Negotiating self, autism, adolescence and school: a participatory inquiry

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Negotiating Self, Autism, Adolescence and School: A Participatory Inquiry

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Declaration

I hereby declare that:

1. I have not been enrolled for another award of the University, or other academic or professional organisation, whilst undertaking my research degree.

2. None of the material contained in the thesis has been used in any other submission for an academic award.

3. I am aware of and understand the University's policy on plagiarism and certify that this thesis is my own work. The use of all published or other sources of material consulted have been properly and fully acknowledged.

4. The work undertaken towards the thesis has been conducted in accordance with the SHU Principles of Integrity in Research and the SHU Research Ethics Policy.

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Abstract

The social experience, including that within the school environment, is highly relevant to the developing sense of self of adolescents. Yet, a lack of focus has been given to the sense of self of autistic young people in this influential school setting. Instead, research has regularly explored autistic sense of self in terms of what is lacking, in comparison with 'normative' others. Autism advocates critique such autism research for the exclusion of autistic voice, in this predominant focus on identifying deficit development.

My research joins these critiques, taking a participatory, Critical Autism Studies approach, with eight autistic adolescents, who attended a mainstream secondary setting. This year-long study placed autistic adolescents' conceptualisations and presentations of the self at the fore, which revealed the heterogenous complexity of their developing sense of self. Participants illustrated how they negotiated a wide range of social influences, with the self actively presented according to social context. This included the social context of school. The role of school pupil was considered as an academic *and* social role, with the school environment identified as a key influence on a positive or negative sense of self. These findings challenged reductive deficit narratives, which suppose a homogenised, unreflective, anti-social self-view.

Within this, it is argued that altering the research methods employed enabled autistic adolescents to share these views and experiences, which countered deficit discourses. This alternative approach was present in the choice-based methodology employed, with participants choosing from a range of visual, oral, and written methods, which could then be further adapted to meet their preferred mode of communication. This was a continuously flexible process, evolving based on persistent dialogue with participant preferences, to ensure that their full contribution could be heard. Taking a participatory stance, active participation and empowerment *across* the project was prioritised. As such, the inclusive process was also evaluated by participants, offering an insider-evaluation of a rarely taken choice-based research approach. These detailed evaluations address the dearth of insider, participant perspectives on the participatory research process for autistic young people, thus providing valuable insights for future research, which also aims to prioritise the autistic voice.

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Contents

List of Tables

List of Figures

List of Abbreviations

APA	American Psychiatric Association
AS	Asperger's Syndrome
BERA	British Educational Research Association
CAS	Critical Autism Studies
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
GCSE	General Certificate of Secondary Education
RD	Research Diary
RQ	Research Question
TA	Teaching Assistant
ToM	Theory of Mind
TST	Twenty Statements Test

Chapter 1: Introduction: Positionality and the Research Topic

The focus of this study is the self-view of autistic adolescents, who attend a mainstream secondary school. The study was undertaken as part of an enrichment club, within a mainstream secondary school, where I had previously been employed as a member of teaching staff. This research involved a qualitative, participatory research design, which was constructed within the paradigm of Critical Autism Studies (CAS) and focused on eight autistic pupils. This placed autistic participants at the centre of the research process, as they considered their presentation and conceptualisation of their self, including in relation to the school environment.

1.1. Sense of Self: Autism, Adolescence and Schooling

The self, and an awareness or 'sense' of that self, has been conceptualised across a wide range of theoretical and empirical papers (Harter, 2012). This sense of self has been argued as developmental in form; a development influenced by social relationships (Hart & Damon, 1988; Harter, 2012; Hobson, 1990;2002). Molloy and Vasil (2004) assert that the question of 'who am I?' becomes particularly central in adolescence; a time when we define who we want to be. In developmental models, adolescence is argued to be when the interpersonal implications of the self become a focus (Hart & Damon, 1986;1988; Harter, 2012). Within this, researchers assert that adolescents prioritise how *who you are* influences others' views and treatment of you. A key environment for the interpersonal relationships of adolescence is secondary school (Harter, 2012; Williams, Gleeson & Jones, 2017). Therefore adolescents, and their school experiences, are highly relevant to sense of self research.

This focus has not carried over into autism research, where a lack of attention has been given to the complex and varied personhoods of autistic young people (Bagatell, 2007; O'Dell, Bertilsdotter Rosqvist, Ortega, Brownlow & Orsini, 2016). There is also a dearth of research into the influence of social experiences, such as those encountered in school, on autistic pupils' sense of self (Williams et al., 2017). This is perhaps due to assumptions that the social world is irrelevant to autistic adolescents, who are characterised as having a deficit in social interaction and communication and, consequently, a self not based in interpersonal relationships (Bagatell, 2007; Winstone, Huntington, Goldsack, Kyrou & Millward, 2014).

My research takes an alternate stance, critiquing deficit views, and aims to consider the full complexity of the sense of self of autistic adolescents. In this, I prioritise the voices of autistic young people, to enable *their* presentation and conceptualisation of their sense of self to come to the fore. The rationale for this position is discussed below. Before this, I set out the key terminology relevant to this stance, to ensure the use of those terms are clearly defined.

1.2. Key Terminology

Key terminology used in the thesis is as follows:

Medical Model of Disability: Disability is seen an 'in-person' problem. There is something biologically disordered or 'broken', which needs treatment; treatment which aims to 'cure' the disabled person and make them 'normal.' (e.g. Gillespie-Lynch, Kapp, Brooks, Pickens & Schwartzman, 2017).

Social Model of Disability: In opposition to the medical model, focus is placed on external barriers, such as a lack of accessible environments, exclusionary societal structures, or discriminatory attitudes. Rather than changing the person, the environment or society should change, removing external barriers, which oppress disabled people (e.g. Shakespeare, 2006).

Deficit Narratives: Discourses which focus on 'lack', characterising people by what they are assumed to be 'missing', rather than considering their areas of strength. These narratives align with the medical model, emphasising a deficit which needs to be cured. (e.g. Orsini & Davidson, 2013)

Critical Autism Studies (CAS): CAS aims to challenge deficit narratives of autism. This approach considers how hierarchies of power can influence how autism is researched and presented in academic, professional, and public discourses (O'Dell et al., 2016; Orsini & Davidson, 2013; Waltz, 2014). When challenging traditional deficit-led research, CAS asserts that autistic people should have the opportunity for meaningful contribution (O'Dell et al., 2016). For this, a commitment to inclusive methodologies is recommended, to enable autistic participants to fully contribute (Orsini & Davidson, 2013). Woods, Milton, Arnold and Graby (2018) take this a step further, asserting that CAS research should be led by autistic people.

Autistic Person: Disability-first language is employed in this thesis, with terms such as autistic adolescent, autistic person, or autistic pupil used.

In utilising these terms, I considered Kenny et al. (2016), who found that there was “no single way of describing autism that is universally accepted” (p.442) amongst the autistic people, family and friends of autistic people, and autism professionals, including researchers, that they surveyed. However, whilst there was no universal agreement, overall, the autistic adults in Kenny et al.’s study preferred disability-first language over person-first terms, such as person with autism. This was based on the principle that using ‘with autism’ separates autism from a person’s identity, “perpetuating the notion that autism is inherently wrong” (p.443). This was echoed by Sinclair (2013) who asserts that ‘with autism’ diminishes something that they view as an important part of themself. They argue that positive or neutral descriptors are placed first, such as athletic or left-handed person; we do not use, for example, person with athleticism. In contrast, negative descriptors are separated, and made less important, by being placed ‘after’ the person (Brown, 2011). Sinclair contends that “autism is not a terrible thing, and that it does not make me any less a person” (p.1). Consequently, it is not a negative entity that needs to be separated from who they are; it is part of the self they accept and value. This was supported by the autistic adults who took part in Kenny et al., who felt that person with autism reinforced ideas about a separate, unwanted entity, behind which a ‘normal’ person exists, who needs to be saved. As one of my research aims considered how to enable a positive sense of self for autistic adolescents, I did not want to employ terms which implicitly marked out autism as a negative element of a person’s identity that needed to be eradicated. Therefore, I also avoided autism spectrum disorder (ASD) due to the implication of a disorder which needs to be cured.

In summary, I subscribe to the view that autism can be celebrated as a positive aspect of a person’s identity; it does not need to be separated or erased.

1.3. Personal Context

Before undertaking this PhD research, I was a mainstream secondary school English teacher, with an interest in special needs support. This led me to complete postgraduate research in setting procedures in English and in reading interventions. In my teaching, I was committed to inclusion and personalised learning: altering curriculum, lesson planning and teaching style to differentiate for the needs of pupils. Yet, I had no awareness of critical debates surrounding models of disability, deficit approaches and the terminology used when discussing autism. As I began to read CAS research, and findings on autistic people's views of the negative impact of deficit narratives and the medical model, I was reminded of the position I occupied as a teacher. A position where I believed that young people should not be homogenised into one group, who must change to fit into the same 'normal' mould but should instead be empowered to feel positively about who they are, or who they want to be. In this, I felt educators should recognise the influence that both they, and the school environment, can have on the wellbeing and self-esteem of the young people they work with. These views resonated with the CAS approach. Here, medicalised, deficit, 'abnormality' narratives were challenged; the predominance of the non-autistic point of view was questioned and the heterogeneity and complexity of autistic people was appreciated (O'Dell et al., 2016: Orsini & Davidson, 2013).

However, taking a CAS approach brought challenges, which troubled me throughout the process. I felt unease at the tension between my stance, which prioritises the autistic voice, and my research project, undertaken by a non-autistic adult. This led me to continually question my position and power- debates which will be highlighted throughout the thesis. Due to a desire to increase the control of my autistic participants, I turned to participatory and emancipatory methodologies and inclusive methods. I would not claim this 'solved' the problem, or fully relieved the unease I continued to feel, and, in future research, I would want autistic researchers involved in leading *every* aspect of the process.

1.4. Positionality of Approach

This section positions my study in relation to previous autism research, demonstrating how I moved against a medical model stance. It therefore critiques deficit outsider-led constructions of autism, and autistic experience, and situates my research within a CAS and participatory research approach. This approach aims to enable insider-led research and to address the power imbalance between autistic participant and researcher. In this, I highlight how my approach contributes to the originality of the study. I then set out the study's research questions and aims, which were influenced by participatory and CAS ideals.

1.4.1. Position Within the Context of Autism Research

Autism advocates often critique autism research for its exclusion of autistic voice, its predominant focus on identifying deficit development, and its resultant focus on 'normalising' through treatment (Chown et al., 2017; Gillespie-Lynch et al, 2017; Milton, 2014). Previous research, which followed positivist, medical model approaches, employed an outsider to phenomenon position, placing the researcher as the expert (Chown et al., 2017; Stone & Priestley, 1996). Within this, the prevailing views were those of the one with the power and access to control the naming process, even if that person was an outsider (Lincoln, 1993; Milton & Bracher, 2013) For example, in previous sense of self research, the non-autistic researcher named the autistic sense of self as lacking in interpersonal affect (Farley, Lopez & Saunders, 2010; Jackson, Skirrow & Hare, 2012; Lee & Hobson, 1998). This 'naming' process meant that these researchers could perpetuate deficit-based perceptions of an autistic sense of self, through their research claims, irrespective of whether these were the prevailing views of autistic people themselves. As Williams (1996) states, a critique is that:

> right from the start, from the time someone came up with the word 'autism', the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced. (p.14)

This 'outsider' research has placed autistic participants only as a source of empirical data, as objects to be studied (Milton & Bracher, 2013). Here, "traditional expert knowledge" has sprung from those who often do not have the lived experience of being autistic (Fletcher-Watson et al., 2019; Gillespie-Lynch et al., 2017, p.1). As discussed in Chapter 2, autism and sense of self research has followed these dominant paradigms, utilising positivist quantifying methods where the autistic sense of self is named and defined by an 'outsider' researcher (e.g. Farley et al., 2010; Jackson et al., 2012; Lee & Hobson, 1998). The issue is, as Orsini and Davidson (2013, p.1) state, that this quantifying process diminishes rich and varied, heterogenous autistic experiences into "objective" numerical data. In such research, the variety of life experiences shared by autistic people are obscured, reduced into a quantitative form by those who do not come from an inside, autistic point of view (Milton & Bracher, 2013; Pellicano, Dinsmore & Charman, 2014a). This can erase the diversity of self that autistic people may wish to express and be recognised by (Ridout, 2017).

The influence of obscuring such lived experience is evident when comparing the lack of interpersonal self claimed by outsider quantitative studies (e.g. Farley et al., 2010; Jackson et al., 2012; Lee & Hobson, 1998) with the relevance of the interpersonal to self-esteem and self-view, demonstrated in the lived experience of autistic people in qualitative research (e.g. Baines, 2012; Humphrey & Lewis, 2008; Molloy & Vasil, 2004). This suggests an outsider perspective can misrepresent the autistic view and illustrates the importance of autistic lived experience for clarifying this understanding (Pellicano et al., 2014a).

1.4.2. Moving Away from the Medical Model

In prioritising an insider point of view, Gillespie-Lynch et al. (2017) found that autistic people wanted to move away from the disease-and-cure narratives of the medical model (see also Pellicano et al., 2014a). My methodology adopts this position, viewing autism as “a form of diversity rather than [a] pathology,” which needs a cure (Gillespie-Lynch et al., 2017, p.1).

In contrast, previous research has been dominated by a medical model approach, focusing on the causes of autism and how it should be treated, rather than on improving outcomes through education, policy, and support methods (Sullivan, 2009 cited in Waltz, 2013). The predominance of the medical model in autism research is demonstrated in Pellicano, Dinsmore and Charman’s (2013) systematic review of 106 funding awards. This review found 56% of research funding was awarded to studies focused on biology, brain, and cognition between 2007-2011, demonstrating an ‘in-child’ problem research focus. Within this individual focus, the societal practices or structures which may constrain autistic people are not considered (Hodge et al., 2019). A lack of consideration of external barriers is evidenced in Pellicano et al.’s (2013) finding that only 1% of funding was directed towards ‘societal issues’ (Pellicano, Dinsmore & Charman, 2014b). This deficit led, medical model approach can be seen in previous autism and sense of self research, which focused on a lack of interpersonal or social self (e.g. Hobson, 2002; Jackson et al., 2012; Lee & Hobson, 1998) or a lack of experiencing self (e.g. Powell & Jordan, 1993) tied to episodic autobiographical memory deficits (e.g. Goddard, Dowda & Pring, 2017; Tanweer, Rathbone & Souchay, 2010).

Current sense of self research mirrors the words of Waltz (2013) it may be “of great interest to basic science, but of little practical benefit to people with autism” (p.159). Such research may be of interest to those who want to develop scientific study of the autistic self but does not practically benefit autistic children and young people. The importance of practical benefit to the autism community was shown in Pellicano et al.’s inquiry (2014b), which considered the views of autistic people and their family members, and autism practitioners and researchers, on UK autism research. Pellicano et al. (2014b) found the management of practical, social, and emotional issues, which can have a day-to-day impact on autistic people’s lives, were considered an area for required research by every group in the autism community. Moreover, Pellicano et al. (2014a) found that autistic respondents felt dissatisfaction with research focused on a ‘cure,’ with Gillespie-Lynch et al.’s (2017) autistic participants also not endorsing cure or normalisation narratives. This may be because an emphasis on a self that needs to change creates a sense that one is not valued by society but instead is an ‘abnormal’ problem (Bagatell, 2007; Brownlow, 2010). This was exemplified by a participant in Pellicano et al. (2014a), who stated that “most autism researchers are engaged in research that I find unacceptable., i.e. looking for ‘cures’ or which seem to ‘objectify’ autistic people as odd or freaks or severely flawed” (p.8). This shows how autistic people may associate ‘cure’ research with a stigmatising view, due to it positioning them as ‘abnormal’ and “odd,” research which they find “unacceptable.”

This indicates a need to move away from a focus on curing what is ‘lacking’ in the autistic sense of self towards the factors within the mainstream school *environment* which impact day-to-day on the sense of self of autistic pupils. Although, the work of Molloy and Vasil (2004), Humphrey and Lewis (2008) and Baines (2012) has demonstrated that the social world can have a clear impact on the identity of autistic adolescents within the secondary school environment, this mainstream school environment, and its influence, has not been a primary focus for research (Williams et al., 2017). Research into mainstream provision for autistic pupils has been primarily child-based, focusing on how the child can be prepared for a mainstream placement, with interventions for social skills and language. There has been a lack of evaluation of the school-based factors and their influence on the development of the child (Osborne & Reed, 2011).

Williams et al. (2017) attempted to address the lack of attention paid to school-based factors by completing a qualitative metasynthesis on the research question “How do young people on the autism spectrum make sense of themselves in the context of their experiences at school?” (p.3). They asserted that the previous research landscape has been influenced by claims of social deficits for autistic people. This resulted in a lack of “research attention” on the impact of a social setting, such as school, on the sense of self of autistic children and adolescents (p.2). This led Williams et al. to complete their review of qualitative studies where autistic participants, who were at school or who had left within the previous three years, relayed their school experiences. This provides a critical analysis of studies, published between 2000 to 2014, which focused on autistic pupils’ insider accounts of school experiences. Furthermore, articles were only included if data had been analysed inductively, so that conclusions were based on pupil experience, as opposed to a predetermined outsider-researcher hypothesis. 4,350 articles were originally found using search terms based on autistic population, school age, educational setting, qualitative analysis, and qualitative data collection. However, only 17 met the criteria for containing autistic pupil accounts and inductive analysis. Additionally, eight of these studies were ‘low rated’ by the authors due to methodological flaws or a propensity to overshadow pupil perspectives with the views of others (such as parents or teachers). This emphasises the lack of insider research in qualitative approaches, conducted in relation to autistic pupils in educational settings. In response to this, I constructed my research programme so that it would position autistic pupil perspectives as the central, leading voice within both data collection and in the subsequent inductive approach to data analysis.

Moreover, whilst Williams et al. (2017) found 17 papers which considered autistic pupils’ views of their school experiences, only two of these studies had research aims which focused on identity and mainstream secondary schooling. One of these studies looked at the USA, the other at Singapore and the UK (Baines, 2012; Molloy & Vasil, 2004). In recent years, this gap has continued. One US-based study has focused on a specific area of autistic pupils’ identity, the academic self-view (McCauley et al., 2018), whilst other studies have included the impact of bullying on self-esteem in Sweden (Bolic Baric, Hellberg, Kjellberg &

Hemmingsson, 2016) or the views of educators on autistic pupils' sense of self in the UK (Hodge et al., 2019). In this, no study undertook an insider-led, participatory approach, which reflected on the full, varied picture of the autistic adolescents' sense of self and the subsequent evaluations of that self.

This demonstrates the gap my research addressed as the primary data are insider views on autistic pupils' sense of self. Within this, it considers the many ways that autistic adolescents may conceptualise and present themselves, alongside the range of influences on that sense of self. This includes a reflection on the influence of the UK mainstream secondary school environment and the impact this environment can have on the self-esteem of autistic pupils. In contemplating self-esteem, I hoped to identify how a positive sense of self could be enabled through improvements to this influential societal structure- the secondary school. This moves my research away from traditional deficit-based work within autism and a sense of self study, towards an enabling, CAS research position.

1.4.3. Moving Towards CAS and a Participatory Approach

In moving to a CAS stance, I drew on the tenets set out by Orsini and Davidson (2013), who suggest that the following elements characterise a CAS inquiry:

> 1. Careful attention to the ways in which power relations shape the field of autism.
>
> 2. Concern to advance new, enabling narratives of autism that challenge the predominant (deficit-focused and degrading) constructions that influence public opinion, policy and popular culture.
>
> 3. Commitment to develop new analytical frameworks using inclusive and nonreductive methodological and theoretical approaches to study the nature and culture of autism. (p.12)

Following this approach, I parted from the dominant, positivist paradigms of autism and sense of self research, with its deficit view. Instead, I aimed to appreciate the complexity of autistic adolescents' personhood, appreciating *all* aspects of the self they may wish to present (O'Dell et al., 2016). In this, I wanted to address the power imbalance between researcher and participant and prioritise the insider perspective of autistic people, focusing on capturing the rich and varied experiences of those autistic people (O'Dell et al., 2016; Orsini & Davidson, 2013).

Hearing from a variety of autistic people can enable an understanding of autistic views and behaviour that non autistic people may struggle to infer from their 'outside' perspective (Gillespie-Lynch, et al., 2017; Milton, 2012; 2014). I therefore wanted to move away from research conclusions framed by "third-person observers," which lack reflection on the varied meanings autistic people make of their experience (Milton & Bracher, 2013, p.64). I hoped that prioritising the lived experience of autistic people could also counter stigmatising views. As Gillespie-Lynch et al. (2017) found, lower stigma towards autism was demonstrated by those who had heightened knowledge of the lives of autistic people. Knowledge of the lived experience of autistic people could, as John, Knott and Harvey (2018) found, challenge non-autistic people's negative stereotypes around autism, such as being violent, having a lack of empathy or being isolated and content to be alone (Biklen, 2005); stereotypes that can drive stigmatised views. Enabling autistic voices to be heard therefore supports the second tenet of CAS, which focuses on challenging predominant negative views within public opinion.

The participatory approach I employed further supported these aims as it "embrac[es] the experience and partnership of those we are normally content simply to measure" (Schwab & Syme, 1997, p.2050). This approach moves away from positivist paradigms, focusing instead on detailed participant-led experiential data, whilst following a "core philosophy of inclusivity" (Cargo & Mercer, 2008, p.326). The inclusive participatory ideals I was influenced by promote the voices of participants; value their expertise on their own experiences; and aim to enhance the power of participants in the research relationship (Vincent et al., 2017; Wilkinson & Wilkinson, 2018). They therefore complemented the CAS aims of inclusive methodologies and of enabling autistic participants, within the power dynamic of the researcher-participant relationship.

Enabling the meaningful contribution of autistic adolescents was a key concern in my research. I follow the assertion that it is the researcher's responsibility to ensure participants are not placed at a communicative disadvantage, which would increase the power imbalance between researcher and participant (Fletcher-Watson et al., 2019; Scott-Barrett, Cebula & Florian, 2018). I was also influenced by the work of Winstone et al. (2014). Their study found that methods which constrain the communication of autistic young people can perpetuate narratives which support deficit discourses around the sense of self. I therefore focused on ensuring accessible methods, with my autistic participants *choosing* from a *range* of visual, oral and written methods, based on those which best suited their needs and preferences. This contrasted with previous sense of self research, which employed only one method, such as structured interviews (e.g. Farley et al., 2010; Jackson et al., 2010; Lee & Hobson, 1998) or assigned the creative methods undertaken, rather than offering choice in this (e.g. King, Williams & Gleeson, 2017; Winstone et al., 2014). In addition, my participants could *further adapt* their favoured method, changing the mode of communication to suit their desired form. For instance, conversations with the researcher could be undertaken as a typed response. This was a continuously flexible process, evolving based on persistent dialogue with participant preferences. In this, the aim was to continually foreground the autistic young people's point of view, prioritising their control and maintaining a sensitivity to their required adaptations, to ensure that their full contribution could be heard.

I was also particularly aware of Jivraj, Sacrey, Newton, Nicholas and Zwaigenbaum's (2014) critique of research which undertakes a participatory approach with autistic people. In their review of such studies, Jivraj et al. found that this research often lacks clarity on *how* the process meets claims of being participatory. Further to this, Ellis (2017) and Scott-Barrett et al. (2018) argue that more discussion of the strengths and challenges of research methods, which aim to enable autistic children and young people to fully contribute, is required. I therefore aimed to meet Ellis, Jivraj et al. and Scott-Barret et al.'s calls for transparent and detailed discussion of the strengths and challenges of research processes, which intend to enable autistic people's full participation. However, unlike Ellis and Scott-Barrett et al., my study completed this evaluation from the autistic adolescents' point of view, rather than the researchers. Therefore, my second research question concentrates on the *autistic pupils'* evaluations of the participatory research methods employed. I set out these research questions, below.

1.4.4. Research Questions and Aims

Based on the research topic focus, and the insider-led, CAS and participatory stance taken, I developed the following research questions:

1. **How do autistic pupils negotiate a developing sense of self?**

1.1. What do pupils identify as influencing the conceptualisation, presentation, and evaluation of their sense of self?

1.2. What are the pupils' views of the school's enablers or barriers to developing a positive sense of self?

2. **What are the pupils' views of the participatory research methods employed in the sense of self study?**

Alongside this, the aims of the research were as follows. To:

- prioritise how autistic adolescents conceptualise, present and evaluate their sense of self, focusing on their individual, insider point of view
- establish what role the mainstream secondary school currently plays in the development of a positive or negative self-view for autistic adolescents
- enable the autistic voice to inform the development of school practice
- employ participatory research methods to support my aim of prioritising the voice of autistic adolescents
- evaluate the participatory research methods employed, focusing on the autistic participants' views of these methods.

1.4.5. Research Position: Summary

My study aimed to move away from dominant, outsider-led, medical model approaches, which focus on a deficit hypothesis. I aimed to place the autistic insider account as central, employing CAS and participatory ideals to shift control to the autistic participants involved. In this, accessible research methods were employed to enable autistic participants to share their views and experiences and to expand, and often challenge, current knowledge of autism, sense of self and mainstream schooling. This research study therefore provides insider-centric, primary data on sense of self, and positive self-worth, for autistic pupils in

UK mainstream secondary schooling, data which is currently lacking. It also addresses the dearth of detail on undertaking participatory research with autistic children and young people, including the benefits and challenges of a ‘full’ participation approach- an evaluation which was also participant led. Consequently, this study contributes to knowledge of the research subject matter of sense of self from an insider point of view *and* employs this insider approach to contribute to the understanding of employing participatory procedures with autistic young people, within a CAS approach.

1.5. Thesis Structure

This **Chapter 1** has established my research position, giving an overview of the context that the study sits within. **Chapter 2** expands this contextual discussion, reviewing existing literature in relation to autism, sense of self, adolescence, and mainstream secondary schooling. In this, I identify the gaps in knowledge that my study addresses and, taking a CAS approach, challenge dominant deficit-focused narratives in sense of self and autism research.

Chapter 2 also highlights how inaccessible research methods can perpetuate deficit conclusions. Ensuring accessible, inclusive methods was a key tenet of my methodology, as discussed in **Chapter 3** and **4.** These chapters clarify my research approach *and* provide the background literature for my second research question, based on participant evaluations of the method employed.

Chapter 3 sets out the theoretical and paradigmatic aspects of the study. It considers the participatory ideals which influenced my study’s design, including how these ideals support a CAS approach, whilst also highlighting how participant evaluation of the participatory process offers an important contribution to methodological knowledge.

Chapter 4 then provides a detailed account of the enactment of the research process, considering the strengths and limitations encountered in meeting my participatory goals. As a key concern, I discuss how barriers to access were addressed, considering how the full inclusion of autistic voices can challenge deficit narratives. This chapter illustrates how a participant-led, choice-based approach adds originality to the project.

The thesis then moves to the findings and discussion chapters, which address my research questions. Each findings chapter offers an overview of the key findings and themes, with detailed thematic analysis presented underneath. **Chapters 5** and **6** report findings on autistic adolescents' conceptualisation, evaluation, and presentation of their self, including in the mainstream secondary school environment. **Chapter 7's** discussion draws together these findings, considering how autistic pupils negotiate a developing sense of self, including the positive or negative influences on their self-view. In following a CAS approach, I consider how these insider-led findings offer a counter to deficit narratives of the autistic sense of self. **Chapter 8** reports on the second research question: participants' evaluations of the participatory research process, offering a detailed review of a participatory process, influenced by CAS tenets, from the autistic adolescents' point of view. This includes how a *choice* of visual, oral, and written modes of communication can enable the full contribution of autistic adolescents.

Chapter 9 draws together the findings of the project to provide final reflections and to consider implications for future research and practice. I discuss the limitations in meeting my participatory aims, considering the next steps or adaptations required, to address such limitations. The chapter then ends by summarising the key contributions to knowledge, offered by the thesis.

Chapter 2: Literature Review: Setting the Scene for Sense of Self, Self-Esteem, and Autism Research

In this chapter, I consider sense of self and self-esteem theory, and autism specific research in these areas. I discuss the significance of the research topic by reviewing existing literature, identifying the gaps in knowledge that my study addresses. This review is undertaken within the CAS approach, which aims to challenge dominant deficit narratives (Orsini & Davidson, 2013). It is also driven by the following key aims, which form the route through the chapter:

- To consider how sense of self has been conceptualised, focusing on those influential discourses which have provided 'norms' against which the sense of self of autistic people has been measured.
- To critically analyse deficit focused autism and sense of self research, challenging dominant discourses.
- To consider how deficit conclusions can be perpetuated through inaccessible research methods.
- To consider specific literature relating to adolescence, autism and sense of self, in line with my participant group and research focus.
- To consider the barriers or enablers to a positive sense of self for autistic adolescents.
- To consider the influence of the mainstream school environment on the sense of self and self-esteem of autistic adolescents.
- To prioritise literature which offers an insider view on autism, school and sense of self, in line with my research aims.

2.1. Sense of Self: Clarifying the Concept

Theories of the self appear in philosophical, psychological, and scientific disciplines, spanning from the 18th century (Harter, 2012). However, as my CAS aims are to focus on *prevailing* constructions of autism, and where these might be challenged (Orsini & Davidson, 2013), the context for my sense of self research is located within the field of psychology. Autism as a diagnosis is based on the DSM-5 criteria from the American Psychiatric

Association (APA, 2013; Hassall, 2016). Consequently, it is often viewed as a psychiatric label (O'Dell et al., 2016; Kapp, Gillespie-Lynch, Sherman & Hutman, 2013; Latif, 2016). This diagnostic definition, as Hassall (2016) asserts, is considered by many as *the* definition of autism; a definition led by cognitive neuroscience and psychology (O'Dell et al., 2016; Milton, 2012). In autism and sense of self research, this psychological, developmental approach has also been the dominant form (Hodge et al., 2019; King et al., 2017). Subsequently, the primary literature in my review of sense of self theory will draw on this *prevailing* psychological perspective.

In such literature, the self has come to encompass a variety of terms and a wealth of research (Harter, 2012). This variety in terms has caused a lack of clarity in what is meant by the 'self' and in subsequent research design in this field (Epstein, 1973; Zahavi, 2010). It was therefore important to draw together the key ideas, theories and terms in psychological literature to form an overall picture of how self and self-understanding has been conceptualised. This overview now follows, considering this descriptive element of the self, which answers the question of 'who am I' and differentiates this I from others (Hart & Damon, 1988; Hodge et al., 2019; Jordan & Powell, 1995; Zahavi, 2010). Table 2 and 3, which end the section, offer an overview of how this self-description has been characterised. Following this, I discuss self-esteem, which evaluates this self-as described to give a positive or negative sense of worth (Harter, 2012; Jordan & Powell, 1995).

2.1.1. Defining the Self: Historical Perspectives from Psychology

William James (1892/2001) is a foundational figure in the psychological literature on sense of self (Harter, 2012). His ideas inform much of the research into the self, including autism-specific research on the topic (e.g. Hart & Damon, 1988; Hobson, 1990; Jackson et al., 2012).

James (1892/2001) underlined two aspects of the self-description- the I (the subjective self) and the me (the empirical self). In James' conception the I is the self-as-knower, the "thinker," which reflects on and senses the self-as-experience (p.63; Harter, 2012). In the I's organisation and interpretation of experiences, a person's self is felt through a sense of continuity, of being "always the same," and of being an "agent," with control over what happens to them (p.63). This self-as-knower also senses how it is unique and different from others (Damon & Hart, 1982). Calkins (1908) work mirrors this Jamesian I-self, suggesting a sense of self-continuity, a ‘core’ sense of self, alongside an awareness of distinctiveness from others (Guardo & Bohan, 1972).

In addition to the I-self, James (1892/2001) asserts that there is a me-self, the qualities a person chooses to define themselves (Damon & Hart, 1982). For James, this is “the sum total of all that he can call his” (p.44), including material (body, possessions, family, home), social (relationships, group roles, perception by others) and spiritual (consciousness, inner states) aspects. The me is the self as known, whilst the I is the knower of that self (Hart & Damon, 1988; Harter, 2012). Reflecting on, and thinking, about the me-self can lead to evaluations, which form the basis for self-esteem (Harter, 2012).

Discussion of the self in psychology fell out of fashion in the 1920s and 1930s, eclipsed by radical behaviourism, which focused on observable behaviours (Harter, 2012; Sarbin, 1952). Researchers moved away from unmeasurable and unobservable self-concepts, based on self-report, which were viewed as inaccurate (Harter, 2012). A consideration of self as a cognitive construct, which actively builds a self-concept, returned in the latter half of the twentieth century (Harter, 2012). Sarbin (1952) and Epstein (1973) were both proponents of such a theory, asserting that the self is a cognitive structure, around which behaviour is organised. They argued that the self is a changing, developmental construct, affected by personal experience. Like James (1892/2001), Sarbin also asserted that the cognitive theory of self includes me-self elements such as bodily (somatic) selves and social selves. These are established in infancy and develop and change through a person’s maturity into adulthood. Epstein aligned even more closely with James’ me-selves: arguing for a bodily self (body, possessions, individuals, or groups identified with), an inner self (personality, cognitions, internal states) and a moral self (evaluations of worth). He asserted that a feeling of agency and distinctness from others is also developed by an infant. After James then, both Sarbin and Epstein generated developmental theories of self; a development they asserted was based in experience and interaction.

Neisser (1988) also argued that a sense of self develops from experience and interaction, however, he outlined 5 aspects of the self. The ecological self- a physical sense of self which is formed from interactions with, and a sense of agency within, the physical environment. The interpersonal self, which is based on human interaction and the emotional rapport and relatedness within relationships. The private self, which is internal and unique to the self, such as dreams, feelings, and memories. The extended self, which includes the past and expected future selves, with memories drawn together in a ‘story’ of the self. Finally, the conceptual self, which holds these disparate selves together in a coherent account of who the self is. This conceptual self is socially influenced by the opinions of others and the role taken in society.

Some key themes, derived from James, emerge from the theories discussed so far. There is a consensus that a reflective, subjective knower, or I-self, organises and ‘pulls’ together a coherent sense of self. This self is based on experience, reflecting on environmental, social, and internal experiences or inner states to create a definition of who a person is. Finally, there is agreement on the developmental aspect of sense of self, which can change through age and experience.

I now discuss in depth developmental models of self, which have heavily influenced autism and sense of self research.

2.1.2. The Development of Self-Understanding: Childhood to Late Adolescence

When considering models of self-development, my primary focus is on Hart and Damon (1986;88). They theorised and tested a model of self-development from early childhood to late adolescence. This enabled them to create their self-understanding interview; a now commonly used tool in evaluating the developmental level of the self-description. I also discuss Harter (2012), whose developmental research created a normative model of self-description *and* self-evaluation. These models both provide ‘norms’ of development, against which autistic people’s sense of self can be measured. Hart and Damon’s model and self-understanding interview are of particular significance. They have been utilised in studies which perpetuate deficit discourses of the sense of self of autistic children and young people (Farley et al., 2010; Lee & Hobson, 1998) and autistic adults (Jackson et al., 2012). As part of my CAS approach, I therefore discuss these models, to make clear the prevailing ‘norms,’ through which dominant deficit narratives perpetuate.

Damon and Hart (1982) derived their theories from a detailed review of existing research with children and adolescents. They developed a theoretical framework, based on the Jamesian I and me concepts (Hart & Damon, 1988). Their aim was to bring together *all* the components, which form the cognitive construction of self (Hart & Damon, 1986). This framework contained the descriptive content of the self as an *objective* me, including physical, social, active, and psychological qualities. The physical (body/ material possessions), social (relationships/ social personality traits e.g. outgoing), and the psychological self (philosophical beliefs/ cognitive ability/ affective states e.g. cheerful) mirrors the Jamesian me. Based on their review of existing research, Damon and Hart also added the active self, which represents capabilities in activities and typical hobbies (Hart & Damon, 1986;88). Their *subjective* I, includes an awareness of agency, continuity, and uniqueness (Hart & Damon, 1988). In this, continuity includes an awareness of a future-self, beyond the current time (Hart & Damon, 1986; 88). Damon and Hart term this all-encompassing form of self-knowledge 'self-understanding', making a clear separation from self-esteem and its positive or negative affect. Self-understanding is considered the *knowledge* of the self and of the self as *knower*, whilst self-esteem is a separate evaluation of that self's content (Hart & Damon, 1986; 88; Harter, 2012).

Hart and Damon's (1988) self-understanding model was finalised through a range of studies, undertaken with children and adolescents (Damon & Hart, 1986; Hart & Damon, 1986; 1988). These studies utilised a self-understanding interview, which they had devised to test their model, discussed in detail below. Their final developmental model suggests that *all* aspects of self, physical, active, social, and psychological, are relevant to all age groups. However, there is a "general organizing principle" in each developmental range (Hart & Damon, 1988, p.10). This principle characterises the self-descriptions which will be given at that age. Hart and Damon's model (1986;1988) asserts that in early childhood, self-understanding is organised by categorical identifications, factual, literal descriptions. It is sufficient that they are categorised in that way, with those categories holding no deeper meaning or subtext., e.g. I am tall. Mid to late childhood is categorised by comparative assessments, where the self's capability or performance is relational. The self is compared with others, and with the norms of society, including physical and social expectations. For example, I am taller than other children. Early adolescence is influenced by interpersonal implications, where the adolescent focuses on how the self interacts with others, and how their personality traits impact on their place in the social group. For instance, I am tall, so I am mocked for being different. Late adolescence is organised by systematic beliefs and plans, meaning identity is drawn from the goals or philosophical and moral beliefs in place e.g. I am a good person as I help others in need. This developmental model is summarised in Table 1, including further sample statements from Hart and Damon (1986).

Table 1

Levels of Self-Understanding (Adapted from Hart & Damon, 1986, p.396;1988, p.10)

	Physical Self	Active Self	Social Self	Psychological Self
Late Adolescence: Systematic Beliefs and Plans (Level 4)	"I don't have many things. It's not fair to have a lot of things when some people don't have anything."	"I go to church every Sunday. I want to be a faithful Christian."	"I try not to hurt my friends' feelings… you should treat people with respect."	"I believe in world peace. I don't think wars solve anything…"
Early Adolescence: Inter-personal Implications (Level 3)	"I am tall… kids make fun of me."	"I play a lot of sports… all the kids like athletes."	"I am friendly. Other kids won't like you if you aren't."	"I am very smart. My friends only like smart kids."
Mid/Late Childhood: Comparative Assessments (Level 2)	"I am bigger than most kids. I can run faster."	"I am good at kickball. I like to be good at it."	"My mother is always running around. I am not like that. I am quite lazy."	"I am not as smart as other kids. It takes me longer to do my homework."
Early Childhood: Categorical Identification/ Facts (Level 1)	"I have blue eyes."	"I play baseball."	"I have a brother."	"I am a happy person."

Alongside the development of the me-self, Damon and Hart assert that the I-self also develops over time. There is an increasing emphasis on continuity and distinctness, an evolving sense of agency and autonomy, and an increased ability to both reflect on the self and to organise various information about that self (Hart & Damon, 1986).

To evaluate this developmental model, Hart and Damon (1986) devised their Self-Understanding Interview. The interview questions covered four areas- how the participant defined themselves; what they judged to be important aspects of themselves; how they viewed their future or continuous self; and who they aspired to be. Throughout, participants were probed on *why* those aspects were important to them. The questions were open, rather than the researcher providing a choice of prescribed responses. Interviewers were also informed that they must rephrase, or add probe questions, should this be required for clarity of response.

Interview responses were scored based on sample responses, which aligned with Hart and Damon's developmental model (see Table 1). The level assigned to the response was based on the explanation of *why* this aspect was important. For example, "I play a lot of sports… all the kids like athletes" (Hart & Damon, 1986, p.396) is an active-self statement as it identifies an activity- sport. This is then placed as a level 3, as the explanation of importance is focused on the social impact of this, where others like them for their athletic ability. This scoring system enabled researchers to produce a quantifiable measure for sense of self development, where self-understanding was assessed based on the frequency of statements from the expected developmental level (Damon & Hart, 1982). Two measurements could be considered: the frequency of responses from a self-scheme *and* the level at which these statements would be placed. For instance, the number of social self and level 3 interpersonal statements provided.

Hart and Damon's (1988) developmental model has also been applied to clinical cases, where self-understanding may be placed at a differing level to the 'norm'. This was seen in one of their clinical studies (Schorin & Hart, 1988 cited in Hart & Damon, 1988). Here, anorexia patients were found to have more level 1 statements of agency, where the self is felt to be determined by biological or external social forces, in comparison to non-anorexic adolescents. Hart and Damon argue that this shows a lack of feeling personal control. This leads to subsequent attempts to regain agency, through controlling food. This illustrates how level models such as this can be used to establish developmental norms- a phenomenon that emerges in autism research (see below).

Harter (2012) also uses a developmental model to represent ‘norms’ of self-development, with departures from the ‘normal’ developmental trajectory linked to pathological processes and mental health difficulties. Harter gives examples such as anorexia, narcissistic personality and dissociative disorders, and violent and suicidal ideation. However, she considers developmental ‘norms’ in how children and adolescents both describe *and* evaluate themselves. Harter’s theories of self-evaluation will be discussed in 2.2, which focuses on this aspect of the self. Here, I consider Harter’s work on self-representations; the way that adolescents choose to describe themselves. Harter draws on psychological literature and her own extensive studies of sense of self and self-esteem. Harter adopts a Jamesian approach, identifying how the development of a changing I-self can influence the content of the me-self. She separates adolescence into three stages: early (ages 11-13), middle (14-16) and late (17-19).

Harter (2012) follows Hart and Damon (1988), in asserting that the self-representation of early adolescence is based in the interpersonal, focused on social skills and how self-aspects and abilities in interaction influence your position with others. Here, social comparisons with others, as seen in mid-late childhood, continue, but there is a greater focus on how these other people view and appraise you rather than on how *you* view yourself in comparison to them (Ryan & Deci, 2009).

In middle adolescence, Harter (2012) asserts that an awareness of contradictions in the characteristics displayed in different contexts, with different social groups, arises. For example, the difference in the self which is presented with close friends, wider peer groups or family (Harter & Monsour, 1992). Harter (2012) argues that the middle adolescent struggles with this “kaleidoscopic self” (p.97), where the me-self varies dependent on the role or context the person is within, and questions which traits represent the ‘real’ self. Harter also asserts that these adolescents compare themselves with key figures in different contexts and becomes focused on the opinions and expectations of these varying groups. Again, this can lead to difficulties, with the young person unsure of *whose* expectations to follow. For example, achieving high grades would please their parents but would lead to negative opinions from their peers.

Finally, Harter (2012) follows Hart and Damon (1988) in her assertion that late adolescents' self-representations focus on beliefs and morals. She argues that comparison with others decreases, and the young person now compares themselves with their own ideals and beliefs. However, as these ideals can be based on an internalisation of the views of others, they do not necessarily escape social influence (Epstein, 1973; Ryan & Deci, 2009). Interest in the future self also increases, such as consideration of future careers. Conflict about varying self-attributes diminishes as contradictory traits are placed together under overriding abstractions. For example, being cheery with friends and miserable with parents can exist simultaneously in a moody person (Harter, 2015; Harter & Monsour, 1992). It is now viewed as normal, and even valuable, to be able to adapt and change based on the context/ role (Harter, 2012; Harter & Monsour, 1992).

To summarise, both Harter (2012) and Hart and Damon (1988) propose developmental models of self-description, which set out normative changes in the self-concept of children and adolescents. Both Hart and Damon and Harter propose a change in the self-concept's focus, with an increased consideration of the interpersonal and social ramifications of the me-self in early adolescence. In later adolescence, morals and beliefs, alongside aspirations for the future take prominence. Harter argues for role-related selves, where young people conceptualise differently attributed selves within differing contexts or relationships; a differentiation which increases with age. Role related selves will be discussed further in 2.1.4. But first, I consider the asserted prominence of the interpersonal in adolescents' sense of self.

2.1.3. Interpersonal Influences on the Self

Harter (2012) and Hart and Damon (1988) both argued that the interpersonal is a dominant element in the adolescent self-concept. However, this does not mean that the interpersonal relationship is irrelevant *across* the other age ranges.

A reflection on the self as unique, and different from the other, is central to James' conception of the I. Being aware of this distinction is key to theories of the self in childhood (Epstein, 1973; Hobson, 1990), adolescence (Hart & Damon, 1988; Harter, 2012) and adulthood (Calkins, 1908; James, 1892/2001). Calkins (1908) goes as far as to say that self in relation to other is the *most* important distinction, more than one's relation to the inanimate environment or to past and future selves. She argues that the self cannot be truly distinguished without comparison to others and is ‘lost’ without a conception of one’s role in relation to others. She therefore places relationships with the other as key.

Hobson (2002) also prioritises the interpersonal aspect, arguing that “one of the most powerful influences on development is what happens *between* people” (p.7). However, he views the self as not only defined by its comparison to others (Calkins, 1908) but as *formed* through these relationships (Hobson, 1990; 2002). Hobson (2002) claims that an essential part of being a self is experiencing that self among other people. Hobson (1990) asserts that a developed concept of self requires a concept of other selves, and an appreciation that individuals have a unique psychological relationship with the world around them (Hobson & Meyer, 2005). Hobson (1990) explains that this knowledge comes from perceiving the subjectivity and mental states of others, through their bodily expression. This knowledge enables infants to partake in a shared perspective of an object within the world, and to see how the other’s view of this may be similar or different (Hobson, 2002). The infant then experiences the existence of other minds, each with their own beliefs and perceptions of the world, including the possibility of alternative perspectives beyond their own (Hobson, 1990). This awareness of other centres of subjective experience enables the child to assume another’s point of view, taking on the role of the other (Hobson, 2002). The child can then evaluate the self from an outer, objective, and alternative point of view. This identification of difference also allows a comparison of attributes where those seen in the self can be identified in others and those identified in others can be placed on the self (Hobson 1990; 2002). Hobson (1990) argues that we can only understand where self originates by exploring how the infant relates to both the inanimate sphere *and* the world of personal relatedness. This means that an interpersonal dimension feeds through into all structures of the self, even the physical.

The ‘other’ is clearly an important concept in establishing the self-other distinction. However, Hobson (1990) has also stated that relatedness with the “inanimate” world must be considered, where a distinction between the self and object, the “I” and “it” is established (p.165). This implies a sense of self that is not dependent on the awareness of other persons; a sense of self which originates from interaction with the physical, non-social environment. Hobson links this with Neisser’s (1988) ecological self, seeing the interpersonal self, which separates self and other people, as a separate aspect from the physical self, which is aware of a boundary between the self and the other, physical world. This physically based sense of self would occupy a sensory world, related to concrete material events, and would not be combined with the awareness of intention and mental states, which spring from interpersonal understanding (Mayes & Cohen, 1994; Vitz, 2003). Yet, Bosacki (2000) argues that a sense of self emanates from social interaction and the understanding of others as having inner psychological selves, rather than just an outer physical form. Without interpersonal relatedness, a person cannot infer events and states that cannot be concretely observed. Individuals would therefore not develop an awareness of an inner world, which allows the definition of a more abstract self. Reflecting on the differentiation between our own mental states and those of the other, enables the differentiation of the psychological self from the contrasting psychological self of another (Mayes & Cohen, 1994). Without exploring this contrast, a person would not form an awareness of mental distinctness. Damon and Hart (1982) assert that this awareness is a core part of the I-self, developed from early adolescence, whilst Guardo (1968) argues this is part of the formation of a separate, unique self-identity.

