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Facilitating communication between students on the autism spectrum and staff in secondary mainstream schools

by

Harriet Hummerstone

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ABSTRACT

FACULTY OF SOCIAL, HUMAN AND MATHEMATICAL SCIENCES

Education

Thesis for the degree of Doctor of Philosophy

Facilitating Communication Between Students on the Autism Spectrum and Staff in Mainstream Secondary Schools

Harriet Kate Mairead Hummerstone

The Special Educational Needs and Disabilities Code of Practice (DfE, 2015) makes it essential for students on the autism spectrum to be involved in making decisions about their education. However, differences in communication between individuals on the autism spectrum and neurotypicals (those not on the autism spectrum) could make these consultations difficult. An exploratory and participatory approach was taken to investigate the processes of communication and support in secondary schools. Six autistic adults advised on interviewing and communication techniques for working with individuals on the autism spectrum. These recommendations informed the first phase of the research: semi-structured interviews with six students on the autism spectrum (involving photo elicitation) and seven staff members from two secondary mainstream schools in the south of England. Thematic analysis of the findings revealed four key examples of the 'double-empathy problem' (Milton, 2012) in their perspectives on the processes of communication and support in school. The four areas were: responsibility for improving staff understanding about students, the nature and frequency of providing effective support, and awareness of students' sensory experiences. These findings informed the second phase of the study: designing four activities to facilitate communication with students on the autism spectrum about these four differences in perspective, then asking educational practitioners to assess whether and how the information from these activities might be used to facilitate communication and support with students. Informant design was used to create four activities with the same six students from the first phase and the same adult autism advocacy group. The information gained from students completing these four activities was summarised and given to sixteen educational practitioners to comment on, including two staff members from the first phase of the research. The findings from the second phase highlighted the importance of personalisation and feeling understood for students, and how personal information about individual students could potentially lead to some development in educational practitioners' communication with and understanding of the students. However, the four double-empathy problems identified in the first phase were not addressed sufficiently to assess whether they were able to be improved. The findings from both phases of the research suggest that the importance of individual differences cannot be over-stated when communicating with and supporting students on the autism spectrum, and that being understood is crucial to students' perceptions of effective support in secondary mainstream schools.

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Academic Thesis: Declaration Of Authorship

I, ...

declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

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I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signed: .....

Date: .....

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Definitions and Abbreviations

AS	Asperger Syndrome
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
DfE	Department for Education
DfES	Department for Education and Skills
DSM-5	Diagnostic and Statistical Manual (5th Edition)
EHCP	Education, Health and Care Plan
ILP	Individual Learning Plan
IEP	Individual Education Plan
LSA	Learning Support Assistant
SEN	Special Educational Need
SENCO	Special Educational Need Coordinator
SEND CoP	Special Educational Needs & Disability Code of Practice
TA	Teaching Assistant

A note on language and terminology

The most recent version of the Diagnostic and Statistical Manual (hereafter referred to as DSM-5, APA 2013) has merged Autistic Disorder, Asperger Syndrome and Pervasive Developmental Disorder Not Otherwise Specified into one umbrella term of ‘autism spectrum disorders’ (ASD). However, my preferred choice of terminology throughout this thesis regarding those who have received this diagnosis will be ‘students/individuals on the autism spectrum’. Similarly, I will refer to those without a diagnosis of autism as ‘neurotypical students/individuals’ to demonstrate the neurodiversity between participants. When referring to the adult participants who were consulted in my thesis, I will refer to them as ‘autistic adults’ in line with their specific requests and how they choose to label themselves.

For a more detailed discussion and justifications for these specific labels, please see Section 1.3.

Chapter 1 Inclusion and students' voices

Within this chapter, I first illustrate the policy and research context in which my research takes place. There are also two key concepts used throughout my thesis that require clarification. The first concept I will be discussing is inclusion. Successful inclusion of students on the autism spectrum within schools can impact positively on students' experiences in numerous ways (Humphrey & Lewis, 2008a; Molloy & Vasil, 2004). I explore my personal conceptualisation of inclusion in relation to educational provision and labelling of these students; specifically, deciding which terminology to use in relation to students who have received a diagnosis. The second part of this chapter focuses on conceptualising the term "students' voices" and discussing the conceptual quality criteria used throughout this thesis to assess the ways in which students' voices are heard. The final section of this chapter explores the potential of listening to students' voices to support their inclusion.

1.1 Introduction and context

Special educational provision in England has undergone significant changes with the Special Educational Needs and Disability Code of Practice (hereafter referred to as the SEND CoP), implemented since September 2014 and revised in January 2015. A key change from the previous Special Educational Needs Code of Practice (DfES, 2001) is the strengthened emphasis on the involvement and consultation of young people with special educational needs (SEN), and specifically, their views regarding decisions that affect their education. This is therefore the educational policy context within which this research takes place.

Although the SEND CoP (DfE, 2015) contains statutory guidance that demonstrates a legal obligation to listen to the views of young people with SEN, there is also a moral consideration for allowing students to share their experiences. Studies such as Kilkelly et al. (2005) and Lundy (2007) have found that children are very concerned with having a say in the decisions that affect them. This echoes Article 12 of the United Nations Convention on the Rights of the Child (UNCRC, 1989). This states that children should be provided with the opportunity to be heard in any judicial and administrative proceedings affecting them, and that their views are given due weight in accordance with their age and maturity. Referring to education specifically, Elliot-Johns et al. (2012) cite student voice as a crucial way of connecting with students and using this information to create educational practices in response. Lundy (2007) argues that the significance of Article 12 relating to

education cannot be overstated, and therefore it is fitting that the newest version of the SEND CoP (DfE, 2015) includes an increased emphasis regarding student consultation.

In relation to students on the autism spectrum, the need to listen to their voices can be argued for several reasons. The first is due to the prevalence of autism within schools in England. According to the Department for Education (DfE, 2017a), autism is the sixth most commonly identified primary need of students with SEN across England, and the primary need of over a quarter of students who have received a statement of SEN or an Education, Health and Care Plan (EHCP). The DfE (2017b) also notes that as of July 2017, this equates to over 60,000 students on the autism spectrum that have either a statement of SEN or an EHCP, and a further 47,500+ students on the autism spectrum who receive some other SEN support across primary, secondary and special schools in England. Students on the autism spectrum – along with other students with SEN - therefore fall under the remit of the new Code of Practice (DfE, 2015), and **must** be consulted about, and involved in, decisions about their educational provision. Although students on the autism spectrum attend a variety of educational institutions, students in mainstream secondary schools specifically form the focus of this thesis as this is an underexplored area (Humphrey & Lewis, 2008b).

In addition to the SEND CoP (DfE, 2015), there is also a wider need for consultation with individuals on the autism spectrum, with many researchers and advocates calling for the more direct involvement of individuals on the autism spectrum in research (Milton, Mills & Pellicano, 2014; Parsons et al., 2011; Pellicano, Dinsmore & Charman, 2014). Pellicano, Dinsmore and Charman (2014) specifically highlight the lack of research with older children and adolescents on the autism spectrum; similar conclusions regarding this lack of focus in research have also been reported by Edwards, Watkins, Lotfizadeh and Poling (2012) and Parsons et al. (2011). A need for greater participation and involvement also applies specifically to the educational experiences of individuals on the autism spectrum (Humphrey & Lewis, 2008a), as these experiences are generally considered under-researched (Holt, 2010). However, Davidson (2010) suggests that a greater understanding of the experiences of students on the autism spectrum is needed before attempts at accommodation under the SEND CoP's (DfE, 2015) legislation, stating that "…bearing witness [to autistic experiences] requires willingness to take action, and do more than simply see" (p.307). The recent changes in educational policy in England - combined with a wider need for involvement - therefore represents an opportunity to involve individuals on the autism spectrum in research that explores their educational experiences within a mainstream secondary school environment.

An additional and equally important reason for involving students on the autism spectrum in discussions about their education is to facilitate the personalisation of the teaching and support they receive in schools. According to the SEND CoP (DfE, 2015), teachers need to know "how to adapt teaching and learning to meet a particular type of SEN" (Section 4.32, p.69). This suggests that teaching approaches considered effective for most children may require further adaptation to be utilised by students with SEN. Regarding students on the autism spectrum, this is supported by Jordan (2005), who observes that "Children with ASDs often (but not always) require different approaches [to teaching] rather than just more (or more focused) of the same" (p.117). Consequently, the input from the students themselves is crucial in assessing whether their needs can be met with general inclusive teaching strategies, autism-specific strategies, or a combination of both to achieve their full potential.

1.1.1 Aims of thesis

As a researcher with almost six years of teaching experience in secondary mainstream schools and further education, I am keen to explore how to engage successfully and meaningfully with the voices of students on the autism spectrum to improve their educational experiences. I am also keen for staff in secondary mainstream schools to feel confident in developing personalised approaches for students on the autism spectrum through working collaboratively with them. This thesis aims firstly to explore the process of communication and support between individuals on the autism spectrum and school staff members and the factors that affect it, from the perspectives of both groups. My secondary aim is to facilitate the process of communication (and subsequently, support) using information gathered from activity-based methods. This study therefore consists of two phases. The first exploratory phase investigated the existing levels of communication and support perceived by students on the autism spectrum and staff members they work with, with the following research questions:

1. What is the process of support being offered to (and by) students on the autism spectrum in a classroom environment?

2. What is the process of communication between students on the autism spectrum and the others (e.g. teachers, LSAs, peers) they work with?

3. What might be the factors that contribute to the process of these communications?

The second phase was developed following the findings of the first phase and reports the design and implementation of four targeted activities and the information gained from

them to facilitate communication with students on the autism spectrum. The research questions for the second phase were as follows:

4. What kinds of methods, from the perspectives of students on the autism spectrum and autistic adults, could be beneficial for facilitating communication and support between staff and students?

5. What kind of information about the students on the autism spectrum, from the perspectives of staff and other educational practitioners, could be beneficial for facilitating communication and support between staff and students?

Six students on the autism spectrum from two mainstream secondary schools in the south of England took part in both phases of the research. In the first phase, each student completed a photo trail of their school to take photographs representing each of their subjects. These photographs were then ranked and discussed to explore their perspectives of communication and support. Seven members of school staff were also interviewed in the first phase about the processes of communication and support in relation to one of the six students. For the second phase, the same six students helped to design four activities exploring ways to facilitate communication and support, and then completed them. The information from these activities was then summarised in a personalised sheet. This sheet was distributed to sixteen educational practitioners (two of which had also taken part in the first phase) and asked to comment on how this information might be used to facilitate communication and support in relation to a specific student.

The first chapter of this thesis explores the concepts of inclusion and students' voices in more detail regarding their involvement in educational discussions. Chapter 2 applies the conceptual criteria for listening to students' voices that was established in Chapter 1 to the existing research literature to explore what we currently know about the educational experiences of individuals on the autism spectrum, and the methods used to listen to their voices. Chapter 3 establishes my epistemological position and details the first phase of my research, the findings of which are reported in Chapter 4. Chapter 5 covers the additional methodological considerations when planning the second phase of my research, the design of the four activities used, and the findings from the perspectives of the students, the autistic adults, and the educational practitioners who took part. A discussion of the overall findings from both phases of my research is detailed in Chapter 6, with Chapter 7 containing an assessment of the limitations of this research and my concluding comments.

1.2 Defining inclusion

Ainscow, Booth and Dyson (2006) note that because inclusion means different things to different people, it is best described in terms of “messy complexities” (p.4). This is especially true when examining my personal definitions of inclusion, and how inclusion is described and defined within the SEND CoP (DfE, 2015).

1.2.1 Personal conceptualisation

Ainscow, Booth and Dyson (2006) describe six approaches to inclusion, two of which are used to create my own working definition of inclusion within this thesis. The first approach I will discuss is inclusion as a concern with disabled students and others with SEN, where inclusion is primarily about educating students with SEN in mainstream settings. Ainscow, Booth and Dyson (2006) note that this approach to inclusion is “deeply entrenched” (p.17) within educational policy and practice in England. As I have previously taught for six years in the English education system, it is perhaps inevitable that this reflects my personal approach to inclusion. However, my motivations for wanting students to be included also align with another of the six approaches suggested by Ainscow, Booth and Dyson (2006): inclusion as a principled approach to education and society, characterised by a set of values that underpin inclusion, regardless of definition and context. Their principles include equity, participation, compassion and respect for diversity, although the authors also acknowledge that even these values will take on different definitions in different contexts. Having attempted to define what inclusion means, the authors suggest what inclusion does under the terms of this approach:

- Increases student participation
- Responds to student diversity with changes in policy, practice and culture
- Focuses on all students at risk of exclusionary pressures, not just those with special educational needs

Theoretically, I strongly agree with these values and goals for inclusion. However, within my own practice and through my discussions with staff members in English schools, it is impossible to ignore the widely-held belief that inclusion is about educating students with SEN in mainstream settings. Therefore, to collaborate more effectively with both students and staff members – and provide possibilities for support that are contextually relevant – thinking about inclusion as a concern for disabled students and others with SEN is the main approach adopted in this thesis, as it fits the beliefs and value system of the research context.

The other key theoretical concept that is reflected in my approach to inclusion is what Lewis and Norwich (2005) describe as the "general differences" (p.3) position to education. This concept identifies students as having three levels of pedagogic need that must be met by their education: needs that are common to all students, needs that are specific to a particular group of students, and needs that are specific to the individual student. This differs from the "unique differences" position (Lewis & Norwich, 2005), which only identifies students as having two levels of pedagogic need: needs that are common to all students and needs that are specific to the individual. Lewis and Norwich (2005) explain that in the general differences position, pedagogy is informed firstly by "needs that are specific or distinctive to a group that shares common characteristics" (p.3). Within this thesis, this group has been identified as students on the autism spectrum.

1.2.2 Conceptualisation within the SEND CoP (DfE, 2015)

The SEND CoP (DfE, 2015) relates closely to the idea of inclusion as a concern with disabled students and others with SEN. Within the parameters of this definition, the successful inclusion of students on the autism spectrum within mainstream schools (my research setting) can have several positive effects. For example, Osborne and Reed (2011) argue that students on the autism spectrum must be included to fully access and take advantage of the benefits of the mainstream school environment. Similarly, Frederickson, Dunsmuir, Lang and Monsen (2004) report that effective inclusion is linked directly to academic achievement, as seen from their interviews with teachers, parents and students who all made this link explicit. In addition, there are negative effects that a lack of inclusion in mainstream schools can have on students on the autism spectrum. Isolation, depression, bullying and anxiety can all stem from a perceived lack of understanding from neurotypical peers and staff (e.g. Symes & Humphrey, 2010; Humphrey & Lewis, 2008a; Ochs, Kremer-Salik, Solomon & Sirota, 2001). Consequently, the first approach I mentioned above - approaching inclusion as a concern with disabled students and others with SEN - matches the policy context of the SEND CoP (DfE, 2015). It is therefore important for me as a researcher to consider this approach to inclusion when investigating the educational experiences of students on the autism spectrum.

There is also evidence that the SEND CoP (DfE, 2015) supports inclusion as a principled approach to education and society. The policy advocates focussing on the individual's unique learning profile when thinking about how to support their inclusion, stating that "The support provided to an individual should always be based on a full understanding of their particular strengths and needs" (p.97), suggesting an approach based on the individual. Inclusion is also represented in the policy as a focus on "removal of barriers to learning and participation in mainstream education" (p. 25), echoing the view of inclusion

as a principled approach where inclusion is about reducing barriers to participation and learning for any student (rather than those who have received a diagnosis of SEN). However, the SEND CoP (DfE, 2015) is written specifically for students with SEN and uses diagnostic labels throughout, which is in direct opposition to inclusion as a principled approach. Booth and Ainscow (1998) suggest that using the term 'SEN' can lead to lowered expectations of students and can neglect the other difficulties that students without a label may be experiencing. Corbett (1995) is similarly wary of using labels to describe individuals, arguing that they affect perceptions and judgements about a student. Categorising people (e.g. through use of diagnostic labels such as "autism") is therefore deemed exclusionary. This use of language in this document is therefore contradictory, suggesting that the conceptualisation of inclusion within it may lack clarity.

This lack of clarity regarding definitions of inclusion can be seen in other areas in the SEND CoP (DfE, 2015) apart from language. For example, Norwich and Lewis (2005) suggest that a key idea of inclusion relating to all students (rather than just those with SEN) is that "particular pedagogic strategies are relevant or effective for all pupils, irrespective of social background, ethnicity, gender and disability" (p.4). Support for this idea of non-specific pedagogies can be seen in the SEND CoP (DfE, 2015) through its promotion of whole-school inclusive approaches which can be used "to build the quality of whole-school provision" (p. 92) and "support schools to improve their core offer for all pupils as the most effective approaches are adopted more widely across the school" (p.106). It also suggests that the promotion of higher quality teaching will reduce the number of students needing additional provision (Section 6.15), promoting general rather than specific teaching pedagogies. However, the policy also states that teachers also need to know "how to adapt teaching and learning to meet a particular type of SEN" (SEND CoP, DfE, 2015, p.69), which seems to be encouraging the use of specific pedagogies. The SEND CoP (DfE, 2015) therefore actively supports whole-school inclusive approaches yet lacks detail on how specific and additional provision is necessary for the inclusion of a specific group of students. The concept of inclusion within the SEND CoP (DfE, 2015) is muddled and contradictory in both its advice and language, which consequently makes it very difficult to conceptualise.

To conceptualise the inclusion of students on the autism spectrum within the context of the SEND CoP (DfE, 2015) and in accordance with my own personal beliefs, these contradictions between the two different approaches to inclusion need to be resolved. Ravet's (2011) integrative approach to inclusion offers a mid-way position between two approaches to inclusion that are relevant to this dichotomy. She describes the tension between a 'rights-based' perspective, which argues that labelling is exclusionary, and all learners have a right to be taught in mainstream classrooms with pedagogies that are

helpful to all learners; and a 'needs-based' approach, where labels are deemed useful, and the notion of 'one size fits all' regarding pedagogies is rejected. Ravet's (2011) solution to these contrasting approaches is to adopt an integrative position, which adopts the middle ground and draws on elements of each approach. In the integrative position, the negative effects of labelling try to be minimised, and neurodiversity is valued. Distinct pedagogies are used for inclusion, which are designed to support students on the autism spectrum but may also facilitate the inclusion of other students. Her use of the term 'distinct pedagogies' – rather than 'special pedagogies' – is also designed to move away from the association with SEN and the needs-based perspective. Ravet's (2011) integrative approach to inclusion is therefore the approach that best aligns with the conceptualisation of inclusion within the SEND CoP (DfE, 2015) and my own personal conceptualisation, and therefore this approach to inclusion is adopted throughout this research.

However, Ravet's (2011) descriptions of integrative pedagogies and neutral labelling suggest that an inclusive environment can be created within a mainstream school for students on the autism spectrum. This contrasts with my own conceptualisation of inclusion as an ongoing process rather than a place. For me, inclusion requires participation from both students and teachers to review inclusive practices and adjust them as necessary to ensure that they continue to be inclusive and effective. Although distinct pedagogies, neutral labelling and whole-school approaches may form the starting point for inclusive practices in mainstream schools, I believe that a student's successful inclusion is an ongoing process that requires careful evaluation and assessment. Consequently, I view Ravet's (2011) integrative position as an approach to starting inclusive practices in mainstream schools that aligns most clearly with my own views; however, this is very much a starting point in my working definition of inclusion as an ongoing process.

1.3 Labelling and inclusion

By taking a principled approach to inclusion, my motivation for wanting students to be included in mainstream secondary schools can be argued in terms of equity, participation, compassion and respect for diversity. However, these inclusive values are ultimately contradicted by using labels such as SEN and/or disability. Graham and Slee (2007) argue that labelling promotes exclusion "…by pointing to exceptional characteristics as the markers of difference" (p.3). The impact of using labels may also be long-term. Higgins, Rashkind, Goldberg and Herman (2002) conducted a longitudinal study over a twenty-year period involving adults with learning disabilities. The (in)accuracy of the labelling that was given in childhood and others' negative reactions to it (especially peers) were

mentioned by many of the participants as having a very negative impact on their childhood experiences, although some described how this became easier to deal with as they moved towards adulthood. Claiming to be inclusive while also using labels therefore presents a personal dichotomy. I am choosing to use a disability label by categorising the students I am working with as 'being on the autism spectrum' yet using labels may have negative effects on the students who take part in my study. My actions therefore do not appear to align with the values of inclusion that I have detailed above. My justification for using labels whilst still adhering to inclusive values is therefore discussed in this section.

1.3.1 Why label?

There are two main reasons for my decision to use labels within this thesis. Firstly, there are advantages to labelling that may outweigh the disadvantages. Receiving a label may be beneficial within education specifically for students on the autism spectrum by allowing them (and their parents and teachers) access to specialised interventions and resources (Ruble & Akshoomoff, 2010). These resources may facilitate the student's inclusion within a secondary mainstream environment. Ravet (2011) concurs, arguing that a label of SEN acts as an indicator that specific difficulties may occur, and that this can offer an important lens through which the understanding of students can be increased. However, Norwich (2014) cautions that categorising individuals in terms of their disability can lead to exclusion and stigma, especially categorising by disability labels which can promote a focus on an individual's difficulties. The stigma of labelling can therefore be avoided by refuting diagnostic labels when supporting inclusion. Unfortunately, Baker (2002) notes that for individuals on the autism spectrum, avoiding a diagnostic label can lead to other, moral, negative labels being applied by others:

> [Other people may] fail to understand how someone so capable in some areas could be so ignorant in basic know-how, so assume they are either being deliberately difficult, or just not caring or not trying hard enough
>
> ("To diagnose or not?", para. 1, n.p.n.)

This highlights how important it is to consider the nature of labels being applied; they do not necessarily have to be negative and deficit-focussed, even if diagnostic and SEN labels are used. Stager, Chassin and Young (1983) found that the effects of labelling were only negative when students believed that the label was negative. More recently, Savaria, Underwood and Sinclair (2011) advise professionals that everyone must be given a chance to participate in the construction of disability labels to allow individuals to explore the idea of their disability as a positive aspect of their self-concept. This suggests that disability labels may therefore impact on an individual's self-concept in a positive way, and therefore could be advantageous.

Regarding autism specifically, Huw and Jones (2008) interviewed adolescents on the autism spectrum about their experiences, concluding that knowledge of a diagnosis could "…assist in the development of a positive self-concept and self-identity" (p.105), and that the diagnosis of autism can provide relief and understanding for an individual regarding their differences. As adolescents on the autism spectrum are particularly prone to low self-esteem (Hofvander et al., 2009), positive labelling may increase the positivity of their self-concepts. Another advantage of labels has been expressed by self-advocates who identify as being autistic and argue strongly that autism is an integral part of their personality (Jaarsma & Welin, 2011). In choosing not to label, I may therefore also be at risk of excluding and marginalising students who see the label of autism as fundamental to their personalities and identities, or who may use it to build positive aspects of their self-identity. To promote access to resources in schools, an understanding of differences, and the possibility of labelling being linked to self-identity, I therefore will be using labels throughout this thesis to promote the inclusion of students on the autism spectrum.

1.3.2 Which label?

Having established that there are disadvantages and advantages to labelling, deciding which label to use is equally complex. A range of terminology is used by professionals, researchers, parents and students when describing students on the autism spectrum (Collier, 2012). These differences can reflect perspectives and opinions that are deeply entrenched and therefore require careful consideration to demonstrate respect for the diversity of these views. For example, a widely-used phrase in the medical and research community is 'autism spectrum disorder (ASD)', the formal diagnostic label in DSM-5 (APA, 2013). The diagnostic criteria for ASD focusses on two main behaviours that individuals are likely to demonstrate. The first criterion relates to deficits in social communication and social interaction across multiple contexts, which include social-emotional reciprocity, nonverbal communicative behaviours, and deficits in developing, maintaining, and understanding relationships. The second is restricted, repetitive patterns of behaviour, which may manifest as motor movements, use of objects or speech, insistence on sameness, interests that are abnormal in relation to intensity and focus and hyper or hypo-reactivity to sensory input. Based on observations from these two categories, individuals are assigned a severity level, dependent on the amount of support the individual requires for their 'noticeable' (Level 1), 'marked' (Level 2) or 'severe' (Level 3) deficits in social communication, social interaction and restricted behaviour patterns. I strongly oppose this use of deficit-focused and medical terminology, as it is highly problematic.

Firstly, as Durig (1996) highlights, focussing only on deficits can be perceived as insulting to those on the spectrum and with other disabilities:

> Something about the deficit approach smacks of character judgement and value judgement based on narrow assumptions of normalcy…the attitude is "If you are not normal, we will try to fix you" (p.12)

Secondly, referring to individuals on the autism spectrum in terms of their deficits and impairments may neglect to recognise strengths and skills associated with autism, suggesting that these criteria are in danger of over-applying a medical model perspective on disability (Mackelprang & Salsgiver, 2015). Even the word 'disorder' may portray autism in a negative light; a sentiment echoed by Baron-Cohen et al (2009) and Ravet (2015), who advocate for the phrase, 'individuals with autism spectrum conditions (ASC)' as a more neutral alternative. However, the term 'condition' still suggests medical overtones, and may not encompass personal characteristics and perceptions as part of this label: therefore, this phrase is also problematic.

A further debate in labelling exists regarding the use of person-first language (i.e. 'individuals with autism spectrum conditions') or identity-first language ('ASC individuals'). The use of person-first language can suggest that autism is a condition that can be affected by the environment, rather than being an inherent characteristic of the individual (Broderick & Ne'eman, 2008). In this respect, using the phrase "individuals with ASC" also reflects what Durig (1996) refers to as an asset approach, which focusses more on the "the qualities and characteristics of organised meaningful perception" (p.12). This approach suggests that behaviour and cognitive processes are viewed as natural and meaningful responses to the environment, and therefore as differing social constructions that must be equally valued. The label of "individuals with ASC" therefore also concurs with the social model of disability, where difficulties experienced are thought to be caused by the organisation of society, rather than seeing the individual as the source of difficulty (Shakespeare, 2006). Similar social perspectives are reflected in descriptions of autism as a culture that is not accepted by the mainstream (Waltz, 2003).

Person-first language can also be used by individuals on the autism spectrum as a way of separating the negative aspects of their autism that may cause them difficulties, as this can be a preferable way of thinking about it (Jaarsma & Welin, 2011). For example, Blackburn (2000) describes herself as follows:

> I am regarded as 'high functioning autistic', although I tend to feel that many areas of my autistic condition have remained very severe…I have a very uneven profile of strengths and weaknesses, where often my strengths mask my very real difficulties (p.9).

In contrast, others actively object to descriptions of themselves as 'individuals **with** ASC' strongly preferring identity-first language. In her online blog, Brown (2011), who describes herself as an 'autistic self-advocate', comments that:

> It is impossible to affirm the value and worth of an Autistic person without recognizing his or her identity as an Autistic person. Referring to me as "a person with autism," or "an individual with ASD" demeans who I am because it denies who I am. (para.15, n.p.n.)

Sinclair (2013) also criticises person-first language, explaining that using labels such as 'person with autism' infers that autism is: "…something bad – so bad that it isn't even consistent with being a person" (para 3, n.p.n.). For autism advocates (e.g. Milton, 2013) and many others, autism is seen as a defining part of a person that cannot be separated or compartmentalised in the same way that other conditions can, which necessitates the use of identity-first language when describing it. This criticism is also problematic for the DSM-5 (APA, 2013) ASD definition. Amalgamating previous diagnostic terms (such as Asperger Syndrome) into the new term of "autism spectrum disorder" reduces the acknowledgement of individual differences that exist between individuals who have received the same diagnosis. Additionally, this is also problematic for those who have internalised these labels as part of their identity, such as those exploring identity through labelling within the online community (Giles, 2013). For individuals who value identity-first language, trying to distinguish autism as separate from their personality through person-first language can therefore be incredibly insulting (Jaarsma & Welin, 2011).

This makes it very challenging to create a single term that accurately incorporates these contrasting points of view, as reflected in Kenny et al.'s (2016) findings regarding suitable terminology associated with autism in the UK. Kapp, Gillespie-Lynch, Sherman and Hutman (2013) have suggested the notion of "deficit-as-difference" to overcome this, where the neurological differences of autism are acknowledged without a critical or medical tone. Kenny et al.'s (2016) findings support this suggestion, as one of the main themes reported by the individuals on the autism spectrum in their study was the idea of "disorder vs. difference", with some respondents arguing that autism needs to be understood as a *different* way of viewing the world rather than as a *deficient* one.

I believe that the views of individuals on the autism spectrum should be represented and respected by researchers. To prevent offense at using either person-first or identity-first language, my preferred terminology throughout this thesis is the phrase "individuals/students on the autism spectrum". Kenny et al. (2016) reported that this term was ranked as being 'liked' across all four groups of respondents - those with a diagnosis of autism, professionals, parents and family/friends - and is seen to be acceptable by

members of the autistic community who may be critical of ‘person-first’ terminology (Nicolaidis, Kripke & Raymaker, 2014). Secondly, I feel that the use of the word ‘spectrum’ (without the accompanying ‘condition’ or ‘disorder’ from the labels discussed previously) better illustrates the variety of presentations, skills and ability in autism without medical overtones that may be overly focussed on deficits.

This phrase is also more aligned with the neurodiversity movement, which argues that there are natural variations of brain function that can affect beliefs, thoughts, and emotions (Ortega, 2009). The neurodiversity view therefore moves away from the medical and deficit-focussed autism narrative that argues for a cure, instead arguing for recognition and acceptance of these neurological differences (Runswick-Cole, 2014). I am in agreement with this view; I believe that autism is a natural variation that deserves recognition and acceptance, yet I am not personally comfortable that the label of SEN is the difference to be highlighted, especially in relation to inclusive practice. I also believe that any individual’s strengths should be considered when planning to improve their educational experiences. I believe that students on the autism spectrum may benefit from labels, yet I do not agree that that label should represent an SEN.

A possible resolution is through the modification of the “general differences” position to inclusion by using a category to define ‘group’ needs that is not solely based on SEN labels. Lewis and Norwich (2005) state that a general differences position could be seen in favour of inclusion if circumstances arose where “the possibility that categorisation of learners may be pedagogically helpful” (p.4). Although categorising students in terms of a specific SEN may not be useful for effective teaching strategies, categorising learners in terms of neurological diversity could be more helpful. Culham and Nind (2003) argue that inclusion no longer means thinking solely about (dis)ability – it also concerns race, gender and poverty. The neurodiversity argument suggests that neurological differences are categorised as a political grouping that is comparable to race and gender (Jaarsma & Welin, 2011), suggesting that neurological differences may be an alternative way of categorising learners. However, at present, there is little evidence (neurological or otherwise) to claim that this categorisation would be beneficial for pedagogies with any confidence.

For the purposes of this thesis, I will therefore adopt the phrase “students on the autism spectrum” to reflect these students’ neurological differences. To promote equal labelling in terms of neurological differences, I will also label individuals mentioned in this thesis who have not received a diagnosis of autism as “neurotypical”. This is a shortened version of the phrase “neurologically typical”, used extensively within the neurodiversity community to describe individuals who do not experience a wide range of neurological differences, such as bipolar disorder and Tourette’s syndrome (Baker, 2011). Consequently, all

individuals I work with will be referred to using a label that is indicative of their neurological diversity, and not of their (dis)ability to illustrate the inclusive values of equity and respect for diversity.

1.4 The challenge of listening to students' voices

As established in Section 1.2, inclusion is a complex concept (Lindsay, 2003) – and following the SEND CoP's (DfE, 2015) recommendations for inclusive practice are complicated. Consequently, the translation from policy to practice may be problematic:

> …policy can be theorised, created and enforced, but without connecting it to people's practice and lives, it can also be rejected, worked around, subverted and ignored (Kozleski & Thorius, 2014, p.3)

A possible solution to this comes from the SEND CoP's (DfE, 2015) strengthened emphasis on the importance of consulting with students with SEN and actively seeking their views and experiences about their education (see Section 1.4 for a more detailed discussion). This may encourage students on the autism spectrum to share information and insights about themselves that can better personalise their educational experiences through listening to their views.

1.4.1 The importance of students' voices

Sometimes referred to as 'student voice', broadly speaking, this approach redefines the roles students play in making changes to their education and taking part in research. It is the argument that students should be actively influencing their education, and that seeking their views is necessary because they can provide a different perspective which is otherwise inaccessible to adults (Bahou, 2011). This approach aligns closely with my personal views as a researcher and as an educator on the importance of students' voices in improving the education that they receive, and therefore I regard the SEND CoP's (DfE, 2015) increased emphasis regarding student consultation as very positive. However, there are difficulties that must be navigated when listening to students' voices to ensure that tokenism is avoided and meaningful information about their educational experiences is gathered.

The origins of student voice start with the UNCRC (1989) which clarified the rights of individuals under the age of 18, explicitly recognising that children and young people require additional protection to adults due to their specific needs and vulnerabilities. One of the four underpinning principles of the convention is respect for the views of the child. This is detailed in Article 12, which states that children should be provided with "the

opportunity to be heard in any judicial and administrative proceedings affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child". To ensure basic well-being for children, the core standards of the UNRC need to be met which includes their right to free education and to express views in all decisions that affect them. This original policy legitimised a moral need for children's views to be heard on a variety of issues in relation to their education. As Marshall and Goodall (2015) observe, a child's right to education is not limited to curriculum content, including educational processes and the pedagogical environment in which their education takes place (if indeed, a child wants to offer their views; a right to a view does not necessarily mean an obligation to give one). Other legal imperatives have since followed, such as the Education Act (2002) in England which placed a legal requirement on schools to follow guidance about consultation with students regarding educational decisions that affect them. In addition, the voices of students are necessary to inform educational practices (Elliot-Johns et al., 2012), with Rudduck, Chaplain and Wallace (1996) arguing for the inclusion of students' opinions in relation to school improvement, challenging the idea of students as passive, silent receivers of education (Cook-Sather, 2003). With both legal and research-based evidence, the importance of listening to students' voices regarding their education is clear; however, the process is far from straightforward.

I ascribe to Wegerif's (2008) belief that constructing meaning "always implies at least two voices" (p.348). Within this thesis, any meanings that are derived from my interactions are inevitably going to represent the voices of the individuals that I am working with, and my own voice as a researcher and educator. Consequently, some of the 'voices' demonstrated in this thesis are presented as a co-construction of meaning between myself and the individuals that I have worked with, such as the dialogue between myself and the participants. However, the interpretation and analysis of this is solely my own. I have tried to consider alternative interpretations of meaning and explicitly acknowledged my own influences on reporting these meanings to demonstrate what Sommer (1994) refers to as "interpretive reticence" (p.548) - learning to listen without expectations of mutuality and shared experiences. Therefore, whenever I refer to students' voices within this thesis, it is with open acknowledgement that the meaning of these words is mostly from my own interpretations. This self-reflexivity, combined with the concept of the multiplicity of voice, is therefore what I am aiming for when describing authenticity: representing the complexities of students' voices and my own interpretations of them.

1.4.2 The multiplicity of students' voices

One of the first challenges when claiming that listening to students' voices reveals their experiences is the danger of combining this information into an ultimate truth or one 'true' voice. To conceptualise the complex nature of student voice, I have adopted Mazzei and Jackson's (2009) recommendation to pluralise voice, and therefore refer to 'students' voices' throughout this thesis. This phrase highlights what Mazzei and Jackson (2009) describe as "the polyvocal and multiple nature of voice within contexts that are themselves messy and constrained" (p.1). I do not believe it is possible to observe one salient truth regarding students' experiences, or regarding an individual student's experiences; consequently, the notion of students' voices that I refer to throughout this section (and indeed, this thesis) is accepted as flawed, incomplete, and inconsistent. Acknowledging the multiplicity of voices further complicates what exactly is interpreted to reflect these voices. For example, a refusal to speak and silence can be used as a form of communication. Lewis (2010) observes that silence may not be "empty or neutral" (p.20) and Cook-Sather (2006) reflects that an individual who chooses not to speak can be communicating that they believe their voice cannot, or will not, be listened to. Mazzei (2009) goes one step further to describe several examples of voices that may not be spoken:

> …when they/we...instead voice displeasure, discomfort or disagreement with silence…other non-verbal forms such as art, or dance, or music…Are there not other unthought ways in which our participants voice their thoughts, resistances and desires? (p.45)

Therefore, an individual's silences also need to be considered when listening and co-constructing meaning from students' voices. Mazzei (2009) argues that voices cannot be 'captured' as a single, stable and certain concept, and so researchers must seek non-verbal expressions of voice to reflect the complexity of an individuals' views and experiences; or, as she describes it, "an impossibly full voice that challenges…truths and authentic meanings" (p.47). As a researcher, I therefore have a responsibility to look beyond the spoken meanings that myself and the individuals that I work with have constructed, and instead make conscious decisions to seek out alternative interpretations. This is a challenge that must be considered in my selection of methods, in my interactions, and within my interpretations of the data that I collect (for further details on how I chose to approach this, please see Chapter 3: Methodology).

1.4.3 Inherent hierarchies

One of the factors that can affect the co-construction of meaning in students' voices relates to inherent hierarchies that exist between myself and the individuals that I am working with, such as age. The previous tendency for research to be 'on' children rather than 'with' children can be seen in others' accounts (Cook-Sather, 2007; Fine et al., 2007; and Thiessen, 2007). However, even working with children requires navigation of these hierarchies, as Meloni, Vantheuyne and Rousseau (2015) observe:

> …once we reconceive of children as autonomous and speaking subjects, or even as research co-participants, new ethical ground opens (p.107)

Kellett (2011) states that unbalanced power dynamics can compromise the validity of the research being undertaken. For example, if children are scared or anxious due to feeling inferior, they may give what they perceive to be socially acceptable or 'correct' answers, rather than their true views. This can then affect any conclusions or recommendations that are based upon these views, further affecting the quality of the research that has been carried out. Within most research contexts hierarchies, researchers are in a higher position than their participants: they form the research questions, set the research schedule, and may ultimately be more likely to benefit from the publication of the research. Therefore, unless considerations are made to compensate for these inherent hierarchies, there is a chance that researchers may not actively listen to the voices of the students they are interviewing (Flynn, 2013). Fielding (2011, p.67) details the different forms of interaction between staff and students specifically, arguing that there is a hierarchy of ways in which student voice is sought and used (starting at the lowest):

- Students as data sources (providing information)
- Students as active respondents (discussion that impacts learning/professional discussions)
- Students as co-enquirers (staff as lead role with student support)
- Students as knowledge creators (students as lead role with staff support)
- Students as joint authors (in deciding courses of action with staff)
- Intergenerational learning as participatory democracy (shared commitment by staff and students to the common good)

Within this hierarchy, Fielding (2011) argues that all forms of these interactions count as authentic engagement of student voice. However, this view is not necessarily shared by others; Kilkelly et al. (2005) performed a large-scale audit of children's rights in Northern Ireland, and concluded that when children's views were sought, it was often tokenistic and did not represent the "ongoing and authentic dialogue" (Mockler & Groundwater-Smith,

2015, p.5) needed for educational change. Irwin (1996) talks about the notion of “authentic expression” (p.108), or voice as being a genuine and honest reflection of the experiences of those communicating, as opposed to communicating what “the teacher or the dominant culture would train us into” (p.108). This suggests that simply asking students on the autism spectrum about their educational experiences without consideration of these hierarchies may produce accounts that lack authenticity.

The innate hierarchies that exist within schools may also impact on students’ voices in other ways. Silva (2001) notes that within a school environment, being asked to give their views “looks unfamiliar, unattractive or out of reach” (p.98) to students. Bahou (2011) concurs, observing that student consultation in schools is complicated by “…an educational structure that does not practice the value of dialogue, and in a context driven by testing” (p.10). Nind (2008) advises that for individuals with SEN, “Previous experience and availability and familiarity with choice-making obviously affect one’s ability to make choices” (p.7), suggesting that an unfamiliarity with being asked about their views could also be reflected in students’ silences. Additionally, it may be that students who are not communicating their opinions may be choosing to withhold them, highlighting yet again the importance of multiplicities in students’ voices and why these must be acknowledged.

The reorganisation of these hierarchies to promote the authenticity of students’ voices is complex, and very difficult to reconcile within the context of the SEND CoP (DfE, 2015) where discussions about educational decisions involve navigating complex power differentials between parents, school staff, outside agencies and students. The necessity the SEND CoP (DfE, 2015) gives for students and their parents to participate in decision-making automatically requires greater equality of the views of the parties involved. The involvement of students therefore may require a rearrangement in perspective at least of the hierarchical roles that normally exist in schools (i.e. students ranking below teachers). This may result in any changes or reforms being actively resisted by the child in demonstration of their new role, regardless of whether the change proposed is in their best interests (Cook-Sather, 2006). Staff may also actively resist changing inherent hierarchies within a school; as Sinclair (2004) observes, even if a school values and respects children’s views, a shift in culture may still be required to reach a situation where children’s views are integral to decision-making. This may be especially salient if it is the student who represents a minority opinion about an educational decision.

Researchers, schools and local authorities therefore need to be aware that hierarchies operating in the contexts in which they work may automatically reduce the ability of an individual student to be heard. This suggests an increased responsibility on the parts of the adults involved to re-balance these power differentials, thereby reducing the negative effects these imbalances can have. If students are listened to (in either research or in

school) without due respect or without visible consequences of their participation they will not be successfully involved in the decision-making process (Lundy, 2007). Implementing the shared decision-making recommended by the SEND CoP (DfE, 2015) may therefore be very problematic within a mainstream secondary school setting if the inherent hierarchies in the school system are not addressed.

1.4.4 Perceptions of expertise

The next challenge associated with the authenticity of students' voices relates to how much 'weight' their views are given by those listening to them. A key argument for listening to students' voices is that they can provide unique insights about their thoughts and feelings that cannot be observed by others, described by Tangen (2008) as "insider epistemology" (p.159). Saggers (2015) argues that asking individuals about their experiences is particularly important for students on the autism spectrum and is "much needed to help inform positive educational experiences and learning outcomes" (p.2). Charman et al. (2011) also note that adapting to an individual student on the autism spectrum is dependent on the school's ability to hear the individual's voice and react accordingly. This suggests that to improve their educational experiences, students need to communicate their own expert views. The SEND CoP (DfE, 2015) is also very clear on this point, stating that (boldface as original): "Local authorities **must not** use the views of parents as a proxy for young people's views" (p.22). For students on the autism spectrum, being heard by neurotypicals is further complicated by the assumption that their viewpoints are likely to be similar. Gray (1998) observes that assuming individuals on the autism spectrum are like neurotypicals can lead to what she calls a shared social impairment, which is characterised by "two parties responding with equally valid but different perceptions of the same event" (p.168). Similarly, Millton (2012) describes the 'double empathy problem', suggesting neurotypicals have a responsibility to be aware of a different perspective when communicating with an individual on the autism spectrum:

> So it is true that autistic people often lack insight about non-AS perceptions and culture, yet it is equally the case that non-AS people lack insight into the minds and culture of 'autistic people' (p.886).

Differences between the perspectives of individuals on the autism spectrum and neurotypicals have also been reported in research. Clark, Magill-Evans and Koning (2015) showed that adolescents on the autism spectrum reported significantly higher levels of quality of life in relation to social acceptance and bullying in comparison to their parents, and significantly lower levels of quality of life in relation to their financial resources. Within an educational context, McNerney, Hill and Pellicano (2015) reported clear differences on the relative importance of factors needed for a successful secondary school placement

between the adult participants (parents and professionals) and the children on the autism spectrum who were also interviewed. For example, the children interviewed placed the greatest importance on social factors when considering their best placement in secondary school (making friends, worrying about bullying), whereas their parents considered the child's personal development to be the most important factor to consider. If children on the autism spectrum share a different perspective from their neurotypical parents and/or teachers, their views may be dismissed due to their dissimilarity. The double-empathy problem may therefore become another factor which affects the assessment of competence and capability – by neurotypical teachers, parents and researchers – on whether students on the autism spectrum are able to make meaningful contributions (Parsons & Cobb, 2013). This is particularly relevant because students on the autism spectrum have been shown to give different perspectives on identical topics when compared to the perspectives of their parents. However, consulting with students on the autism spectrum to hear their views may also allow neurotypical teachers to increase their understanding and knowledge, furthering student-staff collaboration regarding educational decisions.

The seriousness with which students' voices are listened to represents another variable that may complicate their involvement in educational discussions, as students may not be given adequate opportunities to demonstrate they can express views about their education. This means that some children may be excluded whilst others are included in student voice activities and research. Lundy (2007) cautions that it is not always clear "what constitutes the capacity to form a view" (p.935), advising that:

> …while children's best interests must be a primary consideration, their right to have their views given due weight cannot be abandoned on the basis that the adults in their lives know what is best for them (p.938)

Within the context of the SEND CoP (DfE, 2015), any view expressed by a child in relation to their education should be acknowledged. It offers the following guidance taken directly from the UNCRC: "…views should be given due weight according to their age, maturity and capability" (SEND CoP, DfE, 2015; Section 1.6, p.20). However, this can be particularly problematic for children with SEN – and students on the autism spectrum – whose capabilities may be underestimated by teachers (e.g. Baines, 2014; Harrington, Foster, Rodger & Ashburner, 2013). In addition, children's views, especially those with SEN and/or disabilities (Reynaert, Bouverne-De Bie & Vandevelde, 2009), may be disregarded by school staff because they do not reflect a mature and capable assessment of the educational situation being discussed. Students on the autism spectrum therefore experience an elevated risk of being under-estimated, which may create further barriers to having their voices heard.

1.4.5 Engagement

Another factor that may affect the authenticity of students' voices is the level of engagement the student has with those listening. Rudduck and Fielding (2006) note that effective gathering of student opinion requires engagement, confidence and language skills that many students (with or without SEN) may not feel they have, and which therefore may inhibit them from expressing their views. For students on the autism spectrum specifically, Brewster and Coleyshaw (2010) also argue that characteristic traits of autism can lead to specific differences and difficulties in communication and language skills. Individuals on the autism spectrum may also demonstrate different processing skills (Mottron, Dawson, Soulières, Hubert & Burack, 2006) and differing speech patterns (Cleland et al, 2010) compared to neurotypicals which could also impact on their communication and engagement. These differences mean that individuals on the autism spectrum are very likely to be misunderstood by neurotypicals (Hacking, 2009; McGeer, 2009), and therefore language, communication skills and confidence levels need to be carefully considered when working with them. These differences in verbal communication suggest that additional support to augment communication may be required for accessing the experiences of students with SEN. For students on the autism spectrum, for example, Marshall and Goodall (2015) have advocated the use of alternative and augmentative communication (AAC) systems in mainstream schools "…to include [students on the autism spectrum] in any meaningful interaction regarding decision making processes" (p.3164). This is alluded to but not clearly explained in the SEND CoP (DfE, 2015), which states that "some young people may require support in expressing their views" (p.22). However, despite potential issues with language skills, engagement is an area that can be facilitated when listening to the voices of students on the autism spectrum. Bennett Woodhouse (2003) documents several child-identified ways in which engagement and participation can be improved, including giving sufficient time to understand the issue being discussed and giving access to child-friendly documentation and information. Thus, there is a responsibility for the adults involved to carefully choose methods that will facilitate communication and that are appropriate for these students.

1.5 The potential positive impact of students' voices on inclusion

In addition to the crucial need to listen to students' voices mentioned previously, listening to the perspectives of students may help to unpick inclusive practices described by the SEND CoP (DfE, 2015) and facilitate their implementation. By listening to students' voices regarding their educational experiences, it may be possible to begin personalising some of

the more general practices suggested by the SEND CoP (DfE, 2015) and facilitating the implementation of these personalised strategies within a mainstream secondary school environment. The following section therefore outlines some of the ways in which students' voices may contribute to the students' inclusion in secondary mainstream schools.

The first area in which students on the autism spectrum could impact positively on their inclusion relates to clarifying the term "reasonable adjustment". The SEND CoP (DfE, 2015) talks in general terms about schools doing "what is necessary to enable children and young people to develop, learn, participate and achieve the best possible outcomes" (p.27) regardless of whether this is achieved through "special educational provision" or "reasonable adjustment". My research does not take place within special educational provision, therefore it is necessary to identify what "reasonable adjustment" means in a mainstream secondary school, as this is a legal obligation (boldface type as original) for schools, local authorities and others:

> [Schools and other educational providers] **must** make reasonable adjustments, including the provision of auxiliary aids and services, to ensure that disabled children and young people are not at a substantial disadvantage compared with their peers… [and consider] what adjustments might need to be made to prevent that disadvantage (SEND CoP, DfE, 2015, p.17)

Identifying these adjustments to include students with SEN can be problematic. Norwich (2013) observes that in much inclusive thinking, barriers to education are perceived to be external and alterable (e.g. steps are an external barrier to participation and learning for wheelchair users that can be altered through the installation of lifts and ramps), whereas internal barriers are not necessarily alterable (e.g. an individual's impairment). The SEND CoP (DfE, 2015) seems to concur with an external view to barriers to education, suggesting that "Lessons should be planned to…remove barriers to pupil achievement" (p.94). However, students with SEN, and students on the autism spectrum in particular, may possess individual differences which could become barriers to learning if not adjusted for. For example, students on the autism spectrum may experience significant differences in processing sensory information compared to their neurotypical peers (Dunn, Myles & Orr, 2002) – in a classroom situation, these processing differences could become a barrier to their education. This potential barrier is not external and therefore cannot be removed through actions taken by the school; however, Norwich (2013) argues that these types of barriers may be able to be compensated by an external adjustment. For example, differences in processing may need to be adjusted for with pedagogic strategies that allow for processing differences. However, these compensations are not mentioned by the SEND CoP (DfE, 2015).

Individual differences may not always be apparent through mere observation of the student, and so without consultation, these differences may only be acknowledged once they have become barriers to learning. By consulting with students on the autism spectrum, teachers may be able to identify these individual differences, and then discuss practical ways in which these might be compensated for in the classroom environment to avoid becoming barriers to education. Consulting with students on the autism spectrum (and others) about their educational experiences may therefore help schools to define what is meant by 'reasonable adjustment' for each student in their learning context. Thinking about compensation (rather than removal) as a solution to facilitating the individual's progress and attainment in the classroom also allows teachers, parents and students to collaborate and compromise on 'reasonable adjustment' for a student that is also compensatory.

In addition to clarifying what reasonable adjustments can be made for them, students on the autism spectrum may also be able to contribute to the personalisation of their learning through their views. The SEND CoP (DfE, 2015) promotes specific adaptations in the classroom to successfully include students with SEN in mainstream education. However, a potential issue is identifying which specific pedagogies can benefit students on the autism spectrum. Lauchlan and Boyle (2007) argue that SEN labels are not necessarily helpful when looking for ways to support individual students, arguing that "while the labels may be indicative of educational problems, it does not necessarily follow that they suggest relevant solutions" (p.37). The authors use the example of Asperger syndrome to discuss how even specific teaching techniques that are associated with the label may not be relevant to the individual, and vice versa. Flynn (2013) also comments that "Providing for and meeting 'additional needs' requires understanding more than definitions and terminology that categorise specific special needs" (p.79). This means that adapting teaching to 'meet autism' is greatly complicated by the sheer variety of ways in which autism may impact, both positively and negatively, upon a group of individuals sharing the same diagnostic label. Given that individual presentations of autism can also vary over time (Seltzer et al., 2003), this suggests that it is likely to be impossible to develop one teaching method/adaptation that will be effective for every individual with a diagnosis of autism, as concluded by Parsons et al. (2011) in a review of evidence on the best practices in educational provision. This therefore further highlights the importance of the individual student's input in how teaching and learning is adapted to meet their specific and unique needs.

Students' contributions may also impact positively on teachers' confidence in teaching future students on the autism spectrum. Asking teachers to adopt inclusive practices for all and yet also employ specific pedagogic strategies for students with SEN may be affected by their self-confidence in being able to do so. Research suggests that teachers' self-assessed levels of confidence in teaching students on the autism spectrum is generally low. For example, Humphrey and Symes (2013) reported that only 61% of 32 teachers surveyed felt that they had the skills to teach a student on the autism spectrum. This contrasted with over 90% confidence from the 21 SENCOs and senior management team members interviewed, despite no difference in the levels of experience and training between the two groups. In addition, teachers' self-evaluations reporting a perceived lack of expertise, confidence, or knowledge in teaching students on the autism spectrum have been widely replicated internationally (e.g. Cassimos, Polychronopolou, Tripsianis & Syriopoulou-Delli, 2013; Ding et al., 2010; Hall, Grundon, Pope & Balderama Romero, 2010; Koegel, Krasno, Taras, Koegel & Frea, 2013; McGregor & Campbell, 2001; Robertson, Chamberlain & Kasari, 2003; Rodriguez, Saldaña & Moreno, 2012; Sucuoglu, Akalin & Sazak-Pinar, 2010). This suggests that teachers currently do not feel sufficiently confident, knowledgeable, or able to adapt teaching and learning for students on the autism spectrum. Having personalised input from students on the autism spectrum themselves could therefore alleviate some of these issues by allowing teachers to develop a strategy that works for and with an individual student.

Finally, listening to the voices of students on the autism spectrum has potential for supporting longer-term prospects as well as improving their experiences at school. Although focussed on education, the SEND CoP (DfE, 2015) acknowledges the wider implications of the educational experience that is given to students, advising schools and local authorities to promote "the best possible educational and other outcomes, preparing [children and young people] for adulthood" (p.19). For individuals on the autism spectrum, the link between education and longer-term outcomes has been made explicit by Levy and Perry (2011), who concluded that education was the most influential factor affecting social outcomes in their literature review of outcomes for young people on the autism spectrum. This finding was supported by Parsons (2014), who surveyed adults on the autism spectrum about their experiences and concluded that "Experiences at school really matter" (p.417) when assessing the link between school experiences and current ratings of life satisfaction. In addition, Parsons (2014) reports that over half of the respondents felt excluded in terms of their qualifications, their choices after leaving school, and the support and information they received advising them what to do after leaving school. However, Parsons (2014) also notes that participants over the age of 35 were generally more negative about their school experiences than those under 35, and therefore this negativity may not accurately reflect the current provision in schools for supporting students on the

autism spectrum in making longer-term decisions. Nevertheless, the possibility that there is a link between educational experiences and longer-term outcomes for students on the autism spectrum further highlights the need to ensure that negative experiences are reduced as much as possible.

Rather than educational experiences, Howlin (1997) argues that taking individual needs and behaviours into account is one of the most important factors that may influence longer-term outcomes. It is therefore essential that students on the autism spectrum are given the opportunity to share their personal views about both short term and long-term goals whilst in education. However, the measurement of these goals is also important. The medical model of disability values independence (Molloy & Vasil, 2002) when it comes to measuring longer-term outcomes for those with a disability. However, Lawson (2008) cautions against assuming that "inclusion, on all levels, means the same thing for everyone" (p.97), especially for students on the autism spectrum who may not value autonomy in the same way as other students when considering longer-term outcomes. Consulting with students on the autism spectrum is therefore vital to inform relevant outcomes for individual students, regardless of whether these differ to normative assumptions about success that may be made by others.

In conclusion, students on the autism spectrum have an important role to play in making decisions about their education. Seeking the expert and individual knowledge held by students on the autism spectrum about their educational experiences is crucial in providing personalised and relevant support to them throughout their time in secondary mainstream education and potentially beyond. However, potential differences related to their needs as young students, their needs as students with SEN, and their needs as students on the autism spectrum need to be accounted for to achieve this successfully. These same challenges in accessing the expert views of students on the autism spectrum are evident in research. Exploring communication and support processes that are already happening in schools in England will therefore require data collection methods that are appropriate for the students' age and specific needs. In addition, if there are topic areas that students have not discussed in relation to communication and support, it would be beneficial to explore these specifically as part of the scope of my research. Consequently, it is worth considering what research exploring the voices of students on the autism spectrum has revealed so far about their educational experiences, and which methods have been utilised to achieve this.

Chapter 2 A review of the existing literature reporting on the educational experiences of students on the autism spectrum

The previous chapter has illustrated some of the potential advantages in listening to students' voices to facilitate their educational progress. Although the increased emphasis on student consultation from the SEND CoP (DfE, 2015) is relatively new, the current literature still holds multiple educational reports from the voices of individuals on the autism spectrum. It is therefore vital to examine these studies to establish what we already know about educational experiences from these voices, and how these voices have been accessed, enabled, and reported by researchers.

Fayette and Bond (2018) conducted a literature review investigating qualitative methods for listening to the voices of individuals on the autism spectrum. Their evaluation of the twelve studies selected for their review concluded that semi-structured interviews appear to be the most effective research method of data collection, and that data is mainly gathered retrospectively from individuals with high levels of verbal communication who have received a diagnosis of AS (Asperger Syndrome) or HFA (high-functioning autism). Consequently, Fayette and Bond (2018) critique the involvement and representation of the individuals on the autism spectrum in these studies:

> This review highlights that research studies that attempted to elicit the views of young people with ASD about their experiences in education are still being conducted 'to' the participants and not 'with' them (p.14)

Fayette and Bond (2018) also comment on the "scarcity of qualitative research" (p.15) available as only twelve studies are included in their review. However, the authors acknowledge that their review may be limited as it focuses on qualitative methods only; any studies using quantitative or mixed methods research were excluded. This chapter consequently documents the results of a broader search of the literature to identify further evidence of the educational experiences from individuals on the autism spectrum, gaining further insight into what we may know already from the literature, and what may require further investigation.

2.1 Procedural details

2.1.1 Inclusion criteria

Fayette and Bond (2018) acknowledge that their focus on qualitative methods may have limited their inclusion criteria for their literature review, and therefore my first inclusion criterion is the inclusion of articles that have used quantitative methods and / or mixed methods. However, their search criteria could be broadened in other ways. For example, Fayette and Bond's (2018) selection criteria included peer-reviewed journals from 2000 onwards, as peer review aims to reduce problems with interpreting analyses and or/data (Van Klaveren & De Wolf, 2015). This is especially important for the authors' stated purpose of examining the extent to which data collection methods in these studies had been evaluated. However, there is a possibility that the voices of individuals on the autism spectrum published outside of these parameters – such as student dissertations and theses – may have been excluded from this review. To include multiple voices detailing the educational experiences of individuals on the autism spectrum, my own inclusion criteria therefore needed to allow exploration of dissertations and theses. Similarly, Fayette and Bond (2018) targeted studies where educational experiences were mentioned explicitly, using the search terms "school", "education" and "college". However, educational experiences may be mentioned in other studies exploring another topic; for example, a study exploring anxiety in individuals on the autism spectrum may include comments that specifically detail their anxiety in relation to schooling. Broader search terms in relation to education may therefore also elicit further results.

An open search of the literature was repeated periodically between July 2015 and July 2017 using the search engine Google Scholar, which was chosen to include dissertations/theses and research published on university or community websites. Six search strings were used cumulatively for accuracy and breadth (see Table 1 for details), and duplicate results were excluded. To qualify for inclusion in this review, search results were examined to see if they met the following, broader, criteria:

- School experiences were mentioned by individuals on the autism spectrum;
- These experiences were reported separately and distinctively within the results/analyses;
- The experiences of other participants (e.g. parents, peers, others with SEN) were only included when researchers interpreted their findings comparatively (e.g. friendship self-report scores between individuals on the autism spectrum and typically developing peers);
- Qualitative, quantitative or mixed research methods were used.

Table 1 Details of literature search criteria

Search String	Key words used	Initial search results	Selected by abstract	Included in review
1	“asperger”; “self-report”; “school”	9,840	15	26
2	“autis*”; “self-report”; “school”	573	+20	+16
3	“asperger”; “secondary”; “mainstream”	7,200	+68	+35
4	“asperger”; “voice”; “secondary”; “mainstream”	3,760	+3	+2
5	“autis*”; “voice”; “secondary”; “mainstream”	379	+2	+2
6	“autis*”; “experience”; “secondary”; “mainstream”	541	+3	+1
		Total		81

All search results were initially skim-read using abstracts to determine their relevance, and then read fully to establish whether they met the criteria for inclusion in this review. One dissertation (Kammer, 2009) and three theses (Ellis, 2012; Killowry, 2015; and Stirk, 2011) were included in addition to the peer-reviewed articles selected. Any additional papers of interest mentioned in articles were sourced directly and examined using the same criteria. This led to a total of eighty-one articles being included in this literature review.

2.1.2 Conceptual criteria for guiding quality weightings

Fayette and Bond (2018) focussed on evaluating research methods, and therefore their quality criteria were taken from Gough’s (2007) process for assessing research quality and focus. This gave a checklist of twelve criteria for the qualitative studies to be compared against, including sampling rationale, negative case analysis, and evidence of attention to ethical issues. However, although these technical criteria are useful for assessing the methodological aspects of listening to students’ voices, Fayette and Bond (2018) do not report what these voices have revealed about these individuals’ educational experiences, nor examine the authenticity of the accounts. Given the challenges associated with listening to students’ voices described in Section 1.4, I decided to develop conceptual criteria for the ways in which researchers have listened to students’ voices. Adopting this critical lens can reveal the studies that align strongly with my own conceptual approach, and therefore may offer further insight into what has been said and how it has been accessed, enabled and reported.

Four challenges associated with listening to students' voices were explored in Section 1.4 – the multiplicity of students' voices, inherent hierarchies between students and others, perceptions of students' expertise and student engagement. When seeking students' voices, Tangen (2008) argues that the listening process is an active one, and so using passive processes of involving participants may mean this interaction is lacking and that less authentic 'voices' are being reported. For example, students on the autism spectrum have "…associated *strengths* alongside the deficits that often define them" (Benton et al., 2014, p.3747-8; italics as original). However, if individuals are asked only to comment on the difficulties they have experienced, this may not reflect an authentic account of their experiences. Research that allows for the multiplicity of students' voices, can (or attempts to) negotiate inherent hierarchies, perceives students as experts and engages students is likely to discover more authentic students' voices. Consequently, four categories were employed to assess the strength of alignment these eighty-one articles had with each of the conceptual criteria when reporting students' perspectives (see Table 2 for further details). This could be explicit (when highlighted by the authors) and/or implicit and was gauged through examining the research and analysis methods and findings described.

Table 2 Categories used to identify ways of listening to students' voices from the research articles

Conceptual category	Details
Expertise	- Individuals' reports are treated as 'expert' and valid and are respected - Individuals report findings in their own words - Individual voices are reported (as opposed to the collective voices of the participants)
Multiplicity	- Any mentions and interpretations of non-verbal communications - Any mentions and interpretations of silence - Any mentions of strengths and abilities
Engagement	- Any evidence of methodologies (such as visual prompts) to facilitate engagement - Active rather than passive engagement
Hierarchies	- Explicit attempts to acknowledge and compensate for inherent hierarchies within the study: for example, age, knowledge, authority, reflexivity, negotiation - Implicit attempts to acknowledge and compensate for inherent hierarchies

I initially summarised each of the eighty-one articles based on details of the participants, the topics investigated, the research methods used, and the analysis methods used. I then applied the four conceptual categories of expertise, multiplicity, engagement and hierarchies to each article to assess the ways in which the research had listened to the students' voices. Using the criteria in Table 3, each article was assessed to see if it

demonstrated mainly “no alignment”, “partial alignment” or “full alignment” with each of the four conceptual categories of how to authentically listen to students’ voices.

Table 3 Conceptual category criteria for whether a study demonstrates full, partial or no alignment

Alignment	Expertise	Multiplicity	Engagement	Hierarchy
Full	Individuals’ experiences are reported separately and distinctly, in their own words	Examples of silence and/or non-verbal communication and strengths/abilities are explicitly mentioned and discussed	Example of engaging methodologies	Explicit attempts described to acknowledge and compensate for differing hierarchies between participant and researcher
Partial	Individuals’ experiences are amalgamated - without highlighting differences - in their own words, and may be verified by others (e.g. parents)	Examples of silence and/or non-verbal communication and strengths/abilities are mentioned, but not discussed	Active rather than passive involvement of participants	Implicit attempts to compensate for differing hierarchies described; hierarchies may be acknowledged, but not compensated for
None	Individuals’ experiences are reported using pro-forma tools, such as questionnaires, or combined/contrasted with others’ views	Examples of silence and/or non-verbal communication and strengths/abilities are not mentioned	No active involvement of participants	No attempts to compensate for differing hierarchies described

Once each study had received an alignment rating for each of the four conceptual categories, an overall judgement was made of either “no overall alignment”, “partial overall alignment” or “full overall alignment” (see Figure 1 for an illustration of this process). For example, a study could receive a ranking of “partial alignment” for expertise, multiplicity and engagement. As this study has three categories with the same alignment ranking, this would receive a judgement of “partial overall alignment”. However, if a study demonstrated full alignment in two categories and partial alignment in two categories, I would compare the study to others in the overall alignment categories to see which overall alignment demonstrated the ‘best fit’ for that study. This overall ranking determined how closely aligned the research was to my own conceptual criteria of the authenticity of listening to students’ voices. The studies that demonstrated “full overall alignment” are discussed in the most detail in this review, as these represent the strongest fit with my conceptual framework for the thesis, and therefore the methods used are of greater personal interest and relevance to my own research (see Appendices A, B and C for full alignment details of the studies).

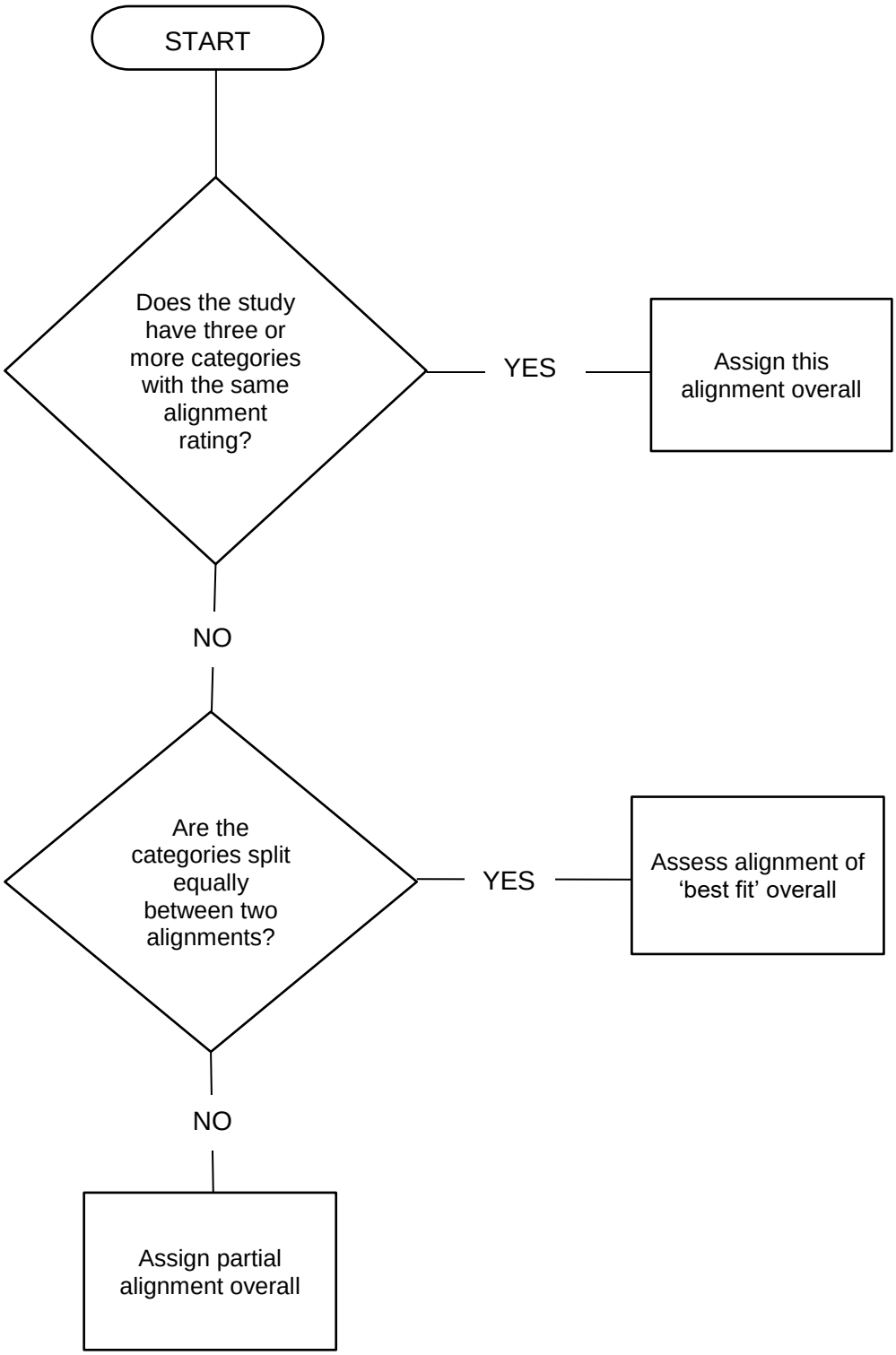


Figure 1 Flowchart demonstrating the procedure for allocating overall alignment

I also went beyond the scope of Fayette and Bond's (2018) review to examine the findings from each of these studies to see how it contributed to our understanding of the educational experiences of individuals on the autism spectrum. The reason for this was two-fold; firstly, it would help me reveal what type of research methods would be best suited to working with students on the autism spectrum, and secondly, it would demonstrate the topic areas that potentially required greater exploration.

2.1.3 Potential limitations of these criteria

Although my inclusion criteria are arguably broader than those used by Fayette and Bond (2018), there are still potential issues with them. Firstly, and most importantly, the criteria I have used are based on my own conceptual lens regarding student voices, and my own interpretation of the extent to which each study aligns with the four categories as no second-rater or inter-rater comparisons were used. The introduction of additional 'voices' of other individuals to assess my own interpretations is not 'fit for purpose'; instead, I have concentrated on highlighting my own personal biases that may have contributed to my interpretations throughout this thesis.

Secondly, the experiences described in these studies should not be taken to represent the views and experiences of every individual on the autism spectrum (a summary of participants' details from these studies where information was provided by the authors is given in Table 4). For example, despite assessing multiplicity, much of the communication about educational experiences reported by the eighty-one studies in this review tends to be verbal. Participant details were also generally lacking; for example, participants' ages tended to be reported as either the mean age of all participants or a general description of ages (e.g. "of primary school age").

Table 4 Participants' details (where provided) from the eighty-one studies

Location (no. of studies)	Total nos.	No. of participants communicating verbally	No. of participants communicating non-verbally	Participant ages		Experiences		No. M/F
				0-17	18+	Current	Past	
Far East (2)	9	9	5	9	0	9	0	8/1
Middle East (3)	41	41	0	40	1	40	1	39/2
Australasia (9)	71**	71	0	70	1	70	1	63/8
North America & Canada (14)	341	341	0	308*	12*	308*	12*	308/21*
Europe (13)	579	579	0	293*	33*	316*	10*	488/65*
UK (40)	615	604	29	315*	65*	515*	65*	281/80*
Total	1656	1645	34	1035	112	1238	89	1187/177

*Participants' details not fully provided

**Two studies used data from the same group of participants

The participants in these studies therefore represent a sub-group of individuals on the autism spectrum. Most of this research was conducted in Western countries, and therefore may provide a limited and potentially Western view of autism (Kim, 2012). In addition, there are far more male participants (87%) than there are female participants within these eighty-one studies. Werling and Geschwind (2013) state that there is a well-documented male bias in autism, with 4 males diagnosed for every 1 female. This would therefore suggest that around 20% of the participants in these studies should be female if sampling was representative, compared to the reported figure of 13%. Although similar, there is therefore a difference in the sex ratio found in these eighty-one studies compared to the ratios found in the general population. It is therefore germane to suggest that the findings from the studies included within this review are most likely to represent the experiences of young, Western, high-functioning males on the autism spectrum, and therefore generalisations to others cannot be made.

2.2 Findings from the research literature

The following section details the 81 studies split into their overall alignment rankings. However, within each overall category, studies varied widely in their rankings regarding the four conceptual categories; a breakdown of this is illustrated in Table 5.

Table 5 Breakdown of how individual studies from the review align with each conceptual category

Conceptual Criteria	Individual Alignment	Overall Alignment Category			Total
		No alignment (41)	Partial alignment (31)	Full alignment (9)	
Expertise	None	29	-	-	**29**
	Partial	12	13	1	**26**
	Full	-	18	8	**26**
Multiplicity	None	39	12	-	**51**
	Partial	2	14	-	**16**
	Full	-	5	9	**14**
Engagement	None	36	-	-	**36**
	Partial	5	26	-	**31**
	Full	-	5	9	**14**
Hierarchies	None	35	-	-	**35**
	Partial	6	17	-	**23**
	Full	-	14	9	**23**

In total, 41 studies demonstrated no overall alignment with the conceptual criteria; 31 demonstrated partial overall alignment; and just 9 demonstrated full overall alignment, reflecting the most authentic ways to listen to students' voices. The methods used in each category are discussed, along with the emerging themes that were revealed regarding the educational experiences of students on the autism spectrum.

2.2.1 Findings and methods from studies demonstrating 'no overall alignment'

Approximately half of the studies (see Appendix A) demonstrated 'no overall alignment'. Of these forty-one studies, twenty-four were assessed to have "no alignment" across all four conceptual categories (such as Chen & Schwartz, 2012; Jennes-Cousens, Magill-Evans & Koning, 2006; Kalyva, 2010; Kloosterman et al., 2013; and Mandy et al., 2015). These studies generally used pro-forma rating scales to explore the experiences of individuals on the autism spectrum, and then discussed the ratings from these forms in comparison to 'typically developing' others (only Mandy et al., 2015, did not compare individuals' scores with a control group). This meant that the expertise of individuals on the autism spectrum is not demonstrated at all, as the opportunity to talk about experiences outside of the pre-set questions is not included, and there is also little opportunity for engagement or multiplicity. In addition, using pre-determined language in questionnaires (e.g. in rating scales) may also limit individuals' abilities to respond in their own words and describe the experiences that are important to them. For example, Chen and Schwartz (2012) concluded that individuals on the autism spectrum are not necessarily aware of how much bullying occurs, as in their study, individuals on the autism spectrum reported significantly lower bullying scores than their teachers. However, this measure of 'bullying' cannot determine any deeper understanding about these scores; for example, how the individuals felt about these lower scores, or how they feel about the impact of bullying behaviour. This difference in scores may therefore demonstrate a mismatch between definitions of abstract concepts rather than a comprehension or awareness issue. Relying on questionnaires as the sole representation of students' voices may therefore restrict the depth of understanding of individuals' experiences that can be accessed.

2.2.1.1 A lack of positivity

The studies in this category also tended to report their findings with a distinctly negative tone. Chen and Schwartz (2010) claim in their abstract that they "explore" bullying, and state that one of their research aims is to "describe the bullying status from the perspectives of students with ASD, their parents and their teachers" (p.3), yet their findings focus only on negative interpretations of the questionnaire scores obtained. Similarly, Kalyva (2010) states that the main aim of the study is to "gather information on the social skills of children with AS attending mainstream settings" and "explore differences in reported aggressiveness/antisocial behaviour, assertiveness, conceit/haughtiness and loneliness/social anxiety between children with and without AS" (p.1203). However, when reporting on the differences between scores, she takes a negative stance; individuals on the autism spectrum reported more aggressive/antisocial

behaviour, more conceit/haughtiness, more loneliness/social anxiety, and less assertiveness than their typically developing peers based on their scores.

This lack of positivity – despite research questions that suggest a more open exploration of topics – is not aligned with my own focus on strengths, as interpretations of the data are mainly negative. This deficit-focussed approach is seen in many studies in this "no alignment" category, and not just in relation to negative interpretations of findings. For example, Bellini (2004) states that one of the aims of his study was an attempt to "…determine whether self and parent reports of social skill functioning are associated with self-reported social anxiety" (p.80). However, his research question relating to this is phrased in a deficit-focussed way, asking, "Are social skill deficits associated with social anxiety in adolescents with autism spectrum disorder?" (p.80). Bellini changes from a description of 'social skill functioning' to 'social skill deficits', demonstrating that he is already taking a deficit-focussed approach and that his findings may be interpreted accordingly. Consequently, for some of these studies, the lack of 'positive' experiences are mainly due to the deficit-focussed approach of the research questions, rather than a tendency to report only negative findings for more open-ended questions.

Another example of this is demonstrated by Rieffe et al. (2012), who state that their study aims to "examine the associations between emotional functioning and bullying/victimisation in children with ASD, as compared to their TD peers" (p.355). The authors then explicitly acknowledge that little is known about the association of guilt and shame with bullying in individuals on the autism spectrum. However, rather than taking an open-ended approach to an unknown area, the authors predict negative interpretations of potential associations, based on the idea that "the impact of moral emotions in ASD children's daily life is limited" (p.355). This may partly explain why mainly negative interpretations of associations are reported by Rieffe et al. (2012); despite little being known, the authors explicitly acknowledge that they are expecting weaker associations of shame and guilt with bullying in students on the autism spectrum because of a perceived deficit in moral emotions.

Barnhill et al. (2000) also focus on emotional and mental health difficulties but differ slightly from the previous studies because they explicitly state that the purpose of their study is to "identify and examine both problem and adaptive behaviours in children and adolescents with Asperger Syndrome" (p.151). This suggests an approach where both the strengths and challenges facing the individuals in the study are going to be reported. Interestingly, Barnhill et al.'s (2000) findings did not show lower/negative scores; instead, students on the autism spectrum within their study perceive themselves to be like their peers and within the 'average' range on several self-perception measures, such as school/clinical/personal adaptive behaviours, and feelings of depression and self-

inadequacy. Barnhill et al. (2000) also report teacher and parent perspectives on these same measures, and these perspectives suggested that the students are more at risk on these measures. The differences in perspectives are initially reported in a neutral fashion, with the authors clearly stating that “student self-evaluation data do not allow for comparisons with adults’ perceptions” (p. 157). However, in their discussion, the authors conclude that “These data [from students] are in sharp contrast to the perceptions of their parents and teachers and suggest a lack of awareness or denial on the participants’ part relative to their disability” (p. 162). Although the students in this study perceive themselves to be average, their parents and teachers believe them to be more at risk, and so this difference in perception is suggested by the authors to be due to the students’ inaccuracy. This is yet another example of how a negative interpretation of a study’s findings demonstrate little regard for the ‘expertise’ of students’ voices by explaining differences in ratings as a lack of awareness: rather than a valid and distinct opinion which differs from their parents and teachers.

2.2.1.2 Evidence of partial alignment to the conceptual criteria

There were occasionally attempts to consider alternative interpretations of data in studies that fall into this “no overall alignment” category. For example, Bauminger et al. (2008) describe being “puzzled” (p. 147) at the lack of difference in interpersonal awareness between students on the autism spectrum and typically developing peers and acknowledge that this could imply a greater level of awareness. Bauminger et al. (2008) also comment positively on the similarities between the two groups, such as the similarity in “leader-follower roles” (p. 146) when interacting with friends, and longer durations of friendships. Similarities between students on the autism spectrum and a control group are also positively reported by Nicpon, Doubay and Assouline (2010) in relation to self-reports of personality; and higher ratings in terms of self-perception of assertion and self-image were reported by Koning and Magill-Evans (2001) and Cottenceau et al. (2012) respectively. This suggests that even when using pro-forma questionnaires that lack engagement and multiplicity, it is still possible to document positive educational experiences. These positive educational experiences demonstrate some evidence of multiplicity, albeit not enough to promote the overall rating to one of “partial alignment”.

Seventeen studies in this overall category of “no overall alignment” differed from the other studies in this category by meeting the partial alignment criteria in one of the four conceptual categories. The main difference between these studies compared to the studies that scored “no alignment” across all four categories is that they tended to take advantage of some additional research methods; either instead of questionnaires, or in addition to them (see Table 6 for further details).

