has made to knowledge and suggests areas worthy of future research that have emerged within this thesis.

9.1 What challenges are pupils, parents and staff faced with in relation to school?

9.1.1 Pupils: All Encompassing and Enduring Difficulties

The findings have demonstrated that the numerous challenges experienced by autistic pupils are not limited to time spent in school but are also experienced in the home and in the space between home and school (Edwards, 2002). During school, pupils experience sensory challenges that create difficulties in various ways. For instance, Chapter 4 showed how wearing school uniform can be problematic due to the uncomfortable feeling of it against their skin. Non-attendance or lack of enjoyment of particular classes can result because of the sound and volume of teachers' voices. Additionally, the general noises expected within a school environment also create sensory issues, such as busy corridors and the school bell, which is a frequent occurrence during the school day. These findings build on understandings of autistic pupils' lived experiences. They underline the impact that sensory challenges have on autistic pupils' wellbeing and education. The discomfort and anxiety that these challenges produce have significant consequences for learning.

While the autistic pupils in this study attended mainstream secondary school, the findings show that this does not equate to inclusion. Pupils are also often excluded in school as a result of the stigma of being autistic or being labelled as different resulting in them experiencing loneliness. In contrast, they can often receive attention from fellow PNT pupils in the form of bullying. This results in impression and stigma management, whereby the pupils mask their 'autistic identity' and often reject support in an effort to fit in and be included (Goffman, 1959; Goffman, 1963; White et al., 2020).

Segregating the pupils in separate support spaces within the school, known as the base, indicates ableist practices. It demonstrates that PNT pupils' educational needs are prioritised

and met over and above those of autistic pupils (Holt, 2007; Tomlinson, 1982). This thesis does not disregard the safety that such spaces within the school do provide for autistic pupils to recover from the challenges of an ableist environment (Holt 2010). However, parents raised their concerns about their child not receiving an adequate education in the mainstream, and this thesis argues that some provisions are tokenistic. Applying the social and social relational model of disability highlights that autistic pupils are excluded by fellow pupils and that the institution of school has failed to make appropriate provisions to afford autistic pupils an education equal to PNTs.

School and home are everyday spaces in which children's experiences shape their identities (Alldred et al., 2002). While home is considered a private and safe place, unless otherwise identified (e.g. abusive or neglectful), it is also a place where stress unfolds for pupils and their parents (Phung et al., 2021). Home, despite being the preferred environment for the young people, is not a school free zone. School is thought about and prepared for in the home in the mornings before school begins and after school when the pupils return in preparation for the following day. This leaves little time for the pupils to unwind and decompress from the pressures they experience in relation to school. Thus, the challenges of school monopolises much of their time and thinking in both the public and private spheres of their social worlds.

The space and transition between home and school is particularly challenging for autistic pupils where they experience sensory issues as well as the fear of other pupils, particularly those in large groups. Sensory issues and bullying are challenges that autistic people experience in school, thus it is not surprising that these lead to anxieties in the space between home and school. Moreover, within the school building, there is the knowledge that staff are there to intervene if necessary, whereas on the way to and from school the pupils are likely to feel more vulnerable without the presence of adults. It should not be overlooked that most of the pupils in this study expressed that they would not attend school if they had the choice. Thus the trauma and distress associated with taking themselves from a space of safety to one that by their own accounts is associated with anxiety and stress is significant. The challenges that are experienced before, during and after school are contributing factors to non-attendance and negatively impacts on their mental health and wellbeing. Thus, these are important findings given the prevalence of school refusal for autistic pupils. This thesis argues that

autistic pupils experience persistent patterns of inequality including adult/child, autism/PNTs and ableist practices, thus the findings will contribute to critical autism studies**.**

9.1.2 Parents: Emotional Pressures and Responsibilities

Parents experience challenges which are largely centred on worry and concern for their children. These concerns relate to the emotional and mental wellbeing of their child and worries that these needs are not being met in school. Witnessing the aftermath of school on their children, which can often materialise as meltdowns, is distressing and stressful to parents. Moreover, Chapter 5 showed that some parents are confronted with the trauma of their child speaking about, or attempting, suicide. Parents not only have to cope with these immediate concerns, but also worry about what the future may hold for their children following secondary school. In addition to these fears, is the worry that as parents they will likely have to navigate the implications of their child no longer being in the education system and the impact that this may have on their child's, and their own, quality of life.

School meetings are an arena for parents and school staff to discuss the pupils' needs. However, parents are attending meetings with a great deal of emotional stress and pressure. Some of this pressure relates to the formal environment but also to the need to act as an advocate for their child to secure the best support. Speaking up on their child's behalf and pushing for support mostly happens outwith school meetings, with regular attempts at contacting the school. Having to constantly call or be in contact with the school has a detrimental effect on parents' wellbeing. The findings have illustrated how this leaves parents feeling judged and labelled as a 'neurotic mother' (see also National Autistic Society, School Report, 2021). As with the pupils, the challenges that parents experience occur before, during and after their child's school day. Time and effort is afforded to preparing their children for their lessons as well as for possible changes to routine and building their confidence. Moreover, in addition to whatever is going on in their own lives during school hours (work etc.), they are dealing with phone calls and text messages throughout the day, both from their children and school staff. This leaves little time for the parent to unwind from the emotional pressures and responsibilities of supporting their child. These findings add to the literature surrounding the impact that supporting an autistic child has on the parent's mental health (Hebron and Bond, 2017; Whitehead, 2017).

9.1.3 Staff: Limited time and Resources

Staff recognise that the typical curriculum is not best suited to autistic pupils and that a more tailored approach would be beneficial (Rogers, 2007). Their frustrations stem from not having the time or the resources to make this happen (Leibowitz, 2000). Autistic pupils, although sharing some common traits, have their own set of challenges, therefore time is needed to design an individual support package. Due to teaching and other administrative responsibilities, there is not enough time in between these responsibilities to develop lessons or support that will enable the pupil to be educated and to attend school. Primary analysis of staff data indicated that school provisions were similar across and within local authorities, with some variations. However, there were similar multiple suggestions put forth by staff across all local authorities for educating autistic pupils, such as teaching outwith the school environment, outside learning, and life skills (using public transport, shopping etc.). Recommendations for adapting learning within the school environment included smaller and more available rooms for small group teaching, some of which may include sensory rooms to help the pupils unwind and de-stress during the school day. However, lack of funding and resources present significant obstacles to these ideas coming to fruition and contributes to the failure of making appropriate provisions for autistic pupils to be included in mainstream secondary school.

Staff can find it distressing and disheartening to witness self-destructive and self-harming behaviour of some of their autistic pupils, and instances when the young people make themselves vulnerable or at risk in the community (Avramidis et al., 2000; Hinton et al., 2008; Humphrey and Symes, 2010). Chapter 6 illustrated that within the school environment, staff can be faced with combative behaviour of some autistic pupils. This behaviour makes it difficult for staff to conduct their lessons and to provide support to all of the pupils in attendance. In addition to disrupting lessons, some behaviour creates stress for staff and instils fear. This does not only have the potential to impact on the staff’s mental health and wellbeing but may impact on their ability to teach and support to the best of their ability in a controlled environment (Bowe, 2004; Lindsay et al., 2014). What can be drawn from these conclusions is that staff, to a large degree, do have awareness of the needs of autistic pupils. However, the key challenges that they experience while educating or supporting autistic pupils are outwith their control and are associated with time and resource constraints and coping with difficult pupil behaviour.