Therefore, we must return to Hobson's (1990) question as to whether interpersonal experience is "essential to all aspects of self-experience" (p.165). If, like Hobson (1990), we consider Neisser's (1988) ecological self, this would suggest that not all aspects of self require interpersonal relationships. The ecological self, which develops from observation of, and actions within, the physical environment, would be intact (Vitz, 2003). The boundary between I-it would be present (Hobson, 1990). However, the ability to take an objective, reflective view on this would, according to Hobson's (2002) theory be absent. This would suggest that a self-centred kind of self-knowledge would be formed, lacking an evaluation which draws in the social mores and expectations (Epstein's (1973) moral self). This would lead to a self-concept lacking the depth in self-understanding Hobson (1990) suggests springs from the self-other relationship. This understanding would not have an interpersonal self to draw on and not relate to roles in society or comparisons with the other. Instead, this self-concept would consider only an internal model of body and mind unrelated to others' reactions; one which would lack the ability to take an outside, reflective perspective on these elements.

In summary, these theories assert that a reflective sense of self is formed from interpersonal interaction and an appreciation of mental distinction from the 'other,' without which, they argue, normative self-understanding cannot be obtained.

Theories which focus on these interpersonal, social elements of self, including the understanding of others' psychological states, can lead to a deficit hypothesis for autism and sense of self (Winstone et al., 2014). Traditional deficit models emphasise the difficulties autistic people may face with social interaction and communication, including the understanding of others' inner states and attitudes towards them (Bagatell, 2007; Williams et al., 2017). If taking this approach, and adhering to the psychological theories above, one would subsequently assume a lack of development in an interpersonally affected self (Bagatell, 2007; Williams et al., 2017; Winstone et al., 2014). Studies have indeed followed this hypothesis, and will be discussed in detail in 2.3, alongside those which counter this dominant view.

2.1.4. The Plural Self: A Multiplicity of Roles

As sense of self theory has advanced, consideration of the multiplicity of roles and subsequent selves that may be presented, across social contexts, has come to the fore (Harter, 2012). This has increased the focus on the self's social influence, as it has been argued that the self is constructed and presented differently, dependent on the social expectations of the group the person is within (Gergen, 2000; Goffman, 1959/1990; Harré & Moghaddam, 2003).

James (1892/2001) argues that expectations of the self are built around the social roles that a person occupies. Such expectations are not necessarily limited to formal roles, and James asserts that *any* social grouping has rules and expectations, which impact on the behaviour and perceptions of a person in the group. He argues that one person may present several social selves, dependent on the context, with an aim to be viewed positively by each social group. Subsequently, each group may see a different side to the person in question. For instance, we may present differently to our family, our friends, or our teachers. Goffman (1959/1990) describes these social roles, and our enactments within them as performances, which aim to give a certain impression to those who are interacted with. In this, he asserts that there are "rights and duties attached to a given status," which will be inherently expected from a person in a certain social role (p.27). These are expectations which James asserts are “one of the very strongest forces in life” (p.47), implying that going against these expectations could be a difficult task.

To mark out their performance as appropriate for the social role they are acting within, Goffman (1959/1990) asserts that people present a “personal front” (p.34) in their appearance, behaviour, and manner (Harré & Moghaddam, 2003). From this, others understand both what to expect and how they might themselves behave; someone appearing shy and unconfident, for instance, would signal that others may take charge. Harré and Moghaddam’s (2003) positioning theory develops these ideas. The self is positioned in a role both by the individual themselves and by others. This positioning is influenced by the speech and actions of an individual and the ‘storyline’ they are in, with its associated expectations and patterns (such as a pupil getting in trouble if they do not follow the school rules (Baines, 2012)). As with Goffman, this positioning is associated with status, having attached “rights and duties,” but these govern both subsequent behaviour *and* access (Harré & Moghaddam, 2003, p.5). For instance, being positioned as a smart student can result in a pupil being offered additional educational opportunities whilst being perceived as a naughty student can result in denied access to extracurricular activities (Baines, 2012). This emphasises how being positioned in a social role can lead to the control of others, and a reduction of rights, dependent on the position a person is placed within.

Even if a favourable social role *can* be maintained by an individual, Goffman (1959/1990) argues that fulfilling an expected performance may exhaust a person, who then cannot function successfully in the role undertaken. Dependent on their compatibility, disparate social roles can cause conflict in a person, who may struggle to align the differences in their behaviour, enacted in each of their social selves (Gergen 2000; Harter, 2012). This conflict is part of Gergen’s (1991;2000) postmodernist psychological approach, where he asserts that a socially constructed self, varying across a multitude of roles, lacks a sense of coherency. Here, modern technology is viewed as enhancing this lack of coherence, by proliferating the social selves which may be formed (Harter, 2012; Hoffman Stewart & Meek, 2009). Gergen (2000) argues that electronic communication enables a wider range of relationships, which can bring in a broader array of contradictory opinions, views and influences (Hoffman et al., 2009). Adapting to the expectations of, and comparisons within, all these differing social groups and contexts can increase feelings of inconsistency from the varied selves presented (Harter, 2012). Gergen (2000) argues that this variation can result in conflict in the self-view, where a consistent sense of being a certain type of person is threatened.

In summary, a multiplicity of role-related selves has been considered by a variety of theorists. These role-related selves are viewed as inherently social in nature and are imbued with social mores, rights and duties. In meeting these expectations, a person may experience exhaustion or internal conflict, over the disparate positions they perform within. Furthermore, being positioned in a particular role can influence the rights of access a person enjoys.

2.1.5. Clarifying Terms: The Self and Self-Understanding

Table 2 and Table 3 draw together the varying descriptions of self considered above. Taken together, they provide an overview of the various elements of self-description, forming the background context for this research project.

Table 2 draws together key literature, categorising the terminology and theories of self-description reviewed. These overriding categories are an attempt to synthesise some of the disparate threads of argument. Table 3 then sets out a description of self and self-understanding, summarising the key ideas present in the literature. This is separated into the me-self (James, 1892/2001), the objective elements which the self is described by, and the I-self, how the objective elements are experienced or reflected on. In the me-self, the concrete outer self is physical in nature, the abstract inner self emotional and the abstract outer self is social in form.

Table 2

Key Literature: Review of Terms

Elements of the Self/ Self-Understanding		
Concrete Outer	Abstract Inner	Abstract Outer
Material self (James, 1892) Somatic self (Sarbin, 1952) Body self (Epstein, 1973) Ecological self (Neisser, 1988) Physical/ active self (Hart & Damon, 1988) Embodied self (Hobson,1990)	Spiritual self (James, 1892/2001) Inner self (Epstein, 1973) Private/ extended self (Neisser, 1988) Psychological self (Hart & Damon, 1988) Mental self (Hobson,1990) Inner mental states (Mayes & Cohen, 1994)	Social self (James, 1892/ 2001; Sarbin, 1952; Hart & Damon 1988) Moral self (Epstein,1973) Interpersonal self/ self-concept (Neisser, 1988) Self/ other distinction/ distinctiveness (Calkins, 1908; James, 1892/2001; Mayes & Cohen, 1994; Hart & Damon, 1988) Interpersonal formation of self (Bosacki, 2000; Hobson,1990; 2002) Kaleidoscopic self (Harter, 2012)/ Role-related selves (Gergen, 1991;2000; Harter & Monsour, 1992) Performance/ positioning of the self (Goffman, 1959/1990; Harré & Moghaddam, 2003).

Table 3

Overview of Self and Self-Understanding

	Elements of the Self/ Self-Understanding		
	Concrete Outer	Abstract Inner	Abstract Outer
Self-Qualities- What the Self is Comprised of (self-as-object/ James' *me*).	Physical: 1. Bodily actions/ sensations/ reactions. 2. Interactions of body with environment. 3. Family/friends as physical bodies. 4. Possessions.	Emotional: 1. Private/ internal. 2. Includes thoughts/ feelings/ beliefs/ dreams/ memories.	Social: 1. Public self as presented to others. 2. Includes interaction with friends/ family/ emotional relatedness to other. 3. Influenced by social (cultural) mores/ expectations/ comparisons. 4. Influenced by perception of others. 5. Role taking- influenced by expectation of these roles.
Reflection/ Awareness/ Self-Understanding (self-as-subject/ James' *I*).	1.Awareness of body boundary with environment. Body self v object/ world. 2.Awareness of agency- body's ability to act on environment/ objects.	1.Awareness of self as continuous. 2.Awareness of agency- mind's ability to act on emotions/ perceptions/ thoughts. 3.Organisation and interpretation of experience (influenced by outer world).	1. Awareness of self as distinctive/ unique. 2. Evaluation of self in relation to others. 3. Self-concept built on reflection from 'other' perspective. 4. Ability to take on the other/ objective/ outer perspective.

In summarising the literature, various aspects of self-description have been identified and categorised, alongside the reflective processes which enable this self to be 'sensed.' Within this, the continued influence of James has been traced and is employed as a framework in Table 3 above. So far, this chapter has outlined how self as a developmental construct has been considered, surveying key developmental models (Hart & Damon, 1988; Harter, 2012). These models have provided 'norms' of self-development, against which children and adolescents have been measured. Through this, the prominence of the social aspects of self for a 'normal' adolescent have been identified. An emphasis on social relationships and interactions with others is presented as a key element in the development of a differentiated social and psychological self across psychological theory (e.g. Bosacki, 2000; Hobson, 2002; Mayes & Cohen, 1994). This focus on the interpersonal persists in theories of the multiplicity of role related selves. As such, an interpersonal emphasis, which privileges the social, has been established as a normative view of the sense of self (Williams et al., 2017).

Before looking at the influence of this on autism and sense of self research, I first discuss the evaluative element of the self- self-esteem. I identify how self-esteem has been conceptualised, including an emphasis on the adolescent age group, due to the relevance to my study.

2.2 Self-Esteem: An Evaluation of Self-worth

Here, I consider the conceptualisation of self-esteem across the literature and the varying influences on negative or positive self-worth that have been identified. In this, I prioritise theories and research which focus on adolescence.

2.2.1 Evaluating the Self: Global and Specific Judgements

In current theory, self-esteem is characterised as having an evaluative function, which ascribes value or worth to the self-description (Du, King & Chi, 2017; McCauley et al., 2017). This can be a global judgement, of overall self-worth, or domain-specific, evaluating the self in certain areas (Crocker & Wolfe, 2001; Jordan, Zeigler-Hill & Cameron, 2015). Harter (2012;2015) asserts that these specific evaluations can be based on self-concept domains (e.g. academic, athletic and social competence or physical appearance). Furthermore, it is argued that both global and domain-specific self-esteem can exist as a stable trait, or “typical,” level of self-esteem, and as a state, that depends on situation or context (Crocker & Wolfe, 2001, p. 594; Jordan et al., 2015). For example, global *trait* self-esteem would evaluate the self as, ‘overall, I am a success’ whereas global *state* self-esteem provides an evaluation of the self at the current time, ‘right now, I feel like a success’ (Crocker & Wolfe, 2001). In domain-specific, *trait* self-esteem evaluations such as overall, I am a successful student could be made, whilst a current *state* based evaluation might also be felt, however, I am currently struggling to complete this assignment and feel like a failure (Crocker & Wolfe, 2001).

Although, as Crocker and Wolfe (2001) assert, not all domain-specific evaluations will influence wider, global self-esteem. Global self-esteem is influenced by the domains the person views as important (Harter, 2012; 2015; Harter & Whitesell, 2003). Crocker and Wolfe argue that the domains which are prioritised can vary in level of importance, both within and across individuals. For instance, one adolescent may view academic competence as most important, whilst physical appearance may factor to a smaller degree. Across individuals, the same level of high self-esteem may be generated by success in *different* areas. For one, this could be success in academia, for another athletics (Harter, 2015). Here, self-esteem is dependent on *which* domains that young person views as most important, and by feeling competent in those prioritised domains (Crocker & Wolfe, 2001; Harter, 2012; 2015). For some, self-esteem can be highly dependent on outside factors, such as success or failures in certain domains, leading to a greater fluctuation in global self-worth. This is a state led self-esteem, which lacks a stable core (Greenier et al., 1999; Orth & Robins, 2014). In contrast, those whose self-esteem has a strong overriding sense of self-worth, would be able to ‘brush off’ this failure more easily (Greenier et al., 1999).

Self-esteem can therefore be considered in global, domain-specific, trait and state-based forms. Both trait and state self-esteem can be influenced by an individual’s evaluation of their self-qualities, interpersonal relationships, and group membership (Cooper, Smith & Russell, 2017; Crocker & Wolfe, 2001; Du et al., 2017). Self-qualities, or specific domains, such as physical appearance and academic and athletic competence may come into play through interpersonal and social evaluations- as I set out in the next section.

2.2.2 Social and Relational Self-worth

As with the development of a sense of self, self-esteem is also considered to be socially influenced. Positive, or negative evaluations can be based on interpersonal relationships and on wider socio-cultural contexts. The judgements of, and treatment by, others can become internalied as part of the self-evaluation (Crocker & Major, 1989; Harter, 2012; 2015; Harter & Whitesell, 2003). This is what Cooley (1902) referred to as the looking-glass self, where others act as a mirror to view how the self might be evaluated, based on their opinions and reactions (cited in Harter, 2015). These social appraisals can come from interpersonal relationships with family, friends, peers or, for children and young people, other key adults, such as teachers or carers (Crocker & Major, 1989; Harter, Waters & Whitesell, 1998). Harter (2012) suggests that whilst praise and approval from these groups can lead to pride, and a sense of acceptance, criticism can result in a sense of shame. On a wider scale, self-evaluations can also be influenced by societal expectations, values and representations in culture, for example in relation to physical appearance (Crocker & Major, 1989; Gerber, Wheeler & Suls, 2018). Therefore, social influences can come from both personal relationships and from wider society.

In addition to the appraisals of others, an individual *comparing* themselves with others can influence self-esteem. As posited in social comparison theory (Festinger, 1954), self-attributes can be compared with those of others, who are considered to be better (an upward social comparison) or worse (a downward social comparison) than the self (Wills, 1981). This can result in higher self-esteem, if the self is seen as more favourable in the comparison, or lower self-esteem, if it is felt one can never achieve the same level (Gerber et al., 2018; Wills, 1981). Upward social comparisons in domains which are viewed as unchangeable are argued to have depressing effects on self-esteem and well-being (Capps, Sigman & Yirmiya, 1995; Crabtree & Rutland, 2001). This sense of lower self-esteem may be heightened if, for example, a person feels they are surrounded by more competent individuals, who they feel unable to emulate (Crabtree & Rutland, 2001). This implies a contextual element to self-esteem, which can be influenced by social surroundings.

This contextual element is supported by Harter et al. (1998) who found that self-worth can vary in relation to situation or time; an individual may evaluate themselves differently dependent on which social group or relationship is being contemplated. Their quantitative study employed global self-worth and relational (contextual) self-worth scales to compare the self-worth of adolescents. They considered self-worth in four contexts: with teachers, parents, male and female classmates, finding that three quarters of the sample's self-worth varied by context. Higher self-worth was seen when participants felt validated and approved of in that relationship; that they were validated for who they were (Harter & Whitesell, 2003). However, certain adolescents reported stable self-worth across contexts, suggesting not *all* adolescents have varying relational self-worth (Harter et al., 1998; Harter & Whitesell, 2003).

Self-esteem can therefore be influenced by the appraisals of others and by comparisons the individual makes with these others. This can be in relation to wider society or to personal social groupings. For adolescents, this can include friends, peers, family, and other key adults, such as teachers. This relational self-worth can, for some, have a wider impact on global self-esteem than for others. In addition, further influence on self-esteem can spring from group categorisation and attribution, which is of particular relevance to the study of autistic students. This is now considered.

2.2.3. Collective Self-worth: Group Labels and Self-Esteem

Self-worth can be further influenced by what is known as collective self-esteem, based on a person's group membership (Brown, 2000; Cooper et al.,2017). Ellemers, Kortekaas and Ouwerkerk (1999) argue that a person not only has a cognitive awareness of group membership, but they also evaluate this position, ascribing a positive or negative value to this group (Tajfel, 1974). This can result in a positively or negatively valanced, collective self-esteem, which is based upon how the group is viewed, both within and outside of the group (Brown, 2000; Cooper et al., 2017; Tajfel, 1974). A devalued group category can become a stigmatized group, which people hold negative stereotypes about (Goffman, 1963/1990; John et al., 2018). This may lead members of that group to attempt to distance themselves from that categorisation or from the negative connotations associated with it (Ellemers et al., 1999; Finlay & Lyons, 2000).

Managing the influence of group membership can be achieved through the social comparisons undertaken. This is demonstrated in Finlay and Lyons' (2000) interview-based study. Here, the social comparison processes of adults were explored. These adults belonged to the stigmatized group labelled as having learning difficulties (Woodcock & Moore, 2018). From this study, Finlay and Lyons argued that social group comparisons are an active process, where people position themselves within positive representations, and distance themselves from negative connotations. They found that upward comparisons (with those who are ‘better’ than yourself) were avoided and were limited in number. Participants focused on downward comparisons, the majority of which were with others classed as having a learning difficulty, who they considered as ‘worse’ than themselves (Wills, 1981). They also focused on lateral comparisons (showing similarity with another), with those who were not classed as having a learning difficulty. Finlay and Lyons claim that this shows self-enhancing comparisons, which move them away from the learning disability label and its related attributes. However, the distancing here was implicit; participants did not share explicit claims of the learning disability label as a negative category, from which they must separate themselves.

Collective self-esteem was also investigated by Crabtree and Rutland (2001). They worked with participants categorised as having learning difficulties but, in this case, focused on adolescents. This was a quantitative approach, employing Harter’s self-perception scale, and a questionnaire examining the academic, athletic, social, behavioural, and physical domains viewed as important (Harter, 2012;2015). In this, those who had a label of learning difficulties had similar levels of self-evaluation to those without such a label. This suggests that it may be too simplistic to suggest that being a member of a stigmatized group unavoidably results in low self-esteem (Camp et al., 2002). Crabtree and Rutland identified a strategy which seemed to enhance the self-esteem of those with learning difficulties. Domains in which participants felt they were failing were devalued, whilst domains of success were valued more highly. Therefore, rather than choosing aspirational domains of importance on which to evaluate the self (following James, 1892/2001 and Harter, 2015), these participants selected important domains *based* on previous success. This subsequently enhanced self-esteem, by prioritising areas which supported a positive self-view. Based on this, Crabtree and Rutland argue for the importance of external agents, such as educators, who focus on successes, in order to bolster the self-worth of pupils. This may be particularly important to those with low self-esteem, who will naturally focus on weaknesses or deficits, and underestimate their strengths (Fennell, 1997; Whelan, Haywood & Galloway, 2007).

Additional protective strategies were seen in Camp, Finlay and Lyons' (2002) interview study. This study explored the global self-esteem of adult women diagnosed with mental illness. Unlike Finlay and Lyons' (2000) study, participants showed full, explicit awareness of the negative associations with their group label. However, they rejected society's unfavourable views as invalid and were critical of the negative stereotypes associated with that label. Rather than "blaming themselves" participants accepted their difference and suggested the issue was within those who stigmatise others (Camp et al., 2002, p.830).

Further to this, Camp et al.'s (2002) participants would actively avoid social groups where they felt discounted and devalued, eschewing social contexts which impacted negatively on their relational self-esteem (Harter & Whitesell, 2003). In contrast, contexts which bring together people with the same group label could have a positive effect. This was seen in the findings of Crabtree, Haslam, Postmes and Haslam (2010). Their questionnaire-based study included 73 mental health support group attendees. They found the group provided wider social support, acting as a place to resist negative stereotypes and to be empowered as a collective group (Camp et al., 2002). However, Crabtree et al. avoid simple conclusions on group membership and self-esteem. Whilst the *support group* offered the positive influences discussed above, identification of the self with the *group label* had a negative impact on self-esteem. A stronger identification with a devalued or stigmatised identity lowered self-worth. Crabtree et al. conclude that whilst negative associations existed, these were supressed by the positive influence of collective support. Research into group membership of traditionally devalued groups has therefore demonstrated effects that are not inevitably or wholly negative (Camp et al., 2002; Crabtree et al., 2010).

In sum, whilst a stigmatised label can have a negative impact on self-esteem, protective strategies can be employed to counter this. For instance, self-enhancing social comparisons can be utilised either to distance the self from the label, or to emphasise the positive attributes of that group. Also, domains of success can be prioritised, so that the focus of self-evaluation is not placed on failures or negative attributes. Finally, the 'problem' of stigmatisation can be focused on those who judge the group in the first place. Negative stereotypes can also be countered through supportive social contexts, such as support groups.

This section has discussed various forms of self-esteem, including global and domain-specific forms. It has shown how self-esteem can exist as both a trait (with a consistent core) and a state (varying according to context). As with sense of self, concepts of self-esteem involve experiences of the social influence, which can come from the direct appraisals of others and the comparisons an individual makes with those others. Moreover, self-esteem can have a collective dimension, with the group category and its perceived attributes influencing individual's self-worth. So far, the group labels of learning difficulties and mental health issues have been considered. I now focus specifically on autism, making links back to the sense of self and self-esteem theories considered above.

2.3. Autism and Sense of Self: Challenging Dominant Deficit Narratives

In this section, I establish how an autistic sense of self has been conceptualised, drawing particular attention to the pervasive influence of deficit discourses. As discussed in 2.1., theories on the interpersonal nature of self-understanding claim that social interaction is *key* to developing a sense of self. The characterisation of autism as an impairment in social communication and interaction has therefore led to assertions that an autistic sense of self is somehow *lacking* in interpersonal affect. This results in widespread claims about a deficit in self-understanding amongst autistic people. To challenge deficit narratives such as these I adopt a CAS approach, taking a critical stance, which problematises the claims made. When challenging deficit views, I am aligning myself with a small number of alternative research studies into autism and sense of self (e.g. Winstone et al., 2014). These studies argue that this deficit is an outcome of the research methods employed and demonstrate how, by altering these methods, these findings can be called into question. I use these studies, alongside my own critique of previous research, to dispute the deficit view of an impaired sense of self and to support enabling narratives, which represent the full complexity and variety of the autistic sense of self.

2.3.1. The Interpersonal Self: Theories of the Other Mind

I begin by considering how self-other understanding has been characterised in autism, relating this to Theory of Mind (ToM) (Baron-Cohen, Leslie & Frith, 1985). This illustrates the link between claims of an impaired ToM and deficit discourses of self-other understanding and self-reflection in autistic people.

Autism as a diagnostic category is characterised by an emphasis on disorder and impairment (Latif, 2016; Timimi & McCabe, 2016). The DSM-5 diagnostic criteria focuses on “persistent deficits,” including “impairments” in social communication, social interaction, and relationships (APA, 2013, p.31; p.52; Wing, 2002). In theories which frame a sense of self as formed through relationships with others (such as Hobson (1990; 2002)), this results in deficit discourses. These discourses inscribe the autistic sense of self as ‘deficient’ in interpersonal, social influence and therefore lacking in self-reflection. Hobson (1990) argues that a lack of connection and formation of emotional relationships can result in an inability to construct a self-concept. Here, he claims that autistic people will have a limited construction of the Jamesian *I*; the ability to think of the self as a thinker. As discussed previously, Hobson (1990;2002) argues that a concept of self is formed through an awareness of others. The awareness of alternate perspectives allows the child to take on the role of other, to take an alternative attitude towards themselves. Therefore, Hobson believes that autistic children fail to build a reflective concept of self since they cannot see others as having alternative perceptions. This, he suggests, prevents them from taking an alternative, and reflective view of themselves. He subsequently argues that autistic children cannot form an “affectively centred “core” self” (p.176), that their sense of self is fragmented because of their supposed inability to reflect.

A belief in these self-other reflective difficulties is rooted in ToM perspectives. This is termed by Bosacki (2000) as “social understanding” (p.709); the understanding of the mental states of others, including their feelings, beliefs and dreams (Baron-Cohen, 2001; Frith & Happé, 1999). ToM also enables a person to infer the intentions of others and to make sense of their behaviour (Bosacki, 2000; Frith & Happé, 1999). Deficit discourses have argued that ToM is ‘impaired’ in autistic people (Davies, 2016; McGuire & Michalko, 2011). Autistic people are claimed to lack empathy and an understanding of the thoughts and intentions of others (Davies, 2016). In these discourses, it is asserted that autistic children cannot appreciate the difference between the mental and the physical; they cannot understand that people may have mental beliefs, which can contradict the concrete reality (Baron-Cohen et al., 1985; Frith & Happé, 1999).

Bosacki (2000) argued that ToM is essential to self-understanding. Her research concurs with Hobson's (1990;2002), concluding that sense of self is created from social experience, where the understanding of others *as psychological beings* builds on understanding of the self. In this theory, difficulties in ToM would result in difficulties in differential, psychological self-understanding. As Mayes and Cohen (1994) argue, a difficulty in understanding the minds of others would impact on understanding the psychological separation between self and other. It would prevent the identification of two distinct minds, with contrasting thoughts, feelings, and beliefs. Without ToM, the alternative psychological stance of the other person cannot be conceptualised (Bosacki, 2000). This alternative psychological stance cannot then be adopted to enable reflection, nor can the self be viewed, and utilised, as a separate psychological entity, which can think and reflect on the self (Hobson, 2002). An impairment in ToM is therefore considered to impair an ability to self-reflect.

Davies (2016) critiques deficit ToM narratives, in which autistic people are presented as being "in a world of their own, and, like aliens on the wrong planet, are only spectrally present in… the world of the 'normal' people" (p.132). Deficit discourses (such as Hobson (2002)) present this "alien" world as a lonely one, detached from others, in comparison to the 'normal' non-autistic world, which is filled with interpersonal engagement. Based on ToM difficulties, Mayes and Cohen (1994) claim that any involvement in the interpersonal world which autistic people *do* partake will be "rudimentary," with "limits [in] the depth" of love experienced (p.213). Furthermore, Davies (2016) asserts that empathy and ToM are perceived as *essential* human qualities. An idea that is embodied in the words of Baron-Cohen (2001) that "a Theory of Mind remains one of the quintessential abilities that makes us human" (p.169). If autistic people lack ToM, as some work suggests, then this leads to the unacceptable conclusion that they are less than human.

This less-than-human narrative is seen in some theories of sense of self and autism. For instance, in Hobson's (1990) assertion that an impersonal relationship with the world results in a "primitive" non-reflective self, which does not identify itself in comparison with other conscious beings (p.172). Claiming that autistic children have an impaired interpersonal self therefore becomes a devaluation of the autistic self. Their sense of self is claimed to be lacking an "essential" interpersonal part (Hobson, 2002, p.212), which would allow it to be valued as a real self, rather than viewed as a "primitive" form (Hobson, 1990, p.172).

Subsequently, studies which are based on Hobson's hypothesis of the autistic sense of self, devoid of interpersonal affect, present a dehumanising view of autism. This will be discussed in the following section, where I consider research studies which tested Hobson's theories.

2.3.2. The Interpersonal Self and Autism: A Critique of Deficit Narratives

A number of studies testing Hobson's hypothesis of an autistic deficit in self have utilised the Hart and Damon (1986) Self-understanding Interview, (described in detail in 2.1.2.) Three of these studies are now considered, chosen based on their significant influence on subsequent research. In critiquing these 3 studies, I identify the key claims they made and expose the deficit discourses at work. The 3 studies are those of Lee and Hobson (1998), Farley et al. (2010) and Jackson et al. (2012).

All 3 studies employed the Self-understanding Interview to consider the quality and construction of the self-concept of autistic people. These studies hypothesised that autistic people would lack social self-understanding and have a sense of self that is not based in social relatedness and interaction. They therefore began with a set of assumptions about the autistic sense of self, based on something which is missing, in comparison with non-autistic others. As such, they focused on how the autistic person deviated from a 'normal,' socially developed self, as represented by the non-autistic comparison group (Davies, 2016; Molloy & Vasil, 2004). Using Hart and Damon's (1988) model included further 'norms' of development, against which the autistic participants could be measured.

Firstly, Lee and Hobson (1998) used the Self-understanding Interview for autistic adolescents and non-autistic adolescents, matched for age and verbal ability. This study was based on Hobson's (1990) interpersonal theories of self-development and hypothesised that autistic children and young people would lack social influence in their self-understanding. This interview study found that autistic participants made social statements in relation to family, bullying and helping others. Demonstrating that self-other awareness was present. Self-understanding had moved beyond "I-It" awareness (Hobson, 1990). However, Lee and Hobson ascribed a significantly lower number of statements in the social category of the interview for autistic adolescents, both when discussing specifically social questions and when exploring other attributes, such as their active or psychological self. Additionally, when social statements were made, they note that half of these related to general traits such as being "nice" (Lee & Hobson, 1988, p.1139). No autistic participant made a social statement which related to being part of a social group or to a friend. If another were referenced, this would be a family member. Based on this, they assert that social self-understanding for autistic participants was not defined in relation to group membership and was very self focused. They argue that these findings show a specific impairment in self in relation to other and that, for an autistic person, self-understanding is not based in social relatedness and interaction.

This study produces a problem centred view of autistic young people, undertaking a medical model stance (Goodley, 1997; Hodge et al., 2019). It does not consider, for instance, that a lack of discussion of friends or social groups may be based on outside influences. For example, several studies have found that autistic children and young people may experience reduced peer-acceptance, resulting in fewer meaningful and reciprocal friendships, and a position on the periphery of social groupings (Chamberlain, Kasari & Rotherham-Fuller, 2007; Kasari, Locke, Gulsrund & Rotherham-Fuller, 2011; Locke, Ishijima, Kasari & London, 2010). Subsequently, *opportunities* to develop a socially affected sense of self may also have influenced the responses of these autistic research participants. Furthermore, whilst Lee and Hobson assert that their interviews demonstrate a lack of social self-understanding, the autistic adolescents in their study were able to describe themselves in physical, active, and psychological categories. In this, autistic participants demonstrated their ability to reflect on themselves, offering this range of self-description. This suggests that a self-concept was constructed. Perhaps it needs to be questioned whether the interpersonal self is a 'glue' holding the "core" self together, as Hobson (1990, p.176) claimed. It could be argued that the self-concept of people with autism may be qualitatively different in comparison with the ascribed 'norm' of a non-autistic other, but this does not necessarily mean it is the deficient form that Hobson's argument seems to suggest. Additionally, as Lee and Hobson themselves admit, the self-reflection of their autistic participants counters the hypothesis that autistic young people have ToM deficits, which hamper their ability to reflect on themselves.

Secondly, Farley et al. (2010) hypothesised an impairment in interpersonal connectedness and self-reflection. Their study of autistic adolescents used a modified version of Hart and Damon's (1986; 1988) interview. They aimed to build on Lee and Hobson's (1998) study of self-as-subject, looking at continuity, distinctness and agency. Farley et al. focus on a quantitative analysis of self-as-subject. They also followed a hypothesis of reduced self-understanding in autistic people, as based on Hobson's (1990; 2002) theory. They view this self as 'impaired' in autistic people, hypothesising that autistic people will have difficulty in taking the perspective of the 'other', to create a position from which they can reflect on the self. They concluded that the autistic adolescents involved were less able to conceptualise themselves from the point of view of another person, than 'typical' adolescents. Thus, continuing a comparison with a non-autistic 'norm.'

Although, Farley et al. themselves identify an important caveat here. They noted that not all questions were asked of the autistic group, which was attributed to attention difficulties for these participants. In short, the method was challenging for autistic participants. It could be argued that these challenges hampered their ability to respond not only with regards to the *unasked* questions, but also for the larger number of *nonresponses* given to those which were asked. As King et al. (2017) assert, limitations can be created by methods which are more suited to a non-autistic 'typical' population, which do not take the needs of autistic young people into account.

Thirdly, Jackson et al. (2012) used Hart and Damon's (1986) Self-understanding Interview. They started from an assumption of an impaired understanding of others' minds that contributed to a 'deficient' self-concept. They suggested that autistic participants might have a less socially formed self and, subsequently, an underdeveloped self-concept, and awareness of self-as-object. This would include poorer self-understanding and an underdeveloped sense of the self-as-subject. Whilst Lee and Hobson (1998) and Farley et al. (2010) focused on autistic adolescents, Jackson et al. included those aged 19-63 years, with a diagnosis of Asperger's syndrome (AS). Jackson et al.'s study used a comparison group and concluded that self-understanding was different between the two groups. Here, if AS participants offered fewer statements compared to non-autistic others, they were considered to have an underdeveloped sense of themselves. For example, less social statements were present, and so it was concluded that this group had a less socially influenced, underdeveloped self-as-object.

Jackson et al. (2012) also consider the self-as-subject categories of continuity, distinctness, and agency. Here, statements were assessed against the expected developmental level of Hart and Damon's (1986) model and compared with the non-autistic group. The non-autistic group gave more statements at the expected level. These statements represented an evolving self, related to the past, present and future, and an awareness of the individuality of their subjective experience and interpretation. In contrast, most AS participants gave statements which represented self-continuity in terms of permanency and unchanging characteristics. Jackson et al. assert that finding less statements which refer to a broader social and chronological context demonstrates that the participants with AS focused on the present, rather than the wider context. For some, living in the "here and now" (Jackson, et al., 2012, p.703), which is partnered with the idea of spontaneity and 'living life to the fullest' is a positive attribute. For Jackson et al., when exploring the self-understanding of autistic people, this becomes a negative attribute.

The use of levels and scores appear to have become, in this research, a yardstick of 'normality,' and demonstrate how a developmental model can be employed to categorise an autistic sense of self as deficient. For instance, Jackson et al.'s (2012) typology describes the AS participants on the lower levels as being "simple" (p.703) and "underdeveloped" (p.698) in comparison with their 'typical', 'normal' counterparts. However, Jackson et al. do admit that some participants demonstrated "normal" (p.704) levels of self-understanding of the self-as-object. Whilst they place 'normal' in inverted commas, holding normal as a comparative standard inherently adds a value judgement to this position. An alternate view is that since Jackson et al. found "a much wider range of understanding than the NT group" (p.703), autistic participants simply had *more* variety in the quality of their self-understanding. It was not that 'higher' level statements were absent from their self discussion but that *in comparison* to a non-autistic other these were fewer in number. Questions therefore arise around the claims made and how difference becomes deficit. As Latif (2016) asserts "being 'different' should not necessarily mean being disordered" (p.292). Yet here, whilst, the non-autistic group are not characterised as deficient in their *range* of statements, for autistic participants, fewer statements, in comparison with their non-autistic peers, are characterised as such.

It is worth examining the methods employed by Jackson et al. (2012) who state that "understanding was not evident" (p.704) when autistic participants were asked about their self-as-subject. They argue that this supports a hypothesis of impaired self-reflection in autistic people. No consideration is made as to whether the way that these participants were asked enabled them to demonstrate their understanding. This critique is furthered by King et al. (2017) and Winstone et al. (2014), who also question the methods of the Self-understanding Interview. They assert that the deficit conclusions found here may spring from the interview process as a method, rather than from the self-understanding of autistic people. For example, King et al. suggest that fewer responses could reflect a difficulty with the interview process, rather than the content of the questions. These are limitations which King et al. argue are based in the methods created for “a typically developing population” (p.2). Here, deficit ideas may be perpetuated by methods which are not adapted for autistic people.

The conclusions reached by all three studies examined above can be influenced by the deficit assumptions embedded in their hypotheses (King et al., 2017; Winstone et al., 2014). Rather than considering whether an inaccessible method has prevented autistic people from sharing, or elaborating, on their views, fewer statements are identified as showing an impairment, whilst a higher number of statements are considered to show repetitive interests or an excessive focus (Farley et al, 2010; Jackson et al., 2012; King et al., 2017).

Finally, drawing together the studies of Lee and Hobson (1998), Farley et al. (2010) and Jackson et al. (2012), conflicting views on the *self-as-subject* can be identified. Lee and Hobson found no discernible difference between the autistic people interviewed and the comparison group but acknowledged a difficulty in obtaining responses that reflected the self-as-subject. Farley et al. found an impairment in the development of an awareness of agency, whilst similar, or even higher, levels of understanding were found in terms of continuity and distinctness in the autistic group. In contrast, Jackson et al. suggest that self-understanding in terms of continuity and distinctness is lesser, whilst agency is shown to be at the most developed level for the largest percentage of their AS participants but is still less than the comparison group. Jackson et al. conclude that their findings show that self-understanding is quantitatively and qualitatively different in autistic people, showing a wider range of responses *across* the levels, less psychological and social statements and reduced self-continuity and distinctness. However, this placing of difference is against the “neurotypical” comparison group (p.698) not a statement of the differences within the group of AS participants themselves. Furthermore, in Jackson et al.’s study, the highest percentage of levelled answers from participants with AS was 50%; the other half of the group answered differently whilst some participants demonstrated ‘normal’ levels of self-understanding. Therefore, a closer look at the data, and the conflicting results shown between studies, suggests a heterogeneity of self-understanding in autistic people (Samra, 2016; Williams et al., 2017). Consequently, producing one overriding hypothesis may not be indicative of the overall group.

To summarise, these studies have followed Hobson’s (1990; 2002) model, of an unreflective autistic sense of self, lacking in interpersonal influence and affect. They have employed the self-understanding interview of Hart and Damon (1986) to test their hypothesis. Through this, various deficit constructions of an autistic sense of self have been asserted, including an ‘impairment’ in the interpersonal self, in conceptualising the self from the others’ perspective, in defining the self in relation to that other, and in subjective awareness, such as a sense of continuity and agency. This leads to claims of an under-developed sense of self, in comparison with the ‘norm’ of the non-autistic other. The non-autistic other, along with the model of development created by Hart and Damon, are utilised to confirm the deficit hypothesis posited. However, conflicting findings between these studies suggest a homogenous theory of autistic sense of self may not represent an accurate picture. Furthermore, the self-understanding interview method itself may perpetuate inaccurate, deficit-based representations. Therefore, in the next section, I consider studies which altered their methods with autistic participants, to research the autistic sense of self in an enabling manner.

2.3.3. Sense of Self and Autism: An Alternative Approach

Studies from an emerging field which directly challenge the impairment discourses of autism and sense of self discussed above are currently coming to light. These studies argue that the interview format creates a barrier for autistic participants, perpetuating deficit findings. In contrast, they employ creative methods, such as photo-elicitation, drawing or collage. This generates alternative findings, in which autistic young people demonstrate an ease in self-reflection and share the importance of others to their self-understanding. In this way, they show how a method can *produce* particular ways of seeing autistic participants.

Based on an extensive literature search, I found two published studies in this field-Winstone et al. (2014) and King et al. (2017). I discuss these studies to offer an alternative view on the self-understanding of autistic young people; one that is central to the aims of this thesis. I begin to highlight how alternative research methods can enable autistic participants to share a sense of self which is at odds with previous deficit narratives. The methodological implications of this will be discussed in detail Chapter 4. Now, the findings of the two key studies are considered.

Winstone et al. (2014) researched self-identity in autistic adolescent boys, considering how they perceived themselves across a range of areas. This included self-as-object awareness (physical and personality traits) and self-as-subject continuity, focusing on the future self. Collective identity was also explored, as they discussed the self in relation to the autism label. The comparison of the self with others (peers, friends, and family), and their distinctness to those others, was also considered. The study compared the findings of standard semi-structured interviews with that of activity-orientated interviews (collage and drawing) in these areas.

The most notable difference in response, across the two methods, was when autistic adolescents compared themselves to others. In the semi-structured interview, they struggled to share how they were different to others, such as peers and siblings, offering few examples. In contrast, detail and depth was obtained in the activity-orientated interviews, where participants discussed their drawing and collage. Here, an awareness of self-other differences in physical attributes, personality traits, likes and dislikes, and educational needs and ability was demonstrated. As Winstone et al. note, this method enabled both a wider range of comparisons to be shared and more detail to be given in those comparisons. These moved beyond the concrete examples given in the interviews, such as being at a different school, to a range of self-attributes, including abstract psychological and social traits, which were directly compared with themselves as a reference point. In addition, one participant discussed how perceptions of the self can vary, stating others have “a different way of seeing me” (p.200). Therefore, autistic participants began to differentiate between the perspectives, personalities and preferences of themselves and others. Winstone et al. claim that this demonstrates ToM, their participants empathising with the differing view that another may have. Movement away from concrete descriptions was also seen in the discussion of a self-portrait. In the traditional interview, participants focused only on the physical self. In the self-portrait, participants shared their personality traits in detail, giving examples to support these. This illustrates how abstract self-descriptions may be present in an autistic adolescents' self-concept, but that the method employed may prevent these from being shared. This can lead to inaccurate conclusions.

Contrasting views were also found when considering the continuity of the self. Whilst Jackson et al. (2012) asserted that autistic people did not consider the broader chronological context, this was not the case in Winstone et al.'s (2014) activity-orientated interview, which focused on a drawing of the future-self. Here, Winstone et al.'s standard interviews produced little to no response from participants on this topic. In the activity-orientated interview participants provided detailed responses, which showed a vivid picture of the future they imagined for themselves. This included those who did not have defined career plans, sharing instead how they would "let the path take its course" (p.198). These responses illustrated philosophies about a future self, regardless of whether they had a set plan. Winstone et al. illustrate their participants' understanding and interest in the future, and their imagined future self. As such, they countered theories of "poorer self-understanding" and a deficit sense of self continuity simply by altering their research method (Jackson et al., 2012, p.698). Winstone et al. conclude that we should reconsider the methods employed, arguing that a sense of self which challenges deficit models "can be surfaced given an appropriate context" (p.202).

A second example of how a change of method enabled autistic adolescents to demonstrate their self-understanding is reported by King et al. (2017). Their photo-elicitation interviews were used with autistic adolescent boys. These methods revealed both self-as-object and self-as-subject awareness, with participants describing themselves through their actions and abilities, comparisons with others, and the continuity of a past, present and future self.

A key finding in King et al.'s (2017) study was the relevance of the social world to the self-understanding of the autistic adolescents involved. The active self was a focus, with participants sharing activities and hobbies they particularly enjoyed. These were markers of personal qualities such as being disciplined or adventurous. One participant also considered music as an activity which defined him, "if I didn't play an instrument… I wouldn't have anything to be" (p.7). However, these activities were not viewed in isolation, but related to their importance in relationship building and maintenance, with both peers and teaching staff. Participants also considered how their skills in an activity could influence how they were viewed by those others. This demonstrated a consideration of interpersonal implications and the value with which participants held their relationships. Consequently, activities were not only discussed as personal traits, but in terms of the interpersonal value they held. These findings challenged the view that autistic young people lack social affect in their self-view (Hobson, 2002; Jackson et al., 2012; Lee & Hobson, 1998).

Social relevance was accentuated when the autistic adolescents in King et al. (2017) compared themselves with family members and peers. In this, social statements were spontaneously made by all participants. In relation to family, they described joint activities or interests and shared traits, such as being funny. Participants also identified shared beliefs or emotions in these close relationships. They focused on how they were *similar* to these family others. In contrast, peers were considered in terms of *difference*. Autistic adolescents would separate themselves through their differences such as preferences, which could mark them out as different to their peers. However, not all viewed this difference negatively. One saw a positive value in being unique in his knowledge, activity, and social responsibility. This was supported by feedback from other adults in his community and personal comparisons with his peers. Therefore, comparisons were based on participants' own views *and* on the feedback of others. These findings show the relevance of the social context to the comparison-based self-understanding of the autistic adolescents involved- a counter claim to Lee and Hobson's (1998) notion of a lack of social relatedness in the self-understanding of autistic young people.

King et al. (2017) also found participant awareness of continuity through time, including who they were the past and who they hoped to become in the future. As seen in social self-understanding, activity was a prominent aspect, used to indicate both consistency and change. For example, activities which a participant had "always done" (p.7) or changes in musical interests. There was also a consideration of personality change, with a new friendship resulting in a different understanding of, and preference for, jokes. Additionally, participants imagined a future self and related this to their current decisions; a desired career path resulted in a commitment to musical activity or to choosing the 'right' GCSEs. In this, there was a heightened awareness of how present actions could influence the future self. Therefore, participants made links to their past self, showed an awareness of how they may have changed in the present and considered what action they needed to undertake now to attain a desired future. All this runs counter to the deficit in these areas found in Jackson et al. (2012).

In sum, changing the methods employed resulted in findings which challenged previous theories and research. Autistic participants shared detailed self-reflection, which highlighted the relevance of the self-other relationship to their self-understanding. This included both comparative description and an awareness of the interpersonal implications of their self-attributes. Participants' also demonstrated their sense of self-continuity. However, studies which employ alternative methods to *directly* challenge the deficit narratives of autistic sense of self research are in the minority. Furthermore, the studies described here were undertaken with a small number of autistic adolescent males and focused on a few specific areas of self-understanding. Further research is required to consider the full complexity of the autistic sense of self, which could be "surfaced" in alternative methods (Winstone et al., 2014, p.202).

Additional support for the relevance of the interpersonal and social world to autistic people can be found in self-esteem research, including that which focuses on the impact of the autism label. This is now considered.

2.4. Self-Evaluation: Navigating Social Narratives and the Autism Label

In this section, I consider self-esteem research relating to autistic people. This includes influences on the formation of a negative self-evaluation. In this, I discuss perceptions of the group label autism. Aligning with my participant group, I then focus on research that addresses autistic adolescents, illustrating how the social world impacts on the self-view of young autistic people and highlighting the negative impact this can have. As such, I aim to emphasise the importance of research, such as mine, which considers enabling and disabling social influences on the positive sense of self.

McCauley et al. (2017) draw attention to the general lack of research on autism and self-esteem. When autism and self-esteem *are* considered, researchers often turn attention to the impact of autistic children on the self-esteem of parents and caregivers (Cantwell, Muldoon & Gallagher, 2015; Lu et al., 2015; Zhou, Wang & Yi, 2018) rather than on the autistic people themselves. The dearth of relevant research on self-esteem is a concern due to links between low self-esteem and depression (Cooper et al., 2017; McCauley et al., 2017). Depression and anxiety are prevalent in both autistic adults and young people (Mazzone et al., 2013; Nah, Brewer, Young & Flower, 2017).