Table 6 Data collection methods utilised by the seventeen studies demonstrating "no overall alignment" overall that demonstrated partial alignment for at least one category

Authors	Data collection methods
Bauminger & Kasari (2000)	Descriptions of loneliness/friendship used in addition to questionnaires
Bauminger, Shulman & Agam (2004)	Projective test on friendship used in addition to questionnaires
Browning, Osborne & Reed (2009)	Structured interview used
Calder, Hill & Pellicano (2014)	Social maps, vignettes and semi-structured interviews used in addition to questionnaires
Camarena & Sarigiani (2009)	Questionnaires included open-ended questions
Carrington & Graham (2001)	Semi-structured interviews used
Carrington, Templeton & Papinczak (2003)	Semi-structured interviews used
Chamberlain, Kasari & Rotheram-Fuller (2007)	Social network centrality questions used in addition to questionnaires
Dixon & Tanner (2013)	Semi-structured interviews used
Hebron & Bond (2017)	Semi-structured interviews used in addition to ratings of school experiences
Hebron, Humphrey & Oldfield (2015)	Semi-structured interviews used
Jindal-Snape et al. (2006)	Interview used
Kasari, Locke, Gulsrud & Rotheram-Fuller (2011)	Student observations and social network maps used with questionnaires
Koning & Magill-Evans (2001)	Video stills investigating perception used in addition to questionnaires
Locke, Ishijima, Kasari & London (2010)	Social network centrality questions used in addition to questionnaires
Poon et al. (2014)	Semi-structured interviews used
Portway & Johson (2003)	Interviews used

As discussed previously, using pro-forma questionnaires in isolation means that "it is difficult to come to deeper understanding of processes and contextual differences" (Muijs, 2010, p.39). Consequently, using additional data collection methods to explore the experiences reported in these studies in further detail may allow more in-depth exploration of educational experiences.

For example, individuals can report their experiences using their own words and meanings, as seen in this quote from David who was interviewed by Poon et al. (2014):

> Autism means [that I'm] not [a] normal person, not related to other people…You know autistic is just like laughing like [I'm] crazy, day dreaming and cannot [stay] active. You know active? Active means quiet (p.1075).

To summarise, the studies in this category of "no alignment" tended to use mainly quantitative data and analyses. This is part of the scientific method, associated with positivism (Cohen, Manion & Morrison, 2007), and suggests a belief that "…careful observation and measurement of the objective reality" (Cresswell, 2014, p.7) is possible. However, this directly contradicts Tangen's (2008) notion of "insider epistemology", which argues that 'insiders' (individuals on the autism spectrum) have access to knowledge that cannot be gained by mere observations; researchers who interpret observed behaviours (e.g. questionnaire scores/ratings) from individuals on the autism spectrum may therefore be inaccurate. Mockler and Groundwater-Smith (2015) concur, arguing that although a positivist approach to educational evaluation is conducive to policy-making, it is not appropriate for the authentic seeking of students' voices. Consequently, using mainly quantitative data collection methods and analyses not only demonstrates no alignment with my own conceptual criteria for listening to the voices of students on the autism spectrum; it may also be restricting the depth of understanding that can be revealed about their educational experiences.

2.2.2 Findings and methods from studies demonstrating 'partial overall alignment'

Thirty-one of the eighty-one studies included in this review were ranked as demonstrating "partial overall alignment". The four conceptual ratings for individual studies varied considerably; only thirteen studies were assessed to demonstrate "no alignment" with a conceptual category (interestingly, all in the multiplicity category) and twenty-six studies demonstrated "full alignment" in at least one category. The biggest demarcation between these studies and the forty-one studies with an overall ranking of "no overall alignment" is within the categories of engagement and expertise, as all the studies in this section achieved at least partial alignment in these categories.

The variety of research methods is also much more pronounced in these thirty-one studies demonstrating "partial overall alignment". Open-ended questions (in both interviews and surveys) rather than closed questions (in Likert scales and questionnaires) were favoured as the most popular data collection method in this category, and feature in some capacity in every single study. Closed questions in the form of questionnaires and

ratings scales are used by only seven studies (Cordier et al., 2014; Dillon, Underwood & Freemantle, 2014; Fortuna, 2014; Hebron & Humphrey, 2012; Kammer, 2009; Parsons, 2014; van Roekel, Scholte & Didden, 2010). Of these, only Cordier et al. (2014) used questionnaires in isolation, rather than combining them with other data collection methods. These studies mostly combine questionnaires with other data collection methods to present more of an in-depth report of individuals' educational experiences. Additionally, all thirty-one studies offered the individuals in their studies the opportunity to speak in their own words – what Irwin (1996) refers to as "authentic expression", and what she believes offers a more accurate description of experiences. Seidman (2013) concurs, arguing that conversing with individuals affords researchers greater insight into their experiences:

> … our access to lived experience is primarily through language: both in the words we use to guide the participant and the words they use to respond
>
> (p.18)

For example, Gulec-Aslan, Ozbey and Yassibas (2013) aim to "describe the life experiences" (p.74) of Kenan, a 23-year-old male on the autism spectrum, using interviews with him and his mother. Kenan's 'insider knowledge' is clear to see in this research, such as in the following extract discussing eye contact:

> The trouble [autism] caused to me was this: if you have just noticed, I mostly avoid looking at your face when I talk. But my avoidance is not intentional. I don't know its cause. When I try to make eye contact, it happens that, how can I put it, as if an arc was occurring in-between, as if an electrical jump was happening…It is not intentional.
>
> (p.78; Gulec-Aslan, Ozbey & Yassibas, 2013)

Kenan's reasons behind his observable behaviour (avoiding eye contact) are not necessarily accessible to others but are clearly explained by him using his own words. Some additional examples of explanations for observable behaviours from other studies are given in Table 7. This is a clear contrast to Koning and Magill-Evans (2001) who demonstrated "no overall alignment", as they simply reported that individuals on the autism spectrum differ significantly from their typically developing peers in the amount of body cues, situational cues, voice cues and facial cues they used. The detail from Kenan's discussion suggests a potential reason for <u>why</u> these differences might occur, rather than simply stating that 'there is a difference'.

Table 7 Examples of explanations given by individuals on the autism spectrum for observable behaviours in studies demonstrating "partial overall alignment"

Study authors	Observable behaviour	Individual Insight
Cordier et al. (2012)	Increased time spent alone/decreased time spent interacting with peers/teacher	Students describe interactions with teachers and classmates as boring, and report feeling least bored when they are alone
Dillon, Underwood & Freemantle (2014)	Lower scores on peer interaction and social skills compared to typically developing peers	Peers are seen as a major distraction in the classroom by students on the autism spectrum, and therefore are avoided to increase focus
Hebron & Humphrey (2012)	Students on the autism spectrum score significantly higher on measures of anxiety and anger compared to peers	The intricacies of social relationships and feeling misunderstood led to feelings of difference, which in turn led to increased anger and anxiety
Kammer (2009)	Increased emotional upset with primary/secondary school transition	A lot of changes happening at once, combined with sensory overload and feeling that they were not understood were incredibly stressful
Penney (2013)	Difficulties with social interactions with peers and teachers	Students felt that behavioural escalations/disciplinary procedures interfered with building relationships with their peers and teachers, and suggested that a better understanding of ASD (and sensory issues in particular) might alleviate this issue
Van Hees, Moyson & Roeyers (2015)	Inappropriate levels of attention (either too much or too little)	Students report that having increased focus and attention to detail makes it very difficult to initially work out 'essential' issues compared to 'side' issues, which can affect their focus

This highlights the importance of an individual being able to use their own words and to be given space for explanations; closed-question rating scales regarding interaction would not have uncovered this detailed explanation of Kenan's avoidance of eye contact. As Seidman observes, "Interviewing allows us to put behaviour into context and provides access to understanding [participants'] action" (p.19).

2.2.2.1 A sense of 'being different' and sensory experiences

The increased level of detail that participants gave due to speaking freely in the partial overall alignment studies also leads to reports of an awareness or a sense of 'being different'. This theme was previously mentioned by only four of the studies that demonstrated "no overall alignment", which also all employed open-ended questioning methods (Caramena & Sarigiani, 2009; Carrington & Graham, 2001; Poon et al., 2014; and Portway & Johnson, 2003). Within the thirty-one studies demonstrating "partial overall alignment", thirteen include reports from individuals on the autism spectrum mentioning a feeling of being different, not fitting it, or being exceptional (Bolic Baric, Helberg, Kjelberg & Hemmingson, 2015; Cridland, Caputi, Jones & Magee, 2015; Gray & Donnelly, 2013;

Gulec-Aslan, Ozbey & Yassibas, 2013; Hay & Winn, 2005; Hebron & Humphrey, 2012; Jones, Huw & Beck, 2013; McLaughlin & Rafferty, 2015; Mitchell & Beresford, 2014; Parsons, 2014; Saggers, 2015; Stewart, 2012; and Van Hees, Moyson & Roeyers, 2015).

In contrast to the studies reflecting "no overall alignment", the differences described by the participants in these studies are also reported in a positive light. Rather than seeing their differences as 'deficits', the studies in this section report many of the participants' mentions of the positive elements of being on the autism spectrum. For example, Cridland, Caputi, Jones and Magee (2015) interviewed seven teenagers on the autism spectrum attending mainstream secondary schools and reported that all seven participants identified both negative and positive impacts of being on the autism spectrum; for example, they can focus more easily than their peers, which is perceived as a strength. Similarly, although all nine of the young people on the autism spectrum interviewed by Jones, Huw and Beck (2013) reported that they were different from others, only four participants linked this to sometimes leading to bullying from their peers. Specific mentions of skills and benefits are also included, as Kenan (mentioned previously) describes autism as "an interesting disease" (p.78):

> I first became aware of my difference when I was at primary school. I thought that I was very different. Difference has a consistent reason here, you know. For example, the reason of being different in primary school is my ability to think from many aspects (p.78; Gulec-Aslan, Ozbey & Yassibas, 2013)

Kenan also reports his "significant skills" (p.78) in mathematical thinking and music as being associated with being on the autism spectrum. Likewise, the young adults transitioning from college to university interviewed by Van Hees, Moyson and Roeyers (2015) reported that their skills in focus, precision, an eye for detail and dedication pleasingly translated to high academic performance within the university environment, and that increased interests in specific subjects meant that talking to new people with the same interests on their courses was much easier than it had been previously.

However, there are also discussions of the negative implications of difference. A specific 'difference' mentioned by eight of the thirty-one studies was participants' discussion of sensory experiences within an educational setting. Overall, the overwhelming noise and chaotic environment of school (and the usefulness of an accompanying 'safe space' to retreat to) was mentioned most frequently and negatively by individuals (Bolic Baric, Helberg, Kjelberg & Hemmingson, 2015; Kammer, 2009; Lamb, Firbank & Aldous, 2014; Penney, 2013; Saggers, 2015; Tobias, 2009). The girls in Stewart's (2012) study also mention other sensory experiences that impacted upon their education, such as sensitivity to fabrics, and transient and puzzling muscle pain (e.g. for one of the girls, ankle pain

indicated frustration). Interestingly, Hwang (2014) is the only study to explicitly address sensory experiences as part of the study's discussion, considering that some of the ambivalence shown by students in their responses to certain objects may be because "These experiences may have provided learners with both pleasant and unpleasant sensory perceptions" (p.1597). Consequently, the sensory differences described by individuals tended to be negative, rather than positive, experiences in their education.

Overall, it seems that individuals on the autism spectrum do not attribute solely negative feelings to an experience of being different. Unfortunately, this interpretation may still be made by the researchers in these studies. For example, Gulec-Aslan, Ozbey and Yassibas (2013) summarise Kenan's "autism story" (p.77) with a focus on only negative experiences, corroborated by his mother's recollections and the researchers' own reflections following meetings with Kenan. Consequently, many studies demonstrated only partial alignment with 'expertise' in this category, with researchers adding increased importance or relevance to their own (or others') views about individuals on the autism spectrum. Holt, Lea and Bowlby (2012) took photos with the five students they interviewed in their study, yet the photos are not reported at all and the interviews are not reported in full when compared to reports from the researchers' diary that was kept throughout the research process. This could suggest to the reader that the authors see their own experiences of the research process as requiring more exploration than the experiences of their participants, reducing the perceived expertise of the students' accounts.

Similarly, Cridland, Caputi, Jones and Magee (2015) discussed the different perceptions of individuals on the autism spectrum, their parents and their siblings when it came to friendship. The individuals on the autism spectrum identified specific people as friends, but these 'friends' were seen to be more as 'acquaintances' from the point of view of both parents and siblings. The authors explain this difference as being either due to "an underestimation of friendship quality by family members" or "the adolescents' misunderstanding of social interactions" (p.360). This arguably differs from their research aim, which is "…to understand the perceptions and experiences of adolescents with ASD from a personal construct psychology perspective" (p.355), which the authors describe as a useful perspective for understanding subjective human thought and action. It therefore appears incongruous to state that the authors are interested in the subjective experiences of adolescents on the autism spectrum, but then apply their own interpretations to the meaning behind the subjective experiences reported. This contrasts with other studies in this category where extra steps have been taken to ensure that the researchers' perspectives are not given more weight than those of the participants. For example, in the study carried out by Jones, Huw and Beck (2013), the third author, who is autistic, performs a credibility check on the interpretations of the first two neurotypical authors.

Therefore, despite both positive and negative experiences being reported, there was still s tendency for the researchers in this category to apply normative assumptions to individuals' accounts and interpret them in a negative light.

2.2.2.2 The importance of individual differences

An additional theme that also emerged in this category is an illustration of the differences between individuals on the autism spectrum, rather than between individuals on the autism spectrum and another group. For example, Parsons (2014) explicitly focuses on the differences between responses from autistic adults by detailing four very different case studies in addition to the commonalities revealed by the online questionnaires used in the study. This demonstrates the heterogeneity of these individuals as well as exploring some common ground between them. Similarly, although Stewart (2012) mainly describes the overall challenges faced by the four girls she interviewed online, she also provides specific examples of the different ways these challenges affected the girls. For example, although all four girls reported issues with processing and sensory experiences in the school environment, for one girl only this manifested as an inability to eat or drink at school due to the noise levels at lunchtime. In addition, although all four reported problems with insomnia, only one girl linked this to sharing a room with her sister.

Another explicit exploration of difference is made by Gray and Donnelly (2013), who interviewed four young children on the autism spectrum about their likes and dislikes of school. The authors detail the differences between the four children and their families in pen portraits (e.g. two are from Irish traveller families), but also explore the differences in responses and engagement between the four children. Rory (four years old) refused to interact with the researchers at all, and Sean (four years old) gave no verbal responses to their questions, instead counting and selecting a favourite toy. The other two children both gave verbal responses, but these demonstrated very different accounts of school. Barney (seven years old) described the positives of school, including a favoured teacher and a school club. Elle (seven years old) initially refused to participate, but then wrote a poem for the researchers which included the lines "I go to school and I am seen but I'm not me. I don't learn they don't teach what I want to know" (p.279). When asked for her thoughts about the poem, Elle replied "I can't be me because people don't know Elle. I would like to be Elle all the time" (p.280). This demonstrates the very different forms of communication these four children used when being interviewed by the researchers. In addition to more general discussions about the overall themes of their findings, fifteen other studies in this "partial overall alignment" category also reported specific differences in the experiences of the participants in their studies (Beresford et al., 2007; Bolic Baric, Helberg, Kjelberg & Hemmingson, 2015; Connor, 2000; Dann, 2011; Fortuna, 2014; Humphrey & Lewis, 2008b; Humphrey & Symes, 2010; Hwang, 2014; Kammer, 2009; Lamb, Firbank &

Aldous, 2014; McLaughlin & Rafferty, 2015; Penney, 2013; Saggers, 2015; Tobias, 2009; Van Hees, Moyson & Roeyers, 2015).

The richer detail and explorations of difference reported by these eighteen studies may be facilitated by employing visual and engaging activities to supplement, clarify and facilitate discussions. Six of the eighteen studies demonstrated "full alignment" with the conceptual category of engagement because of the methods used. Beresford et al. (2007) used photos and posters as visual prompts to facilitate discussions; Bolic Baric, Helberg, Kjelberg and Hemmingson (2015) used a visual timeline; Dann (2011) used Talking Mats and vignettes to supplement her interviews; Gray and Donnelly (2013) provided a variety of props and materials to stimulate discussion, including puppets, cameras, and stickers; Hwang (2014) used participant drawings and drawings of faces with emotions to support discussions; and Lamb, Firbank and Aldous (2014) used an iPad with their participants to take, structure, and discuss photos related to their experiences in Physical Education. These visual methods appear to be more engaging for the children and adolescents than a standard face-to-face interview, as the use of these activities can present information in a more 'child-friendly' way (Bennett-Woodhouse, 2003). Conducting research with methods that do not rely exclusively on language also demonstrates much more potential for exploring the multiplicity of students' voices, hence why these six studies also demonstrated much greater alignment with the concept of multiplicity than others in the "partial overall alignment" category.

Overall, the thirty-one studies in this category demonstrate a much more detailed exploration of educational experiences. They provide a representation of both positive and negative experiences and highlight the range and diversity of experiences that each individual on the autism spectrum describes, including their sensory experiences. These highly personalised accounts are also seen in some of the studies where visual and engaging data collection methods allow individuals to participate in non-verbal ways, as well as facilitating discussions.

2.2.3 Findings and methods from studies demonstrating 'full overall alignment'

Nine studies demonstrated 'full alignment' overall with my conceptual criteria and are detailed in Table 8. Eight of these nine studies (Loyd, 2015, is the exception) demonstrated full alignment across all four concepts of expertise, engagement, hierarchy and multiplicity, despite their differences in methods and approaches.

Table 8 Details of the studies demonstrating "full overall alignment" with my conceptual criteria

Authors	Expertise	Engagement	Hierarchy	Multiplicity
Ellis (2012)	In-depth, ethnographic study of students' views considered carefully without consultations from others	Essay, photography, patchwork quilt, documentary + discussions of activities all used and student-led	Explicit mentions of some measures undertaken; for example, waiting for students to elicit engagement	Multitude of student artefacts created and analysed in addition to verbal contributions; silences also discussed
Healy, Msetfi & Gallagher (2013)	Student-led interviews, 'bracketing mind map' of authors' perceptions to separate student views	Semi-structured interview with visuals (slideshow of questions, poster of interview schedule), paper & pens for drawings	Advice sought from more experienced researchers, students' understanding of research discussed at every stage	Student drawings, laptop presentation, flexibility of interview schedule
Humphrey & Lewis (2008a)	IPA analysis, detailed and in-depth, student commentary on researcher interpretations	Semi-structured interviews, student diaries, student drawings all used to gather information and inform findings	Diaries used as less intrusive; consideration of sensitive topics; students' views on consent sought	3 ways to record diaries used (Dictaphone, pen & paper, laptop), pictures included in analysis
Killowry (2015)	IPA/PCP methodology; three students described separately with no verification from parent/teacher opinions	Same as Williams & Hanke (2007)	Explicit outline of adaptations made to make students more comfortable throughout methodology section	Transcription of interviews only, but drawings and themes outlined clearly
Loyd (2015)	Student views gathered as part of longitudinal case study about teaching outcomes to improve relevance	Discussions around videos and pictures of selves in drama, sentence completion tasks, class observations	Student-led interviews, all levels of participant accepted as data, very detailed consent/assent process	4/10 students non-verbal and used different communication systems, silences and refusals discussed
Moyse & Porter (2015)	Ethnographic case studies of three girls, mainly narrative system of unstructured observations	Observations included interviews, drawings, photographs + learning walk, sorting activities using PECS/text, Venn diagrams	Traffic-light system used to express (dis)comfort during discussions; pen portraits of girls given for context	Wide variety of methods including non-verbal options (PECS, drawings, photos, sorting activities)
Shepherd (2015)	Own words used for interviews, pre-set phrases for sorting, 6 students but one reported as case study	Topic sort/collage, photo trail and 'interrupted interviews' walking around college, ranking of phrases such as "(not) looking forward to..."	Clear and explicit detail given on readjusting hierarchies, such as control over iPad, lead in walking interview	Interactive technology allows for non-verbal communication, such as adjusted size of text to indicate importance
Williams & Hanke (2007)	Students' suggestions explained in detail and illustrated; research guided by personal construct psychology	'Draw the Ideal School' – drawings completed, then discussed with students	Neurotypical perspective explicitly acknowledged; familiar staff working with students	Author of 'Ideal Self' ensured adaptation; explanatory models of results for accessibility
Winstone et al. (2014)	Explicitly consider similarities & differences; drawings not explicitly analysed	Art activities taking part in classroom environment – self-portrait, collage, semi-structured interviews	Students familiar with interviewers; consideration of methods creating more data vs. more insight	Explicit comparisons between interviews vs. activity-oriented interviews to illustrate differences

Loyd's (2015) research received an assessment of "full alignment" for engagement, hierarchy and multiplicity, but received only "partial alignment" in her demonstration of her participants' expertise due to potential inconsistencies in her report. Her methods were creative, inclusive and tailored exceptionally well to the abilities of the students she worked with; in addition, she explicitly mentions that the "trustworthiness of the responses was enhanced by comparing and contrasting them with responses to other questions in the interview which probed the same area" (p.14), demonstrating "full alignment". However, Loyd (2015) also states that the students' responses were verified by "data from observations and interviews with class teachers and drama teachers" (p.14). She describes using the perspectives of others (the teachers, and her own observations as a researcher) "for helping with the interpretation of views elicited by pupils for whom face-to-face communication was challenging and for whom contributions could be misinterpreted or over-interpreted" (p.14). It is not clear from this description how others' perspectives were used to increase trustworthiness, and to what extent they were employed (e.g. for how many students, and on how many occasions), and therefore only partially demonstrated her perceived expertise of the students' accounts. Tangen (2008) argues that although 'insiders' (the students) have privileged knowledge about their own thoughts and feelings, 'outsiders' (Loyd and the teachers) can make "*tentative interpretations"* (p.161, italics as original) of what the participants' observable behaviours might mean to the participants themselves. It may be that Loyd has compared both her own and the teachers' interpretations about the participants' actions to see if any commonalities are revealed, but this is not entirely clear from her description of her analysis. It is this ambiguity that meant I assessed the study as demonstrating "partial alignment" regarding students' expertise.

2.2.3.1 The power of visual methods

Although these studies demonstrated full alignment for almost every conceptual category, there is a wide range of data collection methods used, which have all been tailored to engage and facilitate communication with individuals on the autism spectrum. Although there are some examples of this in the "partial overall alignment" studies, the nine studies demonstrating full overall alignment all involve at least one data collection method that is activity-based and provides options for non-verbal feedback. For example, six of the nine studies (Healy, Msetfi & Gallagher, 2013; Humphrey & Lewis, 2008a; Killowry, 2015; Moyse & Porter, 2015; Williams & Hanke, 2007; and Winstone et al., 2014) included some form of drawing as part of their data collection methods, allowing participants a non-verbal option that requires no interaction with the researchers, can be completed in silence, and at a pace which is dictated by the participant, making it child-centred (Driessnack, 2006). However, as drawings can sometimes be difficult to interpret, discussions about the

content of the drawing are vital to ensure that researchers are reporting correct representations of participants' views, especially when working with 6 to 12-year-old children (Horstman, Aldiss, Richardson, and Gibson, 2008). In these studies, participants' drawings were used as a meaningful visual prompt to initiate discussions with the researchers by clarifying and explaining what the drawings represented – they could then also be used as prompts for further questions.

These studies also used other visual examples to facilitate discussions, such as collages (Shepherd, 2015; Winstone et al., 2015), photographs (Humphrey & Lewis, 2008a; Loyd, 2015; Moyse & Porter, 2015; Shepherd, 2015), video (Ellis, 2012; Loyd, 2015) and even a patchwork quilt (Ellis, 2012). Shepherd (2015) and Moyse and Porter (2015) also increased the activity levels in their interviews with students by taking part in 'learning walks', where the students guided them around their school environment. Perhaps the most striking advantage of this wide use of activity-based methods is the increased depth and insight produced by participants when compared to the use of standard face-to-face semi-structured interviews, as Winstone et al. (2014) concluded from their direct comparisons of activity-based and standard interviews:

> …the activity-oriented interviews were able to bring to the surface abilities not exhibited in the typical interview process…The use of standard interview techniques resulted in responses that have the potential to reinforce standard 'deficit' perceptions (p.202)

This suggests that activity-based data collection methods can engage participants, allow participants to express themselves in a variety of ways (including non-verbally), and can draw focus away from the researcher, putting the participant at the centre of the activity. It is therefore cogent to suggest that the variety of activity-based methods employed by the nine studies in this category lends itself to the increased frequency and importance allocated to the two main themes that emerged from the "partial overall alignment" studies - a sense of being different and the prominence and importance of individual differences – as well as increases in specific mentions of sensory experiences (see Table 9 for some examples). Even within very small sample sizes (e.g. Shepherd, 2015, who examines one case study from a sample of six students, and Moyse and Porter, 2015, who examine three individual children), there is a great range of individual differences both between and within the individuals who took part in these studies. The level of detail that each of the participants describe also allows a much clearer illustration of these differences compared to the studies that demonstrated partial overall alignment.

Table 9 Examples of awareness of difference and sensory experiences reported in studies demonstrating "full overall alignment"

Authors	Awareness of difference	Sensory experiences
Ellis (2012)	Josh: "I have my mum's Aspergers. Dad is what I say as normal, you know, without a disability. Ben has Autism." (p.169) Lydia: "People watch me all of the time" (p.285)	'Chill out' space and 'the quad' used by students when experiencing sensory overload to withdraw and deal with anxieties, and be in a calmer and quieter environment
Healy, Msetfi & Gallagher (2013)	One student explicitly differentiates herself from other students in relation to tiredness (they are more energetic than she is). All students also felt that they were sometimes excluded by physical ability	"Some people in the hall start screaming at each other…. just hurts my ears and ears." (p. 224)
Humphrey & Lewis (2008a)	"Sometimes it's like, "make me normal"' "Oh my God I'm a freak!" "It's like I have a bad brain." (p.33)	Noise and pushing/shoving can cause anxiety
Killowry (2015)	Luke is aware of the difference between his and his peers' attitudes to schoolwork (p.99)	David: "there's a noise that comes out of the projector, like a static noise, that gives me a headache whenever I'm in there" (p.78). Max dislikes the seats, as he cannot rest his back (p.84). All comment on preference for light and space in school environment
Loyd (2015)	None reported (possibly as the research does not take place in a mainstream context)	One student non-verbally reported preference for movement games in drama, as opposed to walking or rehearsing
Moyse & Porter (2015)	"They [peers] don't want me they want somebody else" (p. 193)	11yo participant had no access to fidget tools, so used her hair instead. 8yo reported that fiddling helped her concentrate and made her happy. 7yo reported that handwriting was effortful and difficult. All participants observed making small movements constantly
Shepherd (2015)	"…it's gonna be harder when I do my next course because that's more mainstream but I think I should cope well because I know lots of people" (p. 257)	None reported in this case study
Williams & Hanke (2007)	No explicit mentions	Some potential experiences reported through descriptions of ideal schools as being quiet, clean, well-maintained, naturally lit, and with appropriately sized furniture and classrooms
Winstone et al. (2014)	"Or I could be a little different. No, no wait I'm a little different … I am but I have no idea of it" (p. 200)	"I don't think other people would draw me the way I drew myself … different ways of drawing my features and a different way of seeing me" (p. 200)

This may be partly due to the specific theoretical approaches and methods employed in these nine aligned studies; a combination of Personal Construct Psychology, ethnography, case studies, and interpretive phenomenological analysis. These approaches all value rich details and contexts from the perspectives of the individual. For example, Moyse and Porter (2015) state that the aim of their study was "…to provide rich, detailed data consistent with a qualitative approach and supportive of the children as individuals with different experiences" (p.190); similarly, Williams and Hanke (2007) comment that, "Since [a participant's contribution] is a personal view, it cannot be wrong, and should be respected as such" (p.54). The desire to increase researcher understanding of the meaning and experiences of participants are explicitly mentioned (and sometimes used to justify research decisions) and this sentiment is also explicitly expressed in the remaining seven studies (Ellis, 2012; p. 36; Healy, Msetfi & Gallagher, 2013, p.223; Humphrey & Lewis, 2008a, p. 26; Killowry, 2015, p.57; Loyd, 2015; p.10; Shepherd, 2015, p.250; Winstone et al., 2014, p.191).

2.2.3.2 Understanding and effective support

A key theme that clearly emerges from six of these nine studies demonstrating full overall alignment is participants' explicit discussions of a relationship between understanding and support. The levels of understanding an individual feels other people have or display are linked to the effectiveness of the support that they are offered in an educational environment. Individuals who report feeling understood tend to link this with receiving better support in schools: as well as linking misunderstandings to receiving less effective support. Milton (2012) describes this (lack of) understanding as the "double-empathy problem", detailing the mutual misunderstanding that occurs when two members of different groups (in this context, students on the autism spectrum and neurotypical teachers) try to communicate. Six of the nine studies report instances where understanding has impacted on support: where understanding demonstrated by others has increased the effectiveness of support, and where misunderstandings have decreased the effectiveness of support. This relationship between understanding and support is mentioned by a total of fourteen studies in the previous two categories, but not described in detail compared to the nine studies in this category. Two mentions are from studies demonstrating no overall alignment (Camarena & Sarigiani, 2009, and Carrington & Graham, 2001), with the remaining twelve all reported from studies demonstrating "partial alignment" (Bolic Baric, Helberg, Kjelberg & Hemmingson, 2015; Dillon, Underwood & Freemantle, 2014; Gray & Donnelly, 2013; Gulec-Aslan, Ozbey,& Yassibas, 2013; Humphrey & Symes, 2010; Kammer, 2009; Mitchell & Beresford, 2014; Parsons, 2014; Penney, 2013; Saggers, 2015; Stirk, 2011; and Van Hees, Moyson & Roeyers, 2013).

The examples from the six studies in the “full overall alignment” category focus on the student/teacher relationship regarding teacher levels of understanding of the student, and how this relates to the support provided by that teacher. Some general examples are given by Williams and Hanke (2007), where students described staff at their ‘ideal school’ as being knowledgeable about each individual student; similarly, Killowry (2015) details one student’s (Max) reports of the negative impact that a teacher generally shouting has on him, making him feel like he “should be in a different class” (p.85) where shouting is not an issue. Moyse and Porter (2015) report several examples from their own observations of lessons where the teacher’s lack of understanding about the individual student has led to inefficient support (e.g. confusion about when one student, Amy, is able to ask for help, p.192).

Some of the research gave much more specific and detailed examples of the relationship between understanding and support in relation to teachers. Humphrey and Lewis (2008b) quote a student who explicitly links the negative relationship between understanding and support, saying “It is the teachers [that] are rubbish – they know about their subject but they know nothing about us with Asperger’s syndrome” (p.135). More positive examples come from Ellis (2012) and Healy, Msetfi and Gallagher (2013). Ellis (2012) gives several examples of positive student-teacher relationships, concluding that “understanding was paramount to a relationship, and this required the teachers to demonstrate they understood the students’ needs” (p.121). Healy, Msetfi and Gallagher (2013) also illustrate how the students in their study negotiated with their Physical Education teachers to be excluded from certain activities, to positive effects, as described by Shane: “…it’s ok with my teacher if I just watch. He thinks I’m the best student in the class; he’s great friends with me” (p.225).

The three studies where this link is not explicitly reported are Loyd (2015), Shepherd (2015) and Winstone et al. (2014). However, this may be because of the specific focus of the research in each of these cases. Both Shepherd (2015) and Winstone et al. (2014) adopt a methodological focus when reporting their research, detailing methodology rather than detailing findings. For example, the graphics in Shepherd’s (2015) research demonstrate that Jake (the young man chosen as the case study) mentions that he is worried about ‘teachers’ before he transitioned to college, but because the focus of Shepherd’s paper is methodological, the detail of her discussions with Jake and the other students is not given. Interestingly, Shepherd’s thesis (2016, University of Sussex) details the student interviews, and provides some explicit examples of the relationship between understanding and support: such as a student’s (Beth) recollection of how the levels of teacher understanding made her experiences in mainstream school very negative, and her experiences in a special school much more positive (p.111-112). Similarly, Winstone

et al. (2014) are focussed on illustrating the methodological differences between activity-centred interviews and standard face-to-face interviews, explicitly stating that the responses detailed are brief “to ensure that the article’s focus remains on the usage of the [interview] strategy in future research” (p.195). This suggests that the methodological focus of both these studies may explain a lack of explicit detail regarding the relationship between support and understanding. The focus of Loyd’s (2015) study is stated to “identify outcomes for the pupils from participation in drama education” (p.9); consequently, the interview questions are explicitly focussed on students’ likes and dislikes of drama, activities and goals in drama, and their feelings about drama. Working with other students effectively was reported briefly by one of the verbal students in the study - Ben – who mentions that drama gives him the ability to “work with people I don’t like” (Loyd, 2015; p.12), but this is not elaborated, and is mentioned by Ben by one of the activities and goals he has achieved in drama. It therefore may be that the link between understanding and support is not mentioned by the students in Loyd’s study because the focus on drama outcomes meant they were not explicitly asked about it.

Overall, these nine studies suggest that taking a participant-focussed approach that uses a range of different activity-based methods elicits rich detail and more authentic accounts from individuals on the autism spectrum. Some common themes relating to an awareness of being different, and specific details about sensory experiences, are subsequently described and reported in much more detail. This also reveals the relationship between understanding and support, which is discussed much more explicitly by the participants in studies demonstrating “full alignment” compared to the previous categories. Finally, this rich detail also allows a closer inspection of the individual differences between participants, as well as the overall similarities in the topics that they are discussing.

2.3 Conclusions and implications from the literature review

This literature review is positive in showing the international scope of research that has invited individuals on the autism spectrum to share their educational experiences, and the wide variety of approaches, data collection and analysis methods that have been used to do this. This section therefore summarises what can be concluded from these research studies and identifies how these conclusions will shape my initial research study to investigate the communication and support experiences of individuals on the autism spectrum in secondary mainstream schools in England.

Firstly, there are inevitably limitations to the conclusions that can be drawn from this review. As identified in Section 2.1.3, the demographic of the participants included in this review are limited, as the majority fall into the category of verbal males on the autism

spectrum. Additionally, the most information reported from participants (and therefore the clearest demonstration of reporting participants' insider epistemologies) comes from the nine articles that demonstrate "full overall alignment" with my conceptual criteria. My conclusions are therefore based on a relatively small sample (the total number of participants included in these nine studies is 88, which represents only 5% of the total number of participants included in this review). I am therefore cautious about using these conclusions to support and shape my initial research. For example, although I may conclude that only 5% of the participants in this review have taken part in research which has allowed them to express their voices authentically by successfully navigating the four conceptual categories of expertise, multiplicity, engagement and hierarchy, this does not consider individual studies which may have demonstrated evidence of "full alignment" for one of these categories, and yet have been given "partial alignment" overall.

Indeed, further analysis suggests a more positive overall view of the research. For example, the conceptual category of 'Expertise' links to whether participants' contributions are reported in their own words, and as individual contributions rather than being grouped together and summarised. This category is also linked most clearly to the notion of insider epistemologies, as it reflects the extent to which individuals' contributions are treated as 'expert'. Almost 65% of the studies in this review demonstrated partial alignment with 'Expertise', with over 30% of studies demonstrating full alignment with this category. This therefore suggests that many researchers in these studies have demonstrated that they value participants' contributions, regardless of the research methods used or the overall conclusions drawn. Similarly, the conceptual category of 'Hierarchies' relates to attempts by researchers to adjust and compensate for the potentially limiting effects of inherent hierarchies on the students' voices reported in their research. The alignment in this category is more evenly split across the eighty-one studies, with just over 55% demonstrating either partial or full alignment. Again, this suggests that many researchers are not only demonstrating that they value the contributions of participants; they are also demonstrating attempts to resolve the effects of inherent hierarchies on participants' contributions.

However, the remaining two categories of engagement and multiplicity are not quite as positive when evaluating the literature included in this review. Almost 45% of the studies included in this review did not demonstrate any evidence for the category of 'Engagement'. This figure is incredibly low when considering that most participants in these studies are young people, who tend to require more engagement in research than adults (Rudduck & Fielding, 2006). It is especially concerning considering the importance of using specific strategies to engage and facilitate direct participation with individuals on the autism spectrum (see Harrington, Foster, Rodger & Ashburner, 2013, for a review).

This therefore suggests that although researchers may value the contributions that individuals on the autism spectrum, the research methods employed to explore and record these contributions may not be as effective as it could be. Further evidence for this can be seen in the category of 'Multiplicity', which is mainly associated with the different types of communication individuals may give, and therefore links closely with a choice of data collection methods. For example, if the data collection method chosen does not offer options for non-verbal contributions, then these will not be recorded as part of an individual's potential contributions. Across the eighty-one studies included in this review, over two thirds demonstrated no evidence of multiplicity, with the remaining third evenly split between demonstrating "partial" or "full" evidence. This suggests a need to give much more explicit consideration of what is meant by 'students' voices' and adapt research methods accordingly to allow for this.

Overall, this breakdown of the conceptual categories suggests that although students' voices are valued within the research literature, the way in which students' voices are defined, listened to, and reported requires much greater clarification. This means that my own research working with individuals on the autism spectrum needs to demonstrate "full alignment" with the four conceptual categories by firstly using activity-centred research methods. Not only does this facilitate engagement with the students that I will be working with, it also allows for much better demonstrations of the multiplicity of students' voices (such as non-verbal communications). I also need to take explicit steps to navigate and compensate for the inherent hierarchies that are present in our working relationship to demonstrate how students' voices are given appropriate expertise within the research context. This will encourage more authentic contributions from the students on the autism spectrum that I am working with.

In addition to considering the different ways these studies have demonstrated regarding the reporting of students' voices, it is also important to summarise the five main themes regarding students' educational experiences that emerged. Although these five themes are demonstrated most strongly from the nine studies demonstrating "full alignment" with my conceptual criteria, there is also evidence from the forty-eight other studies that demonstrated either "partial" or "full" alignment for any of the four conceptual categories. Consequently, it is germane to suggest that these themes may be reported by the students I will be working with, and therefore could be explored in further detail.

The five themes that emerged are as follows:

i. Students' awareness of 'difference'
ii. Positive views of being on the autism spectrum, which includes skills and strengths
iii. Students' descriptions of sensory experiences, and how these may impact positively and negatively on educational experiences
iv. The importance of individual differences and personalisation when working with individuals on the autism spectrum
v. The relationship between understanding individuals' differences and providing effective support in an educational context

However, given the limitations of this review, this is not an exhaustive list of what we can learn from students' voices. I cannot conclude that experiences less frequently reported are less frequently experienced by students on the autism spectrum; they may simply be less frequently investigated, or less problematic when compared to other difficulties. Each of these five themes therefore require further and explicit exploration before any conclusions can be tentatively made.

As the aim of my thesis is to explore how communication and support in educational discussions could be facilitated, the first phase of my research will examine the processes of communication and support that are currently experienced by students on the autism spectrum in mainstream secondary schools. Additionally, I wanted to explore the five main themes in more explicit detail, whilst also allowing other potential findings to emerge. Taking an exploratory approach also allows the flexibility for further important factors to be identified by the students organically during the research process rather than focussing solely on specific outcomes (in this case, the five themes from the literature review). Parsons (2014) cautions against relying too heavily on specific outcomes, concluding from the results of an online survey completed by adults on the autism spectrum that successful outcomes for any given individual are "very personal, nuanced and context-specific" (p.418). An exploratory approach therefore also allows me to explicitly investigate the five themes identified in this review whilst also exploring the personalised and individual differences between students on the autism spectrum regarding the communication and support that defines their current educational experiences.

A criticism I have made throughout this review is that neurotypical researchers may be at risk of making normative assumptions about their methods and findings. Like many of the authors of these studies, by co-constructing the meanings associated with students' voices as a neurotypical researcher, these same risks apply to my research. One way to reduce the risk of making normative assumptions comes from Cousin (2010), who suggests that neurotypicals need to increase their "textual experience" (p.15) of being on the autism spectrum. My current textual experience comes from my academic reading, discussions on neurodiversity forums and my own personal and professional experiences of interacting with individuals on the autism spectrum. However, this level of textual experience may still not be sufficient, and may still result in biased interpretations, which is in complete opposition to my own beliefs as a researcher (see Section 3.1 for further detail).

A potential way to address this issue is by consulting with individuals on the autism spectrum - a method used by Jones, Huw and Beck (2013). The benefits of working with individuals on the autism spectrum to enhance research is well-documented. Jivraj et al.'s (2014) findings suggest that involving 'partners' on the autism spectrum in the selection of research methods may "enhance the process and outcomes of research" (p.789). In addition, Nicolaidis et al. (2011) suggest that partners from the (autistic) community can help ensure that my research is "respectful, accessible and socially relevant" (p.145) to the students on the autism spectrum. Although the level of control I need to maintain over my thesis is not complimentary to working with individuals on the autism spectrum as equal partners in my research, consulting with them will further reduce the risk of applying my neurotypical interpretations to the research findings. Lukas (1998) defines consultation as a relationship that is time-limited, where the consultant has "skills and experience" (p.4) that help the individual consulting them to work towards a specific goal or task. I plan to consult with autistic adults to improve my textual experience; their skills and experience will help this to improve. This will subsequently also improve the effectiveness of my choice of research methods and interpretations, as consultations can "illuminate the effectiveness of the research communication in obtaining full and representative data" (Hill, 2006, p. 70).

2.3.1 Research questions for the first phase of my research

The first phase of my research therefore adopts an exploratory approach to discuss the support and communication that students on the autism spectrum are personally experiencing in mainstream secondary schools. Consultations with autistic adults were used in a deliberate attempt to reduce the risk of making normative assumptions in carrying out the research. Research methods were employed that demonstrated full

alignment with my conceptual criteria for listening to students' voices (as identified from this literature review). In addition to the research methods, I also explored whether the five themes that emerged from this literature review were present in the discussions I had with participants. The research questions for the first exploratory phase of this research were therefore as follows:

1. What is the process of support being offered to (and by) students on the autism spectrum in a classroom environment?

2. What is the process of communication between students on the autism spectrum and the others (e.g. teachers, LSAs, peers) they work with?

3. What might be the factors that contribute to the process of these communications?

Chapter 3 Research Methodology

The previous chapter demonstrated how the findings from the literature review have illustrated the advantages of choosing research methods that demonstrate full alignment with my conceptual criteria, and why an exploratory approach is most useful for investigating support and communication in secondary mainstream schools. The first part of this chapter briefly outlines the overall research design of this thesis, detailing the differences between the first and second phases. The second section outlines the personal and epistemological influences that have also influenced my research approach and methodological decisions. The third section of this chapter details my choice of research methods and the findings from my consultations with autistic adults to improve my 'textual experience' of autism, including reflections on how this further influenced and refined my research design. The process of carrying out the first phase of my research is then detailed in the remaining sections of this chapter.

3.1 Overview of the research design

My research into communication and support consisted of two phases. The first exploratory phase (detailed in this chapter) investigated the current processes of communication and support taking place in two secondary mainstream schools in the south of England. Six students on the autism spectrum were interviewed using photo-elicitation to explore their perspectives of the communication and support processes in school. In addition to the six students on the autism spectrum, seven members of staff who worked with at least one of the students were also interviewed to explore their perspectives (for further details of both the schools and student and staff participants, please see Section 3.3.2.1). Six autistic adults from an advocacy group assisted me with developing my approach to interviewing the students and revealed my own biases as a researcher before the interviews commenced (see Section 3.3.1 for further detail).

The second phase of this research (detailed in Chapter 5) developed from the findings of the first. Four key differences in perspective between the students on the autism spectrum and staff members were revealed from analysis of my findings from the exploratory phase. The second phase of the research therefore aimed to facilitate communication and support in these four distinct areas using activity-based interviews. Four activities were designed by me and refined by five autistic adults from the advocacy group (four of whom had taken part in the first phase) and the same six students on the autism spectrum. The six students then completed these four activities, and an information sheet summarising the information acquired by these activities was created. These personalised information

sheets were given to sixteen educational practitioners (two of which had taken part in the first phase of the study) to assess the value and usefulness of the information provided in facilitating communication and support processes (for further details of the educational practitioners, see Section 5.4.2). My philosophical approach was consistent across both the first and second phases of research and is detailed in the following section.

3.2 Philosophical approach

Cousin (2010) states that "the self is the research tool" (p.10), and therefore in addition to my conceptual criteria for listening to students' voices, I need to consider the impact of my researcher positionality on my research and interpretations. Summarising my position from the first two chapters, my research and this thesis may be viewed through three 'lenses', which form my overall conceptual approach (see Figure 2). The first of these is the neurodiversity lens; the second is an inclusive lens; and the third lens relates to my conceptual criteria for listening to students' voices.

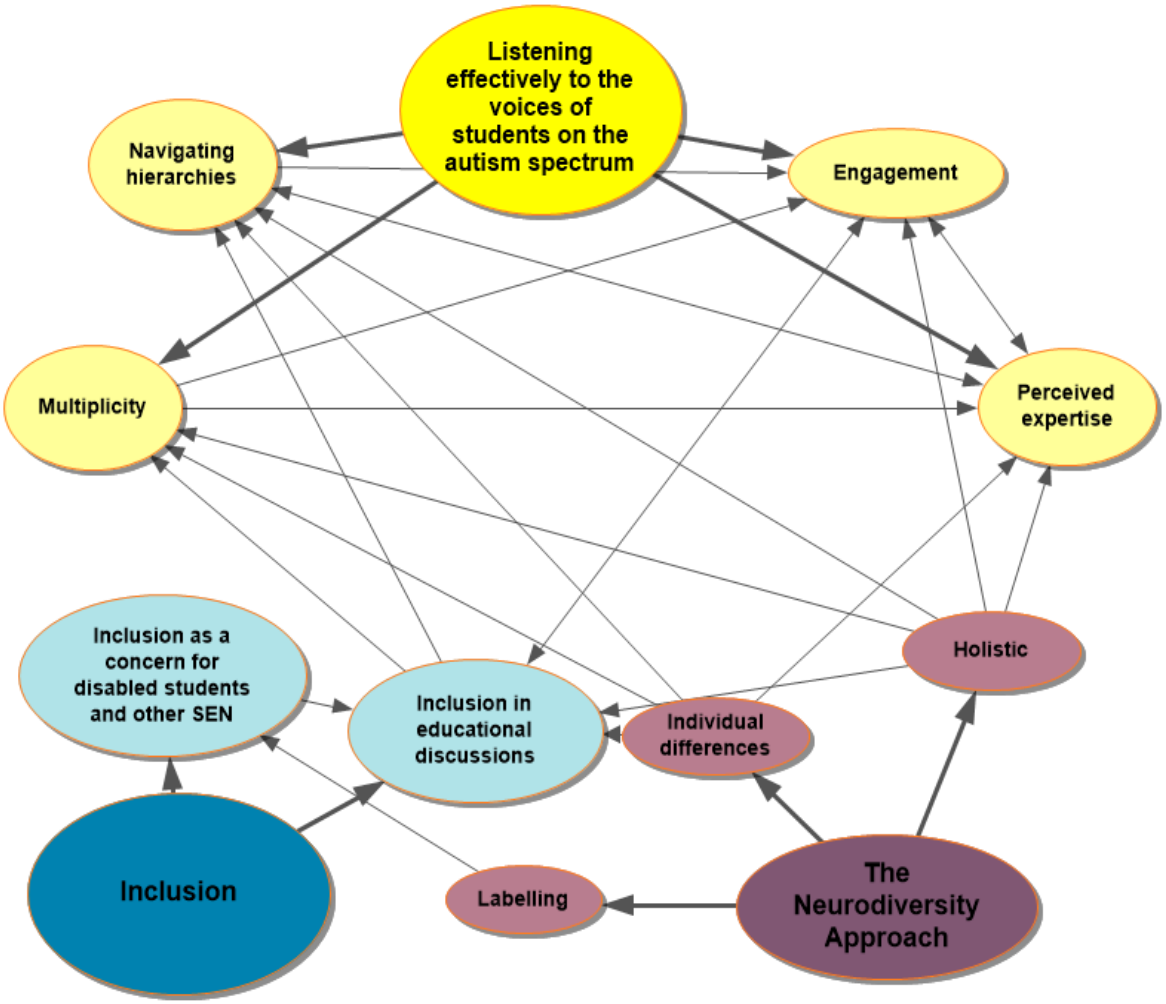


Figure 2 My conceptual framework for this thesis

The reason for sharing these three lenses and their interconnections is to be very transparent about my own biases as a researcher. Guba and Lincoln (1989) argue that transparency is essential for effective researcher reflexivity and increased credibility in the collection of qualitative research, while Lincoln and Guba (1985) observe that establishing the trustworthiness of research findings is also dependent on ensuring credibility. By outlining my own personal influences on my research, I hope to increase both the credibility and trustworthiness of my research findings. As Maykut and Morehouse (1994) suggest that inclusion of personal and professional information relating to the phenomena being investigated increases credibility, this section also details my own personal experiences that relate to the nature of my research.

My main research interest is listening to the voices of students on the autism spectrum regarding their secondary mainstream education. This has been shaped by my professional experiences of working with individuals on the autism spectrum in a variety of educational roles, such as a special education support assistant, a learning support assistant, and a secondary mainstream schoolteacher. In addition, I have personal experience of interacting with individuals with SEN or disabilities, and specifically, individuals on the autism spectrum. This is due to my youngest sister displaying autistic tendencies (although she is not on the autism spectrum as the nature of her disabilities are attributed to a hippocampal tumour) and having a severe learning disability. As she attended specialist schools throughout her education, she, her friends, classmates and housemates gave me multiple experiences as a teenager of the strengths and challenges that young children with additional needs (and their families) can face because of their differences. These adolescent experiences reinforced my commitment to social justice, defined neatly by Griffiths (2003) as “wanting equality at the same time as acknowledging difference” (p.1), and I augmented my personal experiences with theoretical experience by studying Experimental Psychology as an undergraduate, adopting the positivist view of human experience. However, on my return to study for an MSc in Education, Management and Leadership, I slowly realised the unique contributions that individuals provide regarding their own interpretations of a situation. This was best illustrated in my decision to qualitatively explore the different views that teachers and students on the autism spectrum possessed regarding ‘effective’ teaching for my dissertation.

Consequently, my current epistemological approach (and therefore, the approach taken throughout this thesis) is best described as interpretivism. Although this theoretical perspective draws on many different philosophies, it can be characterised by “…the significance given to individual and subjective accounts in the research process, along with reflexivity on the part of the researcher” (Cohen, Manion & Morrison, 2007, p.28). In line with my previous discussions about the inevitability of the influence of my own

experiences on my interpretations about what might be significant, I also align myself with what Mölder (2010) describes as “intermediate interpretivism” (p.82). Using this approach, Mölder (2010) argues that researchers need to uncover an “intentional pattern” (p82) in their data to try and avoid over-projecting their interpretations of what is there. Therefore, although patterns and attributions in the data are identified by me, it is my task to demonstrate that this is due to an ‘intentional pattern’ rather than my own projection. Yanow (2015) concurs, arguing that the analytic rigour of qualitative research can be assessed by examining whether a sound and logical argument arises from adequately supported conclusions. Consequently, taking a stance of intermediate interpretivism reinforces my commitment to transparency in detailing the decisions and interpretations made throughout this thesis, and detailing the evidence base upon which these were made. An interpretivist approach can also be complementary to research about individual differences and experiences of SEN, as illustrated by Avramidis and Norwich (2016):

> …the interpretivist researcher did not accept psychological categories and classifications (e.g. disorders and syndromes) as given and valid across individuals and contexts. Instead, the perceptions of teachers, learning support assistants, parents and, more importantly, children and young adults themselves were sought, with a view to enhancing understanding about the individual and their needs (p.34)

I am interested in the **process** of communication between individuals on the autism spectrum and school staff members. I aim to generate some understanding of these processes which I understand to be unique and specific to each individual. That said, any potential understanding I generate may be applicable and personalisable to individuals in other, different contexts. This supports Guba’s (1981) notion of transferability and, therefore, may also increase the trustworthiness of my research findings.

In keeping with the notion of transparency, the extent to which I am an ‘insider’ or ‘outsider’ when conducting my research is also likely to affect my positioning and reporting of my findings. My researcher role varies considerably with each group of participants I am working with: students on the autism spectrum, autistic adults, and staff members in the schools. This therefore necessitates shifting my role as an insider or outsider as needed by the research situation. This shifting between roles may not necessarily be a limitation; Van der Riet (2008) argues that although an insider approach (termed as ‘empathic’ by the author) can uncover “the meaning or significance of behaviour” (p.547), an outsider approach (termed as ‘distanciated’ by the author) “highlights the contextual and subjective limits of understanding” (p.549). Consequently, adapting both roles may better contribute to my understanding of the processes of communication and support that are present in secondary mainstream schools, and allow me to examine multiple

interpretations of the situation. This will allow me to better determine Mölder's (2010) "intentional patterns" (p.82) of behaviour, rather than relying on my own projections.

There are other potential advantages towards actively promoting my insider/outsider role. For example, highlighting my insider role by expressing my experiences of working in schools to staff participants may facilitate building trusting relationships, thus increasing the credibility of their statements (Dwyer & Buckle, 2009). Accentuating my outsider role may also be advantageous. As an outsider, I will not have access to the same knowledge that the individuals I am working with possess; for example, knowledge of the layout/environment, and established practices that take place within it. Explicitly expressing this lack of knowledge demonstrates my "position of incompleteness and immaturity" (Gallacher & Gallagher, 2008, p.512), which may counteract some of the inherent hierarchies that exist between myself and the individuals I'm working with (e.g. age and level of education). Similarly, I am not representative of a teacher in the schools I will be working with, which may alleviate some of the students' potential reticence in disclosing information about their experiences (e.g. that I could 'report back' to those in positions of power). This distance from the school environment may therefore facilitate the credibility of the student participants' responses (Greene, 2014). I also deliberately accentuated my outsider role with the students to encourage honesty from the student participants (as recommended by Shenton, 2014, p.66) and distance myself from other adults in their school environment. For example, I dressed casually when in school (e.g. jeans, hooded jumper, trainers) and asked students to call me by my first name; what Kellett (2011) calls taking on a 'non-authoritative' role. Consequently, my use of insider/outsider roles can be used to increase the transparency of my approach and increase the credibility of my research findings.

Another aspect of my positioning that may affect the way I carry out and report my research are the conceptual lenses I mentioned previously. The effects on my research of adopting a 'neurodiversity' lens and conceptual criteria for listening to students' voices have already been discussed in depth elsewhere (see Section 1.3 and 1.4). However, I also identified inclusion as one lens through which my research should be viewed (see Section 1.2). It is appropriate to explore the properties of doing inclusive research, although my preferred terminology is Nind's (2014) phrase of 'doing research inclusively'. Walmsley and Johnson (2003) identify five main principles that underpin inclusive research, which is allied with the key values of inclusion discussed in Chapter 1, such as increased participation, changes in policy, and a focus on students at risk of exclusionary pressures. I will take these five principles as a starting point to assess the extent to which I can justify that I am doing research inclusively. Throughout this section, the 'group' mentioned in these principles refer to individuals on the autism spectrum.

Firstly, Walmsley and Johnson (2003) argue that in inclusive research, the research is owned by the group involved in the research. This is problematic for my research, as it is contributing towards my thesis which I take single ownership of. Consequently, it is unlikely that the individuals on the autism spectrum who are involved in my research will be able to claim ownership of the research once it has been completed. Because this research is being conducted as part of a qualification that is contributing towards my own personal gain and academic career, this principle of inclusive research is not being upheld in this thesis.

The second principle of inclusive research states that the research being carried out aims to further the interests of the group. I have previously discussed my commitment to improve the secondary school experiences of individuals on the autism spectrum, and therefore the aim is that this research will improve education and understanding in mainstream secondary schools and positively impact on the individuals I am working with. Pellicano, Dinsmore and Charman (2014) have demonstrated that the research priorities of individuals on the autism spectrum and their families do not always match the research priorities of academics, and therefore I need to assess whether this research furthers the interest of individuals on the autism spectrum, rather than just my own research interests. In the same paper mentioned above, Pellicano, Dinsmore and Charman (2014) identified that individuals on the autism spectrum want autism research to investigate factors that impact on everyday experiences, as well as more research into autism education. More recently, Nicholas et al. (2017) stated that the discussions involving a variety of stakeholders in autism research were unanimous in agreeing that: “Listening to the voices of individuals with ASD in research production and priority determination was viewed as paramount” (p. 19).

Additionally, a steering group of individuals on the autism spectrum ranked the top ten research areas of most importance to them, as reported by the James Lind Alliance (2016). Developing communication and language skills was ranked as the second most important research priority and investigating the best environments/supports for promoting the best level of education, life and social skills was ranked as fifth most important. The theme of sensory processing that emerged from my literature review and highlighted as an area that required further investigation is ranked as the ninth most important area of research that is most important to individuals on the autism spectrum. Bogdashina (2003) has also commented that a range of authors on the autism spectrum who have described their experiences consider sensory processing to be one of the main issues that affects their day-to-day lives.

Conducting my exploratory phase of research into communication and support within an educational context – as well as examining the five specific themes that emerged from the literature review (individuals' awareness of difference, a view of autism that includes strengths, sensory experiences, individual differences, and the personalisation of educational support) - therefore seems to reflect the research interests of individuals on the autism spectrum as well as my own research interests. However, it is worth noting that I will be personally gaining from the participation of the students, autistic adults and staff members involved in my research, as their discussions and this research is contributing towards a qualification for me. Consequently, my own interests are also being met by conducting and reporting this research.

The third, fourth and fifth principles of inclusive research outlined by Walmsley and Johnson (2003) state that the group should be involved with the process of carrying out the research; the group should be able to exert some control over the outcomes; and finally, the research questions, processes and reports must be made accessible to the group. I have combined these three principles together as they all refer to the level of input and sharing of control between the researcher and the individuals who are participating. The necessary empowerment of participants to achieve this shared control automatically means that the power held by the researcher is diminished. As this research contributes to my thesis and future qualification, rather than tolerating the discomfort associated with a loss of power and control (as reported by Povee, Bishop & Roberts, 2014), it is likely that I will inevitably try to reassert control because of my own personal investment in the outcome of the research. However, the fifth inclusive principle - concerning the accessibility of the research questions, outcomes and processes to the group – is a principle that is easier for me to uphold and demonstrate. I ensured that both students and adults were informed of the research questions before I started working with them (presented in an accessible format as required) and met with them several times to update them on the outcomes and processes that I was working on. I will also ensure that any formal publications of findings and outcomes (e.g. within a journal) include an accessible summary, and that other opportunities to present my findings (such as conferences, workshops and informal meetings) are similarly presented in accessible formats.

A potential solution to this tension between inclusive values and control over the research process is through participatory research, which is a form of inclusive research that emphasises partnership rather than empowerment (Walmsley, 2001) and therefore could potentially allow me a greater level of control over the research process whilst still upholding inclusive values. In addition, Wright, Wright, Diener and Eaton (2014), Conn (2015) and Milton (2014) have called for researchers to make use of participatory

approaches to empower individuals on the autism spectrum who are involved in research. However, participatory research still seeks a level of partnership that may not be possible given my vested interests in completing this thesis; for example, it seeks the involvement of those who are being researched in the design and execution of a study (Bourke, 2009). As I am conducting the exploratory phase of my research as part of a qualification that I personally will be assessed on that is based upon an analysis of the existing research literature, the students and adults that I am working with will not be involved in the design and execution of the exploratory phase (the fourth principle of inclusive research).

Ultimately, my need for control over the design and outcome of the first phase means that I cannot argue that I will be conducting truly inclusive or participatory research. For the purposes of this thesis, I therefore describe myself as conducting research with a participatory and inclusive intent. This balances my need for control over the research (as a PhD student with vested interests in the outcomes) with my personal beliefs: firstly, that participants should be treated as equally as possible in the research process; secondly, that hierarchies that may affect the outcome of the research in a negative way should be redressed wherever possible; and finally, that those taking part in research should be allowed to participate (or not) in whatever format they choose, and the topics being researched are of interest and relevance to them.

3.3 The exploratory first phase: detailing communication and support in schools

The first phase of my research involved working with autistic adults, students on the autism spectrum, and staff members in secondary schools to try and identify some of the current strategies used in schools to promote communication and support, and to explore whether these were deemed to be effective. Additionally, this phase also allowed me to see if the five themes identified from the literature review - individuals' awareness of difference, a positive view of autism that includes strengths, sensory experiences, individual differences, and the personalisation of educational support – were reflected in the experiences of the individuals on the autism spectrum that I was working with; and consequently, whether these themes or any others that emerged may be potential facilitators of communication and support to be explored during the next phase of my research.

3.3.1 The invaluable contributions of the autistic adults

My consultations with the autistic adults took place before the interviews commenced with both staff and students. To organise my consultations with the autistic adults, I contacted a gatekeeper (Mark) who was a member of an autism advocacy group via email in September 2015, asking whether the group members would be interested in advising me on communication methods for working with students on the autism spectrum. Once the group confirmed their interest in participating, two specific dates were chosen for me to visit, which coincided with the advocacy group's monthly meetings. Following ethical approval (Appendix E.1), information sheets about the research (Appendix E.2) and consent forms (Appendix E.3) were then sent via email, and the autistic adults were given the option of choosing their own pseudonyms – however, some later waived their right to confidentiality and decided to use their given names (see Appendix E.11 and E.12 for the amendments made because of this).

A total of six different adults participated in the two consultations for this exploratory phase (all six in the first, with Mark missing in the second): Mark (his own name), Emily (pseudonym), Ann (pseudonym), Steven (pseudonym), Peter (pseudonym), and Alex (pseudonym). They had all received a diagnosis of either Asperger Syndrome or ASD as adults – some very recently, some within the last five years. They ranged in age from 30-70 years old and had a variety of occupations. The group's neurotypical moderator was also present during the meetings to act as a familiar and skilled facilitator to the group discussions but did not contribute their own views to the discussions. I met with the group twice – once in November 2015, and then again in February 2016 – and conducted focus groups with them exploring their perspectives about school and their recommendations for effective communication, starting with general questions before narrowing the focus to more specific topics, as suggested by Fern (2001); for a full list of the questions asked, see Appendix D.1.

At the beginning of each meeting, the group would discuss their own objectives and complete tasks and discussions related to their advocacy remit. I was then invited to conduct my focus groups once these discussions were completed. The opportunity to ask any questions about the research was given, and questions answered honestly and to the best of my ability. Once any ethical paperwork had been completed, the questions were read out by me, and discussions were recorded using an iPhone voice recording application for confidentiality, as it required fingerprint identification to access. The group's moderator then gave timing cues, ending the questioning in line with the allocated break time that the group adhered to. The recordings were transcribed and analysed thematically using NVivo 10 software. These findings were used to formulate guidelines for me to follow when conducting the research interviews with the students, relating to

communication (Appendix D.2), environmental considerations (Appendix D.3), and individual factors that may affect the research process (Appendix D.4). Throughout the consultation and analysis, I also kept a research diary to better illustrate the research process and increase the transparency of my own interpretations. The group was also invited to submit any further details or comments to me via email if they thought of anything after the focus groups had taken place, although no one did.

The main impact of my consultations with the autistic adults was on revealing my own biases as a researcher. For example, despite my previous experiences of working with individuals on the autism spectrum, I greatly underestimated the significance, depth and relevance of the observations and advice that the autistic adults offered me regarding how to conduct myself and observe respectful communication behaviour when working with students on the autism spectrum. In addition to underestimating the competence of the adults, I also over-estimated my own competence in being able to understand the experiences that the adults were describing. Thankfully, the adults were keen to ensure that I understood, and therefore happily corrected my misconceptions when needed; for example, how a statement can be patronising rather than reassuring when normative interpretations are applied:

> *Emily: You've grown up with [people saying] 'it doesn't matter, it's fine'…you KNOW it's not fine!* (Focus Group 1, 26.11.2015)

I was quite shocked to realise that despite my criticism of researchers applying normative assumptions to the answers of individuals on the autism spectrum, I was guilty of making the same mistakes. In addition, despite the positive examples from the literature review and my own previous experiences, it became clear that I was expecting a much more negative picture of the adults' educational experiences from my thoughts when transcribing the first focus group:

> *Genuinely surprised about all the good stuff re: friends and people sticking up for them. Why am I so shocked? Need to be aware of this in interviews*.
>
> (Research Diary, 02.02.2016)

Becoming more aware of my own biases as a researcher from talking to the autistic adults had an immediate impact on my approach, and I was particularly cautious in further discussions with both the adults and the students to encourage all experiences and not to assume that there would be more negative than positive examples. I also changed the nature of my follow-up questions when seeking clarification about what an individual said; I made a conscious effort to use more open questions and allow the individual to label an experience as either positive or negative as they saw it from their perspective.

As the focus groups took place, the autistic adults also made me more aware of processing issues and needs for silence, which highlighted a tension between my needs as a researcher looking for information, and the needs of individuals on the autism spectrum. Although I wanted students to answer all the questions that I put to them, I had to understand that there may be good reasons for students not answering. This reinforced the complexity of different types of communication that may occur during the research process (see Appendix D.2). An observation from the autistic adults reinforced this particularly well:

> *Ann: …people think that if you're not talking or you're not answering the questions, then you're stupid. And it's not that.*
>
> *HH: As a teacher, I think there is a tendency to think that if someone doesn't give you an answer, it's because they don't know it, which is not always the case.*
>
> *Steven: Or they need time to take to process it, that's the worst thing.*
>
> *Emily: Or the question you've asked just doesn't make sense when you take it literally!*
>
> *Steven: Yes! Basically, you're asking stupid questions! [laughter]*
>
> (Focus Group 2, 25.02.2016)

For example, if participants were trying to avoid talking about a specific subject, I had to accept that there was more than likely a good reason for avoidance; even if they did not want to tell me what the reason was or did not know how to. Also, if I appeared frustrated that a student was taking a long time to answer a question, this could affect the students' response in a negative way; they could limit the detail they were going to give, or simply reassure me that their answer 'doesn't matter' or that they 'don't know'. This made it imperative for me to think about how I could demonstrate respect to the autistic adults and students on the autism spectrum that I was working with, as demonstrated in the following guidelines I noted:

> *Need to be aware of language. Wait after original answer, don't re-phrase, <u>wait</u> for prompt for clarification. Think about literal meaning of question I'm asking.*
>
> (Research Diary, 26.11.2015)

Another significant lesson that I learnt from speaking to the autistic adults was that the importance of individual differences cannot be overestimated when communicating with individuals on the autism spectrum. Previously, I would have liked to believe that my personal and professional experiences of working with individuals on the autism spectrum would have been sufficient to understand this message. However, the variety of individual differences I saw from the autistic adults in talking about their experiences was much

more significant than what I was naively expecting, revealing my own potential bias and demonstrating that my previous experiences of communicating with individuals on the autism spectrum were not nearly powerful enough to reinforce this message:

> *Loads of differences in experiences, even between these five*.
>
> (Research Diary, 26.11.2015)

This message was also explicitly reinforced during the focus groups:

> *Peter: [Interactions should be more] One to one, then you get to know what they reference to.*
>
> *Emily: It's about finding out what works best for the individual, and not make assumptions. And not assume that because you've worked with one person with Asperger's and they needed X, then that's what every child with Asperger's needs. And if they just don't go for it, they're just being uncooperative and unhelpful, when actually, their needs are different.*
>
> (Focus Group 2, 25.02.2016)

The autistic adults also identified other environmental factors that were likely to affect my research interviews that I would never have considered myself (see Appendix D) iii) for a full list):

> *Emily: …if someone's sat next to the window when the grass has been cut – I start gagging if there's cut grass anywhere near me, so that would affect me.*

> *Alex: …some kids will only – if they're in a certain seat, they'll answer; if they're stuck on the other side of the room, they'll switch off.*

Another new consideration was the relative lack of self-awareness that students on the autism spectrum were likely to have about their own experiences. This was a key example of the individual factors that may affect my research interviews (see Appendix D.4 for details). This was explicitly stated in the discussions, as well as evidenced in the adults' personal recollections of their own adolescences:

> *Mark: [As a child] I don't think I was aware of anything OTHER than words conveying meaning…*

> *Alex: …back then, you didn't think anything…you didn't think like that, you didn't think 'oh, I wonder what's wrong', you just…stumbled through.*

> *Ann: I've always been fidgety, but I don't know whether it's stimming – I feel comfortable doing it, so it probably is…and chewing pens. Which is strange, because I don't like anything else in my mouth that isn't food, but I'm alright chewing a pen.*

These comments made me realise that the students may still not be aware of how being on the autism spectrum impacts on their experiences, and so direct questioning would be needed during the interviews to better explore this.

In summary, consulting with the autistic adults significantly increased my 'textual experience' (Cousin, 2010, p.15) of autism, and revealed additional considerations needed to authentically engage, communicate and work with students on the autism spectrum. This invaluable information and experience positively impacted on my communication skills and interviewing techniques, such as the nature and frequency of follow-up questions I asked, how I asked them, and how I allowed the students more freedom to go 'off-task' (especially during the interviews). In addition, concrete examples emerging from our discussions were incredibly useful in allowing me to form direct questions to the students on the autism spectrum. For example, without the autistic adults' specific examples of their different sensory experiences, it would have been potentially very difficult to encourage students to talk about their sensory experiences with no prompting. The autistic adults also revealed my clear biases as a researcher, such as my focus on negative experiences, and my tendency to 'group' students on the autism spectrum when talking about them in a research context (especially when trying to summarise their experiences). This awareness of my own biases refocussed my attention on the positive experiences and differences between the students. Consulting with the autistic adults was instrumental in the way that I refined my interview technique, questioned my own observations, and challenged my interpretations of my research findings. Thanks to their incredible helpfulness and support, the trustworthiness and credibility of my research was significantly increased.

3.3.2 Procedural details of the exploratory phase

3.3.2.1 Participant details

Student participants were selected using purposive sampling from two mainstream secondary schools in a shire county in the South of England; one rural and one urban. The rural school was rated as 'outstanding' by Ofsted in 2013, and consisted of approximately 1200 male and female students, the majority of which were White British. The school had a below average number of students eligible for the pupil premium (indicating low socioeconomic status), and a below average number of students with SEN

that had received statements of special needs. Particular mentions were given by Ofsted to the school's excellent provision for students with SEN, and teachers' detailed knowledge of individual students. The urban school was rated as 'requires improvement' by Ofsted in 2014, and consisted of approximately 500 male and female students, also predominantly White British. This school's proportion of students with SEN was above average, and over half of the students were eligible for the pupil premium. Particular mentions were given by Ofsted to the school's inconsistent quality of teaching across subjects and departments, yet also praised the close monitoring the school provides that ensures equal levels of achievement for students with SEN compared to their peers. Although the two schools were very different, each had therefore received praise in their most recent Ofsted inspections for their support for students with SEN.

Three students were selected from each school. Five male students and one female student between the ages of eleven and thirteen years old (see Table 10 for further details) responded to initial inquiries about the study from the SENCO of each school in December 2015, although gender neutral pronouns (they/them) and pseudonyms will be used throughout this thesis to avoid possible identification. Each student came from a White British background and had been identified and assessed as being on the autism spectrum by educational psychologists apart from Hanzo, who was still going through the diagnostic process. Genji and Hanzo were identified by the schools as having a lower socioeconomic status than the other students. All the students were told that I was interested in talking to students on the autism spectrum but were given no prompts to refer to themselves as being on the autism spectrum, being autistic, or having autism. This allowed the participants the freedom to choose their own labels (or not) within this study when discussing their experiences.

Table 10 Summary of student participant characteristics at the start of the first phase

Pseudonym	Age	School Year	Diagnosis received
Yazi	11	7	Asperger Syndrome
Sage	12	8	Autism Spectrum Disorder
Genji	11	7	Autism Spectrum Disorder
Hanzo	12	8	Undergoing diagnostic process
Bob	12	8	Autism Spectrum Condition
Jack	11	7	Asperger Syndrome/ADHD

Additionally, seven staff members (two males, five females) across the two schools volunteered to take part in the study following their involvement in a lesson observation where I was observing one of the six students. They all had experience of supporting one of the student participants, six of them as a classroom teacher, and the other as a learning resource centre manager. The members of staff ranged from 20-60 years old and had all been working in schools for at least three years (see Table 11 for further details).

Table 11 Summary of staff participant characteristics at the start of the first phase

Pseudonym	Age Range	Sex	Occupation	Experience
Dave	30-40	M	Classroom teacher	4 years
Amy	40-50	F	Head of Department	17 years
Sarah	50-60	F	Classroom teacher	30+ years
Megan	30-40	F	Classroom teacher	6 years
Nancy	30-40	F	Head of Department	4 years
Steve	20-30	M	Classroom teacher	3 years
Emma	40-50	F	Learning Resource Manager	12 years

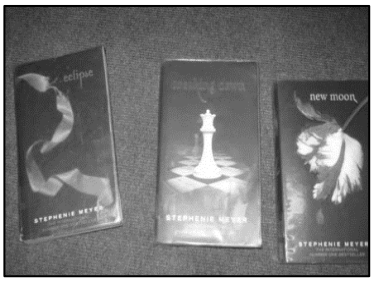
My decision to focus on the views of students and staff without including the students' parents was based on several factors. Although seeking the students' views on communication and support at school was essential, Lancaster and Broadbent (2003) caution that approaching children as experts in their own lives does not necessarily equate to a belief that they are the **only** experts in their lives. Because of the focus on communication and support within a school context, I decided that the views of staff members were also required as an expert view. Although the SEND CoP (DfE, 2015) requires the involvement of parents in discussions about a child's education, Murray, Ruble, Willis and Molloy (2009) suggest that differences between the home environment and school in terms of structure and student levels of relaxation are likely to result in differing types of communication for students on the autism spectrum. My focus is on communication and support within the school context, rather than home. In addition, due to time restrictions on the duration of the exploratory phase, including parents' views would have to have been quick and brief in detail. This does not fit with my approach to gathering rich, exploratory data, and the brevity of contact could mean that the inclusion of parental views may have become tokenistic, which I wanted to avoid. I therefore felt that it was simply not possible to uphold my ideals as a researcher and ensure that parents were sufficiently and effectively included in the research process. Consequently, my focus remained on the students on the autism spectrum and the staff members who worked with them in exploring communication and support within the school environment.

3.3.2.2 Procedure for student participants

Initially, students and their parents were given information sheets about the study to read and discuss with both myself and the member of staff in school who I was liaising with. Students and parents then signed assent and consent forms and school staff who taught the students were emailed by my liaising staff member to ask for lesson observation permission. My fieldwork then commenced in January 2016. I met each student before the first lesson observation in a familiar support room within each school, where I introduced myself. This was usually followed by a brief discussion about the research and our interests before students guided me to the lesson. Members of staff in the lesson observations then signed a consent form before I stayed for the duration of the lesson (see Appendix E.8). After each lesson observation had been completed, I thanked the students for their help, collected the staff observation consent forms, and left. The process of initial meetings and lesson observations required at least two days in the school environments and took place over a period of four weeks.

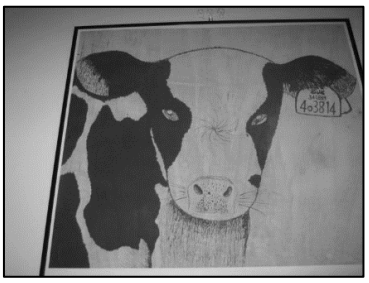
The next meeting with students consisted of a photo-trail activity. I met with each of the students individually and asked them to make a list of all their lessons in school, using their timetables as prompts if required. Once the list was completed, the student was asked to take a photo to represent each item on the list and walked around their school with me to take the photos. This meant that students took between twelve and seventeen photos each. The control of the students was key to this process, as Prosser and Loxley (2008) argue that there is much greater potential for photo-elicitation when the photographs are of personal significance. Completing this activity in lesson time minimised the presence of other students, facilitating picture taking, reducing distractions, and protecting the students' confidentiality. Observations or comments that the students made whilst taking photographs were recorded in my research diary verbatim to enable clearer recollection when reporting them.

My final meeting with students took place no more than five days (including weekends) after the photo trail, when they completed individual semi-structured interviews consisting of a sorting task using hard copies of the photographs they had taken. These took place in a familiar, quiet and private room in the learning support centre of the schools and were videoed so that the photo arrangements and any non-verbal communication could be easily recorded and checked. Students were reminded of their right to stop the interview at any point and given a brief amount of time to familiarise themselves with the controls of the video camera. Once the student was confident with operating the camera, they labelled the hard copies of the photographs from the photo trail with a few words to summarise what lesson or activity the photo represented. This was especially useful when the photographs were abstract representations of the students' subjects (see Figure 3).



A photo of favourite books to represent English, "because I love reading and I love English because we read" (Yazi)

A photo of a Christmas tree to represent History, as "History began when Jesus was born" (Genji)



A photo of a cow to represent Art, "because I like cows, and it's near my Art room" (Sage)

Figure 3 Abstract photographs taken by the students to represent concrete subjects

Students were then given five instructions for arranging the photographs:

1. Put these photos in order of the subjects you look forward to most
2. Put these photos in order of the subjects you are most relaxed in
3. Put these photos in order of the subjects you communicate in most
4. Put these photos in order of the subjects you are helped in most
5. Put these photos in order of how helpful the other students in your class are

The word "communicate" was used in question 3 to allow students to explore other forms of communication apart from verbal communication – however, all the students defined their communication in terms of talking, and therefore ranked the photographs in relation to this. In response to these questions, the students arranged their photographs in a similar way to Thomas and O'Kane's (1999) diamond-ranking method, where nine photographs are ranked in a diamond shape to demonstrate 'most' to 'least' responses to a question. However, as more than nine photographs were used and ranked, a diamond shape was not always apparent or appropriate once the students had completed the tasks, as demonstrated by the ranking patterns in Figure 4.

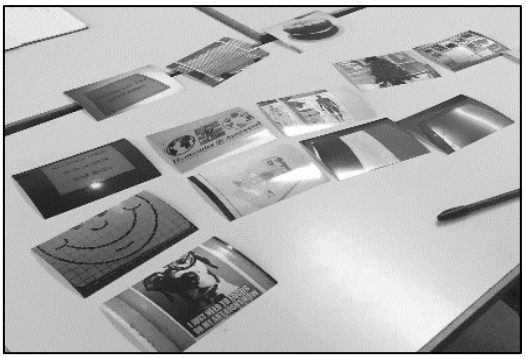


Figure 4. Examples of ranking patterns used by students

Once the students confirmed they were happy with the arrangement/order of the photographs, they were asked to explain their choices. This approach relates to Clark's (1999) concept of 'autodriving', where photographs taken by participants ensure that the discussion is 'driven' by the photos rather than the researcher. Sometimes students spoke freely, and worked their way through each photograph, explaining why it was situated in its position. Occasionally, more direct prompting was required, such as "Why are [the photographs representing] English and Science at the top?" with additional comments also being questioned further for clarification. Any deviations from the five instructions above (e.g. talking about personal interests) were allowed, explored in relation to communication and support if relevant, and then gently redirected to the interview questions. Owen, Hayett and Roulstone (2004) suggest that this approach results in a longer period of active participation for children who may experience communication difficulties.

Once finished, students were given the opportunity to ask any further questions, thanked for their time and instructed to turn off the video camera. They were also given the photographs that we had used in the discussions and could choose to do with them what they pleased. Every student except Hanzo took the photographs away with them; when asked if there were any other questions, Hanzo asked to leave the photos and then put them in the bin. Because of the potential issues with confidentiality, I therefore retrieved the photos after Hanzo had left the room and destroyed them. To resolve the ethical concerns of recognition and feedback highlighted by Lewis (2002), the students received rewards for participating that were consistent with the school's reward systems to make them more meaningful (e.g. merits/good behaviour points). The length of the student interviews varied from 45 minutes to 1 hour and 15 minutes, with most interviews lasting an average of 50 minutes. The entire process from start (initial meeting) to finish (interview) took place over 2-5 months of the school year, negotiated around school holidays and school and student availability.