In summary, pupil challenges are experienced in public spheres, at school and the space between home and school, and in the private sphere of home as they think about and prepare for school. Parents are faced with challenges that are not solely practical, but also emotional. The pressures of acting as an intermediary between home and school, such as attending meetings and frequent contact, impact on their mental health. Thus, the implications that this has for their resolve to continue to support their child navigate secondary school should not be overlooked. Staff face challenges that restrict their ability to support autistic pupils in ways that are best suited to them but are also impacted emotionally and mentally with the demands of meeting the needs of individual pupils and witnessing distressing behaviour. Therefore, this thesis asserts that the challenges experienced by pupils, parents and school staff are interlinked and contribute to autistic pupils being disadvantaged in mainstream secondary school.

9.2 What support is available to autistic pupils, their parents and school staff?

9.2.1 Pupils: No Simple Solution for Complex Challenges

The findings have shown that there are various measures of support available to autistic pupils in mainstream secondary schools. Some felt supported by particular classroom teachers who understood them. However, as it was shown in Chapter 4, all identified a key member of staff, typically a member of support staff, who played a major role in their support and ability to attend school. What could be taken from this is that support staff have a greater understanding of autism than the general school staff population. This support is undoubtedly beneficial to the pupils and their families, however, considering the increasing number of autistic pupils in mainstream school this resource is stretched thin. This thesis argues that widening this understanding to classroom teachers in the form of accessible autism conferences and including it in initial teacher training has great potential for autistic pupils' education. It is clear from the pupils and parents that one of the key issues relating to supporting autistic pupils in mainstream school is that it is often delayed, to the extent that, for some, successful support is not in place by the time the young people leaves secondary school (see also National Autistic Society, School Report, 2021). This has implications for the young person and their families and intensifies anxieties around transitions, future prospects and quality of life. Support from other pupils did not arise a great deal in the data

but some of the pupils and their parents did mention that at times PNT pupils help autistic pupils to understand their schoolwork.

Parents are fundamental to the support that pupils receive in relation to school. As with PNT pupils, parents provide practical support such as organising uniforms and school bags and overseeing homework. What is less common for PNT pupils and more common for autistic pupils is the support required to cope with the challenges they experience in relation to school, such as sensory issues and communicating with others. One crucial way that parents support the pupils with these issues is by advocating for them and communicating their needs to the school. This demonstrates that the young people in this study are dependent on their parents, however, it should be noted that they consented to their parents taking on this role. Thus, the young people are active agents in their own lives (Tisdall and Punch, 2012). Parents also provide support by preparing their child for potential eventualities during the school day that are likely to be experienced by autistic pupils in particular. For example, taking into account the stress and anxieties that can be caused by change and offering solutions or advice on how best to cope. The findings demonstrate that parents are experts in their child's lives and this should be accepted more readily in education policies. Moreover, parents should be supported in this role. Emotional support is largely provided by the parents, and at times by a key member of staff that the pupil trusts. Some pupils were offered emotional support in the form of counselling and mindfulness, with varying degrees of success.

The pupils are also supported in practical ways within school. For example, most schools have a support base, some of which has a specific autism base, that pupils can attend either for lessons and/or during social times such as break or lunch. This provides a space to retreat from the stresses and busyness of the main school environment and allows them to be taught in smaller, more manageable groups. Pupils are also offered amended timetables, enabling them to avoid some of the busiest and most stressful times of the school day; for example, starting later or finishing earlier. It can also mean that for some, they only attend some classes throughout the week and forgo others. Other practical support offered to the pupils include bathroom passes and the use of technology to help with their studies. However, all of the above practical measures were identified as singling out and labelling autistic pupils as being different to other pupils and was often rejected by the young people as a result. This thesis argues that current measures of practical support contributes to the stigma of autism

and creates a divide between PNTs and autistic pupils and negatively impacts on their education and mental health. With this said, it identifies that there are limited alternatives available to support autistic pupils and thus acknowledges the paradoxical challenge

9.2.2 Parents: Inaccessible and Unsatisfactory Support

The findings have emphasised that there is very little support available to the parents of autistic pupils. From the time of receiving their child's diagnosis, parents are left to process what the diagnosis means and how it will impact on their child, their family and their own lives. Part of this process involves seeking out information and doing their own research on autism itself, and what this might mean for supporting their child through school. There was no evidence of formal support for parents via the school, such as links to information or potential support groups. Some parents did, however, find a great deal of support typically from one key member of staff. This member of staff tended to be the source of support for the whole family and provided emotional and practical support and acted as a point of contact between home and school. Less formal groups outwith school were found to be unsatisfactory to parents because they were not autism specific and thus parents felt that they could not fully relate to other parents who attended who had children with varying support needs. Most beneficial outside support was found by the parents themselves, such as attending autism conferences and groups specific to autism. However, these forms of support are costly and are thus not accessible to all. Therefore, this thesis argues that parents of autistic pupils are disadvantaged by the lack of appropriate provisions being available to help them to support their children. This underscores that supporting autistic pupils in mainstream schools should be a whole family approach (Galpin et al., 2017; National Autistic Society, School Report, 2021).

9.2.3 Staff: Breathing Space and the Knock-On Effect of Support

Many of the staff in this study feel supported in their role of educating and supporting autistic pupils by their colleagues. Many learn by observing their colleagues over time, and particularly when they are new to their role. Other forms of support come from training and education in relation to autism from their local authority and various courses or conferences that some, but not all, receive funding to attend. It is of interest what is omitted from the staff accounts of support. For instance, there was no mention of support available to them that would help them cope with the emotional element of teaching, such as how it makes them

feel witnessing pupils being distressed and the effects that this may have on their mental health. Likewise, there was no mention of support for coping with the fear that they can experience with disruptive and combative behaviour from some autistic pupils. This thesis argues that support in these areas is important for staff, taking into account how these pressures and stresses are faced frequently throughout the school week.

What can be drawn from these conclusions is that pupils, parents and staff do receive some forms of support. It is logical that most efforts have been made with regard to supporting autistic pupils in the various ways as mentioned above. However, it has become clear that the most support that pupils receive come from their parents and school staff. With this in mind, supporting these key people with their own set of challenges is vital. Parents need to be supported to enable them to best manage the pressures of supporting their autistic child and all that accompanies this both in relation to school and otherwise. Moreover, there is no evidence of support being available to help parents identify and implement ways in which to prioritise their own wellbeing. Similarly, staff are unsupported in the pressures and stresses that occur due to teaching/supporting autistic pupils. The consequences of failing to implement a whole school approach to the inclusion of autistic pupils in mainstream school are that this responsibility falls on shoulders of the parents and a limited number of school staff. This thesis argues that more support for parents and staff, such as information leaflets and support groups, may provide breathing and thinking space that is perhaps lacking amidst the constant challenges. Ultimately, this would have a knock on effect on the young people and their experiences of attending mainstream secondary school.