This lack of research is perhaps rooted in the characterisation of self-esteem as an evaluative ability, which appraises self-worth through comparisons with, and judgements from, others. Following Hobson's (1990) theory of impairment, it might be argued that a reflective position on the self is not well-established in the autistic population. Consequently, self-esteem would be viewed as less fruitful to study. Such views surface in Jordan and Powell (1995), who argue that the evaluative aspect of self-esteem will be restricted in autistic people. They assert that autistic pupils cannot reflect and make value judgements on themselves. Whilst they acknowledge that autistic young people can have low self-esteem, they state that these are "typically the more able" (p.35). They argue that this low self-esteem springs from the child's failure to meet their own expectations to complete tasks or their unwanted treatment from others, rather than an evaluative sense of self. Yet, it is unclear how these reactions are not evaluative, since they imply both a value judgement, and an awareness of the reactions of others. Furthermore, it could be argued that this is only articulated by 'more-able' autistic children because of the communication challenges that are frequently used to define the 'less-able.'

Recent studies have, however, considered self-esteem, depression and anxiety in autistic children and adolescents (McCauley et al., 2017) and autistic people over 16 (Cooper et al., 2017). Both studies employed a quantitative approach, finding that autistic people rated their self-esteem significantly lower than non-autistic people. This low self-esteem was found to be associated with depression and its symptoms and depression and anxiety was found to be more prevalent for autistic participants (Cooper et al., 2017; McCauley et al., 2017). Alongside this, Goddard et al.'s (2017) comparative study considered overall self-worth and domain specific self-esteem. Significantly lower self-esteem scores were found across global self-worth, close friendship, behavioural, romantic, job, athletic and social domains in the autistic adolescent group. Only school and physical domains were shown to be like the non-autistic group in terms of self-esteem. These findings are corroborated by Jamison and Schuttler (2015), who found lower self-worth across *all* the above domains for the autistic adolescent females in a comparative study. This therefore suggests that autistic young people have both lower domain specific and global self-worth. In contrast to Cooper at al. (2017) and McCauley et al. (2017), Goddard et al. (2017) did not find significantly increased levels of depression or significant links between self-esteem and mood in their autistic participants, which they suggest shows perceptions of the self had weaker impact on mood for autistic people.

Recent self-esteem studies seem to show lower global and domain specific self-esteem for autistic participants but there is a lack consensus over the influence of self-esteem on increased depression and anxiety. With a lack of conclusive agreement, self-esteem cannot be dismissed as irrelevant to autistic young people and adults in relation to its impact on mood (McCauley et al., 2017). Consistent agreement on low self-esteem for autistic people emphasises the importance of supporting autistic people in developing a positive self-view (McCauley et al., 2017). There are acknowledged barriers that autistic young people can face in developing a positive view. Amongst these, social influences can be highly relevant, which I now discuss.

2.4.1. The Social World: Peer Approval and Self-Esteem

I now consider research into domain-specific self-evaluation for autistic children and young people as a way of illustrating the social influence evident in these evaluations, and the negative impact this can have on self-esteem.

Research with autistic children and young people has investigated self-evaluations in specific social competence domains. In this, autistic children and adolescents scored themselves as less socially competent than the non-autistic peers they were compared with (Capps et al., 1995; Jamison & Schuttler, 2015; Williamson, Craig & Slinger, 2008). This suggests that autistic children and adolescents feel they have limitations in the social domain. Following Harter’s (2012) definition, this could impact on self-worth *if* that domain is deemed important to an individual. The importance of peer approval and social competence to autistic adolescents was shown in Williamson et al. (2008). Autistic adolescents felt they received less peer approval than their non-autistic peers although peer and parental approval was equally important to both groups. As acceptance in the social domain was therefore important to autistic adolescents, feeling a lack of this could have a detrimental impact on their self-worth.

The impact of others on the self-esteem of autistic adolescents is explored further in McCauley et al. (2017). Here, autistic participants who showed an increased awareness of the perceptions of others, reported lower self-esteem. This could suggest that these autistic children and young people employed a looking-glass theory of self, which, as Harter et al. (1998) found, can be associated with lower levels of self-esteem. It could be inferred that as these autistic participants were more aware of the evaluations and perceptions of others, they were more influenced by these evaluations (Capps et al., 1995). Subsequently, low self-esteem may spring from negative peer responses, which can be incorporated into the self-esteem of autistic children and adolescents, resulting in a more negative self-view (Grills & Ollendick, 2002; Humphrey & Lewis, 2008; McCauley et al., 2017).

The likelihood of exposure to negative peer responses is demonstrated in the bullying experiences of autistic pupils (Goodall, 2018). Cappadocia, Weiss and Pepler (2012) reported that rates of bullying amongst autistic children and young people were found to be twice as high as their non-autistic peers, and that this victimization was a regular occurrence, over long periods of time (Humphrey & Lewis, 2008). High levels of bullying were also seen in Zablotsky, Bradshaw, Anderson and Law (2013) with 63% of autistic children having experienced bullying at some point and 38% having experienced victimization in the last month. This victimization can impact negatively on self-concept; the victimized pupil is exposed to frequent negative comment from peers, suggesting a negative evaluation by the 'other' (Cook, Ogden & Winstone, 2016; Grills & Ollendick, 2002). Furthermore, increased incidences of, or risks for, bullying were found for autistic pupils in mainstream school settings (Cook et al., 2016; Zablotsky et al., 2013) suggesting that this could be an increased influence on negative self-worth in autistic pupils.

In sum, not only is social approval relevant to autistic adolescents but it can have a negative impact on self-esteem. In this, the group label of autism must also be considered. This can lead autistic adolescents to experience not only negative reactions from peers, but also stigmatised perceptions from the wider community. This is now considered.

2.4.2. Group Membership: Autistic and Non-Autistic Perceptions of The Autism Label

As already discussed, self-esteem can be influenced by the group category a person belongs to. This section discusses the autism label and how it is perceived by both non-autistic people (the out-group) and autistic people (the in-group). As such, I consider both the outside and personal perceptions that may influence the self-evaluations of my autistic participants, in relation to autism as a part of their identity.

As MacLeod, Lewis and Robertson, (2013) assert, the label of autism is a complex construct, with media stereotypes, lay perceptions/ misconceptions and debates around changing diagnostic criteria to be negotiated (Johnson & Joshi, 2016; Lester, Karim & O'Reilly, 2014; Timimi & McCabe, 2016). Media stereotypes and lay perceptions can represent autistic people as lacking in verbal and social ability and isolated from others, as undertaking behaviours such as hand-flapping and rocking, as well as having extraordinary abilities (Davidson & Henderson, 2010; Huws & Jones, 2010; Lester et al., 2014). Alongside this, biomedical paradigms have positioned autistic people as 'abnormal' in comparison to the 'normal' development and functioning of non-autistic others, and they are subsequently seen as in need of a cure to live 'normal', constructive lives (Brownlow, 2010; Glynne-Owen, 2010; Lester et al., 2014). These messages marginalize and stigmatize autistic people as an abnormal 'other' (Brownlow, 2010; Goodley, 2016). As previously discussed, this 'abnormal' positioning is evident in sense of self research, which compares the 'impaired' sense of self development of autistic participants with the non-autistic, 'typically' developing group. These theories asserted that the autistic sense of self was lacking "essential" social, interpersonal aspects; a social affect valued by society as a 'normal' trait (Bagatell, 2010; Hobson, 1990, p.165).

Perceptions of abnormality, stereotypes and the devaluation of autistic people has led the autism label to be associated with stigma and marginalization (John et al., 2018; Johnson & Joshi, 2016). John et al. (2018) demonstrate how stereotypes around autism still pervade within the myths of non-autistic persons. Their qualitative study employed focus groups with a range of non-autistic participants, aged 18-83. Myths around a disinterest in social relationships and a lack of awareness of social rejection; being mad and/or dangerous; having special abilities and not liking to be touched were demonstrated within participant focus groups. These views were influenced by both media stereotypes and the second-hand knowledge of others' accounts, rather than on first-hand experience of autistic people. Participants also focused mainly on a singular description, rather than considering the heterogeneity of autistic people (Masi, DeMayo, Glozier & Guastella, 2017).

The influence of negative, societal views was demonstrated further in Mogensen and Mason (2015) and Humphrey and Lewis' (2008) qualitative studies, which consider autistic adolescents' views of the group label of autism. Negative views in Humphrey and Lewis constellated around feelings of being perceived as 'abnormal.' Participants identified the influence of the non-autistic community, with "being treated differently" heightening feelings of negative difference (p.31). Associations with stigmatizing discourses were seen in one participant's response to their diagnosis, "Oh my God I'm a freak!" (p.31). This echoes the discourse of non-autistic participants, who report societal characterizations of autistic people as "dangerous", "psycho" or "mental" (John et al., 2018, p.850-1) and as "not being a participant in the human race" (Huws & Jones, 2010, p.338-9). Humphrey and Lewis therefore not only demonstrate the autistic participant's characterization of their diagnostic label in a negative light but perhaps also show how that autistic participant has identified with, and subsequently employed negative societal myths and discourses around autistic people as 'freaks' (Williams et al., 2017). As described in Mogensen and Mason, the label can highlight difference, and, with the diagnosis, can come a focus from the non-autistic community on changing. One participant felt that health and educational professionals took away control and power in their attempts to change them. This gave a negative sense of self; a negative view of a 'different' self that needed to be changed to be the same as non-autistic others are (Bagatell, 2007; Huws & Jones, 2015).

Upon diagnosis, autistic people can also experience conflicting messages between diagnostic literature and the autistic community. For instance, the autistic young adults in MacLeod et al.'s (2013) interview study saw the characterisation of autism in research and diagnostic discourses as not representative of themselves or their experiences. This created difficulty in identifying with autism as a collective identity. In contrast, autobiographical accounts of autistic experience were viewed more positively, as a source of self-understanding around shared group traits. MacLeod et al. argue that autobiographical works by autistic authors offer more complex, personal descriptions, rather than simplifying autism in ways that do not represent the personal experiences of their participants. Furthermore, autistic produced autobiographical works are probably viewed more positively as they offer a more affirmative, complex exploration of the autistic identity. In contrast, the diagnostic and research literature focuses on deficit representations and weaknesses

(Bagatell, 2010; Mogensen & Mason, 2015). Brownlow (2010) asserts that, in this focus on the negative aspects of autism, positive aspects are rendered “largely invisible” (p.20). Negative connotations and deficits tend to be a focus in diagnostic and research literature and society at large, but autistic people do not wish to identify with these deficit discourses that hamper the formation of a positive self-view (Brownlow, 2010; Mogensen & Mason, 2015).

These varying discourses are important to consider due to the impact of group membership, and the perceptions of that group, on the self-worth of autistic people (Cooper et al., 2017). Cooper et al. (2017) studied the relationship between self-esteem and autism as a social identity (Tajfel, 1982). Here, an individual forms a connection with the group and identifies shared group traits, which then become part of their self-concept. The individual is not only defined by their personal characteristics but by those shared with other group members (Tajfel, 1974). Cooper et al. found that the positive or negative perception of autism as a group identity, and resulting collective self-esteem, is influenced by the in-group and the out-group views of those group members. Cooper et al. therefore argue that the group identity needs to be defined positively both within and outside the group to increase collective self-esteem, which will then impact on personal self-esteem. This would entail a focus on the group’s strengths and positive characteristics, and on reducing stigma and victimization in society (Berkovits, Moody & Blacher, 2020; Jensen et al., 2016; MacLeod et al., 2013).

It must be noted that not *all* autistic adolescents view the group label of autism as negative. In Mogensen and Mason (2015), some participants felt the diagnosis gave understanding of their sense of being different, that they had always been aware of their difference, and that the label explained this. This opened avenues to information on how difficulties could be addressed, led to increased understanding or support, and gave a sense of control. Participants who viewed the diagnosis positively felt they had been able to identify shared group traits with autistic others and to gain self-understanding through this. In addition, some of Humphrey and Lewis’ (2008) participants focused on accepting autism as an important part of who they were. Conflicting views were seen across *and* within participant responses, suggesting a struggle for these participants in how an autistic identity should be framed.

Overall, autistic people are influenced by autism as a social identity, and the varying discourses surrounding that label. This can include negative stereotypes, which position them as an abnormal 'other.' Conflict in self-evaluation can arise from differing discourses, contrasting, for example, between negative out-group perceptions with positive in-group representations. In the following section, I discuss how some choose to distance themselves from the label- a strategy to protect their self-esteem from negative affect.

2.4.3. Protective Strategies: Positioning Away from the Label and Masking Autism

Distancing oneself from the stigmatised group can be an attempt to protect the self-view from negative influence. Distancing from the autism identity is evident in autistic people choosing to remain separate from the label and from certain perceptions of autism, which can result in different treatment (Davidson & Henderson, 2010; Johnson & Joshi, 2016; Mogensen & Mason, 2015).

This was evident in MacLeod et al. (2013) where participants attempted to distance themselves from the label of autism, and its unsociable associations. In their study, participants made downward social comparisons, emphasising their strengths by stating that they were more sociable than other autistic people. Downward social comparisons were also seen in Huws and Jones' (2015) interview study. Participants regularly positioned themselves as having a less severe form of autism than others and focused on making clear the social skills they had developed. Moreover, one participant emphasized how "inside we're just all the same", making a lateral comparison with non-autistic others (p.88). This positioned autistic people on an equal footing to their non-autistic peers. Both studies demonstrate a distancing from more severe forms of autism, characterized through negative, unsociable generalisations, and the relevance of social comparisons to autistic participants.

Participants in MacLeod et al. (2013) did feel there were benefits to contact with other autistic people, seeing this as an opportunity to learn more about themselves in relation to their autism, through looking for similarities. Shared group traits were an opportunity for self-understanding. Therefore, participants did not distance themselves from *all* autistic traits. MacLeod et al. suggest that what is important is the perception of the self as "*more* social" (p.43). Whilst their participants wanted to learn from other autistic people, through shared traits, they also wanted to protect an image of themselves as more social than others who are autistic. The anti-social generalisation was also rejected by participants in Mogensen and Mason (2015) who critiqued this perception as a “stereotype” (p.261). In this study, participants wanted to distance themselves from views of social incompetence. These findings demonstrate the importance of perceived competence in the social domain. Here, the self is distanced from the negative societal connotations of being an anti-social autistic person, which has a negative impact on self-view (Brownlow, 2010). This could be because, as the participants in Huws and Jones (2015) claim, behaving in “socially acceptable ways”, means you are valued more by others (p.3). The value in conforming to societal norms, including expectations about sociality, was therefore made clear by autistic participants (Lester et al., 2014).

In attempting to distance themselves, autistic people may undertake masking behaviour, in which autistic traits are hidden as a person attempts to “pass” as ‘normal,’ (Baldwin & Costley, 2016; Davidson & Henderson, 2010, p.156). Davidson and Henderson’s (2010) qualitative exploration of biographical accounts demonstrates the range of strategies employed to conceal identity, or to protect themselves when disclosing it. Judging who is trustworthy enough to be disclosed to is considered a way to keep safe. Hiding is also achieved through a variety of methods described as acting or masking, through protective props, such as headphones, or through disclosing a difficulty less stigmatized, such as headaches caused by bright lights. A sense of acting is also shown in Baldwin and Costley’s (2016) study. Here, autistic adult females demonstrated acting behaviours when describing social and employment situations, stating “I have learned to act and developed a list of public responses” and “I had to study acting to appear as normal for the customers” (p.490).

Masking behaviour can, however, have detrimental effects. For example, Bagatell’s (2007), participant reports that, in trying to act more ‘normal,’ his depression worsened. In attempting to change, he did not improve his well-being. Instead, the stress of trying to be ‘normal’ would build up, leading to increased depression and anxiety. Furthermore, he felt that his attempts to appear and be ‘normal’ were failures, that he would never make friends or have another romantic relationship after his first love. His attempts to improve his social competence were also viewed as failures, impacting on his well-being. This led to both self-harm and a suicide attempt, suggesting the negative impact of a perceived failure, to be what society deems ‘normal’, can have (Bagatell, 2007). Bagatell argues that the positioning of autistic people as marginalized, as failing to be ‘normal’, and of normality being the way to have a successful life, were powerful discourses, impacting negatively on her participant’s sense of self. In Baldwin and Costley (2016), a participant discussed the stress and difficulty in going against “my natural grain” and that setting a standard of being ‘socially normal’ is impossible to maintain (p.491). In a similar way, an autistic male in Pellicano et al. (2014b) suggested that keeping up this “façade” can be “exhausting” (p.763). All this, as Molloy and Vasil (2004) suggest, can have a negative impact on self-esteem. In changing yourself to ‘fit in,’ the message is that “people will only like me if I pretend to be someone else,” that who you are is not good enough (p.133). Consequently, whilst autistic people may put on masks, to outwardly protect themselves from societal stigma, as shown in first-hand accounts, these masks do not protect the person from negative impact overall.

Masking and distancing from the autism label are therefore discussed in a range of autistic people’s accounts, and these include the negative impact of such a strategy. These strategies are particularly pertinent to social aspects, with masking deployed in social spaces to appear ‘normal.’ Thus, this emphasises the awareness of social perspectives which autistic people have, and the impact of these on how they choose to *present* that self to others.

2.4.3.1. Masking to ‘Fit in’: Autistic Children and Adolescents. The camouflaging of the self to fit ‘normality’ is further evident in research with autistic adolescents (Baines, 2012; Humphrey & Lewis, 2008; Mogensen & Mason, 2015). It is therefore relevant to the autistic adolescents in my own study.

Humphrey and Lewis’ (2008) adolescents suggest that being perceived as different leads to vicitimisation and therefore deception may be required to keep safe. Participants here wanted their diagnosis to be kept secret to prevent difference in treatment, feeling the need to change their behaviour to appear “normal” (p.40). An awareness of appearing in a socially acceptable manner was also reported in Carrington and Graham’s (2001) case study. One of the adolescent autistic participants was particularly mindful that, to ‘fit in’, he would need to remove the autistic traits he was mocked for. Additionally, both the autistic adolescent males involved shared the stress associated with meeting academic expectations *and* the social expectations of their peers.

Baines' (2012) ethnography further presented the desire of autistic young people to ensure positive peer perceptions, in this case, through distancing themselves from the autism label. One participant, Mark, showed constant concern about the perception of others and changed his behaviour in response to this. He stated he was "autistic in a way, but not really," and felt he had "overcome" his autism (p.551), illustrating his desire to distance himself from his diagnosis by placing himself as 'recovered'. Mark also characterised autistic behaviours as "slips" which make you appear "cuckoo" or "crazy" (p.551). Mark therefore controlled or suppressed these behaviours. Mark followed a normalisation narrative of needing to change, hide or remove autistic behaviour. He wanted to move away from the autism label, which he viewed as a negative difference, resulting in a lack of respect from others.

For these autistic adolescents 'passing' within the school environment was not only a case of suppressing behaviour but also a process of repositioning the self, to be placed within a different 'storyline' (Baines, 2012). Mark focused on being valued within a smart narrative; he wanted to improve his social position through being respected as a successful student by both teachers and peers. He found pride in good grades and in debate team wins, where he felt he was "conquering my enemies". Here, Mark focused on academic success and beating "enemies" to give a positive sense of self. He hid autistic stimming, which he viewed as "crazy," at home (p.551). This was a part of himself he did not want anyone else to see. There is a focus within both participants' discussions on fitting in, and how they behave accordingly to do so. Another participant, Anthony showed conflicting views on whether he wanted to fit in and be valued by peers as an entertainer, a class clown, or be perceived as a smart student. In a context such as debate team, he wanted to move away from being considered "a retard" and enjoyed being viewed as intellectual. He suggested here that he would "dumb myself down" once back in the classroom setting (p.552). Anthony therefore positions himself one way with peers who he feels would not appreciate intelligence being shown and another in debate team, where intellect is valued. He focused on jokes and making fun of himself as a protective strategy in the classroom, when he felt others may laugh at him, to control that laughter. Here, both boys wanted to position themselves within school roles away from the autism label, focusing on different labels which can be given within the school setting.

Runswick-Cole (2016) argues that a label of autism “drowns out all the other stories that could be told” (p.26). Perhaps, in Baines (2012), both boys chose to position themselves within other narratives not only to feel valued and respected, and therefore to feel a more positive perception of themselves, but also to ensure other storylines could be heard. Storylines of strength, in either entertaining others or academia, that would not be “drown[ed] out” by negative perceptions of the autism label. In foregrounding these alternative narratives, autistic adolescents can devalue domains of perceived weakness and value domains of strength and positive feedback (Crabtree & Rutland, 2001). This is further evident in the findings of Williamson et al. (2008). The autistic young people in their study also placed emphasis on domains in which they felt more competence and control and minimised areas of less competence.

In sum, masking and positioning with regards to the autistic label is not only undertaken by adults and is also evident in research with adolescents, who attempt to present a self which is viewed positively by their peers. However, not all autistic adolescents, or adults, take such an approach. Alternative attitudes will therefore now be discussed.

2.4.4. Protection Strategies: Celebrating and Accepting ‘Difference’

I now show how hiding or distancing from autistic identity is not the only strategy for autistic adolescents and adults. In this, I consider the societal barriers to an acceptance or celebration of autism as a social identity, which would enable a positive self-view.

Brownlow (2010) and Bagatell (2010) both studied autistic community groups, who came together in-person and online. These autistic adults celebrated difference and dismissed deficit narratives of change, moving against cures and treatments to become ‘normal.’ In Brownlow, contributors placed value on those traits viewed as indicative of the autism group label and rejected those from outside the group. They countered the negative positioning of autism and discussed positive representations of autism as a group identity, spurning the idea of masking behaviours to appear ‘normal,’ and focusing on presenting themselves ‘as they are.’ In Bagatell, autism was also a valued as a part of the person’s identity with differences, such as “unusual or restricted interests,” or stimming, reframed as positive traits and actions (p.38). This followed Cooper et al.’s (2017) suggestion to focus on group strengths, to redefine a positive group image and have a positive impact on collective self-esteem.

There is, however, a barrier, as in-group redefinitions may not be enough. As discussed previously, outgroup perceptions can impact on group identity (Cooper et al., 2017). In attempting to counter deficit, negative perceptions of autism, some autistic people in Bagatell (2010) encountered difficulty and resistance from the non-autistic community. For instance, Sinclair (2005 cited in Bagatell 2010) asserts that if autism is suggested to be anything other than a "devastating tragedy, there would be accusations and attacks from parents" (p.42). Whilst positive representations may be found within the group, these discourses may not be present outside (Bagatell, 2007). As many autistic people, including autistic adolescents in mainstream school, must exist within these out-group discourses, positive representation within the group may not be enough to counter negative effects. Reducing stigma and victimization in outer *society* is also required (Jensen et al., 2016; John et al., 2018; Mogensen & Mason, 2015).

Positive views of difference have been found in studies of autistic adolescents (Williams et al., 2017). In Mogensen and Mason (2015), one participant reframed difference as a point of pride. He felt he was admired for being "mysterious" and focused on his punctuality and knowledge of security services as strengths (p.260). He directly attributed these strengths to autism. Whilst exploring domains of success and strength, difference was reframed as a positive which peeked his peers' interest and admiration. This participant's experience further illustrates how the positive reactions of *others* can influence self-view. Friends and classmates were seen to react positively to difference in ways which permitted a positive association with the autism label.

In Humphrey and Lewis (2008), some autistic adolescents had accepted their difference and were proud of this, stating "I like being this way." Although it must also be noted, they employed 'normality' as part of their positive self-views, "Sometimes I think I am normal, I am treating this autism very well" (p.32). Both academic strengths *and* social success were employed as evidence of being "normal." In contrast, whilst the participant in Bagatell (2007) was academically successful, their lack of success in social domains left them feeling a sense of failure. Social success can counter feelings of difference and allow an acceptance of the authentic self. This was evident in Mogensen and Mason's (2015) participant who began to feel “normal” when he found a group of people who accepted and valued him “for who I am” (p.264). As in Humphrey and Lewis, social success equates with normality, social failure is seen as representing negative difference and impacts on how the self is viewed, with a sense of not belonging increasing feelings of depression (Bagatell, 2007; Jones, Zahl & Huws, 2001). The importance of fostering positive social relationships to self-worth is further demonstrated in Bauminger, Shulman and Agam’s (2004) study, which compared perceptions of friendship between autistic and non-autistic children and adolescents. This study found friendship and a sense of closeness made an important, positive contribution to these young people, increasing their self-worth. This demonstrates the importance of perceived social success, and friendship, to autistic children and young people.

This section has shown how some autistic people celebrate their differences and aim to reframe autism as a positive identity, even though outside influences can still challenge these attempts. Furthermore, positive representations presented by autistic adolescents are often linked to discourses of normality or to positive treatment by peers, in which friendship is especially valued. Subsequently, the link between social perception and self-evaluation for this group is emphasised.

Throughout 2.4, the relevance of the social world to the self-evaluations of autistic people, including adolescents, has been made clear. A key environment for autistic adolescents to experience the social world is the school setting. Therefore, the educational setting has a central role in either improving, or worsening, the impact of social interaction on self-view (Harter, 2012; Williams et al., 2017). I now consider studies which focus on the impact of this key social environment on autistic young people.

2.5. Sense of Self and School: Enabling a Positive Self-View

In this section, I consider how the school environment can impact on the self-view of autistic pupils, highlighting how, currently, this influence is often negative. I discuss a small number of suggestions, from the literature, on how a positive sense of self can be enabled for autistic adolescents. These suggestions move beyond an in-child problem approach and, as such, align with my own stance (as described in Chapter 1). To conclude, I illustrate the lack of research which considers the influence of the mainstream school environment on autistic pupils' self-view through insider accounts. This demonstrates the gap in knowledge, that my own project seeks to address.

2.5.1. School as a Negative Social Environment

Mainstream schooling can be a problematic place for the autistic pupil with negative influences on self-view from bullying, social exclusion, and narratives of 'abnormal' difference. In what follows, I highlight both areas of difficulty *and* changes that could be made, to enable a positive self-evaluation.

School can be a place where autistic adolescents see themselves as outsiders (Howlin, 2003). Many autistic young people have exclusionary experiences at school, which can leave them feeling socially marginalised (Williams et al., 2017). This includes prevalent bullying and victimisation in mainstream settings (Cook et al., 2016; Zablotsky et al., 2013).

Goodall's (2018) study particularly foregrounds autistic pupils' insider views of isolation and bullying in UK mainstream secondary schools. Whilst sense of self is not a focus of his study, links can be made to my own research. Goodall adopts a similar position to me, prioritising the personal accounts of autistic adolescents, with the aim of identifying how their experience can be improved. In his participatory research, the loneliness and bullying experiences of autistic pupils were emphasised. Participants shared the extremes of bullying that can occur for autistic pupils, with one discussing how peers stated they should kill themselves, and others sharing both physical and sexual examples of abuse. These issues were directly linked to perceptions of autism, with one participant sharing, "if you have a disability they don't want to know, they look down at you" (p.9). This research illustrates the possible extreme nature of autistic adolescents' negative experiences, alongside their clear awareness of a lack of peer acceptance of autistic people.

Such negative experiences have a detrimental impact on the self-view of autistic adolescents (McCauley et al., 2017). The negative influence of these experiences on self-esteem is highlighted in Bolic Baric et al.'s (2016) semi-structured interviews. This study illustrated the dehumanising impact of school bullying, which can make individuals feel unworthy and unaccepted; a victimisation that was linked to being 'odd' and different. Humphrey and Lewis (2008) argue that this sense of being 'abnormal' can become part of an autistic pupils' self-concept. Williams et al. (2017) assert that evidence of the use of terms such as retard, freak or weirdo in autistic pupils' *own* self-description, demonstrates that negative responses from peers have been internalised, with pupils repeating the words heard from bullies, to describe themselves (see Carrington, Templeton & Papinczak, 2003; Humphrey & Lewis, 2008). This can enhance a lower sense of self-worth.

As discussed previously, these negative experiences can lead to masking, the suppression of behaviours that mark autistic pupils out as 'abnormal' (Williams et al., 2017). Pupils may also avoid disclosing their diagnosis, to both peers and teaching staff (Humphrey & Lewis, 2008; Samra, 2016; Stevenson, Cornell & Hinchcliffe, 2016). These strategies aim to counter the effect of standing out from peers, who lack respect for those who display autistic behaviours (Baines, 2012; Carrington et al., 2003). Furthermore, with teachers, a sense of judgement can be experienced. For instance, in Goodall (2018) one participant said that, "Every time I felt I couldn't keep myself together properly I felt like they were just looking down at me" (p.9). Because of this, behaviours may be supressed to maintain a positive image with staff, as well as with peers. In addition, autistic adolescents felt that teachers were influenced by stereotypical views of autistic students and that they viewed them as one homogenous group (Goodall, 2018; Humphrey & Lewis, 2008). Instead, as in Bolic Baric et al. (2016), autistic pupils wanted to be treated as individuals. Furthermore, in Humphrey and Lewis (2008) and Saggers (2015), mainstream autistic pupils in both the UK and Australia, shared a desire not to be treated differently to others, emphasising how they were marked out by highly visible, additional support. This treatment highlighted how they were different to their peers, hampering their attempts to 'fit in'. Subsequently, this may influence a wish to hide diagnoses, to prevent such treatment from school staff.

Similarly, Humphrey and Lewis' (2008) autistic pupils shared how the mainstream school could be dominated by a need to 'fit in' where "it's the culture. Everybody's got to…" otherwise they are open to being "picked on and abused" (p.40). Being 'different' leads to a higher likelihood of rejection within the mainstream school culture of 'normality.' Williams et al. (2017) also found that relationships with, and appraisals from, peers and teaching staff in the mainstream setting influenced autistic pupils' self-view. Most pupils in their analysis perceived their differences as negative in form, with only a few accepting or celebrating difference. Additionally, they identified that social and sensory difficulties and comparisons with peers further enhanced autistic pupils' feelings of difference. Most comparisons with non-autistic peers emphasised a negative difference, with upward social comparisons highlighting things that non-autistic peers 'do better.' These comparisons would be magnified in mainstream school settings, due to a wider number of opportunities to do so. As with the university students discussed in MacLeod et al. (2013), a smaller number of pupils in Williams et al. made downward social comparisons, with those perceived as having more severe autism (McLaughlin & Rafferty, 2014 cited in Williams et al., 2017) or identify areas in which they are more successful than their non-autistic peers (Baines, 2012; Mogensen & Mason, 2015). However, these are in the minority, comparisons with peers most often have a negative effect.

In contrast, positive peer relationships can enable feelings of being liked and accepted, resulting in positive self-evaluations (Humphrey & Lewis, 2008; Williams et al., 2017). This emphasises the importance of addressing these social influences in the school environment. To do so, Williams et al. (2017) argue that interventions with *non-autistic* pupils should be undertaken. These interventions would aim to foster acceptance, challenge negative stereotypes, and enable positive attitudes, which would subsequently improve the self-evaluation and wellbeing of autistic pupils (Berkovits et al., 2020; Humphrey & Lewis, 2008). Saggers (2015) also suggests specific interventions to promote understanding and support from non-autistic peers. This includes listening and social skills support and creating peer-based interest groups, which have teacher supervision. Finally, Hodge et al. (2019) argue that non-autistic peers need to be involved in supporting the development of a positive sense of self for autistic pupils. These researchers all focus on promoting positive peer relationships, and support, without placing the autistic child as the 'problem,' who needs to change.

As shown above, school's social influence is evident for autistic adolescents. Yet, autistic pupils' sense of self in relation to the school experience is a significantly under researched area (Hodge et al., 2019). I now consider this gap in research.

2.5.2. Mainstream Schooling, Sense of Self and Self Esteem

Friendship with peers and bullying experiences in mainstream schooling have been considered by a range of researchers. However, less emphasis has been placed on what this means for how autistic pupils conceptualise themselves, the identity they choose to present, and the impact school can have on their self-evaluation. In this final section, I discuss research into mainstream school, sense of self and self-esteem. I illustrate that these studies are in the minority and that, in comparison to my own research, there is a lack of consideration of the varied ways in which autistic pupils themselves want to be presented, and the wide range of elements which can enable or disable a positive self-view.

The current gap in research may be influenced by the dominant educational focus on improving *academic* achievement, with less attention being given to social, emotional needs (Bolic Baric et al., 2016). This focus is seen in a range of research, which considers academic progress for autistic pupils (Ashburner, Zivani & Rodger, 2010; Fleury, et al., 2014; Keen, Webster & Ridley, 2016). Moreover, Williams et al. (2017) argue that deficit narratives characterise autistic adolescents as unaffected by the interpersonal world. Consequently, a socially formed sense of self for autistic pupils has not been prioritised in either academic or educational fields.

This gap in research is evident in Williams et al.'s (2017) metasynthesis of qualitative studies (see Chapter 1 for process). This review included studies which prioritised insider autistic experiences, relating to their sense of self within the school context. Of the 17 papers identified which studied autistic pupils' views of their school experiences, only two considered mainstream secondary schooling and sense of self- Molloy & Vasil (2004) and Baines (2012).

Molloy and Vasil's (2004) narrative research focused on how adolescents diagnosed with Asperger's Syndrome (AS) answer the question of 'who am I?' Interview transcripts were rewritten into a narrative form, creating an individual story about each participant's life. In this, the aim was to represent an insider view of autistic adolescents' self-identity- the self they chose to present to others. As in my own work, Molloy and Vasil place themselves in opposition to medical, deficit models, which they believe devalue autistic adolescents as 'abnormal.' Themes emerging from this study corroborate themes identified above: the troubled relationships between labelling and identity, concerns about socialising and friendship and the influence of school on the self-view. Here, experiences of bullying and narratives of being an outsider and 'different' continued. Participants also highlighted how it was not having the "right" interests or topics of conversation, that marked them out as "uncool" (p.140).

Whilst social influences were mainly negative, academic achievement could have a positive impact. One participant was proud of being a gifted student and attributed his bullying experiences to *the bullies'* lack of intellectual ability. He was aware he was not "the most sociable of people" (Molloy & Vasil, 2004, p.136), but gained value from his academic achievements. A focus on strengths can also be seen in some participants' views of their AS label. Participants emphasised their concentration, understanding of abstract ideas and intelligence as a positive part of their AS. These were given as counter points to social difficulties. However, it must be noted that not all participants felt this way, with some viewing AS as *the* source of social problems, with *no* positive aspects. Similarly, Berkovits et al.'s (2020) autistic adolescents also shared mixed views, reporting autism as both a burden, resulting in social stigma, and as a positive source of academic ability, creative skills and/or abilities in an area of interest.

Molloy and Vasil's (2004) adolescents linked areas of interest to their future selves, with planned careers based on their current interests. One participant wanted to be defined by this choice, choosing to present his identity in relation to his career aspirations, rather than the AS label. However, although Molloy and Vasil identify that some participants felt negatively about AS, and did *not* want to be defined through this, their discussion of the findings of the study did not reflect this. There was a consistent focus on the AS label and the difficulties in relation to this. This perhaps indicates a prevalence of the researchers' perspective, over that of the participants, and their insider viewpoint. Williams et al. (2017) also criticised this study for a lack of transparency in the findings, which they felt had a paucity of supporting extracts, from the participants' own words. Therefore, Williams et al. assert that this is a 'low' rated study, which does not meet its overall aim of giving voice to autistic pupils' perspectives.

Baines' (2012) ethnography, as discussed, also considered how autistic adolescents positioned themselves, including in relation to the label. In contrast to my study, this was undertaken in a US mainstream school with older adolescent males (aged 16-18). The findings of this study demonstrate how these autistic young men chose alternative school narratives, of entertainer or academic, in which they wanted to present their identities. In this, they aimed to move away from the negative associations they felt autism had within school. Whilst Baines begins to consider how autistic adolescents present themselves in school, she does not discuss the impact of this on their self-esteem. The focus is on autistic adolescents' attempts to create a positive reputation in the school environment. Furthermore, whilst interviews were included, observations of the students were part of the analysis. Therefore, whilst insider perspectives were shared, outsider observations also featured in the conclusions made. This moves away from the participant, insider driven approach of my research.

Since Williams et al.'s (2017) review, a couple of additional studies have considered self-concept and school for autistic pupils. For example, McCauley et al.'s (2018) study of academic self-concept, in maths and reading, compared autistic children and adolescents with an age-matched non-autistic group. All participants were from mainstream schools in the US. The study considered whether academic self-concept (perception) was matched by actual academic performance. This ability to self-assess 'accurately' was viewed as important to improving academic achievements. The researchers employed the hypothesis that autistic pupils would have difficulty developing an 'accurate' self-concept of maths and reading, in contrast to non-autistic pupils. However, they concluded that autistic pupils had an 'accurate' self-concept for maths but an 'inaccurate' one for reading. This study highlights both an outsider, deficit approach and pursues an academic focus, which ignores the emotional impact of self-evaluation (Bolic Baric et al., 2016). It does not consider how academic self-concept, and perceptions of academic competence, can impact on the self-esteem of autistic pupils (Harter, 2012; Molloy & Vasil, 2004). Moreover, it has a narrow view of *one* area of self-concept, instead of contemplating the range of self-elements defined and evaluated within the school environment. In contrast, a wide-ranging approach, including a consideration of the impact on self-worth, is taken in my own work.

Hodge et al. (2019) considered how UK school staff, in mainstream and specialist settings, conceptualise autistic pupils' sense of self and identified the barriers to enabling a positive self-view that the *educators* felt autistic pupils encounter. The views of the educators in this study demonstrate how autistic pupils' relationship with the label, and active positioning of themselves with regards to that, are evident in current UK schooling. Educators shared that some pupils would continually monitor themselves and mask behaviours to appear 'normal', which had a negative impact on their wellbeing. This study argues that the school environment can be a place which emphasises an in-person problem and a need to 'hide' or ‘change’ autism, with school interventions often focusing on the autistic pupil changing to appear more ‘normal’ (Shyman, 2016). Hodge et al. conclude that, whilst the physical and social environment of school is viewed by educators in their study as one which has a negative influence on the developing sense of self of autistic pupils, it is an environment that they are unsure how to alter.

In response, Hodge et al. (2019) propose a framework for supporting the development of a positive sense of self. This includes valuing and accepting autistic pupils’ differences and contributions, identifying and removing physical and social barriers within school, and increasing opportunities for autistic pupils to connect with others from the autism community. Hodge et al. assert that connecting with others who embrace autism as part of their identity could help autistic children and young people in knowing, accepting and valuing themselves as an autistic person.

As in my own research, Hodge et al. (2019) work from a CAS approach, identifying who has the ‘power’ in the construction of a sense of self for autistic pupils. In this, deficit and disabling narratives are identified, alongside those which could empower pupils to feel more accepted and valued. However, as acknowledged in the paper itself, a limitation of their CAS approach was that autistic people were not involved in the design and implementation of the study (Woods et al., 2018). This paper also represents *educators’* perspectives on the autistic pupils’ experiences. In contrast, my research places autistic voices at the centre of the project, both in terms of sharing their views and experiences and in defining their self-description. As such, it prioritises participant control within the process.

In summary, the social environment of the mainstream secondary school can have a negative impact on autistic adolescents. School can be a place of bullying, social exclusion, and a sense of undesirable difference. This can have a detrimental impact on self-worth and wellbeing, leading to masking of the autistic identity. To support positive self-evaluations, it has been argued that schools should promote acceptance and value autism as part of a young person’s self-description. However, it must also be appreciated that they may not wish to be defined by this. Some autistic young people focus on alternative school ‘labels,’ particularly in terms of academic success, which can enable a positive self-view. This choice, in the identity they wish to present, should be respected. Prioritising autistic adolescents’ views and opinions is the driving force of my study, which is led by my participants' perspectives and wishes. This addresses the gap in insider-led research, which brings together *all* the elements of the self-concept for autistic pupils in mainstream secondary school. As such, I consider how autistic pupils conceptualise, present, and evaluate their sense of self within the school setting, including the influence of the school environment on those processes.

2.6. Conclusion

Influential discourses in the conceptualisation of the sense of self have provided 'norms' against which to measure the sense of self of autistic people.

Sense of self has been conceptualised in terms of how the self is described and evaluated. Influenced by the Jamesian model, the self-description is argued to be based on physical, social and emotional aspects alongside a sense of continuity, agency and distinctness. It is asserted that the formation of a reflective, differentiated sense of self is developed though interpersonal relatedness.

These theories have set out developmental 'norms,' which have been utilised to perpetuate deficit narratives. Deficit research claims that autistic adolescents lack an 'essential' interpersonal influence in their self-view and, therefore, are unable to form a fully developed, reflective self.

Challenges to dominant deficit discourses.

Challenges to deficit discourses argue that *expectations,* of finding a 'disordered' difference, and inaccessible research methods have perpetuated deficit conclusions. This was evidenced in studies which used alternative, accessible methods, which enabled autistic adolescents to demonstrate an ease in self-reflection and the relevance of the social world to their self-view. Such studies are currently in the minority, but they do show how the research methods used can produce certain perceptions of autistic adolescents' sense of self.

The barriers or enablers to a positive sense of self.

The evaluation of the self is conceptualised as social in form, influenced by comparisons with, and judgements by, others. This results in a sense of self-worth (self-esteem). Autistic adolescents desire social approval and acceptance and are influenced by the positive or negative evaluation of others. The significantly lower self-esteem found in autistic adolescents could be based on their negative social experiences, which include bullying, social exclusion and societal stigma and stereotypes, which position autism as an 'abnormal' difference.

A person may attempt to protect their self-worth from these negative influences by distancing themselves from the autism label, masking negatively viewed autistic traits and hiding their autism diagnosis. In this, they may attempt to align with societal norms and/or to position themselves within more socially valued categories, which focus on their strengths. However, the pressure and stress such masking entails can have a detrimental impact- changing the self to 'fit' suggests that 'who you are' is not good enough. An alternative approach is taken by some autistic people, who celebrate their difference, reframing this as a positive identity and dismissing a need to fit society's views of 'normality.' However, this is a society that autistic adolescents still encounter daily. Therefore, external, societal barriers need to be considered.

The influence of the mainstream school environment on the sense of self and self-esteem of autistic adolescents.

There has been a lack of insider-led research which considers how the social environment can be a barrier to enabling a positive sense of self for autistic adolescents. This includes the highly relevant social space of the mainstream secondary school setting, where a range of negative judgements and comparisons with non-autistic peers can be made. Here, autistic pupils can experience social exclusion, narratives of abnormal difference and prevalent bullying. This bullying can be extreme in nature and have a dehumanising effect. These negative experiences can be internalised in the autistic adolescents' self-view, having a detrimental impact on their self-worth. This can lead to autistic adolescents employing the protective strategies discussed above, which aim to 'fit in' and to avoid differing treatment. Autistic adolescents can feel pressure from their peers, educators, and school interventions to change and be 'normal.' My research joins those studies which argue that, rather the child having to change, focus must be given to how the school environment can be altered, to enable a more positive self-view.

To address current gaps in research, my study considers how autistic pupils conceptualise themselves, the identity *they* choose to present, and the impact school can have on their self-evaluation. To do so, it takes a participatory approach, which is discussed in the following chapter. This approach aimed to prioritise the voice of autistic adolescents, enabling me to appreciate the varied ways in which *they* wanted to be presented, and the wide range of elements which can enable or disable a positive self-view.

Chapter 3: Towards a Participatory and Emancipatory Approach

In this chapter, I consider the theoretical aspects of the paradigm in which I operated, identifying the participatory and emancipatory ideals which influenced the design of the study. The boundaries that define emancipatory and participatory research are not always made explicit (Chown et al., 2017; Walmsley, 2001) and consequently, research claiming to employ such approaches often requires further definition. In this chapter, I distinguish key elements of these forms of research, considering how these aim to give participant power and control, and place participants as the 'experts' on their lived experience, with a focus on *their* expert voices being fully heard. This can involve a range of inclusive methods, allowing participants some degree of control over which form to employ, to meet their preferred mode of communication.

I explore participatory and emancipatory approaches to provide a solid foundation for the research paradigm which guides this work. I discuss these ambitions and ideals in terms of the power differential between children and adults, showing how they apply to my own participant group. I then outline the stages of my study, in relation to these principles. This includes: the validation of the research topic by my participants; participant choice over the inclusive research methods employed; participant involvement in the interpretation of data; and participant evaluation of the process. When discussing this, I consider the limitations to a 'full' participatory approach. I do this to offer a critical consideration of the ideal of maximum participant involvement. I also make links to Critical Autism Studies (CAS) to clarify how the CAS aims of my research are supported through participatory and emancipatory paradigms. Finally, I discuss how a participant-led evaluation of the study can offer an important contribution to methodological knowledge. This highlights the value of this evaluation, for future research.

3.1 Participatory and Emancipatory Approaches: Participant Power and Voice

A key concern for participatory and emancipatory research is foregrounding participant voice and control throughout *all* the stages of the research process. Through using these insider 'expert' voices, such research seeks to produce beneficial outcomes for the participants' community group.

Both participatory and emancipatory approaches aim to foreground the voices of participants who are traditionally marginalized, recognising these participants as experts on their lives and experiences (Bourke, 2009; Stone & Priestley, 1996). This does not deny the expertise of the researcher in conducting research and analysis but underlines that it is the participant who is the expert “knower” (Stone & Priestley, 1996, p.713).

From this perspective, Macaulay et al. (1999, p.745) describe participatory research as a “partnership among equals with complementary knowledge or expertise.” The researcher’s expertise in research methodologies and methods complements the expert knowledge of autistic people, forming a mutually respectful relationship (Cargo & Mercer, 2008). Research is undertaken *with* participants in a considerate alliance, where decision making is shared (Chappell, 2000). Active participation becomes a fundamental part of the study, with participants involved in project design, choices on data collection methods, analysis, dissemination and outcomes (Bourke, 2009; Macaulay, 2017). Bourke (2009) argues that it is control over the research process which moves power from the researcher as ‘expert’ to the participants; a shift of power which is key to the participatory approach (Nelson & Wright, 1995 cited in Fletcher-Watson et al., 2019). However, Bourke notes that whilst full participation may be ‘ideal,’ this is not always achieved. Research which claims to be participatory can vary in the levels of participation achieved (Jivraj et al., 2014). This is discussed further in 3.1.2.

Emancipatory approaches, in disability studies, take the power shift one step further. A primary objective is research *by* disabled people, where the researcher is at their disposal. Research is ‘owned’ by disabled people- they are in control of *all* aspects of the research process (Chappell, 2000; Stone & Priestley, 1996). Consequently, the researcher’s accountability is to disabled people and their organisations, rather than to non-disabled research funders (Walmsley, 2001).

Both approaches demonstrate a commitment to the people involved in research, and aim to improve their day-to-day lives, removing the barriers which prevent these lives from being fulfilling (Macaulay et al., 1999; Park, 1999). Emancipatory research follows a social model, taking an *overt* political commitment to challenging societal barriers (Chown et al., 2017; Walmsley, 2001). From this point of view, research should be undertaken *only* if it can have positive benefits and, as such, actively seeks to enable change for disabled people

(Walmsley, 2001). In this, it may also challenge dominant, medical model research (Oliver, 1997). This therefore aligns with the CAS principles of challenging dominant deficit-focused constructions of autism (Orsini & Davidson, 2013).