3.3.2.3 Procedure for staff participants

The lesson observation consent forms (Appendix E.8) that staff members originally signed indicated whether staff members were interested in answering further questions about the students I was observing. Staff members who responded positively to this enquiry were contacted by email a few days after their lesson observation to confirm their wish to be involved and send information and consent forms. The interview times were also arranged by email, a process that took between a week and two months depending on our mutual availability (including school holidays) and took place during March-May 2016 in either a small private meeting room/office or an empty classroom. Before the interview

commenced, staff members were given the opportunity to re-read the information sheet and ask any questions. When happy to continue, they signed the consent forms and read a small extract of the information sheet to test the clarity of the audio recordings. Staff were reminded before recording started that they could stop the interview at any point without explanation, and that answers were confidential. The four interview questions asked were as follows:

1. Describe what [student] is like in lessons
2. What is [student]'s communication with staff/other students/yourself like?
3. Do you find yourself making any adjustments to help [student]?
4. What are [student]'s strengths?

Responses were then recorded using a voice memo programme on my personal iPhone, as this required fingerprint identification to unlock and was secure. Once the questions had been asked, staff members were invited to make any final comments or questions. After this, they were thanked for their time and the interview was concluded. The length of the staff member interviews varied between 15 minutes and 53 minutes, with most interviews lasting an average of 30 minutes. The shortest interview was due to the staff member only having worked with a student for three lessons, which inevitably led to less detail being described.

3.3.3 Selection of research methods for the exploratory phase

From an interpretive stance, Gibson (2016) advises that research methods need to not only facilitate reflection, but also allow me to explore complexity and nuance when forming my understanding of the research process. In addition, numerous data collection methods that fully align with my conceptual criteria emerged from the literature review. There were many examples to choose from, and therefore this section details my reasons for selecting focus groups, photovoice (photo trails and photo elicitation), and semi-structured interviews.

3.3.3.1 Focus groups

I conducted two focus groups with the autistic adults from an autism advocacy group to ask for advice on communication strategies when working with the students on the autism spectrum (for further details about the adults involved, see p.65). Focus groups were chosen because I was interested in the adults' in-depth perspectives regarding the single topic of my communication with the students.

Vaughn, Shay Schumm and Sinagub (1996) state that:

> The major assumption of focus groups is that with a permissive atmosphere, [the element of group discussion means that] a more complete and revealing understanding of the issues will be obtained. (p.4).

Prior relationships already existed between the group members and the group itself was set up to be a safe and respectful space to discuss experiences with a familiar neurotypical moderator who managed the monthly meetings. Litosseliti (2003) argues that to facilitate sharing of views within focus groups, participants need to find the discussions "comfortable and enjoyable, [and] not feel pressurised to make decisions or reach consensus" (p.1). Conducting the focus groups within the strict guidelines of the monthly meeting the adults usually attended therefore offered a familiarity that was important in allowing the autistic adults to feel at ease, as new situations and a change to routine can be a source of stress and anxiety for adults on the autism spectrum (Gillott & Standen, 2007). The familiar routines and pre-existing relationships therefore minimised potential levels of anxiety that group members may feel if confronted with unfamiliar situations and people. Additionally, working with a group who had pre-existing relationships can encourage the authenticity of the adults' accounts, as social influence amongst acquaintances may increase candidness in focus groups (Fern, 2001). This social influence can potentially backfire if one person dominates (Litosseliti, 2003), and therefore continuing familiarity by having the meeting moderator act as the focus group moderator seemed the best way to prevent this. As this was a monthly support meeting, the group were more likely to have previously shared intimate information with each other, which may also help the discussion of personal and/or distressing memories which arose from my questions. Therefore, my main reason for choosing focus groups was based on prioritising their preferences for communicating with me.

I had previously met a group member at a conference who consequently became the gatekeeper. I am aware of the demand placed on self-advocacy organisations by researchers that may have led to a rejection of participation (Nind, 2008), and therefore wanted the opinion of the gatekeeper as to whether the group would be interested in participating. I emailed some information about myself that was passed on to the rest of the group to allow them to decide if they wanted to help with my research. As they agreed, I was invited to attend one of their regular monthly meetings to work with them. As an outsider, I did not have access to the same knowledge that the adults possessed; for example, knowledge of the layout/environment, and established practices that took place during each meeting. However, I used this to my advantage by explicitly expressing this lack of knowledge, demonstrating an attitude described by Gallacher and Gallagher (2008) as "methodological immaturity" (p. 511). This is where incompleteness,

incompetence and vulnerability are highlighted to “undermine the dualistic notions of powerful researchers and vulnerable participants” (p. 511) and may also help to re-dress some of the inherent hierarchies relating to authentically listening to voices discussed previously (see Section 1.4.3). I therefore highlighted my outsider status as a neurotypical researcher and was very open that I was lacking knowledge about communication strategies. At my initial meeting, I also stressed my lack of knowledge about the established practices that took place within the group. Although Gallacher and Gallagher (2008) recommend this attitude when working with children, I felt that adopting an attitude of methodological immaturity was complementary to my approach of asking for help from the autistic adults and challenging the “dominant image of the academic as expert” (ibid, p. 511), as building a rapport with the group of autistic adults was vital. Nind and Vinha (2013) state that “trust and rapport are central to the relationships in most qualitative research” (p.17), with Rogers (1999) cautioning that these same relationships need to be managed in terms of expectations, i.e. explaining that relationships established during research may not extend beyond the research period. By positioning myself as an outsider who was asking permission to enter the group temporarily and then leave as soon as the research was over (due to my lack of group membership), these relationships were more easily managed. However, the lack of contact following completion of research is a common area of dissatisfaction for individuals on the autism spectrum who take part in research (Pellicano, Dinsmore & Charman, 2013), and therefore continuing to provide information to the group once the research was over contributed to the maintenance of this relationship over time.

Keeping to the structure of the monthly meetings that was already established by the group members and moderator, I compiled a pre-set list of questions which were sent to the group a week in advance of our first meeting (see Appendix D.1). This allowed the adults and I to consider the questions in more detail before we met. However, I was also able to pursue particular comments that members of the group made that I felt were of interest or needed clarification. This allowed me to explore some of the complexity and nuance Gibson (2016) suggests is required from an interpretive standpoint. Each of the meetings were recorded and transcribed, and the necessary re-visiting of these conversations to achieve this transcription also allowed me to better explore the complexities that were not immediately apparent. I was also careful to write and / or verbally record reflective accounts both before and after each meeting to have an accurate record of my thoughts at the time. This allowed me to challenge some of my own biases that became apparent when looking back through these entries (see Section 3.3.1 for some examples).

3.3.3.2 Photovoice and photo elicitation

The students who took part in this exploratory phase took me on a photo trail of their schools where they took photographs to represent each of their lessons (see Section 3.2.3. for further details about the students and the procedure). These photographs were then ranked by the students in response to my questions about their lessons, forming the main part of our discussions exploring communication and support. Photovoice is an engaging method, with Wang and Burris (1997) commenting that taking photographs is "an unusually motivating and appealing tool for most people" (p.372). However, it also has other advantages for facilitating communication and engagement between myself and the students. Lewis, Newton and Vials (2008) advocate using visual 'cues' to facilitate children's narratives to "provide a structure which, while scaffolding elicitation processes and responses, do not constrain or bias" (p.27). Asking students to rank the photographs that they had previously taken therefore offered a structure that allowed me to focus on the students' capability (Aldridge, 2007) by seeking verbal and non-verbal communication about the photographs. Additionally, Jurkowski (2008) comments that photographic methods encourage a sense of pride, competency and engagement. This could therefore be particularly useful when working with students on the autism spectrum, as they may be prone to low self-esteem (Hofvander et al, 2009) which may have impacted on their levels of relaxation and engagement when communicating with me. Students used a digital camera to take their photographs which allowed the pictures they took to be viewed instantly. Povee, Bishop and Roberts (2014) argue that this instant feedback on photograph quality can build confidence and allows individuals to delete blurry or obstructed photos (e.g. where a thumb was over the lens) if they choose. Students could also choose to re-take the photo if they felt it did not quite capture what they wanted. Using digital cameras to take photographs therefore allowed the students a lot more control over our initial meetings. Looking at a photograph as a shared point of reference also helped to facilitate communication given that I was still a relatively unfamiliar adult, as it can remove the pressure of making immediate eye contact (Barrow & Hannah, 2012; Winstone et al., 2014) and sustained face-to-face interaction (Beresford, Tozer, Rabiee & Sloper, 2004) which may be challenging for students on the autism spectrum. Using photographs can also encourage participants to slow down and think about what they are saying (Leibenberg, 2009). This may also be particularly beneficial to students on the autism spectrum, who may experience different processing skills to neurotypicals (Mottron, Dawson, Soulières, Hubert & Burack, 2006) that I could find challenging when communicating with them.

However, a key reason for using photographs relates to the concept of multiplicity in relation to students' voices; the use of photographs (in addition to verbal communication) can involve different kinds of participation and silence. In relation to taking photos, Gallacher and Gallagher (2008) comment that "no amount of meticulous preplanned and carefully applied technique will alter [participants' actions]. Indeed, to seek to do so would be contrary to the spirit in which 'participatory methods' are offered" (p.503). This suggests that there are many ways of participating involving a camera that differ from my request to take a photo to represent a lesson, and that these different types of participation should be encouraged. For example, Obruznikova and Cavalier (2011) found that the individuals on the autism spectrum that took part in their study took photos of other items outside the remit of the research. Although Obruznikova and Cavalier (2011) chose to discard these five photos from their analyses, this demonstrates a multiplicity of the students' voices that may be present in my own study, and therefore needs to be included as a form of communication. Foster-Fishman et al. (2005) argue that allowing participants to take pictures of whatever they wanted in their study "determined the stories they wanted others to hear and empowered them to tell their story as they wanted" (p.285).

Therefore, despite being frustrating at times during the research process, students were very much allowed to choose how they participated. For example, if students did not initially want to speak when we met (as happened on occasion due to differing moods and levels of motivation), their interactions with the photographs still allowed information to be gained about their views whilst preserving their right to (verbal) silence (Lewis, 2009). Relying exclusively on verbal communication in social situations may lead to distress and anxiety in students on the autism spectrum (White & Schry, 2011). Had I chosen a semi-structured interview alone (see next section), the reliance on verbal communication only could have negatively impacted on the students' responses (Galletta, 2013).

However, there are limitations associated with the use of photographs in research that need to be carefully considered. The first is the critique that photographs may not necessarily be meaningful to the participants using them, which can limit their usefulness in interpreting them as a multi-modal form of students' voices. Cook-Sather (2006) argues that voice needs to be seen as a fluid concept that may change over time, and therefore using static photographs which may only capture an aspect of voice that is meaningful on the day of photographing may affect how meaningful the photographs are to the students at a later date. For the students on the autism spectrum, differences in their visual perceptual processing (Mottron, Dawson, Soulières, Hubert & Burack, 2006) may mean that they are quite literally seeing something different when they look at a photograph compared to what I might see. If I offer my own view of what a photograph contains, this

may conflict with the students' own interpretation; and due to the inherent hierarchies between us they may default to my interpretation, silencing their true voices as the photograph loses its meaning.

Another challenge that relates to taking photographs are the various ethical dilemmas that surround them. The first that affects this research is that photographs will be taken around other people – in this case, schools – which raises ethical issues about who is in the photographs and whether they have given their consent to be photographed. If the students want to take photographs of people to illustrate their voices, curtailing this may again limit the meaningfulness that students ascribe to the photos that they have taken; for example, if students want to take photos of a classroom that is full of their peers to represent one of their lessons, this could present numerous ethical issues regarding consent. However, as Booth and Booth (2003) observe, "Photovoice is all about point-of-viewness: it sets out to capture and convey the point of view of the person behind the camera" (p.432). Denying the students opportunities to take photos of other people may therefore restrict their voices and the "point-of-viewness" (ibid) that is able to be represented by the photos they take. Because of data protection and the issues of consent for their peers in school, I guided students away from taking photos of other people, unless there was a specific adult they wished to take a picture of who was able to give their verbal consent. However, this was done with the knowledge that this may affect the meaningfulness, genuineness and "point-of-viewness" (ibid) of the photographs taken.

Another ethical issue concerns the ownership and sharing of the photographs taken (Nind, 2008). The photographs belong to the students, but they will also be used in my research and potentially shown to other people to illustrate the power of photovoice as a research method. Banister and Booth (2005) worked with children in their study to take 12 photographs of things they disliked/found disgusting, and 12 photographs of things they liked/enjoyed. Banister and Booth told the children that they could take any of the photographs that they had taken home with them to promote the children's ownership of the data, and therefore it is germane to adopt the same approach with the students in this research by giving them the option of taking hard copies of their photographs. To protect the confidentiality of the schools involved when I am using the photos, any identifiable logos or people will be carefully blanked out to preserve anonymity if the photos are shown to wider audiences. Again, although this may affect the "point-of-viewness" (Booth & Booth, 2003) of the photographs, I am prioritising the confidentiality and consent of others who may be in them.

3.3.3.3 Semi-structured interviews

The members of staff who took part in the exploratory phase were asked about communication and support in relation to the students on the autism spectrum who were also taking part. Semi-structured interviews were used to elicit these responses from the seven staff members (see p.75 for further details). The format of the semi-structured interview was also used in combination with the photovoice method mentioned above when discussing the photographs taken with the students. Semi-structured interviews were chosen as they offer the best compromise for gathering rich data with enough structure to encourage discussion (Bellotti, 2014). Shuy (2003) highlights some of the advantages of semi-structured interviews that can improve credibility and trustworthiness; for example, if an individual was unsure about a question, I could clarify or rephrase it. Additionally, when staff members or students gave answers that required clarification, I could easily ask follow-up questions. Using semi-structured interviews therefore gave a level of clarity and a high degree of freedom in the answers staff gave that arguably would not have been possible to achieve in a more structured interview (Kellett, 2011).

3.3.4 Ethical considerations

As with all research involving human participants, this research needed to be carried out safely and effectively. Ethical approval was sought and granted from the FSHMS Research Ethics Committee (see Appendix E.1), but the following section discusses some particularly important issues: consent, confidentiality and the individuals' welfare.

The first major ethical issue concerned informed consent. Approval to conduct the study and approach staff and students, was initially sought from the head teachers and SENCOs of the schools, which was granted. For staff members, gaining informed consent was relatively easy to implement; information sheets were sent by email (Appendix E.9), frequent opportunities to ask questions were given, and consent forms (Appendix E.10) were signed once staff were happy to proceed before the interviews began. For the autistic adults, informed consent required slightly more preparation – firstly, the group needed to unanimously decide if they were willing to participate, as the focus groups were going to take place as an agenda item in their monthly meetings. This therefore meant that any members of the group who did not want to participate would have to miss a section of the support meeting or the entire support meeting, changing their routine. As the group discussed this without my input, I am unsure of the exact process, but ultimately, a date for the first focus group was set by them and my participation agreed. Informed consent for the students was a more complicated process, mainly because they were all under sixteen. Nind (2009) suggests that family members may be needed to give

proxy consent to ensure that ethical requirements of informed consent are met when undertaking research with children on the autism spectrum. Consequently, students received an adapted information sheet (Appendix E.6) and assent form (Appendix E.7), as recommended by Brewster and Coleyshaw (2010). Their parents received a more detailed information sheet (Appendix E.4) and then completed a consent form on behalf of the students (Appendix E.5). Students and parents had the opportunity to discuss the study with their family, members of school staff, and myself before signing their assent/consent forms to ensure that any questions or worries they may have had were resolved before the research began. In addition to forms the students completed, I therefore also adopted an approach of 'ongoing assent' throughout the research, which is represented "within the relationship between the researched and the researcher, by the trust within that relationship, and acceptance of the researcher's presence" (Brewster & Coleyshaw, 2010, p. 257). Cocks (2006) argues that this is a better indication of agreement to participation than informed consent when working with children.

Another key issue is confidentiality; as students and staff members were selected through discussions with my liaison at each school, complete confidentiality was not possible. To mitigate this, individuals were given the option of using pseudonyms when using quotes from their interviews. The students selected their own pseudonyms (see Table 10 above) and I have reported their responses using gender neutral pronouns to limit the chances of identification. The staff members stated that they did not mind what name they were called and left the choice to me. The autistic adults were also given the option to choose their own pseudonyms, which they communicated via email. However, on reflection, when we met for the second phase some of the adults were keen to have their own words recognised and wanted to waive their confidentiality (see Appendix E.12 for the confidentiality waiver), and therefore I have identified when their own names have been used in this research.

The final issue relates to the welfare of the individuals taking part in this phase of the research. For staff members, these were judged to be met through using the above procedures. For the autistic adults, the focus groups took place at their usual meeting place – an environment that was familiar to all participants – to reduce anxiety. I had sent the questions, information sheets and consent forms in advance to the adult participants via email so that they had time to consider the information I was giving them and to make any adaptations to make them more comfortable; for example, Emily changed both the font style and colour of the consent form and re-worded some of the statements so that she was more comfortable with them. Emily also brought a cuddly toy to the first focus group to alleviate the anxiety of meeting me for the first time.

The students on the autism spectrum are potentially more vulnerable because of their age, and therefore required additional consideration. Student meetings took place within the school to reduce potentially high levels of social anxiety, as the presence of unfamiliar adults in the school environment is not as threatening as it might be in the home environment (Beresford, Tozer, Rabbiee & Sloper, 2004). The recommendations from the autistic adults meant that when interacting with the students (in meetings, the photo-trail or in the interview), I offered breaks/time outs, longer times for processing, and avoided re-phrasing questions unless explicitly asked. I also used a low arousal approach during meetings; for example, I wore no perfume, no patterned clothes, and kept the same hairstyle each time I visited to avoid unnecessary stimulation. Students could eat and drink as needed throughout our meetings and were given control over the amount of personal space they wanted as this can vary considerably in individuals on the autism spectrum compared to neurotypicals (Gessaroli, Santelli, di Pellegrino & Frassinnetti, 2013). If students appeared to become uncomfortable during questioning, the line of questioning ceased, and students were again reminded that they could stop at any time. This also applied to any questions that produced a “don’t know” response more than once, as Lewis (2009) observes that students on the autism spectrum may feel safer answering that they ‘don’t know’ rather than trying to answer a question they have no response to. Students were also given the option of bringing a familiar staff member or parent into the interview (Preece, 2002), with the understanding that the adult was there as an observer only and was not permitted to speak for the student. However, this eventuality did not occur and each of the student participants conducted both the photo trail and the interviews by themselves.

3.3.5 Analysis of the findings

Interview transcripts were typed up verbatim where possible; a few of the utterances made were indecipherable, and therefore were recorded within the transcripts as ‘[indecipherable]’. My research diary, lesson observations and field notes were also written up. These data sources were then organised using NVivo 10 software (see Table 12 for a summary) and analysed using thematic analysis. Thematic analysis was chosen as it allows for a ‘bottom up’ approach to the research, as well as allowing me to focus on key themes (Crawford, Brown & Majomi, 2008) relating to communication and support. The process of generating codes with thematic analysis also meant that the context of each school could be considered to see if there were any notable differences between urban and rural environments (Kellett, 2011); however, this was not suggested by the responses.

Table 12 Summary of data sources used in the thematic analysis

	Student Data	Staff Data	My Data
Sources of data analysed	1) Verbatim quotations from initial meetings 2) Verbatim quotations from lesson observations 3) Verbatim quotations from photo-trail 4) Semi-structured interviews 5) Photographs taken (both original photos and arrangements) 6) Any other verbatim quotes recorded in my research diary	1) Verbatim quotations from initial meetings 2) Verbatim quotations from lesson observations 3) Semi-structured interviews 4) Email communications between staff members and myself 5) Any other verbatim quotes recorded in my research diary	1) Descriptions of initial meetings with students 2) Reflections from initial meetings with students 3) Descriptions of lesson observations 4) Reflections from lesson observations 5) Descriptions of photo trails with students 6) Reflections from photo trails with students 7) Reflections from interviews with students 8) Reflections from interviews with staff members 9) Extracts from research diary (kept 08/15-05/16)

A 'template approach' (Robson, 2002) was used throughout the coding, where provisional thematic codes formed a template that was tested and refined throughout the coding process. Initially, this was done by coding the data thematically according to my research questions (see Appendix F.5 for an example). Part of this refining process was formed through negative case analysis (Lincoln & Guba, 1985), which involved examining examples of the data that did not fit into the pre-existing themes (my research questions) and coding it as an additional/emergent theme (see Appendices F.1-F.3 for the first three iterations of the coding key). This also increased the credibility of my findings by ensuring that the thematic constructs eventually accounted for all examples within the data (see Appendix F.4 for the final coding key used).

The data from students, staff and myself were analysed separately to preserve the expert knowledge of the students and staff members. Although similarities inevitably emerged, I was particularly interested in reporting the differences between the students on the autism spectrum (individual differences) in addition to the differences between student and staff perspectives to gain a better understanding of the complexity of the overall picture of communication and support in schools. The best way of achieving this transparently was to use triangulation across my data sources. Although triangulation is traditionally used comparatively (Flick, 2014), this would inevitably result in comparisons between the students' perspectives and others. I wanted to avoid this as it reduces the significance of the students' voices as being valid in their own right (as demonstrated by some of the studies in the literature review, such as Barnhill et al., 2000 – see p.36). I therefore used

triangulation to explore the consistencies **within** each perspective in addition to the differences. This approach is described by Prosser and Loxley (2007) when they explored the process and products of inclusion:

> Rather than use the process of data triangulation to diminish difference and search for commonalities, it was both the difference and similarities we wanted to highlight (p.59)

Although Prosser and Loxley (2007) examined the similarities and differences between methods, I am interested in exploring the similarities and differences between the three perspectives to increase transparency, and consequently, credibility and confirmability (Shenton, 2014). As Conn (2015) comments: "Differing views can be seen to add to the richness of the data and reflect the nature of individual experiences [of individuals on the autism spectrum]" (p.66). This meant that data from myself, the students and staff were kept and coded separately, resulting in a triad of perspectives centred around each of the six students. By exploring perspectives within and across these data triads, I could examine the consistencies and differences in perspectives relating to the common themes of communication and support. Keeping the three perspectives separate within the analysis also allowed for greater transparency of my own interpretations, whilst preserving the expert knowledge of students and staff members.

In summary, I adopted an interpretivist stance to explore the processes of communication and support for students on the autism spectrum in secondary mainstream schools in England. To guide my communication strategies and increase my textual experience and knowledge about autism, I consulted with autistic adults to create guidelines for myself to follow when working with the student participants. Six students took part in photo-trails around their school to represent each of their lessons, before discussing and ranking these photos in a semi-structured interview. Members of school staff who worked with each of the six students also took part in semi-structured interviews to explore their perspectives regarding communication and support. The data from the students and staff members – in addition to my own observations and research notes – were analysed thematically in relation to my research questions to explore the differences and consistencies between perspectives, and to highlight the differences between the perspectives of the six students. The next chapter details my findings by exploring the individual differences between the six students and the differences between students and staff in relation to my research questions.

Chapter 4 Findings from the exploratory phase

The findings from the first phase are structured within this chapter around the research questions, focussing on the processes of support and communication. Two of the five themes from the literature review – the importance of individual differences and the personalisation of support – are discussed explicitly in relation to communication and support throughout this chapter. Students' self-regulation (how they support themselves) and evidence of the remaining themes of interest from the literature review – students' awareness of difference, positive views of being on the autism spectrum and sensory experiences – are reported separately. When reporting these findings, the differences between the individual students and their responses and experiences around each topic are highlighted, as are the differences in perspective that emerged between students and staff members (and myself, where applicable). This structure allowed me to illustrate where misunderstandings about communication and support occurred from the participants' perspectives. Explicitly examining these differences in perspective also helps to identify potential ways to resolve Milton's (2012) "double-empathy problem", as well as ensuring that I am adopting a more transparent and critical approach by keeping my own observations separate from both staff and student perspectives.

4.1 The process of support

My first research question regards the nature and process of support in secondary mainstream schools. The two main subthemes that emerged related to the support that students received and gave to peers, and the support that students received from staff (see Table 13).

Table 13 Summary of subthemes in relation to the process of support

Overall Theme	Sub Theme	Contributing Perspectives	
		Students	Staff Members
Peer support	Lack or failure of support	✓	✓
	Positive examples of support	✓	✓
	Support given to peers	✓	✓
Staff support	Lack or failure of support	✓	✓
	Positive examples of support	✓	✓

4.1.1 Peer support

4.1.1.1 Individual differences between the six students

All six students reported examples of when they felt they had received positive support from their peers. Some of these were quite similar; for example, Yazi, Genji, Sage and Bob all mentioned that they received general help in lessons from peers regarding their work, such as asking the person sat near them in lessons what they were supposed to be doing. However, Jack and Hanzo gave much more emotive accounts of the very specific types of support they received from their friends and trusted peers compared to everyone else. For example, Hanzo described how a trusted friend offers emotional support when the two of them are sat together:

> *Hanzo: …if I get too angry, I will walk out the class and I don't care, I will just walk out – but when I say I'm gonna do that, [friend] calms me down.*
>
> *HH: How does he calm you down?*
>
> *Hanzo: I dunno. He just calms me down, and says not to, because it will make things worse and things like that. And then changes the subject and talks about games we play at home a little bit.*

For Jack, who finds performing in front of the class (e.g. in Drama) challenging because they find it difficult not to smile (which can ruin the mood trying to be created), friends also offered very specific emotional support:

> *Jack: I really want to be with my friends in that dance, because they always go, 'Come on Jack, don't laugh' because they always keep an eye on me.*

For both Jack and Hanzo, their friends are significantly better at working with them compared to their other classmates and teachers, and therefore working with friends became much more important to them, beyond mere preference. When questioned about why they thought their friends worked better with them, Jack seemed uncertain of how to answer. However, elsewhere in our discussions Jack referenced that it was those who understood that offered the best support. Hanzo also thought understanding was key, commenting that friends try harder to understand compared to teachers and peers, accepted them as they are, and calmed them down when they became agitated. For these two students, in addition to the general (and perhaps typical peer support) that is experienced in lessons at mainstream schools, their close friends provided tailored and effective support that went beyond simply dealing with classwork.

Each student – apart from Bob, who gave no instances or general descriptions of a lack of support from peers - also described different and distinct experiences of a lack of peer support, or examples of how peers had specifically challenged them. Jack was the only student to mention bullying in relation to a specific student who had targeted both them and others in the past (although Jack felt the issue had since been resolved through interventions from a personal tutor). Genji mentioned that other students tapping on the shoulder or saying 'hello' as they walked past the desk were distracting, and therefore could break Genji's concentration on the task at hand. Both Sage and Yazi mentioned that sometimes, support in class (in relation to the work) was unhelpful, as peers did not know what they were doing either, and so either guessed and got it wrong or were unable to explain something adequately. Yazi and Hanzo also mentioned friends of theirs who distracted them; Yazi said a friend encouraged being "inappropriate" (being vulgar and making sexual comments), and Hanzo said one friend encouraged having fun instead of doing work. In both these instances, their friends had got Yazi and Hanzo into trouble, yet both students kept the friendships and simply avoided working with these particular friends in some work situations.

In addition to the support that the six students received from peers, all six students also gave examples of support they gave to peers, such as helping with academic work in subjects that they themselves had a strength in or offering advice to those who could not complete work in class. Genji is particularly good at computing, and describes the following as commonplace:

> *Genji: One time, I had to go round and help people because I was done doing quite a lot of my work. They were on question 2 – it was an online question thing – and I'd done up to question 5, so I had to go around helping people. I normally help.*

Interestingly, Hanzo was the only student who mentioned giving emotional support in addition to academic support, describing emotional support given to friends:

> *HH: [talking about friends calming him down] It's nice you've got friends who look out for you like that.*
>
> *Hanzo: I look out for them as well. It works the same way with my [family member] [explains how they always look out for each other, giving the example of a fight in club and how one family member punched someone to protect another] I'm hoping that when I'm older, I'll have mates that will look out for me like that, which I probably will be.*

The support system between the students and their peers therefore seemed to be reciprocal regarding academic support – in addition to receiving academic help from friends and peers in certain subjects, the students also gave academic support to others. However, although all six students identified close friends as incredibly important sources of emotional support, they did not mention (except for Hanzo) that they themselves were sources of emotional support to their friends. From the students' perspective, this suggests that they may see themselves as a source of academic rather than emotional support for their peers.

4.1.1.2 Differences in perspective between the students and staff members

The views of staff members offer some significant contrasts to the students' perspectives of peer support. When describing positive examples of support from peers, staff members also gave examples of specific individuals or friends who seemed to have a good working relationship with the students and 'kept them on task'. My lesson observations also made several references to peers offering general help in class (e.g. offering clarity to support confusion about the work). However, a clear difference in staff and student descriptions of peer support related to individual vs. group support. Whereas students gave specific examples of positive peer support from individual peers, some mentions of peer support from staff related to the whole class:

> *…the other advantage in a class like that is that there are so many kids who will just get on with doing what they need to do, that actually, I CAN then say 'now I'm going to talk Sage…'* *(Megan, Classroom teacher)*

> *I wonder how [Yazi] would behave in a different set. Because [Yazi's] in the super top set one, so [they are] easy to manage. Put [them] and [their] needs in a different group and it would be interesting to see how [they are] in a mixed ability group.* *(Amy, Head of Department)*

> *[Genji] was quite odd in [their] behaviour…But I have to say, the children, because it was a low-ability group, were very accepting of [Genji] and they just carried on with what they were doing, and said 'yes/no' to [Genji] and carried on, which I thought was brilliant, actually, because if they'd reacted to [Genji], that could have made things even worse.* *(Sarah, Classroom teacher)*

This potentially demonstrates that students (by necessity) are concentrated on themselves and how their peers impact on them individually, whereas staff (by necessity) are concentrated on the whole class dynamic. However, staff were not directly questioned

about peer support, only peer communication. The students on the autism spectrum were asked explicitly about the helpfulness of other students, and therefore this may explain why they gave more specific examples.

Despite all six students giving examples of how they helped others in class, there were only two examples given by staff relating to students on the autism spectrum helping others. Nancy (a head of department) described a differentiation strategy used in class, and how Bob had been chosen specifically for ability and personality in leading a group of peers. Therefore, whenever students were asked to get into these specific groups, Bob was responsible for helping the others in the group. The second mention of helpfulness was made by Emma (a learning resource manager) in relation to Hanzo, who was described as kind, sharing an example of seeing Hanzo help another student outside of lessons to illustrate this. This lack of examples may demonstrate that staff are not necessarily aware of the support that students on the autism spectrum can provide to their peers. However, given the ease with which staff members could identify the strengths of the students on the autism spectrum, I believe a more likely explanation for the relatively few examples given is that staff were not asked explicitly about the helpfulness of the students. My lesson observations detailed some examples of the students helping others, but in relation to academic or school-related support (e.g. letting a peer borrow a book, explaining what they were meant to be doing). However, my research diaries mentioned several instances of the helpfulness that the students on the autism spectrum showed to me; for example, explaining school specific terminology, explaining lessons, helping me find my way around, and asking if I was ok when I saw them.

The examples of negative peer support referenced by staff were detailed, demonstrating a very good insight and awareness of the individual issues students may have with certain peers:

> *As long as [Bob is] grouped with people that [they] get on with, [they] will contribute brilliantly and [they] will be very enthusiastic more often than not about the task at hand. However, should there be someone in the group who [they don't] particularly get on well with, then that could completely upset the dynamics, and [they] could in fact become very recluse and even irritable. So grouping - whenever there is some sort of paired work or group work - it is essential to think about those social relationships that Bob has and bear that in mind.*
>
> *(Steve, Classroom teacher)*

Interestingly, three staff members reported Bob experiencing infrequent 'tantrums' or 'meltdowns' following interactions with peers, becoming enraged, verbally abusive, and physically destructive, before finally becoming very upset. Nancy (a head of department)

and Steve (a classroom teacher) mentioned this during their interviews, and another staff member mentioned it to me specifically at the end of a lesson observation, believing that it was very unlikely that Bob would mention this to me. However, this member of staff declined to take part in the interviews due to the busyness of their schedule.

Bob's apparent silence regarding these negative experiences of peer support could be interpreted in several ways. The first possibility is that Bob is in denial of these incidents occurring. Myles and Hubbard (2005) observe that following a meltdown, students on the autism spectrum can "…become sullen, withdraw, or deny that any inappropriate behaviour occurred" ("Recovery Stage", para. 1, n.p.n.). However, Bob's insight into other aspects of peer and individual behaviour in response to other questions I asked demonstrated very good self-awareness. An alternative interpretation is that Bob was aware of this behaviour, but deliberately did not mention it during the research interviews; this may be due to embarrassment, but the reasons are not clear from the available data. Finally, I did not ask any specific questions about meltdowns or problems with peers, and Bob may not associate the influence of peers in relation to meltdowns; therefore, a lack of direct questioning from myself may be responsible. Whatever the reason, I do not think that the data from this study can adequately explain it without further clarification from Bob.

4.1.2 Staff support

4.1.2.1 Individual differences between the students

Both positive and negative examples of staff support emerged from analysis of the data (summarised in Table 14). Despite these commonalities, however, the students varied hugely in their descriptions of the personal importance of each of these categories.

Table 14 Specific positive examples of staff support identified across perspectives

Categories	Contributing Perspectives	
	Students	Staff Members
Clarity of explanations	✓	✓
Concern for student welfare	✓	✓
Use of discipline	✓	-
Prompting	✓	✓
Progress checks	✓	✓
Understanding of individual	✓	✓
Reinforcement and praise	✓	-
Use of visual aids	-	✓

The personal/emotional element to being understood was mentioned by five of the six students, which could suggest that they may have felt misunderstood by staff members at some point in their secondary school experiences. Interestingly, Hanzo, Jack, Sage and Genji gave more emotional accounts of being misunderstood by staff. This finding was also evident in the negative examples of staff support that these four students reported; the negative examples described in detail and with the most emotion were instances where the students on the autism spectrum felt misunderstood. For example, Sage reports the frustration felt when ineffectively 'helped' by a subject teacher:

> *HH: So do you get help from the teacher in [subject]?*
>
> *Sage: Well, I do, but then I feel like it doesn't really…like, you give me a little help and then it feels like it helps me complete that one question, and then I've still got a load of other questions to do. And then I get stuck within, like, the next two questions, and so on.*
>
> *HH: Ah, ok. So you get some help, but it's not always good help?*
>
> *Sage: Yeah, pretty much.*

Yazi, Jack, Sage and Genji all mentioned teacher understanding as having an important impact on the effectiveness of the support they received, but did not rate it anywhere near as highly as Hanzo did, who stressed that a good level of teacher understanding was the most important factor in feeling supported in lessons:

> *Hanzo: He gives me chances, he understands me, and we – I don't know if it's because we both like the same subject or something, I don't know.*
>
> *HH: So if all your teachers could be like [name], would that be best for you?*
>
> *Hanzo: That would be the best thing in the world…*

However, Bob did not give any examples of where staff had been unsupportive or supporting, only mentioning that checks on progress were most useful to ensure that the teachers' expectations of them in class was clear. Yazi expressed only mild irritation that a staff member did not seem to understand a lack of confidence in trying new things:

> *Yazi: I'll be in there and I'll accidentally [do something wrong] [imitates staff member] "No, no, no, that's not right!" And I'm like, "Jesus, woman, it's my first time!"*

The importance of understanding reported by the students echoes the findings from the conceptual literature review, suggesting that effective support may be increased by increasing individual understanding about a student.

4.1.2.2 Differences in perspective between students and staff

Staff members' comments on student understanding demonstrated that they tended to agree with students that individual understanding was important:

> *But you don't wanna change [students on the autism spectrum], you wanna work with what they've got…you've kinda got to know them and their little foibles, and then you've got to work with the foibles!* *(Amy, Head of Department)*

> *[in response to a student's comment that the teacher 'gets' them]: It could be something to do with my academic background…so I guess it's just having a bit more awareness of what [student's] condition is, I suppose – more than most people do. Not a lot of awareness…it's just a different sort of background and understanding, really.* *(Nancy, Head of Department)*

> *[in response to adjustments that are made]: I'm also very aware of students' personalities as well…It's more of [student's] personality – because I do get a lot, I get to know these children quite well really, although I'm not their actual teacher.*
> *(Emma, Learning Resource Manager)*

However, staff members' interpretation of a lack, or failure, of staff support almost exclusively related to feeling like there was a lack of specialised support available to them, which meant they felt it was difficult to effectively support individual students on the autism spectrum. Some specific examples mentioned were: a lack of Learning Support Assistants (LSAs) due to funding; dealing with SENCOs without relevant qualifications or knowledge; and using Individual Education Plans (IEPs) that included only general information about autism and were therefore unhelpful. The following quotes illustrates how time is seen as a precious resource for supporting students on the autism spectrum effectively:

> *Sometimes – frequently – I don't think we have the time to put in place to put in place some of the structures that probably would help those pupils. I think at the beginning of most years, you might get a little chat, IEPs, check your data – and maybe some people do get around to doing lots of that. But sometimes I feel the most I can do is make sure I have font size, changing coloured paper, and asking the pupil…does he understand what I've asked him to do?*
> *(Megan, Classroom teacher)*

This lack of specialised support, in addition to the needs of the other students in the class, meant that staff appeared to feel that they were currently not providing the best support to

students on the autism spectrum and were unable to see a way to change this. This finding corresponds to others reported in the literature relating to teachers' perceived lack of confidence in teaching students on the autism spectrum (e.g. Able, Sreckovic, Schultz, Garwood & Sherman, 2015). Students and staff, therefore, seemed to agree that a lack of information relates to a lack of understanding, and therefore less effective support; but whereas the students see this as staff members' responsibility to increase the level of understanding they have, staff feel that extra resources (such as training and teaching strategies) need to be provided by the educational establishment to feel better supported.

In addition, staff members mainly mentioned academic support as the main type of support they gave to the students, with keeping the students 'on task' in lessons cited as the main adjustment they made:

> *[describing Sage and another student with additional needs] …unless I structure what I give them, they just get completely confused…I need to go back and check they're on task…So I do like to give them independent tasks but I would definitely have to go back and check: are they still on task? Have they done what they need? Have they answered the question? Have they gone off on a tangent?*
>
> *(Megan, Classroom teacher)*

> *I think sometimes, [supporting Yazi] might come down to differentiating in terms of prompting [them] to keep [their] writing focussed and not to go too far off of a tangent and pursue [their] own interests]*
>
> *(Dave, classroom teacher)*

> *…what I notice with [Jack] in lessons generally is that [Jack] does tend to drift off. And I must admit, I used to be a lot more focussed on pulling [Jack] in a lot. And what I do is I ask [Jack] – I get [Jack] to tell the class, to repeat instructions to the whole class…sometimes, you will find that 5-10 minutes into a task [Jack] hasn't actually started, so it's remembering to actually go and see [them] quickly to make sure [they] know what to do.* *(Nancy, Head of Department)*

Two members of staff who worked with the students in pastoral roles as well as academic roles (Nancy, a head of department and Steve, a classroom teacher) also mentioned the emotional support that they offered to students through the roles; however, emotional support was not mentioned by any of the staff members in the context of the classroom.

In summary, support – especially academic support – was described as received and given by all the students on the autism spectrum. However, the specific examples and the context in which this support is offered or taken varies considerably from student to student, and sometimes, within individual students depending on the other factors that may be affecting them. These factors may contribute to why students feel personally let down when staff members do not demonstrate the level of understanding they wish to see, and why staff continue to report frustrations at the lack of resources available in schools.

4.2 The process of communication

My second research question regards the nature and processes of communication that were experienced in these secondary mainstream contexts. I initially coded any references to communication in relation to who the communication was with, and so the subthemes of staff and peers emerged inductively (see Table 15).

Table 15 Summary of subthemes in relation to the process of communication

Overall Theme	Sub Theme	Contributing Perspectives	
		Students	Staff Members
Student-staff communication	Discipline	✓	-
	Instruction	✓	-
	Praise	✓	✓
	Examples of differences	✓	✓
	Positive examples	✓	✓
	Examples of silence	✓	✓
	Personal information	-	✓
Student-peer communication	Lack or failure of communication	✓	✓
	Positive examples of communication	✓	✓

Regarding students' communication with staff members, there were clear examples from both me and staff members of pieces of personal information that students communicated to us. However, as the examples of information that students communicated about themselves to both me and staff were very descriptive and contained personal information, for confidentiality reasons these have not been reported.

4.2.1 Student-staff communication

4.2.1.1 Individual differences between the six students

Overall, there were relatively few explicit examples given by students of how staff members communicated with them. Of these, the most frequent examples were staff members communicating mainly to inform or discipline. Interestingly, it seems that students reported any discipline that staff gave, regardless of whether it was meant for them or not. This contrasted with the students' descriptions of teacher praise, which were all very personalised and specific. However, the way in which this disciplinary communication affected them varied considerably:

> *Yazi: Like, Sir will yell and he will say 'you've got a DT [detention], you've got a DT' [to others misbehaving in class] and it was quite annoying.*

> *Sage: …with the teachers [in a lesson], if you relax, they tell you off and stuff, so you can't really relax in that lesson at all.*

> *Genji: Cos…when we're in [lesson], most of the teachers just shout at me, and I don't like it…And I just get…upset.*

> *HH: So [good teacher] gives you a chance to prove yourself?*
>
> *Hanzo: Yeah, he doesn't go straight away, 'that's a [behaviour warning]'*

> *HH (summarising): So even if [the teacher]'s not shouting at you…you still have to stop your work because she scares you because she's so noisy.*
>
> *Jack: Yep.*

For Sage, Genji and Jack, a member of staff shouting as a form of discipline - even if it was not necessarily directed at them - was a negative experience that left them anxious and unable to relax. Yazi and Hanzo also described shouting in negative terms, but in a much more diluted fashion (e.g. a source of irritation). This could be due to the loudness and unexpectedness of shouting. However, students easily distinguished between shouting as a form of discipline and other shouting that did not cause them negative effects; for example, a teacher shouting when it was necessary to be heard in noisy or chaotic environments, or a teacher shouting because they got excited. Similarly, Genji commented that classroom noisiness was fine when it was "Calm shouting, not like 'yeah!'

like they're having a party…". These comments therefore suggest that the negative experiences of shouting exclusively related to discipline, rather than just a loud noise, suggesting that it is the intention beyond the loud noise that students found challenging. Again, this demonstrates that even when the students on the autism spectrum generally identified a similar topic, their thoughts and feelings regarding the topic are far from identical.

When it came to describing interactions with staff, most of the students provided individual and differing examples of their communications (see Table 16). Some of these examples were mentioned explicitly by the students, and some were implicit from what the students were saying elsewhere in our discussions. As the implicit responses were based on my own interpretations, student views that were not explicit were compared with the rest of their answers to see if any consistency existed.

Table 16 Examples of communication with staff as reported by each student

	Differences in communication with staff members	**Positive examples of communication with staff**	**The use of silence to communicate with staff**
Yazi	Reacts negatively to shouting; believes they are in trouble and become anxious	Constructive criticism	To withdraw (by reading book)
Jack	Gets warnings for talking yet does not understand why	Demonstrating understanding about autism	To stay out of trouble
Genji	Lets others answer questions; negative reaction to shouting can cause anger	Problem-solving	To withdraw
Hanzo	The differences between "monkeys", "humans" and "gorillas" (see p.106)	Demonstrating understanding about autism	
Bob	Prefers individual rather than class explanations		
Sage	Prefers independent working without communication from staff		

For example, Sage made a comment whilst completing the photo trail potentially relating to differences in communication: the amount of questions needing to be asked in primary school compared to secondary school, saying: "It was all "can I go to the toilet? Can I

breathe?!"". Sage mentioned elsewhere about having more relaxed interactions with staff, especially in tutor sessions:

> *Sage: …you can relax and kind of sit back in a chair and not get told off for just sitting there doing nothing…and sometimes it's really fun.*

Consequently, interpreting Sage's comment about having to ask permission to do more things in primary school was consistent with their preference for the more relaxed staff communication experienced in secondary school. Similarly, when discussing a problem with a specific teacher, Hanzo described it as "…tuna and pasta goes, tuna and ketchup don't." To assess whether this was another example of differences in communication, I looked to the rest of Hanzo's comments on staff members. A clearer, more explicit, example from Hanzo is shown below:

> *The way you understand is like, two monkeys can communicate to each other. But one monkey and one human can't. So I'm a monkey trying to communicate with a human if I'm trying to communicate with a teacher. I'm basically a monkey trying to communicate with a human, but [my friends] are all basically monkeys so I can communicate with them easily; where with the teachers, I don't try. It's much harder and they're probably just going to moan at me anyway.*

As Hanzo had made several references to feeling different from staff, not being understood and not wanting to try and resolve the problems they felt they had with staff members, I was confident in interpreting this as another comment on student-staff communication where "tuna and pasta" (student to student communication) works and is successful, whereas "tuna and ketchup" (student to staff communication) is unpleasant and does not.

Yazi, Jack, Genji and Hanzo reported examples of positive communication with staff members that seemed to echo the theme of being understood, with both Yazi and Hanzo mentioning this more explicitly and allocating more importance to this than Jack and Genji. In general, the students' positive references tended to be made in relation to pastoral support and communication (e.g. personal tutors and learning support outside of lessons), rather than positive communication in lessons. This suggests that staff members offering more pastoral and emotional support are also those that students on the autism spectrum find easier to communicate with. This could be further evidence for the theme of (mis)understanding: if staff are felt to understand them, then students view their communications with these members of staff as more helpful.

Yazi, Jack and Genji also specifically mentioned silence when discussing their communication with staff:

HH: So you don't communicate because you don't want to get into trouble?

Jack: Mmm.

HH: Can you tell me a bit more about that so I understand? [long pause] Why might communicating get you in trouble?

Jack: Because I don't want to get any [verbal warnings].

HH: What happens when [the teacher] shouts at you?

Genji: I just wanna be, just…don't talk…I just don't say anything.

Yazi [on getting stressed]: I will not say anything. Generally, if someone starts yelling – and this is what my mum says – books are my home, so if something bad's happening…I've got my book out right now [during the interview] because if I get peed off, or scared, or anything, books will be my friend. They will not yell at me, they will not make me hurt.

For Yazi and Genji, silence represents their withdrawal from communicating verbally whilst indicating being stressed. For Jack, silence is a way of communicating a desire to do well to teachers. In the classroom, Jack associates talking with being told off, yet isn't necessarily aware of why talking can lead to being reprimanded. Consequently, Jack chooses to stay silent in class to avoid the teachers perceiving Jack as naughty; also, to avoid the stress of being given verbal warnings. These examples echo the comments made by the autistic adults in the initial consultations on the many different reasons why students on the autism spectrum may stay silent. All three students, with prompting, explained that there were concrete and varying reasons behind their silences, suggesting that silence does not necessarily mean that a student does not know the answer or is taking too long to process the question.

4.2.1.2 Differences in perspective between staff and students

In contrast to the students, staff members demonstrated very little explicit knowledge of their communication with students, with no-one mentioning instruction and discipline, and only one staff member giving an example of when they gave praise. My observations yielded similar examples of staff communication as the students. These included examples of instructions and encouragement, such as "Teacher then gives instruction to

‘design a [subject-specific] poster – no further detail offered”; “physical touch and a ‘come on’ to [student] when progress was found lacking”. However, I do not believe that the lack of evidence provided by these responses necessarily indicates a lack of awareness. Instruction, discipline and praise are essential tools required for classroom management (Emmer & Sabornie, 2015), and may have become taken-for-granted for these experienced staff members, meaning they may not be explicitly mentioned. In addition, the staff members’ awareness of my previous teaching experience may have negated the need for them to report ‘the basics’ to another experienced, qualified teacher.

While the students discussed their communications with staff in generally positive terms, staff members generally described students’ communications with staff members in a negative way, such as: “[they speak] less than the other students” (Megan, a classroom teacher); “[they want] to talk to me about irrelevant things much more than the other students” (Nancy, a head of department). This was surprising given that staff members were easily able to identify student strengths, suggesting that communication may be a specific topic that staff members associate with difficulties when discussing students on the autism spectrum. My own observations of students’ communication with staff and with myself tended to be more positive, whilst also acknowledging some examples of misunderstandings.

Neither me or the staff members gave any explicit or implicit examples of how silence might be used to communicate with staff; the silences I encountered were interpreted within the context of the research interviews, rather than in relation to students’ communication with staff. However, the most frequently identified examples of students’ communication with staff from myself and staff members related to students’ willingness to volunteer in class. This contrasts sharply with the students’ descriptions of how silence can be used to communicate with staff members in the classroom. Other factors can affect students’ willingness to volunteer in class, such as their confidence in their answer’s accuracy (Turner & Patrick, 2004). It may be that both myself and staff members judged the students on the autism spectrum using normative assumptions about positive communication. Consequently, this is yet another area of mutual misunderstanding with students and staff having different yet equally valid perceptions about why a student on the autism spectrum is remaining silent. Just as there is an onus on students to communicate any underlying reasons for their silence to staff, there is also a responsibility for staff not to make assumptions about why a student may be silent.

4.2.2 Student-peer communication

4.2.2.1 Individual differences between the six students

All students gave very specific and different examples of the ways they communicated with their friends compared to their peers (see Table 17). All six students on the autism spectrum identified that peers could be easy to communicate with when it came to quick questions regarding classwork or general practical information; for example, asking a peer seated near them, 'How do you do this?', or 'Can I borrow your pen?'. Jack and Yazi also mentioned actively seeking conversations with their peers to make friends and discuss their opinions. These short exchanges were described as usually helpful and successful, with peers responding well to the short questions and students feeling pleased that they received quick and simple answers to their questions.

Table 17 Examples of communication with peers reported by each student

	Examples of positive communication	Examples of a lack/failure to communicate
Yazi	Helping with work; discussions to facilitate friendships	Immaturity of other class members
Jack	Helpful instruction; making friends	Bossiness of other class members
Sage	Helping with work	Limited interactions with non-friends
Hanzo	"Monkey" friends vs. peers to demonstrate understanding (p.103)	No motivation for talking to others
Bob	Helping with work	
Genji	Members of the class being "loud in a calm way"	

However, more in-depth discussions with peers were often reported to be more complicated. Hanzo, Sage and Genji all reported avoiding communication with most of their peers. Yazi complained that time spent in tutor was irritating, because the tutor group were "very inappropriate and very immature", which meant that lessons where they were taught together could be "annoying" because "nothing gets done". A similar association with peer work and inefficiency was mentioned by Sage:

> *[In Drama] Whenever we make - do something, people will just be like, 'no, I wanna do this bit, blah blah blah, no I wanna be this person, no way, I'm not being the princess, blah de blah'…you know. And then, like, we never actually get anything done.*

In contrast, communication with friends tended to be reported as more in-depth and emotional than communication with peers. This is consistent with the students' reports on the support they receive from friends compared to peers. A particularly detailed and passionate account of these differences between communication with friends and peers came from Hanzo:

HH: It's always easier when you can talk to someone else about it, isn't it?

Hanzo: It's like two monkeys talking to each other.

HH: Two monkeys?

Hanzo: Like, I don't know why I used that, but like, it would be harder if a monkey was trying to talk to a person. So it's like two monkeys talking to each other, and two humans talking to each other – instead of a human and a monkey. That's the way I think of it.

(later on in the interview)

HH: So you can communicate to [friends] because…

H: Because all of us are monkeys.

HH: And although you can communicate with your other teachers and the other students…

H: …I don't.

HH: You don't. Cos they're all humans.

H: I probably can, it's just more difficult. They don't really listen as well as my other monkey friends.

Hanzo was keen to explain that friends spoke the same language (monkeys), compared to the difficulties with communicating with other peers and teachers who were perceived to be speaking a different language (humans). This fantastic metaphor clearly demonstrates Hanzo's insight and perception of the differences that occur when communicating with others, and the difficulties that this may cause.

4.2.2.2 Differences in perspective between staff and students

Both the staff members and I gave significantly more examples of peer communication compared to the students on the autism spectrum, both successful and unsuccessful. In the literature review, reduced communication by students on the autism spectrum tended to be explained by a lack of awareness and difficulties with defining communication. However, as illustrated above, the students gave balanced and detailed descriptions of their communications with peers; they just used fewer examples to do this. Consequently,

a higher incidence of peer communications noted by me and staff members may demonstrate a tendency (as neurotypicals) to pathologise the communicative behaviour of students on the autism spectrum because we do not understand it (Trevitt, 2013). This therefore means that social interactions are more likely to be interpreted as “successful” communication in students on the autism spectrum, and “typical” communication in neurotypical students. Similarly, problems with communication can be viewed as issues and failures in students on the autism spectrum, rather than demonstrating typical communication patterns between young adolescents in mainstream secondary schools. This may provide further evidence cautioning how easily both myself and staff members pathologised the observable behaviours of the students on the autism spectrum.

4.3 Factors affecting the process of communication

This section explores the findings related to my third research question: factors that may affect the communication process between students and staff members in school. In addition to identifying personal factors that affected the communication process, several contextual factors also emerged (see Table 18).

Table 18 Summary of subthemes in relation to factors affecting communication

Overall Theme	Sub Theme	Contributing Perspectives	
		Students	Staff Members
Personal Factors	Staff members’ teaching style	✓	✓
	Staff members’ approachability	✓	✓
	Frequency and quality of interactions	-	✓
	Student differences in communication	-	✓
	Student differences in personality	-	✓
Contextual Factors	Physical environment	✓	✓
	Content & structure	✓	✓

4.3.1 Personal factors

4.3.1.1 Individual differences between the six students

Five students mentioned that the way individual teachers structured lessons, had preferences for certain activities, and generally conducted the lesson (coded as ‘teaching style’ in the analysis) sometimes affected their communication in lessons. This shares some crossover with their comments on the contextual factor of how the content and

structure of lessons could affect communication. Sage and Genji gave similar examples of how teaching styles affected them:

> *Sage: In my class, I feel like if I answer a lot of questions, Miss will eventually say 'it's the same people putting their hands up', and then she won't pick us…so I kind of find that if I answer a lot of questions at the start, then I can relax throughout the whole lesson, really.*

> *Genji [on why receiving a small amount of help is not negative]: Like I said, [the teacher] doesn't say that much and gives you the sheet and it's all on there.*

For Sage, knowing that the teacher will look to other students for answers throughout the lesson means more control over when communication with the teacher occurs, i.e. answering easier questions at the start of the lesson rather than being overly-challenged by more complicated questions later on. For Genji, the teacher's resource of help sheets (in addition to the teacher's general personality of 'not saying much') meant that the need to ask clarifying questions was reduced. Yazi, Sage and Genji also mentioned how a specific teacher's preferences for group work or silence automatically affected the amount of communication that occurred in those lessons:

> *Yazi: [Teacher] likes people working together; that is what they like.*

> *Sage [talking about a subject]: I don't really – I try not to talk that much cos our teacher likes silence, so he made it quite quiet.*

> *Genji: [Subject] – no questions at all. No, none.*
>
> *HH: How come?*
>
> *Genji: [The teacher] just wants us to get on with our work, so we do.*

Staff members' approachability also emerged as a personal factor that could affect how much students communicated with them. All three students who mentioned approachability described it as feeling like staff members would listen to them and were interested in what they had to say. If a student felt that a member of staff would take time to listen to them and be interested in them, they were more likely to communicate with them. This provides yet further evidence for how a student's perspective of whether they are understood or not can impact hugely on both communication and support in an educational environment. Hanzo details this by expanding the previous metaphor of

monkeys and humans to include “gorillas”: staff members that understand and therefore are easier to communicate with:

Hanzo: It’s like he [specific staff member] should be a monkey communicator or something.

HH: Ah, so he’s a monkey communicator?

H: Or let’s just call him a monkey as well.

HH: Ok, so he’s an honorary monkey…

H: [correcting himself] He’s a gorilla. So like basically, he’s a bigger monkey. Because he’s an adult.

HH: So he’s an adult, who’s human, but is more of a monkey?

H: Because he can talk to monkeys, he can communicate and he understands me.

HH: And the teachers in [other subjects] are trying to learn monkey, aren't they? But they don’t speak monkey very well.

H: Yeah. They’re not going to be able to. It’s basically impossible.

For Hanzo, this situation was perceived to be unresolvable – staff members that did not and could not understand (monkeys) would always struggle to communicate. However, Hanzo was happy communicating with staff that understood and therefore communicated more effectively (gorillas).

4.3.1.2 Differences in perspective between staff and students

Although not mentioning personality or teaching style explicitly, four staff members explained that they consciously do not make any specific adjustments in their teaching for students on the autism spectrum, as treating the students exactly like their peers was beneficial. One staff member explained that there was a tension between treating students differently for success in school, and preparing them for the lack of accommodation that existed outside the school environment:

You do wonder to a certain extent, how healthy is it to continue – and to what extent do you continue – to support students’ particular needs, and are you actually doing your job and preparing them for life outside of school?

(Steve, Classroom teacher)

Treating students on the autism spectrum no differently to their neurotypical peers could be more beneficial in the long term, as this is how the outside world will interact with these

students – but may mean that they under-achieve in school. Alternatively, differentiating between students on the autism spectrum may help students to succeed in their education, then struggle once they leave school because the outside world may fail to accommodate them. As the students want highly personalised education, this demonstrates perhaps another tension experienced by staff: supporting the students' progress towards both short-term and long-term goals when these may contradict each other.

Another contrast in perspective was seen in definitions of staff availability. Whereas students defined staff members' availability in terms of the perceived quality of communications (whether they felt the staff were interested in them or not, and whether they felt the staff member would listen to what they had to say or not), staff members defined their availability in terms of quantity – the frequency and regularity with which they saw students. Staff members generally felt that the more often they had contact time with students, the more opportunities that they had to communicate with them; for example, a student who is taught three times a week is much easier to communicate with compared to a student who is taught once a week. This represents yet another mismatch of student and staff perspectives about the most effective processes of communication and support, which may offer a possibility of how to improve this.

Two student-specific factors affecting communication were observed by the staff members and me. The first of these was the individual differences that students showed in their communication, such as the fluency and confidence with which they spoke, and idiosyncratic uses of phrasing and syntax. The second was the students' individual differences in personality. Amy (a head of department) reported that the high levels of charm that Yazi showed often negated some of the negative feelings of frustration felt when communicating with them. In class, Yazi's charm meant that the irritation never lasted long, with Amy explicitly acknowledging that this would not necessarily be the case for other students:

> *So it's charming that [Yazi]'s coming to tell me [about what they are doing in other lessons] …whereas some students, I don't think maybe you'd have as much tolerance with, because [Yazi] is very charming. But I think there must be some awareness there, because [Yazi] uses [their] charm a little bit.*
>
> *(Amy, Head of Department)*

Staff members also noted that the level of insight between student personalities could also differ; the quieter, more introspective students often gave much more considered and insightful answers to the questions asked compared to those who answered straight away with little reflection.

4.3.2 Contextual factors

4.3.2.1 Individual differences between the six students

All the students mentioned specific environmental factors that affected their communication in lessons. Although the most commonly mentioned environmental factor was the level of noise, it is interesting to note that the personal impact this had on students varied considerably (see Table 19).

Table 19 Personal impact of environmental factors identified by students

	Environmental factor identified	Impact
Yazi	Time restraints	Negative – Yazi is used to working at home where there are no restraints on time, and therefore time restraints in lessons can be worrying and lead to more communication as reassurance is needed
Bob	Seating arrangement	Positive – in one lesson, the seating plan encourages students to work more individually, and therefore Bob can concentrate on work. This decreases communication with others in the class
Jack	Seating arrangement	Negative – in one lesson, the "naughty" children are sat together, make lots of noise, and get shouted at a lot, which is distracting. This decreases Jack's communication, as they become anxious and then withdraw
Sage	Classroom location/ seating arrangement	Negative – Sage is scared of heights and has a lesson on the third floor of a building. Sage is also sat near a window, which means that they are unable to concentrate properly on work. This leads to a decrease in communication as Sage feels anxious and withdraws.
Hanzo	High levels of energy in the classroom	Positive – Hanzo has a large extended family and thrives in busy and energetic environments. High energy lessons therefore increase both focus and communication with others in the class
Genji	High levels of energy in the classroom	Negative – Genji does not like loud noises or a lack of personal space, and therefore cannot concentrate easily in busy classrooms. This decreases their communication as they withdraw from others.

Interestingly, the students gave broadly similar and logical answers in relation to how content and structure in lessons can affect communication:

> *Yazi [talking about communication in Drama]: Because you have to work together and you have to do it to get it to work. And then in P.E., because you have to work together as a team as well, so kind of the same thing as Drama.*

> *Bob: So, PE is definitely like – it's definitely working communication. We do have a bit of a joke here and there, but most of the times it's us talking about the work and what we're doing. And it's sort of the same in Dance and Drama.*

> *Genji: In English, I do communicate because we work in teams quite a lot…we just talk and need to communicate…like we're doing the Hillsbrook [sic] disaster, the football match, and like, we were talking to each other and like getting information down on our iPads and we found it helpful – there were three of us talking.*

Lessons that involved teamwork (e.g. PE, Drama, Dance, and others where group work is used a lot) were identified by the students as automatically requiring more communication than lessons where the work is more individual. A lesson in which a class test is taken obviously has much less talking than a lesson where a class discussion is taking place; and lessons involving a lot of class instruction or class discussion before starting a piece of work meant students were more prepared and felt less need to ask questions. For example, Bob explained that a lesson with minimal communication was because the teacher went through things generally as a class, then spoke in detail to individual tables. Receiving these two different types of explanation meant that Bob generally asked fewer questions.

4.3.2.2 Differences in perspective between staff and students

The only environmental factor either staff or I noted was in relation to noise, and how this could potentially limit communication because it may cause students on the autism spectrum to feel overwhelmed, which is in direct contrast to Hanzo's account of how noise facilitates concentration. Most comments related to how the content and structure of lessons. Staff members highlighted how different teaching activities affected communication, for example, choosing to use more group work/class discussion automatically means more communication happening in the class. Three staff members also identified how students' physical mobility in lessons could have an impact on communication. Practical lessons where students are standing up to work and moving

around equipment mean that students are much more likely to walk up to staff members and ask questions, rather than putting their hand up. In contrast, my observations of content and structure were very limited, although I did note that students sometimes naturally worked in silence without instruction to do so when they were concentrating hard on a task. This may be because I had not previously considered how these lesson-specific factors could affect communication, and therefore my focus when making field notes and observations was on the interactions between student and staff members.

4.4 Additional themes of interest

In addition to the three research questions that related specifically to support and communication, data from the students, staff members and my own observations also contributed to some additional themes that emerged: positive views of being on the autism spectrum, students' awareness of difference, students' identification of support strategies (self-regulation) and sensory experiences.

4.4.1 Student strengths – positive views of being on the autism spectrum

All six students easily identified things that they were good at over the course of this exploratory phase and volunteered this information to me without explicit prompts. These strengths were commonly related to the individual's specific skills and interests; for example, "I'm really good at guitar" (Sage), "I'm pretty good at Maths" (Yazi), "the animation [school] do is kind of easy, [suitable for] kids, but I do quite a lot harder ones" (Genji) and "I know a lot about dinosaurs" (Jack). Less commonly mentioned were more general traits; for example, Hanzo commented, "I look out for my friends", whereas Bob mentioned "I'm pretty intelligent".

Staff members also found it very easy to identify student strengths when directly asked but were much more likely to mention general personality traits, such as enthusiasm, being bright, and having good behaviour. Even when staff members did mention individual interests as a strength, their justification for this was because these individual interests could translate to enthusiasm and focus in the classroom on specific topics. I did not explicitly identify any student strengths that related to their academic work or behaviour, as I was not involved with any aspect of this. However, my reflective accounts of the student photo-trails and interviews mention the friendliness, helpfulness and engagement of all the students that I worked with; all general traits, as reported by staff members.

4.4.2 Students' awareness of differences

All six students mentioned implicit examples that suggested that they were aware of a difference. For Genji, Bob and Sage, this was not directly linked to being on the autism spectrum, and therefore describes a general awareness of being different from others:

> *Genji: Some people are the fastest [at completing tasks] and I can't catch up, cos I can't like…it's like, hard for me to write all the time. And it's - I'm not really neat. I try, and do as much work as possible…but normally, I get to – there's like 20 questions – and I only get to question, like, 9 or 10…*

> *Bob: It's just more when it comes to the aspects of like, working in a pair, I find it quite difficult to find a pair.*

> *Sage: [Staff] say 'it's only an hour of surviving [a lesson], but for me, it feels like three hours, and they seem to go on forever.*

For these more implicit references, it is not possible to determine whether these experiences of being different are related solely to being on the autism spectrum without further discussion. Warrington and Younger (2011) suggest that a desire to fit in is very important for young people, noting that the neurotypical students in their study also expressed feelings of difference. Consequently, these examples may reflect the students' ages and the social setting of school. In contrast, Yazi, Hanzo and Jack made explicit references to being different because of being on the autism spectrum, although the language and labels they used varied significantly:

> *Yazi: I think it's a bit harder for me to understand other people with being Aspergic.*

> *Jack: Because I've got autism, I don't think people are aware of how I feel.*

> *Hanzo: [Teachers] say they understand, but they truly don't because they don't have autism. They don't think like me, they don't know like me, they don't do anything like me. I'm different. But I can still get busy on with my work, and things. It's just sometimes, I think differently; and that's how my brain works, I guess.*

This demonstrates once again how even within a small sample of six individuals, there are varying levels of awareness when establishing whether their experiences of being different can be linked to being on the autism spectrum.

4.4.3 Students' awareness of self-regulation strategies

All six students on the autism spectrum identified self-regulatory strategies that they employed to manage their emotional, sensory and academic needs, even if these strategies were not necessarily explicitly identified with an association of being on the autism spectrum (see Table 20). For example, Genji reported that "if I draw a picture, it helps me calm down sometimes". Similarly, Yazi observed that fiddling with objects "makes the world a more interesting place".

Table 20 Individual self-regulation strategies identified by students on the autism spectrum

	Emotional strategies	Sensory strategies	Classwork strategies
Yazi	Withdraws and reads book when anxious or bored	Fiddling – with hair, glue ball, chewing gum, doodling; using reading to block out extra noise	Working out better method of calculation in Maths that "works with my brain"
Bob	Reminds self that helping others feels good; very meticulous order for things (e.g. neatness of how photos are laid out)	None identified	Blends general chat with work chat to make it more interesting; ask teacher for help with getting into pairs
Jack	Tells others about their "condition", and that they can't express their emotions like others can	Moves away from specific noises to minimise discomfort	Avoids talking at all in lessons in case they get in trouble; avoids working with those who they dislike or do not get on with
Sage	Answers lots of questions at the start of the lesson to feel relaxed in certain lessons	None identified	Avoids working with others they do not know or dislike
Hanzo	Walking out of classroom if they get too angry	Movement – they must be "energetic" to concentrate	Only works with those who understand; avoids others, or avoids work
Genji	Withdraws and becomes silent when anxious; draws pictures to calm down; writes stories to feel control	Ignores any talking and becomes silent when over-stimulated; avoids specific noises	Works on the iPad, because it's easier to erase mistakes and easier to work with other people

Overall, the self-regulation strategies that the students employed tended towards either avoidance or withdrawal from whatever was causing them stress; however, the individual ways in which students did this varied greatly. For example, Hanzo tended to just walk out of the classroom when things became too much, whereas Jack changed their physical position in noisy environments by moving to somewhere that was quieter. Bob noted that the main motivation to help others was to feel good, despite also finding it frustrating:

> *It can sometimes get a bit annoying when people are always like, 'Bob, can you help me do this?' 'How you do this?' and it's...but it can feel very nice, you feel really good about yourself. You think, 'oh, I've helped someone else, I've done something good today'. It makes you feel really nice.*

It is encouraging that the students were able to identify clear examples of self-regulation strategies as their young age could mean that they are still developing their own levels self-awareness, as mentioned by the autistic adults (see p.68-69). However, my own observations of the detail and insight that students provided suggest that with explicit questioning, even more detailed responses would be possible. References made by me and staff members to strategies employed by the students to support themselves were much sparser; there were only four mentions of self-regulation strategies based on staff members' observations of individual students, and/or being explicitly told about a strategy (either by the student in question or another member of staff):

> *[Yazi] can cover up [their] social skills that maybe are a weakness*
>
> *(Amy, Head of Department)*

> *…so [having a chatty person sat next to them] definitely throws [Sage] off, and [Sage] knows that about [themselves], presumably.*
>
> *(Megan, Classroom teacher)*

> *[Bob] brings in [their] own puzzle book, or colour book, so [they keep themselves] occupied. So [they're] actually pro-active in dealing with [their] own needs, in that sense.* *(Steve, Classroom teacher)*

> *That was basically what [Jack] wanted, for [their classmates] to know that [they weren't] ignoring them…it was [Jack's] way, I suppose, of trying to break down that barrier that's there for [them], and maybe [the other students] might be more open towards [Jack], I think.* *(Nancy, Head of Department)*

As staff members were also not asked explicitly about these strategies, again, this lack of detail may be due to the questioning methods used. Considering Tangen's (2008) argument that insider knowledge cannot be gained by mere observations, alternatively, there may always be certain limitations about the conclusions that staff members can draw by themselves about individual students.

4.4.4 Students' sensory experiences

Based on the literature review findings and suggestions from the autistic adults, I deliberately enquired about sensory information, and asked direct and follow-up questions when the students mentioned any sensory information spontaneously. Asking direct questions about experiences – even if students did not have an awareness that their experiences were likely to differ from their peers – resulted in several examples of sensory experiences being identified (see Table 20 in the previous section). The students gave detailed accounts of the nature of their sensory experiences, yet the importance of these sensory experiences and the impact that it had on each individual student were much more difficult to determine. Only Yazi explicitly referenced an awareness of differing sensory experiences, commenting "I have more sensitive hearing than other people". However, Yazi did not explicitly link this to "being Aspergic" unlike other experiences described (see p.111).

The perspectives of myself and staff members are limited in the information we can gain about sensory experiences from direct observations, but nonetheless they are reported here. There was only one mention of a possible sensory experience from staff, where Sarah (a classroom teacher) described a major behavioural incident involving Genji: "…and [Genji was] sort of rocking like this [imitates], looking at the floor…". However, this description was not explicitly linked to be a sensory issue and was described as a general sign of distress or anxiety. The lack of sensory experiences identified by staff was also consistent with their reports that they did not feel adequately supported to understand the students on the autism spectrum. There is a range of documentation for schools on this subject, such as the competency framework provided by the Autism Education Trust (Wittemeyer et al., 2015), which includes information about several types of sensory experiences that students on the autism spectrum may encounter. However, this may not be being utilised effectively.

In contrast to staff, I identified many potential examples of sensory experiences that I saw throughout the study. This may be due to my increased textual experience about sensory experiences from talking to autistic adults in the focus group. However, it is not clear from these observations whether I have accurately identified examples of sensory experience, or whether my researcher bias regarding sensory experiences means that I have

misinterpreted the behaviours of these students. For example, most of the movement-related examples that I observed may be due to natural fidgeting rather than sensory regulation; without confirmation from the students themselves, my observations may therefore lack credibility. These findings therefore demonstrate that the nature of students' sensory experiences and their impact on the educational environment is an area that requires yet further, explicit exploration.

4.5 Implications for the second phase of research: facilitating communication and support

The first phase was designed to explore the complexity of the communication and support processes that already exist within the secondary mainstream environment. A greater understanding of this may then be translated to ways to facilitate this communication and support within the context of the SEND CoP (DfE, 2015) and its requirement for student involvement. The further exploration of these potential factors that may facilitate communication (and consequently, support) therefore directly influenced the nature of the second phase and are outlined below.

Firstly, all the students identified self-regulation strategies that they were already using to support themselves in their educational environment and identified several examples of their awareness of their differences and strengths. The theme of being understood was prominent throughout the findings of this phase, with both students and staff members agreeing that better understanding of individual students is likely to result in more effective communication and support. As the students have demonstrated the detail in which they can discuss complex experiences, it makes sense to suggest that using students' own knowledge about themselves is the most obvious way to increase staff members' understanding of their personal requirements. Milton (2014) describes this as 'interactional expertise', arguing that it is an important step to "build bridges and practice languages…autistic people need to be listened to" (p.7). Increasing students' levels of self-awareness may help contribute to their desire to be understood – the more detailed the personal knowledge they possess, the more detail they can therefore share with members of staff in educational discussions to promote their inclusion in the classroom. Increasing students' self-knowledge to impact positively on their communication and support therefore needs to be explored as part of the second phase of research.

Secondly, the importance and role of individual differences cannot be overstated. The individual differences between the students involved in this small-scale study are numerous despite student similarities in age and geographical location. The individual differences of staff members, school communities, and designs of classroom

environments can also not be overlooked. Staff members' preferences for types and frequency of communication in lessons, teaching and learning activities and lesson content and structure are also part of the individual differences that will influence any discussions taking place about educational experiences and ways to improve them. This suggests that it is likely impossible to develop one teaching method or adaptation for use in every classroom that will be effective for improving support for every student on the autism spectrum and their personal needs (as concluded by Parsons et al., 2011). Consequently, these individual differences have important ramifications for the choice of research method(s) used in the second phase, as they need to be flexible enough to be personalised for each of the individual students' preferences. Any output from the second phase of research also needs to highlight the importance of the individual differences between each of the students.

Finally, four key differences in the perspectives of students and staff members emerged from these findings, suggesting that Milton's (2012) 'double empathy problem' seems to be illustrated across four main areas within this small sample. The first of these regards *the nature of effective support* from staff members. The students equated emotional support as the most effective way that staff could support them (p.93), whereas staff members felt academic support was the most effective way they could support the students (p.95). Secondly, although both students and staff identified that staff members' understanding of individual students needed to increase, the *responsibility for increasing understanding* was perceived very differently; students believed that staff members were responsible for this (p.93), whereas staff members felt that increasing their understanding about individual students on the autism spectrum was the responsibility of the school (p.94). Thirdly, there were very different perspectives on the *definition of staff availability*, with students perceiving the quality of interactions to be most important (p.105), and staff members perceiving the quantity of interactions as most important (p.107). Finally, there was a clear difference in the *knowledge of sensory experiences*; students identified several examples of how they might perceive the world differently, yet staff members showed minimal knowledge about this aspect of autism (p.114). Resolving these four differences in perspective may also facilitate communication and support between the students on the autism spectrum and staff. Consequently, these four areas demonstrating differences in perspectives needed to be explored in the second phase.

In summary, the first phase of my research demonstrated that students on the autism spectrum can give in-depth, reflective accounts about the processes of communication and support and their own experiences in secondary mainstream education. Both students and the staff members interviewed agreed that the key to improving both communication and support was to improve staff members' understanding of individual

students. Consequently, my second phase focused on facilitating communication, support and understanding between individual students and the staff members they work with by concentrating on the three facilitators identified above: increasing self-knowledge/awareness, highlighting and adjusting for individual differences, and attempting to resolve the four 'double empathy problems' between the students and staff members. As the photovoice activities worked so well with the students, I aimed to design similar activities to form the basis of the students' interviews. I decided that four different activities should be used to explore the four differences in perspectives, as this meant that each activity could be personalisable to reflect each student's individual preferences. The design of these four activities also aimed to fully align with my conceptual criteria for listening to students' voices.

Furthermore, because of the importance of individual differences and personalisation – and due to the invaluable contributions in this first phase of research – consultations with the autistic adults and the students on the autism spectrum were continued to ensure the activities were suitable, relevant, meaningful and could be adapted easily. The overall aim of the second phase was to facilitate communication and therefore support between the students on the autism spectrum and the members of staff that they worked with by increasing the staff members' knowledge about the individual students. By completing the four activities, students would be supported to generate further knowledge about themselves that may contribute to their levels of self-awareness and self- knowledge. This expertise can then be offered in their educational discussions, and potentially be used beyond the classroom to help increase others' understanding. Staff members would then be able to use their professional expertise to discuss suitable adaptations within their individual educational contexts with these students, thereby improving communication by opening a dialogue with students about how they can be best supported within very specific contexts. This was the aim in any case; the reality differed somewhat as explored in the following chapter.

Chapter 5 The second phase: facilitating communication and support in schools

The first phase of my research identified the processes of communication and support for six students on the autism spectrum and staff members who worked with them. The findings regarding communication and support suggested three key potential facilitators:

i. Highlighting and adapting for individual differences of the students;
ii. Increasing students' self-awareness and self-knowledge to improve understanding;
iii. Resolving differences in perspectives between the students and staff members across four key areas: knowledge of sensory experiences, definitions of staff availability, definitions of effective support and how to improve staff understanding of students.

My initial plan was to design four activities that fully aligned with my conceptual criteria, explored the four areas of differences in perspectives, could be personalised and could increase students' self-knowledge. These activities could be completed by students with staff members present to facilitate discussions about the four differences in perspectives. However, staff members indicated in the first phase that time is a precious resource that they already feel is lacking (p.94). Working through the four activities with students would have taken considerable time that staff may not have felt was available to them. Consequently, the necessary time needed to establish student perspectives may be incompatible with the amount of time staff feel they can offer to individual students.

This meant that I modified my initial plan to reduce the amount of time staff members had to contribute to this phase of the research. I would complete the four activities with students, and then – instructed by the students - produce a summary of the information revealed by the activities. Staff members could then comment on whether and how the information revealed about the student could be used to facilitate the processes of communication and support with them. Due to a lack of staff availability, in addition to the perspectives of school staff who were involved in the exploratory phase, the additional perspectives of educational practitioners who did not know the six students involved in my research were also sought.

This chapter therefore details: the development of the four activities; summarising the information from these activities; and the responses of staff members and other educational practitioners to this information.

Research questions for the second phase of my research

The perspectives of the students, autistic adults and educational practitioners were key to assessing whether completing these activities and evaluating the information produced from them could lead to the facilitation of communication and consequent support between students and staff members. This led to the research questions for the second phase evolving as follows:

1. What kinds of methods, from the perspectives of students on the autism spectrum and autistic adults, could be beneficial for facilitating communication and support between staff and students?

2. What kind of information about the students on the autism spectrum, from the perspectives of staff and other educational practitioners, could be beneficial for facilitating communication and support between staff and students?

5.1 Additional philosophical considerations

Although I have already justified my researcher positionality in detail in Chapter 3, this section details the additional methodological considerations made in relation to the second phase of my research. As the nature of this second phase differs from the exploratory nature of the first, I required a design philosophy that was in keeping with my researcher positionality. Four differences in perspective of students and staff emerged from the exploratory phase findings, and therefore four thematic activities needed to be designed to explore these differences in perspective. However, as well as completing the four activities, I wanted a design philosophy that allowed me to involve the students on the autism spectrum and the autistic adults in the design process. Many participatory design philosophies I initially explored place great importance on shared decision-making, negotiating, and the re-allocation of power during the design process (Bratteteig & Wagner, 2014). These values align with my own regarding research, yet the design philosophy I chose also had to allow me to exert enough control over the research design to answer my research questions.

I firstly considered user-centred design, where the ‘users’ are seen to have specific knowledge and needs that must be captured to create an effective design. As this aligns very clearly with my own values regarding voices and the concept of ‘insider epistemology’ (Tangen, 2009), this overall approach was a good fit when thinking about how I could involve the students on the autism spectrum and the autistic adults in designing activities to facilitate understanding and communication. Mencia, Pardo, Trapote, and Gomez (2013) note that applying user-centred design principles to children

with SEN can be challenging, especially because of differences in communication. They advise that it is "…important to take special care to involve [children with SEN] in the design process in a way that adequately elicits the required information from them" (p.64). Consequently, the element of adaptation and personalisation required linked clearly to my findings regarding the importance of individual differences.