9.3 In what ways do relationships and communication between pupils, parents and staff impact on using or implementing support?

9.3.1 Intra-generational Relationships

The findings have shown that autistic pupils' relationships with other pupils are complex. For instance, Chapter 4 illustrated how some of the pupils in this study value friendships they have had since primary school, while others witness these friendships fall apart. This thesis argues that friendships failing can in part be attributed to other pupils not wishing to be labelled or stigmatised for befriending an autistic pupil who is treated in this way. Failing friendships, or lack of friendships can also be attributed to what Beardon (2019) terms the cross-neurological theory of mind, in that PNTs and autistic pupils lack an understanding of

each other. The findings underlined that all of the pupils in this study have experienced exclusion from PNTs and bullying, including those who also have some friends at school.

For some of the parents, tensions have arisen either with current partners or previous relationships regarding supporting or understanding their autistic child. Some share parenting responsibilities such as driving their child to and from school, although the mothers in this study took on most of the responsibilities when it came to support and advocating for their child. Thus these findings add to wider literature relating to mothers' caring responsibilities based on cultural gender expectations (Gray, 2003).

Relationships between parents and staff are on the most part positive, with a few exceptions where parents and staff views will clash. Relationships can be constrained by parents being afraid to create consequences for their child. However, what stood out clearly from this study is that there is one key member of staff that each parent trusted and felt supported by, both for themselves and their child. This places much pressure on one key member of staff and can contribute to delays that occur between communication between home and school. Relationships between staff members, although touched upon only briefly in the research appear to be positive and supportive.

9.3.2 Inter-generational Relationships

As with the parents, pupils have one key member of staff that they are able to build a good relationship with that they value and find supportive. For some of the young people, this relationship is key to such an extent that without interactions with this member of staff, they would not attend school. For the pupils, this is a person whom they trust, look forward to connecting with during school hours and who they find to be caring. Thus, the strength of these relationships make it easier for pupils to access support. It could be considered that this staff member acts as a substitute for the caring parent at home. This relationship is likely allowed to develop in this way partly due to the close relationship and communication between the parents and this key member of staff. However, it is important to underline that limiting relationships to one member of staff creates a certain degree of dependency and has the potential to be problematic should this member of staff move jobs or is absent from school for any reason; for example, due to illness.

Not all relationships with staff were positive for the young people and some pupils mentioned how teachers would exclude or not understand them and make them feel scared. For staff some relationships can be difficult to build with autistic pupils which is linked to misunderstanding and time constraints. However staff members mentioned positive relationships between themselves and autistic pupils and sharing sense of humour. Importantly, staff indicated that they would use an autistic pupil's special interest in a positive way to help them understand schoolwork. Therefore, the findings have shown that monotropism, which is often seen as a deficit for autistic people can be a positive tool in education (Murray, 2020; Wood, 2019). This goes someway to support Mannion's (2012) work on generagency and education as a space where pupils and staff build on understanding and common interests.

The relationships between the young people and their parents are supportive and nurturing, but also frustrating and stress invoking. The parents have their child's best interests at the forefront of their actions which involve regular contact with the school, preparing their child for the school day and providing comfort when they return by listening and making the environment feel safe. The pupils recognise the efforts of their parents but also dislike that their parents have the power and legitimate authority to make them attend school given their struggles with it (Beetham, 1991; Hindess, 1996; Punch, 2005; Scott, 2001). These frustrations are often vented and taken out on the parents, which can create tension and cause stress. These findings situate autistic childhoods within disabled childhoods literature and the sociology of childhood and demonstrate that children's lives are constrained by the power of adults, but that they are not powerless in their relationships with their parents.

9.3.3 Face-to-face Interactions

The findings have shown that pupils mostly communicate face-to-face with parents but less so with other pupils and staff. This reiterates the communication difficulties that autistic pupils experience. However, it also demonstrates that these differences do not mean that all autistic pupils will not or cannot communicate with others. Parents have the opportunity to communicate face-to-face with staff but most times is accomplished in other ways. This is likely because the opportunity to communicate face-to-face is not as frequent or available due to time constraints of the staff and those of working parents (Lekli and Kaloti, 2015; Lindsay et al., 2013). Parents although expressing that they can find formal meetings daunting, did not

indicate if they would prefer to speak on a one-to-one and face-to-face basis. Staff communicate with colleagues in a variety of ways but given the large environment of secondary school, face-to-face is mostly used for colleagues within their own department or during meetings with parents and staff together (Eldar et al., 2010).

9.3.4 Technological Exchanges

Pupils communicate using online platforms such as Xbox, PlayStation, or PC as well as social media avenues such as Facebook and Snapchat (Bengtsson et al., 2021). Text messaging is another favoured method of communication for the pupils, both with other pupils and with their parents. One of the most commonly used methods of communication for the parents and staff is via email. However, one parent in particular does not like to send emails. Her preference is via phone, which is the most used avenues for parents and staff to communicate. Staff also use technology to communicate with each other in the form of the pupil profiles, where they can update information about the pupil that can be accessed via a link. Twitter is a further online platform that some schools use to update parents about school events, although, this is whole school information and not just focused on autistic pupils. However, online communication is not an accessible form of communication for all parents who may not have access to the internet (Vickers and Minke, 1995). Thus some parents send hand-written notes to classroom teachers, which can be via a home-school diary or as a separate letter for the pupil to hand to their teacher. Staff also use newsletters to communicate school news to parents and pupils.

What can be drawn from these findings is that both relationships and communication are key for supporting autistic pupils in mainstream secondary schools. Positive relationships between autistic pupils and their parents allow the young person to safely communicate their needs. Equally important are the relationships between parents and staff, which allow the parents to communicate their child's needs to staff and vice versa. This allows staff to implement changes based on the knowledge gained from the parent to support the pupil in school. Similarly, these relationships update the parents on the challenges their child is experiencing at school and better equips them to support them at home. Autistic pupils, their parents, and school staff are interlinked. Therefore, this thesis argues that when designing approaches to help support autistic pupils in mainstream secondary school, the experiences of all have to be taken into account.

9.4 The Importance of Understanding Autism

This qualitative research has found that the support received by autistic pupils is influenced both negatively and positively by understandings of autism. It is particularly positive for some of the pupils in this study who enjoy friendships with other pupils who have known them for a number of years and know of their diagnosis. What this suggests is that some of the pupils are accepted for being themselves (White et al., 2020). In contrast, it emerged that pupils who do not understand autism or do not understand the behaviours of autistic pupils will often exclude them and/or bully them which can lead to increased anxieties and school refusal. Moreover, it can force autistic pupils to attempt to hide their differences by refusing support and masking or camouflaging their autism from others. This is done in an attempt to be included and to avoid stigma and victimisation, which consequently impacts upon the level of support provided and ultimately their education.

Parents who although admitting they do not have a full comprehension of autism, particularly when first diagnosed, nonetheless demonstrate that they understand their child and their needs and are proactive in seeking support for them. Recognising their child's needs is something that has had to be learned over time and often as a result of seeking support or advice or information from outside agencies other than school. Thus, appropriate provisions are essential for parents of autistic pupils who bridge the gap between the public and private spheres of their child's lives.