In being influenced by participatory ideals, my study sits within a growing movement of participatory autism research, which promotes the meaningful involvement of autistic people (e.g. Chown et al., 2017; Fletcher-Watson et al., 2019; Milton et al., 2019). Studies within this field place autistic people as “experts” in autism and “autistic subjectivity and culture” (Milton, 2014, p.800). This emphasises the experiences and priorities of autistic people themselves, which become central to the research findings. This focus on autistic people’s views is, for Fletcher-Watson et al. (2019) and Chown et al. (2017), vital to improving outcomes for autistic people by informing subsequent practice from the ‘expert’ point of view of the autistic people directly experiencing, and impacted by, the issues explored. These approaches align with the CAS aim to enhance the meaningful contribution of autistic voices (O’Dell et al., 2016). This stands in contrast to ‘tokenistic’ involvement in research, which Fletcher-Watson et al. (2019) assert is when participant involvement does not influence outcomes, with the values of the community subsumed by the wishes of the researcher.

Avoiding tokenistic participation in autism research was a concern raised in Pellicano et al.’s (2014a) study, which considered autistic people’s views on being involved in research. Autistic people reported a desire to be involved in research beyond a tokenistic level; they sought to be more involved in the research process. Those who expressed dissatisfaction with research discussed feelings of being objectified “like guinea pigs” or “monkeys in a zoo” (p.4). They felt devalued by the practice, having no awareness of being able to ‘have a say’ in research, or feeling that when they did speak, if it did not fit the researcher’s agenda, it was not listened to. This was linked to a lack of respect for their lived experience as autistic people, and their expertise around being autistic. They desired being equally valued, due to the expertise that they shared. For those autistic participants who felt high levels of satisfaction with the research process, the respectful attitudes of the researcher were a key ingredient. As such, the interactions autistic participants have with researchers can impact on both current and future participation- a voice that feels devalued may cease to be shared (Milton, 2014). Building respectful relationships are therefore a key part of the participatory process, even though this may increase the time and effort required (Fletcher-Watson et al., 2019; Pellicano et al., 2014a).

In summary, participatory and emancipatory approaches both consider the power and active involvement of research participants in the research process, though vary on the degree to which this is aimed for. Participatory ideals are evident in the growing field of participatory autism research, which values the expertise of autistic people and promotes their meaningful involvement in research. Focusing on the power differential also supports CAS aims, which endorse such a focus (Orsini & Davidson, 2013).

In my own project, with secondary school pupils, it was necessary to consider how the interaction between *adult* researcher and *young* participant may also be relevant to the power differential.

3.1.1. Power and Participation: Adults and Children

The power differential between adults and children can further impact on the research process (Clark, 2010). This can be a difficult barrier to address due to the "obvious differences… in terms of cognitive and communicative maturity, power and physical size" (Corsaro & Molinari, 2008, p.242). The power the adult researcher holds is further increased by their control over the research process. Gallagher (2008) argues that research control results in those already marginalised by age, or perceived ability, such as autistic children and young people, being further marginalised, due to their lack of control over the process of knowledge production.

Participatory and emancipatory approaches, which priortise participant control, may be a vital tool in addressing this power imbalance. However, there can be considerable variation in the *levels* of participation seen in research with children which claims to be participatory (Holland, Renold, Ross & Hillman, 2010). Holland et al. (2010) categorise participatory research undertaken with children into four forms. The lowest level is participatory only in the sense that children are invited to take part- the rest of the process is controlled by the researcher. Participants have little choice over the research design, subject matter or form of communication. The second level of participation consists of research which changes the form of communication to suit the participants involved. Here, child-centred methods such as role play, drawing or map making may be used (as in Clark, 2010; 2017). The third level involves children having some influence on the research design, analysis and/or dissemination. The fourth level of participation mirrors emancipatory ideals, with research undertaken *by* children. Here, children initiate decisions and create plans, which they then share with the adult researcher. This level envisages children being trained in research methods, so they can carry out the research themselves.

Hart (1992) and Holland et al. (2010) argue that levels of participation are as relevant to children and young people as they are to adult participants. However, a lack of appreciation of the competency and understanding of children and young people can hold researchers back from requesting full participation. Fletcher-Watson et al. (2019, p.944) suggest that current autism research involves "no power, or only tokenistic forms of power, for the autistic community." A lack of participation for autistic people can spring from similar assumptions about a lack of competence, and concerns over perceived social communication difficulties can add to this (Winstone et al., 2014). Such perceptions can be used "as an excuse not to engage with autistic people" (Fletcher-Watson et al., 2019, p.948; Pellicano et al., 2014a). Subsequently, autistic young people and children may only be able to access tokenistic levels of participation, due to deficit assumptions about their competence to participate.

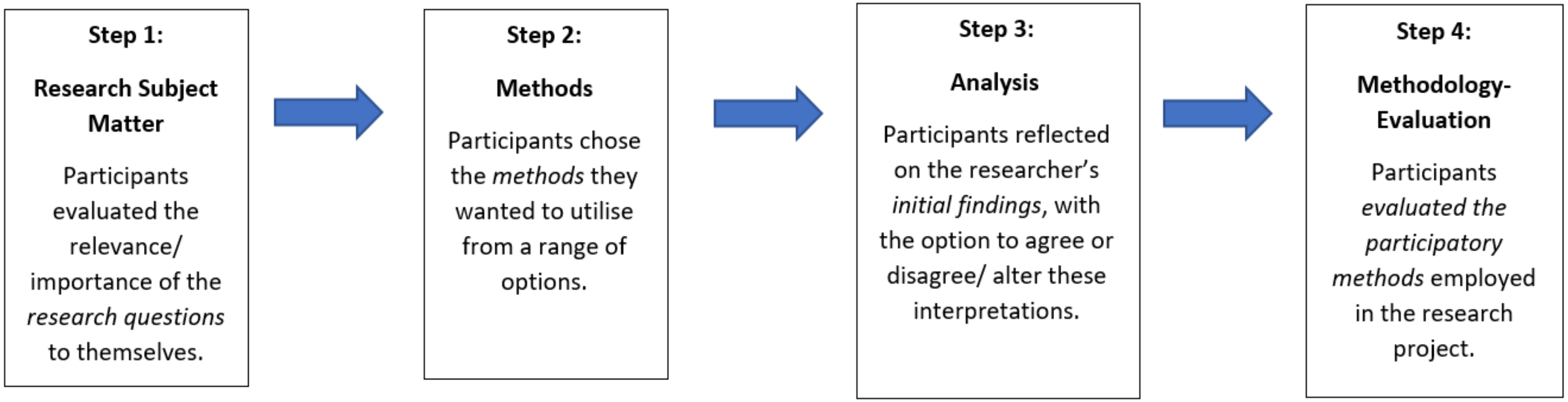
In contrast, I followed the philosophy underpinning Biklen's (2005) qualitative study, which included autistic people as its primary authors. Biklen's premise was that "people classified as autistic, even those who cannot speak, are thinking people with ideas about their lives and their relationship to the world" This is a "presumption of competence" which I adhered to throughout the research project (p.1). I was also influenced by Alderson's (2008) assertions on the importance of not infantilising children, not assuming immaturity, and not shaping research around an idea of incompetence. However, I was aware of the importance of avoiding language which was academic to the point of incomprehension, offering full and clear explanations, so that the young people involved were not made to feel incompetent, due to a lack of understanding. The aim was to create an empowering and supportive space, where the young people involved could fully "speak in their own right" to the extent that they should wish (Alderson, 2008, p.278). The responsibility was on myself as the researcher to enable the autistic young people to have equal participation in research, rather than being excluded, through a presumption of incompetence (Fletcher-Watson et al., 2019; Scott-Barrett et al., 2018). In this, I aimed to reduce the power imbalance between adult researcher and younger participant, by ensuring the active involvement of participants in all stages of research (MacLeod, Lewis & Robertson, 2014). An overview of this process is now provided.

3.2. The Stages of Participation: An Overview

This section gives an overview of the stages followed in my research, focusing throughout on where power and control were placed (Macaulay, 2017; Sense, 2006). Within this process, participants were invited to give their views and opinions on the research questions; to choose their preferred method of sharing their views and experiences; to comment on the findings and to evaluate the methods employed throughout the project. The participatory process undertaken is shown in Figure 1 below, which illustrates the key stages of the research process.

Figure 1

Overview of the Participatory Process of the Research Project



Step 1:

Research Subject Matter

Participants evaluated the relevance/ importance of the *research questions* to themselves.

Step 2:

Methods

Participants chose the *methods* they wanted to utilise from a range of options.

Step 3:

Analysis

Participants reflected on the researcher's *initial findings*, with the option to agree or disagree/ alter these interpretations.

Step 4:

Methodology-Evaluation

Participants *evaluated the participatory methods* employed in the research project.

The following section considers each of the steps in Figure 1, discussing the relevant participatory or emancipatory ideals, alongside any strengths or limitations within such an approach. My own undertaking of this process is then detailed in Chapter 4.

3.2.1. Participant Control Over the Research Focus

The maximum level of participation is viewed as the ideal for participatory research (Bourke, 2009). However, limitations around research questions were identified as an issue in Jivraj et al.’s (2014) scoping review of participatory research, with participants who were autistic or had “neurodevelopmental disorders” such as epilepsy or Down’s Syndrome (p.783). Here, all but two of the studies had research questions in place *before* participants became involved. This illustrates that there is a lack of research in which the focus is defined by the autistic community itself (Chown et al., 2017). This restricts participatory ideals, where questions should be “relevant to the community” (Macaulay et al., 1999, p.774) and found “worthy” by that community (Chappell, 2000, p.39).

Chown et al. (2017) argue that community validation of a non-disabled research focus could be part of an emancipatory approach. However, some would argue that disabled people should be in control of *all* aspects of the research process (e.g. Oliver, 1997; Zarb, 1992). Within this paradigm, the researcher is accountable to disabled people and their organisations (Stone & Priestley, 1996). Therefore, it could be questioned whether a validation approach meets such aims, with the researcher maintaining initial control, over the possible foci presented to the community. Validation of the research questions meets participatory aims, with shared decision making undertaken (Chown et al., 2017; Jivraj et al., 2014). However, it does not align with Holland et al.’s (2010) fourth level of participation (see above), where children initiate decisions and create plans, which are then shared with the researcher. It could be argued that an emancipatory level of participant power is only achieved at this level, with participants in control of *all* aspects of the process, *including* identifying the research focus.

Alongside concerns over research question control, Jivraj et al. (2014) identified further issues, with most of the participatory studies they reviewed having methodologies in place, *before* participants became involved. In contrast to these studies, I now consider how a participatory approach can enhance participant control through the methods process.

3.2.2. Inclusive Methods: Facilitating Communication

Participatory approaches should ensure participant engagement *throughout* the research and knowledge production processes (Cornwall & Jewkes, 1995). As such, Bourke (2009) asserts that it should be the *participant's* choice which methods are employed (Macaulay, 2017). In this, the researcher takes the role of facilitator (as in Sense, 2006): offering resources and creative ideas; ensuring progress within the project and continued engagement of participants; and making adaptations to meet the needs of those participants (Fletcher-Watson et al., 2019). In addition, Stone and Priestley's (1996) emancipatory principles assert that a plurality of methods can be employed, with the primary focus on ensuring these methods enable participants to offer knowledge of the context, their real world, lived experiences, rather than assigning a set method to be used. Emancipatory approaches align themselves with the critical stance as articulated by Orsini and Davidson (2013, p.15) since the emphasis is not on taking a position against the "hard" sciences, but on critiquing those approaches which neglect the voices of those affected by that research.

Therefore, the main aim in both participatory and emancipatory approaches is ensuring participants have access to inclusive methods, which allow them to share their views and experiences, rather than prescribing those methods (Bourke, 2009; Macaulay, 2017). This wide-ranging inclusiveness is, for Fletcher-Watson et al. (2019), a key element of the participatory approach and aligns with the CAS tenet of employing inclusive methods in autism research (Orsini & Davidson, 2013). Offering a range of inclusive communication methods aims to ensure that *all* voices can contribute to the heterogenous picture of autism. Being placed at a communicative disadvantage, through a lack of accessible adaptations, places power with the researcher, whose communicative style is prioritised (Fletcher-Watson et al., 2019). As Scott-Barrett et al. (2018) assert, the researcher must therefore take responsibility to ensure that communication methods are available to allow the participants to be heard, "bridging any gaps that appear" through their own research creativity and ideas, rather than placing the 'blame' on the participants' communication difficulties (p.14; Ellis, 2017). The creative methods employed in this research study, and how they attempted to 'bridge' these gaps are discussed in detail in Chapter 4.

The third stage of the participatory process is now considered- participants' role in data analysis. Whilst 'full' or maximum participation may be deemed the ideal in participatory research, issues have been identified with participant involvement in data analysis. I now discuss these concerns.

3.2.3. Analysis of Data: Issues with 'Full' Participation

Issues of participant involvement in qualitative analysis have included time constraints; accessibility of data; and ethical concerns. I discuss each of these in turn below.

Firstly, time constraints. Bourke's (2009) reflections, on three participatory research studies, found that some participants did not wish to oversee organising the project or take on larger responsibilities, including data analysis, due to the time commitments involved with this. This was also identified as an issue by Vincent et al. (2017), who found two of their seven autistic university students could not take part in data analysis due to their degree study commitments. To attempt to address the 'time issue' of analysis, Vincent et al.'s study employed methods which reduced the volume of transcript analysed by the autistic co-researcher-participants. However, their discussion of employing a "segmented version" in which "all students also had access to the text in its entirety" (p.307) is somewhat opaque in terms of detail. This could suggest that analysis was to an extent controlled by those segmenting the text and therefore that full participation and control of analysis was not given to participants. This implies that methods which reduce the analysis time required may inherently place some control back with the researcher. However, as Bourke has shown, participants may prefer having control over the time spent in the research process, rather than having full access to every element. As researchers, Vincent et al. assert that ethically we must consider, "individuals' personal circumstances" and these must be "given priority over any research outcomes" (p.306). This suggests a need to balance the participatory ideal of 'full' participation with what may be practical for participants in their everyday lives.

Secondly there are issues that concern the accessibility of data. It may, for example, be necessary for the researcher to adapt data, to ensure it is accessible (Nind, 2011). For instance, Spiel, Malinverni, Good, and Frauenberger (2017) assert that raw data often needs to be re-presented, according to a child's preference for a visual or auditory form or to remove any barriers they may face. For instance, one of their autistic participants found reading handwriting “exhausting” (p.5762). In Holland et al. (2010), several of the children and young people involved found reading an excess of words boring, or, in one case, found it uncomfortable to see painful memories down on paper. The analysis may therefore need to take the form of an informal discussion between researcher and participants, produce themes on data presented in a pictorial form, or be based on pre-identified themes (Holland et al., 2010; Nind, 2011; Spiel et al., 2017). Holland et al. concluded that “more immediate or informal involvement of the participants worked better than imposing on the young people our own forms of ‘doing research’” (p.369). Whilst this may mean that the outsider researcher takes some control over the data, in segmenting or transforming it into an accessible form, it could also be argued that this is more effective than providing a wealth of data that cannot be accessed by participants. Indeed, in being unable to access data, any power given in having the original ‘full’ form is lost, as participants cannot collaborate in analysis due to its format. Instead, in adapting the data to be accessible, it could be argued that the researcher follows Macaulay et al.’s (1999) description of participatory research as a “partnership among equals with complementary knowledge or expertise” (p.745). The researcher employs their expertise to present accessible data, ensuring participants can apply their expertise, in their lived experience, to the process of data analysis (Bourke, 2009; Vincent et al., 2017). Rather than being excluded due to that data’s form.

Thirdly, there can be ethical issues in sharing private data with other participants. Conolly (2008) argues that it may not be ethical to share data with a group of participants, should that data be highly sensitive or personal. For example, Bourke (2009) identified that, in a research project about breast cancer experiences, participants chose not to have full participation due to a desire to preserve anonymity. They felt the sensitive subject matter was not appropriate to be shared amongst other participants and that anonymous questionnaire data should be sent directly to the university. Bourke’s participants also wanted to prevent their answers being shared with their health care professionals, due to fears over the negative impact this could have on their subsequent healthcare relationships. Unease about sharing sensitive information with fellow participants may also be why, in Holland et al. (2010), the children and young people involved would share more intimate or personal information when speaking to the researcher alone. Had data been analysed by other participants, they may have chosen not to share certain ideas, views and experiences that they felt comfortable sharing with the researcher. Consequently, in trying to attain 'full' participation, to empower participants, participant analysis would have instead silenced those who felt uncomfortable sharing private information, with those they had a personal relationship.

Bourke (2009) argues that being participatory entails participants choosing *their* preferred level of participation. 'Full' maximum participation may be the researcher's aim but not the preference of all participants. Participant control and power may, at times, mean giving participants the choice as to which areas of the research process they want to be involved in, and in control of. Spiel et al. (2017) support this, asserting that forcing the child involved in their study to take part in areas he did not have an interest in, such as collecting questionnaire data, would mean a "tyranny of participation" (Cooke & Kothari, 2001 cited in Spiel et al., 2017, p.5760). This 'tyranny' of enforced participation would reinforce researcher control, over the participants' preference. Spiel et al. consequently cautions against assuming participants will be interested in being part of every stage of the participatory process. Furthermore, Fletcher-Watson et al. (2019) assert that we must be aware that not all autistic people may want to become advocates or activists for their community. Again here, it must be asked: what are the aims of the participants and what are those of the researcher? For example, participants may wish the researcher to advocate for them as an ally, utilising the data as support for this, rather than being asked to do this themselves.

In summary, as discussed above, there are limitations to the ideal of 'full' participation. The researcher must also be aware of the danger of enforced, full participation, which may ultimately undermine the power and control a participatory approach is attempting to foster.

3.2.4. Evaluating Methods

In this section, I consider how the final evaluative stage adopted in my study could offer an important contribution to methodological knowledge about undertaking a participatory approach, with autistic young people.

The evaluation of the research process is important for future participatory research (Crane, Adams, Harper, Welch & Pellicano, 2019). As Fletcher-Watson et al. (2019, p.951) assert, it is through the consideration of the "*why* and *how,* more than the *what* of research" that the experiences and points of view of the autism community can be equally included, by influencing the inclusive design of future projects. Ellis (2017) and Scott-Barrett et al. (2018) support this, emphasising the need for increased discussion of research processes, including the benefits and challenges of methods which can specifically enable autistic children's voices to be prioritised in research. This knowledge could help those "researchers who feel motivated to engage with autistic community [who] may find themselves unsure about where, or how, to start" (Scott-Barrett et al., 2018, p.949). This is key because, as Ellis argues, a lack of researcher knowledge on how best to access the voices of autistic children, will inevitably hamper those voices being heard. Finally, Jivraj et al. (2014) found that there needed to be greater transparency on how participants were involved in research which claimed to be participatory as often it was not made clear to what extent autistic partners participated (Campbell, 2002). This would require clarity on how decision making was undertaken and an evaluation of this partnership, documenting the strengths and weaknesses of the participatory approach (Jivraj et al., 2014; Macaulay, 2017).

Evaluating *how* my project was undertaken supported my CAS aims to develop "inclusive and nonreductive methodological and theoretical approaches" (Orsini & Davidson, 2013, p.12), approaches which could be employed by future researchers, to further challenge deficit narratives. This evaluation followed Fletcher-Watson et al.'s (2019) idea that tokenism can be avoided, by engaging with the expertise of autistic people, and making changes based on suggestions. I engaged with the expertise of my autistic participants as those who had lived experience of the participatory research process and made changes to the project based on this, asking participants to evaluate part way through the project, rather than only at the end. These evaluations went beyond Scott-Barrett et al. (2018) and Ellis (2017), who focused on the researchers' perceptions of how autistic participants want to be treated within research. Instead, I included the first-hand evaluations of the autistic young people in the study, placing my autistic participants at the forefront, rather than focusing on my own evaluations of success and weaknesses.

The value of the input of the autistic participants is evident in Pellicano et al.'s (2014a) study. Here, a disconnect between researchers' own evaluations of the research process, and that of the autism community members was clearly shown. Researchers reported themselves to be significantly more engaged with the autism community in every level of participation than that reported by autistic adults, practitioners and family members, including in dissemination, dialogue (direct consultation or communication) and/or partnership/ collaborative working. This therefore demonstrates how the research experience may be viewed differently by participants, and the importance of involving them in evaluating the level at which, *they* felt, that process successfully involved them as equal participants, who were fully heard.

Furthermore, whilst a participatory process may enable a meaningful inclusion of the autistic voice, Jivraj et al. (2014) and Chown et al. (2017) assert that the numbers of studies undertaken in this way has remained in the minority. Jivraj et al.'s (2014) scoping review of participatory research with autistic participants found that, of the 636 citations relating to participatory research, only 60 referred to autistic participants, and only 23 included empirical research. This mirrors Pellicano et al.'s (2014a) suggestion that the number of participatory research studies with autistic people is very low. This lack of focus on emancipatory and participatory working was also evident in the 130 researchers who responded to Pellicano et al.'s study. Even though some felt that the autism community should be involved in identifying research priorities, no researcher suggested a fully participatory process where autism community members were equal partners in funding and research topic decisions, designing projects or disseminating results. Additionally, no researcher suggested user-led research and therefore no autism researcher in this study fully subscribed to emancipatory ideals in their research. Pellicano et al. therefore assert that the researchers in their study viewed autistic people as passive subjects, rather than active co-creators of knowledge, who should be fully involved in the process.

Jivraj et al. (2014) also excluded research studies from their review which did not discuss how the participatory research process was implemented, leaving only 7 studies in total. They conclude that a lack of clarity around the implementation of participatory studies may mean that those which claim to be as such may not undertake 'full' participatory research. This was because, for those who did share their process, only three included participants in identifying the research question, whilst only two involved participants in the methodology or choice of methods employed. Most studies included participatory involvement only in the data collection and dissemination stages, where participants provided access to autistic people and undertook tasks implemented by the researcher. Therefore, in those studies which did make their process clear, only two included autistic participants at *every* stage (these were Nicolaidis et al., 2011; 2013), showing a clear lack of full participatory involvement.

Furthermore, Searle et al. (2019) assert that they provide “one of the first [papers] to discuss the challenges and benefits of including autistic participant researchers at all stages of the research project” (p.84). This implies that a wealth of papers providing clarity on a process which *fully* involves autistic people at every stage has not occurred since Jivraj et al.’s (2014) review. However, a small number of additional papers can be found, which do claim to report on a participatory process. Like Searle et al., Vincent et al. (2017) describe participatory research focusing on autistic students’ experiences of higher education in a UK university. Their study details the process and challenges of involving autistic participants as co-researchers in the identification of the areas of university life to be explored, and in data collection and analysis. Whilst the paper states that its *aim* was to involve participants equally in all aspects, the process of the dissemination stage of the research is not detailed. Therefore, as with Jivraj et al.’s critique, a lack of transparency in this area means this study cannot be judged on whether participants were indeed included equally at every stage.

Finally, Spiel et al. (2017) consider how to involve autistic children in the participatory process, within the evaluation of a technological design for Human Computer Interaction. Again, autistic participants were involved from the design stage, identifying the goals and methods of the research and collecting/ analysing data. However, the researchers did not see dissemination as part of the participatory process. Here, it was not a lack of transparency that was the issue, as the paper included detailed case studies of their participants’ involvement in the goal setting, data collection and data interpretation stage. Instead, the researchers did not see dissemination as an element in which the children would be involved. This therefore supports Searle et al.’s (2019) claim, this paper also does not discuss “including autistic participant researchers at *all* stages of the research project” (p.84) though it does consider the benefits and challenges of the elements it does include.

With Jivraj et al. (2014) and Searle et al.'s critique in mind, my research offers a transparent discussion of the *how* of the project, including the benefits and challenges of the participatory process employed (see Chapter 4).

This chapter concludes by drawing together the main elements of participatory, emancipatory and CAS approaches to clarify the paradigms which influenced my research study. I then summarise the originality of this research approach, the detailed process of which will be offered in the following chapter.

3.3. Participatory, Emancipatory and CAS Paradigms: A Summary

Participatory research requires an equal, respectful partnership, aiming for full participation across the study. Control over the research process is enhanced, through shared decision making with the researcher. Emancipatory research takes this control a step further; participants initiate and lead the study, with researcher expertise at their disposal. Both approaches therefore follow the CAS tenet, of paying close attention to the power relationships between participant and researcher. In doing this, meeting the preferences and needs of participants is paramount, including accessible methods to enable participant contribution. Consequently, this sits within the CAS aim of employing inclusive methods to enable the meaningful contribution of autistic people. Participatory and emancipatory research also aims to enable positive outcomes beyond the project, through using the insider expertise of the community group. However, emancipatory paradigms take a more overt political position, directly seeking to enable change through challenges to societal barriers and dominant research paradigms, which can perpetuate these barriers. This aligns with the CAS approach, which challenges dominant deficit constructions of autism.

As discussed in Chapter 1, my research takes an overt stance against deficit and demeaning constructions of the autistic young person's sense of self. My project implemented a participatory design of shared decision-making across the research process. The study followed Searle et al. (2019) in offering a full and transparent record of the challenges and benefits of involving autistic participants at every stage of the research process. This included a participant-led evaluation, focusing on *their* insider views of the participatory approach employed.

My study shows originality in contrast to previous studies of identity and mainstream schooling (see Chapter 2), which did not take a participatory approach with autistic adolescents. Although, Molloy and Vasil (2004) included some collaborative elements, asking participants to approve interview transcripts and the subsequent stories produced from them, their research was not truly participatory. They did position themselves against the medical model, aiming to ensure that the insider view of the autistic adolescents involved was heard. However, the choice of research focus, the methods employed, the analysis of data, and its dissemination, were all researcher led. Research decisions were not shared with participants, power differentials were not considered within the interviews employed, and the ownership of results was questionable. Whilst participants could "negotiate" (p.162) changes to their stories, the analysis and production of this data was mostly controlled by the researchers in the project. This was highlighted by Molloy and Vasil themselves, who identify the limitations of their role, where they shaped the words of their autistic participants as "our interpretation of their interpretations" (Ferguson et al., 1992, p.299 cited in Molloy & Vasil, 2004). Subsequently, as the participatory elements here were negligible, the study does not sit within the participatory paradigm, with a large percentage of outsider-researcher control. Therefore, an aim to reduce the power imbalance between researcher and autistic participant, by ensuring the active involvement of participants in all stages of research, was not employed in the studies which consider identity and mainstream schooling. Consequently, the comparison of my research subject matter *and* methodological approach, with previous studies, emphasises the original position adopted within my research.

The following chapter gives a detailed account of the participatory process I developed, identifying which participatory and emancipatory elements are present and providing a justification for these choices. Further to this, I identify areas where I encountered limitations in my attempts to meet emancipatory and participatory ideals and consider the barriers that caused this. Whilst these limitations mean I cannot claim my project as *fully* participatory; my detailed discussion of the process allows a transparent record of the challenges and benefits of a participatory approach with autistic young people. This can enable an evaluation of the process and provide knowledge for those "researchers who feel motivated to engage with autistic community [who] may find themselves unsure about where, or how, to start” (Scott-Barrett et al., p. 949).

Chapter 4: Methodology: The Participatory Process

This chapter focuses on the research design and methodology, identifying the participatory, emancipatory and CAS principles that guided the choices I made- choices which considered the positioning of power and control at all stages. I begin with an overview of the study, setting out the research context, providing a detailed timeline of the process followed. This aims to address critiques around a lack of transparency in participatory research with autistic participants (Jivraj et al., 2014) by ensuring clarity in the research approach. I then consider a vital feature of my inclusive participatory process- participant choice of a wide range of visual, oral, or written research methods, which could be further adapted, to suit the participant's preferred mode of communication. I consider how barriers to access were addressed and how the full inclusion of autistic voices challenges deficit narratives. I also discuss how a participant-led, choice-based approach adds originality to the project.

Throughout, I consider the strengths and limitations of my approach, reflecting on how far my study met the participatory goal of participants having full engagement in the research process (Macaulay, 2017). I discuss key elements such as participant control over the research subject matter; participant reflection on the researcher's initial interpretations; and participant evaluation of the participatory research process. I reflect on the research context's influence on participant power and control. This reflection highlights how participatory ideals may be impacted by the real-world context in which research is undertaken.

Participatory ideals support the philosophical position taken within the study- to challenge deficit, impairment narratives, which position autistic young people as an 'abnormal' other (Orsini & Davidson, 2013). In this, the participatory aim of promoting autistic participant voice is key as hearing such insider expertise can challenge deficit discourses (Winstone et al., 2014). To prioritise autistic voices, I followed a social model approach, considering the external barriers and *researcher's* responsibility in ensuring participant contribution, rather than placing the 'issue' for such communication on the autistic person (Scott-Barrett et al., 2018). Ensuring accessible research methods, which move away from stereotypical assumptions, was a driving force of the choice-based, participatory approach, with an emphasis on shared decision making in a mutually respectful relationship (Cargo & Mercer, 2008; Chappell, 2000).

Ethical considerations, of control, consent and anonymity are interwoven across the chapter. In the participatory approach, these issues come to the fore and are therefore discussed throughout the stages of the study. I consider how my choice of data analysis and presentation supported my ethical and participatory aims to: maintain anonymity; ensure accurate representation of what my participants intended to convey; present *all* diverse views, without prioritising one over the other; and ensure impactful dissemination. Finally, stand-alone ethical practices, such as how the informed consent process was initiated, are dealt with separately, at the end of the chapter.

In this chapter, a wide range of literature is employed. This supports the justification for my approach and provides the research context for the discussion of my second research question, which focuses on participant views of the methodology employed. Where relevant, I reference reflections from my research diary. Here, I debated researcher-participant power, contemplated the impact of the decisions I made and reflected on the influence of the environment, peers, and other staff members, on the participant group. I use the abbreviation RD for the research diary and reference this to the session number. An example of RD reflections can be found in Appendix A.

4.1. The Research Context

In this section, I discuss the research setting and the composition of my participant group. This provides an overview of the environmental and social context of my project.

4.1.1. Participant Group Composition

The focus of this study was a group of 8 autistic adolescents, attending a mainstream secondary school in the north of England. The main study took place in a school-based enrichment club (see below). The data generated by participants sits at the heart of this thesis. However, I do not include individual biographies of the 8 pupils to ensure that their anonymity is retained. Although pseudonyms are customarily employed as a way of ensuring anonymity, I was concerned that the detailed, biographical information I obtained, when considering their sense of self, would enable participants to be identified. School staff, family members and friends could identify a specific, individual biography as representing the autistic young person they know (Mannay, 2016).

This issue was particularly important because, as part of the project, participants were asked their views on who should know a person is autistic, considering, for example, teachers, family, friends, classmates, or bosses. In this, only one participant felt that everyone should know about their autism. All other participants identified a range of groups they either would not want to know this information, or who they would want to make individual decisions on, depending on their ‘trust’ in that person (see Chapter 5). Being identifiable could permanently align the participant with the ideas of the research, ‘fixing’ the pupils’ identity as an autistic person (Brady & Brown, 2013; Mannay, 2016). This fixed identity would be shared with all who accessed the study, revealing my participants’ autism to groups with which they would not want this to be communicated. As discussed in the previous chapter, participatory ideals emphasise that participants’ decisions must be respected, as they are part of an equal research relationship. Consequently, in respecting their choices, it was imperative for me not to go against participant preferences, ‘outing’ autism diagnoses to those from whom participants wished this to be kept.

I have employed as many anonymising tools as possible in the thesis. Table 4 provides an overview of the students, illustrating the larger ratio of male participants (6:2) and pupils aged 13-14, who made up 50% of the group, and the smaller ratio of the pilot study group (2:6). Due to the main project being year-long, age is represented as a range, showing participant ages over the course of the study. The table contains participant pseudonyms, chosen by the participant as the name that they wish to be represented by.

Table 4

Participant Group Overview

		Participants (n=8)
Pilot Study	Joe; Lightning	2
Main Study	Connor; Fresh Avocado; Harrison; Richelle; Skyler Greenthief; Wolf	6
Age Range During Project	12-13	1
	13-14	4
	14-15	1
	16	2
Gender	Male	6
	Female	2

4.1.2. Sampling of Participants

The participant sample was drawn from a high achieving mainstream (11-16) secondary school. The school was above average in size and the majority of the intake White British. There was a lower-than-average number of students eligible for free school meals or pupil premium.

I was known at the school, having left my role as a member of teaching staff the previous year. The setting provided a wide range of possible participants, due to a large number of autistic pupils on roll. Although a convenience sampling approach means that results cannot be generalised, the context provided the depth and authenticity appropriate to a study of the participants' lived experience (Cohen et al., 2011; Emmel, 2013). As Ridout (2017, p.58) argues, these detailed, individual representations can then form part of a "bigger autistic narrative" alongside other, non-deficit focused, sense of self research (such as King et al., 2017), supporting my CAS approach by enabling the voice of autistic people to challenge predominant, deficit-based views.

I began with an invitation to the parents of 21, year 8-10, autistic pupils in the 2017 summer term. An example of the parental information and permission documents can be seen in Appendix B. 6 parents provided permission for the main study. All 6 of those autistic adolescents then chose to take part. Additionally, two year 11 pupils were invited to the initial, summer 2017 pilot study. Both parents gave permission, and both young men chose to take part. The autistic young people invited to take part were identified using the school's 2016-2017 Special Educational Needs list. This encompassed all pupils with a diagnosis of autism, irrespective of whether they had an Education, Health and Care Plan. The limitation to this sampling method was an inability to identify autistic pupils who did not yet have a diagnosis, or those who would be new entrants (aged 11-12) in the autumn term of 2017. I had originally planned to invite these new entrants to join the main study in the second spring term. However, based on my experience of running the project with the six pupils originally identified, it was evident that inviting more participants to join would not have been practical. Whilst I would have preferred to include everyone, additional pupils would have prevented me from providing all participants with the enabling choices, inclusive methods, adaptations and adult support I employed to facilitate participation. This would have run counter to my participatory aims as, in having a larger group, I would not have been able to employ the range and flexibility of inclusive methods required to ensure all members were fully heard. To meet my CAS and participatory aims, of enabling a full insider response, the research project therefore ran with the six original year 8-10 pupils, for the school year.

4.1.3. Participants' Research Environment

The pilot study was completed in July-August 2017, before the main study began in September 2017. I wanted to test out the planned participatory process on a smaller, more manageable scale in five sessions, with two participants. One participant (Lightning) completed all five face-to-face sessions at home. The other (Joe) completed two sessions: one face to face and another by e-mail. I include this pilot study data in the research study's overall analysis. This followed the philosophy of Ridout (2017), that regardless of the volume of contribution, all participant data should be included. Taking a stance against the exclusion of autistic voice, it would not be appropriate to exclude my pilot study participants from the data analysis, just because, for example, Joe only provided data for the first research question. I did not want any participant at *any* stage of the study to make the effort to contribute their experience if this was not going to inform knowledge and the development of practice. Therefore, both pilot study participants are included in the findings and analysis of the research project.

In the main study, the research took place as a school-based enrichment club. An enrichment club is a timetabled lesson, which aims to give pupils a varied and different learning experience to their academic subjects. I wanted to employ this timetabled form as it enabled autistic pupils to be part of a participatory project, without placing undue pressure on them to commit additional time and energy, which could lead to a negative research experience. The timetabled session also meant that a member of support staff, a teaching assistant (TA), was present. This member of staff was briefed on ethical practice and their presence within the club continually reflected on. This will be discussed, where relevant, throughout the chapter.

In existing school provision, clubs could either be termly, with pupils attending a different club each term, or a yearlong option. My enrichment club ran weekly, for the whole school year, resulting in 36 sessions in total. In line with ethical protocols, participants could choose to take part in the activities of the enrichment club but not to provide data for the research project. However, all six of my main study participants chose to join both the club and the research project and so *each* session involved research activities (see Table 5).

As discussed in Chapter 3, participatory and emancipatory approaches aim to enable the improvement of the lives of the community, through the production of insider-led research (Chown et al., 2017; Macaulay et al., 1999). I did not only want to offer long-term benefits, through the impactful dissemination of participatory research. I also felt that my study should include *immediate* benefits for those involved. Like Holland et al. (2010), sessions offered participants the opportunity to work on individual projects about themselves, whilst also being able to interact with others, to create a fun and enjoyable environment. Equally, my research process enabled participants to socialise and build relationships with peers outside their year group. This supported my aim to offer an immediate social benefit; the opportunity to build or maintain meaningful friendships with others. For all participants, I sought to create a positive research experience, an engaging environment, and a feeling of being valued, supported and listened to. I did this as part of my participatory aims, to ensure participants felt comfortable to fully engage with the process, and to share their views and experiences as they should wish. Finally, I aimed to create an environment which celebrated difference and individual strengths, rather than focusing on deficit constructions. This aligned with the CAS principle that enabling narratives of autism should be promoted, in counter to predominant deficit concepts (Orsini & Davidson, 2013).

4.2. Overview of the Research Process

Having set out the research context, I now provide an overview of the research process. As part of my commitment to providing a transparent account of my participatory approach, Table 5 (below) offers a detailed representation of the stages undertaken. Research questions are shown in abbreviated form in the left-hand column. Stages 2,3,5,7 & 8 refer to sense of self with stages 4 and 9 concerned with the evaluation of methods.

Table 5

Timeline of Research Project

Research Stage	Research Sessions		Process	Example
	Pilot (n=5)	Main (n=36)		
Stage 1: Project Introduction	1 (July 2017)	1-3 (October-December 2017)	1. Informed consent: pupil friendly information sheet with easy, accessible language and images to support the text. Option to have the information sheet and consent form read to them, which a range of participants undertook. Participant information sheets and consent forms available in every session, with copies at home. Pilot study participants discussed each point on the consent form, repeating these points in their own words, whilst main study participants created their own versions of the consent forms, which were then discussed with me. All processes focused on checking participant understanding of the consent that was being given.	Appendix C
			2. Research question validation: accessible versions of research questions provided. Pilot participants discussed individually with me. Main study participants discussed in groups. All participants focused on whether they considered the research questions to be relevant/ important and why.	Appendix D

Stage 2: Research Question 1.1- The Self: Who am I?	2 (July 2017)	4-12 (October-December 2017)	1. Participants completed the Twenty Statements Test: the question who am I? is posed, followed by twenty blank lines, which begin with the sentence stem *I am*. Participants complete these statements to describe their sense of self.	
			2. As a group, participants created a topic list of elements which could be discussed when considering 'who am I?'	Appendix E
			3. Participants' method preferences identified: most to least preferred method choices made-from a given list of visual, oral, and written methods. Open questions for reasons for choosing top and bottom three.	Figure 2
			4. Based on top three choices, I suggested suitable methods for the first research question. Participants chose which method they wanted to begin with. They completed photography, film creation, drawing, collage, PowerPoint creation, pair discussion and discussion with me. Some chose to complete two methods to answer this research question, whilst others preferred to spend time on just one.	Appendix E
			5. For these methods, participants provided either written or verbal feedback to explain what they had chosen to include in answering 'who am I.'	
			6. Participants completed a further task at the request of the researcher- organising the topic list they had created (step 2 above). Each topic was placed on a separate card and organised into most to least important to the self-concept. These same topic cards were then organised into those elements which had a positive or negative impact on the self-view. Participants chose from peer or researcher conversation, or a written response, to share their reasons for their choices.	Figure 9

Stage 3: Validating Researcher Interpretations: Q.1.1.	3 (August 2017)	13 (January 2018)	Participants provided feedback on my initial interpretations of their individual data (as in MacLeod et al., 2014). This was based on *all* the data they had produced for that question. Participants could agree, partly agree, or disagree, with the option to correct any interpretations they felt did not represent their views.	Figure 5
Stage 4: Research Q.2- Evaluating Methods	N/A	14 (January 2018)	Evaluation through a questionnaire: semantic differential scales and open comment sections. Evaluating the choices given; the research topic; the research methods; validation of the research questions; reflection on my initial interpretations; the research environment and working with me and their peers. This mid-way evaluation enabled me to make changes to the main project in the second stage, fulfilling participant requests to include more of their favourite methods.	Figure 7/8
Stage 5: Research Q.1.2- School's Influence on a Positive or Negative Sense of Self	3/4 (August 2017)	15- 24 (January-March 2018)	1. As a group, participants created their own topic lists, identifying elements in school which could influence how someone felt about themselves. 2. Participants created their own possible methods list for this stage then highlighted the methods *they* would like to employ, choosing the method they wanted to start with the following week, alongside, if relevant, who they would like to work with. 3. Participants completed: videogame plans, a Vlog, a diary, photography, drawing, pair discussion, a PowerPoint with text and images, and discussion with me. 4. Participants had the opportunity to complete more than one method, with many choosing to do so. 5. Participants were all asked to organise their sense of self and school topic lists by their positive or negative influence on the self-view. This was completed by colour-coding or using symbols on a topic grid. They then explained their choices (as in stage 2, point 6).	Figure 3 Appendix F

Stage 6: Validating Researcher Interpretations Q.1.2	4	25 (April 2018)	As above.	
Stage 7: Researcher Directed Focus- the Good/Bad Student, Perfect/ Worst School Day, Autism and Sense of Self	4	26-34 (April-June 2018)	1. Participants chose a preferred method to share their views on what a good or bad pupil would be. They then placed themselves on a scale from best to worst student and explained why they felt this way. Their chosen responses included drawing, writing, pair discussion or discussion with me. 2. Participants chose a preferred method to consider their perfect/ worst school day. This included PowerPoint with text and images, writing and group discussion. 3. Participants were given the following prompts: autism is/ who should know a person is autistic/ good things about autism/ bad things about autism. To respond they chose to draw, type and to create a PowerPoint, with text and images.	Chapter 6
Stage 8: Validating Researcher Interpretations (Whole Group)	5 (Individual) (August 2017)	34 (June 2018)	Participants were given a summary of whole group views, on the school elements which had a positive or negative impact on the self-view. There was an opportunity to agree or disagree, and an option to agree that other autistic pupils might feel that way, but they did not.	Figure 6
Stage 9: Research Question 2- Evaluating Methods	5	35 (July 2018)	As above. The pilot study evaluation was completed at the end of the sessions only.	

Stage 10: Debrief	5	36 (July 2018)	1. Plans for dissemination shared, including reiterating how identifiable information would be removed. 2. Withdrawal of data: participants had access to *all* their own data in each session, with individual data folders provided. These included discussion transcripts, visual data, and copies of any written responses. Participants regularly identified data they did not want included in the final report. In this session, they completed a last check and provided me with their data folders- as their final submission for the project. 3. Consent forms revisited: as a yearlong project, it was important to revisit agreements participants had made at the start. 4. Participant thanks, including individualised thank you cards.	Appendix H

I now focus on participant choice of a range of methods and communication modes (stages 2 and 5 above). This is discussed as a vital supporting aspect in my aim to challenge deficit narratives, by addressing the methodological barriers which can prevent autistic participants from being fully heard.

4.3. Participant Choice: Methods and Inclusive Adaptations

Following Chapter 3, my research position includes a commitment to enabling participatory communication. I therefore offered accessible and inclusive methods, with participants choosing how they wanted to share their views and experiences. This aligns with the participatory ideal of giving participants an *active* role in deciding which methods to employ (Macaulay, 2017). Adaptions to chosen methods were also offered, to suit participants' preferred mode of communication. This further supported Orsini and Davidson's (2013) CAS tenet of utilising inclusive research methods, which enable autistic voices to be shared.

I now outline the specific methods and adaptations available, considering their strengths in enabling participant voice and active engagement within the project. I discuss participant control and any choices made by the researcher which diminished this. This offers a transparent account of the participatory process followed and acknowledges any limitations to this. I also discuss the scarcity of such a choice-based approach with autistic children and young people, by making comparison with other studies that employed a range of methods. This emphasises how an innovative approach was undertaken in my project.

4.3.1. Choices: A Range of Research Methods

As shown in Table 5, participants chose which methods they wanted to undertake at two points: at the start, before focusing on presentations of and influences on the sense of self, and in the second term, before considering school influences on sense of self and self-esteem.

Table 6 now provides an overview of the range of methods available in the project, alongside the adaptations to the modes of communication available within those methods.

Table 6

Methods and Modes of Communication

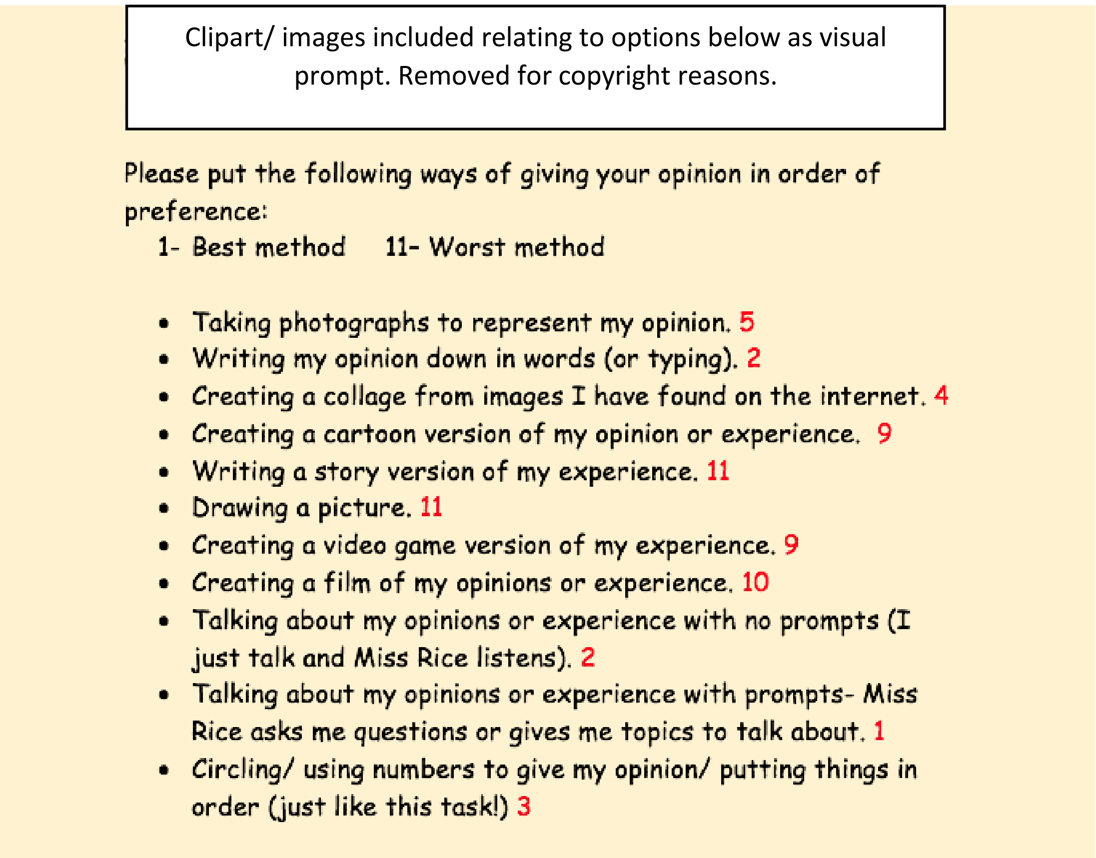
Method Type	Method	Adaptations: Mode of Communication	Research Question
Visual	a) Photography, collage, drawing, film- with subsequent elicitation interview. b) Vlog.	• Typed/ handwritten elicitation interview. • Use of topic prompts.	Q1.
Oral	a) Interview with researcher b) Interview with peer c) Focus group	• Typed/ handwritten conversation. • Topic prompts. • Responses written down verbatim, rather than being recorded.	
Written	a) Diary b) Story* c) Speech* d) Poem* e) Biography* f) Twenty Statements Test	• All written forms could be dictated to the researcher/ teaching assistant and written verbatim. • Topic prompts and sentence starters offered to support written responses. • Pictures could be added.	
Numbering/ Ordering	a) Organising topics by good/bad influence b) Organising topics by importance	• Completed through discussion with researcher or peer. • Organised into order/ category, rather than using numbers. • Symbols or colour-code used.	
Mixed (Words/ Images/ Scales)	a) PowerPoint b) Video Game (plan) c) Cartoon* d) Questionnaires (semantic differential scales/ open questions)	• Use of topic prompts/ sentence starters. • Dictated to the researcher/ teaching assistant and written verbatim.	Q1. Q.2.