As the students would be taking on a significant role in the design process, I found that Druin's (2002) framework of user involvement was helpful for conceptualising the level of involvement the students and adults would take in the design process. The highest level of shared decision-making and power is when children take on the role of 'design partners', where they have equal say in all aspects of the design process. This role necessitates the sharing of a lot of decision-making and power to children throughout the design process. As previously discussed (see p.64), within the context of the PhD, this sharing of power is problematic as I need to take ownership of my thesis, which is "expected primarily to be the work of an individual" (White, 2011, p.138). Because the students could not take an equal role at all stages of the design process for the second phase, I therefore decided that the role of design partner was unsuitable for my research needs.

The next role defined by Druin (2002) is where children act as 'informants' and are involved at various stages of the design process, while the overall shape and direction of the design is researcher-led. This also led me to consider informant design as a possible design approach, which is where adult designers create the designs, and children are then given the opportunity to 'inform' designers how these designs can be adapted to suit their needs (Read et al., 2002). This seemed to fit the process I envisaged for creating the four activities, as the four themes generated from the first phase discussions regarding differences in perspective between the students and staff had already dictated the topic of each activity. Therefore, it made sense for me to create the initial designs for each thematic activity to ensure that they were rooted in a theoretical and practical research context. The input from the students could then refine the design of the four thematic activities further to make them more meaningful. Druin (2010) notes that involving children within an 'informant' role means that "ultimately adults are still in charge" (p.18). Providing the students on the autism spectrum with an informant role therefore meant that I was able to involve them at several stages of the final designs, yet still retained control over the overall design process.

The involvement of the autistic adults in the design process was less easy to define because this meant choosing a design approach that was not wholly focussed on the involvement of 'end users' i.e. those using the designs at the end of the design process; in this case, the students. Informant design therefore not only suited the level of involvement

I wanted for the students but could potentially also ensure that the autistic adults were able to contribute to the design process as well, as it draws on the experiences of multiple stakeholders to “recognise the different contributions made by different contributors” (Brna, 2008). I therefore chose informant design as my design philosophy for the design part of the second phase to allow me to seek the contributions of both the students on the autism spectrum and the autistic adults, yet also keep their design ideas distinct during the overall design process of the four thematic activities. (see Figure 5).

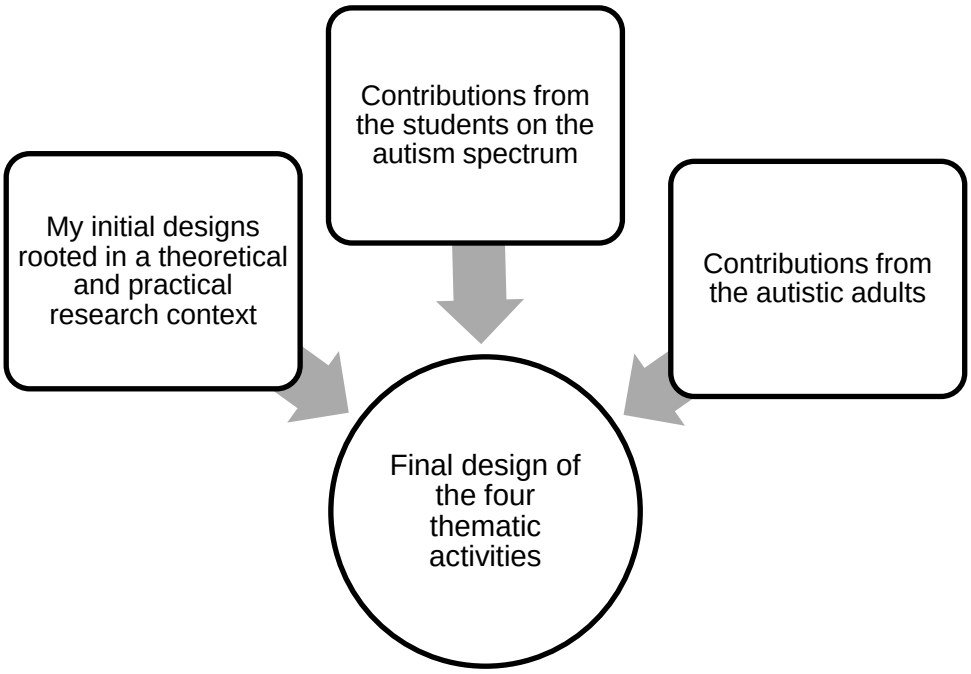


Figure 5 The overall design process of the four thematic activities

5.2 Initial designs for the four thematic activities

The four themes of differing perspectives from the findings of the exploratory phase dictated the need for designing four activities, one relating to each theme. Adopting the principles of informant design meant that I would be creating the initial designs for the thematic activities before seeking the perspectives of the students and the autistic adults about how these could be further refined. Using initial designs as a starting point for discussions during the design process is frequently used when working with students on the autism spectrum. Parsons and Cobb (2014) discussed twelve initial design ideas with their core design team (which included five students on the autism spectrum) to aid the development of a bespoke collaborative virtual environment for facilitating collaboration and social conversation. Similarly, Frauenberger, Good, Alcorn and Pain (2013) created an initial annotator tool to engage children on the autism spectrum to critique designs which was then tested by an 8-year-old student with Asperger Syndrome who commented

on its suitability. Benton and Johnson (2014) used a “structured idea generation process” (p.55) with paper-based templates when working with students on the autism spectrum to design a maths game. Using initial designs can therefore help build a structure to the design process by asking students on the autism spectrum to critique initial designs. The flexibility of these methods was also crucial to reflect the diversity of each students and allow these designs to be personalised (Porayska-Pomsta et al., 2012).

To ensure a grounding in relevant and accessible methods, I researched existing activities that aligned with my conceptual approach and tailored them specifically to the four areas of difference that emerged from the first phase of research. Although each activity was developed with specific content requirements, Table 21 demonstrates some of the general considerations informing these specific designs that emerged from the exploratory phase discussions. Each of the four thematic activities are detailed in the following sections.

Table 21 General considerations for the initial design process for the second phase

Considerations	Evidence/Justification
Visual, engaging and interactive – movement needs to be involved	Engagement of levels of students using similar activities in the first phase (student comments and my own observations)
Minimal input required from staff to create designs as time is a precious commodity	Comments from staff regarding perceived lack of time already in existence when supporting students
Alignment with conceptual criteria is essential	Insights and detail revealed by students from first phase and studies demonstrating full overall alignment in the literature review
Age-appropriate, engaging and personalisable; ideally, no or little training required for students to use the activities	Engagement of levels of students using similar activities in the first phase (student comments and my own observations)
Easy to reproduce, easy to edit, easy to store securely	Travel between different research sites; re-design element; copyright considerations
Activities ideally need to increase student levels of self-awareness and understanding	Findings from exploratory phase and literature review
Activities need to produce personalised information on students	Findings from exploratory phase and literature review

5.2.1 The Motivation Mixer: an activity exploring sensory experiences

This activity was designed to explicitly explore the sensory experiences that students on the autism spectrum had mentioned in the exploratory phase. The information from this activity can then increase staff members' understanding of the students' sensory experiences, potentially resolving this difference in perspective. My findings from discussions with the autistic adults in the first phase (and mentions of sensory experiences in the literature review) suggested that explicit examples were needed to encourage further detail from the participants. The use of concrete examples is also promoted by Hart and Whalon (2008) as being advantageous when working with and communicating with individuals on the autism spectrum. The first design decision I made was deciding which concrete examples of sensory experiences to use to prompt these discussions. To do this, I examined specific examples of sensory experiences detailed in the conceptual literature review and explained in detail by the autistic adults during the focus groups regarding communication (see Table 22).

Table 22 Examples and sources of concrete sensory experiences for use in the Motivation Mixer

Students in phase one	Autistic adults in phase one	Literature
• Fidgeting • Rocking in seat • Verbal tics/noises • Lighting • Colour preferences • No shouting • Eye contact • Food preferences	• Fidgeting • Stimming • Reaction to strong smells • Having preferred seating • Fabric sensitivity • Personal space preferences • Eye contact • Blushing • Processing differences • Sensory overload • Chewing	• Fabric sensitivity (Stewart, 2012) • Physical pain reflecting emotional pain (Stewart, 2012 • Sensory overload (Stewart, 2012; Ellis, 2012) • Sensitivity to shouting (Stewart, 2012; Killowry, 2015; Saggers, 2015; Healy, Msetfi & Gallagher, 2013 • Sensitivity to certain noises (Killowry, 2015 • Pushing/shoving (Humphrey & Lewis, 2008a) • Fidgeting (Moyse & Porter, 2015) • Sensitivity to light and space (Williams & Hanke, 2007) • Preferences regarding amount of movement (Loyd, 2015) • Possible visual differences (Winstone et al. 2014)

When summarising these, the categories of sensory experiences chosen related to movement differences (or stimming), auditory differences, visual differences, personal space differences, olfactory differences, tactile differences, eye contact, and cognitive differences. Representing these categories in an activity that fulfilled my conceptual criteria led me to choosing a visual representation of these sensory categories. The initial design needed to be interactive to promote engagement, yet the visual design needed to be flexible enough to accommodate the needs of individual students (expertise). In addition, it needed to be able to represent changes in the students' sensory experiences (also relating to expertise). Incorporating a visual element also allowed for more

multiplicity when completing the activity, as students could provide non-verbal as well as verbal information. Finally, the activity needed to allow students to complete it in the way that they wanted, allowing for negotiations in the hierarchy between us as well as promoting multiplicity. The initial design therefore adopted a similar approach to other research tools that have produced a visual representation of sensory experiences, such as the Autism Discovery Tool (2015), an app developed by the Spectrum Idea Lab that provides visual representations of different sensory experiences within specific environments, such as the distortion of smells (see Figure 6).

Figure 6 A screenshot from the Spectrum Idea Lab's website demonstrating smells in a kitchen

As I wanted to display information about several different sensory experiences at once, representing this within the app would have been complicated. In addition, my initial considerations as a researcher demanded that any activities I designed would be easy to edit, transport and reproduce for use in the school environment. Producing a design in paper format also reduced the need for technical knowledge that would be required to use an app by myself and others. Consequently, I decided that a visual display incorporating flexibility and adjustment was best represented through the concept of a mixing desk in a recording studio (see Figure 7). I envisaged each 'channel' on the mixing desk as a different sensory experience, the 'level' of which can be adjusted. In terms of usability, the activity needed to suit the requirements of a school context; easily reproduced, clear, effective and simple. Because of the need to potentially adapt the design to suit each student, I decided that black and white 2D line drawings that could easily be edited and re-printed compared to a 3D mock mixing desk with levels that could be physically changed by the students.

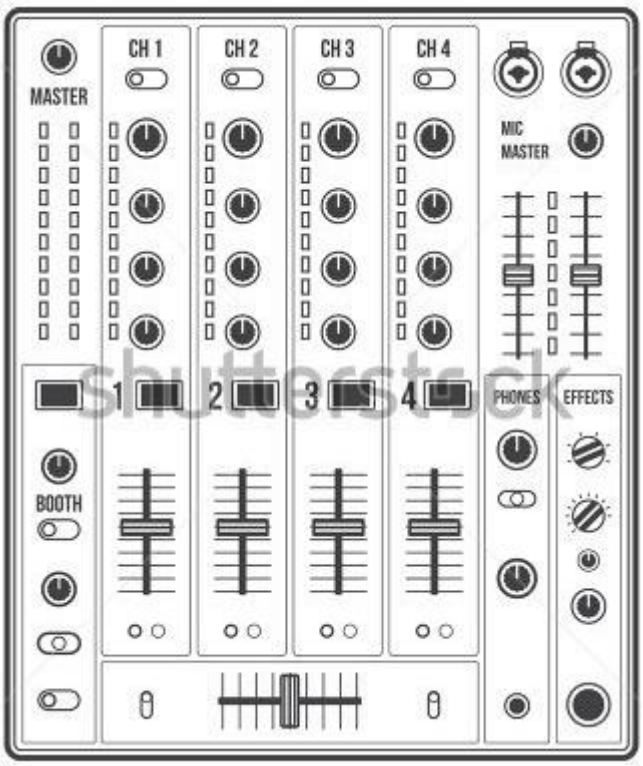


Figure 7 A line drawing illustrating a recording studio mixing desk (Trikona, 2018)

To prompt information, I planned that the students would be presented with the activity and asked, "what are you feeling?". The student could then indicate where their sensory 'level' is; for example, by marking a cross on a sensory 'channel'. For example, if individuals feel like they want a lot of personal space, they would mark their 'level' of personal space close to the top on the personal space 'channel'. Student expertise is central to this activity, as sensory experiences are not necessarily observable to others (although observable behaviours associated with them might be), and the student has a unique sensory perception to communicate. Encouraging students to think explicitly about the 'levels' of their sensory experiences may also increase the student's self-awareness of **how much** they are being affected on each sensory 'channel'. This may then offer further awareness of the impact of each sensory channel, and how this may change according to different situations. Therefore, using the labels of "high" and "low" as descriptors rather than numbers may add further personalisation and expertise of the student's contribution – each category the student measures can be compared to his or her other ratings for context, rather than comparing their ratings to the 'numbers' or ratings of another student. Similarly, "high" and "low" does not indicate positive or negative associations with sensory experiences, allowing students to clarify this when completing the activity (see Figure 8 for the initial design)..

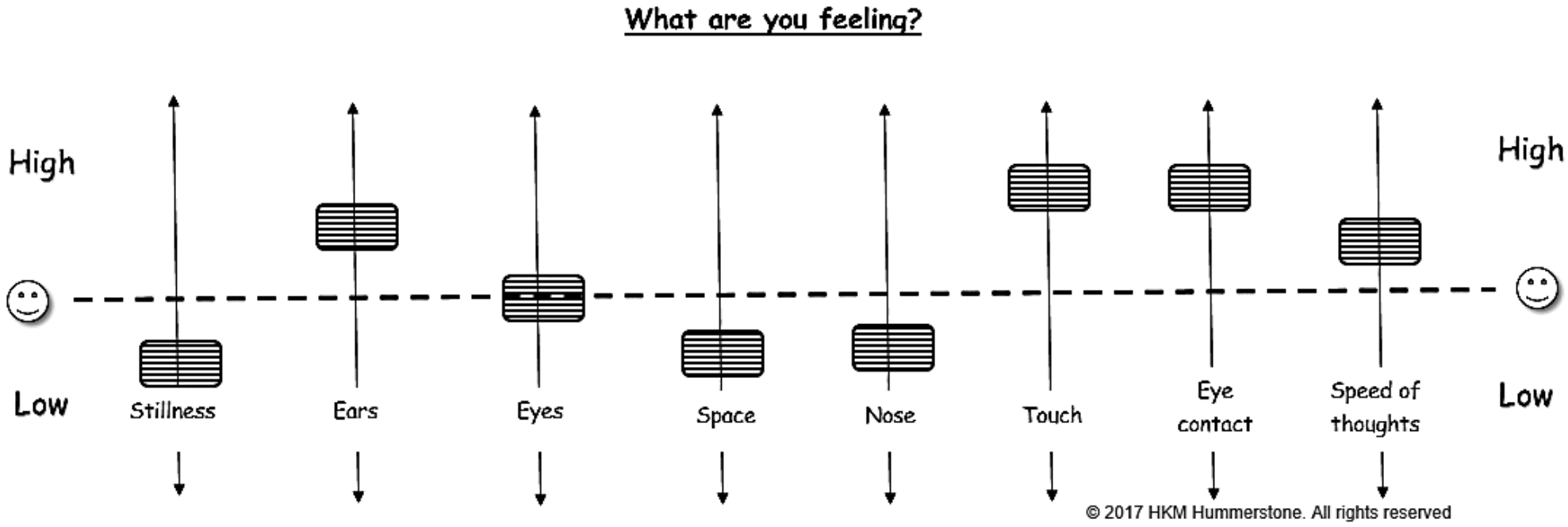


Figure 8 The initial design for the Motivation Mixer – an activity to explore sensory experiences. An example of where a student may 'rate' themselves on different channels is illustrated here through use of the lined boxes

The limited mentions of sensory experiences by staff members from the first phase suggested that general awareness about sensory experiences and how they may differ from the experiences of neurotypicals needed to be raised. The advantage of using a visual representation for sensory experiences is that staff members could potentially compare their own sensory experiences (i.e. where they place themselves on the sensory channels) to the students' placements, offering a visual contrast that may be more impactful than written descriptions in promoting understanding and empathy. Chanlin (1998) compared lessons with no graphics, still graphics or animated graphics in relation to students' prior knowledge and the knowledge they achieved at the end of lesson, concluding that when prior knowledge is limited, graphics are advantageous in learning descriptive knowledge compared to text only. This suggests that including visual representations could help to increase educational practitioners' general awareness – their descriptive knowledge – of the different sensory experiences of students on the autism spectrum that may impact their classroom experiences. In addition, this representation of sensory experiences may allow for more personalised approaches in the classroom. For example, a teacher seeing that a student on the autism spectrum has marked their need for personal space as 'high' can assess what strategies may need to be put in place to support them in the context of their classroom environment. They may decide that instead of completing a group task that has been planned, the student can work individually or with just one other facilitating partner; additionally, there may be room within the classroom to allow the student to sit on a desk by themselves.

5.2.2 Complete the Comics: an activity exploring understanding

To promote students' understanding of both themselves and their teachers, I wanted to create an activity that would help students to reveal their understanding of situations while being engaging and again, offering a non-verbal option to communicate. In the first phase, although both staff and students agreed that staff understanding needed to be improved, they differed in their beliefs of where the responsibility for improvement lay. Students believed that it was the staff members' responsibility to improve their understanding of the student, and therefore creating an activity that would provide personalised student information to staff may help the students to feel less misunderstood. The staff involved in the first phase believed that it was the responsibility of the school to provide adequate training, support and resources. Consequently, an activity that could easily be used by the school may provide an additional resource to help staff members communicate with students on the autism spectrum to personalise the strategies they are using in the classroom.

Promoting understanding and discussions of thoughts and feelings using line drawings and empty speech/thought bubbles is already used widely in the literature as a tool to promote communication with individuals on the autism spectrum and increase the understanding of others' perspectives. Gray's (1998a) 'Comic Strip Conversations' are described by Glaeser, Pierson and Fritschmann (2003) as "a visual interaction between two or more people in which information is enhanced by the use of simple symbols, stick figure drawings, and colour" (p.15). Gray (1994) also highlights that by drawing interactions, "the thoughts and feelings of others [hold] equal to spoken words and actions" (p.2). The students had described many of their interactions with friends, peers, staff and family during the first phase, and therefore an activity invoking a visual representation of these to explore their thoughts, feelings and understanding further was a good fit. More recently, Coogle et al (2017) used comics as a social narrative strategy to enhance the social skills of primary school students on the autism spectrum; however, in this study, the comic was drawn by the teacher rather than the student. The advantage of Comic Strip Conversations is that they are led by the child, offering further suitability in relation to my conceptual elements of hierarchy, engagement, multiplicity and expertise.

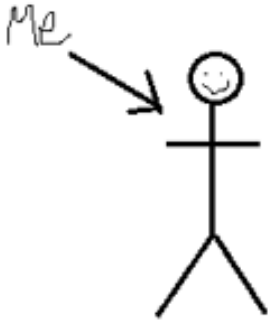
However, the Comic Strip Conversations are ultimately designed to build social and conversational skills and involve structured symbols and colour-coding to achieve this. I did not want to limit or over-structure the students' experiences, and some of the basic symbols used by Gray (such as the talking bubbles, thought bubbles and stick figures) were adapted to explore students' ideas about their education; the overall tool was too restrictive. Similar issues with constriction are evident in Rajendran and Mitchell's (2000) 'Bubble Dialogue' computer program, which aims to improve communication skills by encouraging perspective taking and regulate turn-taking. In addition, a computer program would have been difficult to access in the more private areas of the school without computers where the research was taking place. Consequently, the initial design used some of the basic 2D line drawing symbols from the Comic Strip Conversations with questions to prompt the students' experiences about their education (see Figure 9). Once the students had drawn their comic(s), they would be asked to explain and clarify what they had drawn. The aim of this was to increase students' understanding about themselves, and to explore their own individual understanding and interpretation of situations and others' perspectives. For example, if a student chose to draw a comic with the title "A Misunderstanding" about conflict between themselves and a teacher, this could be used as a prompt for discussion to identify why the misunderstanding had occurred and take steps to prevent it in the future.

Complete the Comics

Using stick figures, thought bubbles and speech bubbles, draw some comics to show what people are doing, thinking and saying. Use these titles:

1. "Getting Told Off"
2. "Doing Good Work"
3. "Working Well With Other People"
4. "Excellent Friends"
5. "A Misunderstanding"

Stick figures (with labels!)



Thought bubble

Speech bubble

Figure 9 The initial design for 'Complete the Comics' – an activity to explore understanding

Drawing was an engaging visual activity that did not require lengthy writing, which many of the students had expressed irritation with during their responses in the first phase. For those students who like to draw and are good at it, the creation of a comic allows them to use as much detail and artistic flair as they wish. Similarly, for students who dislike or lack confidence in drawing, the use of stick figures is designed to negate the need for any artistic skill in drawing the comics. To provide a structure for students, instructions were provided, explaining the ideas of speech bubbles and thought bubbles, and offering suggestions for a title for the comic. The titles were chosen to represent educational experiences described by both the students on the autism spectrum and the autistic adults in the first-stage study, such as “A Misunderstanding”. A choice of five totals was chosen to allow the students the choice of title, as well as the option to draw more than one if they wanted to. This gave students a starting point to drawing their understanding within an educational context, whilst allowing them flexibility to create their own interpretations of the titles, and what they thought others might have been thinking in the interactions they drew.

5.2.3 Helping Hands: an activity exploring the nature of support

This activity was designed to help students on the autism spectrum identify their important forms of support. During the first phase of the study, students had suggested that they valued emotional support more than academic support, and when discussing support options tended to focus on emotional aspects. This contrasted with staff members, who believed academic support was more valuable to support students on the autism spectrum. The more detailed and personalised the support options identified by students, the greater likelihood that this may be able to be used in a meaningful way in the school environment.

A visual representation of this support was explored by detailing each person who supported the students as a “helping hand”. To explore both general and specific forms of support, students were asked: “what does _____ do to help you?” The student could then identify friend/family/staff member names and note down a minimum of three ideas per person on the ‘helping hands’, hand shaped pieces of paper that the students annotate and then cut out (see Figure 10 for the original template used). Rather than using photographic representations of ‘helpers’, or drawings, the ‘helping hands’ template was designed to be a very simple symbol that could be easily cut out and allowed enough space for the students to write inside them.

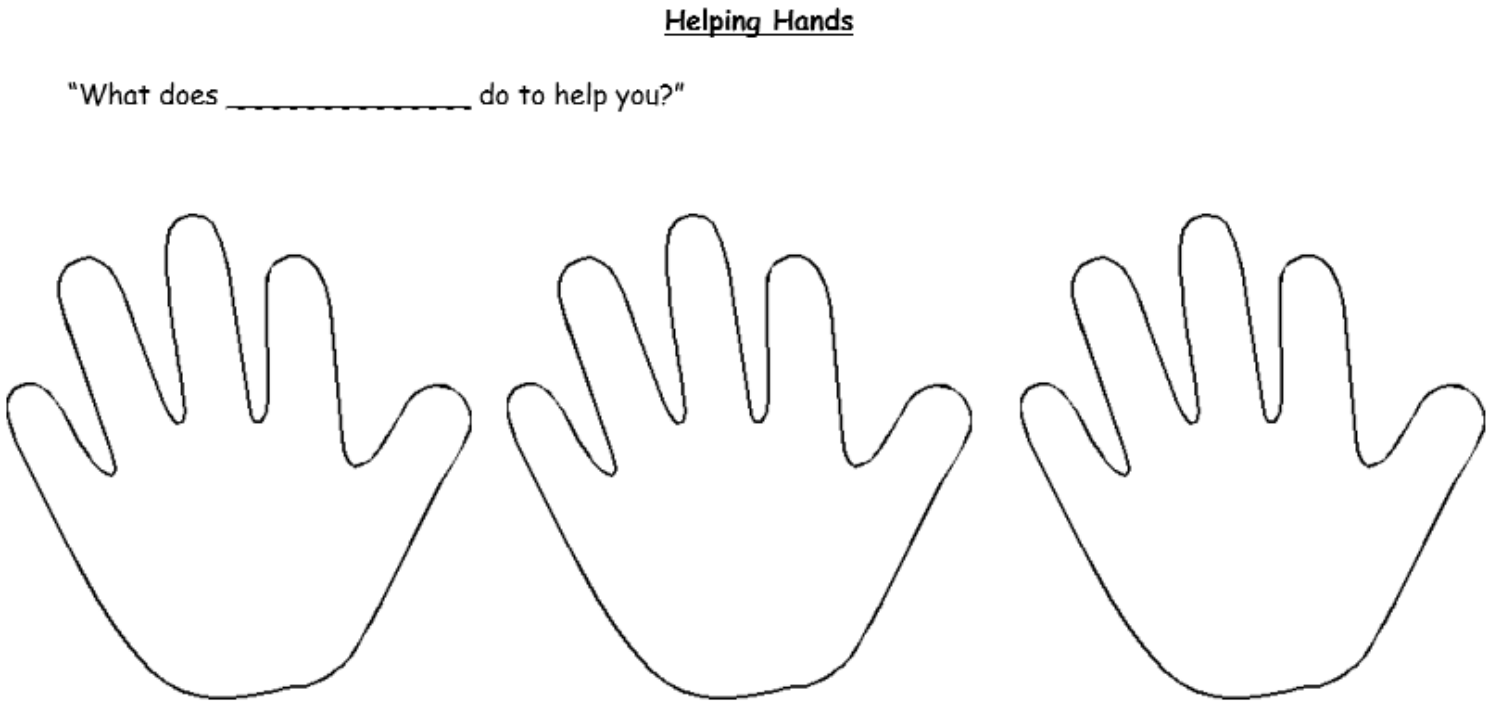


Figure 10 The initial design for 'Helping Hands' – an activity to explore the nature of support

Choosing a very basic line drawing therefore reinforced the idea of the hands as general symbols of 'help' to allow the representation of supportive people in the school environment. Identifying who students perceive to be supportive can help to personalise the support they receive in school through alternative channels; for example, students are usually assigned a personal tutor to deal with emotional and pastoral support in schools. However, if students do not feel that their tutor is supportive, they may wish to seek emotional and pastoral support from elsewhere.

5.2.4 Support Sorts: an activity exploring perceptions of staff availability

This activity was designed to use the information from the Helping Hands activity. The process of sorting the 'helping hands' identified using an adapted version of Thomas and O'Kane's (2000) diamond ranking technique. Students can sort the hands in two ways; firstly, from the 'help' that they find most important to the help that they find least important; and secondly, from the 'help' that they receive most frequently to the 'help' received least frequently (see Figure 11 for some examples of sorting layouts). These two ranking tasks demonstrate the different perspectives of students and staff members regarding the quality compared to the quantity of interactions that contribute to perceptions of staff availability. The interpretations of importance and frequency are individual to each student and will be discussed to ascertain what is most important, regardless of where the support comes from originally. This ranking method was used in the first phase using the photographs students took, and the students' engagement and familiarity with this method gave me confidence that it was an engaging activity. As the helping hands used in the sorting are taken from the students' own examples – and the sorting patterns negate the potential confusion of a right or wrong answer – this method also demonstrates that the students' voices are expert regarding their support in school. It also offers opportunities for multiplicity. For example, when sorting the helping hands in order of importance, if a student places one helping hand some distance away from the next helping hand, the distance suggests a visual representation of the perceived gap in importance between the two examples.

The importance and frequency of the support that students perceive from others can potentially be used to increase the level of support that they feel they are receiving in the school environment, if it is meaningful. The type of support – and who it comes from – in relation to each student may be used to personalise and solidify the support networks they have in school. For example, if support from a friend is ranked as the most important, staff members may consider this when organising group work.

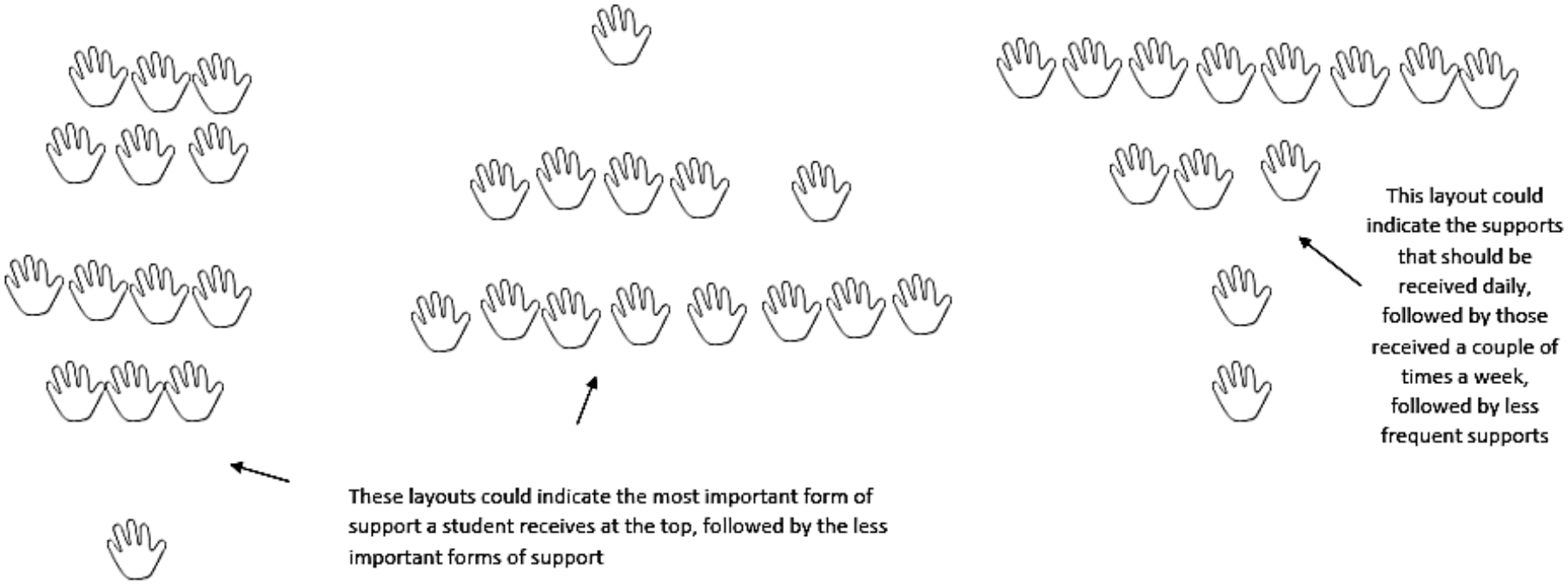


Figure 11 Potential sorting layouts of helping hands, used to support my ethics application form

5.3 Re-designing the four thematic activities

Once I had initial designs for the four activities, the next step was to involve the students on the autism spectrum and the autistic adults to help refine them into meaningful and personalised activities that could be used in school to facilitate communication and support. This section details the process of re-designing, as well as highlighting the changes that were made to form the final designs.

5.3.1 Procedural details

After creating the four initial designs, I submitted a new Ethics application for the second phase of research to the university ethics board and was granted permission to carry out the study (see Appendix G.1). I then met with the students on the autism spectrum and autistic adults in February 2017 to debrief them on my findings from the first phase of the research. As part of these debriefing sessions, I enquired whether they would like to participate in my second phase of research which involved evaluating the four initial designs – the unanimous response from both groups was positive, indicating they were happy to continue working with me on the next phase of the research.

Four adults who had participated in the exploratory phase also elected to take part in the second phase of the research: Emily (pseudonym), Ann (pseudonym), Peter (pseudonym), and Alex (pseudonym). A recent member of the group, Dan (his own name) was interested in the research from the first phase, and therefore also elected to take part in the discussions for the second phase. As mentioned previously (p.65), all individuals had received a diagnosis of either Asperger Syndrome or ASD as adults, ranged in age from 30-70 years old and had a range of occupations. Information sheets about the second phase of the research (Appendix G.2) and consent forms (Appendix G.3) were sent via email to the group two weeks before we met. I then met with the five autistic adults in February 2017 for a single focus group as part of their monthly meeting in which we discussed the four initial designs. I had prepared the following questions to stimulate discussion:

1. Give me three words to describe [name of activity]. Tell me why you chose those words.
2. Do you think this [design] could help students to talk to a teacher/learning support assistant? Why (not)?
3. Do you think this [design] could help a teacher/learning support assistant to support students? Why (not)?
4. What could be done to make this [design] better?

However, only the second and third questions were necessary, as the autistic adults were keen to offer their own individual insights into what worked and what did not regarding the four designs and talked explicitly about their usefulness and usability in an educational context. Their responses were audio recorded using a voice recording application on my iPhone so that I could accurately quote them, but their feedback was noted by me, summarised and agreed upon by the group regarding each activity after we finished discussing it.

All six students who took part in the first phase of the research also took part in the second phase as well (see Table 23). As all the students were still under the age of sixteen, they were given modified information sheets (Appendix G.6) and assent forms (Appendix G.7) to indicate their willingness to be involved in the second phase of the research. Information sheets with greater detail (Appendix G.4) and consent forms (Appendix G.5) for their parents were sent via the school.

Table 23 Summary of student participant characteristics at the start of the second phase

Pseudonym	Age	School Year	Diagnosis
Yazi	12	8	Asperger Syndrome
Sage	12	9	Autism Spectrum Disorder
Genji	12	8	Autism Spectrum Disorder
Hanzo	13	9	Undergoing diagnostic process
Bob	13	9	Autism Spectrum Condition
Jack	12	8	Asperger Syndrome/ADHD

Whereas the autistic adults were keen to discuss all four activities together, the students expressed a preference for discussing each design separately. I therefore met with the students in their schools during February and March 2017 to discuss each of the designs with them in groups (three students in each school). Meetings took place within various private rooms within the schools and were audio recorded using a voice recording app on my iPhone for accuracy of quotations if needed. As with the autistic adults, I had prepared the following questions for the students to prompt our discussions:

1. Give me three words to describe [design]. Tell me why you chose those words.
2. Do you think this [design] could help you to talk to a teacher/learning support assistant? Why (not)?
3. Do you think this [design] could help a teacher/learning support assistant to support you? Why (not)?
4. What could be done to make this [design] better?

However, as with the adults, the students started offering feedback and improvements on each design immediately, and therefore only the second and third questions were asked. Once each discussion was finished, I summarised the feedback I had been given by the group and the students confirmed it was an accurate representation of what they had said.

5.3.2 Impact of the contributions

Following the group discussions of the autistic adults and the students on the autism spectrum, I summarised their feedback and used this to re-design the four activities. This resulted in three sets of feedback; one set from the autistic adults, and two sets from the students (one from each group in the two different schools). The challenge was to try and incorporate the feedback that had been given by both the adults and students, whilst preserving the differences that the students had mentioned so that these could be used for individual personalisation. Feedback from all three groups were tabulated in relation to each activity. Due to the link between the Helping Hands and Support Sorts activities, the discussions naturally evolved to comment on both, and therefore feedback from these two activities were compiled together. Once summarised, I coded each piece of feedback to identify whether the comment made related to the content of the activity, clarification of the activity, or the style of the activity. Once the specific feedback from each group had been coded for each activity, these were combined to compare the feedback between each of the three groups (see Appendices H.1-3).

I then identified possible amendments that could be made depending on the adults' suggestions, and possible amendments that could be made based on the students' suggestions to see if there were any pronounced differences. Interestingly, although the comments between groups differed regarding the activities, the overall nature of the comments were very similar; for example, both students and adults identified that the labels used in the initial design for the Motivation Mixer needed to be changed to increase clarity, even though some of the suggestions for how these should be changed differed. Contrasting stylistic opinions also meant that more than one version of the Motivation Mixer and Helping Hands activities were produced (see Appendices I.1-4). All six of the students were noticeably less impressed and more easily bored with the 'Helping Hands' and 'Support Sorts' activities, which meant the amount of writing and sorting needed to be reduced to make these activities much shorter.

In addition, some aspects of the designs needed to be changed to incorporate student interests more actively – for example, when evaluating the 'Complete the Comics' activity, Sage provided thoughts on the topics provided:

> *'Doing good work' is boring…because you get stuff done, but it's boring, so I don't think I could draw a comic about that*

A summary of the changes made is shown in Table 24. A second round of re-designing was completed with just the students on the autism spectrum acting as informants; this was because they were the 'end users' of the activities that I was designing, and therefore their personalisation was key to ensure maximum usability of the final designs. I met with both student groups again and showed them the design changes I had made and the different design options for each of the different activities based on their feedback. The students commented positively on the changes and chose the designs that best suited them to complete individually as activities (see Appendices J.1-3 for the final designs).

Table 24 Summary of changes made during the first iteration of the activities' re-design

Activity	**Nature of changes made**		
	Content	Clarification	Stylistic
The Motivation Mixer	Sensory categories added	Category labels re-named Written prompt sheet added (1 additional design)	Colour added Pictures added Text could be removed (1 additional design)
Complete the Comics	Additional comic of own choice added	Titles of comics changed for relevance Increased instruction Themes as well as titles added	Stick figure removed
Helping Hands	Addition of 'Not helping hands' added for contrast	Amount of writing reduced Inclusion of animals and hobbies as well as people Numbers added to fingers (1 design)	Colour added 'Not helping hands' differentiated from helping hands (2 additional designs)
Support Sorts	Both helping and non-helping hands sorted together	Non-helping hands added as counterpoint to helping hands Sorting time reduced	Colour added

5.4 Gathering and evaluating the student information

5.4.1 The students' contributions

I met with each of the six students individually between six and eight times throughout March and April 2017 to complete each activity individually (except my last meeting with Yazi and Genji who requested to complete the Support Sorts activity together). Although the 'back and forth' style of discussion established in the group work was much more limited when working with the students individually, these individual discussions were still very informal; students would make fun of me, draw in my research diary, draw on my hand, and pick up objects from the surrounding environment to interact with.

Once all the activities had been completed, the students and I had detailed discussions about the information and graphics that each of them wanted to be included in the information sheet. The students were offered the option of creating their own sheets, but all six of them were reticent about the idea of doing "extra work" outside of our meetings. The level of detail that was dictated during our discussions – including exactly what information they wanted to be included from each activity, preferred colour combinations, writing styles (e.g. first or third person), favourite things that they wished to be featured in the images and even font choices - meant that I therefore used our discussions to design a personalised information sheet for each student (see Appendices K.1-6). Unfortunately, due to time constraints and scheduling issues, it was not possible to show the students their personalised information sheets to receive further feedback on their suitability. However, as I knew this would not be possible ahead of designing the information sheets, I took very detailed descriptions from the students regarding the content and style. Nevertheless, this lack of member checking (Guba & Lincoln, 1989) inevitably limits the credibility of the information presented in these information sheets, and the credibility of my findings that are based upon them.

5.4.2 The educational practitioners' contributions

Originally, I wanted to organise focus groups for all members of staff who worked with an individual student to create some general guidelines about how the information sheet might be used and adapted to inform their communication and support. However, due to the time constraints placed on staff members' availability, it soon became clear that organising a meeting was not possible, with one gatekeeper in the school explicitly advising me that I had more chance of getting responses if I contacted staff through email and invited them to comment individually, which I did in June 2017. The staff members targeted included the six members of staff who had previously worked with me during the

first phase of the research in addition to all the other teachers who worked with each of the six students. However, this only resulted in two responses from staff members I had previously worked with in the first phase study (Nancy and Amy). Due to the limited responses from this initial recruitment for participants, additional educational practitioners were contacted via personal email and social media accounts, asking if they would be interested in taking part in the second phase of this research (please see Appendices G.10-12 for the ethical amendments this required). Their views gave me an opportunity to see how useful the information sheets would be if given to someone who was potentially going to be teaching the students for the first time. This meant that a total of sixteen educational practitioners contributed their views of the information sheets (see Table 25 for details).

Table 25 Summary of educational practitioners involved in the second phase

No.	Sex	Age Range	Sheet received	Knew Student?	Occupation
Nancy	F	30-40	Bob, Jack	Yes	Assistant Head of Department (secondary)
Amy	F	40-50	Yazi	Yes	Head of Department (secondary)
Celia	F	20-30	Hanzo	No	Classroom teacher (primary)
Mira	F	30-40	Jack	No	Lecturer in Higher Education
Siobhan	F	30-40	Sage	No	Peripatetic music teacher (all ages)
Julia	F	30-40	Hanzo	No	Classroom teacher (secondary)
Becca	F	30-40	Genji	No	Special needs assistant (all ages)
John	M	40-50	Sage	No	Classroom teacher (secondary)
Angela	F	30-40	Genji	No	SENCO (secondary special education)
Stella	F	50-60	Genji	No	Classroom teacher (secondary)
Gemma	F	30-40	Hanzo	No	Speech and language therapist (all ages)
Gerald	M	50-60	Yazi	No	Executive Headteacher (secondary)
Sarah	F	20-30	Bob	No	Teaching assistant (primary special education)
Helen	F	30-40	Jack	No	Assistant Headteacher (secondary)
Victoria	F	30-40	Bob	No	Assistant Head of Department (secondary)
Carol	F	30-40	Yazi	No	Head of Department (secondary)

Most of this sample (10/16) consisted of females aged 30-40 years old, which is perhaps unsurprising as all the additional participants selected were known to me and therefore were likely to be similar in age. However, I felt that the variation in their job titles, location and experiences were sufficient to provide a range of views on the personalised information sheets.

For the two staff members involved in the first phase, I arranged to meet with them in their schools face-to-face, sending information sheets (Appendix G.8) and consent forms (Appendix G.9) via email. When we met, consent forms were signed and the opportunity to ask any questions was given. I then showed them the personalised information sheets that were relevant to them (i.e. for the student they worked with) on my laptop, and asked them the following questions:

1. What do you think about the information that [student] has provided?
2. Has this information increased your knowledge of [student]?
3. How might you use this information in the future?
4. What guidelines could you create to help communicate with [student]?
5. What guidelines could you create to help support [student]?

Both semi-structured interviews took place in June 2017 and were audio recorded using a voice recorder on an iPhone to be transcribed later. Once the interview was finished, they were thanked for their time and asked if they had any further questions. The additional educational practitioners were also sent information (Appendix G.11) and consent forms (Appendix G.12) via email, which were also signed and returned to me via email. Once these were received, I randomly allocated one of the students' information sheets to each educational practitioner using a basic name generating program on my laptop. One information sheet was then sent to each practitioner via email, along with the following introductory prompt:

> Attached is an information sheet about a student called [ ] who has a diagnosis of Autism Spectrum Disorder. I want you to imagine that you will be teaching [them] in September. Can you read the information sheet and then answer the following questions (either by email, or arrange a time with me to talk on the phone or Skype!)

The same five questions asked face-to-face to the staff members were then included in the email. Fourteen of the eighteen educational practitioners responded, choosing to send written responses to the questions via email. I responded to each reply, thanking them for their time and answering any further questions that they had. I then assigned each participant a pseudonym. This final part of the data collection process took three months overall between June – August 2017.

5.4.3 Analysis methods

The two audio-recorded interviews were transcribed into written responses and added to the fourteen emailed responses to give sixteen responses to the information sheets. These sixteen responses were uploaded into NVivo and coded inductively using thematic

analysis. Initially, I coded the responses to identify two themes: general comments that were made about the information sheet, and specific strategies that the individuals described relating to communication and support. The sub-themes emerged inductively and evolved as each additional response was coded, leading to two iterations of my coding key (see Appendices L.1 & 2).

5.5 Findings from the second phase

The main aim of this second phase was to attempt resolution of the double empathy problem by designing four activities to facilitate communication between students on the autism spectrum and staff members in the four key areas of difference in their perspectives that emerged from the first phase. Both the students and the staff members' perspectives on the designs, and the viability and usability of the methods within the school context, were examined (see Table 26 for details of how this phase of the research contributed towards answering the research questions).

Table 26 Sources of data contributing to the second phase research questions

	What kind of methods could be beneficial for facilitating communication and support?	What kind of information about students on the autism spectrum could be beneficial for facilitating communication and support?
Students on the autism spectrum	- Individual students' examples from the activity completion - Comments from activity completion - Initial student group design meetings - Student group re-design meetings - Debriefing/update meetings	-
Autistic adults	- Initial design focus group - Debriefing/update meetings - Email communication with myself	-
Educational practitioners	-	- Debriefing/update meetings - Semi-structured face-to-face interviews - Email responses to information sheets - Additional email contact with myself

5.5.1 The perspectives of the students on the autism spectrum and the autistic adults

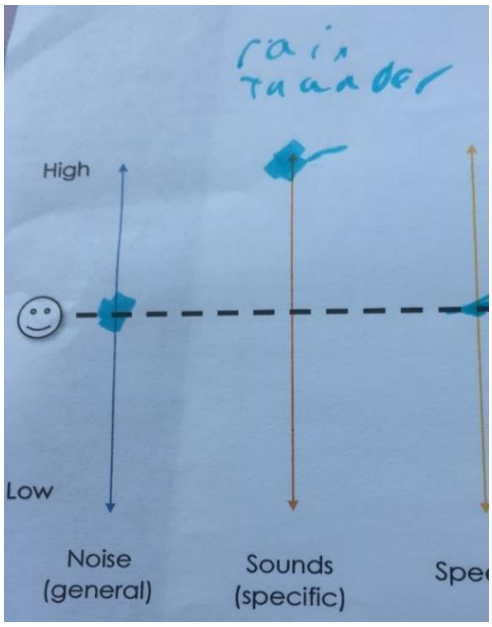
5.5.1.1 The importance of personalisation

This theme emerged very early on in discussions regarding the design of the four activities, where both student groups and the autistic adults highlighted the need for more specific instructions and examples to make each activity more suitable. For example, during the autistic adults' discussions, several comments related to the visual nature of the tasks. For some adults, this was seen to be extremely advantageous, but for others, a familiarity with the written word and further instructions were preferred rather than a visual approach and a verbal explanation, hence the written prompt sheet created for the Motivation Mixer, as this was agreed to need the most explanation out of all the activities. During the students' discussions, all the students commented positively on the ability to draw rather than talk for both the 'Motivation Mixer' and 'Complete the Comics' activities.

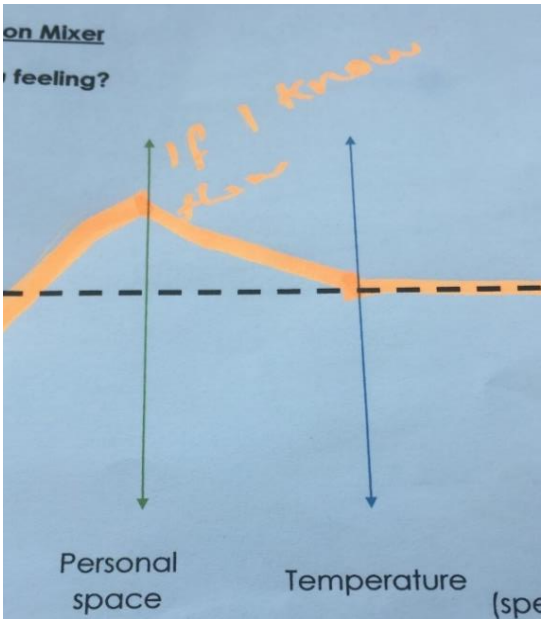
However, the amount of writing involved in most of the activities (and the 'Helping Hands' activity especially) was very off-putting for Jack, Hanzo and Genji, who all expressed strong preferences for the least amount of writing involved possible. Again, we therefore negotiated this as part of the re-designs for 'Helping Hands' to ensure that the amount of 'hands' (and therefore, writing) involved could be scaled down by swapping written explanations for verbal explanations. These examples highlighted yet again that even at the design stage for these activities, the needs of individuals need to be considered to give them the best possible chance for engagement, and the activities themselves need to be easily personalisable and flexible enough to allow this. This finding reinforces similar messages from the literature, such as Nind and Vinha (2013), who advise that doing research inclusively may require greater personalisation of research methods to meet the individual needs of participants. Similarly, Benton and Johnson (2014), Frauenberger, Good, Fitzpatrick and Iversen (2015), and Brosnan, Parsons, Good and Yuill (2016) all argue that individuals on the autism spectrum need to be involved at earlier stages of the design process for precisely this reason. This personalisation also extended to how the students completed the four activities individually. All six students added their own annotations when completing the Motivation Mixer activity (see Figure 12 for examples) to communicate their own preferences and individual answers and provide additional information. For example, Bob talked about the need for background noise to concentrate; fiddling with pens and general stationery helped to channel anxiety in new situations or with new people; and higher levels of excitement led to increased movement, e.g. when playing video games. Sage identified specific noises and smells that induced nausea, pain

and tears. This detailed information illustrates how important this personalised information is when trying to support and communicate with students on the autism spectrum.

Figure 12 Examples of students' personalised annotations for 'The Motivation Mixer'



Genji indicates that although they are generally quite tolerant of noise, importance 'levels' for specific sounds – especially "rain" and "thunder"- are much higher, as they find these very distressing



Hanzo indicates that in general, the importance of personal space for them is quite high; however, they add the caveat of "If I know them" to demonstrate that familiarity reduces the level of personal space they find comfortable

Further evidence of personalisation can be seen in the 'Helping Hands' activity, where the differences in writing preferences that the students had expressed (in terms of the amount of writing they preferred) can be seen (see Figure 13). This demonstrates that even though all the students completed the same activities, the ways in which they completed them were able to be personalised to their own strengths and preferences. This also extended to personalising their experiences during the process of completing the activities. For example, when I met with Jack, they found it very difficult to focus on the 'Helping Hands' activity to complete the sentences about how they were supported. Jack explained that it was because the activity was "boring", asking "can we maybe go outside and do an activity out there where we move around?" Although this was not possible to do at the time, we decided that rather than sitting straight down to complete the activity, Jack and I would go for a quick walk around the school first so that Jack could point out where some of the 'hands' were situated in the school. This also reinforces how including the option of movement in an activity – such as the photo trail Jack had previously completed – may also be advantageous. Incorporating this physical movement first meant that Jack then seemed much happier to sit down and write afterwards and completed the activity

much more quickly. The importance of personalisation was therefore not only demonstrated in the comments made by the students and the autistic adults; it was also demonstrated by the students' levels of engagement and interaction when completing the activities individually.

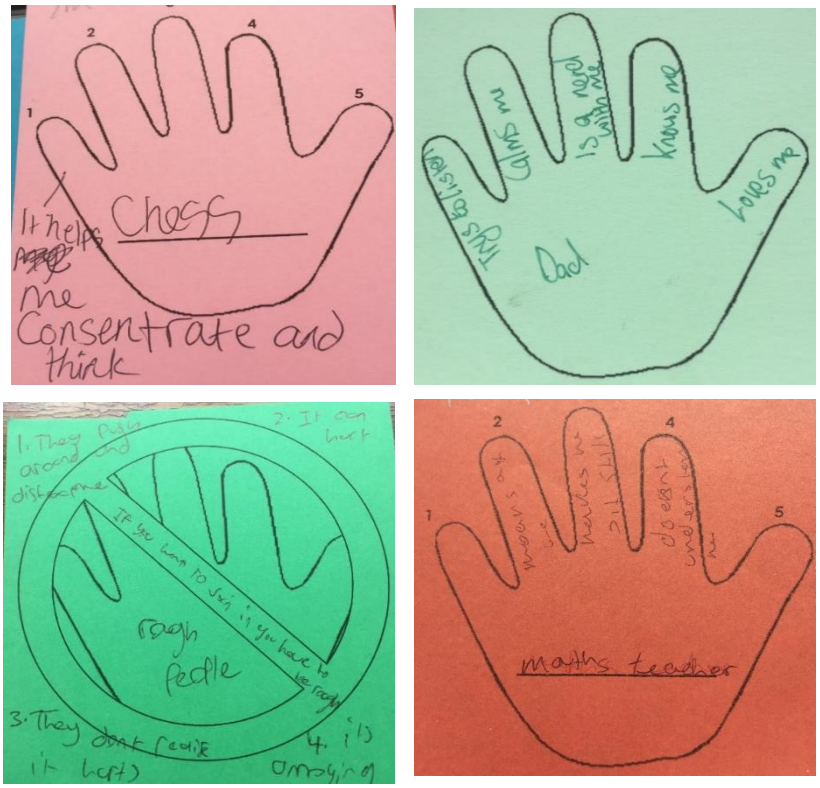


Figure 13 Examples of the 'Helping Hands' activity demonstrating differences in personal writing preferences

The level of personalisation all allowed examples of non-verbal communication to emerge. In general, a common non-verbal communication demonstrated by the students included the positioning of photographs, such as placing one photograph some distance from the others to distinguish extreme feelings regarding what it represented. For example, Sage reinforced verbal descriptions of their extreme dislike towards Maths lessons by placing the photograph over 40cms away from other lessons (see Figure 14). Another example comes from Yazi whilst completing the 'Support Sorts' activity in the second phase. Although the structure of the 'Support Sorts' activity was familiar to the students from the exploratory phase, much more extreme forms of placement were used in this second phase, which added yet another level of communication. Yazi, when asked where the two 'unhelpful' people would be placed in the sort, threw both 'helping hands' over to the other side of the room before declaring *"There. As far away as possible".* This reinforced Yazi's extreme dislike of the two 'unhelpful hands' in a way that may not have been possible to demonstrate verbally.

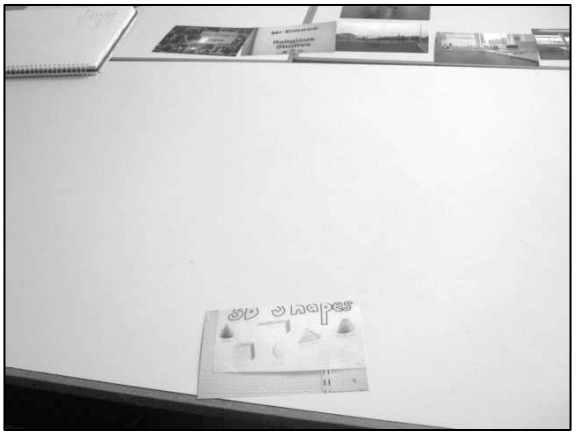


Figure 14 Sage's non-verbal communication of their dislike of Maths represented by positioning

These comments from the students illustrate the importance of personalisation: both in creating activities that are designed with the specific needs of individuals on the autism spectrum in mind, yet also that are flexible enough to be personalised to individual students, such as allowing for movement and elements of non-verbal communication to allow students to choose the way they engage. Gallacher and Gallagher (2008) comment that different kinds of participation from children during interviews can be labelled as "non-participation" (p.507) by researchers rather than seeing this as a different type of communication and/or participation. For example, Jack's comment about wanting an activity with more movement could have been a refusal to complete the intended activity; however, it also communicated Jack's personal requirements at that moment in the research. Billington (2006) argues that one of the main challenges facing professionals working with individuals on the autism spectrum is identifying "ways in which we can access the views of autistic children in order to identify the ways in which they currently manage their 'worlds'" (p.11). The flexibility inherent in these activities offers multiple opportunities for different kinds of participation and communication, and therefore may reveal much more than a standard face-to-face question and answer interview.

5.5.1.2 The importance of understanding and caring

Interestingly, this was one of the few areas that students on the autism spectrum and autistic adults generally disagreed with each other. On seeing the four activities and discussing them, the autistic adults were very positive and very hopeful about the potential of the activities to increase the understanding of staff members and others in schools. Dan particularly liked the Motivation Mixer activity, as he thought that it may give staff a much better understanding of just how different sensory experiences can be. Ann thought that the Helping Hands activity would be a good way for staff to understand that the importance level a student assigns to a person or a source of help may be very different from the importance staff assign to it. For example, a SENCO may think that their role in

working with students is incredibly important in terms of support, whereas the students may not see them as someone who is supportive. Alex also commented that it might help staff to understand the importance of friendships to students on the autism spectrum, and how working with friends is sometimes not just a preference, but a necessity. In general, the autistic adults were therefore optimistic about the possibilities of the four activities in increasing the understanding – and consequently, the communication and support – between students on the autism spectrum and the staff members who were working with them.

In contrast, the students on the autism spectrum were generally not at all hopeful that completing the activities and passing on information to staff members would help to develop their understanding about the students. This was illustrated in both general comments and through discussions and completion of the four activities. Sage, Genji and Hanzo all drew comics that portrayed a member of staff in a negative light, and as someone who is unwilling to listen to the student's side of the story and instead reacts hastily and by shouting. This was also sometimes expressed verbally as part of our discussions. For example, when discussing the comic about school, Genji described a member of staff who they got on well with, explaining this was because the member of staff in question understood Genji's personality and did not respond by escalating the situation, which made Genji more stressed and likely to lash out:

> *HH: Why does he understand you?*
>
> *Genji: I don't know. He just does. Better than other teachers who simply get nothing.*
>
> *HH: How do you know he understands you?*
>
> *Genji: Because he doesn't do the things that other teachers do.*
>
> *HH: Like what?*
>
> *Genji: Shout at me.*

Similarly, Yazi gave the following example of a teacher not understanding their need to stim with the fidget putty they had been given:

> *[The teacher gave me a dirty look] … and I was like, 'well, ok, but I'm still going to fiddle with this…it's in my rights now because I've got a diagnosis'.*

Yazi expressed feeling initially guilty because of fidgeting, before remembering that the use of fidget putty had been included as a coping strategy in a report from the local child and adolescent mental health services. Despite this, Yazi still felt that the member of staff in question disapproved, despite being explicitly told that fidgeting helps Yazi concentrate

in lessons. The Helping Hands activity also reinforced how important 'feeling understood' is to the students, and how other people can be unsupportive if they do not understand. Bob, Yazi and Hanzo all identified people in their lives who did not support them, and all mentioned that one of the reasons for their lack of support was because they did not understand.

Similarly, references to being understood were made regarding people who did offer support. Yazi identified both parents and two best friends as being supportive because of their understanding. Bob named three people that demonstrated knowledge and understood: two family members (mother and sister) and a pastoral support worker in school. This theme of understanding echoes reports from individuals on the autism spectrum in the literature. Students involved in Williams and Hanke's (2007) research designing their ideal school felt that staff should be knowledgeable about each student; a student from Humphrey and Lewis's (2008b) study notes that teachers may know about their subject, but they know "nothing" about the students themselves (p.135). The perspectives of individuals on the autism spectrum involved in this research and other studies therefore suggests that being understood is crucial to feeling supported in school.

Another key finding from the Helping Hands activity closely linked with understanding was the theme of caring and helping. Table 27 illustrates the most important sources of support identified by the six students during the second phase (the top line in their Support Sorts activity). All six students identified at least one person who was supportive to them, including members of their family, close friends, teachers, and me. Interestingly, Yazi, Genji and Sage also identified one of their pets as a key source of support, with Sage also identifying the hobby of playing guitar as supportive because it is calming. When examining the reasons that students identified these sources of support, there are numerous mentions related to caring; such as calming the student down, protecting them, and being kind.

It is also interesting to note that the three examples of staff members identified as sources of support were identified as giving more pastoral support to the students rather than academic support; the only mention of this comes from Jack, who notes that the teacher helped with work in Maths. These findings suggest that the students rank the emotional support that they receive as most important, whether it comes from within school or outside it. These findings support similar examples of important sources of support that individuals on the autism spectrum have identified, including friends, family and pets (e.g. Ellis, 2012).

Table 27 Summary of student-identified sources of support in the second phase

Student	Source of Support	Reasons
Yazi	Parents (2)	Listens; calms me; nerd; knows me; loves me; understands me
	Best friends (2)	Understands me; makes me laugh; nerd; loves me; respects me; loyal; kind; known since birth; amazing; doesn't care [about other's opinions]
	Friendship group	Nerds; kind; funny; loyal; brave
	Cat	Calms me; loves me; doesn't try to make me stop [talking]; sits on me
Sage	Parents	Helpful; caring; kind; stick up for me; feed me
	Dog	Reassuring; comforting; fun; takes my mind off things; entertaining
	Guitar	Helps me calm down
Genji	Mother	Helps me when I'm stressed
	Cat	He lays with me; he sleeps with me; he's a cat [favourite animal]
	Me	Funny; banter; best
Hanzo	Mother	Cares for me; does things for me; looks out for me; protects me; we help each other
	Siblings (2)	Protects me; helps me; makes sure I'm ok; helps me with school and home; helps me if I'm sick
	Best friend	We help each other; calms me down; nice to me
	Pastoral worker	Helps me with everything [in school]
	Me	Helps me with my problems
Bob	Mother and sister	Caring; always there for me; funny & happy; understands my feelings
	Pastoral worker	Understands my feelings; helps me in school; bullying help; help with work
Jack	Teacher	Helps me in Maths; when I do something good he says "well done"
	Friend	Whenever someone takes my stuff, he helps get it back He helped me pack away my trains

Overall, what was very clear from the second phase was the students' belief that the information from the activities would not help them to communicate and be supported by members of staff. The students explained that this was because they believed that staff members were unlikely to change their behaviour following our discussions:

> *Sage: It's great you doing [the activities] with me and the others, but it won't change what [member of staff] thinks about me. [Member of staff] will always hate me; [they] don't get me at all.*

> *HH: Do you think the others [teachers] could learn to understand you?*
>
> *Genji: Nope.*

When I tried to explore the reasons for this, the students did not give any detailed explanation for their feelings; for example, Hanzo replied "they just won't". Similarly, Sage commented that even after staff received the information sheets "how they act in class won't be any different". A slightly more detailed explanation came from Bob, who mentioned that some staff were willing to understand, and some were not. When pressed to explain this further, Bob only replied "I don't know…some just care more, maybe". The students' responses made me aware that on one level, some students felt that not being understood by staff members was a result of the staff members choosing to do so. Consequently, the students' perception was that giving staff members extra information was unlikely to change the way they acted towards them within the classroom. Therefore, although the students were generally positive about the activities themselves, they were not convinced that the information gleaned from them would facilitate their communication and support in the school environment.

5.5.1.3 Levels of student understanding and awareness

One of the possible facilitators of communication and support that emerged from the first phase relates to students' self-awareness and self-understanding. Improving this could help prepare students for later life by increasing their own self-awareness and self-knowledge about how their diagnosis impacts positively and negatively upon them. This was highlighted by the autistic adults again in the second phase, especially as many of them had been diagnosed as adults and had struggled to 'make sense' of why they did things when they were younger. Emily illustrates this in the following quote:

> *Knowing yourself and your own things is vital for surviving…because other people just won't know. And being able to say, 'I need to drink water because I'm Aspergic and it helps me with my anxiety' also helps other people to understand and accept what you're doing, whether they think it's strange or not.*

Although the students were not explicitly asked whether completing the five activities raised their self-awareness and knowledge, the comments they made whilst completing the activities and the interactions they had with each other suggest that the activities may have helped them to focus on understanding about themselves and their sensory experiences. This was best illustrated when discussing pertinent information to be included on the individual student's information sheet. For example, Genji identified that "not shouting" was the most important thing teachers could do to help on a day to day basis, whereas for Yazi, being allowed to fiddle without being told off was crucial in reducing anxiety in lessons.

The way that the students talked about their sensory experiences was much more confident and detailed during the second phase, most likely because they were asked explicitly about them during the Motivation Mixer activity. However, part of this detail came from the sharing of mutual experiences by working together in group settings. For example, when evaluating the Motivation Mixer, exclamations of "me too!" and "I do that as well!" were common in both student focus groups when one student shared information (such as the irritation associated with people shouting). This prompted individuals to share more about their own experiences than they did when originally asked a question individually. For example, Bob and Hanzo talked at length about how energetic and full of movement they became when playing video games, despite preferring very different levels of movement and energy to feel comfortable during a classroom situation. Having the visual prompt of the Motivation Mixer and working in groups therefore allowed the students' easier access to each other's experiences, which allowed them to reflect further on their own. After completing the Motivation Mixer with Hanzo and Jack, Bob commented how different the responses were between them:

> *It's interesting…we're all in different places [on the sensory channel of 'speed of thoughts'] even though we all have autism.*

When asked to elaborate, Bob explained that the students knew that they were 'different' from their brothers and sisters and peers because they "didn't have autism", but it was also interesting to see that Bob, Hanzo and Jack were also different when compared to others "who do have it", i.e. each other. This suggests that Bob's self-awareness relating to others on the autism spectrum may have been increased by taking part in the group activities and then reflecting on the sensory experiences described. These findings suggest that including a group element in activities that ask explicit questions about students' experiences could be a potential way to increase their own levels of self-awareness: not just in comparison to neurotypicals, but potentially in comparison to others on the autism spectrum. As increasing levels of self-awareness can be extremely effortful for individuals on the autism spectrum (Müller, Schuler & Yates, 2008), especially

regarding social interactions, these activities may be useful in offering individuals on the autism spectrum a structured way to explore their individual needs. This increased understanding of themselves and improved self-awareness may then support the students in school when communicating about themselves and the support and opportunities that are best suited to their individual needs.

5.5.2 The perspectives of the educational practitioners

5.5.2.1 Impact on understanding

A clear theme from the comments and strategies reported by the educational practitioners was that the personalised information sheets were useful for both themselves (and could also be useful for others) in increasing their own understanding of individual students. Evidence for this came in a variety of detail. Some individuals made generalised, positive comments about the usefulness of the information sheet's design:

> *I like that it's in [their] own words. So often the conversation about a student involves a myriad of people but not the child.*
>
> *(Siobhan, Peripatetic music teacher)*

> *The information is very helpful – it gives clear links between certain situations, how Bob might feel, and how [they] might therefore react. It covers a wide range of situations and includes lots of things that would be very relevant when dealing with [them] in a classroom setting.*
>
> *(Victoria, Assistant Head of Department)*

The two members of staff who knew the students beforehand both indicated that they were familiar with quite a lot of the information that was given, yet also demonstrated that there were some surprises in the accounts the students had given:

> *Things like the sensory stuff – sensitive to hearing, touch – I mean, these are things that I would never ever have known, and that's not the sort of information that would come through something like that [gestures to Jack's individual learning plan from the school]*
>
> *(Nancy, Assistant Head of Department)*

> *Wow…I've got a major problem with my lighting, it's old and it's noisy and it drives me mad, so if [Yazi]'s got sensitive hearing…oof…*
>
> *(Amy, Head of Department)*

These quotes demonstrate the importance of the students' perspectives – both members of staff knew the students in person, had received IEPs, and had worked with them for at least six weeks yet still were not aware of the sensory differences that Jack and Yazi described. Sensory differences cannot be observed by others, and therefore without the students' perspectives, the impact of these – both positive and negative – may not be considered by educational practitioners when planning to communicate with and support students on the autism spectrum. Information about the students' sensory experiences was therefore seen as something new, that was useful, and that could change the way these teachers had worked with Jack and Yazi.

The educational practitioners who did not know the students gave much more detailed demonstrations of how their understanding of an individual student had been increased:

> *[Genji's] information about memes and cartoons: This suggests an area of expertise, and thus the ability to acquire knowledge. It also expresses a desire to share.* *(Stella, Secondary school teacher)*

> *As Art is a strength of [Hanzo's] and something [they enjoy] this should be encouraged and made time for on a regular basis*
>
> *(Celia, Primary school teacher)*

> *Yazi to meet teachers/LSA(?) individually before entering the classes, or at least seeing each classroom environment before other children come in. This could be before or after school in preparation, so teacher could see [Yazi's] reactions to different physical areas?* *(Gerald, Executive Headteacher)*

> *Allow [Yazi] to fiddle with something as this helps [them] and do not challenge [them] on this. If possible try to use a font that works for [them] in your [PowerPoints] (although this is hard as other advice is to use a different font and you can't please everyone - but you could avoid comic san ms)*
>
> *(Carol, Head of Department)*

These comments are very positive as the individual nature of each student is acknowledged, and the educational practitioners are demonstrating their understanding of each student's needs through personalised strategies that they could use. This suggests that individual knowledge about a student can allow much more personalised strategies to be implemented when communicating with and supporting them. Interestingly, there were also examples of how the information sheets the educational practitioners may use the

information sheet beyond the scope of the individual student. Three of the educational practitioners (one who knew the student, two who did not) mentioned how the information sheets may also contribute to their understanding of other students that they may encounter, as illustrated by the following quotes:

> *I feel that this would have some use in preparing me to work with other students with ASD. Some of it is obviously very specific to Hanzo, but a number of [Hanzo's] characteristics are also indicative of common tendencies and characteristics of people with autism/Aspergers, so having this explained in such detail will help me to understand other students with similar diagnoses in future*
>
> *(Julia, Secondary school teacher)*

> *[The knowledge from Jack's information sheet] would make me question the behaviours of other children and the underlying reasons…I could also use some of the strategies suggested by Jack to see if they help other children whom appear to be struggling.* *(Helen, Assistant Headteacher)*

Although these personalised information sheets were designed for the individual students, these comments suggest that they may also represent a 'starting point' for educational practitioners who feel they are not confident in supporting students on the autism spectrum. Some specific suggestions may be able to be adapted to support other students on the autism spectrum in the future, or prompt consideration of how these strategies may benefit others; for example, how this information could increase others understanding of the students, and how this could also be usefully used within an educational context:

> *It is about 'spelling it out' for an audience that will include a variety of adults, both at home or off site, as well at school, to avoid inadvertent misunderstanding*
>
> *(Gerald, Executive Headteacher)*

> *I may need to explain to the class that Jack can't help the noises, they are like a sneeze* *(Helen, Assistant Headteacher)*

> *It is important that as [their] teacher and other professionals working alongside [them] that we are fair and consistent whilst also remembering that often some of [their] behaviour can't be helped and to ensure that [they are] not disciplined for any of these* *(Celia, Primary school teacher)*

Finally, a variety of comments were made that related to how the educational practitioners could use the information provided to help students increase their own levels of understanding. This related mainly to increasing the student's academic understanding, such as their understanding of the topics being taught and their general understanding in lessons. Interestingly, the educational practitioners with additional knowledge about special education also made comments related to increasing students' personal understanding of additional life skills, such as personal, social and emotional understanding:

> *Using colours to help express how [Genji] feels on a certain day and let it be [their] own thing so perhaps a bit of the wall with [their] name and the colours blue for sad, red for angry, yellow for relaxed, green for anxious and when [Genji] comes into the class room [they put up] what [they are] feeling but only the teacher and [Genji] know what colours mean what.*
>
> *(Becca, Special needs assistant)*

> *I would model appropriate ways of dealing with frustration on a daily basis and model different ways in which we can communicate and words to describe how we are feeling to help…I would do this in a number of ways e.g. visual prompts, scripted language (I think you are feeling angry because... I think you have hurt your friend because...) and role play, acting out scenarios using toys/figures.*
>
> *(Angela, SENCO)*

> *You know something that would be interesting...Two columns – that side is the student [left], this side is how the teacher perceives the student…just saying 'my impression of you is this'…so the students have access to this too, and they can see 'oh right ok, this is what they [member of staff] feel when I do X/Y/Z'.*
>
> *(Nancy, Assistant Head of Department)*

These comments suggest that the educational practitioners recognise that different types of support that can be offered to the students on the autism spectrum, even if the most frequently mentioned examples given were academic support.

Overall, the comments by the educational practitioners suggested that their understanding of individual students, their understanding of other students, the understanding of others (e.g. their colleagues, the student's peers) and the students' own level of self-understanding had the potential to be improved using the details that the personalised information sheets provided, with some explicit references to how these could be used to facilitate communication and support with students on the autism spectrum. This is

extremely encouraging and highlights how important it is for professionals to listen to the perspectives of individuals on the autism spectrum to inform decision-making (Guldberg et al., 2011) that can be used to better support them in an educational environment.

5.5.2.2 Impact on communication

Another key theme related to aspects of communication that the educational practitioners described, and the impact the information sheets may have on this. The most commonly identified strategies and comments related to how individuals would use the information given to adapt the way they communicated with the students to support them:

> *When speaking to Bob, have some form of guide or prop that [they] can choose to look at rather than expecting [them] to maintain eye contact (instruction sheet, work, a demonstration item etc)*
>
> *(Victoria, Assistant Head of Department)*

> - *Allow time and an appropriate space for non-confrontational communication.*
> - *Listen first and allow [them] to express [their] frustrations and problems.*
> - *Explain how you will address [their] issues, or why you cannot*
>
> *(John, Secondary school teacher)*

> *Maybe a communication chart could be developed over a period of time. This will detail [Jack's] verbal and non-verbal messages, [and] development of communication.* *(Mira, Lecturer in Higher Education)*

> *- Allow time for language processing when giving instructions and asking questions. Don't repeat what you have said until Hanzo asks you to.*
>
> *- Allow time for Hanzo to formulate [their] ideas and do not rush [them] or try to finish sentences of [sic] [Hanzo]*
>
> *- Hanzo is a perfectionist- keep this is mind if you need to tell [them that they have] got something wrong/needs to hurry up with work*
>
> *(Gemma, Speech & Language Therapist)*

> *If a loud noise happens or someone shouts, I would immediately and calmly reassure [them] that nothing bad has happened, everything is as it was, or that no one was shouting at [them]*
>
> *(Sarah, Special needs teaching assistant)*

This was very positive to see, as educational practitioners demonstrated that they were able to use the information provided to modify the ways in which they would communicate with the students if they were to teach them. These comments would suggest that the information sheets therefore had a positive impact on these educational practitioners in terms of their perception of ability in creating communication strategies for the students on the autism spectrum. However, comments from three of the educational practitioners suggested that additional information was needed to adequately create communication guidelines:

> *I believe it would be best if I worked with Jack's parents/carer to get as much information and…communicate with [Jack] in a way that [they are] used to. Also, gain an understanding from them [parents/carer] of what I should look out for as initial signs of interest/distraction/distress/difficulty (verbal and non-verbal) when I work with Jack* *(Mira, Lecturer in Higher Education)*

> *I feel there is insufficient information to formulate a means of communicating… I'd say just let [Sage] come to you… [and when interacting] generally avoiding eye contact and confrontation. This is more from my general knowledge of the diagnosis as opposed to specific suggestions here.*
>
> *(Siobhan, Peripatetic music teacher)*

> *One piece of information that I personally might find helpful would be what helps [them] feel calm/safe/less anxious once [they have] begun to feel anxious, and what behaviours [they normally display] when [they do] start to feel anxious so I know what [they are] feeling without [them] having to verbally tell me, as this may be difficult for [them]* *(Sarah, Special needs teaching assistant)*

The theme of additional information and resources is discussed in more detail in the next section, but these comments highlight some of the additional information that the educational practitioners felt might be useful. The examples of additional information mentioned here could be easily obtained through discussions with the students and their parents, as despite these comments, every educational practitioner was able to suggest some communication guidelines to use with the students on the autism spectrum. This

suggests that in general, the information provided could be used to facilitate communication with students on the autism spectrum. The fact that guidelines were able to be developed by all the educational practitioners also suggests that the inconsistency in the perceived usefulness of the information provided may be due to other contributing factors. For example, Able, Sreckovic, Schultz, Garwood and Sherman (2015) have identified that teachers' knowledge and about autism and their levels of confidence in their ability to work with students on the autism spectrum are two crucial factors affecting their ability to support their students.

Educational practitioners also identified the importance of working with others and communicating the information contained within the information sheets to other people. For some, general comments on how they would use the information related to including it in personalised student plans, such as ILPs and EHCPs, where the information would be a static resource that others could access on an 'as needed' basis. Other practitioners gave more proactive and detailed thoughts regarding the challenges of effectively communicating this information to other colleagues in school, and to the families involved:

> *How will all staff know how best to deal with [Yazi]? This could be a case conference, with a review after a couple of weeks, but perhaps on an INSET day at the beginning of the academic year, some pointers given to all staff who may come across [them] in less structured situations - e.g. Break time? ...one of the key features is how to give confidence to* ***all*** *[bold type as original] adults who support Yazi, rather than rely on a few to take the lead so others are potentially deskilled* *(Gerald, Executive Headteacher)*

> *The problem is it's all very well me doing this while I'm teaching [Sage], but what happens if a supply teacher comes in? Or someone shouts at [them] on the playground because that's what we do to be heard above all the racket? Or [Sage] annoys one of the cleaners because [Sage is] upset by some of the smells…I know it's meant to help, but you can't give all this information to everyone who will come into contact with [Sage] just in case [Sage] gets upset – that's just not possible* *(John, Secondary school teacher)*

> *I also think it is important to ensure that… the family are aware of [video games Genji plays] which are appropriate and inappropriate. From my experience as a teacher, children who play inappropriate games can think that violence is how to cope… [and so I would] reinforce that gaming is very different to how we communicate in real life.* *(Celia, Primary school teacher)*

The involvement of several agencies – including the family – is mentioned frequently throughout the SEND CoP (DfE, 2015), and therefore it was very positive to see the educational practitioners reflecting on how this information could be most effectively communicated to others, even if their comments also reflected the challenges involved with this process. This also has wider implications for how student information may be (mis)communicated between agencies (Milbourne, Macrae & Maguire, 2003) and the negative impact this may have on a student's educational experiences (Molteni, Guldberg & Logan, 2013). Overall, these quotes from the educational practitioners suggest that the information sheets could improve their communication with the individual students on the autism spectrum, yet also acknowledged the challenges associated with this and with communicating this information to other relevant parties involved in the students' educational progress.

5.5.2.3 The need for additional resources

As the members of staff involved in the exploratory phase had all mentioned the importance (and sometimes scarcity) of resources, I was unsurprised to see this emerge as another key theme from the educational practitioners' responses in the second phase. Their discussions about additional resources related to two main sub-themes: the design of the information sheet itself, and additional resources that would be needed to implement the strategies they had described. Although the educational practitioners were generally positive about the potential of the content of the information sheet for improving communication and support, the relevance and detail of the information included - and the effectiveness of its design - were questioned. Some practitioners commented that they would require further details from the information sheet:

> *Could you be even more specific about 'full of movement', since it is your opening statement? I understand the general point, but does this include regularly getting out of [their] seat, for example?* *(Gerald, Executive Headteacher)*

> *An indication of the severity of the issue might be helpful too. For example, how 'uncomfortable' is 'visually uncomfortable'?*
>
> *(Nancy, Assistant Head of Department)*

> *I would want more info on receptive and expressive language abilities and higher level language skills, inference, prediction, problem solving and reasoning etc.*
>
> *(Gemma, Speech and Language Therapist)*

In contrast, others commented on the amount of detail in a negative way, suggesting that some of the information could be removed for its irrelevance, or changed in some way to make it more accessible and improve clarity:

> *If you were teaching several students that had these [information sheets] it would take a long time to read them all and information could be muddled*
>
> *(Carol, Head of Department)*

> *I'm not sure how much the interests would help me as a teacher…I would have this [the key information] as a set of bullet points at the beginning…also, [Yazi] could rank them so the first thing we see on this sheet is what is most important to [them]…it would be lovely to have this online with all [Yazi's] other information*
>
> *(Amy, Head of Department)*

> *Understand about the favoured font, but pretty horrible for others to read*
>
> *(Gerald, Executive Headteacher)*

> *I hated the [rainbow] background and couldn't work with it (I took it off). I may well be in the minority and it could be due to my dyslexia*
>
> *(Helen, Assistant Headteacher)*

This seemed to indicate that although staff gave examples of how the information provided could be used to improve communication and support with students on the autism spectrum, there were elements of its design that the educational practitioners felt could be improved to make it more effective. Some of these comments also highlight the tension between catering to an individual student's needs whilst balancing the needs of others (such as the educational practitioners themselves and other students), as illustrated in the following quote:

> *The only thing that worries me as I'm going through it - the information is really interesting and really helpful but it's whether we can do anything to help on some of the things. So I would end up feeling quite guilty because I would feel like our wall displays – I want to put children's work up, so it's this conflict of opinions…there are some things that are gonna be more difficult than others [to adapt]* *(Amy, Head of Department)*

These comments relating to the content of the information and the need for less detail demonstrates the different perspectives and individual differences between the students

and these educational practitioners. This highlights how difficult it is developing a source of information that works for both groups and therefore may help to resolve the 'double-empathy problem'.