Some of the staff in this study are trained and have experience working with autistic pupils. Many demonstrate a good understanding of the challenges associated with autism and support the pupils to the best of their abilities, despite being faced with time and resource constraints. However, it was raised during the study that staff need more training and education to recognise and understand autism and how it may impact on the pupils that they support. This finding builds on a growing body of research that also highlights this need (see also National Autistic Society, School Report, 2021). Pupils and their parents conveyed that at times they were not considered 'autistic enough' for support in school. This signals a further complication of impression management, of pupils masking their autistic identity (Goffman, 1959; Goffman, 1963; White et al., 2020) to fit in and as a result will fall under the radar of staff who may assume that they are coping. Thus staff who perhaps do not have a

holistic understanding of autism may not make support available to those who need it. This may exclude autistic pupils from accessing support such as attending the base, which many students found to be beneficial. It also contributes to current conversations about invisible disabilities (Hendry et al., 2022; Kattari et al., 2018; Morina, 2022).

Importantly, the identity of autism is something that the pupils themselves can embrace or reject. Some of the pupils are open about being autistic and as a result are receptive to some, but not all, measures of support. Rejecting the label of autism (Bumiller, 2008; Nadeson, 2007) largely stems from the pupils' understandings of how others negatively perceive autism and autistic people. This can lead to them refusing offers of support with the intention of avoiding being labelled as different. Identity, therefore, plays a significant role in the inclusion and support of autistic pupils in school both from pupils and staff. What can be taken from these findings is the importance of educating pupils, parents and staff, to equip them to understand autism and recognise the needs of autistic pupils.

9.5 Policy and Practice

Policy Level

- The thesis identifies the need for necessary teacher training to educate and support autistic pupils. - Autism education should be included in teacher training for future staff and made available as a whole school approach for current staff.

- To make support accessible to all, financial support for autistic pupils and their parents should be made available to allow families to afford materials and services - Personal Independence Payment (PIP) or increased rates of Carers Allowance and parents of autistic pupils being eligible for Carers Allowance despite their employment status.

- Funding is needed for social care, charities and youth organisations to support autistic pupils in school with the purpose of assisting better transitions out of school, and to avoid autistic young people becoming NEET (not in education, employment, or training). A dedicated staff member in school whose role is specifically to inform school staff and signpost relevant agencies and support groups for pupils and families.

In the current funding climate this is not likely to be feasible, thus there needs to be real change at a policy level in terms of funding and social support.

- The challenges raised with getting to and from school indicates that funding should be made available to provide autistic pupils with the appropriate means of travel.

Supporting autistic pupils in mainstream secondary school is achieved through the efforts of parents, school staff (particularly support staff), fellow pupils, and outside agencies. It became clear through the interviews with parents that often it is the case that a support package that may appear to be working is not fully in place until the young person is at the stage of leaving secondary education. Thus, there is a need for measures to be implemented with the foundations of understanding and acceptance, as opposed to reacting and to avoid repetitive patterns of delays and unsuccessful support. This thesis argues that a way forward to best support autistic pupils is by supporting their key supporters, namely, their parents and staff. The following points suggest ways in which this could be achieved:

- Face-to-face/online, and ongoing support and advice should be offered to parents following an autism 'diagnosis'. This could be delivered by social services, charitable organisations, and CAMHS. CAMHS at the first step to explain what autism is, what this might mean for school, the impact on the family, meetings centred around the child's needs and the support they require but also checking in with the family if they need support with mental health, with attending meetings, and to determine if face-to-face meetings are suitable for parents. Piloting groups for parents, and young people following a formal identification of autism, would assess the benefits of receiving important information and support from others in similar situations. These support groups should be promoted by their child's school.

- Parents mental health and wellbeing. Support should be signposted to parents when their child attends secondary school or following a formal identification of autism. This could be delivered via information leaflets during school meetings or by mail/email.

- Advocacy support should be available to parents when attending school meetings. This could be delivered via voluntary and charitable organisations.

- Parents experience stress worry and anxiety when considering their child's transition from secondary school. Clear guidelines for options following secondary school should be provided to the parents in advance of their child leaving primary school.

- Emotional support in the form of counselling and support groups within each local authority should be offered to staff to provide assistance with ways in which to help their mental health and wellbeing.

- Autistic pupils feel misunderstood and excluded by other pupils. More information should be provided on neurodiversity for all pupils. This should not be presented as a stand-alone event but delivered regularly within primary and secondary schools. Moreover, information leaflets and posters displayed within schools could aid in raising awareness of autism and neurodiversity more generally[26].

- School practices that create sensory challenges for autistic pupils should be given more consideration and changes implemented, such as an alternative to the school bell (replacing it with lights, or a teacher being notified through a personal notification on phone or buzzer).

- Parents can be inundated with written information and experience feelings of guilt following their child's formal identification of autism. Face-to-face support and advice could be offered to parents following an autism 'diagnosis', with the opportunity to follow up on this support for a period of time afterwards.

- Support staff have a good awareness of autism. However, taking the pupils' experiences into account underlines that more understanding is required, especially with regards to masking. Autism education could be included in teacher training for future staff and made available as a whole school approach for current staff. A dedicated staff member could be appointed to each school whose role is specifically

[26] The researcher aims to develop impact resources for pupils, parents and staff from the findings of this research.

to inform school staff and signpost relevant agencies and support groups for pupils and parents.

- Staff experience stress and distress witnessing and dealing with intense and, at times, aggressive behaviour. Emotional support in the form of counselling and support groups within each local authority could be offered to staff to relieve these stresses and to provide assistance with ways in which to help their mental health and wellbeing.

9.6 Key Contributions and Recommendations for Future Research

Including pupils, parents and school staff together in one study provides a rich insight into the experiences of those in an educational system that claims to be inclusive. This research is valuable as it offers insights into the experiences of autistic pupils in a social domain. In doing so it contributes to autism knowledge with a focus on identity and difference and moves away from diagnosis and the prevailing negative views of deficit. Moreover, it adds to the literature on identity as it brings to light that impression management is a significant challenge for autistic people, in that they have to choose whether or not to disclose that they are autistic to others and that both come with their own set of challenges (Valeras, 2010). In particular, it adds to critical autism studies as it promotes accounts of autism by autistic people themselves, which confront stereotypical views of autism as promoted by the media. Furthermore, it adds to the sociology of disability, particularly current debates surrounding invisible disabilities by highlighting the struggles that are experienced but are not always noticed. This is an important contribution to the sociology of education, which will enhance effective teaching and the learning process. Finally, this research adds to the sociology of childhood, illuminating the social issues of autistic children and young people.