*Methods offered but not chosen.

When making choices at the start of the project, participants completed the sheet shown in Figure 2.

Figure 2

Methods Preference Sheet



Clipart/ images included relating to options below as visual prompt. Removed for copyright reasons.

Please put the following ways of giving your opinion in order of preference:

1- Best method 11- Worst method

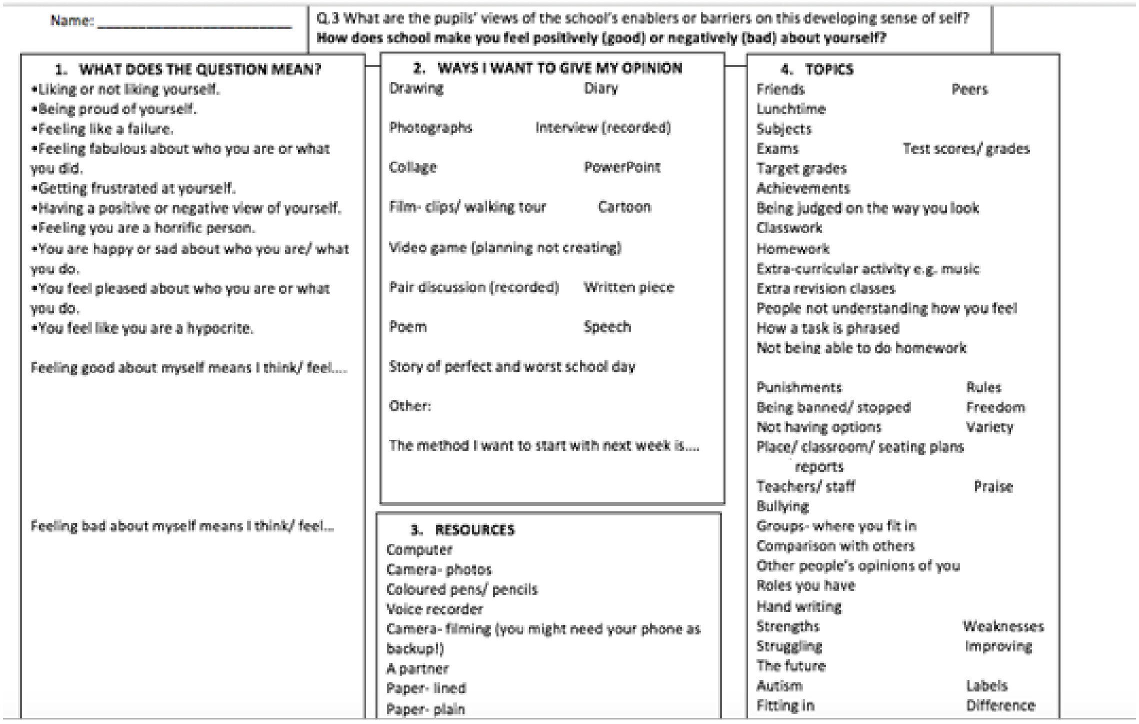
- Taking photographs to represent my opinion. 5
- Writing my opinion down in words (or typing). 2
- Creating a collage from images I have found on the internet. 4
- Creating a cartoon version of my opinion or experience. 9
- Writing a story version of my experience. 11
- Drawing a picture. 11
- Creating a video game version of my experience. 9
- Creating a film of my opinions or experience. 10
- Talking about my opinions or experience with no prompts (I just talk and Miss Rice listens). 2
- Talking about my opinions or experience with prompts- Miss Rice asks me questions or gives me topics to talk about. 1
- Circling/ using numbers to give my opinion/ putting things in order (just like this task!) 3

As described in Table 5, I suggested participants chose a method to complete for the first research question, based on their top three choices (Appendix E). I later questioned whether giving participants a ‘top three’ of methods to choose from was too constricting, retaining too much researcher control. I became aware of the danger of making assumptions, based on the previous preference task. Two participants chose to complete their third or fourth preferred method, whilst three undertook methods they had scored as a low preference, if they were adapted. For instance, ordering by moving topic cards instead of assigning numbers. This demonstrated a need for continuous choice and an option for participants to change their mind, rather than rigid adherence to the preferences collected at the start.

To create a more open choice for Stage 5 (Table 5), focusing on school and sense of self, I asked participants to create their own methods list. This contained some methods from the previous choice sheet, such as photography and drawing (Figure 2). However, participants added poem, speech, diary and PowerPoint. Throughout the project, PowerPoint, an option I had not specified, was especially popular with participants, with several employing this form. This emphasises the importance of participant choice, beyond adult assumptions, as I had not included PowerPoint originally as a method. Participants then chose from the entire list of methods (Figure 3, Box 2). This aimed to give greater choice over the methods employed.

Figure 3

Participant Created Choice Sheet



Name: ______________________

Q.3 What are the pupils' views of the school's enablers or barriers on this developing sense of self?
How does school make you feel positively (good) or negatively (bad) about yourself?

1. WHAT DOES THE QUESTION MEAN?
- Liking or not liking yourself.
- Being proud of yourself.
- Feeling like a failure.
- Feeling fabulous about who you are or what you did.
- Getting frustrated at yourself.
- Having a positive or negative view of yourself.
- Feeling you are a horrific person.
- You are happy or sad about who you are/ what you do.
- You feel pleased about who you are or what you do.
- You feel like you are a hypocrite.

Feeling good about myself means I think/ feel....

Feeling bad about myself means I think/ feel...

2. WAYS I WANT TO GIVE MY OPINION

Drawing Diary

Photographs Interview (recorded)

Collage PowerPoint

Film- clips/ walking tour Cartoon

Video game (planning not creating)

Pair discussion (recorded) Written piece

Poem Speech

Story of perfect and worst school day

Other:

The method I want to start with next week is....

3. RESOURCES
Computer
Camera- photos
Coloured pens/ pencils
Voice recorder
Camera- filming (you might need your phone as backup!)
A partner
Paper- lined
Paper- plain

4. TOPICS
Friends Peers
Lunchtime
Subjects
Exams Test scores/ grades
Target grades
Achievements
Being judged on the way you look
Classwork
Homework
Extra-curricular activity e.g. music
Extra revision classes
People not understanding how you feel
How a task is phrased
Not being able to do homework

Punishments Rules
Being banned/ stopped Freedom
Not having options Variety
Place/ classroom/ seating plans
reports
Teachers/ staff Praise
Bullying
Groups- where you fit in
Comparison with others
Other people's opinions of you
Roles you have
Hand writing
Strengths Weaknesses
Struggling Improving
The future
Autism Labels
Fitting in Difference

4.3.2. Researcher Responsibilities: Tackling Communication Challenges

As previously discussed, my research took the stance that it is the *researcher's* responsibility to bridge communication gaps, to ensure the full participation of autistic young people. As part of this responsibility, the researcher focuses on inclusive, adapted methods to ensure that research is accessible for the autistic participants involved (Fletcher-Watson et al., 2019).

In light of this, I considered the difficulties interview methods might pose for autistic participants- such as the increasing social anxiety, associated with face-to-face interaction, (Beresford, Tozer, Rabiee & Sloper, 2004). As Beresford et al. (2004) found, the anxiety of autistic children and young people, around taking part in interviews, was a key barrier; one which resulted in a lower number who were willing to participate. Similarly, Preece and Jordan (2010) found that autistic children and young people displayed anxiety in the interview setting, with some participants withdrawing from the room. This demonstrates how anxiety around the interview format can have a negative effect on participation.

Preece (2002) identifies how anxiety in the interview process can directly influence the responses of participants. He observed that all three of the autistic children involved showed anxiety within interactions, leading participants to give inaccurate answers, just to bring the uncomfortable situation to a close. Preece and Jordan (2010) suggest that autistic participants may have difficulty with the immediate personal memory retrieval required by the interview format and with processing verbal questions, which can lead to limited responses (see also Cook et al., 2016). Memory difficulties may also result in participants focusing on the most recent event, rather than the most important (Preece, 2002). Consequently, interview responses may not be truly representative of the experiences, views and opinions of the autistic participants involved.

It must be noted that Preece (2002) and Preece and Jordan (2010) are taking a deficit approach to evaluating the interview process for autistic people. In their papers, the limitations of the interview method, and the data produced, are directly associated with the social communication impairment of autistic people. The limitations of interaction take precedence over issues inherent in the consultation method. In contrast, I align with King et al. (2017) and Winstone et al. (2014). Their approach challenges deficit focused constructions and reductive methods, supporting the CAS tenets which influence my study. These researchers turn their focus on the method itself, showing how it is the interview process, which is at fault, rather than the autistic participants. They argue that the interview format creates a barrier to autistic participants' contribution, helping to perpetuate ideas around a deficit in social self, and it is *the method*, rather than autistic participants, which needs to change. The impact of changing the research methods employed is shown in their alternative creative methods of photo-elicitation (King et al., 2017) or activity-orientated interviews, including drawing and collage (Winstone et al., 2014). In these instances, autistic young people showed the significance of others to their self-understanding and an ease in self-reflection not reported in previous self-understanding interviews (e.g. Jackson et al., 2012; Lee & Hobson, 1998).

Winstone et al.'s (2014) comparative study highlights the impact that changing the traditional interview format can have. Their study employed standard semi-structured interviews with one group of autistic adolescent boys and compared their responses with a matched group, who undertook activity-orientated interviews. In the standard interview, participants struggled to discuss self-perception, future selves, autism as part of their self-identity and comparisons of self and others. Those in the activity-orientated interviews gave more detail and depth, showing a consideration of abstract personality traits, the relationship of being autistic to their self-identity, detailed future plans and a comparison with others in their lives. The researchers argue that data from the standard interviews would have supported deficit constructions of autistic people as having a weak self-concept, a difficulty with imagined future selves and a lack of self-other comparison (see Chapter 2). However, activity-orientated interviews generated more data, enabled participants' voices to be heard, and importantly, the results challenged deficit views of the autistic sense of self.

Similarly, Ha and Whittaker's (2016) use of photo-voice challenged assumptions around autistic children's interest only in objects (rather than others). Ha and Whittaker assert that interest in people was shown in the 25% of photographs which included others, particularly family, friends, and teachers, and, when including group activity photographs, photographs of others formed nearly 30% of the total photographs taken. Furthermore, Preece and Jordan (2010, p.18) found more "complete" answers were given when photographs were used whilst Ridout (2017) found that using collage, with a text and image-based diary, enabled the sharing of views on support services, and experiences of anxiety and depression, in ways that were not accessed through the questionnaire method. This all demonstrates how a change in method can enable autistic participants to communicate more fully, and, in so doing, challenge deficit assumptions.

These studies led me to consider alternative approaches to interviews when designing my own research. I looked for methods which would enhance accessibility for autistic participants. Within this, I followed the recommendations of Scott-Barrett et al. (2018), which are based on their interviews with a range of researchers, working with autistic people. Scott-Barrett et al. advise that we should not impose "adult assumptions about how the young people may want to communicate" (p.14). As a result, I did not choose one singular alternative method for all participants because I did not want to assume that *all* participants would want to communicate in a particular way.

The issue of making such an assumption is shown in Preece and Jordan's (2010) study. Here, none of the twelve autistic children and young people interviewed chose to draw when this was offered to them as an alternative. The adult researchers assumed the participants may want to draw based on previous research. However, given the option this was not the case. Acknowledging the variety of preferences, and needs, of young people, even within a small sample, is important. For example, Preece (2002) found that, in a small sample size of three, there was no one method suitable for all his autistic participants' communication needs. This exemplifies the heterogeneity of the needs of autistic children and young people involved in such research (Ellis, 2017).

In what follows, I discuss the variety of methods available to participants in my study, considering the justification for the methods employed and the choices and the adaptations I encouraged within these.

4.3.3. Visual Methods

In this section, I consider how and why visual methods were used. This includes how they support with the difficult, complex discussion of the abstract self-concept (see Gauntlett, 2007) and how they can reduce the anxiety and discomfort which may be encountered in an interview (see above).

Participants began by completing their chosen visual production (see table 6 for examples). In this, I was sensitive to researcher influence and direction, which could undermine the participatory aim of empowering young people by removing the choice of which visual images to include (Gallacher & Gallagher, 2008). However, I still wanted participants to have support, should they need it. My participants therefore created their own topic lists as a group (e.g. Figure 3) and used these, as and when needed, for inspiration in their visual production. In this way, support was available, but direction came from the ideas of the autistic participants, rather than me.

Visual methods follow the principle of auteur theory, where the intentions of the maker are placed as central (Rose, 2016). Conflict often arises between what the creator intended to convey and what the viewer interprets, based on their own assumptions and personal experiences (Mannay, 2016). Such assumptions could be based on stereotypical views, including deficit views of autism (Ha & Whittaker, 2016). Therefore, after a visual production, a subsequent elicitation interview is required, to clarify the maker's intended message (as in Mannay, 2016).

The distorting influence of assumptions was highlighted by Ha and Whittaker (2016), who found discrepancies between the initial views of the researcher and their subsequent interviews, with their autistic participants. For example, the researchers assumed one photograph represented a preoccupation with a pattern on the floor, based on generalisations about autistic fixation. However, this was not the child's intended message. The photograph was taken to show the child's favourite shoes, which were also in shot. Ha and Whittaker discuss how this experience highlighted, for them, issues around imposing their own generalisations onto an image, which can produce a completely different interpretation to the one the photograph was intended to convey. This example supports Mannay's (2016) argument that the image alone is inadequate. The conversation around the image is key to creating understanding *with* participants and grasping the polysemic meaning of an image, preventing framing, fixing and silencing of the creator's voice with our own views.

Image-based interviews can have additional benefits. They can allow easier description of that which is difficult to describe in words, such as the nature of the self, and provide richer data about that self (Rose, 2014). This increased ease was seen in King et al. (2017), whose participants reported that they would have found it more difficult to discuss their self-understanding without the photographs they had taken. Similarly, in Drew, Duncan and Sawyer's (2010) study, participants (aged 10-16), felt that discussions around photographs made it easier to communicate about complex topics, such as the chronic illness and self-management that they focused on. This could be, as Beresford et al. (2004) assert, because photographs provide a concrete discussion point, rather than employing a generic and abstract idea, such as the 'self', as a discussion topic. This view was supported by Drew et al.'s participants, who felt that a photograph could represent the abstract "garbled" ideas in their head, making it easier to both understand and express those ideas (p.1683).

Visual methods can also counter the 'on the spot' style of an interview, allowing time to reflect on the key topic, during the production of the visual form (Gauntlett, 2007; Guillemin & Drew, 2010). This can enable deeper reflection on the sense of self (as in Winstone et al., 2014). In addition, a visual production can act as a memory prompt for discussion (Danker et al., 2017). Drew et al.'s (2010) adolescents commented on how they "remember things better by pictures" (p.1683)- their photographs acted as a memory aid in their subsequent storytelling interviews. Furthermore, Drew et al. found that photography increased enjoyment and engagement for adolescent participants. Some young people chose to take part in the study because of the fun opportunity to use photography. Drawing on existing skills can also increase confidence (Rose, 2016). Drawing pictures and creating collages are common in the school curriculum. Their usage could increase the confidence of adolescent participants, who are familiar with their format. Visual methods can therefore enable participant response by supporting reflection on a difficult topic, acting as a memory cue and increasing participant enjoyment and engagement in the process.

Beresford et al. (2004) support the use of methods which reduce the dominance of the face-to-face interview. Visual methods can be helpful for any autistic children and young people who may find social interaction a source of anxiety. Working around a project or visual production can be a way to conduct 'interviews' whilst reducing discomfort, by creating an alternative focal point. As in King et al.'s (2017) photo-elicitation interviews, this can reduce the focus on the participant, who can also feel that they do not have to produce as much dialogue, with ideas represented in the image. This can reduce the pressure of traditional interview questioning. Discussion around a visual production has also been reported to reduce anxiety for autistic participants in Beresford et al., Ellis (2017) and Scott-Barrett et al. (2018). Furthermore, Scott-Barret et al. and Barrow and Hannah (2012) consider the value in providing the shared focal point of a computer screen, to combat the anxiety felt in direct face-to-face conversation. Barrow and Hannah assert that this creates a three-way interaction between researcher, participant, and screen. The screen becomes a third, inanimate participant in the conversation, an alternative focal point, which can remove the pressure and anxiety direct eye contact may create.

A number of researchers therefore found value in modifying a face-to-face interview style to reduce participant anxiety. I also introduced several modifications such as discussing participant's visual or written productions, including on the computer screen, or joint completion of a task, such as ordering topic cards. This meant that all conversations could be undertaken without direct eye contact or a face-to-face style.

To conclude, visual options offer new avenues for exploring the difficult topic of sense of self and lessen the discomfort or disengagement participants may experience. However, in keeping with the participatory ethos, it was important that these visual methods were an *option*. As Preece and Jordan (2010) show, it should not be assumed that visual methods are best for *all* autistic young people. With a choice of methods, participants are in control of communication. Communicating on their own terms could reduce my participants' anxiety, enabling them to communicate more fully (Ellis, 2017). This participant control of communication also had to be addressed with the elicitation interview, that followed a visual production. I needed to consider how this could be undertaken for those who did not wish to communicate in a one-on-one, oral format. How this was implemented is now discussed.

4.3.4. Adapting the Mode of Conversation

Alongside visual methods, oral and written formats were also included in the research project (see Table 6). In this, I wanted to ensure that participants could communicate in their preferred mode (Clark, 2010) and considered different modes of 'conversation', which moved away from privileging the spoken word (Ellis, 2017). I did not want verbal fluency to be a barrier to participant contribution (Danker et al., 2017). Consequently, conversations in my project could follow a written, rather than oral format, and could be undertaken either with or without the researcher present. This included *all* conversations, not just those which discussed a visual production. For pupils who did not feel comfortable with a face-to-face discussion, a survey style, typed response was offered (as in Mogensen, 2010). Many participants chose to type responses and were offered the adaptations shown in Table 6 to support this. Participant preference for typing may have been due to computers offering a familiar and enjoyable form, with young people often being at ease with utilising technology (Berger, 2006; Danker et al., 2017). Wegerif (2004) also argues that computers offer a greater sense of control, as they provide an interaction with an "ambivalent" object, without independent agency (p.180). This may minimise feelings of interpersonal judgement and seem safer to participate in.

Formulating typed responses offers reflection and processing time, countering the 'on the spot' style of an interview (Rajendran & Mitchell, 2000; Swettenham, 1996). This reflection time can enable further memories of experiences to emerge (Ridout, 2017) and offers opportunities to review and change the answers given (Rajendran & Mitchell, 2000). A shortcoming of this approach is that the researcher cannot adapt questions and prompts based on responses (Ellis, 2017; Tracy, 2013). However, I felt it was important not to exclude those who feel anxious to communicate in this way. Moreover, whilst I could not adapt in action, I did use participant summaries (see 4.4.1.) to probe typed responses, which enabled participants to offer additional insights.

To further support oral or written conversation, participants could employ discussion prompts. In this approach, conversations can be based around a range of "triggers" (Carter & Ford, 2013, p.98). In my study, this included both visual productions and participant-led topic lists (described in Stage 2,5, Table 5). These prompts were organised by participants to create a running order, following the participatory approach of allowing young people to direct discussion. This aimed to negate the power imbalance described by Tracy (2013), where the researcher's control over the direction of talk and topic focus increases their power, leaving pupils feeling they are not comfortable in giving a full or accurate response (Westbrook, 2010; Winstone et al., 2014). In controlling the direction of discussion, autistic participants can undertake the role of teacher, educating the researcher on their choices (King et al., 2017). Control over 'teaching' the researcher about their chosen prompts could increase the empowerment of the autistic young people in my study, as it enabled the positioning of the researcher in the role of "novice", who is there to learn from the participants involved (Clark 2010, p.120). Discussion around participant chosen prompts could therefore be an effective tool in countering the power of the adult/teacher role. King et al. (2017) also assert that participant-led discussion can counter an interviewer's propensity to focus on areas of their own interest or extended knowledge of the topic.

Instead, discussion can be focused on the areas of importance for the autistic participants involved. This was particularly important for my research, which aimed to prioritise participants' voices, focusing on the areas they employed to define their sense of self, rather than being led by an outsider researcher. To summarise, prompts could be utilised by participants to scaffold discussion, whilst retaining control over the direction of that discussion. This supported my aim of ensuring that the sharing of views and experiences was participant-led.

4.3.6. Adult Support

As part of my aim to ensure an inclusive and accessible process I offered varying levels of adult support. In this, I maintained a commitment to participant choice, with participants choosing whether they wanted adult support, and what form this support would take.

Adult support was available from myself or a TA, dependent on participant preference. Here, considerations were made for the literacy needs of some of the young people involved (Keen, Webster & Ridley, 2016). Whilst some participants needed little to no support, others felt particularly constrained by handwriting (as in Saggers, 2015), preferring to ask myself or a TA to write contemporaneous dictated notes. This was often employed if participants preferred option, typing, was unavailable due to difficulties with computer access. All staff who worked with the group were briefed on confidentiality, and on writing contemporaneous notes exactly as the participant dictated them.

Within the adaptations offered in my research project, I felt my positionality as an educator was a strength. As Beresford et al. (2004) assert:

> researchers should remember that health, education and social care practitioners possess a wealth of skills and methods of working with disabled children that might have the potential to transfer to research settings. (p.184)

I drew on the pedagogical principles of a secondary school English teacher, which included making adaptations to remove barriers to participation in the curriculum. This experience heightened my ability to create inclusive methods, which drew on a variety of strengths and employed a range of flexible adaptations to enable communication in a range of styles. My previous experience was a particularly valuable resource in offering further literacy support and structure, for those who needed it.

The benefits and shortcomings of teacher adaptation, including adding structure to a task, were evident in Ellis' (2017) study. Ellis' autistic secondary school pupils employed a range of child-centered methods. To maintain continuity for participants, whilst Ellis designed the method employed, tasks were delivered by the relevant subject teacher, with Ellis observing their undertaking. For example, an essay on an imagined future was completed with the English teacher as lead. The autistic young people involved found this task particularly challenging, so the teacher adapted the essay, to be written in stages, structured by age. Reflecting on this, Ellis highlights the problematic nature of adult control, in providing such a structure. A further critique is offered by Gallacher and Gallagher (2008), who warn that we must also be wary of methods which mirror those undertaken in school, "taking advantage of children's schooled docility" (p.506). I therefore continually reflected on the control my adaptations might entail participants to feel. In these reflections, I was concerned that the supporting structure I provided, such as sentence starters or the organising prompts task (see Stage 2, Table 5), enforced adult control over my participants. However, like Ellis, I found that these supports enabled participants to share their views and experiences. For example, one participant, Connor, particularly struggled with choosing what to include in the open form of his chosen visual methods- a film, and little data was gained from this. In contrast, when he was given a structured task (organising and discussing participant identified topics), he shared a range of views and experiences. The key here was in adapting to individual needs. Therefore, if a participant needed more structure, to enable them to be heard, then adult support and adaptations were offered. Indeed, adult support was utilised by several participants, with one choosing this support based on "topic difficulty" (Fresh). This demonstrates the use of adults to overcome difficulties with the task.

Throughout the study, adult support adhered to the key principle of choice; participants chose the level of support accessed due to the range of preferences they had. I also retained choice in which adult participants worked with- for example, one participant was happy to be recorded talking with myself but not with his key worker. Other participants preferred to work with their peers in the project- the benefits and limitations of which, are now considered.

4.3.7. Working with Peers

Many of my participants preferred working together, requesting to work in this way. I also reflected on their clear enjoyment of peer discussion (RD, Session 8; 11; 15). This runs counter to Ha and Whittaker's (2016) assertion that focus groups can be stressful for autistic children, "due to their limited social abilities and poor social skills" (p.551).

Within peer discussion, participants used discussion prompts and recorded themselves, without the researcher needing to be present. Conversations with peers were therefore free from the researcher's leading influence, and discussion was controlled by the young people themselves (Holland et al., 2010; Menzies, Waller & Pain, 2011). However, a consideration of the power relations *between* participants had to be made (Sloper & Beresford, 2014). In my study, younger or quieter voices were sometimes lost to older or stronger pupils' views; a power differential established by both age and confidence. So, whilst the researchers' influence may have been removed, this could be replaced by dominant peers, decreasing the opportunity for quieter participants to be heard (Holland et al., 2010). As such, I offered these pupils discussion time with myself or a TA, dependent on who they were comfortable with. I also provided opportunities for pair discussion, with quieter participants choosing their preferred partner from the group. In such discussions, less confident pupils increased contribution was clear.

The option for individual work with the researcher also enabled participants to share private information, which they may not feel comfortable sharing with the rest of the group (Holland et al., 2010). Although, for others, the peer group could provide this preferred safe space to share. One participant particularly liked being able to discuss with people who also had difficulties. Hearing the views of peers could act as a helpful memory cue, leading the young people to share their own views and experiences around that topic (Holland et al., 2010; Lile & Richards, 2018). Furthermore, participants would offer aid with a method when another peer had requested it, enabling that supported peer to add further to their discussion of 'who am I.' Peer support could therefore enable participants to provide a fuller response.

However, in a group context, there can be an emphasis on socialising, which may take away focus from the research topic at hand (Holland et al., 2010). This was seen in several sessions of this project, where participants engaged in social and humorous discussions, played games, sang together, and created mini role plays. One participant commented on how the sessions felt different from 'normal' lessons, as they could spend time with people they got along with, whilst the TA voiced positive views on the opportunity for the pupils to be 'silly' and have fun in the club (recorded in RD, Session 31). Rather than seeing socialising as a limitation, my experience mirrored that of Holland et al. (2010), that this was an important part of relationship building between participants. As this was an additional benefit I wanted the enrichment club to provide, I did not want to constrain these social opportunities. I did not want to prioritise data, over my participants' desire to build or maintain friendships. Friendships which could, in turn, increase participant comfort, and confidence, in sharing their experiences and views with each other, *when* the research topic was in focus (Jones et al., 2018; Menzies et al., 2011). For instance, one participant shared little when working with a staff member alone yet offered animated topic discussion when with a peer in the group. Another pair also discussed a range of sensitive and personal anecdotes when working in a peer-led discussion. This could perhaps be due to increased comfort when speaking within these friendships (as in Jones et al., 2018), and a sense of freedom from adult influence (as in Niemi, Kumpulainen & Lipponen, 2018). Therefore, whilst socialising increased the time needed for the project, it also had a positive impact on participant comfort in sharing their views and experiences.

Reprimanding participants for socialising 'off-topic' would have positioned me as a controlling teacher, a role which I aimed to move away from (see 4.5). The intention to step away from the teacher role did have to be broken on occasion, when participants were in, or escalating towards, conflict, upset by excessive teasing, or play fighting. These instances clarified ethical questions I had asked early on in my research diary (Session 4) about which boundaries may need to be enforced as part of my responsible adult role (Kennedy-Lewis, 2012). For example, one independent peer discussion led to a participant being very upset, due to conflict in the group. After this incident, adult support was always present *only* to mediate such conflict, without introducing questions or topics to discussion. Whilst flexibility and freedom were a focus, participant wellbeing had to be prioritised as an ethical requirement to reduce harm (BERA, 2018; Kennedy-Lewis, 2012).

Participants varied in their preferences, some asked me to help them facilitate their pair discussion, when they struggled to stay on track, whilst another pair clarified they did not want any adult contribution. Participants would sometimes request my involvement in social matters, such as asking someone to be their partner or addressing irritation or interruptions from their peers. This shows how not all participants wanted the adult to completely withdraw, with varying levels of preferred involvement. Subsequently, the main driver throughout my research was not to assume to know my participants' preference. I, like MacLeod et al. (2018), found that not all participants adhered to the assumption that autistic people want to avoid direct contact. As discussed, some participants either chose to speak with myself or to work in a group or pair format. The emphasis was on providing *options* to meet participants' preferred communication needs.

In summary, the option to work with peers was important to offer; this was something many participants wanted. Working with peers offered an opportunity to build and maintain valuable social bonds and aided in creating a safe, comfortable space in which to provide views and experiences. In this, it was important to consider the power differentials *between* young people and to respect participants' preferred level of peer and adult involvement in *their* research experience.

This section concludes discussion of the choices and adaptations available to participants. I now discuss why these choices were so important to the study and how this sits in comparison with other research, which also offers participant choice and adaptation.

4.3.8. Participant Choice and Adaptation: A Different Approach

As discussed, to avoid the imposition of adult assumptions, and to appreciate the heterogeneity of needs of my participants, my study retained choice of method as a key feature. As Ellis (2017) asserts it is "not a matter of one size fits all"- a philosophy I followed (p.23-24). Offering a choice of methods drew on Beresford et. al's (2004) assertion that interests, and strengths, can improve participation, by reducing feelings of intimidation, and increasing a sense of enjoyment. In having a choice, my participants could employ a method which interested them, which they felt more comfortable with, and/ or which they felt more capable of completing. In increasing comfort and enjoyment, this could contribute to the participatory aim of enabling autistic voices to be heard, with participants feeling more at ease with sharing their views and experiences.

My methodological approach, by allowing for a high degree of participant choice, takes adaptation for autistic inclusivity a step further than existing research in the field- and is an original contribution. Inclusive adaptations to semi-structured interviews, such as the alternative choices of Skype, e-mail, telephone, individual or group settings (Crane et al., 2019; MacLeod et al., 2018; Nicolaidis et al., 2015; Pellicano et al., 2014a), or simplified questions and adult support in photovoice interviews (Ha & Whittaker, 2016) have already been used in research but, in this study, I move beyond this by offering choice in the *initial* method employed, which can then be *further* adapted for inclusivity.

It must be noted that there are researchers who have included a range of modes of communication in their studies. These studies are represented in the table below. I do this to set out the similarities and differences with my own approach.

Table 7

Studies which Offer a Range of Methods

Study	Participants	Research Focus	Methods/Modes of Communication	Participant Choice
Clark (2010)	Early years pupils (aged 3-7).	Young children's views on their environments.	Mosaic approach: photography, guided tours, map making, role play and discussion alongside interview and observation.	N
Holland et al. (2010)	Children and young people from care settings (aged 10-20).	The identities, experiences and relationships of children and young people from a range of care settings.	Visual: photography, film, and scrapbooking. Oral and written: diary, individual interviews, guided tours and focus groups.	Y
Mogensen and Mason (2015)	Autistic adolescents (aged 13-19).	Autistic adolescents' views on diagnosis, the autism label and identity.	Visual: communication board (employed), drawing and photographs (offered). Oral and written interviews- face-to-face and email (employed).	Y
Ellis (2017)	Autistic secondary school pupils (school years 7-10).	The most effective methods for researching the social worlds of autistic children.	Mosaic approach: photography, quilting, documentary, essay, observation, and parental interviews.	N
Ridout (2017)	Autistic adults and young people (aged 16-18).	The effectiveness of mixed media in enabling autistic people to share their thoughts and feelings about the future, their identity, and their wellbeing.	Narrative diary: text and/or images. Collage: mind map of themes, drafting and final production. Discussion with the researcher around the chosen production.	Y
Goodall (2018)	Autistic children and young people aged 11-17).	Autistic pupils' experiences of mainstream secondary school.	Semi-structured interviews. Drawings- labelled and discussed. Ordering/ ranking by preference, enablers or barriers. Organising statements about school into true or false.	N

The originality of my approach does not simply lie in the diverse range of communication modes. Such diversity is evident in Clark and Moss' (2001) Mosaic approach. This employs a combination of visual, oral and physical methods to facilitate the participation of younger children. This is undertaken alongside more 'traditional' methods such as interviewing and observation. The mosaic is formed from these varying sources of data. This approach is evident across the work of Clark and Moss (e.g. Clark 2010; Clark & Moss, 2005; 2017). The Mosaic approach is also undertaken by Ellis (2017), with autistic participants. Additionally, Goodall (2018) employs visual, oral, written and kinesthetic modes of communication with autistic pupils. Undertaking a range of methods, and modes of communication, therefore mirrors my own study. Both Clark (2010) and Ellis stress the importance of a range of methods in meeting the varied needs and strengths of participants. Goodall also asserts that his methods enhance inclusivity, by offering more accessible forms for participants. However, these methods are not a *choice*; the children took part in *each* of the methods employed across these research studies.

Closer to my approach is the work of Holland et al. (2010), who offer participants a choice of methods. Their participants were able to employ any chosen combination of media. Holland et al. assert that their approach was therefore less directed or controlled and that having a choice of how to share experiences is an important part of the participatory approach. However, there is little detail on *how* this process was enacted. Subsequently, the effectiveness of this in their own project was difficult to judge. This was due to the lack of transparency on how this process was undertaken (Jivraj et al., 2014). Furthermore, Holland et al. offer no discussion of further adaptations, within research methods, to ensure inclusivity for the range of needs involved. In contrast, my study offers a detailed consideration of the choices included, and how these choices, and inclusive adaptations, were enacted.

Considering the studies above, the work of Mogensen and Mason (2015) and Ridout (2017) contain the most commonalities with my own work. As in my study, Mogensen and Mason take a participatory approach with autistic adolescents, focusing on identity. However, they do not discuss in any detail, their methodological process. In contrast, Ridout considers identity-based *and* methodological aspects. She aimed to prioritise autistic voice by enabling autistic people to represent their diverse identities in the way that they would wish, and questioned power within the research relationship. As such, she offers a detailed account of how choice was enacted in her study. Both Ridout and Mogensen and Mason move away from a single method chosen by the researcher. Instead, they offer a range of visual, oral and written methods (see Table 7), and adaptations within these methods, to suit participant needs. For example, Ridout's participants could choose not to complete certain elements of the collage process based on their preference. Mogensen and Mason's adaptations appear to offer less participant control. Changes to more structured questions were based on the *researcher's* perception of participant communication, whilst a move to email was due to time constraints. Moreover, Ridout comments on the need for participant input on the effectiveness of the method used, but her study did not undertake this. Mogensen and Mason do ask for participant feedback on the research process, however, only two of their five participants offered this. The detail here is limited- but does suggest that having direction of the research methods was viewed positively by these participants.

In contrast, *all* participants in my study offer a detailed evaluation of the research process, including their views on being given a choice of methods to complete. Additionally, my research employed its choice-based methodology on a wider scale, with a wider range of methods and adaptations included, to offer a more diverse range of communication options.

To conclude, there are studies which have employed a range of methods with children and young people, including autistic participants. However, studies which offer participants a *choice* of which methods they complete is in the minority. Furthermore, my study not only offered an initial choice, but also then provided a range of accessible adaptations, which participants could employ to further meet their preferred modes of communication. In addition, participants provided a detailed evaluation of the effectiveness of this choice-based approach. In so doing, I supported my participatory aims of ensuring the project was led by participant voices, with participants having an active role in this stage of the research process.

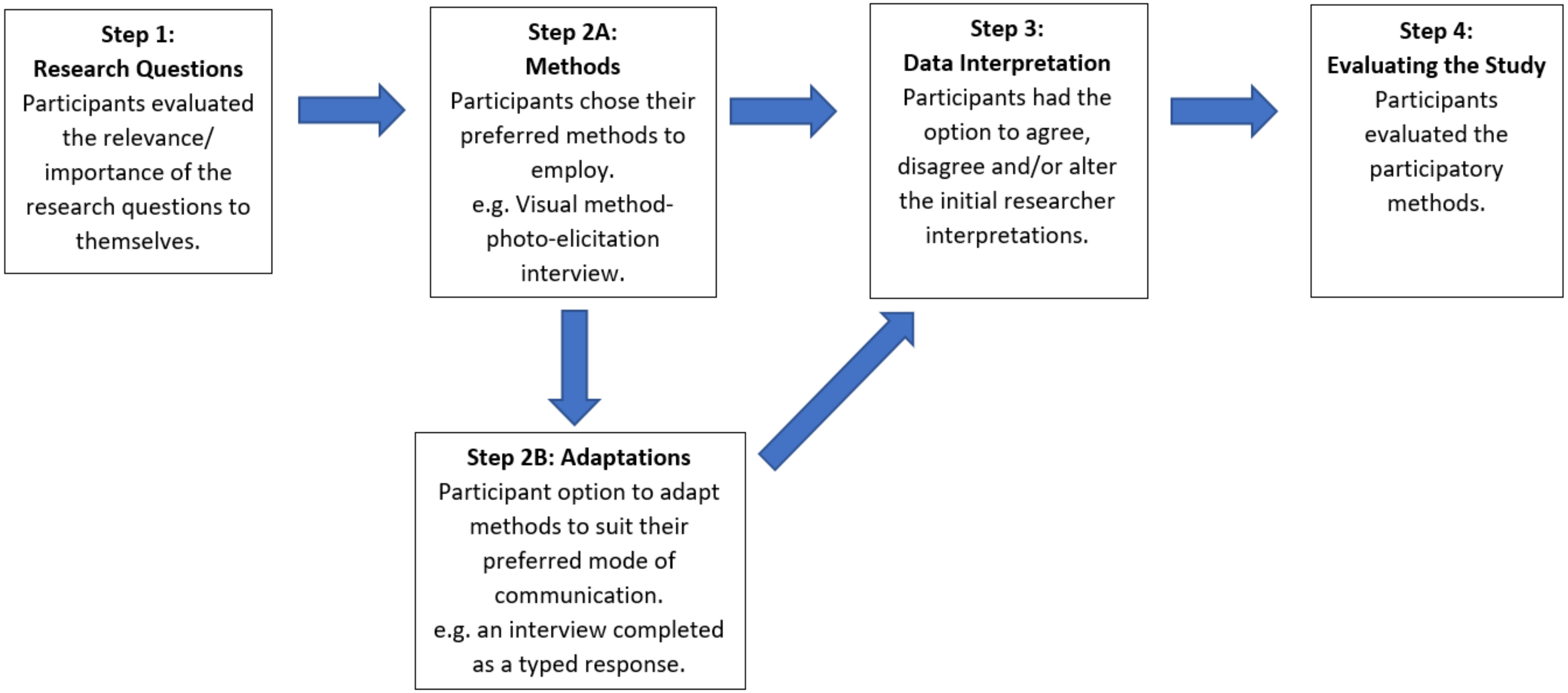
This section concludes my discussion of a key innovative aspect of my participatory project-participant choice of a wide range of methods and further adaptations. I now turn to the strengths and limitations present in the other stages of my participatory process.

4.4. Participatory Process: Strengths and Limitations

As discussed in Chapter 3, my participatory process goes beyond choosing methods, with full participation considered across *all* stages. As seen in Figure 4, accessing the perspective of autistic participants was a key element *across* the process. As such, I now consider how participant views were provided on the research questions, my initial interpretations of data and the research process.

Figure 4

The Participatory Research Design



Step 1:
Research Questions
Participants evaluated the relevance/ importance of the research questions to themselves.

Step 2A:
Methods
Participants chose their preferred methods to employ.
e.g. Visual method- photo-elicitation interview.

Step 2B: Adaptations
Participant option to adapt methods to suit their preferred mode of communication.
e.g. an interview completed as a typed response.

Step 3:
Data Interpretation
Participants had the option to agree, disagree and/or alter the initial researcher interpretations.

Step 4:
Evaluating the Study
Participants evaluated the participatory methods.

4.4.1. Step 1 and 3: Participant Validation

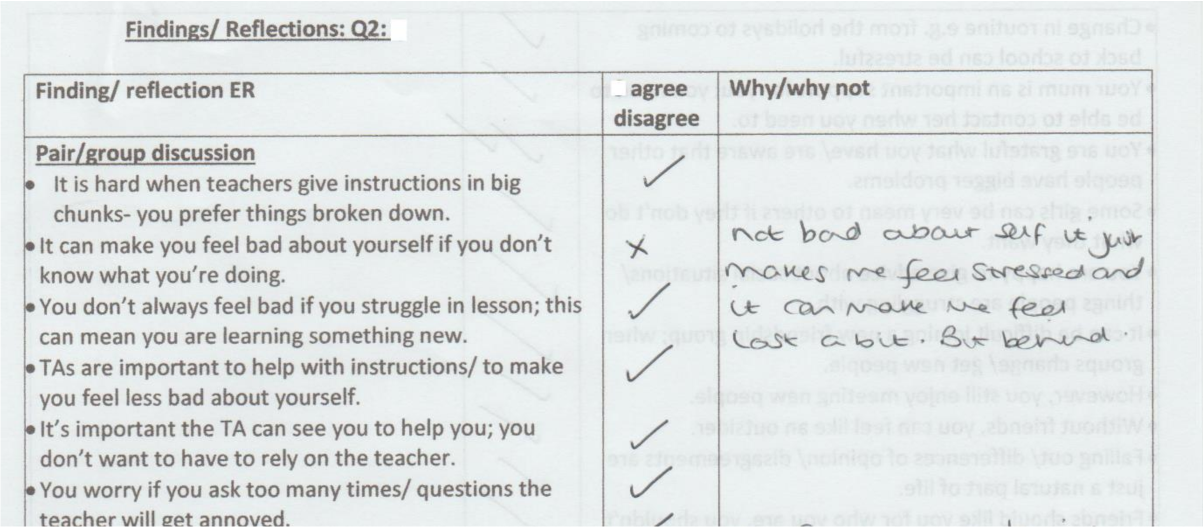
Pilot and main study participants began the process by sharing their views on my proposed research questions (see Stage 1, Table 5). This followed Cocks and Cockram's (1995) participatory research approach, which argues that the research issue may be identified by a non-disabled researcher, who brings this to the disabled community. Similarly, Chown et al. (2017) suggest that autistic people can "validate" a researcher's project (p.727), aligning with the participatory approach of shared decision making, with participants offering input on the research questions employed. By asking the young people in the study to identify which questions were relevant or important to them, I followed the participatory premise of ensuring that my research questions were viewed as relevant and worthwhile by the community group (Chappell, 2000; Macauley et al., 1999). As each of the research questions were viewed as important by half or more of the group, every original research question was used within the research project. Following the participatory aim of creating equal partnerships, I viewed *every* participant's perspective as equally valuable (Macaulay et al., 1999). I felt it would not have been appropriate to exclude any research question perceived as important, even if only one participant within the group viewed it as such.

A limitation was that the initial questions were created by me, an adult non-autistic researcher. The creation and ownership of the research questions and topic focus was not entirely that of the autistic young people involved. This was a constraint to following an emancipatory paradigm, in which disabled people should be in control of *all* aspects of the research process (Chappell, 2000). I did not incorporate autistic perspectives during the initial development and PhD approval processes. The participatory ideal of maximum participation was also compromised in the same way. In future participatory research, I would want to address this, including autistic participants at the primary stage of research question creation.

I also aimed to ensure a reciprocal process of joint reflection within data analysis. For this, I provided a participant summary, which asked participants to feedback on my initial interpretations of their individual data (see Stage 3 & 6, Table 5). I offered an interpretation of their perspectives for each of the sense of self research questions, based on all the data they had produced for that question (see Figure 5). In this, participants could correct any interpretations they felt did not represent their views. For instance, as seen below, this participant corrected my initial interpretation that struggling in school had a negative impact on their self-esteem.

Figure 5

Individual Participant Summary RQ.1.2



Findings/ Reflections: Q2: [redacted]

Finding/ reflection ER	[redacted] agree disagree	Why/why not
Pair/group discussion - It is hard when teachers give instructions in big chunks- you prefer things broken down.	✓	
- It can make you feel bad about yourself if you don't know what you're doing.	✗	not bad about self, it just makes me feel stressed and it can make me feel lost a bit. But behind
- You don't always feel bad if you struggle in lesson; this can mean you are learning something new.	✓	
- TAs are important to help with instructions/ to make you feel less bad about yourself.	✓	
- It's important the TA can see you to help you; you don't want to have to rely on the teacher.	✓	
- You worry if you ask too many times/ questions the teacher will get annoyed.	✓	

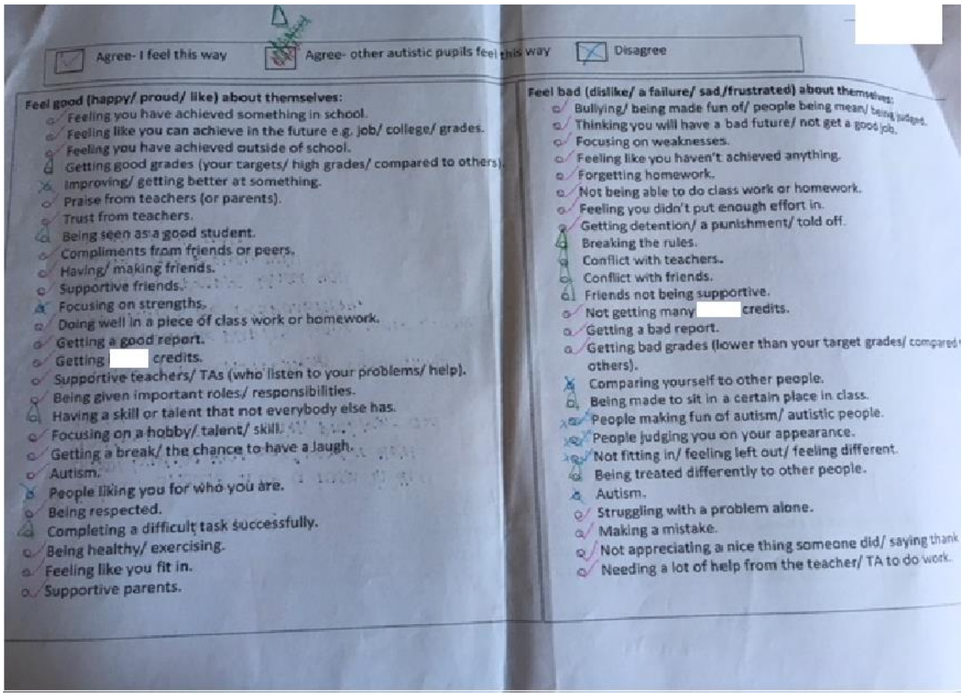
As discussed in Chapter 3, the time, accessibility, and ethical issues of participant data analysis must be considered. In my project, I was concerned that detailed transcript data would be inaccessible or unwieldy, particularly due to the literacy needs of some of the young people involved. I therefore followed Vincent et al.'s (2017) recommendation to reduce the volume of data participants had to manage. As illustrated in Figure 5, I created my own participant summary, which provided my initial interpretations in an accessible, bullet point form. This format also retained confidentiality as it was individualised, containing only interpretations of that participant's data, rather than offering peers' data for reflection. This accessible summary meant an increase in researcher control, as I had created initial interpretations for participants to feedback upon. However, I felt that this limitation was outweighed by creating a mode where participants could comfortably access the interpretations made, within a manageable time frame. This enabled my participants to offer their insider expertise on my initial interpretations, rather than being asked to analyse swathes of original data, which they may not be able to access (Holland et al., 2010; Nind, 2011).