In contrast to the students, whose comments suggested they believed that the responsibility for improving support lay with staff members, several comments detailed the additional resources that would need to be provided for these educational practitioners to implement the strategies they discussed were also highlighted, suggesting effective support would not be something that could be managed by themselves:

> *I would not have enough time to prepare adequately to address [Genji's] issues, so I would have to do my best. At times I would be able to plan enough, but in generally [sic] not. Even with a TA it would be difficult to adequately plan*
>
> *(Stella, Secondary school teacher)*

> *[Genji would need] A dedicated TA who is fully acquainted with [their] issues.*
>
> *(Becca, Special needs assistant)*

> *[The school needs to provide] Access to online materials to help adults at home participate in off site learning* *(Julia, Secondary school teacher)*

> *It strikes me that there are some aspects that I can prepare for on my own, to inform my lesson planning and so on, and other aspects that imply the school needs to have structures and strategies in place for staff to work together.*
>
> *(Victoria, Assistant Head of Department)*

> *I think what [the information sheet] does…it creates a dialogue with the teacher. And then it's up to [Yazi] to keep having a go at the dialogue, say once a term, as a reminder - because as teachers, we get set in things and focussed on other stuff.* *(Amy, Head of Department)*

Although the educational practitioners identified detailed and insightful suggestions for how they could individually support these students, these comments suggest that the educational practitioners feel that there is a limit to how much responsibility they are able to take, and that the wider school community may need to be involved in supporting staff members to conduct these educational discussions. Some possible reasons for this were given by Nancy, an assistant head of department who took part in the first phase of

research and had some additional background knowledge of special education as part of her extensive teaching experience:

> *Our SENCO will always say 'here is all this information, you are responsible for doing this in your classroom, and if you need my help you ask'; but I think on a day-to-day basis, classroom teachers are not very good at taking responsibility for that. And it's not necessarily because they – I mean, it does happen – that they cannot be bothered, but also I think it's because of lack of ownership, lack of knowledge, lack of empowerment to actually genuinely do it.*

This suggests that there are challenges involved when using the personalised information sheets that may not relate to its design or content, but instead relate to the experience and confidence of the educational practitioners using it. This further supports the varying levels of confidence teachers have when supporting students on the autism spectrum, and how this may negatively impact on their ability to communicate with and support their students in an educational environment (Able et al., 2015).

In conclusion, the findings from the second phase of the research are mixed. The autistic adults and the educational practitioners both commented on the potential of the four thematic activities to facilitate communication and support when working with students on the autism spectrum. Although the students themselves appeared to be engaged by the activities and demonstrated increases in their levels of self-awareness, they did not see the activities as being helpful in supporting them due to their belief that the staff members who were working with them did not want to change their behaviour. Unfortunately, some of the staff comments seemed to reveal that their attitudes are in line with this belief. This illustrates the complexity of resolving the double-empathy problem existing between the students on the autism spectrum and the adults they work with and indicates the scale and nature of the potential attitude change that may be needed.

Chapter 6 Discussion

The main aims of this research were firstly, to listen to the experiences of students on the autism spectrum regarding the processes of communication and support in schools, and then to explore the ways in which these processes could be facilitated. In the context of the statutory mandates in the SEND CoP (DfE, 2015) to include students on the autism spectrum in discussions and decisions about their education, exploring ways to facilitate these discussions may prove useful in strengthening the inclusion and support these students receive by creating personalised educational provision within the secondary mainstream school environment. In addition to encouraging students on the autism spectrum to communicate about their experiences, a secondary aim of these discussions was to allow the students to develop greater self-awareness about their own strengths and challenges that could potentially help them throughout their time in education. This chapter details the main findings from my discussions with the students on the autism spectrum, the autistic adults who performed an invaluable advisory role for the project, and the educational practitioners who were involved in this research and discusses them in both the context of my conceptual framework and the research literature.

6.1 The importance of 'being understood' for facilitating communication and support

In the first phase of my research, my discussions with the students on the autism spectrum and educational practitioners provided some insights into the current communication and support processes in their secondary mainstream schools. The definitions of effectiveness of these processes varied between sources – the students, the educational practitioners, the autistic adults, and educational policy, viz. the SEND CoP (DfE, 2015). Although general definitions of what constituted effective communication and support can be surmised from each group, finding an overall definition that encompasses these contrasting viewpoints is incredibly challenging. However, in general, my research suggests that a key area of importance in facilitating support and communication revolves around the concept of a student being understood. This section therefore highlights some of the main challenges around being understood for students on the autism spectrum, and consequently, the challenges in improving the processes of communication and support.

6.1.1 Demonstrating understanding through emotional support

The students all explicitly stressed the importance of being understood when discussing features which facilitated their communication and support in the mainstream environment. General discussions about what effective support 'looked like' for each of them tended to see students favouring emotional and pastoral support as being most effective, as this offered an opportunity to demonstrate an understanding of the individual student's needs. However, the students highlighted that the most effective emotional support tended to come from specific friends and family rather than the school itself, and that these were the individuals who understood them best. The importance of emotional support in coping with school was also mentioned frequently by the autistic adults (although it should be noted that each of them was diagnosed as an adult, and therefore were not offered specific provision when they were attending mainstream secondary schools). Occasionally, educational practitioners were identified by students as offering effective support and this was almost always linked to examples of emotional support that had been provided in the school setting; for example, help with bullying, building of confidence, having someone to talk to about their problems (see p.149). This suggests that the students on the autism spectrum (and the autistic adults) in this research tended to view the most effective support they received at school as emotional, partly because the students felt that educational practitioners offering emotional support demonstrated a greater level of understanding of them and their needs.

Conversely, although educational practitioners from both phases of the research commented on the importance of supporting the well-being of their students, this support was described in terms of specific pedagogic strategies that supported the student academically, such as offering encouragement or checking that instructions given to the whole class were understood by the individual (see p.96). When talking about the importance of getting to know students to personalise their education, the knowledge deemed most important tended to relate to specific guidelines or tasks that they could use within a classroom setting. The only instance where emotional support was mentioned in the first phase of the research were from two teachers who also had pastoral roles with the students. The educational practitioners involved in this research therefore appeared to equate their understanding of students with demonstrations of their pedagogic knowledge. The students, however, equated educational practitioners' understanding of them with demonstrations of emotional knowledge. Consequently, many of the students reported that they were not understood by most educational practitioners that they worked with, despite the same educational practitioners having in-depth knowledge of personalised academic strategies that were used to support their learning in the classroom.

Fouse (1999) comments that providing the emotional support that students on the autism spectrum require could be difficult for some educational practitioners who see their supporting role as “strictly academic” (p.198). There is also support for the positive effects of the link between teachers’ emotional support and students’ motivation; for example, Ruzek et al. (2016) used both observations and student reports from just under 1000 neurotypical students to demonstrate that emotional support led to students reporting increased autonomy and the ability to relate to their peers in the classroom. In relation to students on the autism spectrum, my findings suggest that emotional support is identified as important by them. The relationship between being understood and being emotionally supported is also evident in some of the studies from my literature review, especially from the nine studies that fully aligned with my conceptual criteria for listening authentically to the voices of students on the autism spectrum. For example, Ellis (2012) noted the following from her ethnographic study of an autism-specific unit in a special education secondary school:

> For a relationship to exist and become meaningful to the autistic student, it is imperative that the other individual understands their needs and accommodates them in interactions (p.128).

The students in Ellis’ (2012) study identified the educational practitioners allocated to their tutor groups as the main source of support through the photographs that they took and the accompanying comments about how the tutors helped and ‘were there for them’. These students were taught in tutor groups and had two educational practitioners who moved with them from lesson to lesson to support their learning. The students also described many of their friends as being helpful. This could demonstrate further evidence from students that educational practitioners who offer some emotional/pastoral support are also seen to offer a level of understanding that is noticed and appreciated by students. Descriptions such as kind, smiley and knowing each pupil also emerged from the participants in Williams and Hanke’s (2007) study where students drew their ideal schools, which could also link to the definition of “emotional support” from the perspectives of students on the autism spectrum. It is valuable to view this issue through the lens of the double-empathy problem which suggests that the emphasis should be on neurotypicals to learn about the needs of individuals on the autism spectrum. The findings from my research demonstrate that the students on the autism spectrum would have appreciated more comments that illustrated understanding from staff members, suggesting that the emphasis on understanding lies with the educational practitioners (see p.93). If educational practitioners continue to define understanding in terms of academic strategies, this support may not be acknowledged as effective by the students on the autism spectrum with whom they work.

Similarly, the students on the autism spectrum need to at least be aware of the demands placed on educational practitioners within the classroom (e.g. to achieve academic targets), and therefore acknowledge that these concerns may be easier to identify than concerns for pastoral support. The comments from students throughout my research demonstrate that they are already aware that the educational practitioners valued academic support, as they identified various strategies that the educational practitioners who worked with them employed to support them in a classroom setting (see Table 14, p.92). However, the methods I employed in my research focussed on increasing staff understanding of the students' perspectives, and therefore could have better highlighted the staff members' perspectives to strengthen this understanding. For example, at the end of the first phase, I met with the students to debrief them and explained the four areas of differing perspective between them and the staff members. This discussion could have been structured to encourage more reflection from the students: for example, asking why they thought staff members thought that.

Likewise, in the second phase of the research, the methods I used were designed to improve staff members' understanding of the students, as both staff and students had agreed that this needed improving in the first phase study. To facilitate communication and support between the students on the autism spectrum and the members of staff, there were potential opportunities to explore staff members' perspectives in greater detail, such as asking more probing questions during the activities when staff were discussed, and maybe stating staff members' views from the first phase for the students' consideration. However, viewing educational practitioners' understanding through the lens of the double-empathy problem suggests that the emphasis is on them to increase their understanding of the students, which is why my focus was on increasing educational practitioners' understanding, rather than also increasing students' understanding of educational practitioners' perspectives.

This link between emotional support and demonstrations of student understanding requires further exploration to see if there is evidence for this outside the group of six students involved in this research. If so, this has significant implications for the role of pastoral and emotional support in schools. One potential theory that supports the link between understanding and support comes from Edwards (2018), who states that understanding differing perspectives is crucial to working together towards a common goal. She reflects on the different motivations that practitioners have when working together and how this may present challenges when working towards a common goal. Edwards (2018) believes that communicating "common knowledge" (p.2) – what truly matters to people – is instrumental to working together, as sharing and listening to the 'common knowledge' of each differing perspective is the only way that people can work

together and succeed. She defines the term ‘relational expertise’ as the “capacity [for practitioners] to elicit and hear what matters to others and be explicit about what matters to themselves” (p.2). Edwards (2018) gives the example of teachers, parents and social workers as three groups with potentially differing motives who may all be working towards a common goal (supporting a child in school). However, the amount of relational expertise that is demonstrated predicts an ability to work successfully together:

> Joint understanding of what matters in each practice allows people to sensitively calibrate their responses to the problem so that their work aligns with and supports the responses that are offered by others (p.2)

In the context of my research, the educational practitioners are motivated to support a student on the autism spectrum through their time in mainstream secondary school and beyond. My findings suggest that they place more importance on pedagogic and academic support to achieve this, with less importance attached to emotional support. The students, in contrast, place a greater emphasis on emotional support. Edwards’ (2018) notion of relational expertise therefore can be applied to the extent to which students on the autism spectrum and educational practitioners are able to express their own perspective and listen to each other.

The findings from my research suggest that both students and educational practitioners were able to express the things that are most important to them. My findings also suggest that the six students on the autism spectrum demonstrated at least partial awareness of the educational practitioners’ views relating to the importance of academic support (see p.92); yet also suggested that the educational practitioners were not aware of the importance the students allocated to emotional support. Applying Edwards’ (2018) theory to this situation therefore suggests that the relational expertise of the educational practitioners needs to be improved for them to work with the students on the autism spectrum towards providing effective support in schools. This therefore provides further support for the view that educational practitioners have an increased responsibility for improving communication and support.

6.1.2 Demonstrating understanding through knowledge of personal interests

Although both the students and the educational practitioners involved in this research agreed that understanding was key to providing effective educational provision, their demonstrations of this knowledge differed. Another difference in perspective related to the importance of involving students’ personalised interests in their education. This feature of being understood emerged from discussions with the students about educational practitioners displaying a knowledge of personal information about the student: for

example, hobbies/interests, family, pets, and mentioning this when communicating with them. These views were echoed by the autistic adults in their suggestions for my own communication with the students in the very first part of my research, where they suggested asking about personalised information to help develop a relationship and demonstrate my interest in the students (see Appendix D.2). They also constantly reminded me of needing to treat each student as an individual and how this was a very easy way to start, giving examples from their own lives of how an understanding of themselves as an individual would have led to much easier times at school, at work and throughout their lives. The consistent message from both the students and the autistic adults was, therefore, that personalised knowledge of an individual, including their interests, was essential for effective educational provision. This included being able to demonstrate understanding and build a relationship, and to make classwork motivating and relevant to the student's specific interests, where the breadth and depth of knowledge can be a great strength.

Conversely, discussions with the educational practitioners did not reveal a consistently similar level of importance assigned to this personalised information. In the individual interviews conducted as part of the first phase of the research, the educational practitioners frequently mentioned difficulties in 'getting to know' students, such as having limited lesson hours with them, and linked this explicitly to effective provision, suggesting that the more they understood a student, the better support they could provide. However, only one teacher explicitly mentioning using information about Jack's interests to develop a better working relationship and motivation in the classroom (although this could be a result of not asking about personal information explicitly). In contrast, the personalised information sheets for each student during the second phase of the research included copious amounts of personal information about each student, including their interests. The educational practitioners' responses to this level of personal information seemed to suggest that they placed a much lesser value on this personal information than the students and autistic adults. These included comments querying whether the personal information was relevant or useful to their teaching and asking for the personal information to be removed (p.160). The information that the educational practitioners seemed to find more useful – and therefore, commented on more positively – were explanations of students' underlying motivations that could not be revealed by mere observation, such as sensitivity to certain sounds. This pattern was seen across the responses to all six information sheets, suggesting that although personalised information as a concept was seen to be important, details about students' interests specifically was not held in the same esteem.

The responses from educational practitioners throughout both phases of the research therefore suggests that although they perceive knowledge of the students' strengths and limitations as important, they perceive knowledge of students' individual interests as less important. This is in direct opposition to the views of the students on the autism spectrum and the autistic adults, and therefore presents yet another example of the double-empathy problem, where the perception of importance relating to personal interests differs greatly. Individuals on the autism spectrum value the personal information that allows educational practitioners to demonstrate their knowledge of the individual student, and therefore would prefer more comments and pedagogic strategies where this is evident. However, the educational practitioners need to balance the needs and interests of all their students in a classroom environment, and therefore demonstrating personal knowledge about an individual may be challenging due to the constraints they mention, such as time. This represents another challenge when trying to support students on the autism spectrum to feel understood by the staff they are working with.

The suggested discrepancy regarding the value of personal interests to support educational provision could present a challenge when trying to improve personalisation. If the students on the autism spectrum value demonstrations of their personalised information as a key indicator of 'understanding', educational practitioners viewing this as less valuable could give fewer demonstrations of this in a classroom setting. However, it is not just the students who were keen for educational practitioners to make better use of their individual interests in the classroom - using personal information and interests to improve pedagogic support for students on the autism spectrum is well documented in the educational literature (e.g. Gagnon, 2001; Cowan & Allen, 2007; Leach & Duffy, 2009). A review by the Autism Education Trust (Charman et al., 2011) into good practice for autism education identifies one of the core fifteen principles relating to good practice as: "[those who] use innovative and individualised methods of adapting the curriculum, utilising pupils' strengths **and interests**, to make it accessible and rewarding for pupils with autism" (p.44; emphasis added). Despite using the medical term of 'restricted interests' which carries negative associations, Gunn and Delafield-Butt (2016) reviewed 20 studies reporting a combination of students' interests and teaching. They concluded that using a students' personal interests within a learning environment resulted in mainly positive effects – such as increases in motivation, task engagement, efficacy of reward systems and task performance – which outweighed the negative outcomes of using them or the decision to not use them at all.

Similarly, the National Autistic Society (2017) recommends a key support strategy for teachers in the classroom, advising them to "think about how you can incorporate their intense interests into lessons" (n.p.n). More recently, Martin and Milton (2018) have also

argued that using students' specialised interests is a key way in providing access to information by making it meaningful. This strengthening in meaning, the authors argue, can be used to potentially overcome some of the issues with executive function that can be associated with the diagnosis, adding: "Utilising a child's interests within the learning environment can also be highly motivating and calming, as well as a source of joy" (p.114). The findings from my research therefore illustrates the importance students on the autism spectrum allocate to using individual interests to facilitate communication and support in the school environment, therefore adding to the evidence base that already recommends it as a successful pedagogic strategy. Consequently, if the use of students' personal interests to facilitate their learning is supported, the question is why some of the educational practitioners in this research did not seem to value the personalised information relating to specific interests anywhere near as highly as the students or autistic adults: despite the advantages this has for improving the personalisation and effectiveness of students' support in schools?

A potential explanation comes from Gunn and Delafield-Butt (2016), who concluded from their review that although using students' personal interests to facilitate the learning environment resulted in mainly positive outcomes, the teacher's attitude towards the relevance of these interests was instrumental in whether they used these strategies. For example, if a teacher believed a special interest led to perseveration on one topic to the exclusion of others, they were not likely to value using a student's personal interest in the classroom setting. These beliefs may link to the teacher's level of training, confidence and experience, which are factors that are internationally documented as affecting educational practitioners' perceived ability to successfully include students on the autism spectrum (Blok, Kwon & Healy, 2016; Little, Vibulpatanavong & Evans, 2015; Majoko, 2015; and Odongo & Davidson, 2016). This suggests that a lack of confidence in teaching students on the autism spectrum is a widespread issue, which may be affecting educational practitioners' ability to use information that they are provided with. Able, Sreckovic, Schultz, Garwood and Sherman (2015) conducted focus groups with teachers in Carolina from elementary, middle and high schools (the equivalent to primary, secondary and further education settings in England) to investigate their perspectives on what they needed to effectively support students on the autism spectrum. Able et al. (2015) report that the teachers "strongly expressed their need to know more about ASD and **how to accommodate for students with ASD** in the classroom" (p.50, emphasis added). It appears that at least some of the educational practitioners in my own research may not feel they have the confidence, skills or experience to use the information that they are being given about the students effectively. This may include the personal details valued so highly by the students. This further highlights the necessity of including students' voices as a source of information in their educational discussions and decision-making.

A potential solution to incorporating student interests into teaching strategies in terms of increasing confidence was discussed with one of the educational practitioners in the second phase. She was a head of department and teacher who wanted to talk about developing more subject-specific strategies to support students on the autism spectrum. She suggested that departmental meetings held at the start of the year in her school to discuss the department's targets could also be an opportunity to discuss pedagogic strategies that were subject-specific to students on the autism spectrum who would be taught by members of the department. From her managerial perspective, she reflected that this could allow educational practitioners the chance to share information and challenges with each other and combine their professional knowledge and expertise to offer some basic strategies to try. She then suggested that further reviews of the success of these strategies could be discussed at departmental meetings throughout the term to adjust them as needed. The benefits of this approach, she argued, would mean that members of staff unsure about how best to support students on the autism spectrum could receive advise from more experienced and confident colleagues.

Although the solution discussed with the member of staff in my research related to subject-specific meetings, the idea of educational practitioners meeting in smaller groups to discuss how to incorporate personalised interests into their teaching strategies may be of use in overcoming different levels of confidence. In addition, Koegel, Matos-Freden, Lang and Koegel (2012) summarised research-based interventions for teaching students on the autism spectrum, including the obstacles that can prevent effective implementation of these interventions. One such challenge was the fact that interventions that did not 'fit' with classroom factors (such as expectations and current practices) were often adapted by teachers to fit, which consequently reduced the effectiveness of the intervention. If educational practitioners were discussing strategies for including personal interests in pedagogy, ideas for adapting strategies could also be discussed – especially if these strategies were revisited throughout the academic year, as suggested by the educational practitioner in my research. The importance of context is also supported by the findings from the first phase of my research investigating communication and support (see Section 4.3.1). This suggests that sharing professional knowledge at a local, subject-specific level may be advantageous for educational practitioners to develop contextualised pedagogic strategies in a group environment that utilises the experience, ideas and confidence of multiple staff members. Exploring group meetings to improve communication and support was beyond the remit of my research, yet it offers a potential solution for how the personalised interests of students on the autism spectrum may be used to support their learning in the classroom.

Another potential factor that may contribute towards educational practitioners viewing information relating to students' personal interests as less relevant may be the educational practitioners' perceptions of the amount of information that they are given in general about each student. The discussions I had with educational practitioners throughout my research mentioned the sheer amount of information they were given about each student, making it much more problematic to sort through and know how to apply effectively (e.g. p.94). Similar comments regarding time and the pressure at the start of the year were reported by Able et al. (2015). Many of the teachers involved in their focus groups commented on "the importance of understanding their students' individual learning needs at the beginning of the school year" (p.51), but that individual education plans (IEPs) were "too long to sift through to understand a student's individual characteristics and needs" (ibid). IEPs were also viewed negatively by the educational practitioners I spoke with in my research, describing them as being very wordy and non-specific. Negative comments relating to the amount of information included were also reflected in comments made about the information sheet that I developed in the second phase of the research; several educational practitioners included suggestions that it be trimmed down to a few bullet-points or summarised in some way to make it more accessible (e.g. p.160). Therefore, in addition to the *type* of information being given (the personal interests), the *amount* of information provided may also be a factor that affected the judgement of relevance given to individual interests by the educational practitioners in this study.

A potential solution recommended by Amy, a head of department who was involved in both phases of the research, was to create a 'bookmark' sized piece of card that each student could carry around with them until teachers got to know them. This could be handed to each teacher at the start of the lesson and would have three or four key bullet-points on it relating to teaching strategies. For example, for Yazi, a bullet-point could read: "I need to fidget to concentrate, please don't tell me to stop moving". Amy argued that in this way, teachers would have a few 'bookmarks' on their desk, and could refer back to this as needed. Including strategies which explicitly link to students' personal interests could make this personal information much more relevant and persuade educational practitioners of the value of using these interests to motivate and engage their students.

One encouraging piece of evidence is that similar tools that summarise key information about individuals on the autism spectrum are already in use outside the sphere of education. 'My Hospital Passport' is a booklet available from the National Autistic Society (2017) for individuals on the autism spectrum to fill in and pass to healthcare professionals to support their treatment in hospitals. In addition to sections focussed on medical history and medication, the hospital passport also includes sections related to communication needs, sensory experiences, and special interests. Identification cards that summarise

key information are also sometimes used to help police to effectively communicate and support individuals on the autism spectrum through local schemes such as Pegasus, Autism Alert, Autism Attention and Keep Safe Cymru (National Appropriate Adult Network, 2016). The use of small booklets and cards resolves the issue of lengthy amounts of information that IEPs have been critiqued for and could therefore reduce the workload that educational practitioners may face at the start of the academic year, and that may prevent them from remembering salient information to support their students.

However, all these information cards are voluntary, as are any shortened information booklets/cards that students chose to fill in for use within schools. Interestingly, IEPs are not mentioned specifically by the SEND CoP (DfE, 2015) – a move away from the recommendation for schools to use IEPs in the previous Code of Practice (DfES, 2001) - and therefore presents an opportunity to use other school-based plans to support students. Given the findings from my own research and others relating to the amount of information educational practitioners wish to see, this therefore has implications for developing a new working document within schools to support the progress of students on the autism spectrum that includes personal interests as part of it. This idea needs further investigation and offers a potential avenue to further explore different ways of presenting small amounts of personalised information to educational practitioners in accessible ways to ensure it is being used most effectively.

6.2 The importance of recognising strengths and challenges

Throughout both stages of this research, the six students on the autism spectrum who I was working with continued to surprise me with their insightful and detailed comments about their school experiences, their families, and how being on the autism spectrum affected them in both positive and negative ways. As my fieldwork took place over a two-year period in total (and three academic years), each time I met with the students they shared further information about the new achievements and challenges they were facing. Their experiences also tended to be relatively balanced, discussing both positive and negative experiences in equal depth; for example, although incidences of bullying were mentioned by all the students, each of them also mentioned specific friendships that were meaningful to them in school. In addition, although there were frequent examples of being misunderstood (by peers, educational practitioners and family), each of the students also highlighted key figures in their lives who they felt did understand them, including specific family members, pets, and specific educational practitioners.

The nature of the students' experiences was also mirrored in my discussions with the autistic adults, who again shared an even mix of both positive and negative experiences of their times at school upon our initial meeting. As we progressed further in our meetings, the autistic adults continued to offer me balanced and detailed discussions relating to the four activities, advising what was good and what they felt needed clarification. These comments were almost always illustrated with examples from their own experiences, which again gave me a detailed and comprehensive view of some of the specific successes and challenges in their lives, such as how font choice can make a significant difference in the ability to read written instructions more easily. These discussions highlight the importance of focussing on strengths as well as challenges when working with individuals on the autism spectrum.

6.2.1 Conducting research

I have previously noted my surprise at the level of positivity in my initial discussions with the autistic adults and how this significantly affected the way I conducted myself throughout this research (see p.66). My surprise revealed my own bias regarding my expectations about the autistic adults' experiences, and how I expected our discussions to be filled with mainly negative examples from their lives. This expectation of negativity is also reflected in the approaches of some of the research included in my literature review, where the focus – and indeed, expectation – was geared towards investigating negative experiences. For example, Chen and Schwartz (2012) investigated bullying and victimization of students on the autism spectrum rather than social interactions in general; Kalyva (2010) focussed on lower questionnaire scores representing social interactions compared to typically developing children; Bossaert, Colpin, Pijl and Petry (2012) focussed on investigating loneliness levels in students on the autism spectrum compared with typically developing peers; and Barnhill et al. (2000) interpreted students' views of themselves being at 'average' risk of experiencing emotional and mental health difficulties as a denial of the severity of their disability. Although researchers may want to focus on limitations or challenges to investigate ways in which to support individuals with these challenges – as this is still greatly needed – including strengths and skills may help to explore how these may be used to potentially counteract challenges that students on the autism spectrum may face because of their differences. For example, Williams (2011) describes how her strength in attention to detail allows her to create PowerPoint presentations that override her issues with syntax to allow her to successfully present to large audiences.

In contrast, research studies demonstrating full alignment with my conceptual criteria for authentically listening to the voices of students on the autism spectrum described findings from their participants that revealed similar balances in reporting positive and negative experiences. Ellis (2012), for example, reports on both positive and negative interactions with staff members that the students in her study commented on, as well as positive and negative examples of the photographs the students took and the comments that accompanied them. Similarly, Williams and Hanke (2007) discussed pictures of an 'ideal school' drawn by their participants; some ideal characteristics reflected the participants' positive experiences of school (such as light and airy classrooms), whereas other ideal characteristics were based on the opposite of negative experiences they had (such as wanting fun and caring teachers after experiencing teachers who they perceived to be neither fun nor caring). This suggests that research into the voices of students on the autism spectrum needs to ensure the inclusion of strengths, abilities and positive experiences alongside challenges, areas of improvement and negative experiences.

These views regarding the inclusion of strengths, abilities and positive experiences are also echoed in the wider literature. Robertson (2010) argues that including the strengths of individuals on the autism spectrum is key to shifting to a more neurodiverse perspective (away from a medical model, which is deficit-focussed) when assessing and improving quality of life measures. More recently, Mahdi et al. (2017) are refining an international measure of functioning for individuals on the autism spectrum which includes a broader approach to personality and temperament traits to include strengths related to autism, such as honesty, attention to detail, advanced memory functions, and expertise in specific areas. While autism spectrum disorder remains a medical diagnosis in the DSM-5 (APA, 2013) it is likely that the medical – and deficit-focussed – model of autism continues to pervade autism research. However, for researchers to respect the voices and experiences of individuals on the autism spectrum during the research process and when reporting their findings, an approach that seeks to incorporate both strengths and challenges must be taken.

6.2.2 Using terminology

In Chapter 1, I outlined my reasons for choosing the phrase "individuals on the autism spectrum", arguing that it is a phrase which most effectively allows for both strengths and challenges to be recognised. This decision was reinforced by my research experiences. My discussions with the students demonstrated that labelling could be used in a positive way and to create a positive aspect to self-identity, seen most strongly in Yazi's responses such as the information sheet (see Appendix K.6). When discussing their awareness of difference, Yazi, Hanzo and Jack also explicitly referenced being on the autism spectrum

as a way of explaining their differences to their neurotypical peers and to illustrate the lack of understanding that others demonstrated (p.111), using a mix of identity-first and person-first language. Their comments suggest that being on the autism spectrum plays a role in their identity, and therefore removing this label may have been detrimental. In addition, the autistic adults who chose to use identity-first language did not communicate to me that they were offended by this phrase, yet did offer comments that suggested a dislike of the terms 'ASD' and 'ASC', such as this quote from Mark in the first focus group of the exploratory phase:

> *Who I am is not someone with ASD, who is disordered…ok, yeah, I'll be the first to admit that it sometimes doesn't make sense! [laughter]…but who I am is autistic. It makes me a lot of things, but it doesn't make me a genetic problem to be studied by people who want to cure it.*

The term "students with ASD" was used exclusively in both schools involved in this study, both in formal documents (such as IEPs and EHCPs) and in verbal everyday use by the educational practitioners. However, none of the educational practitioners or students commented on their dislike of the phrase 'on the autism spectrum' when I used it consistently throughout our discussions. For the students particularly – who apart from Yazi did not consistently use either person-first or identity-first language – I felt more comfortable using a more neutral term, even one that differed from the labels that had been used previously by their doctors, parents and schools. The range of both positive and negative experiences described by the students and autistic adults in my research further reinforce the need to move away from language that may promote a focus on deficits – such as the terms ASD and ASC – towards more neutral language that also allows individuals to express autism as part of their self-identity in a more positive way.

6.2.3 Demonstrating inclusive practices

The need for moving away from a deficit-focussed approach also applies to definitions of inclusion. In Chapter 1, I stated that my years of teaching experience in secondary and further mainstream education was responsible for my personal alignment with an approach to inclusion as a concern with disabled students and others with SEN. This approach to inclusion believes that inclusion is primarily about educating students with SEN in mainstream settings (Ainscow, Booth and Dyson, 2006) and is "deeply entrenched" (ibid, p.17) in educational policy and practice in England. However, this approach may reinforce a deficit-focussed approach by concentrating on the individual's disability (rather than broader contextual factors) which can itself create barriers to a student's education (Messiou, 2017). Conn (2018) states that deficit-focussed labels and discourse may also affect inclusive practices, as it may "serve to reduce the capacity of

teachers to be open to their autistic pupils and what they bring to learning interactions" (p.602). My strong desire to avoid focussing on deficits is evident in my justification for the language I use, and therefore approaching inclusion as a concern with disabled students and others with SEN no longer matches my own conceptualisation of inclusion.

However, inclusion as a principled approach to education and society (the other approach I aligned myself with in Chapter 1) is concerned with the inclusion of all students in all schools. Although the values of this approach align strongly with my own (such as equity, participation and respect for diversity), my work with the students on the autism spectrum in this study has reinforced my feeling that their differences compared to other neurotypical students must be recognised and acknowledged to support their presence, participation, and achievement, which Ainscow, Booth & Dyson (2006) argue are also key to inclusion as a principled approach. This echoes the 'general differences' approach described by Lewis and Norwich (2005), where the distinct needs of students on the autism spectrum need to be catered for in addition to their individual differences compared to other neurotypical students. I do not think these differences are deficiencies (as perhaps might be suggested by adopting inclusion as a concern with disabled students and others with SEN), but failing to recognise these differences – which include both the strengths and challenges that students on the autism spectrum may present - may take away a source of identity for young people and lead to further barriers in education. I therefore still believe that my findings suggest that adopting the general differences approach – where the differences of students on the autism spectrum are recognised in addition to their individual differences – may offer these students the best chance of inclusion in mainstream schools.

Looking to the differences that students on the autism spectrum may present has been critiqued by Ravet (2011), who notes that "…if we re-categorise autism as a 'difference' rather than a disability, it might be taken a lot less seriously" (p.672). To try and resolve this tension, Ravet (2011) argues that two approaches to inclusion must be balanced. The first is the 'rights-based' perspective, which is based on the social model of disability and argues that all learners have a right to be taught in mainstream classrooms with pedagogies that are helpful to all learners. This approach also sees labelling as exclusionary, as the right to be the same (rather than different) is valued. In contrast, the 'needs-based' approach is associated with both the social and medical model of disability; labels are deemed useful, and the notion of 'one size fits all' regarding pedagogies is rejected. Ravet's (2011) proposed 'integrative approach' to inclusion occupies the middle ground between these two contrasting perspectives, and best reflects my approach to inclusion following this research. Within the integrative approach to inclusion, the negative effects of labelling try to be minimised using more neutral labels, and neurodiversity is

valued. The integrative position therefore seems to reflect the affirmation model of disability, which Swain and French (2000) describe as "a non-tragic view of disability and impairment which encompasses positive social identities" (p.569). Indeed, there are several similarities regarding the celebration of difference, the positive aspects of a disability identity, and the use of positive language. However, the integrative approach remains focussed on the challenges that students on the autism spectrum may face in an educational environment and aims to reduce them, rather than suggesting that the experiences of this group should be redefined in a positive way and "repudiating the dominant value of normality" (Swain & French, 2000, p.578).

In addition, Ravet (2011) argues that the integrative position includes the use of distinct pedagogies for inclusion, which are designed to support students on the autism spectrum but may also facilitate the inclusion of other students. The example mentioned in her paper include relates to the use of "explicit, structured teaching using low verbalisation and a highly visual approach" (p.677) to facilitate learning idioms. This approach reduces the processing load for students on the autism spectrum but may also be beneficial for students learning English as an additional language. Ravet's (2011) use of the term 'distinct pedagogies' – rather than 'special pedagogies' – is chosen purposefully to move away from the association with SEN and the needs-based perspective. Adopting an integrative position in mainstream secondary schools in England could also reflect the 'whole-school' approaches championed by the SEND CoP (DfE, 2015) in its outline of how students with SEN should be supported:

> School leaders should regularly review how expertise and resources used to address SEN can be used to build the quality of whole-school provision as part of their approach to school improvement (Section 6.3, p.92)

Although the SEND CoP (DFE, 2015) is remains focussed on SEN, the integrative approach could therefore be used to reduce the risk of exclusion of students on the autism spectrum by adopting distinct pedagogies that could be beneficial to other students.

However, Norwich and Lewis (2005) state that in order for a general differences approach to education to work, it requires "a general relationship between a distinctive group, however defined, and a generalised and distinctive kind of pedagogy" (p.216), before concluding that the evidence base does not appear to support a general differences approach to education, commenting that their work "illustrates how far we are from making those kinds of generalisations" (p.216). Ravet's (2011) integrative approach suggests that distinct pedagogies are needed to include students on the autism spectrum, yet she does not offer any insight into what these distinct pedagogies might be beyond the example of "explicit, structured teaching using low verbalisation and a highly visual approach" (p.677)

for learning idioms. This does not reflect the 'generalised' element of the pedagogy that Norwich and Lewis (2005) argue is needed for the general differences approach to education to work, as it only relates to learning idioms. However, my findings suggest that the use of personal interests could be used as a distinct and generalised pedagogical strategy for teaching students on the autism spectrum within the general differences approach. The students in this research stressed that being understood was crucial to their feelings of support and inclusion in the school environment, giving several examples of when misunderstandings had occurred (e.g. p.93). The students felt one way that staff members could demonstrate their knowledge about students was through awareness of the students' personal interests, suggesting that the inclusion of students' personal interests wherever possible could promote engagement and demonstrations of understanding from teachers. Villegas and Lucas (2007) offer support for the theory that this distinct pedagogy may benefit students other than those on the autism spectrum, as they advise that learning about students' lives and building on their interests outside of school are two strategies that can help to engage students from diverse cultural and linguistic backgrounds.

The integrative approach also aligns with the general differences approach to education, as the distinct needs of students on the autism spectrum (in this case, using personal interests in schools to demonstrate understanding) are addressed first, before considering more general teaching strategies and personalisation to account for individual differences. This contrasts with more nuanced approaches to inclusive practices in teaching. Florian and Black-Hawkins (2011) state that these inclusive practices tend to take the uniqueness of all learners into account (the unique differences position) to adapt their teaching to suit the needs of all their students. However, when teaching students on the autism spectrum, their distinct differences mean that taking a unique differences approach to their inclusion runs the risk of operating under normative assumptions about what might be best for all neurotypical learners if the teacher does not have an underlying knowledge of autism. This illustrates the biggest challenge with adopting Ravet's (2011) integrative approach as a starting point for inclusion: it demands that teachers need specialised knowledge about autism. Ravet (2018) herself states that:

> Teachers…require a knowledge and understanding of autism in order to penetrate below the surface of everyday behaviour and responses of children on the autism spectrum to the complex issues that lie underneath. (p.715)

The observable behaviours of students on the autism spectrum cannot necessarily be used to infer meaning in the same way as their neurotypical peers without this understanding. For example, the students in this research all identified differing sensory experiences affecting their educational experiences that have been echoed in research,

such as distracting visual clutter, auditory processing issues, and difficulty remembering and following verbal instructions, which over time may hinder their academic achievement (Ashburner, Ziviani & Rodger, 2008). If teachers are not aware of how differing sensory experiences may help or hinder the classroom experiences of students on the autism spectrum, the 'presenting problems' of underachievement, distraction, and withdrawal may be misunderstood. This may lead to ineffective solutions, such as discipline, which can further increase the problem (see p.97). Conn (2018) expresses concern that inclusive practices are "rooted in the quality of learning relationships experienced by teachers and pupils" (p.595), and that learning relationships are "above all, one of relatedness" (ibid). If neurotypical teachers cannot relate to students on the autism spectrum, knowledge about autism is even more essential. Indeed, my findings from discussions with the educational practitioners involved in this study suggest that a perceived lack of resources and knowledge relating to teaching students on the autism spectrum already exists (see p.161). Adopting an approach that dictates more specialised knowledge of autism than teachers currently have is at best complicated and challenging; and at worst, unrealistic.

In summary, in order to represent the strengths of students on the autism spectrum - as well as acknowledging the challenges they may face- an approach to inclusion that moves away from focussing on deficits is needed. However, to illustrate understanding and knowledge, teaching pedagogies informed by autism are essential to prevent school staff from misinterpreting the strengths and challenges of students on the autism spectrum. Ravet's (2011) integrative approach to inclusion may offer a potential solution for mainstream secondary schools in England; but ongoing dialogue is needed with the integrative approach to ensure that individual differences continue to be accounted for. In addition, further exploration of the distinct pedagogies Ravet (2011) describes is also needed before this approach can fit with a general differences approach to inclusion.

6.3 The difficulty of listening and responding to students' voices

Although a high level of complexity and detail emerged from the students' discussions with me, it is important to remember the policy context which informs this research. The SEND CoP (DfE, 2015) now requires that discussions with students with SEN about their educational provision take place. For students on the autism spectrum, differences in communication may lead to difficulties in supporting them. However, my research suggests that differences in communication are not the only barrier that needs to be overcome, which highlights potential challenges for educational practitioners and students to conduct these discussions effectively. These are discussed further below.

6.3.1 The importance of appropriate methods for facilitating discussions

My review of the literature in Chapter 2 concluded that the choice of research methods plays a vital part in facilitating and encouraging discussions with students on the autism spectrum. Visual methods and activity-based methods generally provide opportunities for individuals on the autism spectrum to speak freely and in detail about their experiences, offering a more balanced view compared to, for example, filling in a questionnaire asking about only negative educational experiences. Using methods in both phases of the research which fully aligned with my conceptual criteria allowed students the opportunity to talk about a range of topics, both positive and negative experiences, and demonstrate other forms of non-verbal communication that may not have been revealed by just asking questions. When conducting educational discussions, it is therefore germane to explore the affordances of methods that fully align with these conceptual criteria and see if it is possible to translate them for use in a school context. However, it should be noted that the strategies discussed here have been demonstrated to be successful when working with young people on the autism spectrum who communicate verbally within a mainstream environment. Although there are some examples of non-verbal communication, these methods may not necessarily be helpful to students who are non-verbal or have additional learning difficulties such that alternative forms of communication may be appropriate.

There is existing research advocating for the benefits of using activities to engage students on the autism spectrum (Winstone et al., 2015; Harrington, Foster, Rodger & Ashburner, 2013; Bishton & Lindsay, 2011). The use of activities and visual cues facilitates communication with students on the autism spectrum by adding additional structure and visual stimuli, which helps to engage participants more effectively in the research process (Sansosti, Powell-Smith and Cowan, 2011). These views were echoed by the autistic adults in the second phase of the research. In addition to specific feedback about the initial designs for the activities, the autistic adults commented positively on the levels of interest and engagement that the students may display when completing the activities. The adults also agreed as a group that taking part in activities reduces the formality of a ‘question and answer’ discussion, making it easier to participate. In addition, Emily, Alex, Ann and Dan also commented that having a sheet of paper to focus on could reduce anxiety about making and receiving eye contact, as both the student and I could focus on the activity rather than each other. Koegel and Ashbaugh (2017) have described that one issue that individuals on the autism spectrum may have with communication is the amount of eye contact deemed comfortable. For example, Robison (2009) explains that he avoids eye contact with people, commenting “I usually look somewhere neutral – at the ground or off into the distance – when I’m talking to someone” (p.3). As he finds visual input distracting, this strategy prevents him from losing his focus on the other

person's speech. The issues regarding other people's expectations and individual differences about making eye contact were also raised in discussions with the autistic adults, suggesting that these are simply individual needs that need to be accounted for during the research process. Using a visual cue or activity therefore offers a shared focus, which greatly reduces the need for levels of eye contact that may consequently negatively affect the student's contributions if this made them uncomfortable.

The activities themselves can also offer opportunities for engagement. For example, the diamond-ranking method students used in the first phase to rank photographs and in the second phase to rank sources of support can be adapted to use in a school environment. For example, members of staff in Genji's learning support department mentioned that Genji had been discussing the ranking of photographs with other students, suggesting an interest in it. They were keen to see if they could use the ranking method in day-to-day discussions with Genji to offer better support. Once this was explained to them, a senior LSA who worked closely with Genji told me in a later visit I made to the school that she had tried the ranking activity following an incident in a classroom that had resulted in Genji walking out. She and Genji had identified all the things that had contributed to walking out of the classroom (e.g. an earlier fight with a student, concerns about family which the school were not aware of, and generally being in a bad mood) and written them on Post-It notes, then ranked them to show which ones contributed the most. They then talked about the items that could not be helped by school (e.g. Genji's concerns about a relative in hospital) but explained that teachers could be made aware that Genji was experiencing some difficulties and therefore could be offered time-out to come to the learning support department if needed. However, on another occasion, she had tried the same approach and Genji had ripped the Post-Its up and refused to talk at all; possibly because the activity was instigated by the same member of staff and Genji perceived this to be too adult-led. However, the act of ripping the notes up still allowed Genji to communicate to the member of staff that it was not the right time for a discussion. This shows that offering an engaging visual support to discussions about educational experiences may be beneficial for students in facilitating their communication, and beneficial to staff regarding the extra information that is gleaned from these discussions.

Additionally, activities offer opportunities for different kinds of participation. Gallacher and Gallagher (2008) caution that focussing on an agenda (behaviour/outcomes) during interviews can lead to any other behaviour being labelled as "non-participation" and "deviant" (p.507), rather than a different type of communication and/or participation. However, this can also be very revealing. An example of behaviour which did not align with my agenda took place on the photo trail in the first phase of the research. Jack took photos of lessons, but also pulled funny faces and took pictures of them, encouraging me

to pull faces and have my photo taken as well. This demonstrated engagement with the activity and helped to build the relationship between us. Jack's actions demonstrate how valuable different 'kinds' of participation can be to the research process, and how completing an activity allowed unprompted and individualised communication. It may therefore be that using activities and visual methods to support interviews/discussions may reveal additional information and behaviours that would not emerge or not have been as easily accessed using a standard face-to-face interview.

Another advantage of using activities during an interview is the opportunity they offer to build relationships due to the amount of time they take. As a researcher who was previously unknown to the students, using activities promoted engagement between myself and the students by resulting in multiple meetings. This is a strategy that Harrington, Foster, Rodger and Ashburner (2013) highlight to make students feel more comfortable, thus allowing greater exploration of their ideas. For educational practitioners who are unknown to a student (e.g. when students transfer from primary to secondary school) building relationships are key. Spyrou (2011) comments that "…to get children to freely and openly express themselves in such a way that the goal of understanding is served" (p.153) is one of the main problems in accessing children's voices in research. He also argues that time is essential to building trusting relationships which allow the exploration of "deeper layers" (p.156) of children's voices, defining these as revealing different or more complex understandings of children's views. This suggests that educational practitioners may be able to use activities to take more time with students, and thus contribute to building an ongoing relationship with them.

The time taken to complete activities as part of educational discussions may contribute to building relationships between students and educational practitioners. In addition, activities offer several ways to navigate the inherent hierarchies in schools which may prevent communication, whilst also offering the students increased levels of perceived expertise, engagement, and multiplicity. Using activities and/or visual cues around an area of interest to individual students may therefore facilitate the effectiveness of educational discussions and offer potential guidance and a structure for how these discussions could take place.

6.3.2 The complexity of the discussion process

Each student was able to give detailed and insightful comments about their own school experiences of communication and support, demonstrating that they have valuable viewpoints about their own educational provision that need to be communicated to staff. However, there is very little guidance from the SEND CoP (DfE, 2015) about **how** these discussions are meant to take place. The actual process of discussing educational

provision with students on the autism spectrum is therefore complex and requires additional skills to teaching them in the classroom environment. Although the intention behind mandating students' involvement in discussions concerning their educational provision is to be welcomed, the lack of detail offered by the SEND CoP (DfE, 2015) about how these discussions are to be carried out may compromise the relevance and usefulness of these discussions. For example, the SEND CoP (DfE, 2015) states that students' views can be sought "…through involving the pupil in all or part of the discussion itself or gathering their views as part of the preparation" (Section 6.70, p.104). The language used throughout this document, such as "consulting with young people" (p. 106) and "discussion with the pupil" (p.99) suggest verbal communication as the main way in which the views of students can be sought, yet also highlights the issues with verbal communication that students on the autism spectrum may experience:

> Children and young people with speech, language and communication needs (SLCN) have difficulty in communicating with others. This may be because they have difficulty saying what they want to, understanding what is being said to them or they do not understand or use social rules of communication…Children and young people with ASD, including Asperger's Syndrome and Autism, are likely to have particular difficulties with social interaction. They may also experience difficulties with language, communication and imagination, which can impact on how they relate to others
>
> (SEND CoP, DfE 2015, Section 6.28-6.29, p.97)

Despite explicitly stating that students with SEN may have difficulty communicating with others, the SEND CoP (DfE, 2015) still fails to address how this may impact on communicating with individual children and young people during these educational discussions. Interestingly, one of the resources highlighted in the SEND CoP (DfE, 2015) is the Communication Trust, which supports those working with children and young people to support their speech, language and communication. Recently, the Communication Trust has published an excellent resource titled 'Communicating the Code' (2018), which offers precisely the detailed information that is missing from the SEND CoP (DfE, 2015), including the importance of an individualised approach, making listening part of everyday practice, and acting on what has been discovered. Communicating the Code also offers practical alternatives for listening to students with language and communication differences, such as using materials and activities that are of interest to the student, using additional supports (examples included photos/pictures/meaningful objects), and checking with the student to ensure that their communication has been understood correctly.

The findings from my research add to this evidence base by highlighting some of the challenges that need to be overcome to conduct authentic discussions with students on the autism spectrum. This could be in the form of practical strategies, such as allowing for multiplicity of voices and using activities to reduce the need for eye contact and promote engagement. Therefore, although the SEND CoP (DfE, 2015) may not offer specific guidelines on how to conduct these educational discussions with students on the autism spectrum, Communicating the Code (2018) used in conjunction with the findings from my research are examples of emerging literature that may be helpful for educational practitioners.

6.3.3 The challenge of changing beliefs

The changes to the SEND CoP (DfE, 2015) largely hold educational practitioners responsible for the inclusion of their students and improving educational provision, stating that:

> Teachers are responsible and accountable for the progress and development of the pupils in their class, including where pupils access support from teaching assistants or specialist staff (Section 6.36, p.99)

This view was also expressed by the students in this research. However, when discussing whether educational practitioners were likely to change what they do to improve the students' classroom experiences, the students were unconvinced that change was likely (as illustrated by Hanzo's "gorilla" and "monkey" explanations for whether teachers were able to understand, p.106). The students' responses were largely negative, with a unanimous feeling that there would be little change from the educational practitioners that they worked with, despite teachers' receiving additional and personal information about each of the students.

Students' perceptions that educational practitioners were either unable or unwilling to change raises the first challenge for effective communication and support. As Hill (2006) notes, actions are important when listening to students' voices (italics as original):

> …young people are primarily *outcome* oriented. When asked their views [in research], they expect a response [from researchers and the school]. Many are disappointed or disillusioned when nothing happens afterwards. (p.72)

Interestingly, the students in this research suggested that they did not expect any outcomes in relation to their teachers' behaviour. This notion that educational practitioners are fixed in their approaches – regardless of any additional information or training that is

given – could be very damaging to any suggestions that emerge from educational discussions. Indeed, it could be argued that there may be little point in participating in these discussions if a student believes that nothing will change because of it. Lundy (2007) observes that tokenistic discussions are "not only in breach of Article 12, but can be counterproductive" (p.938) if children's views are perceived to ultimately not be listened to. Similarly, Quinn and Owen (2014) found that tokenistic efforts at student participation can further distance students from staff members in school. This demonstrates the need to take part in mandated discussions that impact meaningfully upon the student's educational experiences.

When I asked each student why they did not expect to see changes, they found this difficult to explain. Some made comments comparing their teachers to me, suggesting that it was different with me because I had "gotten to know them properly"; others just shrugged, and replied that they didn't know, but they were certain that their teachers "just won't [change]". Although this relates back to the theme of demonstrating understanding, it also demonstrates the advantages of taking on a 'non-authoritative' (Kellett, 2011) outsider role as part of my research identity, which also facilitated 'getting to know' the students. The themes of building rapport and navigating hierarchies has been highlighted as key by researchers working with young people on the autism spectrum who were interviewed by Scott-Barrett, Cebula and Florian (2018). The students' view of me as 'other' to the teachers and other adults in the school, and sometimes as a source of support, therefore suggests that my efforts to take on a non-authoritative role were successful and allowed me to listen to their views in a different way to the other adults in their school. Thomson and Gunter (2011) have detailed how the fluidity of their insider/outsider roles allowed them to act as mediators between students and staff members when working with the students to investigate bullying that occurred in the school, concluding that the flexibility of the researcher identity is key to achieving this successfully. However, this flexibility can have negative effects; for example, when suggesting to the headteacher that the results of the research should be incorporated into school policies, the researchers found significant resistance:

> …the head left us in no doubt that [changing policy] was our opinion, this was his school and that his view was the research could be made to say anything
>
> (p.25)

This suggests that although adopting a fluid insider/outsider role is key to successfully mediating between students and staff when working in schools during the research process, implementing the outcomes of the research in context (i.e. in school) could be made more difficult by adopting such a role. This therefore highlights a tension that educational practitioners will have to overcome to successfully involve students on the

autism spectrum in educational discussions: navigating hierarchies and building rapport with the students to access a different view than might otherwise be given.

Messiou and Ainscow (2015) reported on their findings from a three-year international project exploring how students' voices might inform teachers' professional development, concluding that "…it is [engaging with students' voices], more than anything else, that makes the difference as far as responding to learner diversity is concerned" (p.253). However, Messiou and Ainscow (2015) also note that finding time to engage with students' voice can be challenging in the school environment, highlighting another challenge around conducting educational discussions with students. Messiou (2011) identifies another potential challenge to implementing the results of educational discussions: teacher attitudes. She describes an instance in her study where the teachers and students were discussing the development of a chart to keep track of which students had had work displayed. A student mentioned that she thought that work that had demonstrated great improvement should also be displayed, only to be told immediately by two members of staff that this already happened. Messiou (2011) notes that this defensive reaction can prevent educational practitioners from making changes, commenting that "Children might be wrong – just as adults are sometimes wrong – but we should at least be prepared to consider their perspectives in order to move forward" (p.1318). Even if educational discussions are taking place in schools with appropriate methods and strategies there is, therefore, a possibility that implementing the strategies discussed presents yet another challenge for educational practitioners.

Whilst the students believed that the staff they worked with were responsible for their experiences in the classroom – even if they suggested that this was unlikely to improve – the educational practitioners generally identified the responsibility for improvement of their teaching as lying with the school. Throughout both phases of the research, the educational practitioners often cited extra resources and extra training as being necessary to support students on the autism spectrum, suggesting that the responsibility lay with their school rather than them. Additionally, none of the educational practitioners in either the first or second phase identified their students as a potential source of information or training on how to improve their educational experiences, despite some mentions of parents and how they may occasionally offer insights that can be helpful. This further supports just how vital students' contributions are for informing educational practitioners about the best strategies to support them in school, and the need for including them in discussions about their education. However, these comments also suggest that there needs to be a significant shift in perspective needed for educational practitioners to see their students as a valuable resource, in line with the mandated policy changes in the SEND CoP (DfE, 2015). The low level of expertise that appears to be assigned to

students' views could be potentially challenging when considering Edwards' (2018) notion of relational expertise discussed above; if the educational practitioners do not see the students as having a relevant view of 'what matters', their ability to work with the students in finding a solution to support them will be influenced by this. This also has potentially negative implications for how the discussions that have been legally mandated by the SEND CoP (DfE, 2015) may be carried out. Educational practitioners therefore need to recognise the value of the student themselves as a source of information, and as a contributor in discussions about their education otherwise they are at risk of devaluing students' valuable perspectives that might otherwise be missed.

The perception that there was a low likelihood of improving communication and support demonstrated by both the students and the educational practitioners in this study is concerning, not least because, as Deneen (2010) states, "A belief that change is possible is a prerequisite for bringing about change" (p.viii). This suggests that the students and educational practitioners in this research may struggle to conduct effective discussions about educational provision if neither party is convinced that any changes are possible or likely to occur. Ashton and Gregoire-Gill (2003) suggest that emotion is a key component in changing teachers' beliefs, arguing that workload and intense decision-making lead to teachers "[using] emotions consciously and unconsciously as a basis for their instructional decisions" (p.109). However, this is largely linked to teacher preparation and training, and the authors acknowledge that their theory requires empirical confirmation. More recent research by Gregoire Gill and Hardin (2015) reviewing the research linking teachers' beliefs and the role of emotion concludes that emotion fuels resistance to belief change, guides teachers' attention to/from information, and can also be used to create new beliefs. This suggests that providing more training and/or resources may not be enough to facilitate a change in practice for the educational practitioners in this study; a belief change from both students and teachers is needed to facilitate communication and support.

Although changing student and teacher beliefs was beyond the scope of my research, this could be an avenue for future research that builds upon my findings. One potential solution in changing the attitudes of educational practitioners could be to look at leadership within the schools. Peterson and Deal (1998) argue that school leaders are crucial in influencing the culture of a school, suggesting that changing a school culture to value students' perspectives does not necessarily start and end with individual teachers. Messiou and Ainscow (2015) suggest that it is the leadership in schools that is responsible for creating a climate that was supportive of engaging students' voices to improve teacher development. MacBeath (1999) describes his self-assessment framework for school effectiveness which highlights the importance of the whole school

ethos in supporting teachers to support students. He also concurs with the importance of a whole-school approach to changing beliefs:

> The good school climate was important in underpinning a congenial classroom ethos, and support for learning ran continuously from the bottom to the top of the organisation (p.29)

Additionally, the importance of leadership was also mentioned by the educational practitioners when describing the extra resources and training they felt they needed. Blase (2000) surveyed over 800 teachers to identify the impact of leadership on their classroom instruction, concluding that effective leadership is embedded in school culture, and that personal reflection and opportunities for growth were key to supporting these teachers. Jamal (2014) reviewed the literature on leadership styles and school improvement, concluding that it was leaders who adopted a transformational style of leadership – where leaders are focussed on the needs of their employees – that improved school function and teaching processes overall. The role of leadership in developing inclusive practices and culture is also emphasised by the Index for Inclusion (Booth & Ainscow, 2002). This suggests that one way in which to change the culture of a school to one where students' voices are valued may be to assess the leadership style that is currently in place.

The students and educational practitioners involved in this research strongly communicated their belief that staff understanding of individual students needed to be increased, even if their motivations for doing so were different: staff wanted to understand students to develop pedagogic strategies, whereas students wanted staff to understand them as an individual. The other main difference in their perspectives was that students believed that increasing understanding was staff's responsibility; and the staff members believed the responsibility for increasing their understanding lay with the school. The SEND CoP (DfE, 2015) states that schools must ensure that consultation with students is undertaken, but that it is ultimately the teacher who is responsible and accountable for a child's progress and development in their classroom, which includes a student's access to support from other specialists, such as LSAs (Section 6.36). This policy therefore requires that classroom teachers who teach students on the autism spectrum (and others with SEN) should feel personally responsible for the student's progress and take steps accordingly to improve this when needed. The educational practitioners in this study who took on teaching roles did not reflect this level of personal accountability, and therefore a possible avenue for future research may be to explore the reasons for why this might be to contribute to the wider discussion on belief change.

6.4 Implications for practice and future research: a summary

The findings from both phases of my research present avenues for further exploration in research and potential implications for how schools and educational practitioners might facilitate communication and support with students on the autism spectrum. These implications for practice are summarised below.

Regarding implications for practice in schools, my research suggests that educational practitioners need to take greater responsibility than students for listening effectively and understanding students' perspectives to better communication and support them. Educational practitioners may not feel the level of personal accountability allocated to them by the SEND CoP (DfE, 2015) for the progress of their students, and therefore the reasons for this may also need to be explored. The educational practitioners' beliefs from my findings also demonstrate that they may not allocate the importance to students' perspectives about their education that is called for by the SEND CoP (DfE, 2015), and therefore changing these attitudes is yet another avenue of exploration. A potential solution could be to examine the leadership structures in schools to bring about the changes in ethos that are disseminated to all school staff where students' voices are valued and recognised for the unique perspective they offer which might otherwise be missed. In addition, replacing lengthy amounts of information (such as IEPs) with shorter and more relevant working documents may also help educational practitioners with their workload and the extraordinary amounts of information about their students that they are expected to assimilate, especially at the start of the academic year. Discussions at a departmental level may also help to re-dress perceived limitations in confidence and experience that may prevent the educational practitioners in this study from communicating with and supporting students on the autism spectrum in the classroom.

My findings also suggest that there are implications for practice when working with individuals on the autism spectrum in a research context. There is a potential link between emotional support and feeling understood that has emerged from my research which will benefit from further exploration to see if this can be used to better communicate with and support students on the autism spectrum. The importance of recognising strengths as well as challenges is key to avoiding autism research that is overly-focussed on difficulties; similarly, the language used needs to reflect individuals' strengths as well as challenges, and a move away from seeing students on the autism spectrum as just being students with SEN by adopting Ravet's (2011) integrative approach to inclusion.

When working with individuals on the autism spectrum, researchers need to be aware that it may be difficult and time-consuming to ensure that communication differences do not present a barrier to the research questions, but that it is vital that young people's

perspectives continue to be heard to better comprehend their unique experiences. Visual activities are advantageous as research methods in terms of their engagement, multiplicity, and potential to disrupt inherent hierarchies between researchers and participants and may yield more authentic results than might be generated with a standard face to face interview when working with individuals on the autism spectrum.

Finally, researchers – including myself - have a responsibility to ensure that their findings are disseminated in an appropriate format and are accessible to those who may find them most useful. This involves looking beyond the academic sphere and considering how key stakeholders might best access and discuss the relevance and implications of these findings to their own situations. For example, within my own research, the findings from my research have been disseminated to the schools, students, autistic adults and parents through email and face-to-face communications, and I am currently in discussions with two of the autistic adults about co-producing information for individuals on the autism spectrum about the benefits and challenges of working with researchers.

In conclusion, my research has illustrated the importance of students' voices for improving both communication and support in mainstream secondary schools. It has also demonstrated the detailed and in-depth contributions that students on the autism spectrum can provide about their school experiences – including the impact of sensory differences – and revealing information about themselves that is highly useful and not accessible through mere observation or discussions with others. The use of activities in my research to engage the students demonstrates that utilising methods other than face-to-face interviews may be helpful in engaging with students' voices. My research is also important in exploring how crucial it is to create an ongoing dialogue between students on the autism spectrum and the educational practitioners that they work with in a school environment – such as teachers, LSAs, SENCOs, and educational psychologists. This is key for allowing students to share their expert knowledge about themselves and work together with the expertise of educational practitioners to build on the support they receive in schools. My research therefore offers several avenues for future research for further exploration of facilitating this dialogue between students on the autism spectrum and educational practitioners to improve the students' participation in discussions about their education, and consequently, improve the quality of their educational experiences.

Chapter 7 Conclusion

It is clear that effectively involving students on the autism spectrum in discussions about their education is a complex process. Considerations and adjustments need to be made at every stage of the process, and even then, discussions will also be affected by the personalities and individual beliefs of the people involved in carrying them out. However, the contributions of the students on the autism spectrum, the autistic adults and the educational practitioners have demonstrated some key messages for practice and research.

Firstly, the role of individual differences when working with individuals on the autism spectrum cannot be overestimated. Even though students may share a diagnostic label, they are unique individuals with specific insights and information into their own strengths, abilities and challenges. Educational practitioners – and researchers – need to be aware that with personalised methods that support, engage and respect the voices of students on the autism spectrum, they can share this insider information more easily. These experiences can be used in schools to personalise their education and potentially improve the nature of the support they receive. In addition, their contributions will continue to build upon our understanding of the unique abilities and challenges that this group of students may face in secondary mainstream environments and beyond. These insights may also prove beneficial for other students, as suggested by Ravet's (2011) integrative position. The differences in communication between individuals on the autism spectrum and neurotypicals therefore need to be carefully navigated to ensure that these voices are heard, respected and acted upon.

Resolving double-empathy problems that may occur between students on the autism spectrum and the neurotypical educational practitioners they work with is a complicated and on-going process. During the first phase of this research, four key areas where perspectives between the students and staff differed significantly were identified; an awareness of sensory experiences (aware vs. less aware), the availability and type of support that was deemed most effective (infrequent and emotional vs. frequent and academic); and the responsibility for increasing staff members' understanding about students (staff responsibility vs. organisation responsibility). Despite the information from the activities that were specifically designed to address these four areas of differing perspective, evidence of these perspectives continued to emerge from the second phase of the research. It may be that presenting information about an alternative perspective (as happened in my research, where staff were presented with students' information about their sensory experiences) offers a possibility for resolving the double-empathy problem;

however, this did not happen in my study. It may be that further discussion and more practical discussion of that information could help to realise and accept another perspective, and therefore this presents an interesting avenue for future research that will benefit from further exploration.

Communication differences between individuals on the autism spectrum and neurotypicals can lead to misunderstandings and issues if not appropriately navigated. Using activity-centred interviews offer good opportunities for researchers to facilitate students on the autism spectrum communicating their experiences and opinions. Firstly, the conceptual criteria for listening authentically to students' voices to which I ascribe (expertise, navigating hierarchies, multiplicities of communication, and engagement), are all met by using activities as the basis for interviews. Secondly, the reduced need for communicative behaviours that individuals on the autism spectrum may find awkward, such as levels of eye contact, means that activity-based interviewing methods may also reduce anxiety in such contexts, though this remains speculative. Although all the students I worked with in this research were verbal and responded well to questioning, the use of activities provided an additional resource to facilitate communication on both sides that is likely to lead to improved insights and communications. Although the activities used in this study were designed exclusively for use by the six students, there may be aspects that are relevant to other students with SEN and other students on the autism spectrum; for example, the use of the Motivation Mixer specifically as an activity to prompt discussions about sensory experiences. Investigating the usefulness of these activities in different contexts may offer another opportunity for future research.

My research revealed some interesting views from the students on the autism spectrum, the autistic adults and educational practitioners, however any study will have its limitations. The first of these relates to the amount of control that I maintained throughout the course of this research and the production of this thesis. Although I have been very transparent about my need for control throughout the research process – and have tried to illustrate the participatory values that I believe in – my decision to keep control meant that the participation of the students, autistic adults and practitioners was likely to have been compromised. In particular, the students on the autism spectrum and the autistic adults could have taken much bigger roles in the design of both phases of the research, which would have inevitably changed the findings. Though I have tried to reveal my own biases throughout this research, increased contributions from the students on the autism spectrum and the autistic adults would have increased my confidence of avoiding normative assumptions throughout the analysis. In future research, I hope to take a much more creative participatory approach to my research methods and investigate the

challenges of co-design to ensure that individuals on the autism spectrum who choose to work with me are as fully involved as possible.

Another limitation of this research relates to the nature of my student sample. Using six participants is comparable to other sample sizes investigating the experiences of students on the autism spectrum (e.g. Shepherd, 2015; Maras & Aveling, 2006; Stewart, 2012). However, only one of these students was female, which may result in an androcentric bias to my findings. Similarly, my findings from the literature review are based on participant samples which have very few females compared to males. With only one female in my student sample, it is not possible to comment on any differences between male and female experiences in mainstream secondary schools. The potential differences between males and females on the autism spectrum and the impact this might have on the support offered to them has already started to be explored by researchers, such as Gould and Ashton-Smith (2011). In relation to education specifically, Honeybourne (2015) reported on the school experiences of 67 women on the autism spectrum. She notes that some of the challenges identified by the participants may be experienced by males and females alike. However, Honeybourne's (2015) findings identify three potential gender-specific challenges for females on the autism spectrum: higher expectations from teachers, an expectation of neater work compared to boys, and a tendency for girls on the autism spectrum to keep quiet about their difficulties. Potential gender differences between male and female students on the autism spectrum is therefore something that merits further investigation in future research.

In addition, my student sample was taken from two schools (one rural and one urban), which were both state schools from the south of England. This therefore means that the experiences of students on the autism spectrum – and staff - in private mainstream secondary schools and other contexts (such as verbal students attending specialist education units for behavioural purposes) may differ from those described here, and therefore generalisations should be avoided. Finally, all the students involved in this study were verbal and competent in their communication, requiring no communicative aids. Their experiences may therefore differ significantly from students on the autism spectrum who use communicative aids and/or are non-verbal. When considering the wider impact of the SEND CoP (DfE, 2015) which calls for all students with SEN to be involved in their educational discussions, the voices of students who are non-verbal are likely to require different research methods and strategies to authentically listen to their views, such as those demonstrated by Loyd (2015). Consequently, the educational experiences of these secondary mainstream students on the autism spectrum cannot be generalised to all students on the autism spectrum.

In conclusion, mainstream secondary students on the autism spectrum face a range of additional challenges navigating their educational environment compared to other neurotypical students. Respecting their voices and experiences and recognising the potential of their contributions is vital for educational practitioners and researchers to help improve the nature of communication and support in schools and provide students with an inclusive approach and personalised strategies for success that will help them both in the classroom and in their future endeavours.

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Appendix A Tabulation of alignment rankings for studies demonstrating "no overall alignment" from the literature review

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
1. Chen & Schwartz (2012) Washington, USA	30M, 3F, 8-13yo ASD – 9 in SE classes, others mainstream	- 16/25 ASDs reported bullying and/or victimisation - Reported sig. lower bullying scores than teachers	Bullying Survey for ASD (Likert)	Descriptive statistics, ANOVA (on 25 students)
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
2. Jennes-Cousens, Magill-Evans & Koning (2006) Alberta, Canada	Recruited from M-E & K (2001): 12 ppts w/AS (MA = 20.3 yrs) & matched 13 TDs	- Described academic problems, often related to social and communication deficits (no direct quotes) - Reported feeling happier and less stressed once finished/quit high school	Quant.questionnaires via email (WHOQoL Brief version & Perceived Support Network Inventory), + semi-structured interviews (interviewer blind to diagnosis)	ANOVA
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
3. Kalyva (2010) Greece (mainland)	17M, 4F, 9-16yo with AS	- TD kids more advanced social skills than AS - AS kids reported more aggressive/antisocial beh., more conceit/haughtiness, more loneliness/social anxiety, & less assertiveness than TDs. - Showed sig. differences between self-assessments and those of teachers & fathers, but not mothers	Matson Evaluation of Social Skills with Youngsters (Likert)	ANOVAs, MANOVA
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
4. Kloosterman et al. (2013) Ontario, Canada	24M 11-18yo with HFA from SE and mainstream	- HFA students on victimisation: sig. more report than TD, no sig. diff to other SEN - HFA students reported sig. more incidences of being left out on purpose than TD and other SEN; and sig. more hit, kicked or pushed than TD	Bullying/victimisation questionnaire (Likert)	ANOVAs, Chi squares, MANOVAs, MANCOVAs
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
5. Mandy et al. (2015)	20 primary school children with AS/ASD (some attrition on measures therefore further info lost)	- No increase in psychopathology over the transition period - Non-significant decrease in peer victimisation	Beck Youth Inventory Schwartz Peer Victimisation Scale	T-tests
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
6. Barnhill et al. (2000) Midwest, USA	19M, 1F with AS (6y6mo-16y9mo) from special and mainstream	Perceived selves to be similar to peers on School, Clinical and Personal Maladjustment Composites. Also saw depression, emotional symptoms index and sense of inadequacy scores as average	Self-Report of Personality (part of Behavioural Assessment Scales for Children)	Descriptive statistics
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
7. Begeer et al. (2015) Amsterdam,Netherlands	26M (11y4m-14y1m) with AS from special school	- Children with AS report less defending behaviour than TDs	Bullying Role Nomination Procedure (reporting on peers' and self bullying behaviour) – Likert scale (self)	T-tests
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
8. Bellini (2004) Indiana/ Louisiana, USA	35M, 6F, 12-18yo with ASDs	Anxiety & social skills: - Reported sig. higher levels of anxiety on MASC - 20/41 indicated high social anxiety on SAS-A	Social Skills Rating System, Multidimensional Anxiety Scale for Children, SAS-A (anxiety) – all Likert	Descriptive statistics, t-tests, Pearson correlations
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
9. Bossaert, Colpin, Pijl & Petry (2012) Flanders, Belgium	58 mainstream students with ASD from a selection of 54 schools	- Students with ASD twice as lonely as TD, and 2.5x lonelier than other SEN students, and reported higher feelings of loneliness than both other groups - Same-sex social self-concept scores correlated with loneliness; girls with ASD reported higher levels of loneliness than boys - Opposite-sex social self-concept had less effect on loneliness for students with ASD	Online surveys: - No. friends (5 max) - Likert rating of friendship quality (4qs) - Same/Opposite-Sex Relation subscales of Social Desc. Q.aire - Loneliness & Aloneness Scale for Children & Adolescents	ANOVAs Spearman's rho Regression analyses
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
10. Knott, Dunlop and Mackay (2006)	19 students with ASD (17M, MA = 11yr11mo, 2F, MA = 14yr2mo) – both girls and 10 boys from west Scotland	Parents scored children sig. lower than they did themselves on Spence Social Skills and Social Competence with Peers Parent items: main three themes of conversation, peer relationships, and socio-emotional reciprocity	Questionnaires: Spence Social Skills, Social Competence with Peers, parent identification of 3 main social issues	Inferential statistics: t-tests
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
11. Rieffe et al. (2012) The Netherlands	57M, 7F ASD (M=approx. 11yo) from special institutions	- ASD children reported more victimisation than TD children, but equal amounts of bullying others - Also reported higher scores on fear than TD children, but lower scores on guilt, shame & anger - Anger associated with victimisation in ASD, but not in TDs; TDs associated fear	The Bully/Victim/Mood Questionnaires (three), Maladaptive & Adaptive Scales (SCEMAS), all Likert	t-tests, Pearson's correlations, regression analyses
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
12. Pisula & Lukowska (2012) Warsaw, Poland	22M, 3F, 12-17yos with AS from mainstream schools	- AS students scored higher on total perception of relationships with classmates, support from others, sense of security, sense of being appreciated, readiness to engage in pro-social behaviour, and sociability (much worse assessment of relationships than TDs) - AS students: readiness to engage in prosocial behaviour & sociability +vely correlates w/ support from others & sense of being appreciated. Sociability also +vely correlated sense of security - AS students reported lower social support overall, but perceived less appraisal support and emotional support, less support from peers & more support from teachers compared to TDs. - Total social support –vely correlated with poor relationships with classmates, indifference from others, sense of being under-appreciated & tendency towards social isolation (higher scores indicate poorer support)	'My classmates' attitude towards me'; 'My attitude towards my classmates'; Social Support Scale (all Likert)	t-tests; Pearson's correlations
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
13. Wainscot, Naylor, Sutcliffe, Tantam and Williams (2008)	30 students on the autistic spectrum + 27 controls (3 with dyslexia, 24 without) matched on age, gender, academic ability, physical size, lessons attended, and, where possible, SES and ethnicity. All from sec. mainstream	Sig Diffs: how much of the day is spent with friends (AS – 53%, Cs – 81%); time spent alone at break/lunch (AS – 27/33%, Cs – 0/4%); physical activity (Cs sig. more active); perception/frequency of bullying (AS sig more likely to be bullied, and more frequently); no. of good friends = significantly lower for AS. No sig diffs: enjoyment of school/lessons, rating of lessons, attendance, perception of best friend, best friend = no significant differences) Not analysed: Where time spent at break/lunch (AS – inside, Cs – outside)	Structured 30 minute interview about social experiences during the school day School attendance records Pedometer (for measuring physical activity)	Inferential statistics (t-test, Chi-Square, Mann-Whitney U, Wilcoxon Paired Sign Rank)
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
14. Whitehouse, Durkin, Jaquet & Ziatas (2008) Western Australia, New South Wales & Queensland	28M, 3F (12yo-17y6mo) from 3 schools in 3 states with AS	FQQ scores – rated poorer than TD ppts FMQ scores – less self-determined desire to develop friendships than TD ppts LS & CES-DS – greater levels of loneliness & depression than TD ppts	Friendship Quality Questionnaire; Friendship Motivation Questionnaire; Loneliness Scale; CES Depression Scale – all Likert scales	Independent t-tests; MANOVA; regression analysis
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
15. Williamson, Craig and Slinger (2008)	19 students (16M, 3F) diagnosed with AS (11-15yo) from 3 boroughs and 19 TD controls matched on age, sex, ethnicity	Perceptions of social/athletic competencies (AS sig. lower on both) Social approval (AS report sig. lower levels) Psychological adjustment (AS report sig. more anxiety)	Questionnaires: Self-Perception Profile, Depression Inventory, Anxiety Scale, Peer & Parental Approval	MANCOVAs Regression analysis
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
16. Cottenceau et al. (2012) France	26 (M=15yo) adolescents with AS/HFA, mostly from mainstream (2 other)	- Sig. lower quality of life than TD controls and diabetics, in areas of friends, leisure, affective and sexual relationships - Reported greater satisfaction with parental relationships, and higher scores in self-image - Greater satisfaction with school work before the age of 15; but quality of relationships with peers improved with age - Students with ASDs who had more friends were more satisfied with their leisure time & their relationships with friends, but had lower satisfaction with school work than other 2 groups - Students with ASDs attributed less importance to activities involving friends, and more importance to activities involving parents	Experience & Perceived Health Questionnaire (VSP-A) – Likert Additional questions on social skill training, social support, and importance of social activities	ANOVAs
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
17. Falkmer, Granlund, Nilholm & Falkmer (2012) - Sweden	22 (16M, 6F, M=10y7m) students with ASCs from 21 mainstream schools	- Sig. differences btw ASC students and TD classmates on 57% of statements - (In)formal relations, activities & self-knowledge: ASC students rated items lower in regard to participation than TDs, but rated being alone more highly. Generally more negative than TDs.	Children's/Adolescents' Participation in Schools (questionnaire; adapted for mainstream settings by removing irrelevant items)	Mann-Whitney U & Spearman's
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
18. Hannah & Topping (2012)	9M participants with AS in Year 6 (M=11y8.9mo). 5 to mainstream, 4 to communication support unit	– Only 8 completed q.aire at both time points - Few subscales reached significance with group analysis - Individual analyses:5/8 students had substantial scores for anxiety prior to transition; decreased by second q.aire	Spence Children's Anxiety Scale (no open/filler items) x2	Wilcoxon
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
19. Lasgaard, Nielsen, Eriksen & Goossens (2010) – Denmark	39M 13-17yo with ASD from 2 special schools	- 21% of ASD students described themselves as often/always feeling lonely vs. 4% TD; 38% as sometimes lonely vs. 19% TD - Feelings of loneliness and difficulties in making friends associated with having ASD - Higher feelings of loneliness reported by ASDs, but not associated with friendship issues	UCLA (Loneliness; Likert); self-estimate of loneliness (1 Likert q); Social Support Scale for Children	Regression analysis, ANOVAs
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
20. Nicpon, Doobay & Assouline (2010) - USA	25 children (5-11yo) & 14 adolescents (12-17yo) with HFA from mainstream	All mean scores for both children and adolescents fell within normal limits in comparison to the normative sample (this differed from parent and teacher reports)	Self-Report of Personality (part of Behavioural Assessment Scales for Children-2)	Descriptive statistics (M, SD)
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
21. Rowley et al. (2012)	51 M/S children (10-12yo), sub-sample from Special Needs & Autism Project + parents, teachers	Self-report scores on Friendship & Victimisation scale did not differ between mainstream/specialist schools Children in mainstream had sig. higher IQ and language scores, and sig. lower repetitive beh. scores than special schools	Module 3 of ADOS-G (play-based activities and structured prompts) Parent + teacher responses to Strengths & Difficulties q.naires	Coded using two six-point ordinal scales for friendship and victimisation – then Chi Square, t-tests
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
22. Symes and Humphrey (2010)	40 ASD students, 40 dyslexia students, 40 TD students (109M, 11F, MA: 13y9mo) from 12 secondary mainstream schools	Perceived levels of peer support – ASD report sig. lower levels of peer support Frequency of bullying – ASD students report sig. higher levels of bullying Sociometric status (peer acceptance/ rejection) – ASD students report sig. lower acceptance scores and sig. higher rejection scores than the others	Questionnaires: Social Inclusion Survey, My Life in School, Social Support Scale for Children	Descriptive statistics MANOVA ANOVA Post-hoc testing
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
23. White & Roberson-Nay (2009) Virginia, USA	20 children & adolescents with ASD (7-14yo), 18M, 2F. 19 at mainstream	- Highest elevation for clinical scales was separation anxiety, lowest was harm avoidance. - Anxiety did not vary by age (child vs. adolescent), but did by IQ (below & above 92) - Overall, no sig. correlation between loneliness and anxiety. However, those who scored 'above average' anxiety reported more social loneliness	Multidimensional Anxiety Scale for Children; Loneliness Questionnaire (both Likert)	Inter-item correlations, t-tests
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
24. Bauminger, et al., (2008) **ISRAEL/**USA	23M, 1F 8-12yo with HFA (M=9yo approx.) (Israel)	HFA children reported lower perceived friendship scores in dimensions of help, intimacy and closeness compared to TDs No differences between Israeli & American kids	Friendship Qualities Scale (23 item Likert) – read to children	ANOVAs
Expertise = NA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
25. Bauminger, Shulman & Agam (2004) Israel	15M & 1F btw 8y3mo-17y2mo from special schools	- Title: 50% HFA vs. 81.3% TD named 'friendship' - Story of picture: 63% HFA vs. 12.5% TD = low-quality description of the 'friends' - Are they friends? (in the story): 93.8% HFA vs. 100% TD said yes. Justification: HFA=close proximity & talking, TD= much more varied - Stats: HFA lonelier, less socially accepted. High correlations btw friendship, loneliness & self-perception	Friendship Picture Recognition Interview (4q projective test); Friendship Qualities Scale (Likert); Loneliness Rating Scale (Likert); Self-Perception Profile (Children) (Likert)	Content analysis (FPRI); MANOVA (FQS & SPP); ANOVA (LRS)
Expertise = NA, Engagement = PA, Hierarchy = NA, Multiplicity = NA				
26. Browning, Osborne & Reed (2009)	10 participants with ASD (8M, 2F) M=15yo	- Worries leaving school: education (6), relationships (9), external (5), none (1) - Solving problems: personally (4), external consultation (1)/assistance (3), failure (4)	Structured interview (1 question related to school, rest to stress)	Content analysis to gain frequency data (quant) for each question
Expertise = PA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
27. Carrington, Templeton & Papinczak (2003) - Australia	4M (215, 17, 18) 1F (14) from a mainstream secondary school with Aspergers	- Understanding of concepts or language regarding friendships limited and difficult for all participants. - Description of what is not a friend easier (e.g. rude, inconsiderate, naughty, annoying) - Description of what is a friend generally hard to explain; idea of people with similar interests, who you're comfortable with & are like you. - Description of an acquaintance; 4/5 described someone you don't know really well (easier to describe) - "Masquerading" (hiding deficits) from 2M.	Semi-structured interviews	QSR NUD*IST – thematic analysis
Expertise = PA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
28. Hebron & Bond (2017)	4M secondary students from 9 students (3F, 6M) 8-15yo with ASD/SLI + parents – attending SEN unit in mainstream school	Asked about social inclusion & resource provision – parents' views mostly reported. Admit parent and child data combined - +ves of mainstream: broader curriculum, not perceived as different - Bullies in "other school" mentioned by 1 student; most reported it as infrequent - Wide range of +ve views about school; felt supported and proud of successes	3 x semi-structured interviews across school year Ratings of school experiences (1-10)	Thematic analysis
Expertise = PA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
29. Poon et al. (2014) Singapore	3M (12, 13, 16) & 1F (14) HFA students from 2 secondary schools	*Construction of HFA:* - Described in +ve & -ve terms; e.g. being different, not normal, but also being special - Other people have –ve perceptions, e.g. stupidity *Peers:* - Some idea of friendship ideals, e.g. support - Difficulties with classmates; bullying, teasing - However, very diff exps, even within same school *School:* - 1M & F mentioned academic pressures; 1M, little difficulty; 1M, disengaged	Semi-structured interview (4 questions)	Thematic analysis (NVivo)
Expertise = PA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
30. Kasari & Bauminger (2000) - Los Angeles	21M, 1F with HFA, 7y11mo-14y8mo	- Sig. less likely to provide complete definition of loneliness than TDs, but greater loneliness scores - Sig. less likely to provide complete definition of friendship than TDs, and reported lower scores on subscales of companionship, security and help - Loneliness and friendship had no association	Loneliness Rating Scale, Friendship Qualities Scale, descriptions of loneliness/friendship	Content analysis, Chi square, ANOVA, MANOVA
Expertise = NA, Engagement = PA, Hierarchy = NA, Multiplicity = NA				