Gaining an insight into autistic pupils' experiences and perceptions of interacting with other pupils was valuable. Future research involving PNT pupils' understandings of autism and their relationships with autistic pupils might shed light on issues raised within the thesis. For instance, it may underscore where the difficulties surrounding communication and building relationships with autistic pupils stem from. This in turn, could inform where education on autism is needed most. It was touched upon within the thesis that parents and siblings can offer support to one another while supporting an autistic child through secondary school. More in-

depth research in this area would draw attention to the benefits and obstacles to support within the home. Staff shared the challenges that they experienced while educating and supporting autistic pupils in secondary school. Further research that delves more deeply into these issues would underline these difficulties in more detail and help build a picture of what support might look like for them moving forward.

Learner profiles is a popular method of highlighting pupils' needs to staff. Exploring staff experiences in more detail would help identify the advantages and obstacles of utilising this system and thus is worthy of future research. Finally, attempts were made to use an advisory board of young autistic people to inform the research design in this study. However, due to time constraints and the breakdown of a group run by a charitable organisation who were initially on board, this was not achieved. Future research that includes autistic people at the centre of the research design would be advantageous and keeping with the goals of critical autism studies.

9.7 Reflections on the Research Process

The methods used worked very well for the pupils in this study. The various written exercises for the young people enabled their views to be taken into account with less pressure than multiple face-to-face meetings. It was reassuring that some of the young people felt able to request alternative methods. This reaffirmed to me as the researcher that they were not feeling pressured to do things that they were not comfortable with. For example, Jason refused to work with the structured diary and Christina was more comfortable with email communication. However, given the findings of this research, that the young people have various preferred methods of communication, future research of this kind would benefit from offering the young people a variety of ways of participating that do not solely rely on written methods, for example, photographs, drawing or online video interviews (see Punch, 2006). Utilising a pilot group in future research would help identify methods that are best suited to autistic pupils participating in research.

Face-to-face and Skype interviews with the parents gathered rich data, which was helped by my positionality as a parent of an autistic child. However, for future research it would be beneficial to conduct focus groups with parents as it would allow them to discuss their experiences in more depth and highlight shared or differing experiences. This would not have

been possible in this research due to the access delays. Similarly, focus groups would be a useful data collection method for school staff in that they could demonstrate similarities and differences of experiences within and across schools. However, these would have to be carefully implemented due to staff time constraints. This method would also enable the school staff to open up with one another. While the interviews, both face-to-face and email gathered rich data, there were instances where it could be considered the staff were holding back or being defensive about their school to me an outside researcher.

Accessing schools proved to be more time consuming than initially anticipated. Once access was granted to specific schools via the local authority, headteacher's would pass my information on to their respective support departments. This allowed me access to school support staff. However, despite efforts to have the invitation to take part in the research shared with all members of school staff, no classroom teachers participated. This may have been due to a lack of interest or time constraints of the classroom teachers. However, it is possible that information about the research was not communicated further than the support departments. Access delays also impacted on the overall sample size of the research. The invitation for parents and pupils to participate in the research gained a lot of interest, largely with families outwith the scope of this study; for example, families of primary school age children or with children who had been out of education for some time. Nonetheless, the relatively small sample did not impact on the depth of the data. Instead, it allowed me as the researcher to know my participants well and resulted in producing rich data.

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Appendix 1: About School Activity

Things I like about school	**Things I don't like about school**
Things I get help with in school	**Things I would like help with in school**

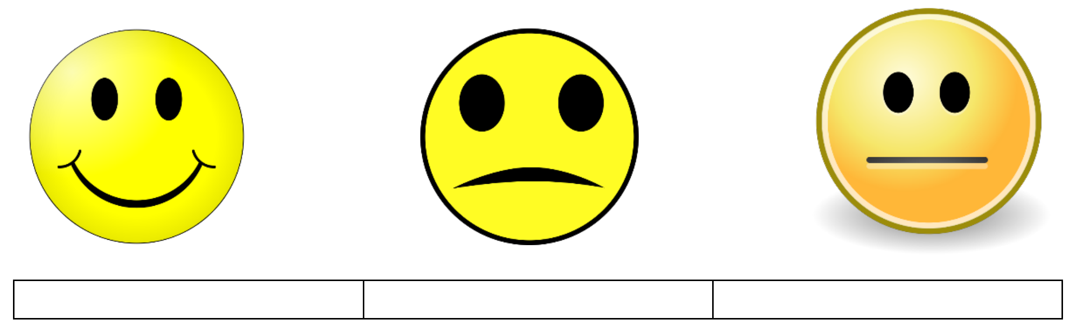
Appendix 2: Structured Diary

My Structured School Diary

= Happy/ Good	= Sad/Bad	= Bit of both or just okay

In the morning before I leave for school

Overall I am:



I like…

I don't like…

It would help me if…

On the way to school in the morning

Overall I am:

I like…

I don't like…

It would help me if…

When I get to the school building

Overall I am:

I like…

I don't like…

It would help me if…

When I go to registration/form class

Overall I am:

I like…

I don't like…

It would help me if…

When I go to my first class

Overall I am:

I like…

I don't like…

It would help me if…

My Favourite class

Overall I am:

I like…

I don't like…

It would help me if…

My least favourite class

Overall I am:

I like…

I don't like…

It would help me if…

During break/interval

Overall I am:

I like…

I don't like…

It would help me if…

At lunchtime

Overall I am:

I like…

I don’t like…

It would help me if…

My Favourite teacher

Overall I am:

I like…

I don't like…

It would help me if…

My least favourite teacher

Overall I am:

I like…

I don't like…

It would help me if…

The person who helps me most with school

Overall I am:

I like…

I don't like…

It would help me if…

Other pupils

Overall I am:

I like…

I don’t like…

It would help me if…

On the way home from school

Overall I am:

I like…

I don't like…

It would help me if…

When I get home from school

Overall I am:

I like…

I don't like…

It would help me if…

At night when I think of going to school the next day

Overall I am:

I like…

I don't like…

It would help me if…

When I am at school meetings about me

Overall I am:

I like…

I don't like…

It would help me if…

I want my parent/carer to know that for me school is

Overall:

I like that they…

I don't like that they…

It would help me if they…

I want my teachers to know that for me school is

Overall:

I like that they…

I don't like that they…

It would help me if they…

I want other pupils to know that for me school is

Overall:

I like that they…

I don't like that they…

It would help me if they…

I want ___________ to know that for me school is

Overall:

I like that they…

I don't like that they…

It would help me if they…

I want _____________ to know that for me school is

Overall:

I like that they…

I don't like that they…

It would help me if they…

Other things I think are important about the support I get in school

Appendix 3: Parent Interview Schedule

Support available

- If we could just start off with you describing what you think successful support is for young autistic people in school? How would you define successful support?
- Who would you say are the key people who help support your child in relation to school?
- What support does your child receive at school?
- What do you do to support your child through school? What forms does this support take?
- What do you think your child needs most support with at school?
- How important is it to you that your child fits in at school?

Positive and Negative Experiences

- Is there anything in particular about the support your child receives at school that you think is good?
- Is there anything about the support your child receives at school that you feel is not particularly working?
- Can you describe any positive experiences of supporting your child in school?
- Can you describe any negative experiences of supporting your child in school?