In addition, my interpretation of whole group views, on the school elements which had a positive or negative impact on the self-view, were also validated by participants (Figure 6).

This summary addressed the ethical concerns around participants accessing the private data of others by removing any specific, personal information. Instead, I employed generalised thematic statements on elements which participants had identified as influencing their self-view, e.g. “comparing yourself to other people.” This was an important stage to support my research aim of autistic voices informing school practice by enabling participants to comment on overriding implications for such practice, without analysing the personal data of their peers.

Figure 6

Participant Summaries- Group Data: School and Sense of Self



[redacted]

☐ Agree- I feel this way ☐ Agree- other autistic pupils feel this way ☒ Disagree

Feel good (happy/ proud/ like) about themselves:
- Feeling you have achieved something in school.
- Feeling like you can achieve in the future e.g. job/ college/ grades.
- Feeling you have achieved outside of school.
- Getting good grades (your targets/ high grades/ compared to others).
- Improving/ getting better at something.
- Praise from teachers (or parents).
- Trust from teachers.
- Being seen as a good student.
- Compliments from friends or peers.
- Having/ making friends.
- Supportive friends.
- Focusing on strengths.
- Doing well in a piece of class work or homework.
- Getting a good report.
- Getting [redacted] credits.
- Supportive teachers/ TAs (who listen to your problems/ help).
- Being given important roles/ responsibilities.
- Having a skill or talent that not everybody else has.
- Focusing on a hobby/ talent/ skill.
- Getting a break/ the chance to have a laugh.
- Autism.
- People liking you for who you are.
- Being respected.
- Completing a difficult task successfully.
- Being healthy/ exercising.
- Feeling like you fit in.
- Supportive parents.

Feel bad (dislike/ a failure/ sad/frustrated) about themselves:
- Bullying/ being made fun of/ people being mean/ being judged.
- Thinking you will have a bad future/ not get a good job.
- Focusing on weaknesses.
- Feeling like you haven’t achieved anything.
- Forgetting homework.
- Not being able to do class work or homework.
- Feeling you didn’t put enough effort in.
- Getting detention/ a punishment/ told off.
- Breaking the rules.
- Conflict with teachers.
- Conflict with friends.
- Friends not being supportive.
- Not getting many [redacted] credits.
- Getting a bad report.
- Getting bad grades (lower than your target grades/ compared others).
- Comparing yourself to other people.
- Being made to sit in a certain place in class.
- People making fun of autism/ autistic people.
- People judging you on your appearance.
- Not fitting in/ feeling left out/ feeling different.
- Being treated differently to other people.
- Autism.
- Struggling with a problem alone.
- Making a mistake.
- Not appreciating a nice thing someone did/ saying thank
- Needing a lot of help from the teacher/ TA to do work.

A limitation was that participant summaries were not completely individualised to preferred modes of expression (Spiel et al., 2017). They were all produced in the same written format. Within this, some mitigating adaptation was included, such as colour-coding, typing or asking for adult support, to reduce the volume of handwriting required. My main aim was to enable participants to exercise control over their data, how it was interpreted and how it was utilised, with the hope that offering adaptations to how summary sheets were completed would allow this. Though, in being transparent, it must be highlighted that there were limitations with the individual choice in the modes of communication used.

I felt Step 3 was an important part of the process, which balanced demands on participant time with the opportunity to undertake accessible joint reflection with the researcher- in an ethical and accessible form. This joint reflection enabled the autistic adolescents involved to address any misinterpretations made by myself, refocusing these on to what they intended to convey (Pretty 1995). This increased the internal validity of the findings, by ensuring that the interpretations offered *aligned* with the views and experiences of the autistic adolescents involved (Pretty, 1995; Wahab, 2003). Participant summaries became a key reference point, which I returned to repeatedly in my subsequent thematic analysis (see 4.6) to ensure that I did not move away from participants' views.

In Step 1 and 3, participants were asked to share their opinions on the work of an adult-teacher-researcher (see 4.5.1 for further discussion). The researcher may be viewed as an expert and it may be assumed that their research questions or interpretations of data are automatically 'correct' (Bourke, 2009). Furthermore, the power imbalance between children and adults (Clark, 2010) and between teachers and students (Kim, 2012) may enhance this sense of the researcher knowing better. Participants may have felt uncomfortable disagreeing with the questions or interpretations I had formed. Therefore, with the research questions, I emphasised that there were no wrong choices and that individual perspectives were my priority. In participant summaries, I followed MacLeod's (2018) advice and offered a direct, explicit option to disagree, aiming to counter any tendency to comply with my perspective. Only two of the eight participants chose all the research questions as important, suggesting that participants were comfortable in identifying *only* the questions that they felt were relevant to them. Furthermore, all participants chose to disagree with, and correct, some of my interpretations. This illustrated both the need for such opportunities for correction and my participants willingness to do so. Within these checks, participants were also given individual follow-up questions, for points I would like clarification on (as in MacLeod et al., 2014). This enabled participants to provide additional information, which may not have been shared at the time, but which they felt was an important part of their view or experience.

Finally, a limitation, in both steps, was that the participatory ideal of *maximum* participation was not met; participants were not involved in the initial interpretation of data *or* creation of research questions (Bourke, 2009; Cornwall & Jewkes, 1995). However, participatory, shared decision making was undertaken, with my initial interpretations and questions either validated, or corrected, by my participants (Macaulay, 2017; MacLeod et al., 2014).

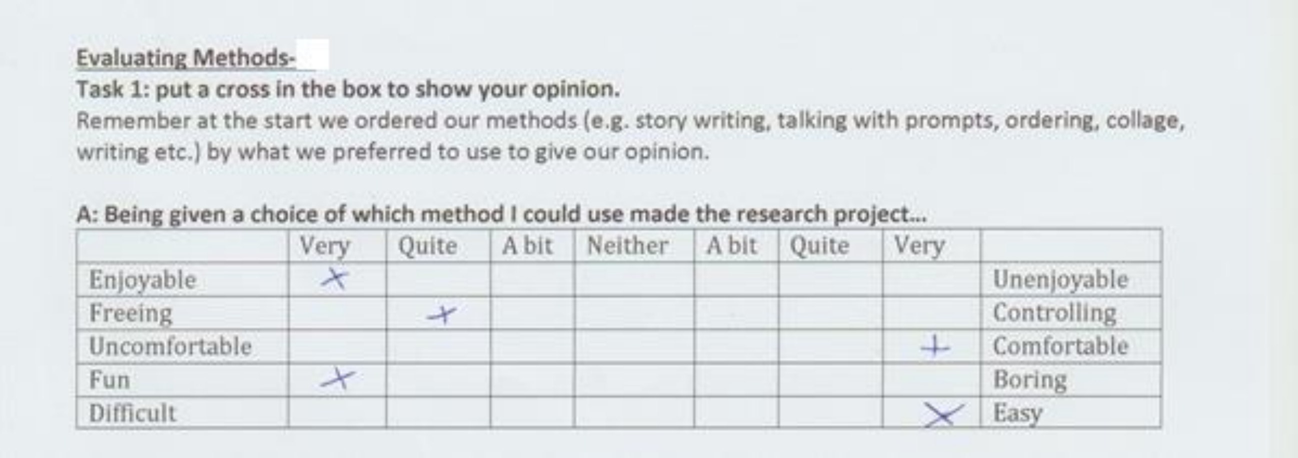
4.4.2. Step 4: Evaluation

I now report on Step 4, evaluating the participatory process undertaken. Both pilot and main study participants were given the opportunity to evaluate the participatory research process (see Stage 4 & 9, Table 5). This was an evaluation of methods *for* autistic young people, *by* those young people, offering participants' views on the strengths and limitations of the process undertaken. The evaluation data can be found in Chapter 8.

Participant evaluations took the form of a questionnaire, providing comparable quantitative data, in the form of semantic differential scales, and qualitative data from open comment sections (Cohen et al., 2011). Semantic differential scales offer opposing adjectives, which participants employ to evaluate a given statement (Frey, 2018; Salkind, 2007), as shown in Figure 7.

Figure 7

Evaluation: Semantic Differential Scale



Evaluating Methods- [redacted]

Task 1: put a cross in the box to show your opinion.

Remember at the start we ordered our methods (e.g. story writing, talking with prompts, ordering, collage, writing etc.) by what we preferred to use to give our opinion.

A: Being given a choice of which method I could use made the research project...

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Enjoyable	X							Unenjoyable
Freeing		X						Controlling
Uncomfortable							X	Comfortable
Fun	X							Boring
Difficult							X	Easy

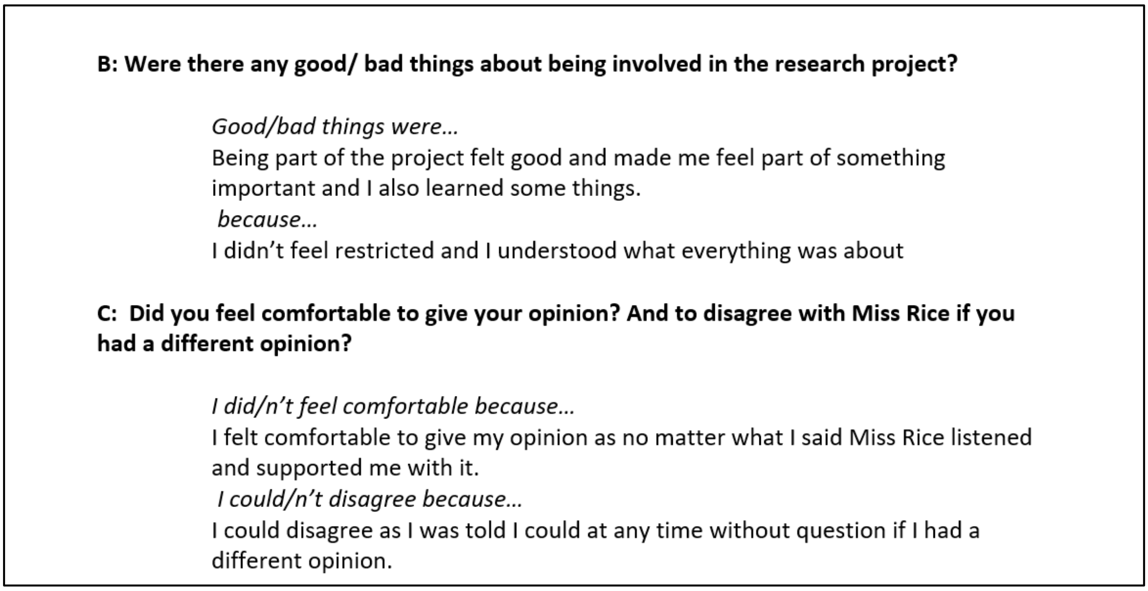
Stone and Priestley (1996) argue that quantitative approaches should not be excluded from emancipatory paradigms. Both quantitative and qualitative approaches can be oppressive- *or* emancipatory- depending on how they are used. Stone and Priestley assert that the theoretical position guiding the data collection must be considered, when choosing which form to employ.

In my participant evaluations, I aimed to employ a format where direct quantitative comparisons between responses could be made. These evaluations, unlike previous activities in my research project, were not based on negotiation of self. Therefore, they were not hampered by the concerns discussed previously, about objectifying, and erasing, the diverse autistic self that can arise in quantitative approaches (Orsini & Davidson, 2013; Ridout, 2017). In choosing to employ a quantitative comparison, I had to consider what sort of evaluative scale to use. Geake and Goss (2008) state that Likert scales can lead participants to preferred responses, through the 'obviousness' of purpose in the statements given. Similarly, Friborg, Martinussen and Rosenvinge (2006) argue that Likert scales can increase acquiescence bias; respondents are drawn towards positive responses and influenced by the one dimensional positive or negative valence of the statement given. Their comparison of Likert and semantic differential scales found that the semantic differential scale tend to avoid such bias, producing more consistent and realistic judgements. I therefore chose to employ semantic differential scales.

Alongside this, open comment sections provided additional data on positive or negative aspects, changes participants would want to see, and views on how comfortable they felt in the research relationship. This enabled participants to give specific views, adding detail and qualification to their scaled responses (Cohen et al., 2011). An example of this is given below. The question is shown in bold and sentence scaffolds, provided to support additional literacy needs, are in italics.

Figure 8

Evaluation: Open Comments



B: Were there any good/ bad things about being involved in the research project?

Good/bad things were…
Being part of the project felt good and made me feel part of something important and I also learned some things.
because…
I didn't feel restricted and I understood what everything was about

C: Did you feel comfortable to give your opinion? And to disagree with Miss Rice if you had a different opinion?

I did/n't feel comfortable because…
I felt comfortable to give my opinion as no matter what I said Miss Rice listened and supported me with it.
I could/n't disagree because…
I could disagree as I was told I could at any time without question if I had a different opinion.

A limitation of using semantic differential scales was that this did not provide the same choice of varied modes of communication as offered for the first research question. Adaptions were made to enhance accessibility, including adult support and a detailed instruction sheet (Appendix G). Whilst I was concerned about the complexity of the scales, most participants quickly picked up how to complete this, after my initial explanation. All participants were able to give their views on the research project in this form, with some support. However, participants provided some negative feedback on this process. For example, the positive and negative adjectives in the semantic differential scales were not placed on the same side of the table, but mixed in position, to prevent response bias (Cohen et al., 2011). One participant was dissatisfied with working in this mixed form, whilst also expressing some unhappiness at the volume of questions to complete. I also reflected on a sense of participants not being keen to complete the evaluation forms (RD, Session 14). Reflecting on Stone and Priestley's (1996) comments on the oppressive aspects of quantitative approaches, I have questioned whether, at this point, my preference for a comparative method prevailed over participant choice. The method may not have been a barrier to participant views on the process being shared, however, I feel that the questionnaire format added control over participant communication choices. This went against my participatory ideal of participant freedom within the process.

There were also ethical questions to be considered. With the adaptations for support, and some questions being specific to a method a participant had completed, the questionnaires were not completed anonymously. Whilst multiple participants welcomed adult support to complete their evaluations, I have questioned the influence of my presence, and my relationship with participants, on their responses (RD, Session 14; 15). As Holland et al. (2010) claim, participants may wish to please the researcher, with whom they have a good relationship, or may be fearful of losing a positive experience. However, I considered how a lack of anonymity may have *encouraged* participants to share concerns. After explaining the research process and consent at the start of the project, several of my participants were very aware of what they should or should not include, in terms of identifiable information. If I had enforced anonymity with the evaluations, I wonder if in 'sticking to these rules' some participants may not have shared their concerns around their evaluation responses, and so missed out on the opportunity for reassurance (Dowling & Brown, 2010). For example, one of my participants shared their anxiety that any negative evaluation may lead me to change the way the club was run, which they did not want to happen. By hearing their concerns, I was able to reiterate that they would not lose elements of the club that they enjoyed, and that they could clarify their views in the open comments section. One participant also commented on their apprehension that their evaluation was less positive. This enabled me to assure them that this evaluation would have no negative impact on their position in the club or our relationship. Finally, when one participant was told I would not look at their responses until later, they asked to share their views so that they could discuss them with me immediately. Therefore, in not enforcing anonymity, participants voiced a range of views and concerns, that may have been silenced otherwise.

Overall, the semantic differential scales and open comments did enable autistic participants to share their evaluations of the participatory study. Supportive adaptations aided this process but led to ethical questions around anonymity of response. However, in foregoing this anonymity, participants could access reassurance for any concerns raised. Additionally, in future research, I would want to address the lack of choice and flexibility in the questionnaire evaluation. Whilst this did not appear to be a barrier to participants sharing their views, it hampered the participatory aim of participant control and freedom in their modes of communication.

This section concludes my consideration of the stages of the research process undertaken by participants. However, in considering *how* participation was enabled it is also important to reflect on the social and discursive context, including researcher-participant power dynamics (Holland et al., 2010). This key influence is now discussed.

4.5. Participant Power in a Real-World Context

As Newby (2014) argues, “the real world is not as clearly defined as research templates require” (p.29). Within the real world setting of shifting and sometimes hidden power dynamics, participatory and emancipatory aims are difficult to achieve. Ensuring that voices are fully heard is not a straightforward matter (Cargo & Mercer, 2008). Consequently, I now reflect on the influence of my research environment, and my position within that setting, on participant power.

4.5.1. My Position as Adult-Teacher-Researcher

My role within the enrichment club format of the project could create an additional layer of difficulty in breaking down the adult-child power differential. As the enrichment club was undertaken in curriculum time, I was positioned as the assigned teacher to lead this. I had also previously worked at the school I was researching in. Whilst I had not taught any of the participant group, they knew of me as a former teacher from the school. This placed expectation upon me as, whilst I was there to conduct a research project, to the participants I was also their enrichment teacher. The effect of this hybrid researcher-teacher role on the power dynamic between researcher and participant must be considered (Kennedy-Lewis, 2012). There is an inherent power structure implied by being teacher and student within the educational setting, with an expectation that pupils follow the school rules and complete the work that the teacher has set (Gallacher & Gallagher, 2008). Therefore, if participants perceived me as a teacher, this could hamper my participatory aims. Participants could feel that they must follow the traditional teacher-pupil relationship, with the teacher-researcher in the position of control. This runs counter to the participatory ideal of empowering the pupil-participant group.

In what follows, I explore some of the key aspects of my hybrid researcher-teacher role, considering the conflicts between my aims as a participatory researcher and the inherent expectation of how an enrichment club teacher-pupil relationship should be. I also consider the influence of other staff members in this environment, who could further impact participant power. This was a process of continual reflection, in which I had to carefully, and continuously, consider my approach, adapting when necessary, to address any negative effect on participant power my position may have.

Firstly, I was aware that participants may feel the need to give the correct answers- ones that the teacher was looking for, due to the requirement of this within the traditional teacher-pupil relationship (as seen in Kim, 2012). Therefore, repeatedly clarifying that there were no right or wrong answers, or even a requirement to answer in the first place, was necessary because, as Pratt (1990) found, children and young people may feel they have to answer questions posed, even if those questions make no sense. Such feelings would be compounded further in my study, with the expectation that pupils answer their teacher ‘correctly’ and that the teacher is an ‘expert’ questioner (Bakx et al., 2015; Inglis, 2012; Kim, 2012). Participants might also feel obligated to provide answers to ‘please’ the researcher, to retain a positive relationship (Holland et al., 2010). Therefore, it was vital for me to fully identify the “demand characteristics” of my research situation, countering these by being explicit about there being no expectation for participants to answer, or to create a right answer (Pratt, 1990; p.175).

There was also a need to address the expectation that participants must complete *everything* a teacher asks, respecting that non completion may be a behavioural cue that consent is withdrawn (see Bourke & Loveridge, 2014 for commentary). As such, I repeatedly clarified that participants could say don’t know, no comment, don’t want to answer or don’t want to complete any more, without any subsequent detriment. Ensuring that barriers to access were removed (as discussed in 4.3) was important to ensure that participants could choose this option because they did not *want* to contribute- not because they *could not*. Additionally, I wanted to move away from the traditional time pressures of the academic, classroom environment, allowing participants the opportunity to complete their chosen method at their own pace. Whilst this lengthened the time needed for the project, I felt it was important to avoid the idea that this was ‘work’, which must be completed in a timeframe dictated by the teacher. Participants could choose when they had finished, regardless of the level to which the method was completed. In this, I had to be aware of outside adult control. This was evident when Richelle chose to leave the group, in the third term of the project, and was sent back to finish her work, by her key worker. She seemed uncomfortable not doing as she was told by this adult. This led me to explain that she did not need to finish any work, that she could go to her new enrichment club immediately, and that she could return to us anytime, should she so choose. I also reiterated with the whole group that they could leave, and equally return, at any time without issue. Richelle independently chose to return at session 35, attending the final two sessions. This was one of several occasions where I had to counter support staff suggestions that participants needed to complete a task in full- something I had to be aware of throughout the project.

The classroom environment, and school staff, can therefore reinforce an expectation to follow school rules, perpetuating the traditional position of adult control (as also seen in Thornberg, 2009). As Ellis (2017) notes adults exercise overt control in the school setting. I therefore had to consider the pupils' experience of continual adult observation of their behaviour in relation to the school rules. Within this, participants may have concerns about getting into trouble with adults, and this could impact on the power dynamic (Conn, 2015). I had to consider the additional control that could be applied by the TA present, who would often enforce the expectations of their everyday, school practice. In addition to the completion of work, rules around taking off coats, or allowing phones to be used, were an area of conflict with my own position, where I wanted to allow participants freedom in these choices (reflected on in RD, Session 11; 13). As Davis, Watson and Cunningham-Burley (2008) identify, rules within the school setting can place the researcher at risk of either affecting their standing with staff members, or alienating students, depending on where support is given. This was addressed in my own project by shifting the blame to myself. I would often tell support staff a rule break was my fault, aiming for participants to feel less like they had done something 'wrong' in the situation. This implied to the TA and the pupil that the rule was 'OK' to be broken in *this* classroom, without directly challenging the staff member's position in front of a pupil.

Throughout the research, I reflected on my responses to participants' behaviour, considering how these might be influenced by my position as the enrichment teacher in the room, alongside my previous career as a secondary school English teacher (RD, Session 25). I felt that behaviour which would be considered inappropriate in class sometimes called for a different response to that expected of the 'teacher' role. For example, when a pupil chose to wear a task sheet as a hat, I treated it as it was, an amusing moment. In this situation, I laughed. However, the expected response of the teacher would be to chastise the student. Joining in with humour, which adults may consider “silly and inappropriate”, can, as Corsaro and Molinari (2008, p.245) found, enhance trust and relationships with pupils. This can enable the researcher to be positioned within participants’ peer culture, that which is based around what is funny, rather than being placed as the adult who admonishes such behaviour. Scott-Barret et al. (2018) also report on a long-term project which enabled the formation of a different kind of fun relationship, a relationship in which becoming a ‘known adult’ can increase feelings of security and comfort for the young people involved (see also: Clark & Moss, 2005; Preece, 2002).

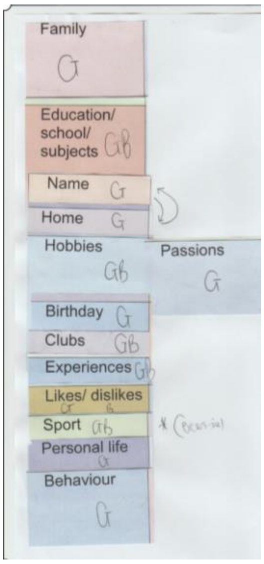
As I developed this relationship, I observed the importance of a two-way interaction. This included the sharing of my own experience, which helped build rapport (as in Danker et al., 2017). Participants wanted to discuss my PhD, my previous career and my interests and experiences. Whilst every conversation may not have included data relevant to the research question, I felt it was highly relevant to the research process, ensuring that a relationship could be built where the participant felt comfortable to speak, and be heard. I also viewed divergence from planned routes as an opportunity for participants to express their views as they so wished. For example, one participant discussed an interest in aeroplanes with me for some time. I was aware that this digression may only give minimal data for the research questions. However, I viewed digression differently to Danker et al. (2017) who assert that divergences should be deftly managed to refocus participants to the research topic at hand. Instead, I reflected that sharing such interests was important, allowing me to get to know participants in more depth (RD, Session 21;22), and building relationships with a particular participant. It is in this sense that, Bondi (2003) argues that relationship building can aid communication across differences, whether that be differences in gender, class, race, sex or, in my case, across teacher-student and autistic-non-autistic divides. Of course, taking time to empathise, to see the position of another, does not eradicate difference or inequality but as Bondi (2003) argues taking the time can convey to participants “a respect for differences as well as a recognition of similarities, and it is this process that matters, enabling us to communicate (however falteringly) across differences” (p.74). Taking this position appreciates the researcher’s need to empathise with what may be a differing autistic perspective (Milton, 2012), using discussion of interests to enhance the researcher's understanding of that differing point of view.

Reflecting on my position, I particularly debated those points in the project where I directed participants to complete a method, rather than having this as an open choice (RD, Session 23-24). This researcher direction has already been discussed in relation to data analysis and evaluating the process (4.4). I now consider two further researcher directed methods: The Twenty Statements Test and the organising of topic cards.

4.5.1.1. Researcher Directed Methods. I asked *all* participants to take part in three organising tasks in the project (see Stage 2 & 6, Table 5). I did this to provide easily comparable data on participants' views from across the whole group. Firstly, participants organised the topic list they had created for question 1.1. into most to least important to the self-concept and into those elements which had a positive or negative impact on their self-view. Participants were encouraged to make adaptations within this task, choosing to physically move cards into position, to number, or to use colour-coding or symbols. Participants then chose from oral, peer or researcher conversation, or a written response, to share their reasons for their choices. In Figure 9's example (below), the participant placed topic cards in order of importance, then labelled whether these elements made her feel G-good or B- bad about herself. She discussed her choices with the researcher, in a recorded conversation.

Figure 9

Organised Topic Cards



Later in the project, topic lists focusing on sense of self and school were created. Participants organised list to show the influence of these school-based elements on their self-view. In this research activity, participants used colour-coding or symbols on a topic grid (Appendix F), rather than being able to move separate topic cards. These organising tasks enabled me to compare elements which had a positive or negative impact, across the group.

Whilst there was less choice in the overall method, which asked *all* participants to organise topic lists, within this, there was a range of options on how to communicate views, dependent on individual preference or need. This included the option to say that they did not want to complete the task at all, which was taken by one participant. Organising was not generally placed low on preference for participants (as long as numbers were not used- see Chapter 8), however, I questioned in my research diary the researcher control in this task, as it asked all participants to take part (RD, Session 23-24). Adaptations around writing and working with others were made but I was still concerned that these tasks moved away from my priority of allowing choice. This process highlighted a tension between producing comparable data and ensuring participant choice of response.

Further tensions in producing comparable data were present in the completion of the Twenty Statements Test (TST). This was undertaken by all participants, at the start of the focus on question 1.1 (for details see Stage 2, Table 5).

Since its creation by Kuhn and McPartland (1954), the prevalence of the TST across sense of self research is evident (see for example, Driver, 1969; Emanuel et al., 2014; Madson & Trafimow, 2001; McCrae & Costa, 1988). It has also been employed with autistic participants, to consider memory and self-identity- chosen as a method which allows "participants to define their sense of self in their own words" (Tanweer et al., 2010, p.903). Following Winstone et al.'s (2014) comparison of semi-structured interviews and creative methods, I employed the TST to compare an established, structured method, with my own adapted approach. Unlike Winstone et al., the evaluation of those methods was completed by the participants. I did this to offer participant views on the benefits or limitations of a prescribed method for producing data on the sense of self, in comparison with a choice of accessible alternatives. The findings from this have formed part of the discussion on participant views of the research methods employed (see Chapter 8). This, alongside participant consideration of the organising tasks, offers participant evaluation of a prescribed method. Whilst this has provided valuable data, researcher directed tasks have continued to be an area of unease. I have questioned this as a limitation to my participatory aims.

This section has shown how the power dynamics of a teacher-pupil relationship must be closely considered in a participatory approach- particularly due to the inherent expectation for pupils to follow the wishes, and rules, of the teacher and classroom. The relationship building focus taken in this research project was part of my aim to break down this power differential; an approach which focused on humour, comfort, and rapport, alongside a clear appreciation for the different interests of my participants. Whilst this approach might have resulted in divergences from data collection, it was an important part of my aim to enable both participant power, and communication across the differing positions, of non-autistic adult researcher and autistic young person. In this, I have had an awareness of the limitations in my approach, particularly when my aims to produce comparable data have impacted on participant power and choice.

4.5.2. The School Environment

As discussed above, the school environment meant that myself as adult-teacher-researcher, support staff and peers (see 4.3.7.) could impact on participant power, drawing on pre-existing power asymmetries. These issues bring in questions around research location. It could be suggested that the pilot study avoided the effects of this, as it was undertaken in the participants' home. In some ways, the home data was more straight forward to collect. It was easier to ensure that participants had my full attention, and the option for 1:1 discussion and support was present in every session. This also meant that the process was quicker to complete (see Table 5). But the school environment is perhaps a place where participants are used to seeing new or unfamiliar faces, such as a researcher, and therefore research undertaken here may be more comfortable. This was evident in Preece and Jordan's (2010) study, which included autistic children and young people. In this study, one participant became distressed at being observed at home, so the researchers left within ten minutes. In contrast, the researcher's presence was accepted in the same participants' respite care placement; a place of 'other faces.'

Beresford et al. (2004) also argue that it is less confusing to talk about an aspect of life when you are within that environment. For example, discussing school barriers to a positive sense of self *in school* would be easier. Conn (2015) and Ellis (2017) further argue the importance of research taking place in the relevant educational environment. They assert that this allows the researcher to witness the daily structures and systems of young people's experiences, observing the "unfolding nature of real-life contexts" (Conn, 2015, p.62; Ellis, 2017). This allows the researcher to further understand the real-life context which influences young people's experience. This was important for my second research question, where the school context's influence on sense of self was a key focus. Indeed, in my research, the school setting allowed me to see issues in action, such as room changes, absent TAs or problems acquiring necessary technology, such as computers, for preferred typing. This hampered the ability to adapt to participant needs, however, it also illuminated issues that may be faced by pupils in their day-to-day classroom experience, that need to be addressed.

Finally, the timing of a study can aid discussion (Holland et al., 2010). In my project, if something had happened that day, participants would share detailed recounts of their experiences. This included other personal matters, alongside experiences relevant to the research topic, such as exam scores or arguments with others, that impacted on their self-esteem. The location itself could act as a memory cue- for example, a move to an English room led Connor to share his views on that curriculum subject. Furthermore, regular meetings, with the project undertaken every week for a school year, meant that there was a higher possibility of 'catching' immediate events for discussion (Holland et al., 2010). The continuous, weekly meeting also allowed participants to share changing views, when the emotion of the event had passed. For example, a punishment which had been discussed in detail in the previous session was viewed differently the following week, when the situation had been resolved.

In summary, there were limitations and challenges in the location, particularly with regards to the inherent power dynamics of the school environment. However, positives were found in the school location, including experiencing and sharing issues 'in the moment' and the location acting as a memory cue, which enabled an increased participant response.

This concludes my consideration of the participatory process undertaken by participants. I now consider my subsequent thematic analysis of the data, alongside the format in which I chose to present that data.

4.6. Thematic Analysis

Due to the range of methods employed, my analysis needed to follow a system which could draw data from varied forms, into overarching conclusions. This was achieved through an application of thematic analysis. Thematic analysis can be applied to interview data (Braun & Clarke, 2006; King et al., 2017), visual forms (Cresswell, 2007) and written responses (Humphrey & Lewis, 2008; Mogensen & Mason, 2015). It is therefore useful for research studies such as mine, which have a variety of qualitative data (Winstone et al., 2014). For a detailed summary of the data collected, see Appendix H.

To ensure a defined, methodical, and transparent system, I followed the stages of thematic analysis set out by Attride-Stirling (2001) and Braun and Clarke (2006). This enabled me to create thematic networks to represent my data. This supported my research aims to move away from previous sense of self studies (Farley et al., 2010; Jackson et al., 2012; Lee & Hobson, 1998), which created a *hierarchy* of self-understanding, prioritising the interpersonal and devaluing the autistic sense of self (Bagatell, 2007). The thematic network acts as an organising, web like form. Themes are presented simultaneously, with no hierarchical order or prioritising of one theme; *all* themes are given equal representation (Attride-Stirling, 2001). Thematic networks therefore aligned with my aim to equally value all elements of my autistic adolescents' sense of self, including in the presentation of data (see Chapters 5,6 & 8 for examples).

Table 8 (below) sets out the stages of my thematic analysis:

Table 8

Stages of Thematic Analysis

	Process	Example
Step 1- Coding	1. Immersion: repeated reading/ revisiting of *all* the data to create an initial coding list (Braun & Clarke, 2006). 2. Code creation through an inductive, data-driven approach. Codes based on salient details arising from participant views or experiences, rather than a predetermined coding framework (Attride-Stirling, 2001; Braun & Clarke, 2006; Danker et al., 2017). 3. All visual and word-based forms employed to answer the research question coded. 4. Data which departs from the "dominant story" retained, ensuring any heterogeneity in findings remains clear (Braun & Clarke, 2006, p.89; Humphrey & Lewis, 2008).	Coding charts (Appendix I;J) Figure 10 (Below)
Step 2- Organise themes	1. Codes organised into meaningful groups/ patterns, clustered around shared issues or concepts (Attride-Stirling, 2001; Braun & Clarke, 2006). 2. Where appropriate, sub-themes utilised for large, complex themes (Allen, 2017; Braun & Clarke, 2006). 3. Themes reviewed using Patton's (2002) criteria, checking for internal homogeneity and external heterogeneity. Data must be coherent within the theme, clearly distinct from other themes, and broad enough to encapsulate a range of codes (Attride-Stirling, 2001). 4. Create theme titles which encapsulate the "essence" of that theme (Braun & Clarke, 2006, p.92); the key interpretation or element is made clear to the reader through the title choice (Allen, 2017).	Coding charts (Appendix I;J) Figure 10; 11 (Below)

Step 3- Construct thematic map	1. Create thematic maps, with a separate network formed for each research question (Attride-Stirling, 2001). 2. Ensure maps illustrate the 'big picture' for the reader; the overall meanings evident and the connections between themes and subthemes (Attride-Stirling, 2001; Braun & Clark, 2006).	Findings (Chapter 5, 6 & 8)
Step 4- Describe and explore themes	1. Analysis sectioned by theme, exploring the underlying patterns, through reference to data (Attride-Stirling, 2001). 2. The "story" each theme has told is identified (Braun & Clarke, 2006, p.92), making sense of the data for the reader. 3. Cross reference with participant feedback on initial interpretations (4.4), to ensure I have aligned with what participants intended to convey.	Findings (Chapter 5, 6 & 8).
Step 5- Summarise themes	1. The main themes and patterns summarised explicitly for the reader, with links made to the overarching research topic (Attride-Stirling, 2001). 2. The place of the themes within the "broader story" of the whole data set is made clear (Braun & Clarke, 2006, p.92).	Discussion (Chapter 7 & 8).
Step 6- Interpret patterns	1. Deductions are brought together with relevant theory. 2. Significant concepts, patterns, and arguments from across the thematic networks are related to the research questions asked (Attride-Stirling, 2001).	Discussion (Chapter 7 & 8) and Conclusion (Chapter 9).

I now discuss the strengths and limitations of this analytic approach in meeting my participatory aims.

I used an inductive, data-driven approach to coding research question 1. I did not employ a pre-set coding system, which can be based on current theoretical assumptions about autism and/or led by the researcher's areas of interest (Braun & Clarke, 2006). Instead, my participants' data guided the codes created. This aligned with my research aim to be led by my participants' voice, placing them as the 'expert' on their sense of self, rather than analysing the data purely through an outsider-research perspective (Milton & Bracher, 2013).

This analytic process is displayed below. Analysis moved from left to right in Figure 10, starting with the initial coding, moving towards the sub themes and main theme. This demonstrates how the process was rooted in participant data. The themes are formed from the pattern of meaning in the coded data (Braun & Clarke, 2006). Whilst the sample data is all coded as grades, the first row is grouped into the concept the importance of grades for future achievements and the second row the relevance of grades to being a bad student. These sub themes both contribute to the "broader story" of the main theme- how participants perceived themselves as positioned within the student role (Braun & Clarke, p.92).

Figure 10

Coding and Theme Organisation- RQ1.

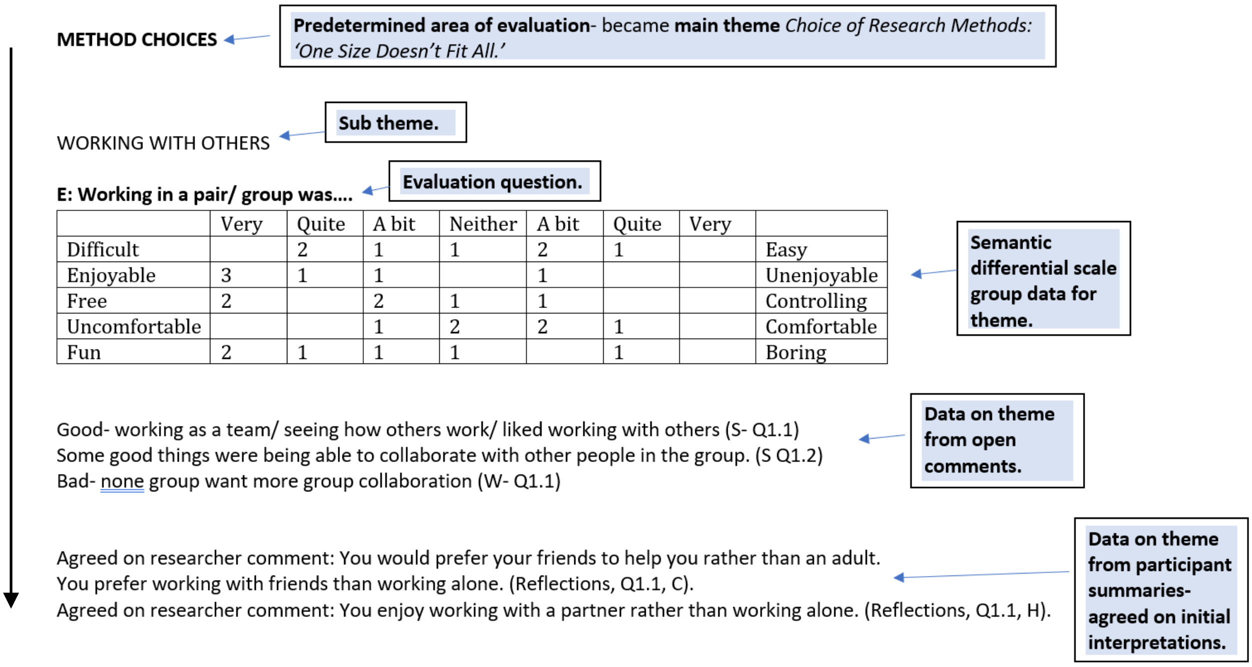
Sample Data	Code	Sub-theme	Main Theme
It can kind of make you feel erm good if you've got a good future because it's like you'll be proud of yourself. And er like if you got good results. **(Pair Discussion with Researcher)**	Grades Future	**The Importance of Grades**	**Positioning Oneself as Student**
And your final exam is also in that hall when you get your final grades, which can potentially determine your future. **(Photo Elicitation Conversation with Researcher)**	Grades Future Exams		
Sometimes low grades drag me down, like I'm useless. **(Written Response)**	Grades Worthless	**'Bad' Student as Failing**	
 **(Drawing of a 'Bad' Pupil)**	Grades Bad Student		

All qualitative data for question 1 was coded in this way, including the participant checking summaries discussed in 4.4.1. Any point where participants had disagreed, and corrected my initial interpretation, was important to code. Using NVivo software for this coding allowed me to cross reference participant corrections, with any initial interpretations made. These were referenced not only in the initial coding and thematic map creation, but also when describing and summarising themes. Therefore, when the "story" of the data was considered, it could be led by what participants intended to convey (Braun & Clark, 2006, p.92).

A limitation in following a participant-led approach was evident in the thematic analysis of research Q.2: participants' views on the participatory research process. The evaluation questionnaires provided specific questions about participant choice and control, the research methods and topic, relationships with the researcher and with peers, and the research environment (Appendix K). This resulted in deductive thematic analysis, due to the preidentified areas of evaluation contained in the questionnaire format (Braun & Clark, 2006). Main themes were therefore based on the participatory and inclusive design concepts I asked participants to evaluate (Drew, Hardman & Hosp, 2008). Consequently, data was formed within a predetermined framework, for example, the theme of choice, including responses around choosing to work with peers. Thematic organisation was led by themes of the researcher’s interest, with both the qualitative and quantitative data produced in the questionnaires organised under these themes. The labelled example below demonstrates how this data was collated and how the themes were applied. The arrow down the side illustrates how this was a top-down approach, led by the predetermined area of evaluation.

Figure 11

Thematic Organisation- RQ2



METHOD CHOICES

Predetermined area of evaluation- became **main theme** *Choice of Research Methods: ‘One Size Doesn’t Fit All.’*

WORKING WITH OTHERS

Sub theme.

E: Working in a pair/ group was….

Evaluation question.

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult		2	1	1	2	1		Easy
Enjoyable	3	1	1		1			Unenjoyable
Free	2		2	1	1			Controlling
Uncomfortable			1	2	2	1		Comfortable
Fun	2	1	1	1		1		Boring

Semantic differential scale group data for theme.

Good- working as a team/ seeing how others work/ liked working with others (S- Q1.1)
Some good things were being able to collaborate with other people in the group. (S Q1.2)
Bad- none group want more group collaboration (W- Q1.1)

Data on theme from open comments.

Agreed on researcher comment: You would prefer your friends to help you rather than an adult.
You prefer working with friends than working alone. (Reflections, Q1.1, C).
Agreed on researcher comment: You enjoy working with a partner rather than working alone. (Reflections, Q1.1, H).

Data on theme from participant summaries- agreed on initial interpretations.

Including participant evaluations of the research process sat within my participatory and CAS ideals (see Chapter 3), but the method employed to do so was a weakness, containing too much researcher driven organisation. Some mitigation to these limitations was employed. I maintained my commitment to including data which departed from the “dominant story” of analysis, aiming to ensure that divergent participant views were not silenced (Braun & Clarke, 2006, p.89). When analysing the open comment sections, I coded for additional elements, that went beyond the researcher-led themes I had devised for the evaluation. This resulted in additional participant-led sub-themes, such as difficulty discussing personal topics. These were placed in the thematic map, alongside the overarching, researcher-applied themes. These participant-led, inductive themes were included equally in the following step of analysis- to describe and explore.

When describing and exploring the data, I considered how that data would be presented. I had ethical concerns, around retaining participant anonymity, and impact concerns, around retaining the emotive power of what participants had shared. This led me to consider alternate ways of presenting data, through approaches such as poetic transcription and word clouds. The justification and considerations surrounding these choices are now discussed.

4.7. Presentation of Data

I employed 3 main methods of representing the data: poetic transcription, word clouds, and verbatim quotation. This section offers my justification for these key choices in data representation, considerations which were driven by three significant aims. Firstly, to retain the emotional valence of participants' voices in the representation of the data. Secondly, to ensure participant anonymity was maintained, particularly if the data was accessed by people known to them. Thirdly, to create impactful representations, for subsequent dissemination, which could have greater influence on those who develop practice. These aims drew me to Rose's (1993 cited in Glesne, 1997) "multi-genre" approach, which places "emotional reactions" alongside "analytic description" (p.204). This approach can include essays, narrative, poems, drawings, and photographs (Holt, 2012). Within this, I employed forms which enhanced the anonymity of my participants, whilst increasing accessibility for, and impact on, the audience to which they are conveyed. I now consider the process of employing this range of 'genres', discussing how these forms aided the philosophical drivers set out above.

4.7.1. Poetic Transcription

As discussed in Chapter 1, I wanted to move away from 'objective' quantifying approaches to sense of self research, instead representing the rich detail of human experience (Fletcher-Watson et al., 2019; Orsini & Davidson, 2013). I was concerned that, as Scheurich (1995) states, an interview transcript can have "the juice of the lived experience squeezed out" (p. 241 cited in Holt, 2012) and that the emotion of participant voices can be lost, through the detached process of the researcher's analysis (Carroll, Dew & Howden-Chapman, 2011). I wanted to avoid research detached from feeling, which shares only *what* the experience is, defining this in an objective, unemotional manner (Hunter, 2002; Kooken, Haase & Russell, 2007). I considered how to best represent the emotional quality of what participants had shared. This led me to explore poetic transcription, which takes the words of participants and places them into poetic forms (Glesne, 1997). I discuss the procedure of this in 4.7.1.1. Before this, I consider how the form supported my main three drivers of retaining emotional valence, providing impactful dissemination and ensuring ethical concerns of anonymity were addressed. This provides the justification for choosing to present my data in this way.

Poetic transcription draws on the literary arts to enable the reader to access the emotion of participants' views (Glesne, 1997; Prendergast, 2009). Kooken et al. (2007) argue that poetic transcription can "merge the logic of data analysis with human emotional experiences often expressed in qualitative data" (p.904). In a similar vein, VanWyk et al. (2012, p.121) suggest that it can help the reader to "sense" human experience, and "connect" with the emotions presented or to place themselves *in* the experience described by feeling, rather than just hearing, of that experience. This leads Prendergast (2009) to claim that poetic forms enable a more authentic representation of human experience whilst Glesne (1997) even goes as far as to argue that this can "heal wounds of scientific categorization and technological dehumanisation" by introducing "spirit, imagination and hope" (p.214-215).

With my own concerns about the "scientific categorization" of the autistic sense of self (see Chapter 1), I considered how poetic transcription might achieve this reintroduction of the humanity and 'soul' of the words presented. As Burdick (2011) argues, poetic transcription enables data to be presented in a compressed form and this can create a deeper feeling in the reader, evoking emotion through knitting together thoughts, feelings, and ideas from a range of participant voices (see also Carroll et al. (2011) and Gasson, Sanderson, Burnett and van der Meer (2015) for commentary). Poetic transcription can contain the emotions of memories of the past, present experiences and future hopes and fears (Holt, 2012; Hunter, 2002). In placing participants' thoughts together, the "essence" of that experience or feeling can be conveyed (VanWyk et al., 2012, p.121). As Glesne (1997) argues, this contrasts with the separation of participant quotation in analytic writing (Cohen et al., 2011). Although poetic transcription involves word reduction, she asserts that it retains the "wholeness and interconnections of thoughts" (p.206). Indeed, in my own study, I found that I could present ideas in poetic transcription as a 'whole', enabling the reader to immediately access *all* the participants' ideas around a theme. This presented the 'big picture' or full 'story' of the participant experiences and emotions in relation to that theme (Gasson et al., 2015). Grouping participants' words also demonstrated repetition of ideas or emotions (Henderson, 2018) Consequently, this heightened the emotional experience of that data.