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
31. Calder, Hill & Pellicano (2012)	12 primary school children (8M, 4F) with autism from 9y3mo – 11y2mo (M=10y3mo)	Friendships in school: 11 reported friends; 7 had friends outside of school too - Friendship described in terms of companionship - Also described as confusing; and sometimes want to be alone; but also sometimes feel isolated and left out	Friendship Qualities Scale (questionnaire) Strange Stories Test (vignettes) SCM (social map) Semi-structured interviews w/kids	Interviews – thematic analysis FQS & SS – ANOVA SCM - correlations
Expertise = PA, Engagement = PA, Hierarchy = NA, Multiplicity = NA				
32. Camarena & Sarigiani (2009) - USA	20M, 1F, 12-19yo with HFA; approx. 50% at mainstream	- All students aware they were 'exceptional', all acknowledged extra help at school. 68% did not mention diagnosis - Academic & social problems rated lower than parents; social more problematic than academic, but college rated equally important. Obstacles: academic, others' awareness	57q interview (36 open-ended qs, 21 Likert ratings)	Descriptive statistics, content analysis
Expertise = PA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
33. Carrington & Graham (2001) Australia	2M (both 13) from two mainstream schools	Difficulties: making friends and being saddened by that. Specific interest of computers makes Maths difficult; distracting. Both experienced stress at school; teasing from others, wishing they were like others, wishing others understood them.	Semi-structured interviews	Thematic analysis
Expertise = PA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				
34. Dixon & Tanner (2013) Australia	2M (14, 15) from two mainstream schools	Both aware of diagnosis; 1M has issues with lack of clear instructions. Same ppt mentioned transitioning difficult due to difficulty making friends and because school did not support needs. Transitioning within school (years) is easier. Both identified adults as helping with transitions. Maps orient new layout.	Semi-structured interviews	Thematic analysis
Expertise = PA, Engagement = NA, Hierarchy = PA, Multiplicity = NA				

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
35. Chamberlain, Kasari & Rotheram-Fuller (2007) - USA	14M, 3F with HFA 5-10yo from seven primary mainstream schools	- Correlations indicated that as HFA students got older, reciprocity of friendship decreased; indicate lower peer acceptance than TDs - Sig. lower scores in social network centrality than matched TDs, indicating less social involvement, but more likely to connect with girls - Sig. lower scores on companionship subscale of FQS, indicating doing fewer things and spending less time with friends than matched TDs	Loneliness Scale; Friendship Qualities Scale (both Likert); social network centrality questions	Correlations
Expertise = PA, Engagement = NA, Hierarchy = NA, Multiplicity = PA				
36. Hebron, Humphrey & Oldfield (2015)	5 primary & secondary pupils: 3M, 2F, 4P, 1S Interviewed: 1F(S), 2M(P)	Experience of bullying and school - All 3 interviewed defined bullying, but struggled explaining why person might be bullied - All reported on positive relationships with adults at school; 1M commented his friends were nice because they liked football - 1M commented that school was too long; this was linked to participation in clubs after school	Semi-structured interviews with 3 participants	Thematic analysis
Expertise = PA, Engagement = NA, Hierarchy = PA, Multiplicity = NA				
37. Jindal-Snape et al. (2006)	5M 12-13yo students with AS/ASD	- Response to idea of new school generally positive; knew which school they were going to, and only 1 did not visit - Practical participation in school activities valued - Thought new school was big; lots of rules to learn - Thought adults could help them be prepared for the new school; this included visits	Interview	Thematic analysis
Expertise = PA, Engagement = NA, Hierarchy = NA, Multiplicity = NA				

Authors, year & country	Participants	Topic(s) investigated	Methodology	Analysis
38. Kasari, Locke, Gulsrud & Rotheram-Fuller (2011) - USA	60 5-10yo with ASDs from 30 mainstream schools	- ASD students more likely to be isolated than TDs, with sig. lower social network centrality scores - Sig. diffs between ASDs and TDs: fewer friends nominated, fewer nominations received, fewer classroom connections, and less reciprocity - Reported poorer friendship quality than TDs	Friendship Qualities Scale, Social Networks & Friendship Survey	Descriptive statistics, ANOVA, MANOVA
Expertise = NA, Engagement = PA, Hierarchy = PA, Multiplicity = NA				
39. Koning & Magill-Evans (2001) - Canada	21M 12-15yo with AS	- Sig. differences on scores for body cues, situational cues & voice cues compared to TDs - Facial cues used more often than others for emotions - Self-ratings of assertions sig. differ from parent and teacher ratings; generally rated selves higher - Sig. diffs to TDs in no. of friends, frequency of contact with friends & social competence scores	Child and Adolescent Social Perception (video stills), Social Skills Rating System	MANOVA, t-tests
Expertise = NA, Engagement = PA, Hierarchy = PA, Multiplicity = NA				
40. Locke, Ishijima, Kasari & London (2010) USA	4M, 3F, M=14y7mo from autism programme attached to high school	- Adolescents with autism report sig. more loneliness than TD classmates; also sig. poorer scores in companionship & helpfulness subscales, sig. lower social network score, fewer connections - Friendship = security and intimacy; described qualities they liked in themselves as relating to talents/abilities, rather than personality. Dislikes related to personality.	Loneliness Scale, Friendship Qualities Scale (both Likert), Friendship survey, school activity q.aire, social network centrality scores	ANOVA
Expertise = NA, Engagement = NA, Hierarchy = PA, Multiplicity = PA				
41. Portway & Johnson (2003)	18 18-35yo with AS	School – particularly problematic, lots of friendship issues – viewed as particularly negative, and that they had been failed by schools. Feeling of being different, but desperately wanting to join in	Interviews	Grounded theory
Expertise = PA, Engagement = NA, Hierarchy = PA, Multiplicity = NA				

Appendix B Tabulation of alignment rankings for studies demonstrating "no overall alignment" from the literature review

Authors, year & country	Participants	Topic(s) investigated	Methodology	Analysis
1. Connor (2000)	16 students (15M, 1F) diagnosed with AS from 9 MS Partial: 9 SENCOs from students' schools	Subjects/activities at school (preferred, best at, worst at, best for learning); social relationships (what students did if they had a problem at school, what students did at break/lunchtime, particular friends and why students liked them, particular people that students do not get on with); changes needed for self and school; plans after leaving school. SENCOs: Ongoing concerns	Structured interview (12 questions) with students Discussions with SENCOs	Thematic analysis by frequency (tallied number of mentions) Verbatim quotes
Expertise = PA, Engagement = PA, Hierarchy = PA, Multiplicity = NA				
2. Cordier et al. (2014) Australia	6M (8-12yo, M=10y7mo) from six mainstream primary and secondary schools	More positive experiences and emotions when conversing with friends compared to others (sibling, parent, teacher, etc). Conversing with people (teacher, classmate) = boring, least interesting & enjoyable. See school as important. Least bored when alone, but report feeling lonely.	Experience Sampling Method (iPod Touch): random survey 20-37 times about what they were doing, with who, where, etc. for 7 days	Linear regression analysis
Expertise = PA, Engagement = PA, Hierarchy = PA, Multiplicity = NA				
3. Dillon, Underwood and Freemantle (2014)	14 students with ASD (11M, 3F, MA = 13.57) and 14 controls (9M, 5F, MA = 13.43) from MS	Understanding of own behaviours – more angry/aggressive behaviour in ASD group Relationships with school staff – generally positive views; good relationships associated with caring teachers/other staff. Strong dislike of HWK. Peer interaction and social skills – peers are major distraction for ASD group; all prefer group work.	Questionnaires: Teenage Inventory or Social Skills, Quality of Student-Teacher Relationship Scale, Behavioural & Emotional Ratings + discussions	Iterative coding (content analysis) ANOVA
Expertise = PA, Engagement = PA, Hierarchy = FA, Multiplicity = NA				

Authors, year & country	Participants	Topic(s) investigated	Methodology	Analysis
4. Fortuna (2014)	5 primary students transitioning to secondary (3M, 2F)	Social and emotional well-being changed over transition (4+,1-) 4/5 mentioned friendship issues with starting 3/5 mentioned bullying 1 mentioned interest in learning new stuff	- SDQ - Semi-structured interview - Student diaries	Mixed methods: thematic analysis
Expertise = FA, Engagement = PA, Hierarchy = PA, Multiplicity = PA				
5. Gulec-Aslan, Ozbey,& Yassibas (2013) Turkey	23yo man with HFA	Feels treated unfairly by parents, teachers and friends. Driven by fear of failure. Issues with eye contact and link to socialising. Problems with friendships, teasing. Aware of being different. Good teachers in primary school due to values taught. Worried about social interactions in future jobs.	Semi-structured interview (4hrs)	Thematic analysis
Expertise = FA, Engagement = PA, Hierarchy = PA, Multiplicity = NA				
6. Hebron and Humphrey (2012)	22 students with AS (19M, 3F, MA = 14yr2mo); 4M, 1F interviewed. Also 21 dyslexic students and 23 TD controls	AS students significantly worse mental health scores on anxiety and anger than both other groups, and sig. worse scores for depression and self-concept compared with TDs Interviews: Social relationships and understanding AS (e.g. feeling different) affected mental health difficulties (anxiety and anger), which led to different coping mechanisms (self-reliance, internalisation, predictability and routine)	Beck Youth Inventories Semi-structured interview	MANOVA Thematic analysis
Expertise = PA, Engagement = PA, Hierarchy = PA, Multiplicity = NA				

Authors, year & country	Participants	Topic(s) investigated	Methodology	Analysis
7. Humphrey and Lewis (2008b)	19 students with ASD (11-17yo)	School ethos and commitment to inclusion – integration rather than inclusion, very dependent on commitment shown by SMT. Communication and inclusive practices – passing of information between SENCO and teachers is crucial. Responsibility for students' learning and role of LSA – teacher's perceptions varied. Distinct needs of students with ASDs – order and predictability/routine, explanations for literality of thought, quieter environments	Case study of 4 mainstream schools: interviews with students/teachers/ SENCOs/LSAs/ parents/SMT, observations of students in and out of lessons, policy documents, student diaries	Content analysis
Expertise = FA, Engagement = PA, Hierarchy = PA, Multiplicity = PA				
8. Kammer (2009) – dissertation	41 SOTAS, 4 of which were them interviewed, from secondary schools in Scotland	Looking at emotional upset caused, what is useful and helpful in dealing with it, and navigating primary/secondary transition: - Lots of changes happening at once, sensory issues and a lack of understanding felt by majority; peers need to be taught about ASD - Boredom and having too much work was also found stressful by the majority - Found having a staff member/friend that understood was most helpful	Questionnaires (open & closed questions) Semi-structured interviews	Descriptive statistics A bit of content analysis
Expertise = PA, Engagement = PA, Hierarchy = PA, Multiplicity = PA				
9. Maras & Aveling (2006)	6 11yo with SEN (2 with ASD, 1M, 1F)	Pre-transition: Appreciated visits to new schools. Anxious about not knowing new people; would have preferred to go to a school where they knew people from primary. Concern about autism-specific provision (or lack thereof) and knowing about things in advance, e.g. LSAs to work with. Post-transition: only F interviewed. Benefit of special needs space mentioned again. Worries about diff. teachers for diff. subjects did not materialise	Semi-structured interviews x 2	Content analysis Thematic analysis
Expertise = FA, Engagement = PA, Hierarchy = PA, Multiplicity = NA				

Authors, year & country	Participants	Topic(s) investigated	Methodology	Analysis
10. Penney (2013) Canada	3M (19, 21, 21), 1F (18) with ASDs and depression/ anxiety, ex- mainstream	- Felt beh. escalations interfered with teacher/peer relationships; better understanding of ASD would alleviate this, especially sensory issues - All mentioned teachers not accommodating to their needs (despite IEPs) & peer difficulties, e.g. other students not following the rules - Teachers with knowledge and understanding of beh/sensory differences had major +ve impact on ability to cope within classroom - Reported victimisation directly by peers, and indirectly by teachers	Online/face-to-face unstructured interviews	Thematic analysis
Expertise = PA, Engagement = PA, Hierarchy = FA, Multiplicity = PA				
11. Stewart (2012)	4 girls diagnosed with AS (10-15yo) from mainstream secondary schools – and their mothers	Girls felt needs not met at school or home; often experienced emotional outbursts. Need clarity on what is being asked of them in school; wanted teachers to adhere fairly to the rules. Identified as 'different'; linked to increased incidences of bullying. Ongoing sensory issues; high anxiety School environment "unsupportive and damaging to their sense of identity and self-esteem"	'In My Shoes' interview software Online diaries Maternal interviews	Thematic analysis
Expertise = FA, Engagement = PA, Hierarchy = FA, Multiplicity = PA				
12. Stirk (2011) T (thesis)	4M 16-17yos attending special and mainstream schools	- Generally positive experiences reported - Seven themes: belonging, independence, comparisons, managing self-presentation, sense of self, 'who knows?' and external factors. Affected by participants' levels of social understanding. - No bullying reported. Transition raises self-awareness and gives more independence. Question of who is told about diagnosis.	Semi-structured interviews (4 sections of pre-set questions)	IPA
Expertise = FA, Engagement = PA, Hierarchy = PA, Multiplicity = PA				

Authors, year & country	Participants	Topic(s) investigated	Methodology	Analysis
13. Van Hees, Moyson & Roeyers (2015) Belgium	23 young adults (17M, 6F) transitioning from college to university	Challenges: Ppts report being intimidated and finding new activities confusing – AT FIRST; unexpected/last-minute changes; disclosure & independent living. Dealt with challenges by training themselves to deal with the unexpected. Focussing on the little details & working-out side issues vs. essentials can be problematic, due to paying attention to everything. - Clear need for friendships; 'easier' than school because of shared interests at university. Group projects/SU activities cause some concern. Difficulties with meeting people due to hesitation and some difficulty with social situations. General autism misunderstanding. Focus, precision, eye for detail & dedication = high academic performance	Interviews	Grounded theory
Expertise = FA, Engagement = PA, Hierarchy = FA, Multiplicity = NA				
14. van Roekel, Scholte & Didden (2010) The Netherlands	208M, 22F, 12-19yos, with ASDs, from 3 special secondary schools	- ASD students report less bullying than teachers, more than peers - No differences in perceptions of bullying when compared with TDs on video fragments - The higher frequency with which ASD students reported being bullied, more false-+ mistakes	Peer/self-ratings on bullying & victimisation, bullying perceptions (14 video fragments), ToM task (Sally-Ann test, Ice-Cream/Strange Stories)	Correlations, Chi square, regression analyses
Expertise = PA, Engagement = PA, Hierarchy = PA, Multiplicity = PA				
15. Cridland, Caputi, Jones & Magee (2015) Australia	7M 13-16yo from mainstream secondary schools	Adolescents reported friends that parents and siblings saw as acquaintances Felt that ASD impacted both -vely and +vely on them; can focus more easily (strength)	Application of Personal Construct Theory (authors' previous theory) Semi-structured interviews	Deductive thematic analysis (based on PCT)
Expertise = FA, Engagement = PA, Hierarchy = FA, Multiplicity = NA				

Authors, year & country	Participants	Topic(s) investigated	Methodology	Analysis
16. Hay & Winn (2005) Queensland, Australia	9 secondary students (7M, 2F) with AS attached to SEN unit	18% ppts: special education teachers worked hard to assist others. Want +ve teacher relationships, but unsure of how to get this. Teasing from peers; different to others. Secondary harder than primary	Individual interviews Focus group	Content analysis
Expertise = PA, Engagement = PA, Hierarchy = FA, Multiplicity = NA				
17. Humphrey and Symes (2010)	36 students (4F, 32M) diagnosed with ASD (11-16yo) from 12 secondary schools	Responses to bullying behaviour (e.g. seeking support vs. own resources) Mediating factors in use of social support (e.g. history/quality of relationships, desire for solitude)	Semi-structured interviews	Thematic analysis of interview transcripts
Expertise = FA, Engagement = PA, Hierarchy = FA, Multiplicity = NA				
18. McLaughlin & Rafferty (2015)	Review of qualitative studies looking at individuals with AS/HFA between the ages of 10-19yo PLUS 6 (1F, 5M) adolescents with AS	Review: findings usually closely related to diagnostic criteria, and therefore there's a lack of identity/voice. Need to present voice "without any competing adult perspectives" Study: 4 main themes - Not fitting in (missing out, regret prev. beh) - Impact on world (diff to describe, changing) - Equality desire (-ve impact of TAs) - Fitting in (friendships, isolation, bullying)	Literature review Semi-structured interviews	Thematic analysis (of interviews)
Expertise = FA, Engagement = PA, Hierarchy = FA, Multiplicity = PA				
19. Saggers, Hwang & Mercer (2011) Australia	7M, 2F (13-16yo) from secondary school	Same students and results described in Saggers (2015) - see next study.	Semi-structured interview (1) and unstructured interview (1)	Thematic analysis (constant comparison)
Expertise = FA, Engagement = PA, Hierarchy = FA, Multiplicity = PA				

Authors, year & country	Participants	Topic(s) investigated	Methodology	Analysis
20. Saggers (2015) Brisbane, Australia	7M, 2F secondary school students	**Relationships with peers**: positive relationships = enabling factor for inclusion as provide support. Friendships = fragile; preference for solitude (4M). Teasing mostly unreported, unless physical. **Anxiety & stress:** class noise, teacher yelling & chaotic environment = anxiety-inducing. Also workload, homework, deadlines and handwriting. **Working with teachers & other staff**: positive teacher characteristics = relatedness, fairness, active listener, flexible, conscious of students' needs, humorous and firm/able to provide structured classroom. Visibility of support an issue. **Negotiating difference**: did not like to be treated differently/singled out. Best help from those who understood their needs.	Semi-structured interviews x 2	Thematic analysis (constant comparison)
Expertise = FA, Engagement = PA, Hierarchy = FA, Multiplicity = PA				
21. Tobias (2009)	10 students diagnosed with ASD (14-16 yo)	Most helpful support: effective transition planning, mentors, quiet spaces, individual support. Additional: less bullying, life skills	Focus group Drawings Video recordings	IPA
Expertise = PA, Engagement = FA, Hierarchy = FA, Multiplicity = PA				
22. Beresford et al (2007)	5M 3-19 year olds (direct involvement) 12 teens (10M, 2F) observed in therapeutic group setting, 23 others (17M, 6F) reported on"	- Mental health, bullying, social skills, "lagging behind others" academically are concerns - All had favourite lessons and some mentioned enjoying learning new things and doing well academically - Friends seen as an "important and valued part of their life" p.12	Photos taken by child Poster of child's life (made by researcher and child) Interviews with 5 children	Reports from interviews around main themes discussed with adults; photos and posters not discussed
Expertise = PA, Engagement = FA, Hierarchy = PA, Multiplicity = FA				

Authors, year & country	Participants	Topic(s) investigated	Methodology	Analysis
23. Mitchell & Beresford (2014)	Sampled from larger project – 18 15-25yo, 14M, 4F (2M at special school, rest mainstream	Move from school to college shifts from decision making to anticipating and preparing to move; during this time, support is needed in: - Co-ordination and administration - Emotional support (but not from school/college staff) - Information (from school & college) - Engaging - Planning learning support (school & college) - Planning travel (mostly parents) - Developing social skills (from parents) > High levels of parental involvement > Visits (especially multiple) highly valued > Practitioner knowledge valued more when young people felt they were known well, and when they were reliable, i.e. did what they said they'd do (lots of negative experiences). Also, knowledge/understanding about ASC whilst understanding it is not possible to experience it	Semi-structured interviews	Thematic analysis
Expertise = FA, Engagement = PA, Hierarchy = PA, Multiplicity = NA				
24. Holt, Lea & Bowlby (2012)	5 children from an AS facility attached to a mainstream school	- One student mentioned the controlling nature of the unit - Photographs not reported - Interviews not reported in full	Semi-structured interviews Photos Research diary	Thematic analysis (NVivo)
Expertise = PA, Engagement = FA, Hierarchy = PA, Multiplicity = PA				
25. Jones, Huw & Beck (2013)	9 16-21yo (6M, 3F) Comments from 1M 18+	- All ppts reported being seen as different at school – this sometimes led to bullying (4/9) - 18+: communication to NTs can be learnt, but takes time. Also, friends who are also on the spectrum helped with sense of belonging.	Semi-structured interview	IPA Credibility check from 3rd author
Expertise = FA, Engagement = PA, Hierarchy = FA, Multiplicity = NA				

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
26. Bolic Baric, Helberg, Kjelberg & Hemmingson (2015) - Sweden	10 (6M, 4F) young adults with AS - 20-29yo	Individual learning experiences: - Difficulties with learning = secondary school was particularly negative, associated with feelings of meaninglessness, boredom & bad memories. Homework, difficulty in concentrating, & sensory overload described. - Difficulties with social relationships & emotional wellbeing = sense of being different, excluded, ignored and rejected by peers → anxiety & depression. Support for learning: - Small groups: Seen as beneficial for quiet and easier individualised support. - Individualised teaching methods: e.g. use of computers, MP3 players to screen out noise, schedules, provision of choice. Involvement in own support was also valued. Felt knowledge about AS could increase support. - Teachers who care: recognition of individuality. Emotional & practical support: parent and friendship support is important	Semi-structured interviews, timeline	Hermeneutic – Thematic analysis
Expertise = FA, Engagement = PA, Hierarchy = PA, Multiplicity = FA				
27. Dann (2011)	Six Year 6 pupils (5M, 1F) – 3 to mainstream, 3 to ASD unit attached to mainstream school	Pre-transition: knowing and trusting teachers; layout of the school was problematic (e.g. where toilets are). Lots of anxiety. Lessons discussed as fun/boring, what teachers do to help (but no specifics mentioned), what they hope will happen (but no specifics mentioned). Looked forward to new lessons, rooms and equipment Post-transition: supported by helpful staff, but missed primary school. Specialist provision valued, but want to be seen as individual. Inc. interest in social interaction; bullying issues	Semi-structured interviews – Talking Mats for visual structure, vignettes and questions	Thematic analysis
Expertise = FA, Engagement = FA, Hierarchy = PA, Multiplicity = PA				

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
28. Gray & Donnelly (2013)	2 Irish traveller families with autism & 2 non-traveller families; M=6y2mo of children, 3M, 1F	Likes & dislikes regarding school: 1st child - no verbal responses to questions, but counted. Selected favourite toy. 2nd child – likes school, because "teacher is nice" because "she listens". Likes "the club" to play, but issues with non-traveller kids. 3rd child (non-traveller) – wrote poem "I go to school and I am seen but I'm not me. I don't learn they don't teach what I want to know". Worries about being invisible. 4th child – no engagement.	Case study – general activity-based discussions with children	Thematic analysis
Expertise = FA, Engagement = PA, Hierarchy = FA, Multiplicity = PA				
29. Hwang (2014) Seoul, Korea	5M (2x16, 3x17) from 3 special schools, not officially diagnosed with AS, with cognitive difficulties	1. Affection: Expressed for parents/siblings and selves; mother preferential (love). Like for classmates, teachers, researchers. 2. Feelings: Pleasant feelings expressed more frequently, but wider variety of negative feelings. Also empathy for family. Difficulties in identifying and expressing feelings; interpersonal relatedness varied between and within students 3. Perceptions: Generally positive self-image (from drawings); mixed feelings for other people (+& -) 4. Ambivalence: Like/dislike: same responses to questions; could be due to mixed sensory experiences with these items. Alone/together: mixed feelings regarding both	Semi-structured interviews/ conversations with visual aids; drawings of 4 facial expressions (H/S/A/F) and scenarios; 2 drawings created by students (self-portrait and friend's portrait). Interview cards (spoken), booklet (written)	Thematic analysis
Expertise = PA, Engagement = FA, Hierarchy = PA, Multiplicity = FA				
30. Lamb, Firbank and Aldous (2014)	5 students (4M, 1F, 11-16yo) from 1 mainstream secondary school	Opinions of physical education (PE) lessons: changing rooms as source of negative emotions, teacher's office/corridor are better, small team games are preferred General: need for personal space	Photo-elicitation (iPad photos and interview) with teacher/ researcher	Thematic analysis
Expertise = PA, Engagement = FA, Hierarchy = PA, Multiplicity = FA				

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
31. Parsons (2014)	55 adults (26F, 28M) on the spectrum 17-59; M=35y4mo. 43 official diagnosis, 10 didn't	- 76%-78% attended mainstream primary & secondary schools - Overall, less satisfied with their school experiences and how well it prepared them for adult life; need for more support and awareness - Most useful: academic skills learnt; social, communication & life skills; environmental support; impact of hurtful attitudes OR school was a struggle; did not help - Least useful: specific topics; social & communication difficulties; not fitting in	Online survey (31qs) – quantitative, 8 qs on school experiences (Likert scales, 2 open) Case studies	Thematic coding for open qs; chi-squared on rating data
Expertise = FA, Engagement = PA, Hierarchy = FA, Multiplicity = PA				

Appendix C Tabulation of alignment rankings for studies demonstrating "full overall alignment" from the literature review

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
1. Ellis (2012) Thesis	11 (8M, 3F) 11-16yo from autistic provision in special needs secondary school	Relationships heavily dependent on understanding students' needs. Students need "chill out time" & issue own 'time-outs' to regulate behaviour/withdrawal; points system & schedules help keep focus. Irritation easily leads to anger: "Everybody watches me all the time". Friendships related to proximity; siblings, objects and animals are all seen as friends. Parents are important, & teachers offer support.	Essay, photography, patchwork quilt, documentary + discussions of activities	Ethnography; interpreted through Goffmanian perspective of social worlds
Expertise = FA, Engagement = FA, Hierarchy = FA, Multiplicity = FA				
2. Healy, Msetfi & Gallagher (2013) Limerick, Ireland	11M, 1F, 9-13yo students with ASD from mainstream primary school	Experiences of PE: - Individual challenges = physical ability, physical fitness, sensory issues (auditory, heat & tactile), fear of injury - Peer interactions = teamwork, initiation of friendship, social comparison, bullying - Exclusion = by teacher/lack of ability/own request	Semi-structured interview with visuals; Slideshow of questions, poster of interview schedule, paper & pens for drawing	Thematic analysis
Expertise = FA, Engagement = FA, Hierarchy = FA, Multiplicity = FA				
3. Humphrey and Lewis (2008a)	20 students with Aspergers (11-17yo) from 4 mainstream secondary schools	Characteristics associated with AS, student understanding of AS, anxiety and stress in school Working with teachers and other staff, negotiating 'difference', relationships with peers	Semi-structured interviews Pupil diaries Pupil drawings	IPA (coding of data & establishment of analytical themes)
Expertise = FA, Engagement = FA, Hierarchy = FA, Multiplicity = FA				

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
4. Killowry (2015) Ireland, Thesis	3M 13-16yo in 3 mainstream secondary schools in Ireland (+ parents & teachers)	David – noise of OHP (sensory), -ve primary school exps. -ve teacher characteristics: shouting, too angry, too loud. +ve = helpful, patient, willing to listen. Sees value of edun, but doesn't believe it's worth working for. Max – "forced to go" to school (no control). Uncomfortable seats, scraping noise of chalkboard (sensory?), doesn't like sharing tables (personal space). Teacher shouting assoc.d with nervousness, even if not directed at him. +ve teacher characteristics: being nice, setting achievable HWK. Likes safe space of games room at school and not being treated like children. Luke – just wants to study for exams (anxiety). High standards; frustrated when others don't meet this (e.g. HWK, behaviour in class). Lots of frustration with peers. +ve teacher characteristics: prepared and planned, take instructions slowly. Overall: all three like light and space, do not feel adults understand them	Adaptation of 'Drawing the Ideal Self' (Moran, 01) to 'Draw the Ideal School' – draw, then interviewed	Thematic analysis
Expertise = FA, Engagement = FA, Hierarchy = FA, Multiplicity = FA				
5. Loyd (2015)	10 (6F, 4M) 16-18yo SEN Drama	Likes/Dislikes: all enjoyed drama, 6/10 favourite; identified different favourite & less liked activities Activities & Goals: learning dance and drama skills, 4 talked about importance of working with peers. Also talked about make-believe aspects & playing roles, impact of own performance on others (e.g. entertainment) Feelings about drama: all chose happy from selection of options. Verbal: excited	Sentence completion Pictures of self in drama Video of self in drama ToM test Observations and interviews with class teachers and drama teachers	Thematic analysis
Expertise = PA, Engagement = FA, Hierarchy = FA, Multiplicity = FA				

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
6. Moyse & Porter (2015)	3 primary girls – 7, 8, 11	- 11yo: annoyed if expected to "muddle through"; dislikes working with others as they didn't listen. Often felt "lonely", like does not exist, dislikes break time. No opportunity to use fidget tools; used hair. Anxiety = hidden - 8yo: did not like break times, bullied and cried, few friends; did classroom jobs. Fiddling helped concentration & happiness; would be helpful to have a place to withdraw to in school. - 7yo: enjoyed break times; handwriting is a problem. Likes ICT, science, climbing frame; said school was "just a tiny bit over okay"	Activity-based discussions with girls Learning walk + photos Venn diagrams, drawings and mind maps	Case study – triangulation with parent and teacher interviews
Expertise = FA, Engagement = FA, Hierarchy = FA, Multiplicity = FA				
7. Shepherd (2015)	6 young people with autism, MLD; 1 used as case study Transition to college	Jake describes work as being easier than expected. Looking forward to new friends, free time, new facilities, new teachers, travelling, being with old friends, course, social activities, lunchtimes, timetable. Worried about getting lost, friends, teachers, missing school, not enough routine, lunchtimes, free time, social activities, work being too hard & not enjoyable, feeling lonely & making friends	Topic sort using iPad Phrase rank using iPad ([not] looking forward to) Photo-trail of places of interest	Thematic analysis
Expertise = FA, Engagement = FA, Hierarchy = FA, Multiplicity = FA				
8. Williams & Hanke (2007)	15 students with ASD (13M, 2F,) between 6-14 yo (secondary and primary)	Environment: Design of school building & equipment: natural light, appropriate size, uncramped classrooms, good-sized & comfortable furniture. Ethics: fun, clean, well-maintained, appropriate beh. rewarded. Staff: Knowledgeable about subject, prepared, smart appearance, know each pupil, willing to play games, smiley, happy, friendly	Adaptation of 'Drawing the Ideal Self' (Moran, 01) to 'Draw the Ideal School' – draw, then interviewed	Thematic analysis related to 2 explanatory models
Expertise = FA, Engagement = FA, Hierarchy = FA, Multiplicity = FA				

Authors and year	Participants	Topic(s) investigated	Methodology	Analysis
9. Winstone, Huntington, Goldsack, Kyrou and Millward (2014)	13 boys, 12-14 yo (5 using standard interview, 8 using activity interviews) from the same school (unclear whether it is mainstream or specialist)	Self-perception and self-awareness (more detailed in activity interviews); future projections of self (easier to describe in activity interviews); perception of self as diagnosed with autism (unable to give description in standard interviews; able in activity interviews) Comparison of self to others (concrete examples and difficulty in describing in standard interviews; much easier in others)	Semi-structured interviews (9 questions) Looking in a mirror Self-portraits Collages	Thematic analysis; analytic comparison between standard and activity-based interviews
Expertise = FA, Engagement = FA, Hierarchy = FA, Multiplicity = FA				

Appendix D Consultations with the autistic adults

D.1 Questions asked in the focus groups

1. How would you describe your overall experience of secondary school?

2. What can you remember about how teachers communicated with you in school?

3. What can you remember about how other students communicated with you in school?

4. Can you remember feeling supported in school?

5. Were you aware of any interesting sensory experiences that you had in school?

6. Is it easy to work out self-regulation/stimming strategies?

7. In your opinion, what is the best way to communicate with an individual on the autistic spectrum?

8. If you could give me one piece of advice for working with you, what would it be?

9. Are the five questions I want to ask the students (see previous section) easy to understand?

10. Are there any other things that you think I should consider before I start my work?

D.2 Guidelines for communication

Emergent theme regarding communication	Recommendations
Importance of clarity in language	1) Keep language simple; explain metaphors or expressive language as you use them 2) Be as literal as possible 3) Use concrete examples for description or comparison 4) Ask direct questions, e.g. rather than 'can you give me an example', instead link to memories, e.g. 'can you remember a time when [specific thing] happened?'
Knowledge of autism	1) Be aware of the difference between knowledge of **experiences** of being on the autistic spectrum and knowledge of **being** on the autistic spectrum 2) Do not say you understand experiences described; relate back to individual, e.g. "Well, that sounds horrible, so I can understand why it upset you" 3) Do not re-word questions if no immediate answer; wait for 10 seconds or for prompt from individual if re-clarification is needed
Respectful attitude	1) Be polite and keep individuals informed 2) Be honest – do what you say and say what you do 3) Do not tell students "it's fine" if they get stressed 4) Be accepting as possible of experiences mentioned 5) Do not focus on mistakes if they occur; take lead from student on how to act (e.g. ask them what they want to do) 6) Ask about individual interests to build a relationship
Awareness of variety of individual experiences	1) Do not assume anything when an individual starts to describe an experience 2) Be aware of hyper and hypo sensitivity varying in different situations

D.3 Guidelines for environmental factors

Emergent theme regarding environmental factors	Recommendations
Environmental characteristics	1) Allow students to adjust seating as needed 2) Interview somewhere without interruptions (consider all senses if possible) 3) Interview somewhere familiar if possible 4) Run interviews/photo trails in line with normal routine (e.g. a lesson) wherever possible
Impact of peers	1) Be aware of strong friendships and positive examples of peer support and encourage these
Openness to positive experiences	1) Be encouraging of positive experiences 2) Do not assume examples given will be negative – prompt to explore ideas
Sensitivity to negative experiences	1) Do not be overly sensitive to negative experiences

D.4 Guidelines for individual factors

Emergent theme regarding individual factors		Recommendations
Knowledge	*Coping Strategies*	1) Look for implicit as well as explicit coping strategies
	Sensory Regulation	1) Allow as many distracted behaviours as possible; question about them if needed
	Autism	1) Likely to be differences in the way students talk about being on the autistic spectrum 2) Some students may have phrases from parents or others – explore these if unsure
Awareness	*Differences*	1) Use direct questions to elicit perceived differences, as students may not be aware of them
	Sensory Experiences	1) Use direct questions using examples given to elicit descriptions of sensory experiences, as students may not be aware of them
Motivation	*Talking*	1) Don't force talking of a difficult subject 2) If students are avoiding a subject, try one direct prompt to elicit information, then move on 3) Be aware of individual differences in confidence when talking to strangers, especially at the beginning of the study
	Working	1) Allow students to stim/be off task as needed 2) Do not discipline – re-direct 3) Praise often

Appendix E Ethics: First Phase

E.1 Ethics application form

October 2015

SSEGM ETHICS SUB-COMMITTEE APPLICATION FORM

Please note:

- ***You must not begin your study until ethical approval has been obtained.***
- ***You must complete a risk assessment form prior to commencing your study.***
- ***It is your responsibility to follow the University of Southampton's Ethics Policy and any relevant academic or professional guidelines in the conduct of your study. This includes providing appropriate information sheets and consent forms, and ensuring confidentiality in the storage and use of data.***
- ***It is also your responsibility to provide <u>full and accurate information</u> in completing this form.***

1. Name(s): Harriet Hummerstone

2. Current Position: Postgraduate Student

3. Contact Details:

Division/School School of Education

Email h.hummerstone@soton.ac.uk

Phone 07525 070441

4. Is your study being conducted as part of an education qualification?

Yes ☒ **No** ☐

5. If yes, please give the name of your supervisor

Dr Sarah Parsons

6. Title of your project:

Communication, support and self-regulation: a Stage 1 study of the mainstream experiences of students on the autistic spectrum

7. i) What are the start and completion/hand-in dates of your study?

Start: 01/10/15, Completion: 01/02/16

ii) When are you planning to start and finish the fieldwork part of your study?

Start: 01/11/15, Completion: 31/12/15

8. Describe the rationale, study aims and the relevant research questions of your study

There is a limited amount of research into the secondary mainstream school experiences of students on the autistic spectrum in the UK (15 studies, to be exact). These fifteen studies are overwhelmingly focussed on the deficits that students on the autistic spectrum are likely to demonstrate, e.g. communication, cognition, social interaction. Also, despite this being a very under-researched area, there has been little research that has taken an exploratory approach to find out what students on the autistic spectrum think generally about their secondary mainstream experiences; or specifically, to look at the strengths that they have in dealing with day to day situations.

This is a Stage 1 study that aims to explore the views of students and adults on the autistic spectrum and the views of school staff; this initial investigation will consequently form the basis of my thesis. Although it is an exploratory study, there are three main areas that I am interested in exploring; support (what is being offered and whether it is judged to be useful), communication (between students, teachers, and support assistants) and self-regulation (the awareness of students on the autistic spectrum in self-regulating strategies). These areas are reflected in some of the current literature investigating these students' perspectives, and are also part of the wider focus in which I am setting my thesis, which aims to facilitate a dialogue between students on the autistic spectrum and the staff that support them.

I am aiming to gather these perspectives on three different levels. Firstly, I am hoping to conduct a focus group with members of an adult autism advocacy group in order to seek some guidelines about interviewing students on the autistic spectrum, and also to talk in general terms about the three topics mentioned above in relation to their own experiences in secondary school. Secondly, I will observe and interview adolescent students on the autistic spectrum about their classroom experiences, again focussing on these three areas. The observations will allow me to identify the staff and peers that these students work with, as well as giving me concrete examples of classroom experiences to discuss with the students during the interviews. Thirdly, I will interview some of these members of staff about their opinions on the student's communication, support needs and self-awareness strategies.

The aim of this Stage 1 study is to build a picture of each individual student and the dialogues they have with the adults and other students around them. This will allow me to identify and approach staff to interview for Stage 2 (the main crux of the study), where I am hoping to trial a number of different methods for improving the dialogue between students on the autistic spectrum and the adults which support them. These methods which will be selected according to the specific requirements of the students and their teachers, but are likely to include a number of visual methods (such as photo-elicitation) and exploratory talk, a metacognitive method used in primary schools which I am attempting to translate into a secondary school environment. As the three main areas I am interested in are support, communication and self-regulation; consequently, the research questions for this initial study are therefore as follows:

RQ1: What is the nature of support being offered to (and by) students on the autistic spectrum in a classroom environment?

RQ2: What is the nature of the communication between students on the autistic spectrum and the others (e.g. teachers, LSAs, peers) they are working with?

RQ3: What might be the factors that contribute to the nature of these communications?

RQ4: Are students on the autistic spectrum aware of any self-regulation strategies they possess?

RQ5: From the perspectives of the adult autistic community, what communication strategies are likely to be less/more suited to individuals on the autistic spectrum?

9. Describe the design of your study

The first level of data collection will take place with an adult autism advocacy group. I will be seeking their advice and guidelines on general communication strategies (and specifically, interviewing strategies) when working with individuals on the autistic spectrum. Although I do not think that a general consensus will be reached given the highly heterogeneous nature of autism, the aim is to give me as many different perspectives as possible to aid my data collection with students. In addition, I will be asking the adults about their experiences with communication, support and self-regulation while they were in secondary mainstream school. The initial questions that will be asked in the focus group are as follows, with follow-up prompts being used as necessary. Links to research questions are included in the brackets.

1. How would you describe your overall experience of secondary school? (RQ3)

2. What can you remember about how teachers communicated with you in school? (RQ2/3/5)

3. What can you remember about how other students communicated with you in school? (RQ2/3/5)

4. Can you remember feeling supported in school? (RQ1)

5. Were you aware of any interesting sensory experiences that you had in school? (RQ3/4)

6. Is it easy to work out self-regulation/stimming strategies? (RQ4)

7. In your opinion, what is the best way to communicate with an individual on the autistic spectrum? (RQ5)

8. If you could give me one piece of advice for working with you, what would it be? (RQ5)

9. Are the five questions I want to ask the students (see further on in this section) easy to understand? (RQ5)

10. Are there any other things that you think I should consider before I start my work? (RQ5)

These questions will be approved by the advocacy group leader, and will be disseminated to the group a few weeks before our meeting to allow them time to think about their answers. I will then ask the group these questions and audio record their responses. This feedback will help guide my interviews with adolescent students on the autistic spectrum, and hopefully further my understanding of autism as a neurotypical researcher to allow me to gain a more authentic expression of these students' voices.

The second level of data collection will take place through informal observations of lessons with the students who are going to be involved (e.g. shadowing the student for a day). This will take place over a period of about three days. The purpose of these observations is to see the student in as many different subjects as possible and to gather information about the people they work with to facilitate the interviews. The reason for the observations taking place over three days is to allow the student to have some time away from me, and also for practical and scheduling reasons. Following these observations, the students will be asked to take a series of photos that represent each subject they study. These photos will then be printed out to use during the initial interviews. The students will be asked to explain what the photos are and what subject they represent. They will then be asked to rank the photos in response to the following questions (brackets indicate references to research questions):

1. Can you put these photos in order of the subjects you look forward to most? (RQ1/2/3/4)

- This question will be asked as an initial "ice-breaker" to familiarise the students with the diamond ranking exercise. The students will be asked to explain their rankings, including why a particular subject is "liked" best, which could include references to teachers, other students, and sensory environments - follow-up questions will be asked as necessary to determine this.

2. Can you put these photos in order of the subjects you are most relaxed in? (RQ1/2/3/4)

- This relates to self-regulation, and may also relate to the support of others, e.g. LSAs, peers, teachers, sensory environment. Again, students will be asked to explain their rankings, including why they think they are more relaxed in some lessons than others. Students will also be asked to think about what being relaxed means to them, e.g. whether it means being well-supported, or having sensory experiences regulated, or feeling like a subject is well-explained.

3. Can you put these photos in order of the subjects you communicate in most? (RQ2/3/4)

- This question will most likely relate to the communication that exists between teachers and support staff, although support from peers and an awareness of the students' own abilities may be applicable here as well - follow-up prompts will be used to determine what factors may affect these ratings, as well as potentially exploring non-verbal communication seen in the observations. The word "communicate" will deliberately be left undefined to allow students to interpret the question as they see fit, e.g. participating, talking to people, volunteering answers to teacher's questions, etc. Follow-up questions will then be used to help students expand on their answers, or to clarify using examples if they are unsure of how to answer this question.

4. Can you put these photos in order of where you are helped most? (RQ1/2/3)

- This again relates to the support that may be on offer, and whether the students feel it is effective or not - however, this may also link to communication if discussing how effective a teacher/peer/LSA is at explaining things that are not understood.

5. Can you put these photos in order of how helpful the other students in your class are? (RQ1/2/3/4)

- There is flexibility with this question to talk generally about the other students in the class, and also to look at any particular friends that students may have in specific classes and how this may impact on their enjoyment of their lessons. This may also lead to discussions about the noisiness or disruptiveness of certain classmates and how this may impact on a student's classroom experiences.

Using semi-structured interviews means that salient points can be expanded, and clarification sought (on both sides) if needed. All interviews will be recorded on a video camera to promote clarity of answers. The decision to video-record students is so that information regarding photo choices can be easily detailed - this is not as easy on standard audio recordings. However, the students will be given control of the recording equipment so that they have complete control over the video camera and can stop the recording at any time.

This method of photo-elicitation is something I already have experience of using, as it was the main data collection method I used for my Masters' dissertation. Consequently, I have already used this method to facilitate communication with a number of students on the autistic spectrum who all differed in their particular needs. As this dissertation research took part in a secondary mainstream school, I am also already aware that it can work effectively within this environment.

I will also interview school staff who work with particular students about their views of the students in question. These participants will be self-selected from all of the teachers and support staff that I encounter whilst observing the students. The questions they will be asked are as follows (references to RQs in brackets, where appropriate):

1) Describe what [student name] is like in lessons

- This is a deliberately open-ended question which is designed to help staff relax and give some general ideas about their perceptions of the students they work with. There may be a variety of ideas which are expressed at this stage, which can be explored in more depth as necessary. Staff may also give information that is relevant to more than one research question

2) What is [student name]'s communication with staff/other students/yourself like? (RQ2/3)

- This will allow for any differences between communication to be identified more easily, as well as potentially identifying reasons for these differences.

3) What adjustments do you find yourself making to help [student name]? (RQ1/3)

- This is another deliberately open-ended question to allow staff to describe general strategies as well as specific planning or adjustments that they make when working with a student. Again, this may cover a range of topics, such as academic, social and cognitive support.

4) What are [student name]'s strengths? (RQ1/2/3)

- Rather than asking specifically about issues (which are likely to be mentioned anyway), I want to see what awareness staff have of these individuals' strengths, and how this might be used to support them.

All three groups of participants' responses to these questions will be written up as a transcript and analysed using thematic analysis to identify emergent themes; these themes will then give me a picture of the current classroom experience. Once this is established, I can then shape the main research project for my thesis, which aims to improve the existing dialogue between students and the people they work with in a secondary mainstream environment.

10. Who are the research participants?

The initial sample will be adults from the Autism Sussex advocacy group (potentially 5-10 individuals). The second sample will require students on the autistic spectrum from two schools - Ringwood School (Ringwood, Hampshire) and the Arnewood School (New Milton, Hampshire). These schools already have links with Southampton Education School, and both have gatekeepers that are personally known to me and who will therefore facilitate access. The aim is to identify as many students as possible from each school; ideally, at least 10 students in total. The students will range between 11-16 years of age, and will all have a diagnosis of ASD/Asperger's Syndrome. The final group of staff participants will self-select from the student observations I complete, and may potentially be 3-5 individuals working within these two schools

11. If you are going to analyse secondary data, from where are you obtaining it?

N/A

12. If you are collecting primary data, how will you identify and approach the participants to recruit them to your study?

Please attach a copy of the information sheet if you are using one – or if you are not using one please explain why.

For this initial study, the sampling frame will be opportunity sampling for both sets of participants on the autistic spectrum. For the adult participants, the focus group members will be recruited and coordinated using a contact of mine at Autism Sussex who runs the advocacy group. For the student participants, the SENCO of each school will identify students who have been statemented and given an official diagnosis of either ASD or Asperger's Syndrome. The SENCO will then approach these students and their parents to gain consent to take part in this initial study. Information sheets for both the SENCOs/parents and the students are attached.

Once the students and parents have given consent, the SENCO will communicate with the student's subject teachers, acquiring their permission for me to observe the students in their lessons. Once I have carried out my observations, I will then contact all of the school staff I have observed and ask them whether or not they would be interested in answering some follow-up questions; the final sample of staff participants will therefore be self-selected.

13. Will participants be taking part in your study without their knowledge and consent at the time (e.g. covert observation of people)? If yes, please explain why this is necessary.

No.

14. If you answered 'no' to question 13, how will you obtain the consent of participants?

Please attach a copy of the consent form if you are using one – or if you are not using one please explain why.

Consent will be sought prior to undertaking the study. Adults at the advocacy group will be given consent forms a few weeks in advance, along with the information sheets and the questions to be asked. For the student participants, consent forms will be given to the parents of students taking part. Students will complete an assent form demonstrating their willingness to take part in the study. Teachers and LSAs will initially be asked by the SENCO if they are happy for me to observe their lessons. Consent forms and information sheets will be sent to all the staff who I have observed once the observations are complete, asking them to return the consent forms if they are willing to answer some follow-up questions.

15. Is there any reason to believe participants may not be able to give full informed consent? If yes, what steps do you propose to take to safeguard their interests?

The student participants are under 16 and may arguably not grasp the implications of their consent due to their age and diagnosis, so parental consent is also being sought.

16. If participants are under the responsibility or care of others (such as parents/carers, teachers or medical staff) what plans do you have to obtain permission to approach the participants to take part in the study?

The first point of contact and consent within the schools will be made with the headteachers. Contact will then be made with the SENCOs and Child Protection Officers in each school to ensure the safety of all participants. Following this, the SENCO will then approach the parents and students about the study by passing on the information forms and consent/assent forms to them.

17. Describe what participation in your study will involve for study participants. Please attach copies of any questionnaires and/or interview schedules and/or observation topic list to be used

The data collection from adults will take place at a pre-scheduled advocacy meeting. I will be attending for only part of the session (to allow those who do not wish to participate to meet the group as usual). Once I arrive, I will be introduced and will then ask the participants if they are still happy to continue. I will then ask the questions detailed in Q9 and take audio recordings of participants' answers. Clarification on both sides will be sought if necessary. Once all questions have been asked and answered, I will thank the group for their time and ask them if they would be interested in hearing about the results of my study. If so, I will make arrangements to communicate these details at a later date.

The data collection from students will take place over a four week period to allow for any issues with scheduling and observations. I will initially meet with the students to introduce myself, and will then discuss with them and a SENCO/LSA which lessons will be appropriate for me to observe. Once this observation schedule has been confirmed (i.e. consent has been gained from the teachers of the lessons), I will “shadow” the student to a few of their lessons each day where I will observe them. I will not interact with the student or with any other individuals in the class, and will be merely creating a written record of what the student is doing in relation to the three areas of support, communication and self-regulation detailed in Q8.

Before the students are interviewed (and after the informal observations), students will be given a camera and instructed to take a photo that represents each of their subjects. This activity will be supported by me, and is likely to take place during lesson time. The next day, I will return with hard copies of the photos that they have taken. Students will then take part in an interview where we will discuss the photos, and will be asked five questions about them (see Q9). The interview will be video-recorded, but students will have control over when the recording starts and finishes. Once the interview is completed, the students will be thanked for their time. As this is a Stage 1 study and I intend to conduct a follow-up study, I will also ask students at this point whether they would potentially be interested in working with me again.

Data collection from school staff will also take place after the observations have finished. This will take between 1-2 weeks to carry out, depending on participant numbers and availability. I will meet with these participants and audio-record their responses to questions (see Q9). Once the interview

is over, participants will be thanked for their time. As this is a Stage 1 study, I will also ask staff participants if they would potentially be interested in working with me again in the near future.

18. How will you make it clear to participants that they may withdraw consent to participate at any point during the research without penalty?

Information about withdrawing is given on both the information sheet and the consent form for parents, adults, staff and students. I will also give my participants a verbal reminder when I initially meet them (and at each subsequent meeting for the student participants). Teachers and LSAs who are consenting to lesson observations may also withdraw their consent at any time and will be asked whether they are happy to reschedule.

If any participants wish to withdraw their consent to participate after data collection has been carried out, I will remind them that they can withdraw their data without consequence - as long as they let me know in a timely fashion so that I can exclude their responses from my analyses.

19. Detail any possible distress, discomfort, inconvenience or other adverse effects the participants may experience, including after the study, and you will deal with this.

All participants may experience some stress or discomfort if they are talking about unpleasant or difficult experiences. This is raised in the information sheets that participants are given, and they are able to discontinue the study at any time without explanation. I will also explain to the student participants that if there are any issues raised as a result of the interviews that will impact on the safety of themselves or someone else, I will need to let either the SENCO or an LSA know to offer them any support that might be needed. In addition, if participants experience any distress after the study, they are also allowed to withdraw their results if they notify me within a timely period so that their data can be withdrawn from the analysis.

I have almost six years of teaching experience and over twenty years of both personal and professional knowledge regarding individuals on the autistic spectrum, including some with very challenging behaviour. Consequently, I am trained to look for the first signs of anxiety/distress, and deal with them appropriately to prevent further upset (e.g. using a low arousal approach to communicate, offering a time out/break if needed, asking if they want to continue). I have also conducted interviews using photo-elicitation with students on the autistic spectrum before for my Masters qualification, and therefore have experience already in using this method. If I judge that an individual is continuing with the interview or focus group despite feeling uncomfortable (due, for example, to the authority that I represent or out of a desire to please) then I will reassure them and, if necessary, stop the interview myself.

Finally, there may be some discomfort experienced by teaching staff in talking to me due to my pre-existing relationships with those in their schools. I will reassure participants that everything is confidential unless it puts either themselves or another at immediate risk of harm.

20. How will you maintain participant anonymity and confidentiality in collecting, analysing and writing up your data?

Complete anonymity cannot be guaranteed, but all participants' data will be coded so that they are not individually identified (see Q23). All data will be kept on a password-protected computer, and individual transcript documents will also be password-protected. Any photos that student participants take that directly identify the school or an individual will not be published - they will be modified (e.g. names/faces/identifying details blurred out).

21. How will you store your data securely during and after the study?

See above.

22. Describe any plans you have for feeding back the findings of the study to participants.

Participants are given the option of providing their email address on the consent form to allow me to email them with the overall results of the study once the data has been analysed. This will be a brief and simple summary of the main findings.

23. What are the main ethical issues raised by your research and how do you intend to manage these?

1) Informed consent - as stated previously, students may not fully understand what they are consenting to, given their age and the nature of their diagnosis. To ensure that fully informed consent is sought (and given that all the children are under 16), parental consent is required in addition to an assent form being signed by the child.

The information sheets provided for all participants are detailed, and include my contact details so that if there are any further queries, they are able to contact me with relative ease.

There is also a possibility that the students will want to take photos of people to represent their subjects. I will be supervising their photography, so can ensure that permission is sought (and if necessary, can provide consent forms to be signed). Where people may appear in the background of photos (e.g. if a participant is photographing a corridor, and children are walking at the end of it), permission will be sought if possible. I will also liaise with the CPO of the school and give them an opportunity to highlight any issues with photos before they are used in the study, and if necessary, they can be edited. For example, a photo of a corridor may be cropped so that the students in the background are not included.

2) Right to withdraw - in addition to stating that participants can withdraw at any time in the information sheet and consent form, I will also be offering verbal reminders at each meeting with the participants.

3) Welfare of participants - it is possible that when recalling their experiences of teaching/learning, adult and student participants may experience some distress. This will

be handled sensitively and with respect. The student participants have control over the recording of the video camera, and therefore can turn it off it at any point they do not wish to continue; adults are free to leave the focus group at any time. If such circumstances arise, participants will be offered some time to compose themselves, and then may carry on if they wish to do so. If parents request to be present at the interview, then this can be accommodated with the understanding that they there as an observer only.

4) Confidentiality - although complete confidentiality is not able to be given (as participants have been specifically selected and therefore others in the school/advocacy group will know that they have taken part in the research), all participants will have their data coded to ensure that they cannot be individually identified.

My own welfare as a researcher will be looked after by ensuring that the rooms used for interviewing the students/adults include see-through doors, and by recording the interviews. It may be that I am emotionally affected by the responses of the participants if they describe any issues. I will deal with this by practising the interview process beforehand to ensure that my data collection is not compromised, and if needed, can seek support from my supervisors regarding any distressing comments that may be made.

24. Please outline any other information you feel may be relevant to this submission.

N/A

E.2 Information sheets for the autistic adults

Focus Group 1

Adult Information Sheet

Study Title: What do individuals on the autistic spectrum think about school?

Researcher: Harriet Hummerstone **Ethics number**: 17434

Please read this information carefully before deciding if you are happy to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

I am a qualified Psychology teacher who is currently working towards a PhD in Education at the University of Southampton. For my study, I want to investigate the classroom experiences of students on the autistic spectrum.

I want to ask adults on the autistic spectrum for advice on the best ways of communicating with these students, and also to ask about their experiences of secondary school.

By interviewing current students and adults on the autistic spectrum, I am hoping to do another study that might improve the dialogue between students on the autistic spectrum and those they work with (e.g. teachers, learning support assistants, other students) in secondary mainstream schools.

Why have I been chosen to take part?

For this project, I am focusing on adults who have received a diagnosis of autism/Asperger's Syndrome who are willing to talk about their secondary school experiences, and offer me advice on how to interview students. Mark Bushby from Autism Sussex has helped me to get in touch with adults who he thinks might want to help me.

What will happen to me if I take part?

I will meet with the group of individuals who have agreed to take part. I will be making audio recordings of what everyone says to help me remember things clearly.

In the first part of this meeting, I will explain how I am using photos and questions to ask students about their experiences at school (see P3, Section 1 for these questions). I want to know whether you think these questions are easy to understand.

The second part of this meeting involves me asking the group some questions about their time at secondary school (see P3, Section 2 for these questions). It may be that I ask additional questions if I need someone to explain what they have said in more detail.

You can answer as many or as few questions as you like. Once everyone is happy that they have said what they want to say, the meeting will be over and I will thank everyone for their help.

Are there any benefits of taking part?

Representing the views of individuals on the autistic spectrum is a key area that needs exploring in more detail; I believe there is not enough of it in the current autism research. Your advice and knowledge of autism will help me to communicate more effectively with the students in my study.

Are there any risks involved?

There is very minimal risk involved in this study. You will be asked questions about your experiences of secondary school; in some cases, this may lead to remembering potentially stressful memories. However, you do not have to answer every question, and can withdraw from the study at any time. This study has been ethically approved by the University of Southampton, and I have experience of working with a number of individuals on the autistic spectrum, so will try my hardest to work effectively and respectfully with you.

Will my participation be confidential?

Data from this study (e.g. the audio recordings and the analysis of your answers) will be kept in compliance with the Data Protection Act and stored on a password protected computer. Data will also be coded so that your real names are not published and quotations are not identifiable. To do this, you can choose another name that I can use to refer to you in the study.

What happens if I change my mind about taking part?

Participation is completely voluntary, and therefore you can withdraw from the study at any time. If you do not want your data to be used for analysis after our meeting, please email me and tell me this by **30th December 2015**.

What happens if something goes wrong?

In the unlikely case that you are concerned or wish to make a complaint, please contact the Head of Research Governance at the University of Southampton (02380 595058, rgoinfo@soton.ac.uk)

Where can I get more information and/or ask questions?

Please feel free to contact me regarding any further questions or queries you may have via email: Harriet Hummerstone h.hummerstone@soton.ac.uk

Section 1: Questions I will be asking the students

1. Can you put these photos in order of the subjects you look forward to most?
2. Can you put these photos in order of the subjects you are most relaxed in?
3. Can you put these photos in order of the subjects you communicate in most?
4. Can you put these photos in order of where you are helped most?
5. Can you put these photos in order of how helpful the other students in your class are?

Section 2: Questions I will be asking the group

1. How would you describe your overall experience of secondary school?
2. What can you remember about how teachers communicated with you in school?
3. What can you remember about how other students communicated with you in school?
4. Can you remember feeling supported in school?
5. Were you aware of any interesting sensory experiences that you had in school?

Focus Group 2

Adult Information Sheet

Study Title: What do individuals on the autistic spectrum think about school?

Researcher: Harriet Hummerstone **Ethics number**: 17434

Please read this information carefully before deciding if you are happy to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

I am a qualified Psychology teacher who is currently working towards a PhD in Education at the University of Southampton. For my study, I want to investigate the classroom experiences of students on the autistic spectrum.

I want to ask adults on the autistic spectrum for advice on the best ways of communicating with these students, and also to ask about their experiences of secondary school.

By interviewing current students and adults on the autistic spectrum, I am hoping to do another study that might improve the dialogue between students on the autistic spectrum and those they work with (e.g. teachers, learning support assistants, other students) in secondary mainstream schools.

Why have I been chosen to take part?

For this project, I am focusing on adults who have received a diagnosis of autism/Asperger's Syndrome who are willing to talk about their secondary school experiences, and offer me advice on how to interview students. Mark Bushby from Autism Sussex has helped me to get in touch with adults who he thinks might want to help me.

What will happen to me if I take part?

I will meet with the group of individuals who have agreed to take part. I will be making audio recordings of what everyone says to help me remember things clearly.

I will ask the group some questions about their time at secondary school (see P3 for these questions). It may be that I ask additional questions if I need someone to explain what they have said in more detail.

You can answer as many or as few questions as you like. Once everyone is happy that they have said what they want to say, the meeting will be over and I will thank everyone for their help.

Are there any benefits of taking part?

Representing the views of individuals on the autistic spectrum is a key area that needs exploring in more detail; I believe there is not enough of it in the current autism research. Your advice and knowledge of autism will help me to communicate more effectively with the students in my study.

Are there any risks involved?

There is very minimal risk involved in this study. You will be asked questions about your experiences of secondary school; in some cases, this may lead to remembering potentially stressful memories. However, you do not have to answer every question, and can withdraw from the study at any time. This study has been ethically approved by the University of Southampton, and I have experience of working with a number of individuals on the autistic spectrum, so will try my hardest to work effectively and respectfully with you.

Will my participation be confidential?

Data from this study (e.g. the audio recordings and the analysis of your answers) will be kept in compliance with the Data Protection Act and stored on a password protected computer. Data will also be coded so that your real names are not published and quotations are not identifiable. To do this, you can choose another name that I can use to refer to you in the study.

What happens if I change my mind about taking part?

Participation is completely voluntary, and therefore you can withdraw from the study at any time. If you do not want your data to be used for analysis after our meeting, please email me and tell me this by **30th March 2016**.

What happens if something goes wrong?

In the unlikely case that you are concerned or wish to make a complaint, please contact the Head of Research Governance at the University of Southampton (02380 595058, rgoinfo@soton.ac.uk)

Where can I get more information and/or ask questions?

Please feel free to contact me regarding any further questions or queries you may have via email: Harriet Hummerstone h.hummerstone@soton.ac.uk

The questions I will be asking the group:

1. Is it easy to work out self-regulation/stimming strategies?

2. In your opinion, what is the best way to communicate with an individual on the autistic spectrum?

3. If you could give me one piece of advice for working with you, what would it be?

4. Are there any other things that you think I should consider when working with students on the autistic spectrum?

E.3 Consent forms for the autistic adults

Focus Group 1

CONSENT FORM FOR ADULT PARTICIPANTS

Study title: What do individuals on the autistic spectrum think about school?

Researcher name: Harriet Hummerstone

Ethics reference: 17434

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (SSEGM Initial Study Participant Information Sheet (Adults) V2) and have had the opportunity to ask questions about the study	☐
I agree to take part in this research	☐
I don't mind my conversation with Harriet being audio-recorded	☐
I understand that Harriet will only play the recordings to people who are helping her with her research (e.g. her supervisor)	☐
If Harriet wants to repeat what I've said in her research, I don't mind her using my words	☐
I understand that Harriet will not use my real name in her research and I am happy to provide a false name for her to use	☐
I understand that I can stop working with Harriet at any time if I feel uncomfortable, and do not have to explain why I want to stop	☐
I would like to be informed of the results of Harriet's study once her initial analysis has been completed	☐

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study.

Participant's name.....

Participant's signature..... Date.....

Signature of researcher..... Date.....

Focus Group 2

CONSENT FORM FOR ADULT PARTICIPANTS

Study title: What do individuals on the autistic spectrum think about school?

Researcher name: Harriet Hummerstone

Ethics reference: 17434

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (SSEGM Initial Study Participant Information Sheet (Adults) FG V3) and have had the opportunity to ask questions about the study	☐
I agree to take part in this research	☐
I don't mind my conversation with Harriet being audio-recorded	☐
I understand that Harriet will only play the recordings to people who are helping her with her research (e.g. her supervisor)	☐
If Harriet wants to repeat what I've said in her research, I don't mind her using my words	☐
I understand that Harriet will not use my real name in her research and I am happy to provide a false name for her to use	☐
I understand that I can stop working with Harriet at any time if I feel uncomfortable,	☐
I would like to be informed of the results of Harriet's study once her initial analysis has been completed	☐

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study.

Participant's name.....

Participant's signature..... Date.....

Signature of researcher..... Date.....

E.4 Information sheets for parents

Parent Information Sheet

Study Title: What do students on the autistic spectrum think about school?

Researcher: Harriet Hummerstone **Ethics number**: 17434

Please read this information carefully before deciding if you are happy for your child to take part in this research. If you are happy for them to participate you will be asked to sign a consent form.

What is the research about?

I am a qualified and experienced Psychology teacher who is currently working towards a PhD in Education at the University of Southampton. I have both personal and professional experience of working with a wide range of individuals on the autistic spectrum, especially in a secondary school environment. For this initial study, I want to investigate the classroom experiences of students on the autistic spectrum, looking into the three main areas of support, communication and self-regulation. By interviewing students on the autistic spectrum, I am hoping that the findings of this study will inform a second investigation into improving the dialogue between students on the autistic spectrum and those they work with (e.g. teachers, LSAs, other students) in a secondary mainstream school.

Why has my child been chosen?

For this project, I am focusing on students who are currently attending secondary schools and who have received a diagnosis of Autism Spectrum Disorder or Asperger's Syndrome.

What will happen to my child if he/she takes part?

The study will take place over a four week period (to allow for scheduling/timetabling). I will initially meet with students to introduce myself, and arrange a chance to "shadow" their lessons. In these lessons, I will observe each student and those around them. Following my observations, students will be given a camera to take a photo that represents each of their subjects. This is likely to take place during lesson time, and will take approximately 30 minutes to complete.

I will then return with hard copies of the photos that the students have taken. We will then have a short interview which should last no longer than 30 minutes. We will discuss the photos they've taken, and the students will be asked five questions about the photos, allowing them to "rank" the

photos in response to each question, e.g. “Can you put these photos into the order of subjects that you look forward to the most?”.

The interview will be recorded using a video camera. Students will have control over when the recording starts and finishes, and can stop the recording at any time. Once the interview is completed, the students’ contribution to this study is over, and they will be thanked for their time. If desired, I can notify individuals at a later date (via email) of the outcome of my research, once my analysis has been completed.

Are there any benefits in my child taking part?

Representing student views is a key area that needs exploring in more detail; I believe there is not enough of it in the current autism research. In addition, the views of your child (and the other students taking part) will be used to help me decide what is most relevant to investigate for my main research project. This may help to identify successful strategies for improving the dialogue between students and those that they work with, and could potentially be used on a larger scale.

Are there any risks involved?

There is very minimal risk involved in this study. Students will be asked questions about their experiences of secondary school; in some cases, this may lead to students sharing potentially stressful memories. However, students are under no obligation to answer every question, and can withdraw from the study at any time. This study has been ethically approved by the University of Southampton, and I have an enhanced and current DBS check.

Will my child’s participation be confidential?

Data from this study (e.g. video recordings, analysis of participant answers) will be kept in compliance with the Data Protection Act and stored on a password protected computer. Data will also be coded so that individual names are not published and quotations are not identifiable; students will choose another name that they will be known by in this study. Photos that directly identify an individual or the school will be modified (e.g. faces blurred out) to assist confidentiality.

What happens if I (or my child) change our minds?

Participation is completely voluntary, and therefore the student can withdraw from the study at any time. If you do not wish for your child’s data to be used for analysis after they have completed the study, please can you inform me of this by **30th December 2015**.

What happens if something goes wrong?

In the unlikely case of concern or complaint, please contact the Head of Research Governance at the University of Southampton (02380 595058, rgoinfo@soton.ac.uk)

Where can I get more information and/or ask questions?

Please feel free to contact me regarding any further questions or queries you may have via email: Harriet Hummerstone h.hummerstone@soton.ac.uk

E.5 Consent forms for parents

CONSENT FORM FOR PARENTS

Study title: What do students on the autistic spectrum think about school?

Researcher name: Harriet Hummerstone **Ethics reference**: 17434

Please **initial** the box(es) if you agree with the statement(s):

I have read and understood the information sheet (SSEGM Initial Study Information Sheet (Parents) V3 09.10.15) and have had the opportunity to ask questions about the study	☐
I agree that my child can take part in this research project and agree for my child's data to be recorded and used for the purpose of this study	☐
I understand that my child's responses will be anonymised in reports of the research so that my child's name and the name of the school is not used	☐
I consent to having my child's anonymous responses and photos used in reports of the research	☐
I understand my child's participation is voluntary and my child may withdraw at any time without their legal rights being affected	☐
I would like to be contacted regarding the overall results of the project	☐

Email.....

Data Protection

I understand that information collected about my child during their participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study.

Name of child (print name)……

Name of parent (print name).....

Signature of parent…… Date……

Signature of researcher..... Date.....

E.6 Information sheets for students

Student Information Sheet

Study Title: What do students on the autistic spectrum think about school?

Researcher: Harriet Hummerstone **Ethics number**: 17434

Please read this information carefully before deciding to take part in my research. If you are happy to participate you will be asked to sign a form.

What is the research about?

My name is Harriet, and I am a teacher who is currently studying at university in Southampton. I want to find out about the classroom experiences of students on the autistic spectrum.

Here is a photo of me so that you know what I look like:

Why have I been chosen?

I want to talk to students who are currently at secondary school and who have received a diagnosis of Autism Spectrum Disorder/Asperger's Syndrome.

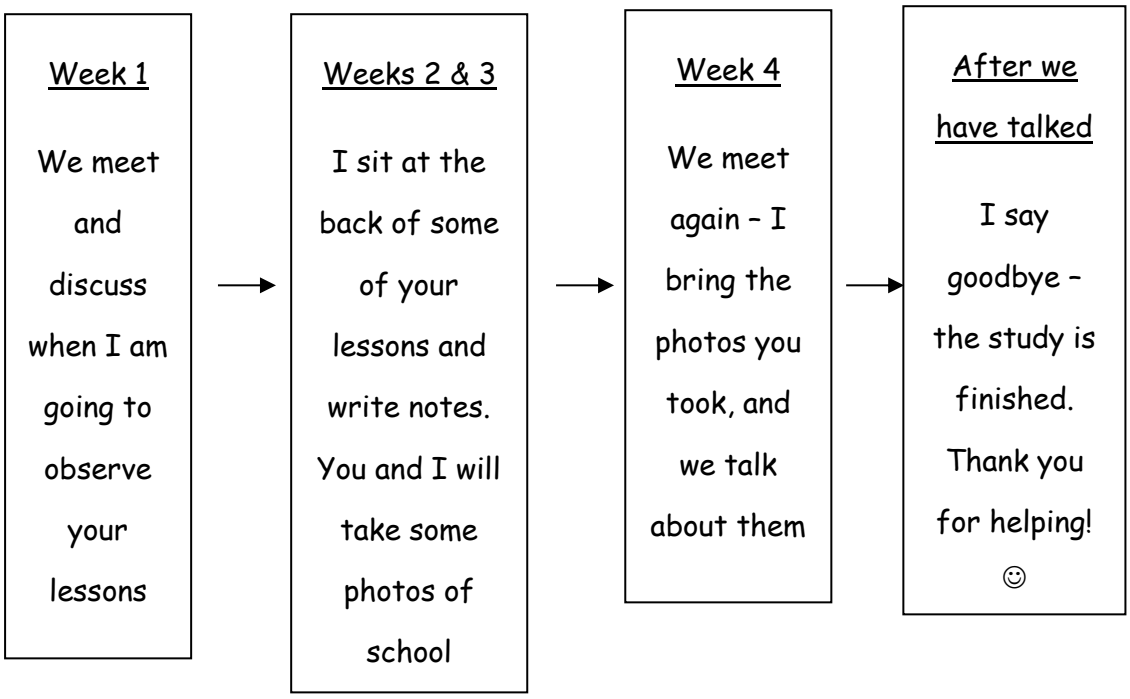
What will happen to me if I take part?

I will meet with you and introduce myself, and then come and observe some of your lessons.

After this, I will meet you again during lesson time. We will go around the school and you can take some photos to represent each of your subjects. For example, you might want to take a picture of a classroom.

A few days later, we will meet to talk about the photos you took, and sort them a few times. There will be a video camera so I can record our talking and remember what we say! ☺

After we have finished talking, the study is over. I will say goodbye and then go back to the university to write up my results.



What's good about taking part?

By sharing your views and opinions on your subjects, it will help me to understand a bit more what students on the autistic spectrum think about school.

Are there any risks involved?

There is very minimal risk involved in this study and no more than you would experience during a typical day at school. I will be asking you questions about your experiences of secondary school and there may be some happy as well as not so happy memories. However, you do not have to answer my questions if you do not want to, and can stop the study at any time.

Will anyone else know that I have taken part?

Confidentiality means that I will not tell other people your real name. The video recordings will be kept on a password protected computer. If I quote you (i.e. use something you said in my write-up of the study), you can choose a different name that I can use to keep things private! ☺

I may show other people who are helping me at the university the photos you have taken, unless they show a particular person or the name of your school (to stop other people knowing).

What we talk about is private, unless you tell me something that might put yourself or someone else at risk. To make sure that you are safe, I may need to tell another adult.

What happens if I change my mind?

You can stop taking part in the study at any time, and do not have to tell me why ☺

What happens if something goes wrong?

If you are worried about something to do with the study, please let me know.

If you do not want to talk to me, please tell your worries about the study to someone in your family, a friend, or a helper at school so that we can help.

Where can I get more information or ask a question?

Please email me if you have any further questions.

My email address is h.hummerstone@soton.ac.uk

E.7 Assent forms for students

ASSENT FORM FOR STUDENT PARTICIPANTS

Study title: What do students on the autistic spectrum think about school?

Researcher name: Harriet Hummerstone **Ethics reference**: 17434

Please **initial** the box(es) if you agree with the statement(s):

I have read and understood the information sheet (SSEGM Initial Study Participant Information Sheet (Students) V3 09.10.15) and have had the opportunity to ask questions about the study	☐
I agree to take part in this research	☐
I don't mind my conversation with Harriet being recorded with a video camera	☐
I understand that Harriet will not use my name in her research and will only show my video to people who are helping her with her work (e.g. her teacher)	☐
If Harriet wants to repeat what I've said in her research, I don't mind her using my words	☐
I don't mind Harriet using the photos I've taken in her research (unless you can identify my school or a specific person in them)	☐
I understand that I can stop working with Harriet at any time if I feel uncomfortable, and do not have to explain why I want to stop	☐

Participant's name.....

Participant's signature.....

Date.....

Signature of researcher..... Date.....

E.8 Observation consent forms for staff

OBSERVATION CONSENT FORM FOR STAFF

Study title: What do students on the autistic spectrum think about school?

Researcher name: Harriet Hummerstone

Study Overview

I want to investigate the classroom experiences of students on the autistic spectrum, looking into the three main areas of support, communication and self-regulation. By interviewing students on the autistic spectrum and the people they work with, I am hoping that the findings of this study will inform a second investigation into improving the dialogue between students on the autistic spectrum and those they work with (e.g. teachers, LSAs, other students) in a secondary mainstream school.

Please **initial** the box(es) if you agree with the statement(s):

I agree to letting Harriet observe a student on the autistic spectrum in my lesson	☐
I agree to letting Harriet take notes on a student on the autistic spectrum in my lesson	☐

As part of this study, would you be potentially interested in being interviewed to discuss the students on the autistic spectrum that you teach? (please circle)

YES **NO**

Name (print name)……

Signature …… Date……

Signature of researcher..... Date.....

E.9 Information sheets for staff

Staff Information Sheet

Study Title: What do students on the autistic spectrum think about school?

Researcher: Harriet Hummerstone **Ethics number**: 17434

Please read this information carefully before deciding if you are happy to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

I am a qualified and experienced Psychology teacher who is currently working towards a PhD in Education at the University of Southampton. I have both personal and professional experience of working with a wide range of individuals on the autistic spectrum, especially in a secondary school environment. For this initial study, I want to investigate the classroom experiences of students on the autistic spectrum, looking into the three main areas of support, communication and self-regulation. By interviewing students on the autistic spectrum and the people they work with, I am hoping that the findings of this study will inform a second investigation into improving the dialogue between students on the autistic spectrum and those they work with (e.g. teachers, LSAs, other students) in a secondary mainstream school.

Why have I been chosen?

For this project, I am focusing on staff who work with students who are currently attending secondary schools and who have received a diagnosis of Autism Spectrum Disorder or Asperger's Syndrome.

What will happen if I take part?

The study will take place over a two week period (to allow for scheduling/timetabling). I will meet with you to introduce myself and complete any administration. We will then have a short interview which should last no longer than 30 minutes where I will ask you about a particular student you work with. The interview will be audio-recorded to allow me to remember everything that has been said, but you can stop the recording at any time. Once the interview is completed, I will thank you for your time. If desired, I can notify you at a later date (via email) of the outcome of my research, once my analysis has been completed (not until January 2016).

Are there any benefits to taking part?

The experiences of students on the autistic spectrum in secondary mainstream schools is a little investigated area; I believe there is not enough of it in the current autism research. In addition, your views will be used to help me decide what is most relevant to investigate for my main research project. This may help to identify successful strategies for improving the dialogue between students and those that they work with, and could potentially be used on a larger scale.

Are there any risks involved?

There is very minimal risk involved in this study. It may be that answering my questions about a particular student could lead to sharing potentially stressful memories. However, you are under no obligation to answer every question, and can withdraw from the study at any time. This study has been ethically approved by the University of Southampton, and I have an enhanced and current DBS check.

Will my participation be confidential?

Data from this study (e.g. video recordings, analysis of participant answers) will be kept in compliance with the Data Protection Act and stored on a password protected computer. Data will also be coded so that individual names are not published and quotations are not identifiable; you will be assigned (or can choose!) another name that you will be known by in this study.

What happens if I change my mind?

Participation is completely voluntary, and therefore you can withdraw from the study at any time. If you do not wish for your data to be used for analysis after you have completed the study, please can you inform me of this by **30th December 2015**.

What happens if something goes wrong?

In the unlikely case of concern or complaint, please contact the Head of Research Governance at the University of Southampton (02380 595058, rgoinfo@soton.ac.uk)

Where can I get more information and/or ask questions?