Interactions

- Do you have a good relationship with your child's school?
- Do you think you and the school work together to support your child?
- How would you describe your communication with the school?
- Do you think your interactions with your child impacts on their support in school, if so in what ways?
- Are your interactions with your child different on school days than at weekends or holidays? If so, in what ways?
- In what ways do you think your interactions with the school impacts on your child's support in school, both negatively and positively?
- Do you think that your views are listened to in relation to your child's support?
- Do you attend meetings at school regarding your child's support? Can you tell me a little about those?
- Is there anything you wish the school understood about your role in supporting your child?
  Is there perhaps anything you wish you could say to them that you feel you haven't been able to until this point?
- How would you describe your child's experiences with their peers?

Improvements

- What do you think is needed to support your child in secondary school?
- Are there any particular aspects of your child's support that you feel could be improved?
- If you could implement support in school, what would you do differently?

- Is there anything further you would like to add regarding support for autistic pupils in mainstream secondary school?

Appendix 4: Staff Interview Schedule

General questions

- If you could just start by telling me your role within the school and how long you have been in this role – any related roles?

Support available

- If we could just start off with you describing what you think successful support is for autistic pupils in school? How would you define successful support?
- Who would you say are the key people who help support autistic pupils in relation to school and their education?
- What support is available to autistic pupils in this school?
- What support do you in your role personally provide for autistic pupils in school?
- What support is available to you, to help you support an autistic pupil in school? Training?
- What do you think autistic pupils need most support with at school?
- How important is it to you that a child or young person fits in at school?

Positive and Negative Experiences

- Is there anything in particular about the support autistic pupils receive at this school that you think is good?
- Is there anything about the support autistic pupils receive at school that you feel is not particularly working?
- Can you describe any positive experiences you have had of supporting autistic pupils in school?
- Can you describe any negative experiences you have had of supporting autistic pupils in school?

Interactions

- How would you describe your relationships with autistic pupils?
- How would you describe your relationships with parents of autistic pupils?
- In what ways do you and the parents work together to support autistic pupils in school?
- How would you describe your communication with the parents of autistic pupils?
- In what ways do you think your interactions with autistic pupils impacts on their support in school, both negatively and positively?
- In what ways do you think your interactions with the parents of autistic pupils impacts on the pupil's support in school, both negatively and positively?
- How would you describe the level of input you have in terms of how an autistic pupil is supported within school?
- How would you describe communication between school staff in relation to autistic pupils?
- Do you attend meetings at school regarding autistic pupils support? Can you tell me a little about those? What is your role during the meeting?

- Is there anything you wish the parents of autistic pupils understood about your role in supporting their child? Is there perhaps anything you wish you could say to them that you feel you haven't been able to until this point?
- Based on your own observations, how would you describe autistic pupils interactions with their peers?

Improvements

- If you were in charge of how autistic pupils were supported, what would you do differently? If you had the power to run things how you would like to, no headteacher nothing standing in your way.
- Is there anything further you would like to add regarding support for autistic pupils in mainstream secondary school?

Case study

Anxiety (night before, that morning, during school) – is there any support to help manage this?

Non- attendance (how school helps with this)

Bullying- is this something you witness in relation to autistic pupils? How do you deal with it?

Stimming – has this issue arisen with pupils, where they are being told off for stimming in class

Parent support groups – any offered to parents here?

Feeling like a neurotic mother- what do you think of this statement?

Feeling almost bullied in meetings - what do you think of this statement?

Social time (feeling physically sick, feeling alone, the noise too much)

Parents having to fight for their kids to sit exams, go for qualifications, reach their full potential

Parents having to fight for equipment for their children, e.g. iPad, computers etc.

Support being pulled away from young people e.g. one-to-one support in class, lift keys, iPad etc.

Appendix 5: Pupil Information Booklet

A study about supporting pupils with Asperger's (ASD) in Secondary School

Information Booklet

About Me

Hi, my name is Liz Graham and I am a PhD student at the University of Stirling. I have four children, and two cats, Sookie and Eric. One of my children has Asperger's. Being a PhD student means that I get to carry out some research on a topic that I think is important. I have decided to research the support available for pupils with Asperger's or those on the autism spectrum in secondary school.

My Research
I am really interested in autistic pupil's experiences of the support they get in high school. I think it is really important to hear from pupils like you who are offered support because I think it will help parents and schools know what works for you and what doesn't. I am also interested in parents and teachers experiences of putting that support in place, to get a better understanding too of what they think is working or not working. So overall my research is looking at the experiences of receiving and giving support for autistic pupils in secondary school.

Why You?
I am inviting you to take part in my research as you have a diagnosis of Asperger's or ASD and are registered with a secondary school, which means your views would be very important.

Taking Part
If you agreed to take part in my research, I would visit you at home over a number of visits and chat to you and ask you to complete a few tasks. You can do the tasks in your own time and then we can talk over them together. You can chat to me on your own or if you want a parent or carer to sit in the room with you that is fine too.
I really understand that this could make you feel nervous or anxious, so I am happy to use other ways of chatting if it helps; for example chatting to each other through WhatsApp. If you think that would be helpful, just let me know. I would bring a phone to your home and we could use them to chat either in the same room or in separate rooms. I really wouldn't mind chatting this way, I understand about feeling anxious because I get anxiety too, so it is important to me that you are as comfortable as possible about taking part.
The tasks that I would ask you to do are designed to help you get your thoughts out in a creative way and without too much interaction. There are no right or wrong answers, I only want to understand how you experience support in school.

So the first task would be an about school exercise
As part of this task you will be given a template on an A4 piece of paper that is divided into four sections. These sections each have a heading - *Things I like About School*, *Things I don't Like About School, Things I get Help with at School* and *Things I would Like Help with at School*. This can be linked to any aspect of school life and doesn't have to just be linked to schoolwork and you can write as many things as you like in each section.

For the second task you would be given a structured diary.
I know that sometimes it can be difficult to express how you are feeling or to know and explain how something makes you feel. Because of this, I have made a structured diary to really help you describe your experiences of lots of different things about school. But, there is also space at the end of the diary if you want to add anything in that hasn't been included.

Recording Interviews
After completing each of the tasks, we will go over them together and I will ask some questions just to make sure I understand. If it is ok with you, I would like to record us talking on a little digital recorder so that I don't forget what we say. But no one else but me will hear the recording and once I have typed the interviews up, I will delete the audio file.

Don't worry

I have only gone over these tasks briefly, but I will go over them with you again if you decide to take part in the research. Also, although you can complete the activities in your own time, if you would like to ask me any questions or would like to fill it out while I am with you then that is fine too, whatever makes it easier for you. It is really really important though that you complete the activities in your own words because it is your experiences that I am interested in.

Parent/carer Consent
I want to highlight that if you agreed to take part in my research, I would also want to speak to your parent/carer(s) and some staff at your school who help with your support. Also, if you do think you would like to take part, I would have to ask your parent/carer(s) permission to visit you in your home. But, again, your parents/carers and teachers will only know what we spoke about in detail if you choose to tell them and your tasks will not be shown to them. The completed tasks will be locked in a filing cabinet so that no one can see them but me. If I wish to take a picture of your completed task to use in my research I will ask your permission first, and it is ok to say no.