This emotional impact is demonstrated in the poetic transcriptions of Gasson et al. (2015) and VanWyk et al. (2012). Gasson et al. (2015) drew together the experiences of students with complex behavioural needs into a poetic form, arguing that their poem on time out rooms drew attention to the negative feeling pupils had about being "shoved" and "spied on" (p.738). VanWyk et al.'s (2012) study focused on caring in the nursing profession. Their poems prompted emotional reactions from many members of the audience they were shared with. Therefore, it is argued that poetic transcription can better embody the emotional meaning behind participants' words (Carroll et al., 2011; Gasson et al., 2015). Here, the reader can connect their feelings with those of others, whether those be similar or different, enabling an appreciation of the variety of views and experiences presented (Glesne, 1997).

Poetic transcription can also increase accessibility, by employing a form familiar to those outside of the academic community (Carroll et al., 2011; Richardson, 2001). The condensed nature of a poetic transcription brings forth key ideas- the "essence," without the need to read dense transcripts (Freeman, 2006; VanWyk et al., 2012, p.121). Freeman (2006) also states that the shortened form increases access to meaning, leading to "a more direct response than if people were asked to read a more complex narrative" (p.88). When combined with the emotional aspects of poetic transcription, this can enhance reader engagement with what is expressed in the poem; readers can be "moved by their simplicity and power" (Poindexter, 2002, p.713). As Glesne (1997) asserts, poetic transcription can be engaged with beyond our cognitive functions; we can learn through our emotions as well as through logical argument. This can therefore make poetic transcription useful in advocacy, by fostering empathy and understanding (MacNeil, 2000; Poindexter, 2002).

Fostering empathy and understanding is an essential part of my emancipatory and participatory ideals. I am committed to advocating for autistic pupils, highlighting the barriers faced, including those encountered in the school environment. I am therefore aligned with the participatory and emancipatory focus on knowledge creation for *action*, which benefits the lives of the people involved (Chown et al., 2017; Park, 1999). To enable this action, my research needs to be accessed by a range of stakeholders, many of whom are outside of the research community (Lakey, Rodgers & Scoble, 2014). These research users are considered key to facilitating impact (Morton, 2015) In my project, the user community could encompass not only school staff, but parents and practitioners working with autistic children and young people, in fields outside of education. It is important that those who support autistic pupils can access research findings, to act on this, and to disseminate it to others, to inform knowledge and understanding, and perception, policy and practice changes (Morton, 2015; Ross & Morrow, 2016). I have considered both direct dissemination to research users, and distribution through knowledge brokers, such as professional bodies or lobbying groups (Lakey et al., 2014), for example, the National Autistic Society. This entails dissemination to a wide audience, with a range of backgrounds. Therefore, ensuring accessibility for those outside of an academic background is vital for my future participatory aims. Consequently, poetic transcription's ability to be accessible and engaging, and to have an impact on such an audience, made it a viable choice for data presentation.

As discussed, maintaining anonymity for participants was a key concern and became a prominent influence on how data was presented. Poetic forms, as Mannay (2016) argues, can enhance anonymity by decontextualising textual data whilst retaining the emotion of experiences. This was Mannay's (2013) experience when exploring women's encounters with violence. Condensed poetic forms removed the detail of individual lived experiences, which could be found in the verbatim presentation of participant interview responses. In my project, I created group poems, utilising participants' words, *without* directly attributing those words to an individual pseudonym (see Figure 12). This prevented identification as participants' key characteristics could not be combined to create an individual biography (Wiles, Crow, Heath & Charles, 2008). In these choices, I considered Mannay's (2016) argument that participants may wish to be visible and that waiving anonymity could lead to images with emotional and affective power, which challenge stereotypes. However, consent to waive this anonymity would be based on present feeling. In the future, opinions about being identified by certain ideas, positions or identities may change, and continued contact for later consent would be difficult to obtain (Wiles, Coffey, Robinson & Heath, 2012). I was concerned that a future ‘outing’ of a participant’s autism was a choice that should remain with the participant themselves, something that would not be able to be ensured, if they were identified in this research project.

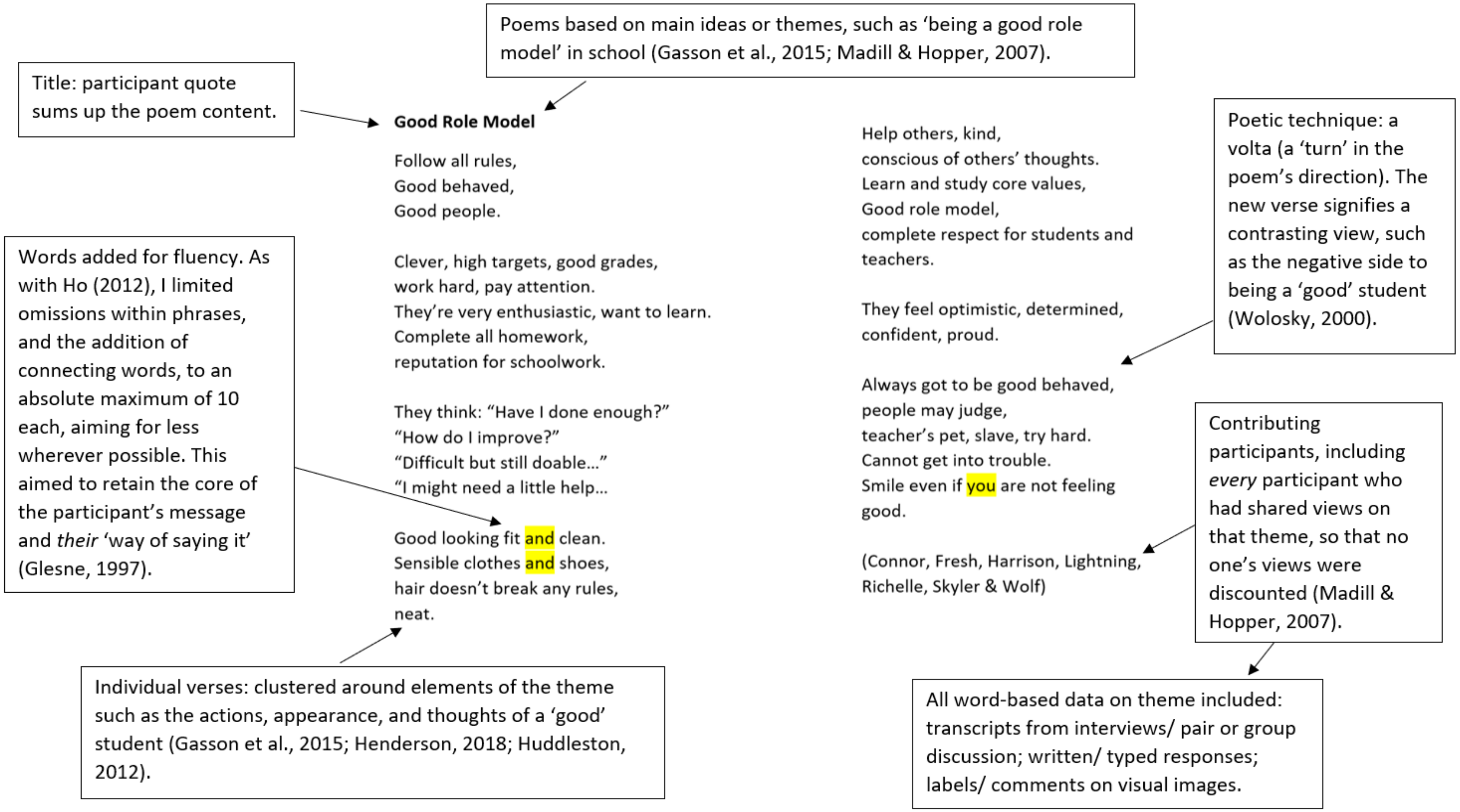
Consequently, poetic transcription was chosen to present participant data. This choice was influenced by its capacity to retain the affective impact of participants’ views and experiences; its accessibility for a range of stakeholders and its ability to maintain participant anonymity. A critique of such poetic transcription has been a lack of clarity on how the process was undertaken (Gasson et al., 2015; Henderson, 2018). As it is important that my own role in shaping the data is made apparent, I now provide a clear account of how I completed my poetic transcription.

4.7.1.1 Poetic Transcription: The Process. Glesne (1997) terms poetic transcription a form that is “poem-like” (p.202) as it uses poetic devices and forms (Madill & Hopper, 2007; Prendergast, 2009). My poetic transcriptions are found poems, where words are taken from another text, and rearranged into a poetic form (Burdick, 2011; Prendergast, 2006). Many studies use participant words from interviews or focus groups for their found poems (e.g. Gasson et al., 2015; Glesne, 1997; Kooken et al., 2007). In contrast, I included participant words from the wider range of written and oral methods employed in my project. My poems take the form of free verse, not adhering to a set number of lines, such as in a haiku or sonnet (Wolosky, 2001). This allows the inclusion of all the rich detail and range in participant views (VanWyk et al., 2012).

The transcription process is set out in the labelled poem below.

Figure 12

Labelled Poetic Transcription



Poems based on main ideas or themes, such as 'being a good role model' in school (Gasson et al., 2015; Madill & Hopper, 2007).

Title: participant quote sums up the poem content.

Good Role Model

Follow all rules,
Good behaved,
Good people.

Clever, high targets, good grades,
work hard, pay attention.
They're very enthusiastic, want to learn.
Complete all homework,
reputation for schoolwork.

They think: "Have I done enough?"
"How do I improve?"
"Difficult but still doable…"
"I might need a little help…

Good looking fit and clean.
Sensible clothes and shoes,
hair doesn't break any rules,
neat.

Help others, kind,
conscious of others' thoughts.
Learn and study core values,
Good role model,
complete respect for students and
teachers.

They feel optimistic, determined,
confident, proud.

Always got to be good behaved,
people may judge,
teacher's pet, slave, try hard.
Cannot get into trouble.
Smile even if you are not feeling
good.

(Connor, Fresh, Harrison, Lightning,
Richelle, Skyler & Wolf)

Words added for fluency. As with Ho (2012), I limited omissions within phrases, and the addition of connecting words, to an absolute maximum of 10 each, aiming for less wherever possible. This aimed to retain the core of the participant's message and *their* 'way of saying it' (Glesne, 1997).

Individual verses: clustered around elements of the theme such as the actions, appearance, and thoughts of a 'good' student (Gasson et al., 2015; Henderson, 2018; Huddleston, 2012).

Poetic technique: a volta (a 'turn' in the poem's direction). The new verse signifies a contrasting view, such as the negative side to being a 'good' student (Wolosky, 2000).

Contributing participants, including *every* participant who had shared views on that theme, so that no one's views were discounted (Madill & Hopper, 2007).

All word-based data on theme included: transcripts from interviews/ pair or group discussion; written/ typed responses; labels/ comments on visual images.

My transcriptions followed the practice of retaining participant words as closely to the original as possible (as in Holt, 2012). Following the advice of Glesne (1997) and Ho (2012), my changes were only in word endings, for example bowling to bowl, and the addition of connecting words, such as it, and, is. I omitted redundant words such as erm or like. This was to create fluency and cohesion. Additionally, as Glesne (1997) argues, poetic transcription can enable a movement from an either/or to a both/and point of view, representing diverging views, without claiming one as 'right' over another. This supports my analytic philosophy, to include data which departs from the main narrative, and to avoid prioritising the dominant voice as the 'right' answer (Braun & Clark, 2006). These divergent views can be shown by a volta in the poem, (see Figure 12), which represents the alternate, negative side to being a 'good' pupil. To emphasise particularly emotive points, I set these as individual lines, and often placed them at the end of the poem. For example, the line "Teachers still hate me" (Redmond, 2006). Where relevant, I placed participant images that related to the theme at the end of the poem, so that those who chose to communicate in a visual way were included (Holt, 2012; Prendergast, 2009).

In addition, I employed poetic transcription for sensitive subjects and for those areas which could be attributable to specific participants, such as unusual hobbies (Mannay, 2013; 2016). This supported the maintenance of my ethical promise of anonymity, by removing identifiable information (Hammersley, 2017). These ethical considerations were applied to the visual images presented alongside the poems, because, as Rose (2016) considers, photographs and drawings are likely to produce identifiable information. I was careful not to include any such images in my presentation of findings.

In undertaking the poetic transcription approach, I have questioned my role in the process. The words of the poetic transcription are those of the participants, but the stanzas were organised by the researcher (Huddleston, 2012; Madill & Hopper, 2007). As Richardson (2001) asserts, all textual data is staged by the researcher, regardless of form. However, Glesne (1997) argues that poetic transcription *acknowledges* this staging, in the obviousness of its reorganisation. I further enhanced this transparency, by providing the detailed description of my role in the 'staging' process above. I have questioned whether participant checking of the poems would have improved my approach, by ascertaining levels of participant agreement with the message conveyed (Carroll et al., 2011; Holt, 2012). Although, as discussed in Chapter 3, this adds to debates around the continued use of participant time in participatory analysis. I would need to return to participants after the enrichment club had ended, the data was processed, and my poetic transcriptions were complete. I have contemplated next steps, which adapt the participatory criteria of Chown et al. (2017), that autistic researchers should confirm the validity of their research problem. Subsequently, I have considered disseminating the poetic transcriptions to a range of autistic people, outside of the participants involved. This could enable insider comment on the “essence” of the message, without drawing further on the time of the original group (VanWyk et al., 2012, p.121). It would extend the range of autistic voices involved, enhancing the rich detail of the lived experience by providing a wider point of view.

Glesne (1997), an advocate of poetic transcription, asserts it may not always be suitable to use this form. The considerations of *how* to present data must include the purpose and manner of the data to be presented. Due to its emotive nature and anonymising qualities, poetic transcription was employed when exploring themes with an emotional meaning, data which could create an identifiable biography, or for topics which were particularly sensitive. There were, however, points where the manner of the data called for an alternative approach, including word clouds, and individual verbatim participant quotation. I now consider my purpose in employing these other forms.

4.7.2. Word Clouds and Verbatim Quotation

As discussed, I was concerned about quantifying participants’ sense of self, particularly when representing a ‘big picture’ view of the pattern of responses. For example, when presenting the *range* of roles or traits participants identified as part of their self-view. I sought to avoid a hierarchical system, which prioritised the ‘most’ or ‘least’ answers. Instead, I wanted to present *every* diverse aspect my participants had shared, without placing one aspect as more valued than the other. This led me to use a visual representation- a word cloud (Henderson & Segal, 2013).

Word clouds were chosen when I wanted to display the *range* of ideas presented within a theme alongside their prevalence across the participant group. For instance, to display the various roles or interests that participants felt were part of their sense of self (see Figure

13). Ideas more frequently mentioned are displayed more prominently, in a larger font size (Viégas, Wattenberg & Feinberg, 2009). This offers a representation of frequency, whilst moving away from a quantifying hierarchy. Instead of top to bottom presentation, words are mixed into a randomised 'cloud' (Viégas et al., 2009). As with the thematic maps (see 4.6), this removes a position of priority of a 'top' element, by presenting all topics immediately, in one visual form. This supports my aim of shifting away from previous sense of self studies, which created a hierarchy of self-understanding, placing the interpersonal as the most important aspect of the self. Instead, the word cloud displays all the diverse aspects of the participant sense of self. This builds on the aim of presenting the totality of what participants shared. Representing *every* idea mentioned within that theme, retains data that depart from the "dominant story," preserving the heterogeneity of findings (Braun & Clarke, 2006, p.89).

Figure 13

Interests Word Cloud

As with poetic transcription, word clouds have a direct impact on an audience. In a study by Viégas et al. (2009), users commented on how word clouds engaged them, with one stating that, "they look like art and make you look twice, then all of a sudden you are reading, thinking, feeling good, learning." This contrasts with linear prose, which one participant felt "is flat and toneless" compared to the "drama" and interest of the word cloud form (p.5).

This implies that word clouds, as with poetic transcription, could offer a deeper connection to data, albeit in a compressed and accessible style. Moreover, word clouds can present data in a decontextualised manner, without links to assigned pseudonyms. They are therefore an additional creative form which can protect participant identity. Therefore, word clouds helped to further my aim of ensuring engaging, accessible dissemination, which protects the anonymity of participants.

McNaught and Lam (2010) note that word clouds do not show the context of the data, with words removed from the participant's original, detailed contribution. As such, when considering individual contributions, linking to word use in context is sometimes needed, to represent the whole meaning the participant wanted to convey (Henderson & Segal, 2013). Participants in my study offered longer explanations as to why they felt a certain way, detailed anecdotes of experiences, or had paired conversations, which needed to represent both partners' responses alongside each other, for their meaning to be conveyed. This meant that poetic transcription, which uses short units of text, was also not suitable as the only method of presenting such detailed textual responses (Freeman, 2006). In the Findings Chapters, participants longer, richer descriptions are therefore placed separately and explained as a whole. At points, there was also not a wide enough range of participant quotes to create a poetic form, but I did not want this to mean these participant views were silenced. In both these cases, it was more suitable for the traditional approach of identifying and explaining verbatim participant quotation to be employed (Corden & Sainsbury, 2007; Henderson & Segal, 2013). This process closely considered the sensitivity of experience shared and the inclusion of quotation in these sections, which would identify the key characteristics of an individual biography (Saunders, Kitzinger & Kitzinger, 2005; Wiles et al., 2008). If quotation could not be used in poetic transcription, it may be ascribed to 'one participant' should I feel that it was identifiable, or particularly sensitive, and did not want this to be linked to the participant's pseudonym. This retained the key focus of maintaining the anonymity of my participants.

The range of representations, poetic transcription, word clouds and verbatim quotation, have followed the "multi-genre approach" to data presentation (Rose, 1993 cited in Glesne, 2007, p.204). Throughout, I followed the advice of Glesne (1997), to consider the shape and purpose of the data, when making the choice of which form to present. Whilst poetic transcription was favoured for its emotive and accessible style, other forms, which also supported impact and anonymity, were included when poetic transcription was not appropriate. In this, ethical concerns were a key consideration, with ethical principles an inherent part of the decisions made across the research project.

4.8. Additional Ethical Considerations

Due to the participatory aims of the project, participant power and control have been discussed throughout the chapter. I have contemplated withdrawal from the project, the personal participant benefits, social and reflective, I wanted the club to provide, and the wider benefits aimed for, in the impactful presentation of the data. I have identified the methods employed which sought to reduce harm, especially in lessening the anxiety or discomfort participants may feel in the research process. Finally, tools for ensuring anonymity, and the importance of this, were discussed.

This section addresses further ethical considerations that have not been reflected upon so far, specifically the informed consent process; and the further procedures employed for participant withdrawal of data.

Ethical approval was gained from the Faculty Research Ethics Committee, at Sheffield Hallam University (Appendix L). The project then began by seeking ethical consent from parents as per ethical requirements (Cohen et al., 2011). However, parents were made aware that they were giving consent for their child to be *asked* to take part and that the final decision remained with their child (Thomas & O'Kane, 1998). With my focus on participant control, it would have been counter to my participatory aims for the young people in my study to undertake parent enforced participation (Fletcher-Watson et al., 2019). When the young people attended the first session, it was clear that their choice was not apparent to them. I therefore spent the first three sessions ensuring clarity on this (see Stage 1, Table 5 for details) and offered regular opportunities to withdraw throughout the project.

It was important that the informed consent process was not a one-off session and that ethical principles ran continuously throughout the project (see Cox et al., 2014). As such, consent for data inclusion was part of ongoing discussion with participants, who were encouraged to manage their own data (Holland et al., 2010). As discussed in Stage 10, Table

5, participants had access to *all* their own data in each session and regularly identified data they did not want included in the final report. One participant, who produced many photographs, created his own symbol system, identifying which photographs we could discuss, but not print, and those which could be used in disseminated work. We agreed that I would email for permission if any of his choices were unclear, an option which I have undertaken when creating the findings chapter. In the final session, I again clarified *how* data might be used and disseminated so that participants were fully informed on their data's usage. Participants then had extra dedicated time to go through and ensure that they were happy with their final data submissions (see Appendix H for content).

Whilst this section represents additional processes, which had not yet been discussed, ethics were not an 'add on' in my project. As seen throughout this chapter, ethical considerations were interwoven in the project design, which had a continuous focus on respecting the autonomy and needs of the participants involved, and on the possible benefits of the project for the wider autistic community.

4.9. Time Constraints and Complexity

In aiming to be transparent about the participatory research process, the final section of this chapter discusses two further difficulties faced by the researcher; the time required and the complexity of the project and its resultant data.

The time required for the project was extended by my partnership approach, with the consultation and shared decision-making procedures increasing the time required (Bourke, 2009; Fletcher-Watson et al., 2019). It was also extended by the choice of communication methods offered and the inclusive adaptations within this. As Danker et al. (2017) found in their use of participant-driven photo-elicitation, time is needed to prepare information and access materials for participants, to support with the technology, materials or elements of the methods employed. This was echoed in my own study, where extra time was needed for both the preparation and delivery of informed consent, and for the preparation of individualised task sheets, which supported participants in completing their chosen method (Appendix M). Research time was also increased by participants first completing a visual or word-based production and then engaging in a subsequent conversation around that piece. This at least doubles the time that would be needed in traditional interview-based studies

(Danker et al., 2017). Additionally, in my project, time had to be managed across participants, with some completing quicker than others, dependent on the method choice they had made. However, similarly to MacLeod et al. (2014), I was at an advantage, as my deadlines were not as tight as those of some external funders. My PhD research was able to follow a yearlong design that could engage closely with participants and adapt to their individual needs. As MacLeod et al. (2014) question, “how such a flexible and individualized design would fit within a tightly prescribed and externally driven research agenda is debateable” (p.415).

Employing a range of methods increased the breadth and complexity of data, which needed to be organised, and then analysed (Clark & Moss, 2005). As Jivraj et al. (2014) identify in their review of participatory research, participant choice of methods can increase depth, detail and range in data collected. This was certainly the case in my study, which produced copious data, varied in form. This therefore added to the time necessary for data analysis, which also required cross-reference with participant checking summaries (4.4). However, as Clark (2010) asserts, whilst this approach may not have the quick results obtainable, for example, through a questionnaire, participatory visual methods can mean “more rewarding and surprising results” (p.122). As argued by King et al. (2017) and Winstone et al. (2014), whilst an alternative design may take longer, it can offer “surprising” results, which counter deficit findings, through the rich data mixed media can provide (Ridout, 2017). Therefore, I felt the limitations of time and complexity of analysis were outweighed. Priority was placed on the ability of participatory and accessible approaches to enable the meeting of the CAS aims of the research- challenging deficit-led constructions of the autistic sense of self.

4.10. Conclusion

This chapter has offered a detailed and transparent account of the participatory process undertaken. This was a flexible, inclusive process, evolving based on participant feedback and preference, rather than following a set, prescribed approach. I aimed for the active involvement of participants across *all* stages, prioritising their control and maintaining a sensitivity to their required adaptations, to ensure they could fully contribute. This was due to my alignment with the argument that such an approach can enable autistic young people to fully express their self-view, in contrast to previous studies, which have hampered autistic participants' contributions, through inaccessible methods. Subsequently perpetuating deficit narratives about a 'lacking' sense of self.

As part of my aim to prioritise autistic young people's insider perspective, I had to consider the school-based research context. My role in leading the enrichment class meant that I was viewed as both researcher and teacher. Promoting an equitable research relationship was therefore made more difficult through the inherent expectation of pupil-participant compliance in the school setting. I had to negotiate the conflict between such a position and my aim to empower participants. Continually reflecting on my participatory and emancipatory principles, a researcher-participant relationship evolved built on respect, rapport, and comfort, with participants choosing their desired level of support. I also had to counter the control which may be taken by peers or other adults in the school environment. However, peer presence was also a positive, building relationships and enjoying social time was a key benefit I had wanted to ensure for participants, and this was evident as the project progressed.

Ethical principles, which prioritised participants' needs, were at the heart of the project and were interwoven with my participatory and emancipatory ideals. As an equal partnership, I respected my participants' wishes to keep their autism diagnosis from certain groups and, as such, ensuring anonymity was a key principle. I also want to enable impact in the dissemination of my research. This is part of my participatory aims to achieve positive *action* for autistic young people by engaging with relevant stakeholders (Chown et al., 2017; Park, 1999). These aims influenced my choice to represent the data through poetic transcription and world clouds. These forms supported my aim to avoid the quantification or prioritisation of one perspective over another; to retain the emotional valence of participants' responses; to ensure anonymity; and to enable impact in dissemination, through an engaging and accessible form.

I do not claim this project as perfectly participatory or emancipatory and this chapter has discussed the strengths and weaknesses of my methodology. A particular limitation was the lesser choice of communication mode in the latter steps of analysis and evaluation. In future research, I would want to address this, offering a wider range of communication modes in this stage. Further limitations could be the time needed for the process, and the complexity of analysis. However, I felt that the ability of these participatory and accessible approaches to enable the full contributions of autistic young people outweighed the time and complexity required.

Finally, the methodology, methods and participant-led evaluation of the participatory process described in this thesis provides an important contribution. Participants were offered an initial choice, from a diverse range of methods, which could then be further adapted to suit communication preference. The strengths and limitations of the research process were also evaluated, from the participants' point of view. This offers an original contribution to methodological knowledge not currently available in the few studies which do employ a *choice* of communication modes. This chapter addresses the need to provide detailed knowledge on how inclusive participatory approaches can increase the participation of autistic people, enabling their insider accounts to be shared (Fletcher-Watson et al., 2019; Searle et al., 2019).

The following chapters of the dissertation now turn to presenting the findings from these insider accounts.

Chapter 5: Findings: Conceptualising, Presenting and Evaluating the Sense of Self

This chapter presents data produced in response to the question- who am I? Here, participants considered how they would define themselves and how they would want to be defined by others. They identified influences on their self-evaluation, considering how these influences had a positive or negative impact on their self-view. This chapter therefore considers the bigger picture of how participants defined themselves, and the influences on that sense of self.

The key findings are that:

- Participants include a complex range of elements in their self-description, conceptualising and evaluating themselves in multiple ways. This encompasses considerations of themselves in the present and in the future.
- The social world is highly relevant to the autistic participants' sense of self. They consider themselves in relation to varied social contexts, roles, and relationships. They are therefore influenced by their interactions with others, including the reactions of those others.
- Participants act to protect a positive self-view- prioritising strengths and minimising a focus on weaknesses, or areas of negative difference.
- Participants carefully consider how they present themselves, aiming to engender acceptance and positive treatment from others.

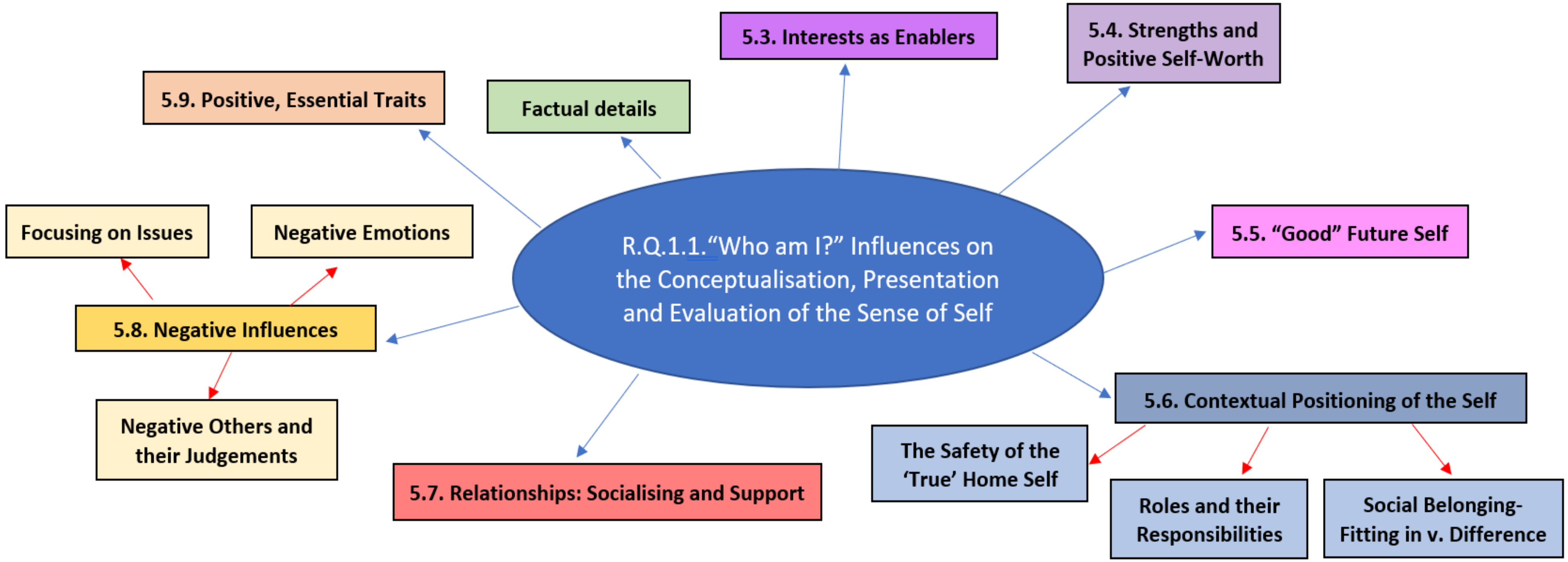
To provide the big picture of the analysis, on which these key findings are based, I begin the chapter with a thematic map, presenting an overview of the themes relating to participant negotiation of the question of 'who am I?'

5.1. Overview of Themes

In the thematic map (Figure 14), overarching themes radiate from the central idea- influences on autistic young people's conceptualisation, presentation and evaluation of their sense of self. These are represented by a blue arrow. Some themes are broken down further into subthemes, represented by a red arrow. The data represented in this thematic map was generated through inductive analysis, with coding led by the participant data. These codes were collated into the main and sub-themes in Figure 14. This thematic organisation can be traced through the coding chart in Appendix I, where matching themes and codes are color-coded, to show their relationship (see Chapter 4, for further detail).

Figure 14

Thematic Map: RQ 1.1.



Note. Numbers refer to the main sections of this chapter.

5.2. Thematic Analysis

This section drills down into the key themes from the thematic map (Figure 14), considering the visual, oral and written data participants generated to present their answer to the question ‘Who am I?’ (see Appendix H). Data is presented as discussed in Chapter 4. The decisions behind this representation are reiterated here:

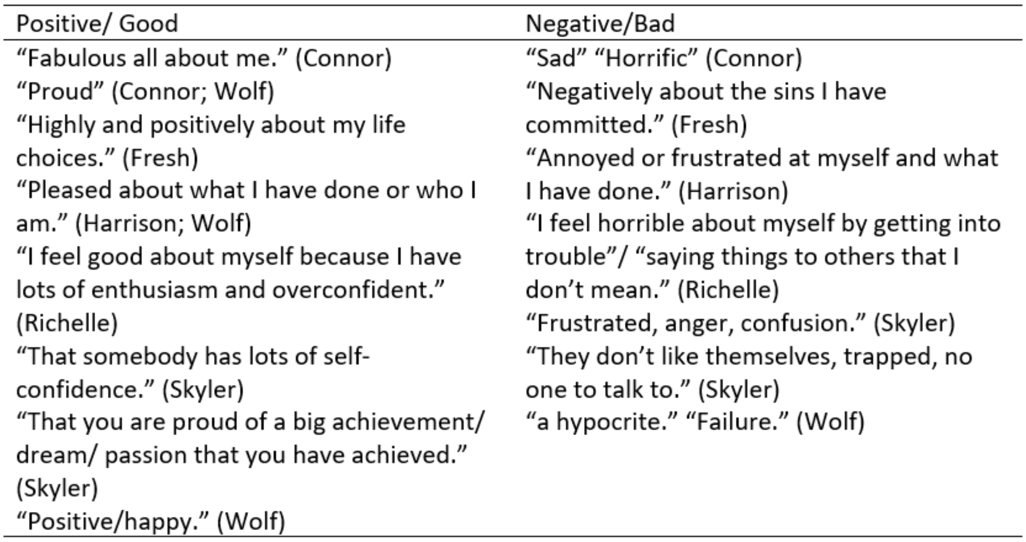
- Poetic transcription is used to convey the emotional aspect of participants’ contributions (Kooken et al., 2007). I employ this when considering themes with strong emotional force e.g. strongly negative influences, such as weaknesses.
- Poetic transcription can also reduce the risk of creating identifiable, individual biographies (Mannay, 2016). I employ this with topics such as hobbies and interests, which are attributable to specific participants, and could create an identifiable biography. I also use this to ensure anonymity for particularly sensitive themes, e.g. being judged by others.
- Word clouds are employed as a representation of frequency (Viégas et al, 2009). I use them to show the number of participants who included a certain idea within that theme e.g. how many participants mentioned friendly as a personal trait.
- Links to context are used to demonstrate the whole meaning the participant wished to convey (Henderson & Segal, 2013). Therefore, I place longer, richer descriptions separately, as verbatim quotation, and explain them as a whole.

Where relevant, reference to organising the sense of self topic cards by importance/ good or bad influence is included (see Table 5, Chapter 4). The detailed data for this can be found in Appendix N. For this data, it is important to consider *how* participants characterise feeling good or bad about themselves, making clear the definition participants have in mind, when identifying positive or negative influences on their self-view. This is shown in Table 9.

Participants associated a positive sense of self with feeling “proud” about who they were and what they had done and with being confident. In contrast, a negative sense of self was associated with being “frustrated” about what you have done. They characterised this as someone who feels like they have failed and who feels “horrific” about themselves.

Table 9

Participant Definitions- Good/ Bad Sense of Self



Positive/ Good	Negative/Bad
“Fabulous all about me.” (Connor) “Proud” (Connor; Wolf) “Highly and positively about my life choices.” (Fresh) “Pleased about what I have done or who I am.” (Harrison; Wolf) “I feel good about myself because I have lots of enthusiasm and overconfident.” (Richelle) “That somebody has lots of self-confidence.” (Skyler) “That you are proud of a big achievement/ dream/ passion that you have achieved.” (Skyler) “Positive/happy.” (Wolf)	“Sad” “Horrific” (Connor) “Negatively about the sins I have committed.” (Fresh) “Annoyed or frustrated at myself and what I have done.” (Harrison) “I feel horrible about myself by getting into trouble”/ “saying things to others that I don’t mean.” (Richelle) “Frustrated, anger, confusion.” (Skyler) “They don’t like themselves, trapped, no one to talk to.” (Skyler) “a hypocrite.” “Failure.” (Wolf)

The chapter now moves through the key themes of the thematic map, following main themes, in a clockwise direction. As part of my participant-led approach, I begin with those themes that *participants* wanted to be foregrounded in their self-description: their interests and strengths.

5.3. Interests as Enablers

As an overarching theme within the self-description, interests, alongside likes and dislikes, were considered a key marker of individuality, of who a person was, one which could influence a positive sense of self if seen as a strength. Interests also offered social opportunities; a way to bond as a cohesive group, offering a shared activity around which to do so.

Participants included a wide range of interests and hobbies when exploring RQ 1.1., as demonstrated in Figure 15. This word cloud shows which interests or hobbies were mentioned most frequently and demonstrates the range of interests discussed. Larger words denote a higher frequency of respondents including this interest as part of their self-definition. For example, sport was included by 7 participants and videogames by 4.

Figure 15

Hobbies and Interests

5.3.1. Prominence of Interests

Interests were prominent within participant data. Interests, hobbies, and preferences formed a key part of how participants wanted to answer the question of 'who am I'. Data coded for hobbies, passions and interests came in top position in terms of frequency (Appendix O). This was followed by favourites and likes. Some participants also explored why, when describing 'who am I?', that interests, hobbies, and likes were something that others should know. Participants felt that their interests were part of their individuality, part of who they were and, when asked which topics were most important in describing their sense of self, were chosen by Lightning, Connor, Harrison and Richelle as the top three topics (Appendix N).

The importance of interests to participants is shown in the poetic transcription “This is What Makes Me be Me”. The first stanza contains those participants who felt that likes and dislikes went beyond a superficial preference to being part of “what makes me be me.” These preferences and interests were an element that defined who they are. These interests could be used as an expression of personality, such as in the description of music performance in stanza two. Definition by interest is shown further in the third stanza, where participants’ use of interests as defining identities is displayed, with interests making you a “type” of person. In contrast, the poetic turn in the final stanza demonstrates differing views on the importance of interests. Here, whilst interests and likes were enjoyable, they were not something participants “wouldn’t be able to live without” and “it’s not as important as family.”

This is What Makes Me be Me
Likes/dislikes- it’s what I do.
This is what makes me be me,
My interests and my hates.
People can know,
what type of person I am.

Show my personality,
In so many different ways, sounds, expressions.

I am a gamer, a dog person, a musical person.
Clubs are not important in life,
Family are more important.
I do really love baking,
I do like it,
but it’s not as important as family.
It’s not something,

that I wouldn't be able to live without.

(Connor, Fresh, Lightning, Richelle, Skyler & Wolf)

5.3.2. Social Opportunities and Influences

Interests and hobbies were also characterised as having social elements. This included providing opportunities to socialise with family, friends and new acquaintances, with bonding enabled around the shared interest.

An example of the social element to interests is shown in Harrison's view of games as a social event, which remove an unpleasant feeling of loneliness. He stated, "something that makes me feel bad is being alone, which is why I spend lots of time playing games with friends and family." Here, games are a way of socialising. However, this is not the only interest Harrison characterises as important in relation to socialising. He regularly referred to theme parks, which are a "good time to have fun with family and friends" where he is "happy to spend time with people." This was echoed by Richelle, who enjoyed her sports club due to "being with my friend" and discussed positive experiences of watching the same sport with her father.

Interests can also provide opportunities to meet new people. Harrison explained that extra-curricular clubs made him feel good "doing exercise and meeting new people." Skyler also explored the social aspects of being part of an interest-based club:

> in a nice way as I am around people my age. I also think that because we are all choosing to do it, we are all interested, we won't think badly of each other. We are all friendly.

Skyler suggests that such clubs allow a focus on something in which "we are all interested", with less risk of being thought badly of for having that interest or opinion. Being around people with a similar interest can lead to decreased judgement, with club members bonding through their shared interests.

5.3.4. Interests as Strengths

Participants also explored hobbies and interests as a strength which can enable a positive sense of self. They focused on interests and hobbies they felt were a strength in their discussions of ‘who am I’ and linked this to the positive feelings associated with those interests. This is demonstrated in the poetic transcription “I am good at”.

I am good at

I am good at games,
I am good at badminton.
I read quickly,
I am good at videogames,
that’s why I put it on the good side.

I’m a specialist,
I’m basically lead,
the most experienced there.
That’s like a strength,
that’s why I love music.
The positivity I have received from this,
keeps me motivated and happy.

(Connor, Harrison, Lightning, Richelle, Skyler & Wolf)

Hobbies were seen as something that participants wanted to be good at, that they wanted to succeed in. If they lacked success in an interest, this could have a negative impact on their sense of self.

For example, Harrison wanted to spend time on his hobbies to improve and to be good at it. Whilst Connor explained that “I love playing on my Xbox it makes me happy unless I am full of badness on the game I am playing.” Connor showed how he wanted to succeed at this hobby and the negative feelings which resulted from weakness within this; he felt “bad if I was a failure.” However, overall, he has characterised himself as “good at games.” As these videogames formed a key element of his work on sense of self, this focus could spring from this interest being viewed as a strength. He may have regularly included this because he is good at it.

5.4. Strengths and Positive Self-worth

Interests and hobbies may be something participants focused on if seen as a strength due to the positive feelings about the self this could imbue. Most participants considered strengths to be a positive influence on their sense of self, associating this with good feelings (Appendix N). Skyler also included achievements in passions in her definition of a positive sense of self, where “you are proud of a big achievement/ dream/ passion that you have achieved.” Lightning regularly returned to achievements, what you are “good at,” as a key, important feature in describing who you are, one which has a positive influence on your self-view. Harrison also suggested that strengths are good for your self-worth.

Indeed, apart from Joe, all participants discussed things they were good at or achievements they had made. Participants discussed skills in interests or hobbies and achievements at school alongside the pride they felt from these achievements. Being proud was a word repeated across participant discussions of achievements and strengths, something also seen in their definitions of a positive sense of self. Wolf was particularly focused on his strengths, including leadership, competition and extracurricular achievements, and the volume of knowledge he had acquired in his area of interest, with “200 stats”. Positive impact for participants came from having “worked for something for a long time and achieving what we wanted” (Wolf) and overcoming “challenges” to feel “proud” of what was achieved (Skyler).

Interests could also act as a defensive force against negative comments from others, a buffer against the negative influences of others’ derogatory comments. Confidence and a “positive mindset” could be regained from engaging in an interest considered a strength. This was exemplified in Skyler’s comments that:

> This makes me feel more confident and expressive with what I do. This also makes me have a more positive and fresh mindset if I am witnessing negative comments about what I do and why I do it.

Strengths and achievements therefore had a positive influence on how participants viewed themselves.

5.5. The "Good" Future Self

Participant interests also demonstrated a link between future selves and present selves, with a range of participant job and career aspirations being directly linked to current sporting, cooking, musical or extracurricular interests. There was an awareness of the pressure on the current self, as school student, to achieve in education, which was considered a key element to acquiring the desired future. Except for Joe, all participants chose to discuss their future self, including careers or jobs, showing the prevalence of participants considering the self in the future.

Participant views on a good future self, and how to get there, are shown in the poetic transcription "I'll Be so Good in the Future." This demonstrates not only the pressure to achieve "good results," but also participant views are of what the good future self looks like- a good job, earning good money, to be proud of who you are. However, jobs were not the only focus, with the fourth stanza demonstrating how "just get-getting married, settling down make sure you're not in a panic" was a desired future. Not being "in a panic on my own," suggests a good future includes being with others, creating your own home, getting married and feeling the security provided by that.

I'll Be so Good in the Future

School will be able to carry me to them.
Hopes and passions,
in the future.

If you don’t have your GCSEs,
you can’t do anything,
I’m not getting a job.
Simple.

However, if you get good results,
you’ll be like oh wow.
I’ll be so good in the future,
in a good job,
earn good money, a decent wage, be well off.

Just getting married, settling down,
I don’t want to be in a panic on my own.

Be so good in the future-
You’ll be proud of yourself.

(Connor, Fresh, Harrison, Lightning, Skyler & Wolf)

In contrast to this, a bad future would be “not getting a job” (Harrison). Participants suggested this is due to the status associated with a job role, if a job was lost “you lose a lot of like status” (Lightning). Participants were aware of the associations given with having a job within society, not having a job means low “status” and a bad future, whilst a good job with good money is considered a good future self. They were focused on achieving a good future for themselves.

5.6. Contextual Positioning of the Self

In the same way that participants considered status and position of the future self, they also showed an awareness of how the self was presently positioned. They explored the influence of the context they were within, for example home or school, on how they actively sought to be seen within that context. There was a sense of conflict between the self at home and that which may be presented outside the home environment, particularly a self that may be perceived as different. This sense of difference also permeated accounts of the autism label, and participants explored their characterisation of autism, alongside how they positioned themselves in relation to this. Finally, there was a consideration of the roles and responsibilities taken both at home and in outside contexts, including the positive impact on the sense of self those roles and responsibilities could have.

5.6.1. The Safety of the Home Self

Participants discussed where they lived and who they lived with. The home environment was a focus for Fresh, who included a wide range of photographs of his home, bedroom, and the items within that room.

Figure 16

Harrison: 'Who am I?' Drawing

Participants reported how the home space could be an important positive focus, associating home with a sense of comfort, relaxation and safety. These views are presented in the poetic transcription "At Home I Can Truly be Myself." This demonstrates the positive feelings associated with the home space and a possible explanation for these feelings. As shown from stanza two onwards, the freedom and comfort of home and family may come from escaping any need to change and being able to embrace the true self, without having to adapt. Home can be a place where family offer a lack of judgement and unconditional support; a place where there is no pressure to fit in.

“At Home I Can Truly be Myself.”

At home, it’s a very relaxed and chilled environment,
where I can feel safe and relaxed.
Relaxing in my room,
I don’t have to feel stressed and uncomfortable.

I feel safe and secure,
in where I live and who I live with.
I can truly be myself
and not be judged.
Whatever I do, whatever I say.

I don’t have to feel like I have to fit in.

When you’re with your friends and family,
You can just be yourself.
Having family around you,
you belong somewhere.

There’s no place like home.

(Fresh, Harrison, Lightning & Skyler)

5.6.2. Social Belonging: Fitting in

In contrast to the self at home, participants showed how they may not fit in outside of this space. They explored how far they thought they changed their behaviour to fit in and why it may be important to do so.

Participants felt the “odd one out” for not having a certain game, handbag or make-up, for not being as intelligent or for not having the same physical appearance. They also showed an awareness of needing to change themselves to fit in in wider society, to not be the “odd one out”, particularly in the school environment. This was summarized by Skyler who stated, “when I am at school and in class I may need to act slightly differently and I need to analyse what I say and do to not stand out in a strange way. People may mock me.” Here, the focus was on not standing out, being different in a way that was considered “strange.” Participants suggested that this was important to avoid mockery. Skyler and Richelle discussed how people who “walk differently to us” will have “people take the mick out of them.” There was an awareness amongst participants that to be different in a way other people considered “strange” led to mockery. Therefore, it could be necessary to change your behaviour. Acceptance and an avoidance of mockery in the social sphere came from putting on a front. Here, some participants felt that they needed to change themselves. This was shown in Skyler’s words:

> Like you have to put on a front so people accept you but that front like becomes like that personality that you’re showing can be completely different to your normal personality, who you really are.

The pressure to change was not just based on participants’ own desires but seen as being actively sought by others:

> People can be like mistreating you and like persuading and like manipulating you to be somebody that you really don’t want to be or be a certain way that they want you to be to help them or just so you fit in with the group.

Here Richelle suggested that it was not only the person themselves who policed their actions to fit in but that others did this also. Pressure from the group could result in changing the self to fit in.

However, not all participants followed traditional routes to fitting in or felt they changed their behaviour because of others. Fresh felt, “My behaviour very rarely changes, but sometimes, I can become serious.” Lightning positioned himself against concerns around social popularity, feeling that he did not engage with social media. He only used it to “talk to people if I don’t have their phone number or you know to talk if I don’t have any credit on my phone.” He also felt that he did not change his behaviour except in “smarter” situations such as interviews or weddings. This contrasted with his response that, “I well act different ways around different people. So, not everyone knows every side of me except me.” This suggests that Lightning felt no one could know his true self in its entirety. That others could not know all sides of him. Although he felt, “with your friends and family you can just be yourself”, no one sees every role, side or behaviour he takes on. Only he knows his whole self.

5.6.3. Autism, Difference and Fitting in

Participants also discussed fitting in in relation to autism. In this sense, autism was seen as a negative difference, which made life difficult, in terms of communication, emotions and fitting in. It could leave participants open to bullying and insults. Participants were therefore wary of who could be trusted to know of their autism diagnosis, often hiding this to blend in with their peers. However, some participants also considered positive aspects to this difference. For example, having special gifts or talents.