Please feel free to contact me regarding any further questions or queries you may have via email:
Harriet Hummerstone h.hummerstone@soton.ac.uk

E.10 Consent forms for staff

CONSENT FORM FOR STAFF

Study title: What do students on the autistic spectrum think about school?

Researcher name: Harriet Hummerstone **Ethics reference**: 17434

Please **initial** the box(es) if you agree with the statement(s):

I have read and understood the information sheet (SSEGM Initial Study Information Sheet (Staff) V2 09.10.15) and have had the opportunity to ask questions about the study	☐
I agree to take part in this research project and agree for my data to be recorded and used for the purpose of this study	☐
I understand that my responses will be anonymised in reports of the research so that my name and the name of the school is not used	☐
I consent to having my anonymous responses used in reports of the research	☐
I understand my participation is voluntary and that I may withdraw at any time without my legal rights being affected	☐
I would like to be contacted regarding the overall results of the project	☐

Email.....

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study.

Name (print name)……

Signature …… Date……

Signature of researcher..... Date.....

E.11 Amended ethics application form

January 2017

SSEGM ETHICS SUB-COMMITTEE APPLICATION FORM

Please note:

- ***You must not begin your study until ethical approval has been obtained.***
- ***You must complete a risk assessment form prior to commencing your study.***
- ***It is your responsibility to follow the University of Southampton's Ethics Policy and any relevant academic or professional guidelines in the conduct of your study. This includes providing appropriate information sheets and consent forms, and ensuring confidentiality in the storage and use of data.***
- ***It is also your responsibility to provide full and accurate information in completing this form.***

1. Name(s): Harriet Hummerstone

2. Current Position: Postgraduate Student

3. Contact Details:

Division/School School of Education

Email h.hummerstone@soton.ac.uk

Phone 07525 070441

4. Is your study being conducted as part of an education qualification?

Yes ☒ **No** ☐

5. If yes, please give the name of your supervisor

Dr Sarah Parsons

6. Title of your project:

Communication, support and self-regulation: a Stage 1 study of the mainstream experiences of students on the autistic spectrum

7. i) What are the start and completion/hand-in dates of your study?

Start: 01/09/2014

Completion: 30/09/2017

ii) When are you planning to start and finish the fieldwork part of your study?

Start: 01/11/2015

Completion: 31/07/2016

8. Describe the rationale, study aims and the relevant research questions of your study

There is a limited amount of research into the secondary mainstream school experiences of students on the autistic spectrum in the UK (15 studies, to be exact). These fifteen studies are overwhelmingly focussed on the deficits that students on the autistic spectrum are likely to demonstrate, e.g. communication, cognition, social interaction. Also, despite this being a very under-researched area, there has been little research that has taken an exploratory approach to find out what students on the autistic spectrum think generally about their secondary mainstream experiences; or specifically, to look at the strengths that they have in dealing with day to day situations.

This is a Stage 1 study that aims to explore the views of students and adults on the autistic spectrum and the views of school staff; this initial investigation will consequently form the basis of my thesis. Although it is an exploratory study, there are three main areas that I am interested in exploring; support (what is being offered and whether it is judged to be useful), communication (between students, teachers, and support assistants) and self-regulation (the awareness of students on the autistic spectrum in self-regulating strategies). These areas are reflected in some of the current literature investigating these students' perspectives, and are also part of the wider focus in which I am setting my thesis, which aims to facilitate a dialogue between students on the autistic spectrum and the staff that support them.

I am aiming to gather these perspectives on three different levels. Firstly, I am hoping to conduct a focus group with members of an adult autism advocacy group in order to seek some guidelines about interviewing students on the autistic spectrum, and also to talk in general terms about the three topics mentioned above in relation to their own experiences in secondary school. Secondly, I will observe and interview adolescent students on the autistic spectrum about their classroom experiences, again focussing on these three areas. The observations will allow me to identify the staff and peers that these students work with, as well as giving me concrete examples of classroom experiences to discuss with the students during the interviews. Thirdly, I will interview some of these members of staff about their opinions on the student's communication, support needs and self-awareness strategies.

The aim of this Stage 1 study is to build a picture of each individual student and the dialogues they have with the adults and other students around them. This will allow me to identify and approach staff to interview for Stage 2 (the main crux of the study), where I am hoping to trial a number of different methods for improving the dialogue between students on the autistic spectrum and the adults which support them. These methods which will be selected according to the specific requirements of the students and their teachers, but are likely to include a number of visual methods (such as photo-elicitation) and exploratory talk, a metacognitive method used in primary schools which I am attempting to translate into a secondary school environment. As the three main areas I am interested in are support, communication and self-regulation; consequently, the research questions for this initial study are therefore as follows:

RQ1: What is the nature of support being offered to (and by) students on the autistic spectrum in a classroom environment?

RQ2: What is the nature of the communication between students on the autistic spectrum and the others (e.g. teachers, LSAs, peers) they are working with?

RQ3: What might be the factors that contribute to the nature of these communications?

RQ4: Are students on the autistic spectrum aware of any self-regulation strategies they possess?

RQ5: From the perspectives of the adult autistic community, what communication strategies are likely to be less/more suited to individuals on the autistic spectrum?

9. Describe the design of your study

The first level of data collection will take place with an adult autism advocacy group. I will be seeking their advice and guidelines on general communication strategies (and specifically, interviewing strategies) when working with individuals on the autistic spectrum. Although I do not think that a general consensus will be reached given the highly heterogeneous nature of autism, the aim is to give me as many different perspectives as possible to aid my data collection with students. In addition, I will be asking the adults about their experiences with communication, support and self-regulation while they were in secondary mainstream school. The initial questions that will be asked in the focus group are as follows, with follow-up prompts being used as necessary. Links to research questions are included in the brackets.

1. How would you describe your overall experience of secondary school? (RQ3)
2. What can you remember about how teachers communicated with you in school? (RQ2/3/5)

3. What can you remember about how other students communicated with you in school? (RQ2/3/5)

4. Can you remember feeling supported in school? (RQ1)

5. Were you aware of any interesting sensory experiences that you had in school? (RQ3/4)

6. Is it easy to work out self-regulation/stimming strategies? (RQ4)

7. In your opinion, what is the best way to communicate with an individual on the autistic spectrum? (RQ5)

8. If you could give me one piece of advice for working with you, what would it be? (RQ5)

9. Are the five questions I want to ask the students (see further on in this section) easy to understand? (RQ5)

10. Are there any other things that you think I should consider before I start my work? (RQ5)

These questions will be approved by the advocacy group leader, and will be disseminated to the group a few weeks before our meeting to allow them time to think about their answers. I will then ask the group these questions and audio record their responses. This feedback will help guide my interviews with adolescent students on the autistic spectrum, and hopefully further my understanding of autism as a neurotypical researcher to allow me to gain a more authentic expression of these students' voices.

The second level of data collection will take place through informal observations of lessons with the students who are going to be involved (e.g. shadowing the student for a day). This will take place over a period of about three days. The purpose of these observations is to see the student in as many different subjects as possible and to gather information about the people they work with to facilitate the interviews. The reason for the observations taking place over three days is to allow the student to have some time away from me, and also for practical and scheduling reasons. Following these observations, the students will be asked to take a series of photos that represent each subject they study. These photos will then be printed out to use during the initial interviews. The students will be asked to explain what the photos are and what subject they represent. They will then be asked to rank the photos in response to the following questions (brackets indicate references to research questions):

1. Can you put these photos in order of the subjects you look forward to most? (RQ1/2/3/4)
   - This question will be asked as an initial "ice-breaker" to familiarise the students with the diamond ranking exercise. The students will be asked to explain their rankings, including why a particular subject is "liked" best, which could include references to teachers, other students, and sensory environments - follow-up questions will be asked as necessary to determine this.

2. Can you put these photos in order of the subjects you are most relaxed in? (RQ1/2/3/4)
   - This relates to self-regulation, and may also relate to the support of others, e.g. LSAs, peers, teachers, sensory environment. Again, students will be asked to explain their rankings, including why they think they are more relaxed in some lessons than others. Students will also be asked to think about what being relaxed means to them, e.g. whether it means being well-supported, or having sensory experiences regulated, or feeling like a subject is well-explained.

3. Can you put these photos in order of the subjects you communicate in most? (RQ2/3/4)
   - This question will most likely relate to the communication that exists between teachers and support staff, although support from peers and an awareness of the students' own abilities may be applicable here as well - follow-up prompts will be used to determine what factors may affect these ratings, as well as potentially exploring non-verbal communication seen in the observations. The word "communicate" will deliberately be left undefined to allow students to interpret the question as they see fit, e.g. participating, talking to people,

volunteering answers to teacher's questions, etc. Follow-up questions will then be used to help students expand on their answers, or to clarify using examples if they are unsure of how to answer this question.

4. Can you put these photos in order of where you are helped most? (RQ1/2/3)
   - This again relates to the support that may be on offer, and whether the students feel it is effective or not - however, this may also link to communication if discussing how effective a teacher/peer/LSA is at explaining things that are not understood.

5. Can you put these photos in order of how helpful the other students in your class are? (RQ1/2/3/4)
   - There is flexibility with this question to talk generally about the other students in the class, and also to look at any particular friends that students may have in specific classes and how this may impact on their enjoyment of their lessons. This may also lead to discussions about the noisiness or disruptiveness of certain classmates and how this may impact on a student's classroom experiences.

Using semi-structured interviews means that salient points can be expanded, and clarification sought (on both sides) if needed. All interviews will be recorded on a video camera to promote clarity of answers. The decision to video-record students is so that information regarding photo choices can be easily detailed - this is not as easy on standard audio recordings. However, the students will be given control of the recording equipment so that they have complete control over the video camera and can stop the recording at any time.

This method of photo-elicitation is something I already have experience of using, as it was the main data collection method I used for my Masters' dissertation. Consequently, I have already used this method to facilitate communication with a number of students on the autistic spectrum who all differed in their particular needs. As this dissertation research took part in a secondary mainstream school, I am also already aware that it can work effectively within this environment.

I will also interview school staff who work with particular students about their views of the students in question. These participants will be self-selected from all of the teachers and support staff that I encounter whilst observing the students. The questions they will be asked are as follows (references to RQs in brackets, where appropriate):

1) Describe what [student name] is like in lessons

- This is a deliberately open-ended question which is designed to help staff relax and give some general ideas about their perceptions of the students they work with. There may be a variety of ideas which are expressed at this stage, which can be explored in more depth as necessary. Staff may also give information that is relevant to more than one research question

2) What is [student name]'s communication with staff/other students/yourself like? (RQ2/3)

- This will allow for any differences between communication to be identified more easily, as well as potentially identifying reasons for these differences.

3) What adjustments do you find yourself making to help [student name]? (RQ1/3)

- This is another deliberately open-ended question to allow staff to describe general strategies as well as specific planning or adjustments that they make when working with a student. Again, this may cover a range of topics, such as academic, social and cognitive support.

4) What are [student name]'s strengths? (RQ1/2/3)

- Rather than asking specifically about issues (which are likely to be mentioned anyway), I want to see what awareness staff have of these individuals' strengths, and how this might be used to support them.

All three groups of participants' responses to these questions will be written up as a transcript and analysed using thematic analysis to identify emergent themes; these themes will then give me a picture of the current classroom experience. Once this is established, I can then shape the main research project for my thesis, which aims to improve the existing dialogue between students and the people they work with in a secondary mainstream environment.

10. Who are the research participants?

The initial sample will be adults from the Autism Sussex advocacy group (potentially 5-10 individuals). The second sample will require students on the autistic spectrum from two schools - Ringwood School (Ringwood, Hampshire) and the Arnewood School (New Milton, Hampshire). These schools already have links with Southampton Education School, and both have gatekeepers that are personally known to me and who will therefore facilitate access. The aim is to identify as many students as possible from each school; ideally, at least 10 students in total. The students will range between 11-16 years of age, and will all have a diagnosis of ASD/Asperger's Syndrome. The final group of staff participants will self-select from the student observations I complete, and may potentially be 3-5 individuals working within these two schools

11. If you are going to analyse secondary data, from where are you obtaining it?

N/A

12. If you are collecting primary data, how will you identify and approach the participants to recruit them to your study?

Please attach a copy of the information sheet if you are using one – or if you are not using one please explain why.

For this initial study, the sampling frame will be opportunity sampling for both sets of participants on the autistic spectrum. For the adult participants, the focus group members will be recruited and coordinated using a contact of mine at Autism Sussex who runs the advocacy group. For the student participants, the SENCO of each school will identify students who have been statemented and given an official diagnosis of either ASD or Asperger's Syndrome. The SENCO will then approach these students and their parents to gain consent to take part in this initial study. Information sheets for both the SENCOs/parents and the students are attached.

Once the students and parents have given consent, the SENCO will communicate with the student's subject teachers, acquiring their permission for me to observe the students in their lessons. Once I have carried out my observations, I will then contact all of the school staff I have observed and ask them whether or not they would be interested in answering some follow-up questions; the final sample of staff participants will therefore be self-selected.

13. Will participants be taking part in your study without their knowledge and consent at the time (e.g. covert observation of people)? If yes, please explain why this is necessary.

No.

14. If you answered 'no' to question 13, how will you obtain the consent of participants?

Please attach a copy of the consent form if you are using one – or if you are not using one please explain why.

Consent will be sought prior to undertaking the study. Adults at the advocacy group will be given consent forms a few weeks in advance, along with the information sheets and the questions to be asked. For the student participants, consent forms will be given to the parents of students taking part. Students will complete an assent form demonstrating their willingness to take part in the study. Teachers and LSAs will initially be asked by the SENCO if they are happy for me to observe

their lessons. Consent forms and information sheets will be sent to all the staff who I have observed once the observations are complete, asking them to return the consent forms if they are willing to answer some follow-up questions.

15. Is there any reason to believe participants may not be able to give full informed consent? If yes, what steps do you propose to take to safeguard their interests?

The student participants are under 16 and may arguably not grasp the implications of their consent due to their age and diagnosis, so parental consent is also being sought.

16. If participants are under the responsibility or care of others (such as parents/carers, teachers or medical staff) what plans do you have to obtain permission to approach the participants to take part in the study?

The first point of contact and consent within the schools will be made with the headteachers. Contact will then be made with the SENCOs and Child Protection Officers in each school to ensure the safety of all participants. Following this, the SENCO will then approach the parents and students about the study by passing on the information forms and consent/assent forms to them.

17. Describe what participation in your study will involve for study participants. Please attach copies of any questionnaires and/or interview schedules and/or observation topic list to be used

The data collection from adults will take place at a pre-scheduled advocacy meeting. I will be attending for only part of the session (to allow those who do not wish to participate to meet the group as usual). Once I arrive, I will be introduced and will then ask the participants if they are still happy to continue. I will then ask the questions detailed in Q9 and take audio recordings of participants' answers. Clarification on both sides will be sought if necessary. Once all questions have been asked and answered, I will thank the group for their time and ask them if they would be interested in hearing about the results of my study. If so, I will make arrangements to communicate these details at a later date.

The data collection from students will take place over a four week period to allow for any issues with scheduling and observations. I will initially meet with the students to introduce myself, and will then discuss with them and a SENCO/LSA which lessons will be appropriate for me to observe. Once this observation schedule has been confirmed (i.e. consent has been gained from the teachers of the lessons), I will “shadow” the student to a few of their lessons each day where I will observe them. I will not interact with the student or with any other individuals in the class, and will be merely creating a written record of what the student is doing in relation to the three areas of support, communication and self-regulation detailed in Q8.

Before the students are interviewed (and after the informal observations), students will be given a camera and instructed to take a photo that represents each of their subjects. This activity will be supported by me, and is likely to take place during lesson time. The next day, I will return with hard copies of the photos that they have taken. Students will then take part in an interview where we will discuss the photos, and will be asked five questions about them (see Q9). The interview will be video-recorded, but students will have control over when the recording starts and finishes. Once the interview is completed, the students will be thanked for their time. As this is a Stage 1 study and I intend to conduct a follow-up study, I will also ask students at this point whether they would potentially be interested in working with me again.

Data collection from school staff will also take place after the observations have finished. This will take between 1-2 weeks to carry out, depending on participant numbers and availability. I will meet with these participants and audio-record their responses to questions (see Q9). Once the interview

is over, participants will be thanked for their time. As this is a Stage 1 study, I will also ask staff participants if they would potentially be interested in working with me again in the near future.

18. How will you make it clear to participants that they may withdraw consent to participate at any point during the research without penalty?

Information about withdrawing is given on both the information sheet and the consent form for parents, adults, staff and students. I will also give my participants a verbal reminder when I initially meet them (and at each subsequent meeting for the student participants). Teachers and LSAs who are consenting to lesson observations may also withdraw their consent at any time and will be asked whether they are happy to reschedule.

If any participants wish to withdraw their consent to participate after data collection has been carried out, I will remind them that they can withdraw their data without consequence - as long as they let me know in a timely fashion so that I can exclude their responses from my analyses.

19. Detail any possible distress, discomfort, inconvenience or other adverse effects the participants may experience, including after the study, and you will deal with this.

All participants may experience some stress or discomfort if they are talking about unpleasant or difficult experiences. This is raised in the information sheets that participants are given, and they are able to discontinue the study at any time without explanation. I will also explain to the student participants that if there are any issues raised as a result of the interviews that will impact on the safety of themselves or someone else, I will need to let either the SENCO or an LSA know to offer them any support that might be needed. In addition, if participants experience any distress after the study, they are also allowed to withdraw their results if they notify me within a timely period so that their data can be withdrawn from the analysis.

I have almost six years of teaching experience and over twenty years of both personal and professional knowledge regarding individuals on the autistic spectrum, including some with very challenging behaviour. Consequently, I am trained to look for the first signs of anxiety/distress, and deal with them appropriately to prevent further upset (e.g. using a low arousal approach to communicate, offering a time out/break if needed, asking if they want to continue). I have also conducted interviews using photo-elicitation with students on the autistic spectrum before for my Masters qualification, and therefore have experience already in using this method. If I judge that an individual is continuing with the interview or focus group despite feeling uncomfortable (due, for example, to the authority that I represent or out of a desire to please) then I will reassure them and, if necessary, stop the interview myself.

Finally, there may be some discomfort experienced by teaching staff in talking to me due to my pre-existing relationships with those in their schools. I will reassure participants that everything is confidential unless it puts either themselves or another at immediate risk of harm.

20. How will you maintain participant anonymity and confidentiality in collecting, analysing and writing up your data?

Complete anonymity cannot be guaranteed, but all participants' data will be coded so that they are not individually identified (see Q23). All data will be kept on a password-protected computer, and individual transcript documents will also be password-protected. Any photos that student participants take that directly identify the school or an individual will not be published - they will be modified (e.g. names/faces/identifying details blurred out).

Following the study's completion, some adult participants requested the use of their own names and did not want to be known by pseudonyms - a confidentiality amendment form has been uploaded for approval for them to sign.

21. How will you store your data securely during and after the study?

See above.

22. Describe any plans you have for feeding back the findings of the study to participants.

Participants are given the option of providing their email address on the consent form to allow me to email them with the overall results of the study once the data has been analysed. This will be a brief and simple summary of the main findings.

23. What are the main ethical issues raised by your research and how do you intend to manage these?

1) Informed consent - as stated previously, students may not fully understand what they are consenting to, given their age and the nature of their diagnosis. To ensure that fully informed consent is sought (and given that all the children are under 16), parental consent is required in addition to an assent form being signed by the child.

   The information sheets provided for all participants are detailed, and include my contact details so that if there are any further queries, they are able to contact me with relative ease.

   There is also a possibility that the students will want to take photos of people to represent their subjects. I will be supervising their photography, so can ensure that permission is sought (and if necessary, can provide consent forms to be signed). Where people may appear in the background of photos (e.g. if a participant is photographing a corridor, and children are walking at the end of it), permission will be sought if possible. I will also liaise with the CPO of the school and give them an opportunity to highlight any issues with photos before they are used in the study, and if necessary, they can be edited. For example, a photo of a corridor may be cropped so that the students in the background are not included.

2) Right to withdraw - in addition to stating that participants can withdraw at any time in the information sheet and consent form, I will also be offering verbal reminders at each meeting with the participants.

3) Welfare of participants - it is possible that when recalling their experiences of teaching/learning, adult and student participants may experience some distress. This will be handled sensitively and with respect. The student participants have control over the recording of the video camera, and therefore can turn it off it at any point they do not wish to continue; adults are free to leave the focus group at any time. If such circumstances arise, participants will be offered some time to compose themselves, and then may carry on if they wish to do so. If parents request to be present at the interview, then this can be accommodated with the understanding that they there as an observer only.

4) Confidentiality - although complete confidentiality is not able to be given (as participants have been specifically selected and therefore others in the school/advocacy group will know that they have taken part in the research), all participants will have their data coded to ensure that they cannot be individually identified. Adult participants who have requested to be known by their real name will need to complete a confidentiality amendment form following their initial consent forms.

My own welfare as a researcher will be looked after by ensuring that the rooms used for interviewing the students/adults include see-through doors, and by recording the interviews. It may be that I am emotionally affected by the responses of the participants if they describe any issues. I will deal with this by practising the interview process beforehand to ensure that my data collection is not compromised, and if needed, can seek support from my supervisors regarding any distressing comments that may be made.

24. Please outline any other information you feel may be relevant to this submission.

N/A

E.12 Autistic adults' confidentiality amendment form

CONFIDENTIALITY AMENDMENT FORM

Study title: What do individuals on the autistic spectrum think about school?

Researcher name: Harriet Hummerstone

Ethics reference: 17434

Thank you for taking part in my study. Some people who have taken part would like me to use their real name when I tell other people about my research, but I am not allowed to do this unless I get your permission.

You do not have to complete this form, but please complete it if you want me to use your real name.

Please **initial** the box(es) if you agree with the statement(s):

I am happy for my real name to be used in this study ☐

☐

I understand that by using my real name, other people who read this study may be

If Harriet wants to repeat what I've said in her research, I don't mind her using my words ☐

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study.

Participant's name.....

Participant's signature..... Date.....

Signature of researcher..... Date.....

Appendix F Analysis: First Phase

F.1 Coding key (1st iteration)

Exploratory Study – Coding Key 18.02.16

Data – 2 x student interviews, 1 x focus group

RQ1: What is the nature of support being offered to (and by) students on the autistic spectrum in a classroom environment?

- Support
  - Support given (by individuals to others)
  - StaffSup: support given (or not given) by staff
    - +StaSup
    - -StaSup
  - StuSupport: support given (or not given) by students
    - +StuSup
    - -StuSup

RQ2: What is the nature of the communication between students on the autistic spectrum and the others (e.g. teachers, LSAs, peers) they are working with?

- Communication
  - Self-Concept: comments about an individual's view of themselves
    - +SelfCon
    - -SelfCon
  - StaffCom: communications described with staff
    - +StaffCom
    - -StaffCom
  - StuCom: communications described with other students
    - +StuCom
    - -StuCom

RQ3: What might be the factors that contribute to the nature of these communications?

- Comm Factors – a node representing some of the different factors that can affect individuals' communications
  - Concepts (Adults): examples of where concepts have been misunderstood
  - Concepts (Students): examples of where concepts have been misunderstood
  - Factors of other people:
    - Acceptance (of individual)
    - Friendship (level of friendship)
    - Motivation (to understand)
    - Understanding (of individual)
    - IndFactors (individual factors, e.g. personality)
  - Individual Factors
    - Age (of individual)
    - IndFactors (individual factors, e.g. personality)

  - School & Lesson Factors (this is something that is definitely going to need much further refinement, but everything's in here at the moment!)
  - Sensory (factors that impact on communication specifically)
    - Smell
    - Sound
    - Touch

RQ4: Are students on the autistic spectrum aware of any self-regulation strategies they possess?

- Awareness (Students) - a node representing students' awareness of their own sensory experiences/differences

- Awareness (Adults) – a node representing adults' awareness of their own sensory experiences/differences

Additional themes

- Experiences
  - Difference: any comments about a feeling of difference, either positive or negative
  - School: general experiences of school that are described
    - +SchExp
    - -SchExp
  - Sensory: any sensory experiences that individuals describe
    - Kinetic
    - Smell
    - Sound
    - Space & Layout
    - Touch
    - Visual

F.2 Coding key (2nd iteration)

Exploratory Study – Coding Key 04.04.16

Data – 2 x student interviews, 1 x focus group

RQ1: What is the nature of support being offered to (and by) students on the autistic spectrum in a classroom environment?

- Support
  - Support given (by individuals to others)
  - StaffSup: support given (or not given) by staff
    - +StaSup
    - -StaSup
  - StuSupport: support given (or not given) by students
    - +StuSup
    - -StuSup

RQ2: What is the nature of the communication between students on the autistic spectrum and the others (e.g. teachers, LSAs, peers) they are working with?

- Communication
  - Self-Concept: comments about an individual's view of themselves
    - +SelfCon
    - -SelfCon
  - StaffCom: communications described with staff
    - +StaffCom
    - -StaffCom
  - StuCom: communications described with other students
    - +StuCom
    - -StuCom

RQ3: What might be the factors that contribute to the nature of these communications?

- Comm Factors – a node representing some of the different factors that can affect individuals' communications
  - Concepts (Adults): examples of where concepts have been misunderstood
  - Concepts (Students): examples of where concepts have been misunderstood
  - Factors of other people:
    - Acceptance (of individual)
    - Friendship (level of friendship)
    - Motivation (to understand)
    - Understanding (of individual)
    - IndFactors (individual factors, e.g. personality)
  - Individual Factors
    - Age (of individual)
    - IndFactors (individual factors, e.g. personality)
  - School & Lesson Factors
  - Sensory (factors that impact on communication specifically)
    - Smell
    - Sound
    - Touch

RQ4: What is the nature of individuals' awareness of their (sensory) differences?

- Awareness (Students) - a node representing students' awareness of their own sensory experiences/differences

Experiences of difference, school and sensory experiences

- Experiences
    - Difference: any comments about a feeling of difference, either positive or negative
    - School: general experiences of school that are described
        - +SchExp
        - -SchExp
    - Sensory: any sensory experiences that individuals describe
        - Kinetic
        - Smell
        - Sound
        - Space & Layout
        - Touch
        - Visual

F.3 Coding key (3rd iteration)

Exploratory Study – Coding Key 15.05.16

Data coded:

- 3/3 complete student data from School A (initial meeting notes, photo trail notes, 2 x lesson observations, interview)
- 3/3 partial student data from School B (initial meeting notes, photo trail notes, 2 x lesson observations)

RQ1: What is the nature of support being offered to (and by) students on the autistic spectrum in a classroom environment?

- Support (RQ1)
    - Students (perspective)
        - StaffSup: support (not) given by staff
            - +StaSup
            - -StaSup
        - StuSupport: support (not) given by students
            - +StuSup
            - -StuSup
            - Support Given To Others

RQ2: What is the nature of the communication between students on the autistic spectrum and the others (e.g. teachers, LSAs, peers) they are working with?

- Communication (RQ2)
    - Students (perspective)
        - With Staff: communications described with staff
            - +StaffCom
            - -StaffCom
        - With Students: communications described with other students
            - +StuCom
            - -StuCom

RQ3: What might be the factors that contribute to the nature of these communications?

- Comm Factors (RQ3) – a node representing some of the different factors that can affect individuals' communications
    - Staff Factors:
        - Approachability (of individual)
        - Clarity of explanations
        - Reinforcement
        - Teaching Style
        - Understanding of individual
    - Subject Specific Factors
        - Classroom Environment
        - Subject Content
    - Student Factors
        - Acceptance
        - Friendship

RQ4: Are students on the autistic spectrum aware of any self-regulation strategies they possess?

- Awareness Self-Reg (RQ4) - a node representing students' awareness (or lack thereof) of their own self-regulation strategies

Emergent and additional themes (coded inductively)

- Communication (RQ2)
    - Students
        - Regarding Self (comments about an individual's view of themselves)
            - +SelfCon
            - -SelfCon
            - Awareness of difference
                - Explicit
                - Implicit
            - Sensory
                - Kinetic
                - Sound
                - Visual

F.4 Coding key (final iteration)

Exploratory Study – Coding Key 27.06.16

RQ1: What is the nature of support being offered to (and by) students on the autistic spectrum in a classroom environment?

RQ1 – Support:

- **From Peers**
  - *+PeerSup* (and who it has been identified by)
    - Researcher
    - Staff
    - Students
  - *-PeerSup* (and who it has been identified by)
    - Researcher
    - Staff
    - Students
- **From Staff**
  - *+StaSup* (and who it has been identified by)
    - Researcher
    - Staff
    - Students
  - *-StaSup* (and who it has been identified by)
    - Researcher
    - Staff
    - Students
- **From Students** (and who it has been identified by)
  - Researcher
  - Staff
  - Students (self-identified)

RQ2: What is the nature of the communication between students on the autistic spectrum and the others (e.g. teachers, LSAs, peers) they are working with?

RQ2 – Communication:

- **Student Communication**
  - *With Staff*
    - +StaffCom (and who it has been identified by)
      - Researcher
      - Staff
      - Students
    - -StaffCom (and who it has been identified by)
      - Researcher
      - Staff
      - Students
  - *With Peers*
    - +PeerCom (and who it has been identified by)
      - Researcher

        - Staff
        - Students
    - -PeerCom (and who it has been identified by)
        - Researcher
        - Staff
        - Students
- **Staff Communication**
    - Researcher
    - Staff (self-identified)
    - Students

RQ3: What might be the factors that contribute to the nature of these communications?

RQ3 – Factors Affecting Communication:

- **Staff Factors:**
    - Approachability (of individual)
    - Clarity of explanations
    - Reinforcement
    - Teaching Style
    - Understanding of individual
- **Subject Specific Factors**
    - Classroom Environment
    - Subject Content
    - Peers in class
- **Student Factors**

RQ4: Are students on the autistic spectrum aware of any self-regulation strategies they possess?

RQ4 – Awareness of Self-Regulation Strategies:

- **Aware**
    - Researcher Observations
    - Staff
    - Students (self-identified)
- **Unaware**
    - Researcher Observations
    - Staff
    - Students (self-identified)

Emergent and additional themes from school data (coded inductively)

Inductive 1 – Student Strengths:

- Students (self-identified)
- Staff
- Researcher

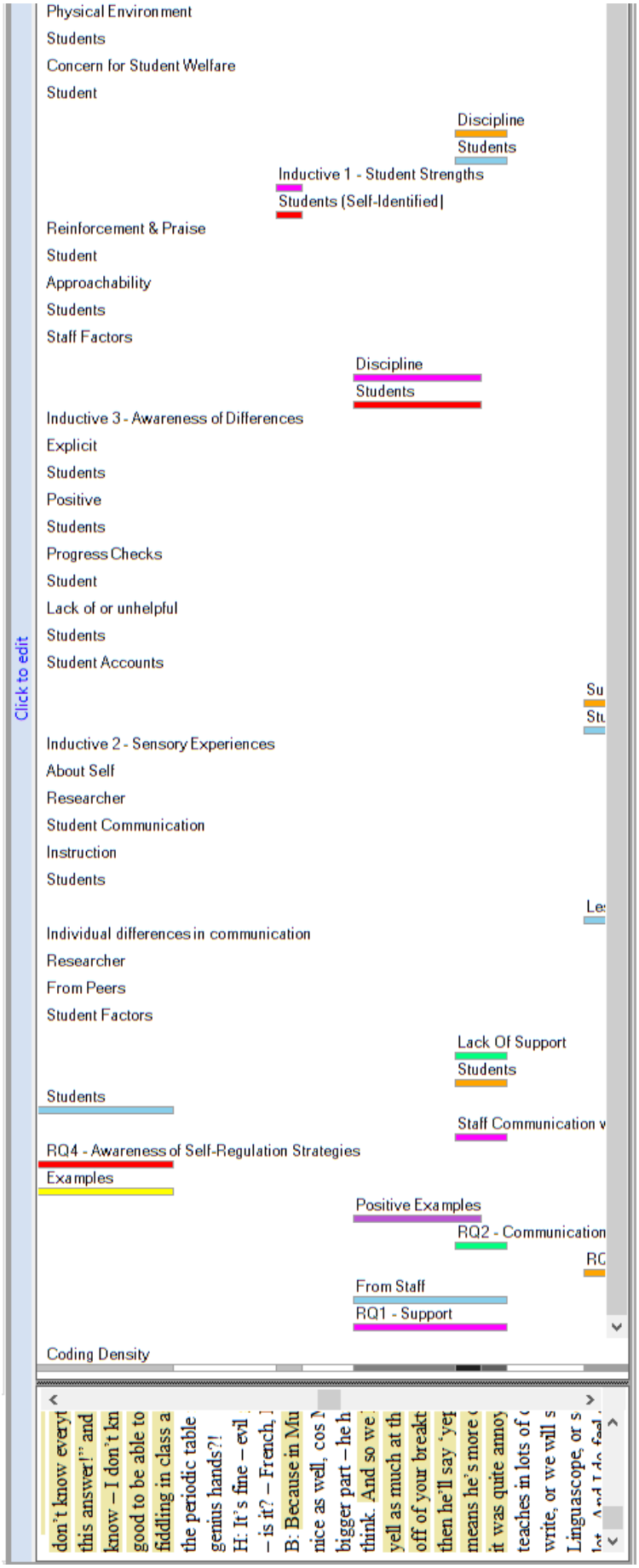
Inductive 2 – Sensory Experiences:

- Student Accounts
- Researcher Observations

Inductive 3 – Awareness of Difference:

- **Observations of Awareness**
  - Researcher
  - Staff
  - Students
- **Observations of Unawareness**
  - Researcher
  - Staff
  - Students

F.5 NVivo screenshot illustrating coded data source



Appendix G Ethics: Second Phase

G.1 Ethics application form

January 2017

SSEGM ETHICS SUB-COMMITTEE APPLICATION FORM

Please note:

- ***You must not begin your study until ethical approval has been obtained.***
- ***You must complete a risk assessment form prior to commencing your study.***
- ***It is your responsibility to follow the University of Southampton's Ethics Policy and any relevant academic or professional guidelines in the conduct of your study. This includes providing appropriate information sheets and consent forms, and ensuring confidentiality in the storage and use of data.***
- ***It is also your responsibility to provide <u>full and accurate information</u> in completing this form.***

1. Name(s): Harriet Hummerstone

2. Current Position: Postgraduate Student

3. Contact Details:

Division/School School of Education

Email h.hummerstone@soton.ac.uk

Phone 07525 070441

4. Is your study being conducted as part of an education qualification?

Yes ☒ **No** ☐

5. If yes, please give the name of your supervisor

Dr Sarah Parsons

6. Title of your project:

The design and implementation of four activities to facilitate the processes of communication and support between students on the autism spectrum and staff members: a second phase study

7. i) What are the start and completion/hand-in dates of your study?

Start: 01/10/14

Completion: 31/09/17

ii) When are you planning to start and finish the fieldwork part of your study?

Start: 16/01/17

Completion: 30/07/17

8. Describe the rationale, study aims and the relevant research questions of your study

The design and focus of this study is informed by the analysis and findings of my previous phase one exploratory study (Ethics ID 17434), which aimed to explore the views of students and staff members, regarding the processes of communication and support that currently exist in the secondary mainstream

school environment. This initial study also involved consultations with an adult autistic self-advocacy group to inform my interviewing techniques.

Thematic analysis of the interviews conducted in schools demonstrated that both students and staff members report the 'double-empathy problem' (Milton, 2012). This theory suggests that just as individuals on the autism spectrum lack understanding about neurotypicals, neurotypicals also lack understanding about individuals on the autism spectrum. Within the initial study, there were four main areas where staff and students differed:

1) The theme of understanding - although both students and staff members agreed that this was crucial to effective support and communication, they differed in their perspectives on how to increase levels of understanding. Students felt that it was staff members' responsibility to increase their understanding of the individual ways that being on the autism spectrum affected them. Staff members felt that there was a lack of specialised resources or training to allow this to happen, e.g. lack of training, generic information provided on school support plans, reduced numbers of staff members in the classroom.

2) The nature of support - both students and staff members emphasised the importance of support in a mainstream secondary environment, but the nature of the most effective support described differed between the groups. Students felt that the most effective support they received from staff was emotional and personal support. However, staff valued the academic and practical support that they gave to students as being most important.

3) Staff availability - again, although staff and students both agreed that this was an important factor that influenced both communication and support, their definitions of staff availability varied. For staff, their availability to students was defined in terms of quantity, such as the number of lessons they taught students for in one week, and the number of other students in the class who required their help. However, for students, the **quality** of these interactions with staff were deemed to be most important; for example, feeling that staff were interested in listening to what they had to say.

4) Sensory experiences - generally, staff members were not aware of any sensory experiences that students on the autism spectrum may encounter, or how this may impact on their communication, support and learning. The students in this study, however, were all able to identify different examples of sensory experiences that impacted both positively and negatively on their educational experiences; even if they were not explicitly aware that these experiences may relate to being on the autism spectrum.

The aim of this second phase study is therefore to develop four activities that can be completed to reduce the 'double empathy problem' by increasing students' own awareness of their potential differences, and to increase staff members' understanding of the students' experiences and how these may impact on their education. These four activities aim to facilitate the processes of communication and support by informing both staff and students on the four topics identified above - understanding, nature of support, staff availability and sensory experiences. Initially, I will develop prototypes of the four methods to target each individual area. The autistic adults and students on the autism spectrum from the first phase study will assess the suitability and appropriateness of these methods through focus groups where the prototypes are evaluated. These recommendations will be analysed and acted upon to complete revised designs of the four activities, which will then be checked again to see if they have been re-designed sufficiently, setting the students in the role of "tester/informant" (Druin, 2002) in the design of these methods. The four revised activities will then be carried out with students on the autism spectrum, and their responses and outcomes of the activities video-recorded. These will then be summarised into an information sheet. Staff members who work with each individual student will then take part in a focus group (one for each of the students involved) which will discuss the information sheet, and co-construct some basic guidelines for how this information may be used within a secondary mainstream environment. Consequently, the research questions for my second phase study are as follows:

RQ1: From the perspectives of students on the autism spectrum and autistic adults, in what ways could the four methods proposed facilitate communication and support?

RQ2: From the perspectives of staff members, in what ways could the information from these activities facilitate the processes of communication and support?

9. Describe the design of your study

The first stage of the study is to develop four activities to increase information about support, understanding, availability and sensory experiences. I have designed four prototype methods in order to do this:

Method 1 - The Motivation Mixer (motivation and sensory experiences): This incorporates a visual representation of individuals' motivations and sensory experiences. There will be a number of categories on a board (e.g. calmness, talking, personal space, writing) relating to these experiences, with each category having a vertical scale and a moving indicator marker. Individuals will be asked "how are you feeling?" and then will move the markers from each category up or down the scale to represent how they are feeling. For example, if individuals are feeling like they want a lot of personal space, they would move the marker related to personal space up to the top. This aims to increase student awareness of **how** they are being affected, as well as providing an immediate visual representation for staff members to assess what strategies may need to be put in place to support an individual. For example, reporting a need for personal space may mean that the individual is allowed to work by themselves rather than in pairs or groups.

Method 2 - Complete the Comics (understanding): Line drawings depicting a student and staff member in a variety of situations (e.g. having a disagreement, working together) will be presented to students with titles. Students then discuss what they think might be going on in the picture. They then have to fill in speech/thought bubbles for the characters, or assess whether they think the thought/speech bubbles are correct, and explain why (not). The aim of this method is not to teach students on the autism spectrum the "right" answer regarding understandings of social situations; it is a prompt to explore their own individual understanding and interpretation of situations to reveal how this may be used to support them and communicate with them more effectively.

Method 3 - Helping Hands (nature of support): students write down very specific tasks or questions for others to do that they feel will offer them better emotional support. These need to be specific to staff members, lessons, types of activities, friends, classmates - the more personalised and detailed, the better. This aims to illuminate student perspectives of what they consider effective support.

Method 4 - Support Sorts (staff availability): using the tasks/questions identified by Method 3, students then sort the tasks using the diamond ranking technique from most important to least important. This interpretation of importance is individual to each student. Tasks/questions that relate to staff (if applicable) will also be separately sorted by students the tasks based on frequency, i.e. what they would like to happen most often, and what can happen more sporadically.

I will conduct a maximum of twelve short (15-20 minute) focus groups (one for each method, completed by all three groups of participants) to assess the ways in which these methods may facilitate communication and support. There will be two groups of three students who participated in the initial study (one group from each school), and one group consisting of the autistic adults (between 5-8 adults, depending on availability). The aim of these focus groups is to come up with some recommendations for each method (during the discussions) that will allow me to re-design the methods to improve their suitability and appropriateness in facilitating communication and support. Each method will be presented in advance to the students and adults, along with the questions that will be asked (as follows):

1) Give me three words to describe [method]. Tell me why you chose those words.

2) Do you think this [method] could help you to talk to a [teacher/LSA]? Why (not)?

3) Do you think this [method] could help a [teacher/LSA] to support you? Why (not)?

4) What could be done to make this [method] better?

This is to allow additional processing time before the discussions take place. During the course of the focus groups, I aim to identify specific recommendations for each method which I will then be able to compile with the recommendations from the other focus groups. Once all three recommendations from these focus groups

have been amalgamated, these four activities will be re-designed accordingly. All four designs will then be checked again in a final discussion with the groups to see if they feel their recommendations have been implemented correctly. This means that the student participants will take part in a total of five short focus groups over the course of this second study, whereas the adult participants are more likely to take part in three longer groups. This was decided in conversation with both groups - as the adults meet once a month, it makes sense in terms of their availability to have two methods discussed per meeting, followed by a final check of all four methods. The students expressed their desire to concentrate on one method at a time to avoid confusion, and as they are much more flexible in terms of their availability while in school, it was decided to conduct a series of five focus groups in total (one for each method, plus a final check) to accommodate their wishes.

Once the methods have been finalised, the students will then complete all four of them. This will be the third time they have seen the methods, and so they will be familiar, yet also different based on any re-designs to reduce boredom. Their responses will be video-recorded, and their reasons and motivations for their responses discussed. The information that is produced from these activities will then be summarised in an information sheet relating to each individual, written by myself and checked by the student to ensure accuracy. Focus groups (with a maximum of eight participants) will then be conducted with staff members who work with a particular student to establish basic guidelines for how this information could be used within the secondary mainstream environment (in relation to the second research question). This means that a total of six staff focus groups will be run (one to discuss each student). The questions asked to staff members in these focus groups will be as follows:

1) What do you think about the information that X [student name] has provided?

2) Has this information increased your knowledge of X [student name] in relation to understanding/support/availability/sensory experiences?

3) How might you use this information in future?

4) What guidelines could you create to help communicate with X?

5) What guidelines could you create to help support X?

During the course of the focus groups, two sets of guidelines relating to communication and support will be created for each student by the staff members and myself.

Transcripts of the student video recordings and the staff focus groups will then be analysed to explore whether they believe that these activities and guidelines have facilitated the amount of support and communication between them, with specific regard to the four areas identified in the first stage study.

10. Who are the research participants?

The research participants are likely to have already participated in the first stage exploratory study. The first focus group will involve adults from the Autism Sussex advocacy group (potentially 5-6 individuals). The second and third focus groups will require students on the autism spectrum from two schools - 3 students from Woodlands School (Southampton, Hampshire) and 3 students from the Arnewood School (New Milton, Hampshire). These schools (and the six students) have already expressed their interest at being involved in the second phase study, and both have gatekeepers that are personally known to me and who will therefore facilitate access. The students will range between 11-16 years of age, and will all have a diagnosis of ASD/Asperger's Syndrome. These students will also complete the activities once they have been redesigned. The staff members are also likely to have been involved in the first phase study within the two schools, and will self-select themselves to participate in the focus groups.

11. If you are going to analyse secondary data, from where are you obtaining it?

N/A

12. If you are collecting primary data, how will you identify and approach the participants to recruit them to your study?

Please attach a copy of the information sheet if you are using one – or if you are not using one please explain why.

The sampling frame for this second phase study is likely to be through self-selection. For the autistic adults, my ongoing relationship with them means that they have already expressed an interest to be involved in the next stages of my research (most recently, Sept 2016, when I last visited the group to discuss my findings), and therefore recruitment can take place via email. The students are also likely to be self-selected based on

their experiences of the previous study and discussions regarding the findings of the first phase study (also taking place in September/October 2016). The coordinating member of staff in each school (usually the SENCO) will approach these students and their parents to gain assent/consent respectively to take part in this second study. Information sheets for both the SENCOs/parents and the students are attached.

Once the students and parents have given assent/consent, the staff coordinator will communicate with the student's subject teachers, acquiring their permission for the students to miss lessons to take part in the focus groups and activities. The staff coordinator will then contact school staff who teach the students who are involved in the study, allowing them to volunteer to take part in the focus group. This is likely to include self-selected staff members from the initial study who have already expressed an interest in being further involved.

13. Will participants be taking part in your study without their knowledge and consent at the time (e.g. covert observation of people)? If yes, please explain why this is necessary.

No.

14. If you answered 'no' to question 13, how will you obtain the consent of participants?

Please attach a copy of the consent form if you are using one – or if you are not using one please explain why.

Consent will be sought prior to undertaking any data collection. The autistic adults will be given consent forms a few weeks in advance, along with the information sheets and the questions to be asked and photos of the proposed methods. As the student participants are under 16 and may arguably not grasp the implications of their consent due to their age and processing differences, consent for the students' participation will be sought from their parents. However, in addition to parental consent, students will complete an assent form demonstrating their willingness to take part in the study. Staff members will also receive information sheets and consent forms to indicate their willingness to participate in the focus groups.

15. Is there any reason to believe participants may not be able to give full informed consent? If yes, what steps do you propose to take to safeguard their interests?

Yes - the student participants may not be able to give informed consent, and so their assent will be sought. Consent will be sought from their parents (see question 14).

16. If participants are under the responsibility or care of others (such as parents/carers, teachers or medical staff) what plans do you have to obtain permission to approach the participants to take part in the study?

The first point of contact and consent within the schools will be made with the headteachers. Contact will then be made with the SENCOs and Child Protection Officers in each school to ensure the safety of all participants. Following this, the staff coordinator I have worked with previously in each school will then approach the parents and students about the study by passing on the information forms and consent/assent forms to them.

17. Describe what participation in your study will involve for study participants. Please attach copies of any questionnaires and/or interview schedules and/or observation topic list to be used

The adults' focus group will be conducted as part of a pre-scheduled advocacy meeting. I will be attending part of the session (to allow those who do not wish to participate to meet the group as usual). Once I arrive, I will be introduced and will then ask the participants if they are still happy to continue. I will then ask the questions detailed in Q9 and take audio recordings of participants' answers. Clarification on both sides will be sought if necessary. Once all questions have been asked and answered, I will thank the group for their time and ask them if they would be interested in hearing about the results of my study. If so, I will make arrangements to communicate these details at a later date.

The data collection from students will take place in their schools. I will initially meet with the students to re-introduce myself and relate the findings from the first phase study in October 2016. Following this, I will also ask students whether they would potentially be interested in working with me again. Depending on which students are interested in offering further opinions, I will then arrange a time to meet with all of them in each school. The focus groups for each method will then be conducted using the questions detailed in Q9. Students

and their parents will be contacted again by the school coordinator once I have re-designed the activities to seek further assent/consent to be involved with the activity-based interviews. Once the consent and assent forms are received, students will work through each of the activities with me. Their responses and comments will be video-recorded to ensure accuracy. I will then create a summary sheet listing specific and important information about each student following analysis, which will be checked by the student themselves for accuracy.

Data collection from staff members will take place after the student interviews have finished. This will take between 4-6 weeks to carry out, depending on availability. I will meet with staff members and audio-record their responses to questions (see Q9). Once the focus group is over, staff will be thanked for their time.

18. How will you make it clear to participants that they may withdraw consent to participate at any point during the research without penalty?

Information about withdrawing is given on both the information sheet and the consent form for parents, adults, and staff members, and on the assent form for students. I will also give all focus group participants a verbal reminder each time I meet with them of their right to withdraw.

If any participants wish to withdraw their consent to participate after data collection has been carried out, I will remind them that they can withdraw their data without consequence - as long as they let me know in a timely fashion so that I can exclude their responses from my analyses.

19. Detail any possible distress, discomfort, inconvenience or other adverse effects the participants may experience, including after the study, and you will deal with this.

All participants may experience some stress or discomfort if they are talking about unpleasant or difficult experiences. However, this is likely to be minimal and the procedure for dealing with this is raised in all the information sheets that they are given: they are able to discontinue participating in the focus groups/interviews at any time without explanation, and do not have to answer all the questions asked of them. The adult participants are also given the option of using pseudonyms or their own names to minimise anxiety around confidentiality and/or ownership and recognition. Participants can also ask for their data to be withdrawn following completion of the data collection to avoid any anxiety or distress that they might feel at a later date about participating. I will also explain to the students particularly (due to their increased vulnerability of a young age) that if there are any issues raised as a result of our interactions that will impact on the safety of themselves or someone else, I will need to let a member of school staff know to offer them any support that might be needed.

I have almost six years of teaching experience and over twenty years of both personal and professional knowledge regarding individuals on the autistic spectrum, including some with very challenging behaviour. There is also a strong likelihood that the individuals involved in this study will have worked with me previously on the first phase study. Consequently, I am familiar with the first signs of anxiety/distress that these individuals may demonstrate, and know how to deal with them appropriately to prevent further upset (e.g. using a low arousal approach to communicate, offering a time out/break if needed, asking if they want to continue). I have also conducted interviews using photo-elicitation with students on the autistic spectrum before for my Masters qualification and first phase study, and therefore have experience in using this method. If I judge that an individual is continuing with the interview or focus group despite feeling uncomfortable (due, for example, to the authority that I represent or out of a desire to please) then I will reassure them and, if necessary, stop the interview myself. Finally, there may be some discomfort experienced by teaching staff in talking to me due to my pre-existing relationships with those in their schools. I will reassure participants that everything is confidential unless it puts either themselves or another at immediate risk of harm.

20. How will you maintain participant anonymity and confidentiality in collecting, analysing and writing up your data?

Complete anonymity cannot be guaranteed, but all student and staff member data will be coded so that they are not individually identified by their real names - they will be identified by pseudonyms (see Q23). The autistic adults were keen to use their real names in the previous exploratory study, so this will be offered as an additional option to pseudonyms for them. However, if adults feel that they want their contributions to be recognised, their first names will be used to comply with their wishes for ownership as long as they accept that

this will not guarantee them confidentiality. All data will be kept on a password-protected computer, and individual transcript documents will also be password-protected.

21. How will you store your data securely during and after the study?

See above.

22. Describe any plans you have for feeding back the findings of the study to participants.

Parents and staff members are given the option of providing their email address on the consent form to allow me to email them with the overall results of the study once the data has been analysed. This will be a brief and simple summary of the main findings. In addition, I plan to visit the schools and advocacy group to meet face to face with the other individuals involved to share my results.

23. What are the main ethical issues raised by your research and how do you intend to manage these?

5) Informed consent - as stated previously, students may not fully understand what they are consenting to, given their age and the nature of their diagnosis. To ensure that fully informed consent is sought (and given that all the children are under 16), parental consent is therefore required. However, in addition to parental consent, an initial assent form also needs to be signed by each child. Their ongoing assent will be indicated by the students' interactions with me throughout the focus groups and activities.

   The information sheets provided for all participants are detailed, and include my contact details so that if there are any further queries, they are able to contact me with relative ease. These queries can then be resolved to inform the individual's decision to take part in the study. Opportunities for questions will also be provided every time I meet those involved.

6) Right to withdraw - in addition to stating that participants can withdraw at any time in the information sheet and consent form, I will also be offering verbal reminders at each meeting with the participants. Participant data will be coded using pseudonyms (or real names where elected by the adult participants), but I will keep a private record of the pseudonyms used to allow elimination of data if requested by a particular participant after the study/activity is completed.

7) Welfare of participants - it is possible that when evaluating the new methods, adult and student participants may experience some distress. This will be handled sensitively and with respect. The student participants have control over the recording of the video camera, and therefore can turn it off it at any point they do not wish to continue; students and adults are also free to leave the focus group at any time without explanation. If such circumstances arise, participants will be offered some time to compose themselves, and then may carry on if they wish to do so. If parents request to be present at the students' focus group/interview, then this can be accommodated with the understanding that they there as an observer only.

8) Confidentiality - although complete confidentiality is not able to be given (as participants have been specifically selected and therefore others in the school/advocacy group will know that they have taken part in the research), all participants will have their data coded to ensure that they cannot be individually identified. In order to recognise the wishes of the autistic adults, the option of using their given names will also be offered, as long as they understand that this means that I cannot ensure confidentiality for them.

   My own welfare as a researcher will be looked after by ensuring that the rooms used for interviewing the students/adults include see-through doors, and by recording the interviews. It may be that I am emotionally affected by the responses of the participants if they describe any issues. I will deal with this by practising the interview process beforehand to ensure that my data collection is not compromised, and if needed, can seek support from my supervisors regarding any distressing comments that may be made.

24. Please outline any other information you feel may be relevant to this submission.

N/A

G.2 Information sheet for autistic adults

Adult Information Sheet

Study Title: What might help students on the autism spectrum and their teachers to understand each other better?

Researcher: Harriet Hummerstone **Ethics number**: 23921

Please read this information carefully before deciding if you are happy to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

I am currently working towards a PhD in Education at the University of Southampton. You may recognise me if you have taken part in my first study investigating the classroom experiences of students on the autism spectrum.

I have designed four tools to help the students on the autism spectrum from my first study communicate their needs more easily to secondary school staff. I now want to ask adults on the autism spectrum for their advice and feedback on these four tools; for example, if you think they need to be changed.

I want to improve the communication between students on the autism spectrum and those they work with (e.g. teachers, learning support assistants, other students) in secondary mainstream schools.

Why have I been chosen to take part?

The Asperger's Voice support group helped me enormously when I was carrying out my first study by giving me advice on how to communicate with students on the autism spectrum. I am therefore asking the members of this group if they would be willing to give me some more help with the next part of my study – designing tools to make communicating about their experiences easier for students on the autism spectrum.

What will happen to me if I take part?

I will meet with the group of individuals who have agreed to take part two times. These will take place in the first part of the Asperger's Voice monthly meetings on dates which the group agrees to, and will consist of me, the group members who choose to take part, and James, the group moderator.

The dates that I will visit will be arranged between all the group and James. James will then contact me to let me know the dates that are most convenient for everyone, and who would like to take part. You will be able to discuss this as a group before I come to visit – some group members have met me before, and may be able to answer some of the questions you have. Anyone who is not happy to take part can make it very clear before I arrive.

We will discuss two of the tools in each meeting (I will send them to James ahead of our meetings so you can have a look at them). I will be making audio recordings of what everyone says to help me remember things clearly.

I will ask the group some questions about the tools that I have designed (see Page 3 for a list of the questions). I may ask additional questions if I need someone to explain what they have said in more detail to help me understand.

You can answer as many or as few questions as you like. Once everyone is happy that they have said what they want to say, the meeting will be over and I will thank everyone for their help.

Are there any benefits of taking part?

Representing the views of individuals on the autism spectrum is a key area that needs exploring in more detail; I believe there is not enough of it in the current autism research. Your advice and knowledge of autism will help me to communicate more effectively with the students in my study.

Are there any risks involved?

There is very minimal risk involved in this study. You will be asked what you think about the tools that I have designed. However, you do not have to answer every question, and can withdraw from the study at any time. This study has been ethically approved by the University of Southampton, and I have experience of working with a number of individuals on the autistic spectrum, so will try my hardest to work effectively and respectfully with you.

Will my participation be confidential?

Data from this study (e.g. the audio recordings and the analysis of your answers) will be kept in compliance with the Data Protection Act and stored on a password protected computer. Data will also be coded so that your real names are not published and quotations are not identifiable if you would prefer this. To do this, you can choose another name that I can use to refer to you in the study. Also, the same rules apply to these discussions as they do to normal meetings: respect other people's opinions, and don't discuss what is mentioned outside of the group setting.

What happens if I change my mind about taking part?

Participation is completely voluntary, and therefore you can withdraw from the study at any time. If you do not want your words or comments to be used for analysis after our meeting, please email me or James (aspergersvoice@gmail.com) and tell us by **30th July 2017**.

What happens if something goes wrong?

In the unlikely case that you are concerned or wish to make a complaint, please contact the Head of Research Governance at the University of Southampton (02380 595058, rgoinfo@soton.ac.uk)

Where can I get more information and/or ask questions?

Please feel free to contact me regarding any further questions or queries you may have via email: Harriet Hummerstone h.hummerstone@soton.ac.uk. You can also ask James any questions that you may have, and he can then contact me for answers.

The questions I will be asking the group

I will ask these four questions about each of the four tools.

1) Give me three words to describe [Tool 1/2/3/4]. Tell me why you chose those words.

2) Do you think [Tool 1/2/3/4] could help you or a student on the autism spectrum to talk to a member of staff in school? Tell me why.

3) Do you think [Tool 1/2/3/4] could help a member of staff to support you or a student on the autism spectrum? Tell me why.

4) What could be done to make [Tool 1/2/3/4] better?

G.3 Consent form for autistic adults

CONSENT FORM FOR ADULT PARTICIPANTS

Study title: What might help students on the autism spectrum and their teachers to understand each other better?

Researcher name: Harriet Hummerstone

Ethics reference: 23921

Please **initial** the box(es) if you agree with the statement(s):

I have read and understood the information sheet (SSEGM Initial Study Participant Information Sheet (Adults) V2 06.12.17) and have had the opportunity to ask questions about the study	☐
I agree to take part in this research	☐
I don't mind my conversation with Harriet being audio-recorded	☐
I understand that Harriet will only play the recordings to people who are helping her with her research (e.g. her supervisor)	☐
If Harriet wants to repeat what I've said in her research, I don't mind her using my words	☐
I understand that Harriet will not use my real name in her research if I don't want her	☐
If I want to use my real name, I understand that this means I could be identified by other people who read Harriet's research.	☐
I understand that I can stop working with Harriet at any time if I feel uncomfortable,	☐
I would like to be informed of the results of Harriet's study once her analysis has been completed	☐

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study.

Participant's name.....

Participant's signature..... Date.....

Signature of researcher..... Date.....

G.4 Information sheet for parents

Parent Information Sheet

Study Title: What might help students on the autism spectrum and their teachers to understand each other better?

Researcher: Harriet Hummerstone **Ethics number**: 23921

Please read this information carefully before deciding if you are happy for your child to take part in this research. If you are happy for them to participate you will be asked to sign a consent form.

What is the research about?

I am a qualified and experienced Psychology teacher who is currently working towards a PhD in Education at the University of Southampton. I have both personal and professional experience of working with a wide range of individuals on the autistic spectrum, especially in a secondary school environment.

I have already worked with the students during my first study, where I was investigating the experiences of students on the autism spectrum in schools. Based on the findings of this study, I am now planning a second investigation into helping communication between students on the autism spectrum and staff they work with (e.g. teachers, LSAs) in secondary mainstream schools.

Why has my child been chosen?

For this project, I am focusing on students who are currently attending secondary schools and who have received a diagnosis of Autism Spectrum Disorder or Asperger's Syndrome. Your child has also already worked with me on the first stage of this study, which took place from December 2015-March 2016.

What will happen to my child if he/she takes part?

The study will take place over a four week period (to allow for scheduling/timetabling). I will be meeting the students who have agreed to take part in groups (of no more than three students). Four meetings will initially take place, where we will discuss four tools that I have designed to facilitate communication. Based on what the students say, I will redesign these tools as required. There will then be a fifth group meeting to ensure that the students feel that the tools have been changed sufficiently.

Each student will then work with me and use each of the tools in a final sixth meeting. Our discussions will be recorded using a video camera. Students will have control over when the recording starts and finishes, and can stop the recording at any time. Once completed, the students' contribution to this study is over, and they will be thanked for their time. If desired, I can notify individuals at a later date (via email) of the outcome of my research, once my analysis has been completed.

Are there any benefits in my child taking part?

Representing student views is a key area that needs exploring in more detail; I believe there is not enough of it in the current autism research. In addition, the views of your child (and the other students taking part) will be used to help me design better tools for them to use. These tools may help to identify successful strategies for improving the dialogue between students and those that they work with, and could potentially be used on a larger scale.

Are there any risks involved?

There is very minimal risk involved in this study. Students will be asked four questions about each tool. However, students are under no obligation to answer every question, and can withdraw from the study at any time. This study has been ethically approved by the University of Southampton, and I have an enhanced and current DBS check.

Will my child's participation be confidential?

Data from this study (e.g. video recordings, analysis of participant answers) will be kept in compliance with the Data Protection Act and stored on a password protected computer. Data will also be coded so that individual names are not published and quotations are not identifiable; pseudonyms will be used. The students will all be reminded before, during (if applicable) and after group discussions to respect others' opinions and not discuss specific details of what has been talked about outside of our meetings. They will also be reminded that talking about what they themselves have said is ok (e.g. with parents/guardians/friends), but they cannot mention what other students have said.

What happens if I (or my child) change our minds?

Participation is completely voluntary, and therefore the student can withdraw from the study at any time. If you do not wish for your child's data to be used for analysis after they have completed the study, please can you tell me by **30th March 2017** so that I can destroy their data.

What happens if something goes wrong?

In the unlikely case of concern or complaint, please contact the Head of Research Governance at the University of Southampton (02380 595058, rgoinfo@soton.ac.uk)

Where can I get more information and/or ask questions?

Please feel free to contact me regarding any further questions or queries you may have via email: Harriet Hummerstone h.hummerstone@soton.ac.uk

G.5 Consent form for parents

CONSENT FORM FOR PARENTS

Study title: What might help students on the autism spectrum and their teachers to understand each other better?

Researcher name: Harriet Hummerstone

Ethics reference: 23921

Please **initial** the box(es) if you agree with the statement(s):

I have read and understood the information sheet (SSEGM Second Study Information Sheet (Parents) V2 06.01.17) and have had the opportunity to ask questions about the study	☐
I understand that my child's responses will be anonymised in reports of the research so that my child's name and the name of the school is not used	☐
I agree that my child can take part in group discussions for this research project and agree for my child's data to be used in this study	☐
I agree that my child can take part in individual discussions for this research project and agree for my child's data to be video-recorded for use in this study	☐
I consent to having my child's anonymous responses used in reports of the research	☐
I understand my child's participation is voluntary and my child may withdraw at any time without their legal rights being affected	☐
I would like to be contacted regarding the overall results of the project	☐

Email.....

Data Protection

I understand that information collected about my child during their participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study.

Name of child (print name) ……

Name of parent (print name).....

Signature of parent…… Date……

Signature of researcher..... Date.....

G.6 Information sheet for students

Student Information Sheet

Study Title: What might help students on the autism spectrum and their teachers to understand each other better?

Researcher: Harriet Hummerstone **Ethics number**: 23921

Please read this information carefully before deciding to take part in my research. If you are happy to participate you will be asked to sign a form.

What is the research about?

My name is Harriet, and I am currently studying at university in Southampton. Here is a photo of me so that you know what I look like:

You may recognise me from the first piece of work we did together, where we took some photos and I asked you about your experiences in school.

Why have I been chosen?

I want to talk to you because you have worked with me before, you are currently attending school, and you are an individual on the autism spectrum.

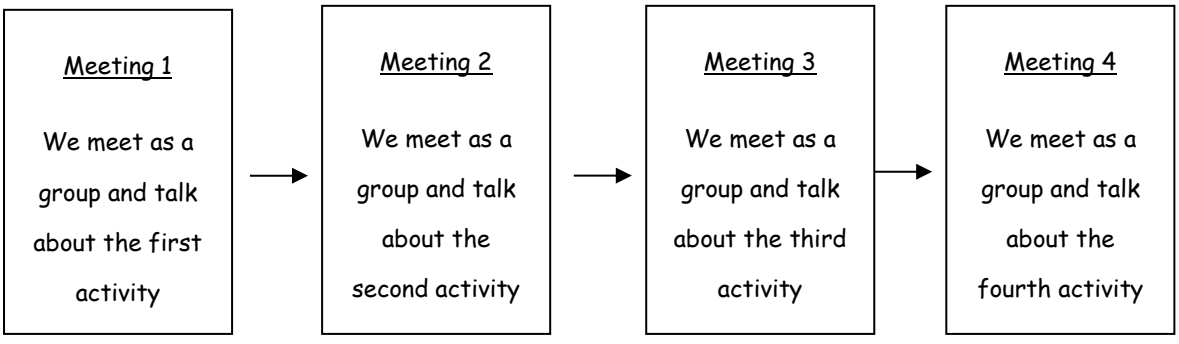
What will happen to me if I take part?

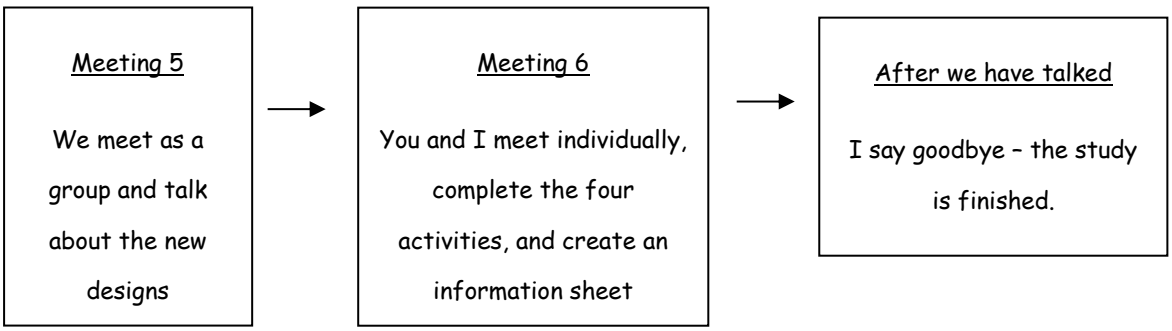
I will be talking with you and other students who worked with me before. We will talk in groups of four (me, you, and two other students). I have designed some activities to help students and teachers understand each other better, and I want to know what you think about the activities ☺

There are four activities, and we will meet as a group four times to discuss each one separately. You can tell me what you think I could do to make the activities better. I will then go and work on the activities to make them better. We will then meet as a group for a fifth time, where I will show the new designs to you and you can decide if they are better. You can talk about what **you** have said to people outside of our meetings, but you cannot talk about what **others** have said to anyone outside our meetings. This shows respect for other people's words.

A few days later, I will meet with you individually to complete the four activities and talk about them. We will be recording our discussion with a video camera so I can remember exactly what we say, but you are in charge of starting and stopping the recording! We will then work together to create an information sheet about you for your teachers to try and help them understand you better.

After we have finished talking, the study will be over. I will say goodbye and then go back to the university to write up my results. I will come back and tell you what I found out when I have finished (but this might be as late as September 2017).





What's good about taking part?

By sharing your views, it will help me to design better activities for students on the autism spectrum. Creating information sheets may also help others to understand you a little better.

Are there any risks involved?

There is very minimal risk involved in this study and no more than you would experience during a typical day at school. However, you do not have to answer my questions if you do not want to, and can stop taking part at any time.

Will anyone else know that I have taken part?

Confidentiality means that I will not tell other people your real name. The video recordings will be kept on a password protected computer. If I quote you (i.e. use something you said in my write-up of the study), you can choose a different name that I can use to keep things private! ☺

What we talk about is private, unless you tell me something that might put yourself or someone else at risk. To make sure that you are safe, I may need to tell another adult.

What happens if I change my mind?

You can stop taking part in the study at any time, and do not have to tell me why ☺

What happens if something goes wrong?

If you are worried about something to do with the study, please let me know.

If you do not want to talk to me, please tell your worries to someone in your family, a friend, or someone you trust at school so that we can help.

Where can I get more information or ask a question?

Please email me if you have any further questions.

My email address is h.hummerstone@soton.ac.uk

G.7 Assent form for students

ASSENT FORM FOR STUDENT PARTICIPANTS

Study title: What might help students on the autism spectrum and their teachers to understand each other better?

Researcher name: Harriet Hummerstone

Ethics reference: 23921

Please **initial** the box(es) if you agree with the statement(s):

I have read and understood the information sheet (SSEGM Initial Study Participant Information Sheet (Students) V2 06.01.17) and have had the opportunity to ask questions about the study	☐
I agree to take part in this research	☐
I don't mind my conversation with Harriet being recorded with a video camera	☐
I understand that Harriet will not use my name in her research and will only show my video to people who are helping her with her work (e.g. her teacher)	☐
If Harriet wants to repeat what I've said in her research, I don't mind her using my words	☐
I don't mind helping Harriet create an information sheet about me for my teachers to read	☐
I understand that I can stop working with Harriet at any time if I feel uncomfortable, and do not have to explain why I want to stop	☐

Participant's name.....

Participant's signature.....

Date.....

Signature of researcher..... Date.....

G.8 Information sheet for staff

Staff Information Sheet

Study Title: What might help students on the autism spectrum and their teachers to understand each other better?

Researcher: Harriet Hummerstone **Ethics number**: 23921

Please read this information carefully before deciding if you are happy to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

I am a qualified and experienced Psychology teacher who is currently working towards a PhD in Education at the University of Southampton. I have both personal and professional experience of working with a wide range of individuals on the autism spectrum, especially in a secondary school environment. For the first phase of my research, I spoke to staff members and students on the autism spectrum about their school experiences of communication and support, and noted that there were some significant differences in their views.

I am now conducting a second study that aims to facilitate the communication between students on the autism spectrum and staff who work with them (e.g. teachers, LSAs) in a secondary mainstream school.

Why have I been chosen?

For this project, I am focusing on staff who work with students who are currently attending secondary schools, who have received a diagnosis of Autism Spectrum Disorder or Asperger's Syndrome, and who are taking part in this study. Each of these students will be completing four activities with me that have been designed to elicit information about their specific learning needs, preferences and strengths. The student and I will then create an information sheet (specific to them) that is designed for their teachers. I need your views on the usefulness of this information, and how it might be implemented (or not) within the classroom environment.

What will happen if I take part?

I will meet you and other staff members who have agreed to take part (and also teach a particular student) at school. I will introduce myself and complete any administration. We will then have a discussion about the information sheet that the student and I have co-constructed. The group discussions should last no longer than 60 minutes, and will be audio-recorded to allow me to remember everything that has been said. You may leave the discussion at any point and contribute as much or as little as you feel comfortable with. I would ask you to respect others' opinions and keep the details of our meeting confidential. Once the discussion is completed, I will thank you for your time. If desired, I can notify you at a later date (via email) of the outcome of my research, once my analysis has been completed (July 2017).

Are there any benefits to taking part?
Communication is a two-way process, and therefore in addition to speaking to students, I need staff views on the information they have provided. Using opinions from both sides, I can then
be more informed (and relevant) regarding any conclusions from my research that may be useful in a secondary mainstream school (classroom) context.

Are there any risks involved?
There is very minimal risk involved in this study. It may be that discussing a particular student could lead to sharing potentially stressful memories. However, you are under no obligation to answer every question, and can withdraw from the study at any time. This study has been ethically approved by the University of Southampton, and I have an enhanced and current DBS check.

Will my participation be confidential?
Data from this study (e.g. audio recordings, analysis of participant answers) will be kept in compliance with the Data Protection Act and stored on a password protected computer. Data will also be coded so that individual names are not published and quotations are not identifiable; you will be assigned (or can choose!) another name that you will be known by in this study. In respect for others' opinions, please do not communicate specific details about this meeting and the views expressed within it outside the discussions themselves.

What happens if I change my mind?
Participation is completely voluntary, and therefore you can withdraw from the study at any time. If you do not wish for your data to be used for analysis after you have completed the study, please can you inform me of this by **30th March 2017**.

What happens if something goes wrong?
In the unlikely case of concern or complaint, please contact the Head of Research Governance at the University of Southampton (02380 595058, rgoinfo@soton.ac.uk)

Where can I get more information and/or ask questions?
Please feel free to contact me regarding any further questions or queries you may have via email: Harriet Hummerstone h.hummerstone@soton.ac.uk

G.9 Consent form for staff

CONSENT FORM FOR STAFF

Study title: What might help students on the autism spectrum and their teachers to understand each other better?

Researcher name: Harriet Hummerstone

Ethics reference: 23921

Please **initial** the box(es) if you agree with the statement(s):

I have read and understood the information sheet (SSEGM Initial Study Information Sheet (Staff) V2 13.03.17) and have had the opportunity to ask questions about the study	☐
I agree to take part in this research project and agree for my data to be recorded	☐
I understand that my responses will be anonymised in reports of the research so that my name and the name of the school is not used	☐
I consent to having my anonymous responses used in reports of the research	☐
I understand my participation is voluntary and that I may withdraw at any time	☐
I would like to be contacted regarding the overall results of the project Email.....	☐

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study.

Name (print name).....

Signature .....

Date.....

Signature of researcher..... Date.....

G.10 Amended ethics application form

March 2017

SSEGM ETHICS SUB-COMMITTEE APPLICATION FORM

Please note:

- ***You must not begin your study until ethical approval has been obtained.***
- ***You must complete a risk assessment form prior to commencing your study.***
- ***It is your responsibility to follow the University of Southampton's Ethics Policy and any relevant academic or professional guidelines in the conduct of your study. This includes providing appropriate information sheets and consent forms, and ensuring confidentiality in the storage and use of data.***
- ***It is also your responsibility to provide <u>full and accurate information</u> in completing this form.***

1. Name(s): Harriet Hummerstone

2. Current Position: Postgraduate Student

3. Contact Details:

Division/School School of Education

Email h.hummerstone@soton.ac.uk

Phone 07525 070441

4. Is your study being conducted as part of an education qualification?

Yes ☒ **No** ☐

5. If yes, please give the name of your supervisor

Dr Sarah Parsons

6. Title of your project:

The design and implementation of four activities to facilitate the processes of communication and support between students on the autism spectrum and staff members: a second phase study

7. i) What are the start and completion/hand-in dates of your study?

Start: 01/10/14, Completion: 31/09/17

ii) When are you planning to start and finish the fieldwork part of your study?

Start: 16/01/17, Completion: 30/07/17

8. Describe the rationale, study aims and the relevant research questions of your study

The design and focus of this study is informed by the analysis and findings of my previous phase one exploratory study (Ethics ID 17434), which aimed to explore the views of students and staff members, regarding the processes of communication and support that currently exist in the secondary mainstream school environment. This initial study also involved consultations with an adult autistic self-advocacy group to inform my interviewing techniques.

Thematic analysis of the interviews conducted in schools demonstrated that both students and staff members report the 'double-empathy problem' (Milton, 2012). This theory suggests that just as individuals on the autism spectrum lack understanding about neurotypicals, neurotypicals also lack understanding about individuals on the autism spectrum. Within the initial study, there were four main areas where staff and students differed:

1) The theme of understanding - although both students and staff members agreed that this was crucial to effective support and communication, they differed in their perspectives on how to increase levels of understanding. Students felt that it was staff members' responsibility to increase their understanding of the individual ways that being on the autism spectrum affected them. Staff members felt that there was a lack of specialised resources or training to allow this to happen, e.g. lack of training, generic information provided on school support plans, reduced numbers of staff members in the classroom.

2) The nature of support - both students and staff members emphasised the importance of support in a mainstream secondary environment, but the nature of the most effective support described differed between the groups. Students felt that the most effective support they received from staff was emotional and personal support. However, staff valued the academic and practical support that they gave to students as being most important.

3) Staff availability - again, although staff and students both agreed that this was an important factor that influenced both communication and support, their definitions of staff availability varied. For staff, their availability to students was defined in terms of quantity, such as the number of lessons they taught students for in one week, and the number of other students in the class who required their help. However, for students, the **quality** of these interactions with staff were deemed to be most important; for example, feeling that staff were interested in listening to what they had to say.

4) Sensory experiences - generally, staff members were not aware of any sensory experiences that students on the autism spectrum may encounter, or how this may impact on their communication, support and learning. The students in this study, however, were all able to identify different examples of sensory experiences that impacted both positively and negatively on their educational

experiences; even if they were not explicitly aware that these experiences may relate to being on the autism spectrum.

The aim of this second phase study is therefore to develop four activities that can be completed to reduce the 'double empathy problem' by increasing students' own awareness of their potential differences, and to increase staff members' understanding of the students' experiences and how these may impact on their education. These four activities aim to facilitate the processes of communication and support by informing both staff and students on the four topics identified above - understanding, nature of support, staff availability and sensory experiences. Initially, I will develop prototypes of the four methods to target each individual area. The autistic adults and students on the autism spectrum from the first phase study will assess the suitability and appropriateness of these methods through focus groups where the prototypes are evaluated. These recommendations will be analysed and acted upon to complete revised designs of the four activities, which will then be checked again to see if they have been re-designed sufficiently, setting the students in the role of "tester/informant" (Druin, 2002) in the design of these methods. The four revised activities will then be carried out with students on the autism spectrum, and their responses and outcomes of the activities video-recorded. These will then be summarised into an information sheet. Staff members who work with each individual student will then take part in a focus group (one for each of the students involved) which will discuss the information sheet, and co-construct some basic guidelines for how this information may be used within a secondary mainstream environment. Consequently, the research questions for my second phase study are as follows:

RQ1: From the perspectives of students on the autism spectrum and autistic adults, in what ways could the four methods proposed facilitate communication and support?

RQ2: From the perspectives of staff members, in what ways could the information from these activities facilitate the processes of communication and support?

9. Describe the design of your study

The first stage of the study is to develop four activities to increase information about support, understanding, availability and sensory experiences. I have designed four prototype methods in order to do this:

Method 1 - The Motivation Mixer (motivation and sensory experiences): This incorporates a visual representation of individuals' motivations and sensory experiences. There will be a number of categories on a board (e.g. calmness, talking, personal space, writing) relating to these experiences, with each category having a vertical scale and a moving indicator marker. Individuals will be asked "how are you feeling?" and then will move the markers from each category up or down the scale to represent how they are feeling. For example, if individuals are feeling like they want a lot of personal space, they would move the marker related to personal space up to the top. This aims to increase student awareness of **how** they are being affected, as well as providing an immediate visual representation for staff members to assess what strategies may need to be put in

place to support an individual. For example, reporting a need for personal space may mean that the individual is allowed to work by themselves rather than in pairs or groups.

Method 2 - Complete the Comics (understanding): Line drawings depicting a student and staff member in a variety of situations (e.g. having a disagreement, working together) will be presented to students with titles. Students then discuss what they think might be going on in the picture. They then have to fill in speech/thought bubbles for the characters, or assess whether they think the thought/speech bubbles are correct, and explain why (not). The aim of this method is not to teach students on the autism spectrum the "right" answer regarding understandings of social situations; it is a prompt to explore their own individual understanding and interpretation of situations to reveal how this may be used to support them and communicate with them more effectively.

Method 3 - Helping Hands (nature of support): students write down very specific tasks or questions for others to do that they feel will offer them better emotional support. These need to be specific to staff members, lessons, types of activities, friends, classmates - the more personalised and detailed, the better. This aims to illuminate student perspectives of what they consider effective support.

Method 4 - Support Sorts (staff availability): using the tasks/questions identified by Method 3, students then sort the tasks using the diamond ranking technique from most important to least important. This interpretation of importance is individual to each student. Tasks/questions that relate to staff (if applicable) will also be separately sorted by students the tasks based on frequency, i.e. what they would like to happen most often, and what can happen more sporadically.

I will conduct a maximum of twelve short (15-20 minute) focus groups (one for each method, completed by all three groups of participants) to assess the ways in which these methods may facilitate communication and support. There will be two groups of three students who participated in the initial study (one group from each school), and one group consisting of the autistic adults (between 5-8 adults, depending on availability). The aim of these focus groups is to come up with some recommendations for each method (during the discussions) that will allow me to re-design the methods to improve their suitability and appropriateness in facilitating communication and support. Each method will be presented in advance to the students and adults, along with the questions that will be asked (as follows):

1) Give me three words to describe [method]. Tell me why you chose those words.