Confidentiality
What you say to me won't be repeated to others, however, I have to point out that if you told me something that made me worry about your safety, then I would speak to you first about getting some help. As well as writing up my research in a big document for my degree, I may also write about it in other ways, like in journal articles or books, or I may present the research to groups of other people in presentations. However, no matter what way I write up my research or talk about it in presentations, no one will know who you are because you will be given a false name, and the name of where you live and what school you attend will all be changed.

Your choice
It is important that you know that you do not have to take part in this research, this is simply an invitation asking if this is something you might be interested in doing. If you do decide to take part but then later on decide that you don't want to, you can just let me know at any stage of the research and that will be absolutely fine.

Pack contents
If you think you would like to take part in this research, there are consent forms in this pack. If you sign this, it lets me know that you are happy to go ahead and have understood what taking part involves after reading this information. But remember… even if you agree to take part, you can change your mind at any time.

Questions?
If you are still unsure if you would like to take part and have any questions at all you can (or ask your parents/carers to) contact me to ask these questions by:

Email: eg17@stir.ac.uk
Phone: 01786 466264

Or you can contact me to arrange for me to come and chat at a time and place that suits you.

Thank you for your interest in my research

Appendix 6: Invitation to Participate

Autism school support study

My name is Liz Graham and I am a PhD researcher at the University of Stirling. I am conducting a study into the experiences of giving and receiving support for autistic pupils in mainstream secondary schools in Scotland.

If you are an autistic pupil, or parent of an autistic pupil registered with a mainstream secondary school in Scotland, or if you work within a Scottish secondary school, I would love to hear your views.

If you live in central Scotland and would like to take part in face-to-face interviews, please contact me on eg17@stir.ac.uk for more information. For practical reasons, I can only interview face-to-face in the central belt, but if you live anywhere else in Scotland and would like to share your experiences please get in touch as we can chat via Skype, telephone or email.

This study aims to put pupil's, parents and teachers experiences on the same page to help build a picture of what is working, what is not, and what can be done to improve things that is practical and achievable for all concerned.

Many thanks
Liz Graham

Appendix 7: Social Media Advert

** AUTISM SCHOOL SUPPORT STUDY **
I am a PhD researcher at the University of Stirling researching the experiences of support in secondary school for pupils with a diagnosis of Asperger's or Autism Spectrum Disorder (ASD).

I am looking to explore pupil's experiences of support in school and parent's experiences of supporting an autistic child in secondary school. I will also be exploring teacher's experiences of support.

If you or someone you know lives in central Scotland and are either a pupil or parent/carer and would be interested in taking part and would like more information, please email eg17@stir.ac.uk

Please share this post so it reaches as many families as possible.
Thanks in advance.

Appendix 8: Information for Staff

Information
The Experiences of Receiving and Implementing Support for Pupils with a Diagnosis of ASD in Secondary School

My name is Elizabeth Graham and I am a PhD student at the University of Stirling. My research involves exploring pupils, parents and school's experiences of supporting a pupil with ASD in secondary school. I am keen to understand how pupils experience the support, how interactions between pupils/parents/school impact on the support and what changes you feel could be made to improve the support currently available.

Your participation would involve a one-to-one interview, no longer than 50 minutes, at a time most convenient to you, which would be centred on the topics mentioned above: support provided; positive and negative experiences of support; interactions with pupils and parents; recommendations for improvement. The interview will be recorded on a digital recorder but only I will have access to this recording, and it will be uploaded on to a password protected PC to be transcribed by me and then deleted from the recording device.
When I write up my research, for my thesis or for journal articles and presentations, you will be given a false name, and your location, school and the pupil's name will be changed. Therefore, you will not be identifiable on a wider scale, although it should be noted that you may identify the pupils and parents who may be associated with your school and vice-versa. I would like to highlight that you are free to withdraw your participation at any stage without prejudice.

If you would like additional information, you can contact me by **Email**: eg17@stir.ac.uk
And I am happy to meet with you to discuss your participation at a time that it is convenient for you.

Should you wish to discuss the research with my supervisors, or if you have any concerns, you can contact them via their email addresses below:
Dr Ian McIntosh: ian.mcintosh@stir.ac.uk Professor Samantha Punch: s.v.punch@stir.ac.uk

Appendix 9: Local Authority Access Request

To whom it may concern,
I am an ESRC funded doctoral researcher from the University of Stirling and my research is titled: *The Experiences of Receiving and implementing Support for Pupils with Asperger's Syndrome (ASD) in Secondary School.* This is because the challenges to, and efforts of, pupils, parents and school staff to help support a child with Asperger's are often overlooked. There is no study to date which has explored these interactions and the impact they may have on the pupil accessing and utilising the support available. Therefore, the current study has four aims to explore 1) what support is currently available to the pupils with ASD in secondary school? 2) What are participants' positive and negative experiences of using and implementing this support? 3) In what ways do interactions between pupils, parents and staff impact on receiving or delivering support? 4) What do pupils, parents and educators think can be done to improve the support available to pupils with AS in secondary school?

I am writing to request permission to approach your schools to negotiate access to teaching and support staff for participation in this study. Subject to your approval I would approach the head teachers of the schools in order to ask their permission to conduct research on school grounds with their staff, or via an email interview schedule.

Pupils and parents will not be accessed via schools but through support groups in the community.

I can assure you that all data generated in this study will be completely confidential and anonymous, including the names of the schools included in the study. Feedback from the research will be given to your Educational Department and the schools in the form of a summary report.

If you would like further information about the research, I would be pleased to answer any questions and can be contacted on **01786 466264** or eg17@stir.ac.uk . I look forward to hearing from you.

Yours sincerely,
Elizabeth Graham

Should you wish to discuss the research with my supervisors, or if you have any concerns, you can contact them via their email addresses below:
Dr Ian McIntosh: ian.mcintosh@stir.ac.uk Professor Samantha Punch: s.v.punch@stir.ac.uk

Appendix 10: Head Teacher Access Request

Dear,

I am an ESRC funded doctoral researcher from the University of Stirling and my research is titled: *The Experiences of Receiving and Implementing Support for Pupils with Asperger's Syndrome (ASD) in Secondary School.* My research is motivated by my experiences as a mother of supporting a child with Asperger's Syndrome in two separate secondary schools. These experiences have been both positive and negative and the challenges to, and efforts of, pupils, parents and school staff to help support a child with Asperger's are often overlooked. There is no study to date which has explored these interactions and the impact they may have on the pupil accessing and utilising the support available. Therefore, the current study has three aims to explore 1) what support is currently available to the pupils with ASD in secondary school? 2) What are participants' positive and negative experiences of using and implementing this support? 3) In what ways do interactions between pupils, parents and staff impact on receiving or delivering support? 4) What do pupils, parents and educators think can be done to improve the support available to pupils with ASD in secondary school?

I am writing to request permission to approach teaching and support staff within your school for participation in this study. Subject to your approval I would provide members of staff with a letter of informed consent, informing them of what the research is about and what their participation would involve. Great efforts will be made to interview the staff at a time that is not disruptive to their commitments within the school.

Pupils and parents will not be accessed via schools but through support groups in the community. I have gained consent to approach schools from **** Council (attached).