2) Do you think this [method] could help you to talk to a [teacher/LSA]? Why (not)?

3) Do you think this [method] could help a [teacher/LSA] to support you? Why (not)?

4) What could be done to make this [method] better?

This is to allow additional processing time before the discussions take place. During the course of the focus groups, I aim to identify specific recommendations for each method which I will then be able to compile with the recommendations from the other focus groups. Once all three recommendations from these focus groups have been amalgamated, these four activities will be re-designed accordingly. All four designs will then be checked again in a final discussion with the groups to see if they feel their recommendations have been implemented correctly. This means that the student participants will take part in a total of five short focus groups over the course of this second study, whereas the adult participants are more likely to take part in three longer groups. This was decided in conversation with both groups - as the adults meet once a month, it makes sense in terms of their availability to have two methods discussed per meeting, followed by a final check of all four methods. The students expressed their desire to concentrate on one method at a time to avoid confusion, and as they are much more flexible in terms of their availability while in school, it was decided to conduct a series of five focus groups in total (one for each method, plus a final check) to accommodate their wishes.

Once the methods have been finalised, the students will then complete all four of them. This will be the third time they have seen the methods, and so they will be familiar, yet also different based on any re-designs to reduce boredom. Their responses will be video-recorded, and their reasons and motivations for their responses discussed. The information that is produced from these activities will then be summarised in an information sheet relating to each individual, written by myself and checked by the student to ensure accuracy. Focus groups (with a maximum of eight participants) will then be conducted with staff members who work with a particular student to establish basic guidelines for how this information could be used within the secondary mainstream environment (in relation to the second research question). Alternatively, staff members can complete the questions via email contact. This means that a total of six staff focus groups will be run (one to discuss each student). The questions asked to staff members in these focus groups and via email will be as follows:

1) What do you think about the information that X [student name] has provided?

2) Has this information increased your knowledge of X [student name] in relation to understanding/support/availability/sensory experiences?

3) How might you use this information in future?

4) What guidelines could you create to help communicate with X?

5) What guidelines could you create to help support X?

During the course of the focus groups, two sets of guidelines relating to communication and support will be created for each student by the staff members and myself. Transcripts of the student video recordings and the staff focus groups/email responses will then be analysed to explore whether they believe that these activities and guidelines have facilitated the amount of support and communication between them, with specific regard to the four areas identified in the first stage study.

10. Who are the research participants?

The research participants are likely to have already participated in the first stage exploratory study. The first focus group will involve adults from the Autism Sussex advocacy group (potentially 5-6 individuals). The second and third focus groups will require students on the autism spectrum from two schools - 3 students from Woodlands School (Southampton, Hampshire) and 3 students from the Arnewood School (New Milton, Hampshire). These schools (and the six students) have already expressed their interest at being involved in the second phase study, and both have gatekeepers that are personally known to me and who will therefore facilitate access. The students will range between 11-16 years of age, and will all have a diagnosis of ASD/Asperger's Syndrome. These students will also complete the activities once they have been redesigned. The staff members are also likely to have been involved in the first phase study within the two schools, and will self-select themselves to participate in the focus groups, or self-select via email response if they cannot attend the focus group meeting.

11. If you are going to analyse secondary data, from where are you obtaining it?

N/A

12. If you are collecting primary data, how will you identify and approach the participants to recruit them to your study?

Please attach a copy of the information sheet if you are using one – or if you are not using one please explain why.

The sampling frame for this second phase study is likely to be through self-selection. For the autistic adults, my ongoing relationship with them means that they have already expressed an interest to be involved in the next stages of my research (most recently, Sept 2016, when I last visited the group to discuss my findings), and therefore recruitment can take place via email. The students are also likely to be self-selected based on their experiences of the previous study and discussions regarding the findings of the first phase study (also taking place in September/October 2016). The coordinating member of staff in each school (usually the SENCO) will approach these students and their parents to gain assent/consent respectively to take part in this second study. Information sheets for both the SENCOs/parents and the students are attached.

Once the students and parents have given assent/consent, the staff coordinator will communicate with the student's subject teachers, acquiring their permission for the students to miss lessons to take part in the focus groups and activities. The staff coordinator will then contact school staff who teach the students who are involved in the study, allowing them to volunteer to take part in the focus group. This is likely to include self-selected staff members from the initial study who have already expressed an interest in being further involved.

13. Will participants be taking part in your study without their knowledge and consent at the time (e.g. covert observation of people)? If yes, please explain why this is necessary.

No.

14. If you answered 'no' to question 13, how will you obtain the consent of participants?

Please attach a copy of the consent form if you are using one – or if you are not using one please explain why.

Consent will be sought prior to undertaking any data collection. The autistic adults will be given consent forms a few weeks in advance, along with the information sheets and the questions to be asked and photos of the proposed methods. As the student participants are under 16 and may arguably not grasp the implications of their consent due to their age and processing differences, consent for the students' participation will be sought from their parents. However, in addition to parental consent, students will complete an assent form demonstrating their willingness to take part in the study. Staff members will also receive information sheets and consent forms to indicate their willingness to participate in the focus groups.

15. Is there any reason to believe participants may not be able to give full informed consent? If yes, what steps do you propose to take to safeguard their interests?

Yes - the student participants may not be able to give informed consent, and so their assent will be sought. Consent will be sought from their parents (see question 14).

16. If participants are under the responsibility or care of others (such as parents/carers, teachers or medical staff) what plans do you have to obtain permission to approach the participants to take part in the study?

The first point of contact and consent within the schools will be made with the headteachers. Contact will then be made with the SENCOs and Child Protection Officers in each school to ensure the safety of all participants. Following this, the staff coordinator I have worked with previously in each school will then approach the parents and students about the study by passing on the information forms and consent/assent forms to them.

17. Describe what participation in your study will involve for study participants. Please attach copies of any questionnaires and/or interview schedules and/or observation topic list to be used

The adults' focus group will be conducted as part of a pre-scheduled advocacy meeting. I will be attending part of the session (to allow those who do not wish to participate to meet the group as usual). Once I arrive, I will be introduced and will then ask the participants if they are still happy to

continue. I will then ask the questions detailed in Q9 and take audio recordings of participants' answers. Clarification on both sides will be sought if necessary. Once all questions have been asked and answered, I will thank the group for their time and ask them if they would be interested in hearing about the results of my study. If so, I will make arrangements to communicate these details at a later date.

The data collection from students will take place in their schools. I will initially meet with the students to re-introduce myself and relate the findings from the first phase study in October 2016. Following this, I will also ask students whether they would potentially be interested in working with me again. Depending on which students are interested in offering further opinions, I will then arrange a time to meet with all of them in each school. The focus groups for each method will then be conducted using the questions detailed in Q9. Students and their parents will be contacted again by the school coordinator once I have re-designed the activities to seek further assent/consent to be involved with the activity-based interviews. Once the consent and assent forms are received, students will work through each of the activities with me. Their responses and comments will be video-recorded to ensure accuracy. I will then create a summary sheet listing specific and important information about each student following analysis, which will be checked by the student themselves for accuracy.

Data collection from staff members will take place after the student interviews have finished. This will take between 4-6 weeks to carry out, depending on availability. I will meet with staff members and audio-record their responses to questions (see Q9). Once the focus group is over, staff will be thanked for their time. Alternatively, staff members may provide responses to the questions via email if this is more convenient.

18. How will you make it clear to participants that they may withdraw consent to participate at any point during the research without penalty?

Information about withdrawing is given on both the information sheet and the consent form for parents, adults, and staff members, and on the assent form for students. I will also give all focus group participants a verbal reminder each time I meet with them of their right to withdraw.

If any participants wish to withdraw their consent to participate after data collection has been carried out, I will remind them that they can withdraw their data without consequence - as long as they let me know in a timely fashion so that I can exclude their responses from my analyses.

19. Detail any possible distress, discomfort, inconvenience or other adverse effects the participants may experience, including after the study, and you will deal with this.

All participants may experience some stress or discomfort if they are talking about unpleasant or difficult experiences. However, this is likely to be minimal and the procedure for dealing with this is raised in all the information sheets that they are given: they are able to discontinue participating in

the focus groups/interviews at any time without explanation, and do not have to answer all the questions asked of them. The adult participants are also given the option of using pseudonyms or their own names to minimise anxiety around confidentiality and/or ownership and recognition. Participants can also ask for their data to be withdrawn following completion of the data collection to avoid any anxiety or distress that they might feel at a later date about participating. I will also explain to the students particularly (due to their increased vulnerability of a young age) that if there are any issues raised as a result of our interactions that will impact on the safety of themselves or someone else, I will need to let a member of school staff know to offer them any support that might be needed.

I have almost six years of teaching experience and over twenty years of both personal and professional knowledge regarding individuals on the autistic spectrum, including some with very challenging behaviour. There is also a strong likelihood that the individuals involved in this study will have worked with me previously on the first phase study. Consequently, I am familiar with the first signs of anxiety/distress that these individuals may demonstrate, and know how to deal with them appropriately to prevent further upset (e.g. using a low arousal approach to communicate, offering a time out/break if needed, asking if they want to continue). I have also conducted interviews using photo-elicitation with students on the autistic spectrum before for my Masters qualification and first phase study, and therefore have experience in using this method. If I judge that an individual is continuing with the interview or focus group despite feeling uncomfortable (due, for example, to the authority that I represent or out of a desire to please) then I will reassure them and, if necessary, stop the interview myself. Finally, there may be some discomfort experienced by teaching staff in talking to me due to my pre-existing relationships with those in their schools. I will reassure participants that everything is confidential unless it puts either themselves or another at immediate risk of harm.

20. How will you maintain participant anonymity and confidentiality in collecting, analysing and writing up your data?

Complete anonymity cannot be guaranteed, but all student and staff member data will be coded so that they are not individually identified by their real names - they will be identified by pseudonyms (see Q23). The autistic adults were keen to use their real names in the previous exploratory study, so this will be offered as an additional option to pseudonyms for them. However, if adults feel that they want their contributions to be recognised, their first names will be used to comply with their wishes for ownership as long as they accept that this will not guarantee them confidentiality. All data will be kept on a password-protected computer, and individual transcript documents will also be password-protected.

21. How will you store your data securely during and after the study?

See above.

22. Describe any plans you have for feeding back the findings of the study to participants.

Parents and staff members are given the option of providing their email address on the consent form to allow me to email them with the overall results of the study once the data has been analysed. This will be a brief and simple summary of the main findings. In addition, I plan to visit the schools and advocacy group to meet face to face with the other individuals involved to share my results.

23. What are the main ethical issues raised by your research and how do you intend to manage these?

1) Informed consent - as stated previously, students may not fully understand what they are consenting to, given their age and the nature of their diagnosis. To ensure that fully informed consent is sought (and given that all the children are under 16), parental consent is therefore required. However, in addition to parental consent, an initial assent form also needs to be signed by each child. Their ongoing assent will be indicated by the students' interactions with me throughout the focus groups and activities.

The information sheets provided for all participants are detailed, and include my contact details so that if there are any further queries, they are able to contact me with relative ease. These queries can then be resolved to inform the individual's decision to take part in the study. Opportunities for questions will also be provided every time I meet those involved.

2) Right to withdraw - in addition to stating that participants can withdraw at any time in the information sheet and consent form, I will also be offering verbal reminders at each meeting with the participants. Participant data will be coded using pseudonyms (or real names where elected by the adult participants), but I will keep a private record of the pseudonyms used to allow elimination of data if requested by a particular participant after the study/activity is completed.

3) Welfare of participants - it is possible that when evaluating the new methods, adult and student participants may experience some distress. This will be handled sensitively and with respect. The student participants have control over the recording of the video camera, and therefore can turn it off it at any point they do not wish to continue; students and adults are also free to leave the focus group at any time without explanation. If such circumstances arise, participants will be offered some time to compose themselves, and then may carry on if they wish to do so. If parents request to be present at the students' focus group/interview, then this can be accommodated with the understanding that they there as an observer only.

4) Confidentiality - although complete confidentiality is not able to be given (as participants have been specifically selected and therefore others in the school/advocacy group will know that they have taken part in the research), all participants will have their data coded to ensure that they cannot be individually identified. In order to recognise the wishes of the

autistic adults, the option of using their given names will also be offered, as long as they understand that this means that I cannot ensure confidentiality for them.

My own welfare as a researcher will be looked after by ensuring that the rooms used for interviewing the students/adults include see-through doors, and by recording the interviews. It may be that I am emotionally affected by the responses of the participants if they describe any issues. I will deal with this by practising the interview process beforehand to ensure that my data collection is not compromised, and if needed, can seek support from my supervisors regarding any distressing comments that may be made.

G.11 Amended information sheet for educational practitioners

Staff Information Sheet

Study Title: What might help students on the autism spectrum and their teachers to understand each other better?

Researcher: Harriet Hummerstone **Ethics number**: 23921

Please read this information carefully before deciding if you are happy to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

I am a qualified and experienced Psychology teacher who is currently working towards a PhD in Education at the University of Southampton. I have both personal and professional experience of working with a wide range of individuals on the autism spectrum, especially in a secondary school environment. For the first phase of my research, I spoke to staff members and students on the autism spectrum about their school experiences of communication and support, and noted that there were some significant differences in their views.

I am now conducting a second study that aims to facilitate the communication between students on the autism spectrum and staff who work with them (e.g. teachers, LSAs) in a secondary mainstream school.

Why have I been chosen?

For this project, I am focusing on staff who work with students who are currently attending secondary schools, who have received a diagnosis of Autism Spectrum Disorder or Asperger's Syndrome, and who are taking part in this study.

What will happen if I take part?

You can choose whether to respond to the questions I am asking by email or face-to-face depending on what is most convenient. If you would prefer to answer questions by email, I will send these to you for you to reply to at your convenience. For face-to-face questions, I will meet you and other staff members who have agreed to take part at school. I will introduce myself and complete any administration. We will then have a discussion about an information sheet that the student and I have co-constructed. The group discussions should last no longer than 60 minutes, and will be audio-recorded to allow me to remember everything that has been said. You may leave the discussion at any point and contribute as much or as little as you feel comfortable with. Once the discussion is completed, I will thank you for your time. If desired, I can notify you at a later date (via email) of the outcome of my research, once my analysis has been completed (July 2017).

Are there any benefits to taking part?

Communication is a two-way process, and therefore in addition to speaking to students, I need staff views on the information that has been provided to make any conclusions from my research more relevant to the secondary mainstream school (classroom) context.

Are there any risks involved?

There is very minimal risk involved in this study. It may be that discussing a particular student could lead to sharing potentially stressful memories. However, you are under no obligation to answer every question, and can withdraw from the study at any time. This study has been ethically approved by the University of Southampton, and I have an enhanced and current DBS check.

Will my participation be confidential?

Data from this study (e.g. audio recordings, email responses, analysis of participant answers) will be kept in compliance with the Data Protection Act and stored on a password protected computer. Data will also be coded so that individual names are not published and quotations are not identifiable; you will be assigned (or can choose!) another name that you will be known by in this study.

What happens if I change my mind?

Participation is completely voluntary, and therefore you can withdraw from the study at any time. If you do not wish for your data to be used for analysis after you have completed the study, please can you inform me of this by **7th August 2017**.

What happens if something goes wrong?

In the unlikely case of concern or complaint, please contact the Head of Research Governance at the University of Southampton (02380 595058, rgoinfo@soton.ac.uk)

Where can I get more information and/or ask questions?

Please feel free to contact me regarding any further questions or queries you may have via email:
Harriet Hummerstone h.hummerstone@soton.ac.uk

G.12 Amended consent form for educational practitioners

CONSENT FORM FOR STAFF

Study title: What might help students on the autism spectrum and their teachers to understand each other better?

Researcher name: Harriet Hummerstone **Ethics reference**: 23921

Please **initial** the box(es) if you agree with the statement(s):

I have read and understood the information sheet (SSEGM Initial Study Information Sheet (Staff) V2 13.03.17) and have had the opportunity to ask questions about the study ☐

I agree to take part in this research project and agree for my data to be recorded and used for the purpose of this study ☐

I understand that my responses will be anonymised in reports of the research so that my name and the name of the school is not used ☐

I consent to having my anonymous responses used in reports of the research ☐

I understand my participation is voluntary and that I may withdraw at any time ☐

I would like to be contacted regarding the overall results of the project ☐

Email.....

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study.

Name (print name)……

Signature ……..

Date……

Signature of researcher..... Date.....

Appendix H Tabulated feedback on the four prototype activities

H.1 The Motivation Mixer

	Comments
Student Focus Group 1	• Change font to "not Comic Sans" (B) • "I'm not sure what I'm meant to be doing" (N) – instructions needed • "If it high, does it mean you're very hyper?" (N) – confusion about high/low of stillness • "When it says 'ears', does that mean certain noises that annoy you? Cos I have so many noises that annoy me" (N) • Students decide to change "ears" to "noise" • Need to have room for mentioning specific noises: example list = sounds and voices, "your situation with the amount of noise that you have" (B): Need gaps so that you can fill them in depending on which ones annoy you • Differentiates between background noise ("noises outside") and people noise ("fidgeting") and specific noise (what you personally find annoying – list = nail files, tapping pens, bottle flips, projector, chair noises, whiteboards, food noises, music)→ three types of noise • "Eyes" need extra details; flashing, lights, textures, colours, certain fonts, distracting displays in classrooms
Student Focus Group 2	• Suggest changing "ears" to "noise" and listening" • Suggest changing "eyes" to "focus" • Suggest changing "touch" to "touching" and "being touched" • Suggest "types of questions" also needs to be included in "speed of thoughts" to clarify • Different coloured lines as opposed to black and white • Keep high and low markers • Add pictures • Have a straight face instead of a smiley face
Adult Focus Group	• Change "stillness" to "movement and stillness" • Change "ears" to "noise" (general) and "sound" (specific) • Change "eyes" to "visual" • Change "space" to "personal space", and clarify that this is the space that an individual requires • Change "nose" to "smell and aroma" • Change "touch" to "touch and feel" • More categories needed for "touch": light/firm, given/received, how things feel (texture) Differentiate between "receiving" and "giving" in relation to eye contact. • Clarify "speed of thoughts" by adding "processing" • Add a measure of "temperature" • Add a measure of "speech" – and differentiate between speed of your own, speed of others', and others' tone of voice • Add pictures • Written instructions and examples of questions that might be asked needed • Need for different designs to allow personalisation: blank vs. information vs pictures • Font could be changed from Comic Sans

+/- Content +/- Clarification +/- Stylistic

Possible amendments	- Investigate different font x 2 - Provide written script for instruction x 2 - Change “ears” to three different and specific categories: background, people, and specific OR change “ears” to “noise and listening” OR change “ears” to “noise” (general) and “sound” (specific) - Change “nose” to “smell/aroma” - Add example lists to “noise” and “eyes” to provide clarity OR change “eyes” to “visual” OR change “eyes” to “focus” - Separate “touch” into “touching” and “being touched” OR change “touch” to “touch and feel” OR specify categories of touch, e.g. light/firm, given/received, how things feel (texture) - Add pictures and colour x 2 - Change “stillness” to “movement and stillness” - Clarify “speed of thoughts” by adding “types of questions” OR by adding “processing” - Add a measure of temperature - Add a measure of speech – own speech speed, others’ speech speed, tone of voice x 2 - Consider more than one design template for personalisation
Amendments Made	- Changed from Comic Sans to Century Gothic - Two different versions: one with basic words (blank) and one with pictures and colour (pictures) - Additional prompt/instruction sheet made <u>First page: auditory & visual</u> - Divided “ears” into two categories – “noise (general)” and “sounds (specific)” with gaps to personalise - Added speech as a separate category with gaps to personalise - Divided “eyes” into two categories – “visual (general)” and “focus (specific)” with gaps to personalise - Divided “eye contact” into “giving” and “receiving” <u>Second page: olfactory, tactile, cognitive</u> - Changed “nose” into “smells” with gaps to personalise - Dividing touch into “touch (general)” and “texture (specific)” - Combined “space” and “being touched” into “personal space” - Changed “stillness” to “movement” - Added measure of temperature

H.2 Complete the Comics

	Comments
Student Focus Group 1	• Liked “Getting Told Off” and “A Misunderstanding” • Changed “Excellent Friends” to “Bad Friends” • Added a “choose your own” option • Added a “books/movies/war” option • Added “Most Recent Argument” • Added “Least Annoying People” • Change Comic Sans • Wanted to draw other characters, e.g. cats, ninjas, instead of stick people
Student Focus Group 2	• Clarify that “Getting Told Off” could be about you or someone else • Clarify that “Doing Good Work” should be “Doing Good School Work” • Changed “Excellent Friends” to “Good Friends” • Wanted to draw other characters instead of stick people, e.g. dinosaurs, potato people
Adult Focus Group	• Titles are too vague and need to be clearer • Clarify that these titles are not necessarily just to do with school • Give more examples to help structure information, e.g. themes vs. examples vs. titles • Give other examples apart from stick figures • Clarify writing words first, drawing bubbles second

+/- Content +/- Clarification +/- Stylistic

Possible amendments	- Change “Getting Told Off” to clarify you or someone else - Change title: “Excellent Friends” - Add create your own option - Add more examples of different characters apart from stick figures x 3 - Add “Most Recent Argument” - Add “Least Annoying People” - Change “Doing Good Work” to “Doing Good School Work” - Look at different versions – titles vs. themes w/examples
Amendments made	- Separate “titles” and “themes” with examples - Instructions changed to add own option first - Instructions changed regarding drawing bubbles - Stick figure deleted - Themes: behaving in school, working in class, friendship, misunderstanding, arguments - Titles: when I got told off, doing good school work, least annoying people, they don’t know what I mean, bad friends

H.3 Helping Hands/Support Sorts

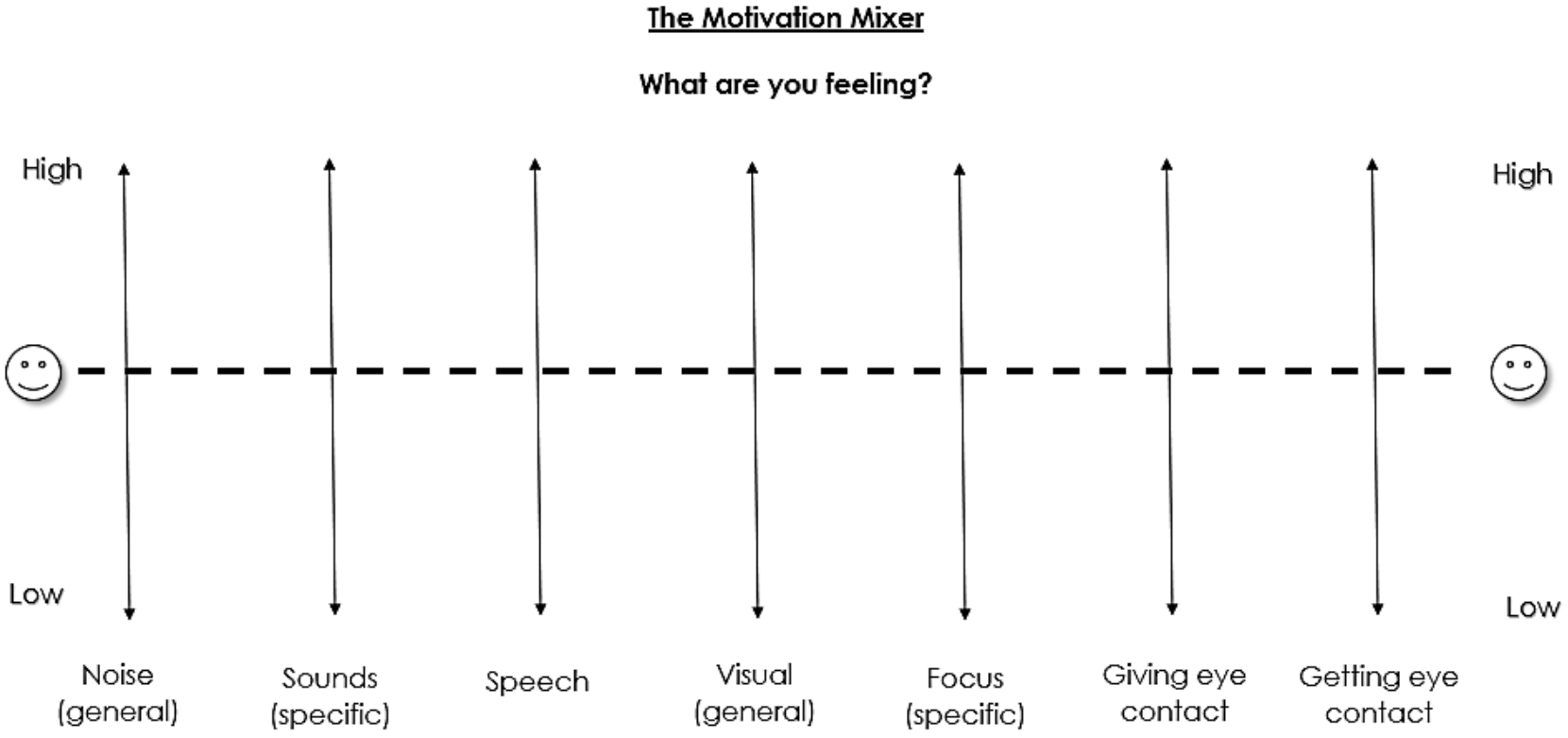
	Comments
Student Focus Group 1	• Liked concept of drawing on hands • Wanted a negative version as well • Suggestions for negative version: choking hands, a fist, hand with a line (decided on third option) • Sort for "importance" easier than "frequency" • Did not hold attention of all students • Suggested different colours for hands to differentiate between different people/animals/objects
Student Focus Group 2	• Suggested negative version could also be useful – thumbs up vs. thumbs down • Did not hold attention of all students "it's boring because I don't like writing" • No input on Support Sorts activity – did not want to participate
Adult Focus Group	• Provide space for names underneath hands for when they are cut out • Option of drawing name on hand and writing a few key words on thumbs/fingers

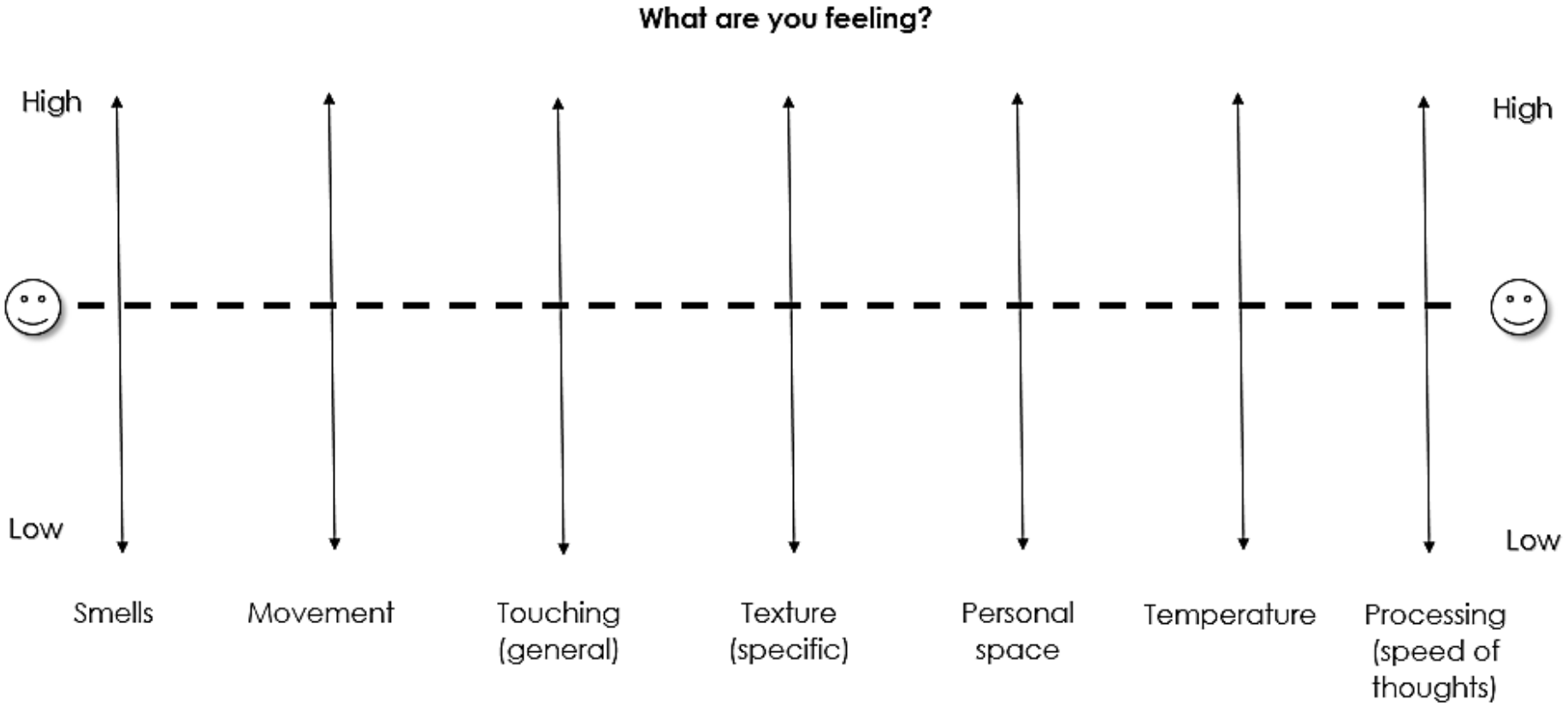
+/- Content +/- Clarification +/- Stylistic

Possible amendments	- Add negative examples x 3 - Reduce writing by offering names on hands and writing on fingers - Colours to differentiate between people - Need to maintain interest levels – much less engaged
Amendments made	- Reduce amount of writing needed through options of colours vs. thumbs vs. hand - Comic Sans changed to Century Gothic - Switch to starting activity to promote interest - Take photos of sorts to increase engagement

Appendix I Alternative designs

I.1 The Motivation Mixer (without pictures)




What are you feeling?
High
Low
High
Low
Smells
Movement
Touching (general)
Texture (specific)
Personal space
Temperature
Processing (speed of thoughts)

I.2 The Motivation Mixer (prompt sheet)

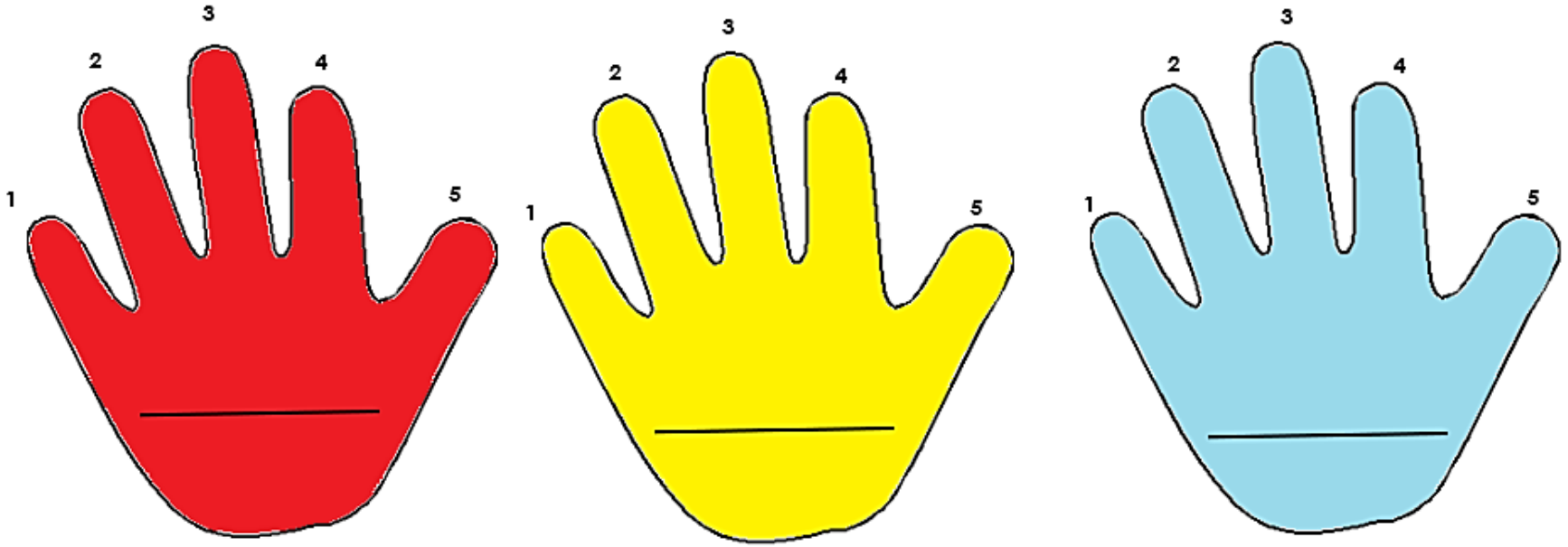
Noise (general)	- What background noise do you notice? - What noises made by other people do you notice? - What noises do you hear that nobody else seems to?
Sounds (specific)	- What sounds do you notice? - What sounds do you like? - What sounds do you dislike?
Speech	- Do other people speak fast or slow? - Do you speak fast or slow? - What voices do you like? - What voices do you dislike?
Visual (general)	- Do you get distracted by new things that you see? - What colours do you like? - What colours do you dislike? - Do you prefer bright light or dim light?
Focus (specific)	- Do you see details easily? - Do you notice patterns that other people do not notice?
Giving eye contact	- Do you feel comfortable giving eye contact to other people? - What makes giving eye contact easier? - What makes giving eye contact harder?
Getting eye contact	- Do you feel comfortable getting eye contact from other people? - What makes getting eye contact easier? - What makes getting eye contact harder?
Smells	- What smells do you like? - What smells do you dislike? - What smells do you notice that nobody else does?

Movement	- Do you move around a lot? - Do you get told you fidget a lot? - How does it feel when you sit still and don't move?
Touching (general)	- Do you prefer to touch things firmly or gently? - How does being touched by other objects (including people and animals) make you feel?
Texture (specific)	- What textures do you like touching? - What textures do you dislike touching?
Personal space	- How much personal space do you like to have? - What makes you need more personal space? - What makes you need less personal space?
Temperature	- Do you get hot easily? - Do you get cold easily?
Processing (speed of thoughts)	- Do you prefer questions to be repeated? - Do you sometimes need to think about what to say? - Do other people get confused by the way you think?

I.3 Helping Hands (with numbers)

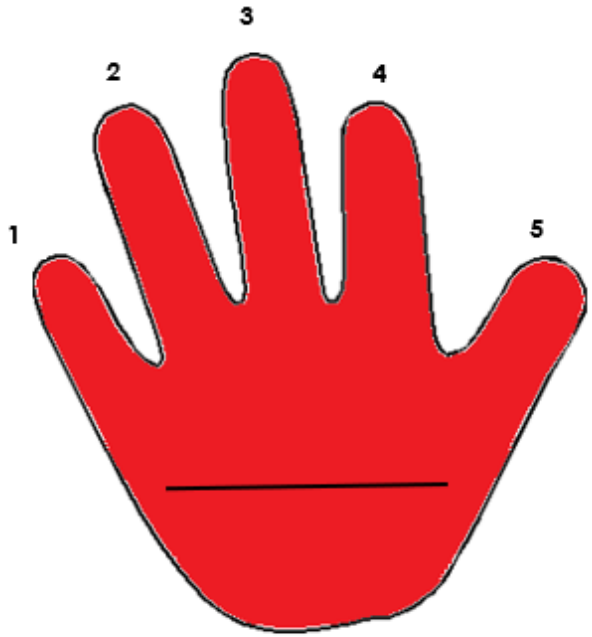
Helping Hands

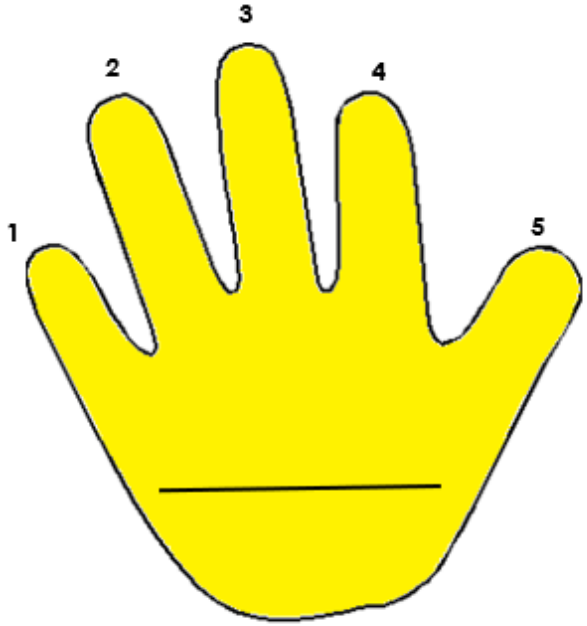
"What does _____ do to help you?"

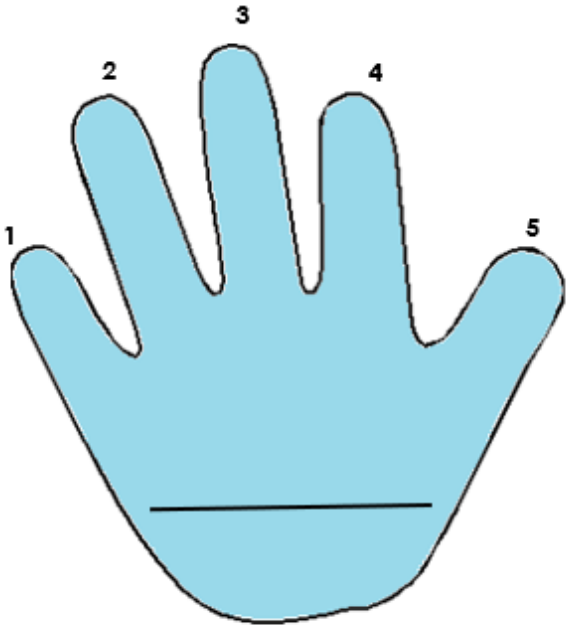


Not Helping Hands

"What does _____ do that doesn't help you?"







I.4 Helping Hands (thumbs design)

Helping Hands

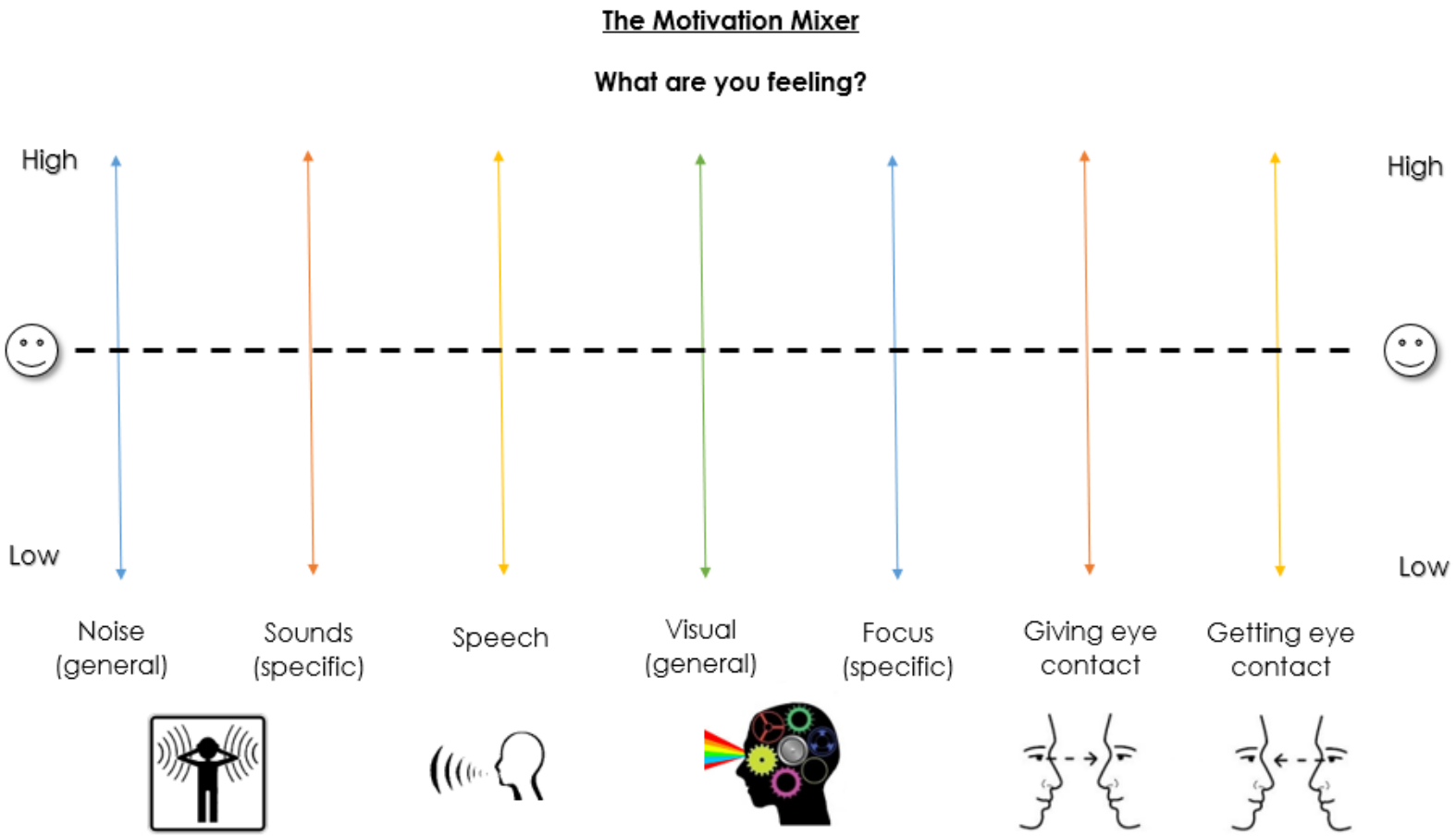
"What does _____ do to help you?"

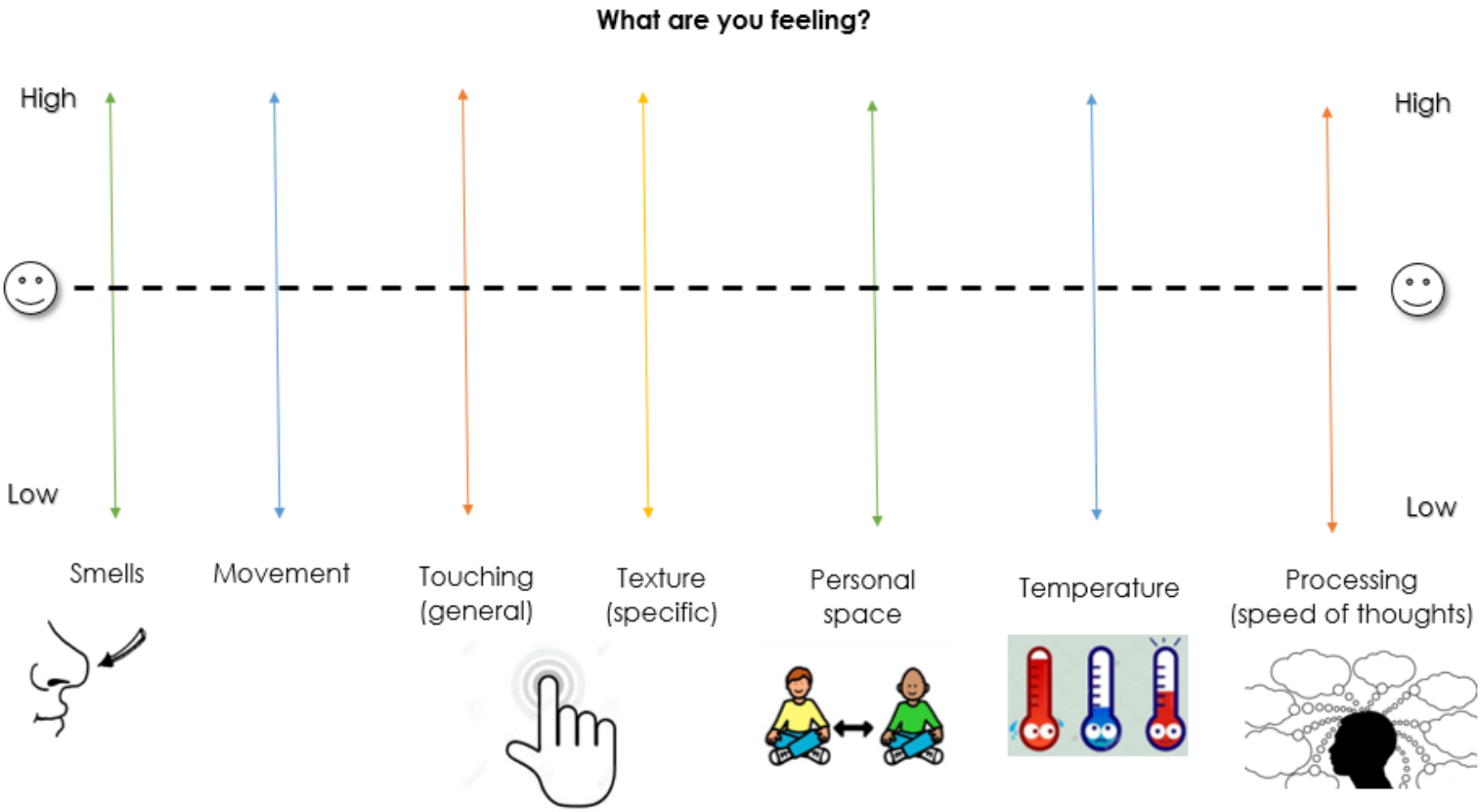
Not Helping Hands

"What does _____ do that doesn't help you?"

Appendix J Final designs

J.1 The Motivation Mixer




What are you feeling?
High
Low
High
Low
Smells
Movement
Touching (general)
Texture (specific)
Personal space
Temperature
Processing (speed of thoughts)

J.2 Complete the Comics

Complete the Comics

Draw a comic about anything you want. Show what characters are thinking and saying by writing what they are saying or thinking first, and drawing a thought/speech bubble around it afterwards. Your story can have a maximum of nine boxes/panels, and can feature animals, people and machines.

Thought bubble

Speech bubble

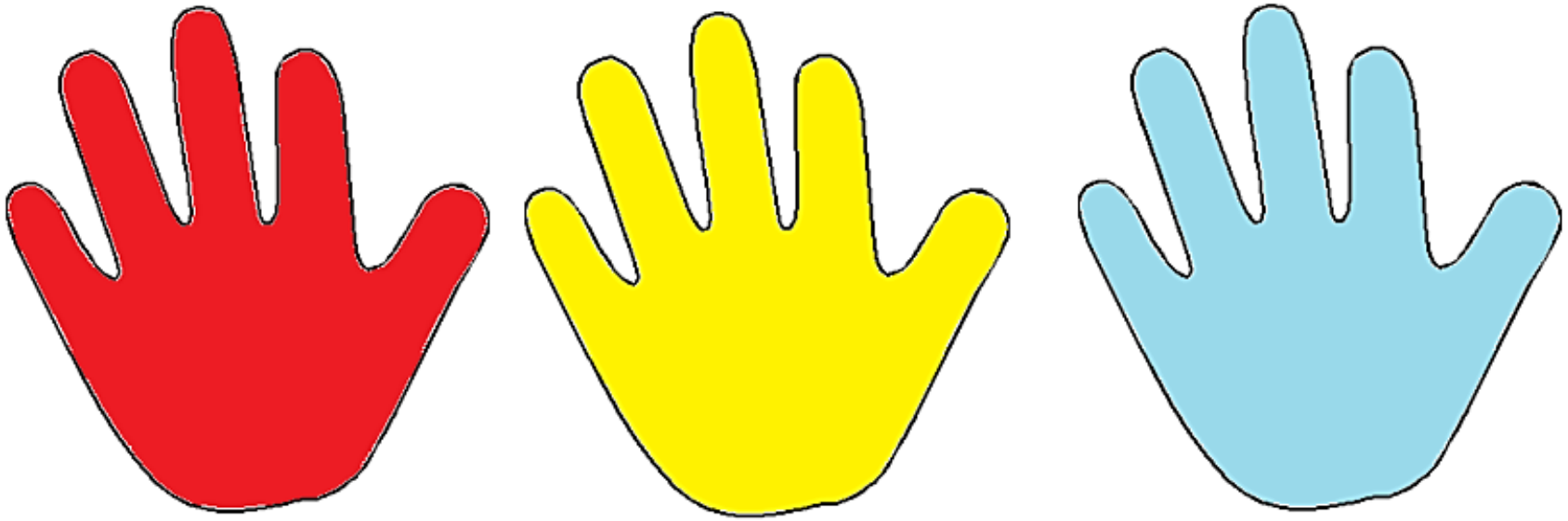
Now draw one more comic about school - here are some examples of themes and titles to help you:

Themes:	Titles:
Behaving in School	"When I Got Told Off"
Working in Class	"Doing Good School Work"
Friendship	"Least Annoying People"
Misunderstandings	"They Don't Know What I Mean"
Arguments	"Bad Friends"

J.3 Helping Hands & Support Sorts

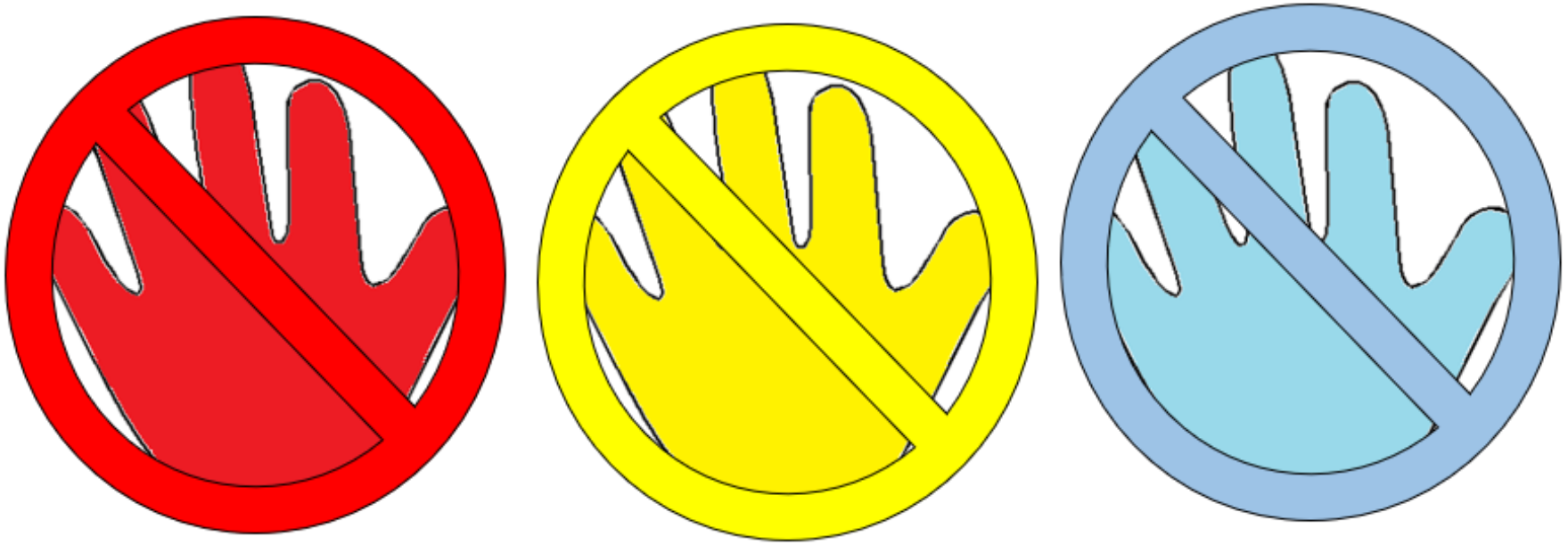
Helping Hands

"What does _____ do to help you?"



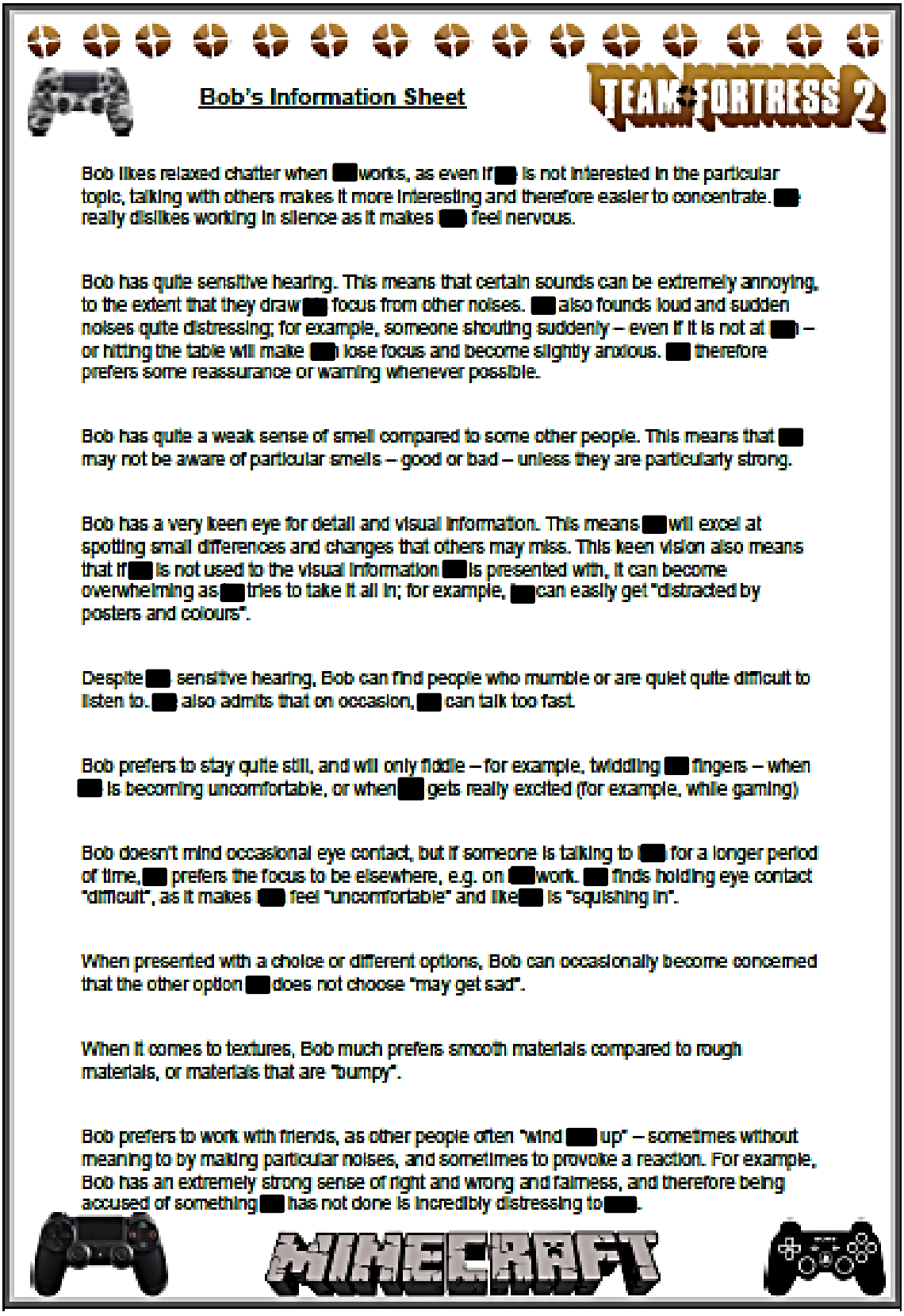
Not Helping Hands

"What does _____ do that doesn't help you?"



Appendix K Personalised information sheets

K.1 Bob (gendered information redacted)



Bob's Information Sheet

TEAM FORTRESS 2

Bob likes relaxed chatter when [redacted] works, as even if [redacted] is not interested in the particular topic, talking with others makes it more interesting and therefore easier to concentrate. [redacted] really dislikes working in silence as it makes [redacted] feel nervous.

Bob has quite sensitive hearing. This means that certain sounds can be extremely annoying, to the extent that they draw [redacted] focus from other noises. [redacted] also founds loud and sudden noises quite distressing; for example, someone shouting suddenly – even if it is not at [redacted] – or hitting the table will make [redacted] lose focus and become slightly anxious. [redacted] therefore prefers some reassurance or warning whenever possible.

Bob has quite a weak sense of smell compared to some other people. This means that [redacted] may not be aware of particular smells – good or bad – unless they are particularly strong.

Bob has a very keen eye for detail and visual information. This means [redacted] will excel at spotting small differences and changes that others may miss. This keen vision also means that if [redacted] is not used to the visual information [redacted] is presented with, it can become overwhelming as [redacted] tries to take it all in; for example, [redacted] can easily get "distracted by posters and colours".

Despite [redacted] sensitive hearing, Bob can find people who mumble or are quiet quite difficult to listen to. [redacted] also admits that on occasion, [redacted] can talk too fast.

Bob prefers to stay quite still, and will only fiddle – for example, twiddling [redacted] fingers – when [redacted] is becoming uncomfortable, or when [redacted] gets really excited (for example, while gaming)

Bob doesn't mind occasional eye contact, but if someone is talking to [redacted] for a longer period of time, [redacted] prefers the focus to be elsewhere, e.g. on [redacted] work. [redacted] finds holding eye contact "difficult", as it makes [redacted] feel "uncomfortable" and like [redacted] is "squishing in".

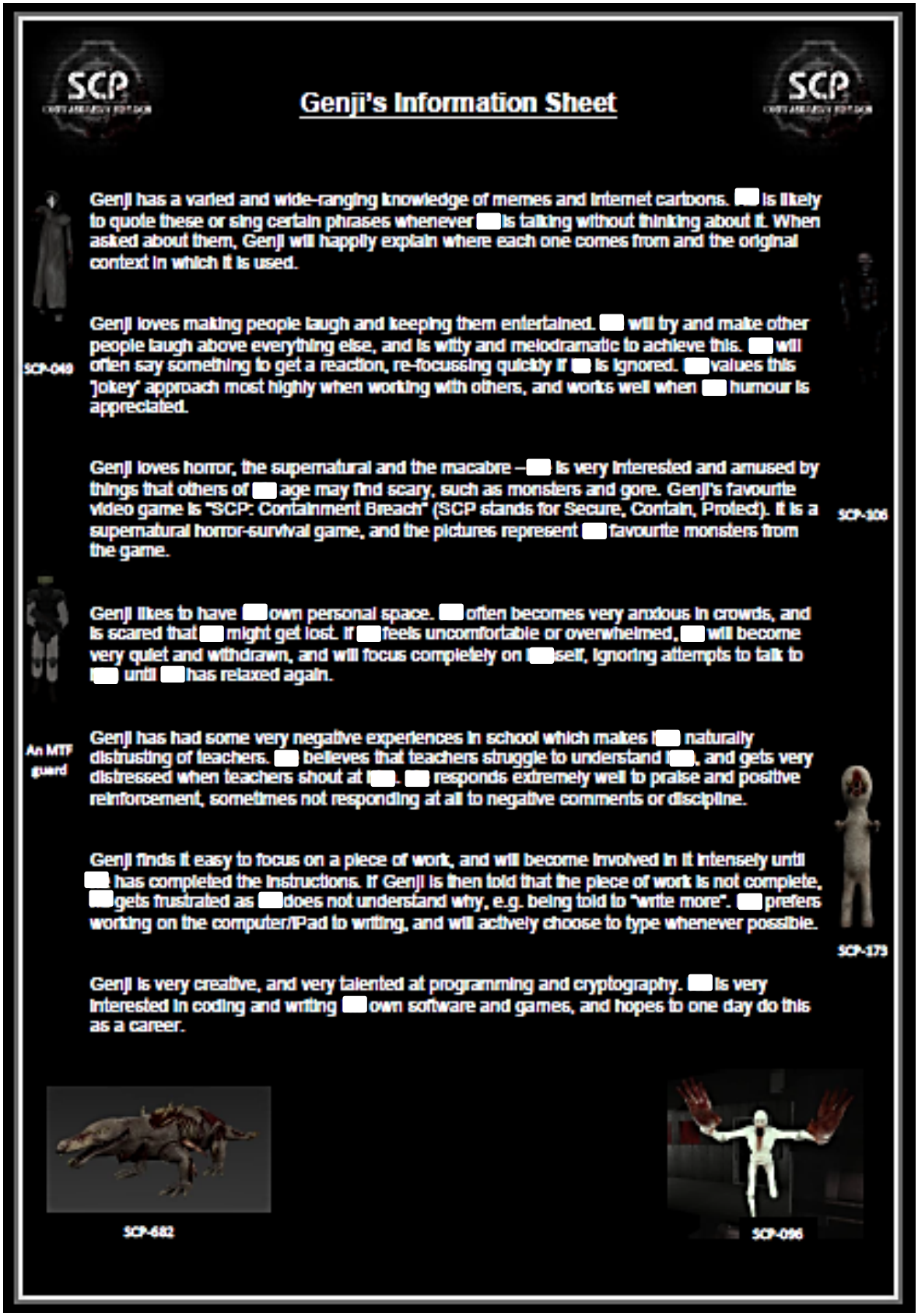
When presented with a choice or different options, Bob can occasionally become concerned that the other option [redacted] does not choose "may get sad".

When it comes to textures, Bob much prefers smooth materials compared to rough materials, or materials that are "bumpy".

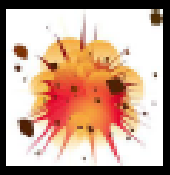
Bob prefers to work with friends, as other people often "wind [redacted] up" – sometimes without meaning to by making particular noises, and sometimes to provoke a reaction. For example, Bob has an extremely strong sense of right and wrong and fairness, and therefore being accused of something [redacted] has not done is incredibly distressing to [redacted].

MINECRAFT

K.2 Genji


Genji's Information Sheet
Genji has a varied and wide-ranging knowledge of memes and internet cartoons. [redacted] is likely to quote these or sing certain phrases whenever [redacted] is talking without thinking about it. When asked about them, Genji will happily explain where each one comes from and the original context in which it is used.
SCP-049
Genji loves making people laugh and keeping them entertained. [redacted] will try and make other people laugh above everything else, and is witty and melodramatic to achieve this. [redacted] will often say something to get a reaction, re-focussing quickly if [redacted] is ignored. [redacted] values this 'jokey' approach most highly when working with others, and works well when [redacted] humour is appreciated.
Genji loves horror, the supernatural and the macabre – [redacted] is very interested and amused by things that others of [redacted] age may find scary, such as monsters and gore. Genji's favourite video game is "SCP: Containment Breach" (SCP stands for Secure, Contain, Protect). It is a supernatural horror-survival game, and the pictures represent [redacted] favourite monsters from the game.
SCP-106
Genji likes to have [redacted] own personal space. [redacted] often becomes very anxious in crowds, and is scared that [redacted] might get lost. If [redacted] feels uncomfortable or overwhelmed, [redacted] will become very quiet and withdrawn, and will focus completely on [redacted]self, ignoring attempts to talk to [redacted] until [redacted] has relaxed again.
An MTF guard
Genji has had some very negative experiences in school which makes [redacted] naturally distrusting of teachers. [redacted] believes that teachers struggle to understand [redacted], and gets very distressed when teachers shout at [redacted]. [redacted] responds extremely well to praise and positive reinforcement, sometimes not responding at all to negative comments or discipline.
Genji finds it easy to focus on a piece of work, and will become involved in it intensely until [redacted] has completed the instructions. If Genji is then told that the piece of work is not complete, [redacted] gets frustrated as [redacted] does not understand why, e.g. being told to "write more". [redacted] prefers working on the computer/iPad to writing, and will actively choose to type whenever possible.
SCP-173
Genji is very creative, and very talented at programming and cryptography. [redacted] is very interested in coding and writing [redacted] own software and games, and hopes to one day do this as a career.
SCP-682
SCP-096

K.3 Hanzo



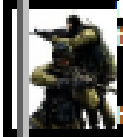
Hanzo's Information Sheet

Hanzo is naturally full of movement. [redacted] channels [redacted] energy into occupying [redacted] hands – fidgeting with an object allows [redacted] to relax and concentrate more effectively. [redacted] is happiest when moving around, and is not in control or always aware of [redacted] need to move – [redacted] will move without consciously thinking about it!

Hanzo has sensitive hearing, and this makes [redacted] particularly skilled at focussing on specific noises to the exclusion of all others. However, certain types of noises (e.g. someone tapping repeatedly, the creaking of foam packaging, and cardboard bending) cannot be ignored or tuned out because of this sensitivity

Hanzo's excellent hearing, combined with [redacted] very good social skills, means that [redacted] can become very easily distracted, and [redacted] openly admits this. [redacted] is working on strategies to focus, but is usually unaware that [redacted] attention has switched. [redacted] finds clear prompts/reminders (rather than disciplinary action) about what [redacted] is doing to keep [redacted] on task and help [redacted] switch [redacted] attention back.

Hanzo comes from a big family, and loves talking and socialising. [redacted]e is fiercely loyal to [redacted] friends and family, and any threat or harm to them is always taken as a personal threat to [redacted]. [redacted] will put [redacted] family's and friends' needs above [redacted] own, even if [redacted] actions get [redacted] into trouble.



Hanzo has anxiety and can become very "wound up" very quickly, where [redacted] feels like [redacted] can't breathe or think. Hanzo has a few very close friends that have earnt [redacted] loyalty, understand [redacted], and help [redacted] to relax, and therefore has very little interest in working with other students who [redacted] doesn't know. Sitting next to [redacted] friends helps with [redacted] anxiety and helps [redacted] concentrate.

Hanzo is happiest when a bit of humour or "banter" is used, as [redacted] is naturally very smiley and a bit cheeky; this is also the form of communication [redacted] is most familiar with from [redacted] family. [redacted] finds working in silence extremely difficult, and will unconsciously make noise and move about to bring [redacted] own personal levels up to a more manageable state.

Hanzo has an incredibly strong sense of fairness. If [redacted] feels that [redacted] – or friends/family – have been treated unfairly, [redacted] reacts much more strongly than other students may. [redacted] will become agitated, and start clenching [redacted] fists.

Sometimes, Hanzo's anxiety means that [redacted] frustration gets "over the limit" – [redacted] eyes change, [redacted] veins "come out", and "Angry Hanzo" takes over and Hanzo is no longer in control. Hanzo is not aware of what "Angry Hanzo" is doing or saying. [redacted] can remember at a later date once [redacted] has calmed down and "Angry Hanzo" has gone, and is incredibly regretful of what [redacted] has done. [redacted] hates and is a bit scared of Angry Hanzo.

K.4 Jack

Jack's Information Sheet

Jack likes to be constantly on the move. [redacted] needs to keep active in order to keep focussed, and therefore will sit on [redacted] legs, rock, and play with whatever objects are available to keep [redacted] hands busy. [redacted] finds sitting still almost impossible as [redacted] gets very uncomfortable when is not allowed to move.

Jack likes making noises – including copying sounds that [redacted] hears, and occasionally making sounds as [redacted] is doing [redacted] work or talking. [redacted] will do this without realising, and because [redacted] occasionally has been told off for making noise, [redacted] tries to stay as quiet as possible in lessons (including not speaking). When relaxed, [redacted] is loud and chirpy and full of energy!

Jack likes working with a variety of people, and is willing to try and work with everyone which makes [redacted] an excellent team player and group worker. However, [redacted] doesn't like other people who shout and swear – especially if they then make [redacted] feel bad for not shouting or swearing, as [redacted] is extremely focussed on behaving well and not getting into trouble.

Jack has relatively sensitive hearing, and so does not like too much noise. However, it is the pitch, frequency and tone of noises (rather than the volume) which [redacted] is much more likely to notice and react to. For example, a harsh tone of voice, a high-pitched whine or a sudden loud noise – even if not directed at [redacted] – makes [redacted] uncomfortable.

Jack is incredibly smiley, and this is [redacted] natural facial expression. [redacted] worries that sometimes [redacted] may be seen to be smiling when it is not appropriate (for example, in a serious scene in Drama). [redacted] may occasionally have a blank face where it does not look like [redacted] is reacting, and [redacted] smile fades slightly – this usually means [redacted] is troubled by something (e.g. not understanding the work [redacted] is supposed to be doing).

Jack is extremely sensitive to touch, which gives [redacted] excellent physical self-awareness and coordination. [redacted] prefers very light pressure when having physical contact from other people.

Jack processes some information very quickly, and other information a bit more slowly. For example, [redacted] finds Maths and Art easy because [redacted] is interested and "good" at these topics. This may sometimes be reflected in [redacted] speech – [redacted] will speak much faster about topics [redacted] is confident in, and much more slowly if [redacted] is thinking a lot as [redacted] answers.

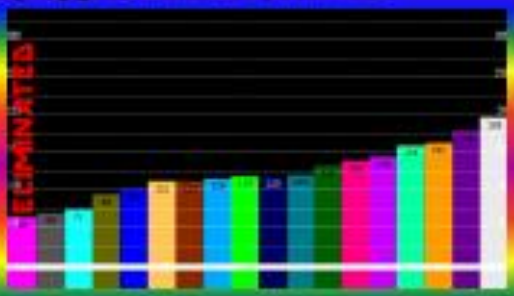
Jack has a variety of keen interests that are likely to be reflected in [redacted] work, and is incredibly creative. [redacted] detailed knowledge of these topics and [redacted] enthusiasm for them make for very interesting conversations. Some of the things [redacted] is interested in are detailed below:

The trains from Thomas the Tank Engine – [redacted] favourites are Bertram & Donald)

Chess – [redacted] is very good at this, and often plays against others at lunchtime

Hexbugs

Colours (in particular, colour names) – [redacted] also really likes an app called Algodoo, which is a physics-based designing game that allows you to "race" colours against each other.



Mixed Martial Arts – Jack has a black belt in MMA, and takes [redacted] physical health and fitness very seriously

Dinosaurs – Jack has extensive knowledge of different species of dinosaur, including facts about their heights, their formal names, and their different physical characteristics.

WWE – Jack has particular favourite wrestlers (both male and female) and likes to rank them in order of preference. [redacted] also follows the storylines closely, and knows about the detailed history of each wrestler.

K.5 Sage

Sage's Information Sheet

Sage has a very good visual system, and perceives colours much more vividly than others may. [redacted] has several preferred colour combinations (such as black and light green/dark red/yellow, and white and light blue/red). There are also some colours that [redacted] finds visually uncomfortable, such as dark green and brown, and textures that are very visually unappealing (such as corrugated cardboard). Bright lights can also be quite overwhelming.

Sage needs to keep [redacted] hands occupied to concentrate. [redacted] is a keen and talented guitar player, and likes playing with objects that keep [redacted] hands busy, such as stress balls and spinners. However, [redacted] knows that this can be distracting, and so tries to avoid doing this in lessons. This occasionally means that [redacted] will rhythmically tap [redacted] pen, tap [redacted] feet, and swing [redacted] legs without realising it – this can make [redacted] anxious if [redacted] suddenly realises [redacted] is distracting others.

Sage is extremely focussed on being well-behaved and not getting into trouble. [redacted] has an extremely strong sense of fairness, and therefore gets frustrated when different people committing the same behaviours get different punishments. Sage thrives on positive reinforcement, whether verbal praise or ADDs points. [redacted] can become very withdrawn and uncommunicative if [redacted] feels [redacted] has been disciplined unfairly.

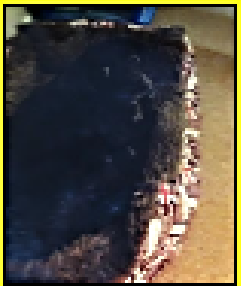
As a keen musician, Sage also has very sensitive hearing. Some noises annoy [redacted] "so much it hurts"; nail files, and other "rubbing noises" (such as mini whiteboards rubbing against the table, sandpaper) are the most distressing. This can also include certain voices and accents which makes Sage feel like [redacted] wants to "send [people] away and make them stop talking". [redacted] also finds other people imitating noises very uncomfortable.

Sage likes quite a bit of personal space if possible. This is partly because [redacted] likes [redacted] equipment to be laid out in a certain way when [redacted] is working: "I like certain things to be in certain places… if they get out of place, I get really annoyed. Certain stuff has to be in the right place". Working in [redacted] own space means that other people do not move [redacted] things.

Sage has an excellent sense of smell, and can often detect odours that others can't: "I can smell so much that other people can't. It's like, too much. If it's a good smell, then I work better". This sensitivity means that [redacted] may react to smells that other people are not able to detect.

Sage forces [redacted] self to make eye contact with other people, but finds it uncomfortable: "It just feels weird, like, it's not nice…it can be too intense". This occasionally means that others may not think [redacted] is listening, as [redacted] will not make eye contact for any long period of time.

Sage describes [redacted] mind as being very slow, especially when [redacted] is trying to talk about what [redacted] is thinking. [redacted] is sometimes unsure if people have understood [redacted], or if [redacted] has explained [redacted] self clearly enough, which can be very frustrating: "I think that most things that I say don't make sense".



This is Waffles, Sage's dog. Despite making weird noises, Waffles always relaxes [redacted], comforts [redacted] when [redacted] is feeling sad, and relaxes [redacted] when [redacted] is able to stroke [redacted].

K.6 Yazi

YAZI'S INFORMATION SHEET

Yazi is full of movement and needs to fiddle – with [redacted] hair, [redacted] fidget putty, or [redacted] feet. This movement is relaxing and allows [redacted] to concentrate – being told to stop fidgeting makes [redacted] feel guilty, because [redacted] cannot physically stop.

Yazi finds absolute quiet "daunting". [redacted] likes background chatter as [redacted] has very sensitive hearing, and "working noise" drowns out all the very quiet and incredibly distracting noises that [redacted] hears when people are working silently (e.g. the hum of lights, people breathing, people tapping pens, overhead projectors, rain on windows). When things are quiet, small and specific noises become [redacted] only focus.

Yazi has very strong views about the types of visual information [redacted] likes. Certain colour combinations and shades of colours can be alternately reassuring or distressing; for example, certain shades of green annoy [redacted], and [redacted] hates the font of Comic Sans (but likes Papyrus, which is why [redacted] has chosen this font for [redacted] information sheet). If [redacted] receives a lot of visual information (for example, unfamiliar wall displays) [redacted] has to absorb this visual information before [redacted] can switch to another task. [redacted] has an exceptional eye for detail, and is very good at spotting details that may have changed that others are unlikely to notice.

Yazi prefers a lot of personal space – if it was up to [redacted], [redacted] would have a table to [redacted]self in lessons. [redacted] hates big crowds because [redacted] is constantly fearful that [redacted] will bump into someone and have to interact with them, or that [redacted] will have people [redacted] doesn't know or like pressed up against [redacted]. For people that [redacted] knows and trusts (e.g. family and close friends), [redacted] requires very little personal space, and will get very close to them, e.g. drawing on their hands. However, any physical touching has to be on [redacted] terms and instigated by [redacted] in order for [redacted] to feel safe and stop becoming angry.

Yazi is very good at smelling particular and faint scents, and will be able to smell these much more strongly than other students. If this is a scent [redacted] likes (e.g. lavender), this can help [redacted] to relax. However, if it is a scent that [redacted] dislikes (e.g. cheese), this can provoke a very strong and negative physical reaction. As [redacted] sense of smell is so sophisticated, [redacted] may report smells that others are not able to detect.

Yazi hates making and receiving eye contact, as it makes [redacted] feel awkward, uncomfortable and panicked. [redacted] can meet your eyes for a few seconds, but then becomes very uncomfortable and will move [redacted] gaze around the room.

Yazi's brain never switches off. It constantly jumps from one topic to another, and [redacted] thoughts are always racing. [redacted] describes [redacted]self as thinking in a different way from other people who are not autistic, following a different process to come to the same answers.

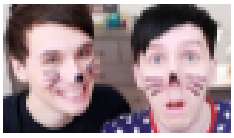
Yazi has very strong likes and dislikes when it comes to textures and fabrics. Generally, [redacted] prefers smooth surfaces to rough surfaces, so will concentrate on making things smooth.

Yazi is incredibly creative, and is a great advocate for the positive aspects of being autistic. Even [redacted] close friends and teachers who know [redacted] well do not see autism as a positive thing, and this misunderstanding makes [redacted] incredibly frustrated, angry and sad.

Yazi has very strong opinions about being [redacted]self and not changing yourself to fit in with other people. [redacted] also has a very keen sense of fairness, and will always stand up for what [redacted] believes in, no matter what the consequences may be to [redacted] personal or social situation.

Yazi has a variety of keen interests that are likely to be reflected in [redacted] work. [redacted] favourite activities include reading, writing and drawing – [redacted] loves being able to do anything creative. [redacted] detailed knowledge of these topics and [redacted] enthusiasm for them make for very interesting conversations. Some of the things [redacted] is interested in are detailed below:

Peggy Schuyler – a character from the musical 'Hamilton'



Dan and Phil – YouTube presenters who started out on Radio 1 doing a music request show and discuss humorous things on the internet

Undertale – a role-playing video game where a human child falls underground and has to escape

Warrior Cats – a series of adventure/fantasy novels about four feral clans of cats

Appendix L Coding keys from the second phase

L.1 First iteration (20.08.17)

1. **Comments** – any comments made by staff in their responses regarding the information sheets
    i. Negative **–** comments communicating something negative
        - *Design* – negative comments made in relation to the aesthetic design of the information sheets
        - *Missing* – additional information that staff 'would like to see' (or similar) in addition to the information provided

    ii. Positive – comments communicating something negative
        - *Design* - positive comments made in relation to the aesthetic design of the information sheets
        - *Generic* – positive opinions/comments that are not explained, e.g. "I really like this information sheet"
        - *Personality* – positive comments relating to the personality of students
        - *Understanding* – positive comments relating to an increased understanding/preparedness

2. **Strategies –** any specific strategies suggested by staff in their responses that they might use based on the information sheet
    i. Academic – strategies used to support learning, generally in a classroom environment
        - *Communication* – communication strategies aiding learning
        - *Support* – support strategies aiding learning

    ii. Personal – student-specific strategies
        - *Communication* – personalised communication strategies
        - *Support* – personalised support strategies

General – any mentions of general strategies regarding students on the autistic spectrum taken from their own knowledge; mentions of using the personalised strategies with other students

L.2 Second iteration (17.09.17)

1. **Comments** – any comments made by staff in their responses regarding the information sheets
    i. Changes **–** comments suggesting changes to the information sheet
        - *Detail* – comments regarding a request for further detail on specific aspects of the information sheet
        - *Missing* –information that staff 'would like to see' (or similar) in addition to the information provided
        - *Resources* – comments regarding additional resources that might be needed to work with the information sheet

    ii. Design – comments on the design of the information sheet
        - *Negative* – negative comments about the design of the information sheet
        - *Positive* – positive comments about the design of the information sheet
    iii. Generic – generic comments about the information sheet
        - *Positive* – positive generic comments about the information sheet
        - *Vague* – vague generic comments about the information sheet
    iv. Understanding – comments regarding an increased understanding from the information sheet
        - *Of Students* – comments about increased understanding of the students detailed in the information sheet
        - *Of Others* – comments about increased understanding of other students (e.g. other students with SEN)

2. **Strategies –** any specific strategies suggested by staff in their responses that they might use based on the information sheet
    i. Academic – strategies used for academic support
        - *Additional Resources*– additional resources needed to support academic strategies
        - *Curriculum* – adaptations to the curriculum to increase academic support
        - *Environment*– adaptations to the environment to increase academic support
        - *Teaching Methods* – adaptations to teaching methods to increase academic support

ii. Communication – strategies used to support communication

- *About Student* – strategies for communicating with others (e.g. other staff members) about the student
- *With Student*– strategies for communicating with the student

iii. Life Skills – strategies to support the development of longer-term life skills

- *Emotional* – strategies for supporting emotional development
- *Practical*– practical strategies for supporting life skills
- *Social* – strategies for supporting social development