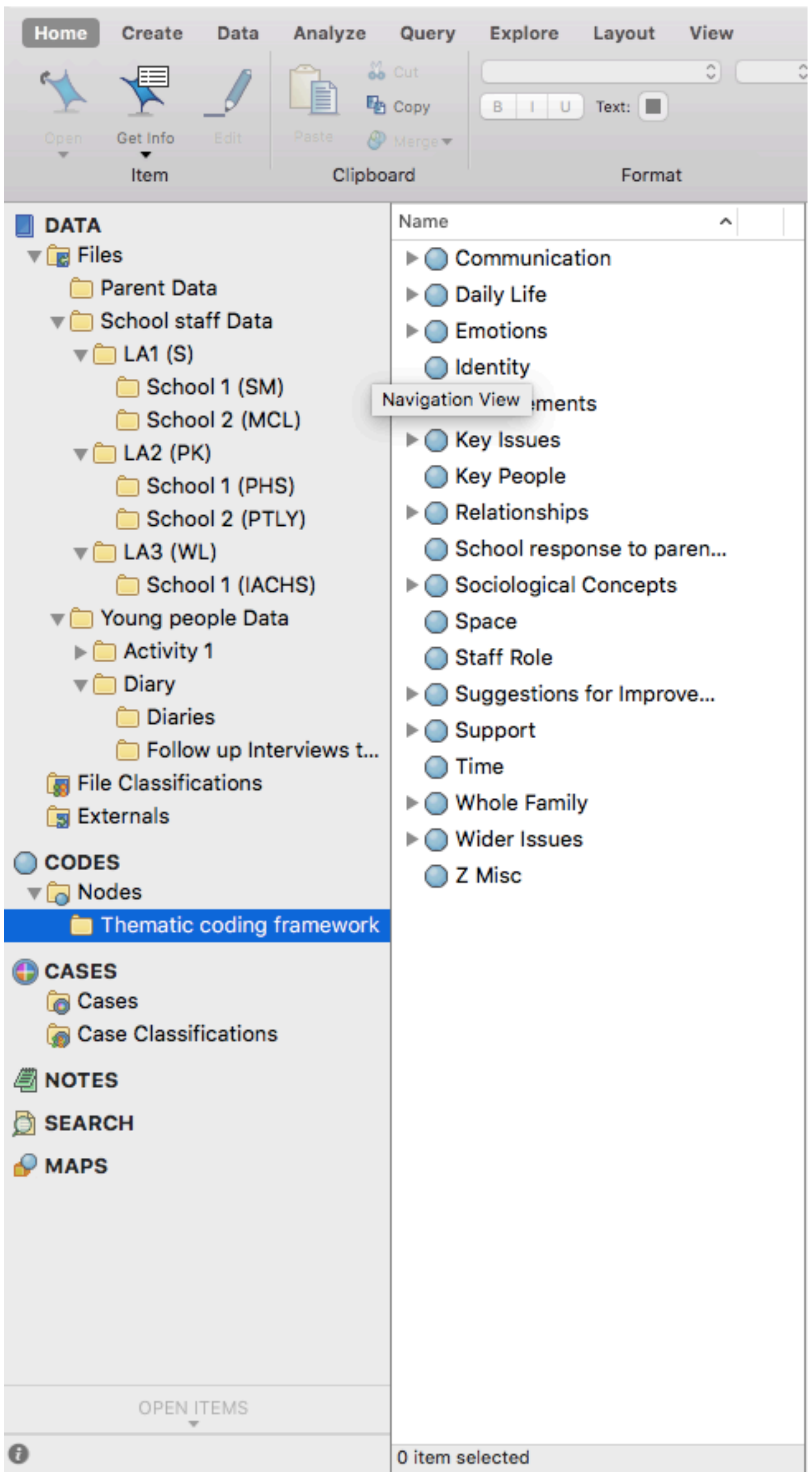
I am particularly keen to explore experiences in your school because of the autism unit based within the school and feel that this would make an interesting contribution to the research.

I can assure you that all data generated in this study will be completely confidential and anonymous. Feedback from the research will be given to the Educational Department and the schools involved. With the findings from this research my aim is to produce a toolkit that will be useful to pupils, parents and staff when supporting a pupil with ASD in secondary school.

If you would like further information about the research, I would be pleased to answer any questions and can be contacted on 07955234273 or eg17@stir.ac.uk . I look forward to hearing from you.
Yours sincerely,
Elizabeth Graham

Should you wish to discuss the research with my supervisors, or if you have any concerns, you can contact them via their email addresses below:
Dr Ian McIntosh: ian.mcintosh@stir.ac.uk Professor Samantha Punch: s.v.punch@stir.ac.uk

Appendix 11: Thematic Coding Framework



Appendix 12: Pupil Consent

Consent for Autism School Support Study

This consent form is being used to reassure Liz that you understand what taking part in this research will mean. It would be really helpful if you could answer the following questions. Don't worry about the answer having to be exactly right, it is not a test.

1. This research is about____________________
2. Tasks and interviews will take place at____________________________
3. I understand that Liz may record some of the chats we have but I know that no one else will hear them. YES / NO
4. If I don't want to take part any more at any stage I can________________________

The following statements will just give Liz an understanding about how you feel taking part in this research:

I feel very nervous/ a little nervous/ not nervous at all about taking part in the research

I agreed to take part because I wanted to/ I was asked to/ my parent/carer wanted me to

Thank you for filling in this form. By signing your name below you are agreeing to take part in the research.
Name:__________________
Date:___________________

Appendix 13: Parent Consent

Supporting Pupils with a diagnosis of ASD in Secondary School

This consent form is to reassure the researcher that you understand what the research is about and what your participation involves. By signing the consent form you understand that the statements below refer to the current research and potential future publications and presentations.

I understand what the research is about and what my participation involves. ☐
I agree to my approved informal discussions being used. ☐
I agree to my interview data being used. ☐
I agree to my interview being digitally recorded. ☐
I understand that I can withdraw my participation at any stage without prejudice. ☐

Print Name: ___________________________
Signature:_____________________________
Date: ___/___/___
……
This section of the consent form relates to your agreement (where necessary) for your child to take part in the research. By signing your name below you are agreeing for your child to take part in task-based activities and an interview within your home and for the data generated from this to be used in the write up of my research and potential future publications.
Signature:________________________
Relation to the child:________________
Date: ___/ ___/ __

Appendix 14: Staff Consent

My name is Liz Graham and I am a PhD student at the University of Stirling exploring experiences of supporting autistic pupils in secondary school. This is a rare opportunity to bring pupils, parents and school staff experiences together. I would really appreciate you taking the time to answer the attached questions and returning them directly to me (for ethical reasons) via email at eg17@stir.ac.uk

As well as the insights of support staff I would be keen to hear from classroom teachers experiences of supporting autistic pupils, particularly experiences of using the pupil passport that was mentioned during a discussion with ******** today.

By sending back your completed interview schedule you are consenting for it to be used in the research.

A summary of the findings will be provided to all participants on completion of the PhD.

Many thanks and kind regards

Liz