5.6.3.1. Autism and difference. Autism as difference is represented in Harrison’s drawing (below), which was created in response to the statement autism is… Harrison explained that the colours in the drawing show how he is different to others but not necessarily better or worse.

Figure 17

Harrison: Autism is…

Lightning also stated that autism, “makes me know that I’m different but I won’t let that like change who I am.” The statement suggests that autism is something that defines difference;

the diagnosis means Lightning *knows* that he is “different.” The statement “I won’t let that change who I am” suggests autism is a separate entity to the sense of self, the “who I am.” The label of autism and its ensuing sense of difference was something Lightning saw as needing to be worked against, in not letting that change his sense of self.

Participants also reported the difficulties with communication, negative emotions and the reactions and actions of peers that they associated with autism. Participants described how they may be made to feel left out or bullied due to others’ perceptions of autistic people. This is demonstrated in the poetic transcription “It Can Make My Life Difficult.” The first half of the poem highlights the difficulties participants identify in relation to communication and emotions. The second half presents difficulties in relation to fitting in and bullying. The end of the poem is illustrated by Harrison’s drawings on the bad aspects of autism, which further show the idea of being left out whilst others sit together enjoying a TV programme, and where bullying is represented by “people jab[bing] you with sticks”.

It Can Make My Life Difficult

Autism is a burden, a disability.
Something that impacts on one’s life.
Autism does make things difficult sometimes,
it can make my life difficult.

I have bad anxiety,
Which can stop me doing/ feeling,
like everyone else.

I get angry really quickly,
I say things I’m not supposed to,
or like hit them.

Struggling to speak,
Finding it harder to make conversation,

You might not know what people mean,
interpret what people say wrong,
struggle to understand other people's expressions.

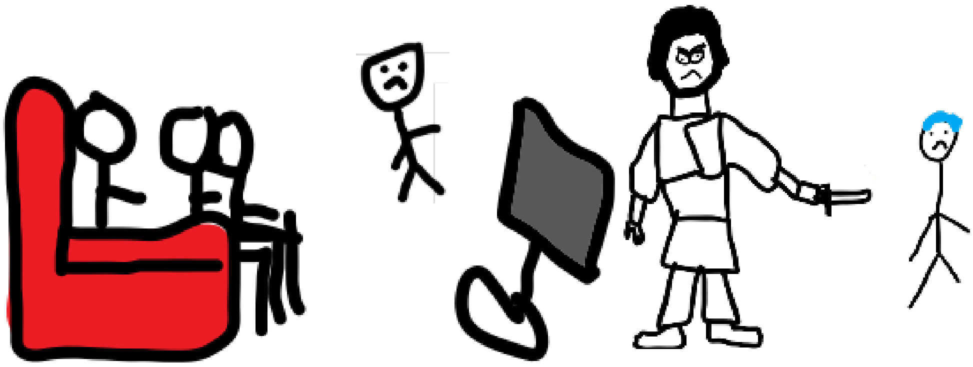
Autistic adolescents focus on the question,
'Who are my friends?',
as many of them struggle to fit in.

Being left out in conversation,
Left out because you're different,
Being judged on the way I act, called names, picked on,
treated unfairly, people take the mick,
making fun of people who have it.

I am always insulted about my condition.
(Connor, Fresh, Harrison, Joe, Lightning, Richelle & Skyler)

Figure 18

Harrison: Autism- Bad Aspects



5.6.3.2. Distancing from the autism label. Based on their view of others' treatment of autistic people, participants chose to distance themselves from the autism label. They described how they may hide their autism diagnosis to protect themselves from the upsetting emotions of negative comments. Skyler stated people, "treat me differently, think of me differently, or take the mess" if they know of her autism. Skyler suggests that autism and difference could be used as a tool to upset her:

> I do not want people to know who don't need to because I don't want people to think of me any different or treat me any different. Some people who maybe are not that nice underneath may abuse this idea and upset me as much as they can.

Skyler suggests that autism is something people "make a mockery of" and this can be "in person or on social media." Skyler provided the example of "autistic" being used as an insult on peers' social media videos. This shows how participants can experience negative attitudes from the wider community through social media. The view of peers, and of wider society, of autism as something to be mocked, can lead participants to distance themselves from the autism label.

This was exemplified in Richelle's account of autism being discussed by a teacher at school. She showed her need to not only not tell anyone of her diagnosis but to also hide *any* reaction to the discussion of autism:

> R: sat there you're thinking don't tell anyone that you have it. Just sit there. Don't look embarrassed. Sit there and don't do anything.
> S: Yeh like blend in.

As Skyler stated, you must "blend in" and not associate yourselves with the autism label in any way. As she stated later, "It is mild for me. I am in mainstream. I can hide it." This suggests a desire to "hide" autism from others to avoid differing treatment. This often means, as Richelle explains, "I've not like told anyone. I've told like two people I erm have autism but I-I don't want my friend to treat me differently."

The need to "blend in" and "hide" was shown in the account of what happened after the school discussion of autism by a teacher, "it just made everyone…just take the mick out of people that have it…just making fun of people that have it and it was just not very kind." This bullying can have a negative impact on participant feeling. For example, Fresh states it makes him feel “empty inside.” Such experiences led these autistic pupils to feel they had to hide their autism from their peers.

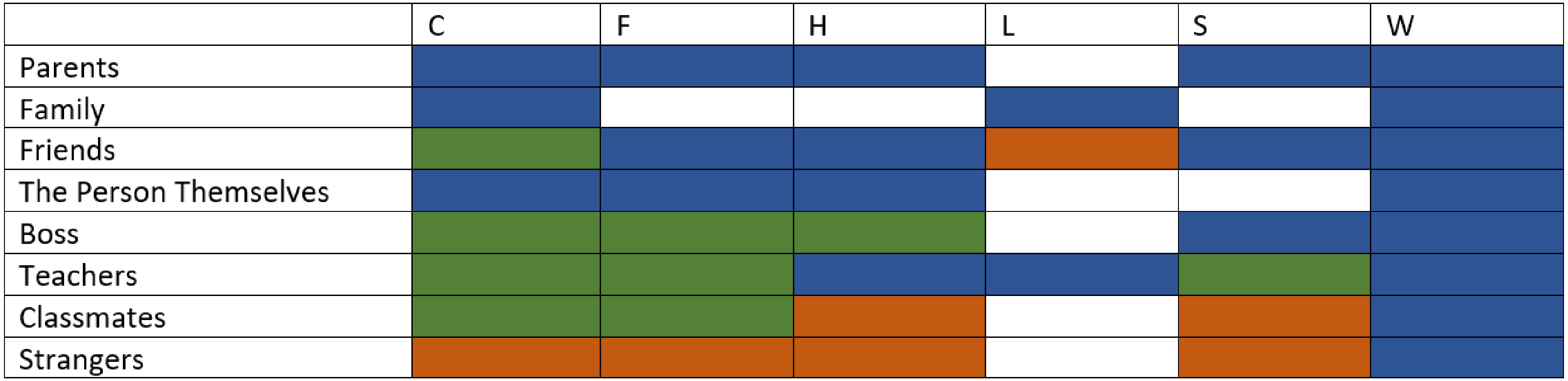
Interestingly, Richelle felt that this mocking behaviour came from the fact that her peers had not “experienced it as you have, and you’ve gone through the experience but they haven’t.” Here, she views the issue as springing not from herself as an autistic person but from a lack of empathy from others, who are unable to put themselves in the shoes of autistic people, as they have not experienced the same life. However, even with this awareness, she still hides her diagnosis and must not “tell anyone that you have it.”

Participants separating themselves from the autism label was further evident in participants’ choices when considering the question of ‘Who am I?’ Only one participant chose to spontaneously include this as a feature to describe his sense of self stating, “I am autistic” in the Twenty Statements Test (Joe). All other comments on autism were given when the topic was suggested by the researcher, based on Joe’s addition of autism to the choice of topic prompts. Here, 3 participants chose autism to discuss. The final 4 chose not to discuss autism until prompts were suggested by the researcher which related *only* to this. Even within this, participants chose in places to answer “No comment” when considering what autism is and how it may be good or bad. Therefore, autism was only really discussed when prompted by the researcher. This may suggest that participants did not wish to include autism within the way they defined their sense of self. When answering the question of who am I, this was not something participants wanted to include or explore in detail.

5.6.3.3. Autism: who should know? Participants suggested that this part of themselves may not need to be hidden from *everyone*. There were certain people who could be trusted with this knowledge. I asked participants who should know a person is autistic, providing a list of suggested groups. The responses to this are in Figure 19, which illustrates the conflicting views on who the autism diagnosis should be shared with. Participants agreed on parents/ family and the person themselves knowing a person is autistic. Most also agreed that strangers should not know. However, contrasting views were given on sharing this knowledge with classmates, teachers, and friends.

Figure 19

Who Should Know a Person is Autistic?



	C	F	H	L	S	W
Parents	🟦	🟦	🟦		🟦	🟦
Family	🟦			🟦		🟦
Friends	🟩	🟦	🟦	🟧	🟦	🟦
The Person Themselves	🟦	🟦	🟦			🟦
Boss	🟩	🟩	🟩		🟦	🟦
Teachers	🟩	🟩	🟦	🟦	🟩	🟦
Classmates	🟩	🟩	🟧		🟧	🟦
Strangers	🟧	🟧	🟧		🟧	🟦

🟦 Yes

🟧 No

🟩 Maybe/ depends

Note. White boxes represent a participant choosing not to comment. Richelle/ Joe had left the project when this task was undertaken.

Participants discussed the reasons why they would tell someone of the diagnosis. For instance, if that knowledge would enable that person to help and support you, understanding any difficulties you have. Teachers should know because “might not be as harsh or can help you more” (Connor). Participants also shared common ideas around trust- those who should know about an autism diagnosis should be “trustworthy” and someone you “know well enough” (Fresh, Harrison & Skyler). This was why some participants felt it “depends” for certain categories whether that group of people should know. For example, Harrison felt friends should know as “you trust them” whilst Skyler stated, “people close to me or that I have masses of trust in should know.” For some participants, friends would be best not having this knowledge as “they could think of you quite a lot different” (Lightning) and “I don’t want my friend to treat me differently” (Richelle). Difference of treatment was also the reason given by Skyler for why “I don’t want people to know who don’t need to” where there could even be a risk of “abuse.” Therefore, the trust needed might be that the person will not change how they act or treat you. If they can be trusted as such, then they can know that autism applies to you. Even though Lightning suggested that friends who know you well, who you have known for a while might not treat you that differently, he also suggested friends should still not know, “not really your friends because you want to like (pause) be like more part of them. Not have something in the way.” This suggests that even though friends he knows well may not treat him that differently, he still felt that autism would be “in the way”. Being autistic means he may not feel “part of them” in the same way. This suggests that there is something about non-autistic people knowing about an autism diagnosis, which Lightning felt separates you from that group.

Finally, Wolf suggested *all* people should know, “all my classmates know that I’m autistic and a lot of people know except for strangers.” He suggested that his diagnosis was widely known, in contrast to the discussions of Skyler and Richelle about keeping this quiet from classmates and peers. Unlike Lightning’s characterization of autism as something separate that will not “change me”, Wolf suggested autism is an intrinsic part of himself. When exploring the positive aspects of autism, he stated, “Just like being me” whilst he also stated autism is “my entire life.” Wolf saw autism as part of who he is, as “being me”, as interwoven with his “entire life.” Autism is an intrinsic part of himself and perhaps therefore it could not be hidden or ‘blended in’. Therefore, not *all* participants separated or distanced themselves from the autism label.

5.6.3.4. Autism: Contrasting Views. In addition, not all participants equated autism with being wholly negative. In the school topic sort (Appendix P), participants had mixed views on whether autism made them feel good or bad about themselves. Positive elements of autism included an association with special gifts, talents or abilities, receiving support from TAs, and being able to jump queues.

Harrison suggested that autism can make you “stand out both good and bad” and that you may feel “special.” Harrison showed this in his drawing (Figure 20), based on the statement autism is…

Figure 20

Harrison: Autism is…

Skyler felt autism could make you “the best people ever known.” She stated:

> I think that every autistic person has a special gift/talent and that they thrive in this. Some of the best people of all time in their talent/gift are actually the best people ever known and also the most famous.

Even though Skyler felt she did “not want people to know who don’t need to,” about her autism, she was particularly positive about autism itself, seeing those special gifts or talents as a place to “thrive.” She felt the good outweighed the bad and she wanted to “embrace” the positive aspects of autism:

> For me, overall, the good aspects of autism that I have over-ride the bad aspects making me feel happy/ proud to have autism and the more negative aspects are buried in the positive. This is very good for me as I like to embrace these positive things about me.

There is an interesting contrast here with Skyler’s previous focus on not appearing “strange” and keeping her diagnosis to herself, to avoid differing treatment and mockery from others. Autism as a label may be something to keep from peers and wider society, but the positive aspects, those which are seen as strengths, may still be personally celebrated. For example, Skyler felt autism made her “very social” as her observant nature and being “very mature” meant she picked up on how people were feeling. She felt “autism helps me to learn things/ pick things up really quickly.” Skyler therefore viewed autism as having a direct impact on her ability to learn and progress, to achieve strengths in “new talents/skills.” All these skills and maturity were attributed to autism as were the positive aspects that arose from this. Skyler therefore felt these aspects of autism had a positive impact on her sense of self. Therefore, not *all* aspects of difference associated with autism had a negative impact on the self-view.

5.6.4. The Right Kind of Difference

Participant data suggested a sense of there being a right way to be different. Aspects of difference which had a positive impact on the views of others and of the self were celebrated, whilst negative differences were hidden away.

Alongside the positive aspects about autism discussed above, three participants reported positive feelings around unique features, such as a more unique name or having unique knowledge. Wolf chose having had a range of unique experiences as the top influence on making him feel good about himself and these experiences were a key part of his discussion in relation to the question of ‘who am I?’ He had visited places “not open to the public”, broken records and “had more experiences than most,” “that very few people have.” He chose to share several photographs which represented these experiences, which he felt had "helped me develop." Certain roles and responsibilities were also seen as the right kind of difference, with Harrison stating, "I am proud of my roles because they are what makes you stand out from the crowd."

Therefore, standing out and being different was not always a negative; it could be dependent on whether it was perceived as strange by peers and wider society.

5.6.5. Roles and their Responsibilities

Roles were considered by several participants to make them feel good about themselves, they were proud of how these roles made them stand out, of the responsibility they had taken, and been trusted to take, and of their achievements within these roles.

Participants discussed a range of roles, as represented by Figure 21. This shows the most mentioned role types were family roles, followed by roles in extracurricular clubs.

Figure 21

Participant Roles

Responsibility was considered a key element of the roles explored by participants. For example, family roles might mean supporting family members during difficult times or looking after siblings. Taking responsibility might require a change in behaviour. Lightning suggested that the responsibility of being a big brother may lead you to change your behaviour to ensure you do not do anything “wrong,” acting as an “example” and a role model, whilst, as a son, Harrison feels you should “behave properly.”

Fresh focused on the responsibility of being a pet owner. This gave him confidence, teaching and caring for “another living being” resulted in positive feelings, “being a pet owner makes me feel more confident because I get to take care of another living being and help it to adapt to human emotion.” Helping others was also a positive for Skyler, who felt good about taking part in a school charity project whilst Harrison felt that being part of one after school organization meant you “help people and be kind”; a responsibility which had a positive impact on sense of self (Harrison).

Roles which resulted in responsibility, and helping others, were particularly important to Wolf, who felt he was good at helping those who were “younger and less experienced” improve across a range of extracurricular clubs and interests, taking a leading role of responsibility. Wolf felt good about his responsibilities and leadership roles as he felt trusted and respected. This had a positive impact on his sense of self. He felt this was something he would want people to focus on when describing who he was. Skyler also felt that being given responsibility and chosen for roles within school meant “I am being noticed as like my hard work and reputation.” As with Wolf, this had a positive impact and she felt good about herself because of the recognition that she could undertake such responsibility. This was supported by Richelle, who felt that if “autistic pupils have more bigger opportunities and responsibility” within school, it would have a positive impact on those pupils.

Therefore, opportunities for responsibility both inside and outside of school could have a positive impact on the self-view of participants.

5.7. Relationships: Socialising and Support

Participants explored a range of supportive relationships with family and friends. Relationships were an important source of interaction, with social time with family and friends associated with enjoyment and fun. Moreover, friendships could be a marker of being a good person, who others like, whilst family could offer a space of understanding and belonging.

5.7.1. Friendship

All participants discussed friends or friendship to varying degrees. Most participants explored the positive influence of friendship, including the enjoyment of socialising and having fun *and* the support offered by those friends in times of need. This is demonstrated in the poetic transcription "Good Friends: Makes You Feel Good."

Good Friends: Makes You Feel Good
Having good friends,
makes you feel good.
It feels bad being alone.

To play games, bowl, party, watch films,
be stupid, have a laugh.
It's fun, good to talk to,
and be stupid with.

Friends can help you in so many ways,
support me in my troubles,
if you're struggling,
tell you how to do something,
give me some advice,
or just give you a hand.

Friends cheer me up.
They understand what to do,
understand my needs
and reassure.

You've got someone to be there when you need 'em.
I have people to turn to.

(Connor, Harrison, Fresh, Lightning, Richelle & Skyler)

Friends were viewed as an important source of support for anything you are "struggling with." They were there to talk to and to receive advice from. They offered reassurance for anxiety and could be important to "tell you it in a different way to make you feel better about yourself" (Skyler).

The importance of these friends was also related to feeling good about yourself as a person. This was seen with six participants identifying this as an element that made them feel good about themselves (Appendix P). The reasoning for this was explained by Harrison:

> ER: Why does having friends make you think that you're good?
> H: Well because (pause) erm (pause) it's just like you- if you can make friends you're a good person to some people so it makes you feel good about yourself because some people like you.

This demonstrates how having friends can reflect on how you see yourself as a person. A person can make friends because they are viewed as a good person by others. The implication being if you cannot make friends there may be an issue with you as a person; if you are unable to fit in you may be a bad person. Negative feelings about the self in relation to lacking friends was seen in Lightning's statement that you would feel bad if you "didn't have many friends" and in Joe's comment that, "I am least proud of not being very sociable, as I would prefer to have proper friends and talk to people more." Joe chose this as a negative aspect of his self-description, as something which made him feel bad about himself. This was something he wanted to change. In all, a lack of friends could have a negative impact on the self-view.

5.7.2. Family

Family were considered of importance to participants, with 7/8 participants choosing to discuss family when answering ‘who am I?’ Importance was seen in the prior discussion of interests being “not as important as family” as “family are more important.” The relevance of being part of a family to participants’ sense of self was seen in the number of family roles discussed by participants (Figure 21), such as being a son, brother and “a loving member of my family.” Furthermore, participants discussed various family members, including parents, grandparents and siblings, and the time spent with them. This suggests these relationships were something participants wished to share.

Family members were described as offering supportive and accepting relationships, suggesting a key role they could have in participants’ positive or negative self-views and emotions. This may be why six participants chose family as associated with positive feelings when organising sense of self topics (Appendix N). These positive feelings towards family were summed up by Richelle, “family this makes me feel good because I love my family so much especially my dad because I am closest to him.” Positive and supportive relationships were further shown in the words support and supportive appearing in a range of participant comments on family. Skyler also stated, “If I have any problems, I feel like family would be like the first place I would go.” This support and guidance could be in smaller everyday tasks, such as homework, or big decisions, such as careers, “my family support me with homework, getting ready or packed up… and they give me advice for things like options and future jobs” (Harrison). Family also supported participants with negative feelings such as feeling sad, depressed or anxious, with Richelle describing her sibling as “always there to talk to when I am down.”

Skyler explained how this support can link to feelings of safety, understanding and contentment:

> This is because my family and friends are very supportive and understanding like nobody else. This makes me feel secure and content as I can say whatever I feel to them. This makes me feel grateful as not everyone is like this.

Family were considered people who will support no matter what and could create a sense of belonging. This was shown in Lightning's explanation, "having family like around you and feels like you like you know belong somewhere (pause) and people are like there to support you with anything."

Overall, participants have suggested that being part of a supportive family results in feelings of belonging and acceptance in a space where there is safe and secure guidance for difficulties or decisions big or small.

5.7.3. Socialising

Relationships with family and friends were also discussed in relation to their social aspects. Harrison stated that he spent time with friends and family as it "makes me feel bad… being alone" and that he felt "happy to spend time with people." He particularly enjoyed opportunities to socialise with family and friends. Both Harrison and Skyler enjoyed "meeting new friends" and "new people," showing a desire to expand their relationships. As previously discussed, making "proper friends" was also desired by Joe even though he viewed himself as a "person who prefers to be on their own." This shows how participants not only discussed enjoyment at socialising with current family and friends but that some participants expressed a desire to meet new friends.

Additionally, Skyler characterised herself as a "very social," with her socialising abilities being a strength:

> I'm very good socialising with people and like-like meeting others and new people or… showing them around school or like things like that I would like love to do that because I just love meeting new people and socialising.

This shows how, for this participant, being social was not just an enjoyable act but something she viewed as a strength, within her sense of self.

In contrast, Richelle was “scared to make new friendships with people” who did not know her. She felt that it could be hard to make the same connection with new people and that old friends may question why she was not spending time with them instead.

Therefore, participants expressed varied views on new people, however, socialising and spending time with friends and family was a positive for participants overall.

5.8. Negative Influences

Participants also discussed a range of negative influences on their self-view and emotions. They explored the negative impact of others’ views, including feeling judged. They also explored issues and weaknesses they felt they had and the impact of these on their self-view, alongside discussing a range of negative emotions they may experience.

5.8.1. The Negative Judgements of Others

When considering the views of others, being judged was a recurrent idea explored by participants. Participants felt they could be judged on the way they “act” or “behave” or if they “make a mistake” and that they could be “teased”, “insulted” or mocked for this (Fresh, Harrison, Lightning, Richelle, Skyler). As well as being judged for being autistic, participants explored being judged on their appearance and the negative feelings this results in. This was shown in the school topic sort (Appendix P) where 5 participants felt being judged on appearance could result in negative feelings about the self.

Participant discussion of being judged and mocked suggests that the comments of others on their appearance can be negative in form. They discuss how these comments can have a negative impact on someone’s sense of self. This is shown in the poetic transcription “Doesn’t Everyone Hate Being Judged.”

Doesn’t Everyone Hate Being Judged

Doesn’t everyone hate being judged on the way they look?
I think we all do.
It could make them feel sad.
Like-
they’re the only person who doesn’t look very good.
They’re not good enough.
When they say bad things.
It makes you feel bad
because you feel worse than everyone else.

It’s hurtful.
If someone bragged about their looks
it could hurt someone.
I’d feel like I don’t look too good.
(Connor & Harrison)

Here, Connor and Harrison compare themselves with others, as not looking as good as them. Negative comments not only made them “feel insulted” but could also make them place themselves in a lower position compared to everyone else, having a negative impact on their self-view. Others bragging about how they look could influence another person to compare themselves, and to conclude that they are not as good as that other. However, positive comments about the appearance or self, can make you “feel important” and it “makes me feel good when complimented” (Harrison).

Alongside actual comments, participants also explore perceived negative opinions. For example, Skyler discussed how some people may be “paranoid” about interests which are considered more unusual due to the views of wider society/ peers:

> What would this person think of me doing this, ah, they wouldn’t like it so I’m not going to do it. Why would you- like they’re not even here and even if they were just do the things that make you happy.

Skyler suggests a position of standing against these negative views and doing what makes you “happy” regardless. However, she also shows an awareness of how people can be influenced to behave in different ways, due to perceived judgement of others on the way they act.

5.8.2. Focusing on Issues

Participants identified a range of difficulties and weaknesses they felt they had, including anxiety, social behaviours- such as bluntness and standing up for themselves, and abilities in school subjects and other areas of interest. However, they did not want these issues to be a focus in how they were defined.

When organising sense of self topics, (Appendix N), participants generally placed weaknesses as lowest in importance, as something they did not want to focus on when describing themselves. This may be due to the negative feelings which are associated with these weaknesses, which all participants identified as making them feel bad about themselves (Appendix N). This is shown further in the poetic transcription “That’s Totally B for Bad.” This first two stanzas show how participants feel “horrible” about being “weak” whilst the final stanza demonstrates how these feelings may lead to weaknesses being minimized as a focus, both for the participant themselves and in their presentation of themselves to others.

That’s Totally B for Bad

Don’t really want weaknesses.
What you’re bad at.
You’re not really going to feel good about them.
Horrible.
I am weak. I don’t like being weak.

Bad because you have them.

The only one that's totally B for bad.
I don't think yay it's a weakness
I don't think oh yes!

It doesn't have a positive mind-set on anybody.
That's probably why it's the lowest one.
It's not very important to me-at all.
I try not to focus on these.
They are not the important stuff people need to know.

(Connor, Harrison, Lightning, Richelle, Skyler & Wolf)

Despite this, some participants showed a desire to be *personally* aware of their weaknesses so that these could be addressed. Wolf stated he must "attempt to overcome them when they arise" and Fresh stated, "we should try to tackle these weaknesses because there is always a way to sort these problems out." Harrison felt, "knowing what your weaknesses are is good" so you can address them and improve. He also stated, "everyone has weaknesses" therefore "I don't feel that bad about it." Harrison had fewer negative feelings about weaknesses because he felt they could be worked on. Moreover, in comparison, they were something that Harrison felt affects *everyone*, perhaps suggesting that he did not feel these areas made him any worse than anyone else.

Overall, weaknesses and difficulties were something that participants did not want to be focused on by others' when describing themselves, though this did not mean they ignored them- problems were something to address.

5.8.3. Negative Emotions

Participants expressed a range of negative emotions and their causes. They experienced stress from the responsibility associated with being older, from the pressure of achieving at school and from life events, such as the loss of a family member. One participant focused particularly on their anxiety as they, "worry about everything", whilst another discussed the guilt felt about not showing gratitude for the effort others put in for them (Harrison, Richelle & Skyler).

All participants, except Joe, explored dislikes or annoyances within the sense of self topic. These were associated with negative feelings. As Harrison states, "It didn't really make me feel nice to think of dislikes." Dislikes included things participants were afraid of, such as spiders and things that annoyed them, such as being disturbed when they were working (Fresh). These dislikes and annoyances were particularly important to Fresh, who chose these as his top three important topics when discussing his sense of self. For Fresh, it was important for me to know his dislikes. Wolf also felt that, alongside likes, these dislikes are "what makes me me." Part of knowing who he is, is that we know what he does *not* like as well as what he is interested in. Therefore, although dislikes were associated with negative emotions, they were something that participants might feel should be known as part of "what makes me me."

5.9. Positive, Essential Traits

Participants discussed a range of personality and behavioural traits when discussing their sense of self (Figure 22). In this, predominant traits were those which would traditionally be viewed as positive such as loyal, friendly, funny. The most commonly mentioned trait was friendly, a particularly positive social trait. This may again show participants focusing on traits which were considered a strength rather than a weakness.

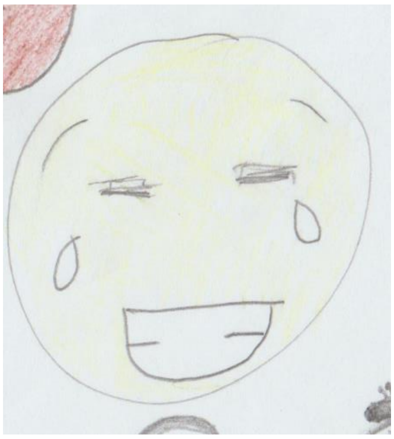
Figure 22

Participant Traits

Being funny was viewed as an important trait. Both Joe and Lightning stated, “I am funny” and Connor enjoyed being “stupid” with friends. Harrison characterised himself as someone who likes “silly/ funny things” and “messing around” (Figure 23).

Figure 23

Harrison: ‘Who am I?’



The importance of humour as a trait was shown in Fresh statement that, “you need to be somewhat funny, not boring.” This was shown further in Wolf’s view that:

> We need to have a laugh, because you need to have a sense of humour because if you don’t have a sense of humour then (pause) why-why are you here if you don’t have a sense of humour. You need to have one.

This suggests that participants felt a sense of humour was essential, something you *need* to have. It was something which not only makes you “happy” (Richelle) but also enhances social standing with friends- you are viewed as someone, who is “not boring” (Fresh), and is fun to spend time with.

In sum, participants predominantly focused on positive social traits, such as being funny or friendly, when describing themselves.

5.10. Summary

I now return to the key findings, summarising the main points from this chapter. Countering previous reductive, deficit narratives, autistic participants ***provided a complex range of elements when describing themselves, conceptualising and evaluating themselves in multiple ways***. They discussed a heterogenous range of interests and preferences, emotions, strengths and weaknesses, personality traits, roles and responsibilities and relationships with others. In this, interests were an important element in participants’ self-definition, a marker of individuality, which could promote social bonds and provide a basis for future careers- careers which were part of their desired, successful future self.

As seen in participant discussion of interests***, the social world was highly relevant to autistic young people. They contemplated their sense of self in varied social contexts, roles, and relationships.*** A range of supportive and accepting relationships were important to participants, with friendship marking acceptance as a ‘good’ person. This is perhaps why positive social traits, such as being funny or friendly, were prioritised by participants in their self-description- as they were important in engendering such friendships. Furthermore, when given responsible roles, participants felt trusted by others, which had a positive influence on their self-view. However, the negative impact of others was also evident- being judged, mocked, or unfavourably comparing themselves with peers had a detrimental impact on participants' self-view.

Participants therefore ***offered certain presentations of themselves in peer contexts, to engender positive reactions from others***, including putting on a 'front.' This was in contrast with home- a safer space, where you can be a freer self, with accepting family. This shows how ***participants acted to protect their self-view*** from negative influences, by changing their behaviour. Participants further protected their self-view by ***prioritising strengths and self-elements which aided a positive sense of self***- aspects of the self that they were happy to share. They ***avoided a focus on weaknesses or elements of negative difference***. This included distancing themselves from the autism label, to avoid the negative, differing treatment this could lead to.

This completes the presentation of findings for the 'big' picture of how participants conceptualise, present, and evaluate themselves. The next chapter focuses on findings for the mainstream school experience, and its influence on autistic pupils' sense of self.

Chapter 6: Findings: Sense of Self in a Mainstream Secondary School

In this chapter, I consider how the pupils in my study negotiated their sense of self in relation to their mainstream school environment. I present findings which focused on the sense of self within school, including how the self was conceptualised, presented and evaluated in the school setting. The key findings are:

- Participants consider themselves in relation to both academic and social aspects when conceptualising themselves as a school student.
- Participants position themselves as a good or bad student, utilising academic achievements and school systems to evaluate their position. This can influence how positively or negatively they feel about themselves.
- The academic and social selves are linked, with the interpersonal implications of being perceived as a good or bad student considered.
- The social sphere continues to be a key influence on the self-view, with interactions, comparisons and interpersonal relationships in the school setting all impacting on how participants evaluate themselves.
- Participants consider how their achievements provide a foundation for the desired success of the future self.

To provide the big picture of the analysis, on which these key findings are based, I begin the chapter with a thematic map, which presents an overview of the themes relating to negotiating the self within the school setting.

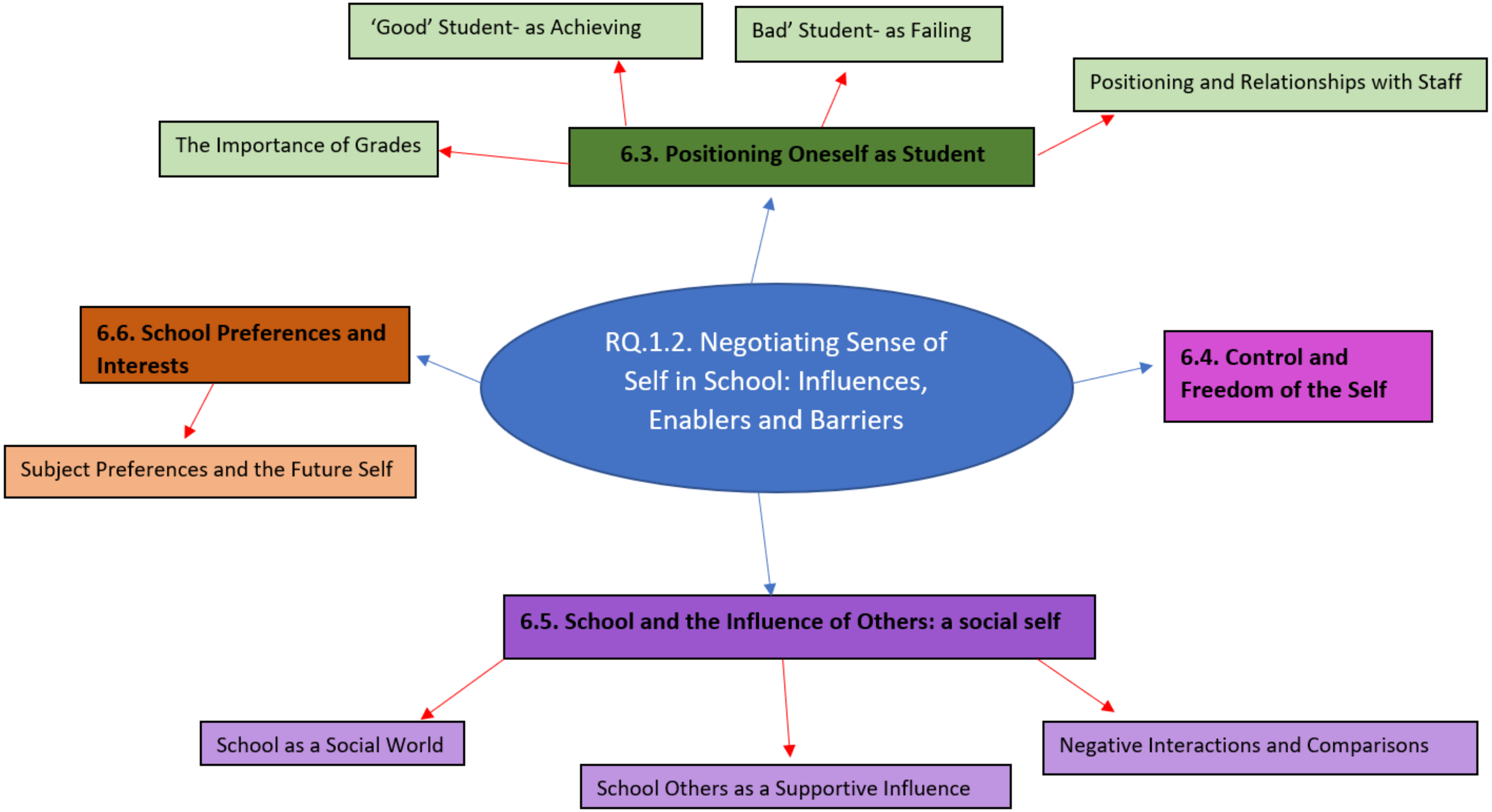
6.1. Overview of Themes

In the thematic map (Figure 24), overarching themes radiate from the central idea of negotiating sense of self in school, including school's influence on developing a positive sense of self. These are represented by a blue arrow. Some themes are broken down further into subthemes, represented by a red arrow.

As discussed in Chapter 4, the data represented in this thematic map was inductively analysed. The codes created were therefore led by the participant data. These codes were collated into the main and sub-themes. This organisation can be found in the coding chart in Appendix J, where matching themes and codes are color-coded, to show their relationship.

Figure 24

Thematic Map: RQ1.2.



Note. Numbers refer to the main sections of this chapter.

6.2. Thematic Analysis

I now offer a detailed analysis of the themes set out above, considering the influences on the sense of self of autistic pupils in the mainstream school environment, alongside pupils' definition and presentation of themselves within that setting. As such, themes are discussed in relation to RQ1.2. Links are also made to the relevance of the school setting to the *big picture* of the self. Therefore, the overarching RQ.1.- how sense of self is negotiated- is also considered in this chapter.

Findings are presented through the same forms- poetic transcription, word clouds, and quotations- with the same justification, as Chapter 5. In addition, where relevant, reference is made to the number of participants who felt an aspect of school had a positive or negative influence on the self-view. Participants considered this through colour-coding school topics by good or bad influence on the self *and* through reflecting on the whole group findings for the school topic (as described in Table 5, Chapter 4). The detailed data for these tasks can be found in the matrices in Appendix Q.

The chapter now moves through the themes of the thematic map, following the main themes, in a clockwise direction.

6.3. Positioning as a Good or Bad Student

As shown in Chapter 5, participants identified student as a role which formed part of how they described themselves. Throughout the project, several participants considered how students can be positioned as “good people” or a “bad person” (Richelle & Skyler). This led me to ask the whole group how they characterised a good or bad pupil (see Table 5, Chapter 4). Across these discussions, participants identified how academic and school systems such as examinations and grades, classwork and homework, and punishments and rewards, could identify a student as good or bad. They discussed how characterisation as a good or bad student may influence the perceptions, reactions or actions of staff, peers and the student themselves. Within this, participants defined their own position as a good or bad student and how the achievements, failures, punishments or rewards that marked them out as such impacted on their self-view.

6.3.1. Achieving as a Good Student

Participants characterised a good student as one who achieves through hard work and good behaviour. These achievements could be identified through good grades and reports and through the number of rewards received, which acted as recognition of their success. Participant characterisations of a good student are represented in the poetic transcription "Good Role Model", illustrated with a drawing by Harrison. These demonstrate how a good student achieves "high" grades, keeps working to improve and achieve their best and follows the rules. They were someone who treats others well, helping those who need it, and who may therefore feel "proud" of themselves. However, as shown in the final stanza, a good student may feel pressure to maintain this position, may be negatively judged by others as a "teacher's pet" and may have to "smile" even if they are "not feeling good." Therefore, the role is not entirely positive.

Good Role Model

Follow all rules,
Good behaved,
Good people.

Clever, high targets, good grades,
work hard, pay attention.
They're very enthusiastic, want to learn.
Complete all homework,
reputation for schoolwork.

They think: "Have I done enough?"
"How do I improve?"
"Difficult but still doable…"
"I might need a little help…

Good looking fit and clean.
Sensible clothes and shoes,
hair doesn't break any rules.

Help others, kind,
conscious of others’ thoughts.
Good role model,
complete respect for students and teachers.

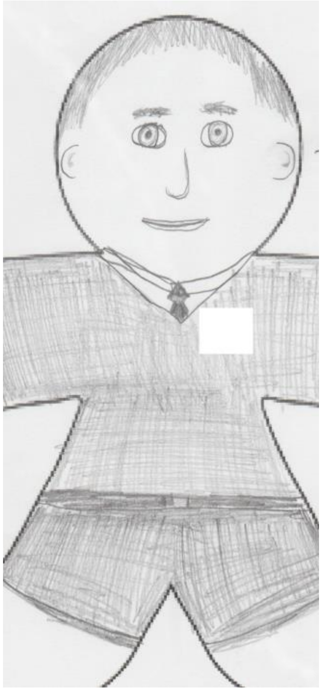
They feel: optimistic, determined,
confident, proud.

Always got to be good behaved,
people may judge,
teacher’s pet, slave, try hard.
Cannot get into trouble.
Smile even if you are not feeling good.

(Connor, Fresh, Harrison, Lightning, Richelle, Skyler & Wolf)

Figure 25

Harrison: Good Student



6.3.2. Failing as a Bad Student

Participants considered how they would characterise a failing, bad student. This characterisation also looked at behaviour, work ethic, appearance, and treatment of others. A bad student was characterised in terms of naughty behaviour, including a lack of work ethic. Failing to maintain good behaviour leads to punishments, such as detentions, whilst a poor work ethic results in low grades and future failure. Participants explored how being positioned as a bad student can influence how they are perceived, and subsequently treated, by staff. They discussed how someone struggling with work may be viewed negatively by both staff and their peers.

Participant views on a bad student are represented in the poetic transcription "A Troublemaker Type of Person," illustrated with Harrison's drawings. A bad student "doesn't have a brain", has low grades and a low work ethic, with one participant even stating, "grades like mine". They appear not to care about school and their appearance represents the rules they are breaking. They treat others badly, being rude and unhelpful, and bullying others, however, they may still be popular. In the final stanza, participants again show their awareness of how this may be a façade. Whilst one participant viewed the bad student as feeling "cocky" and "powerful" another suggested this may be "a front" and that inside the bad student there may be hidden difficulties or feelings of worthlessness. As with the good student, behind the position or role taken on, a bad student may also be struggling with negative emotions.

A Troublemaker Type of Person

Get into trouble, naughty,
bad behaved,
getting into bad situations.

Doesn't have a brain.
Not doing their work,
not getting good grades.

Slack off, low concentration,
talk when unnecessary,
fail to hand in homework.

A person that doesn’t do much.

Not very grateful, they think:
“I couldn’t care less…”
“I don’t need this”
“I’m not doing this.”

Uniform is absolute rubbish,
banned haircut, jewellery, trainers, no tie,
swearing and gum.

Gossip, bully,
call people names, insult others, verbal abuse,
fighting.
Unkind, not helpful, disrespectful, hurtful and rude.
May be popular or have no friends?

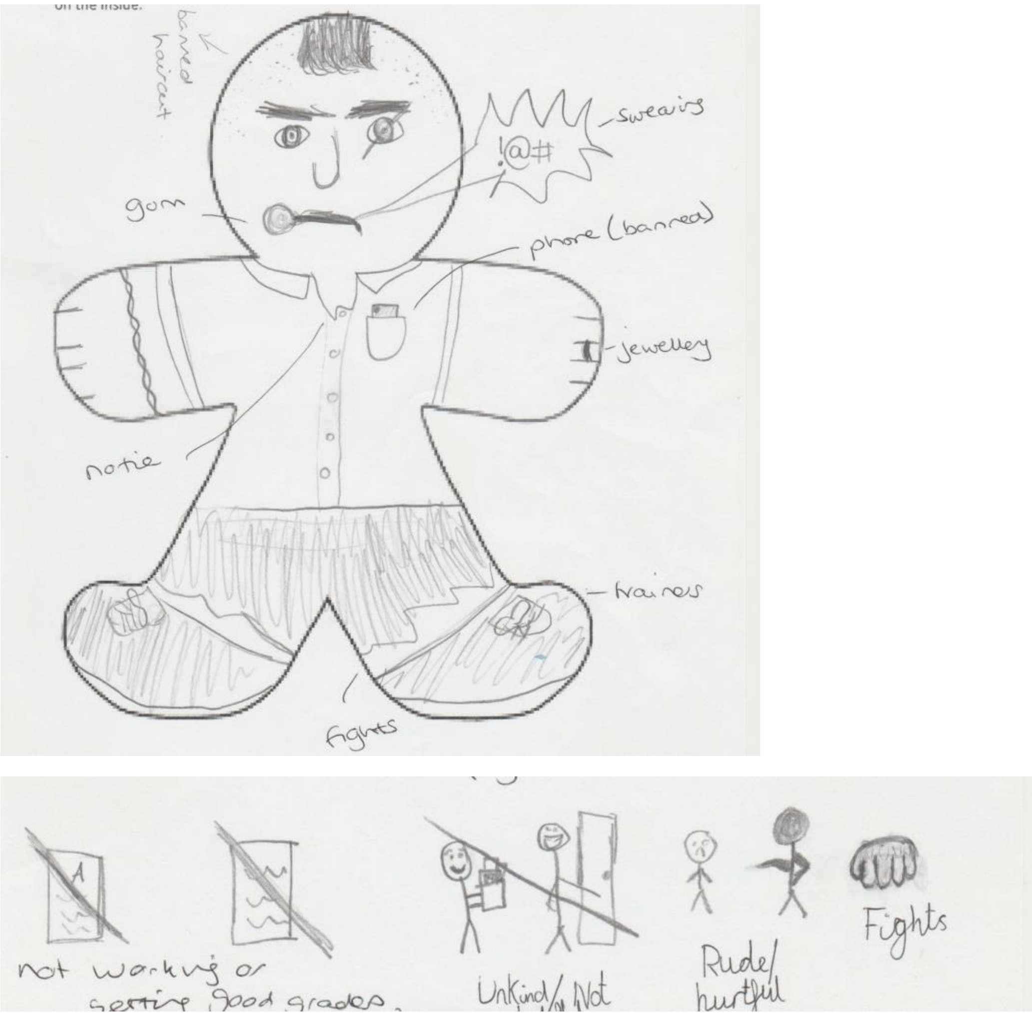
They feel: cocky, powerful, invincible.

A front to feel/look good,
May have troubles at home.
Inside they make themselves feel worthless.
No point being good. Doesn’t matter.

(Connor, Fresh, Harrison, Richelle, Skyler & Wolf)

Figure 26

Harrison: Bad Student



The poetic transcription suggests that students viewed as bad or naughty may feel that there is "no point" being good. This was explored further in Richelle and Skyler's discussion:

> S: If I'm like good behaved they are more likely to believe somebody who's not really in trouble, who's erm, who's
> R: got good grades
> S: yeh or like is good behaved because they're not getting in them sort of situations rather than somebody who's getting into bad situations… even if they're innocent they are more likely to believe the person who is good behaved rather than the person who's not.

Here, the participants address how staff have preconceptions about students characterised as naughty- these students may not be believed even if they are not at fault. This may create a sense of there being “no point” to changing behaviour as, once they have been characterised in as such, the role or label of bad student is hard to remove.

Richelle suggested that you can be influenced to join the position of bad student by others:

> If you get talking then get a friendship and become friends then that other person’s gonna turn you their type of way. Like refuse to do that, don’t talk to her and like get into one big hot mess.

Participants also considered the areas they themselves felt they had failed in as a student and how this impacted on their self-view, such as struggling with schoolwork and receiving punishments. They demonstrated mixed views on how much, and how negatively, this impacted on them, views which are presented below.

6.3.2.1. Struggling with schoolwork. Participants discussed how they felt being viewed as struggling with their schoolwork, either by themselves or by others- as shown in the poetic transcription “I Don’t Know What to Do.” This shows the negative impact of struggling in lessons. For example, when asking for help they may be viewed as not listening, leading to trouble with staff, or they may experience mockery from peers. Participants discuss how they may want to avoid these perceptions- not wanting to sit at the front of the class and be seen as needing “the most help.” Two participants share the view that there is not much mockery in relation to difficulties achieving. They believe that those with “low grades” are the ones who say “bad stuff” to others, rather than having comments made to them. This suggests that some participants feel that the comments of others are not as much of an issue in relation to struggling in class.

As shown at the end of the poem, one participant understands that not all subjects should be “plain sailing.” One participant also suggests that whilst they may feel a “bit behind” they don’t feel bad about themselves because of this whilst another feels they sometimes feel bad but other times they just think “I’ll do that next lesson.” This suggests that struggling in class may not always impact on how participants view themselves.

I Don’t Know What to Do

It is a weakness,
because some people get things straight away.
Difficult language may leave me clueless.
I didn’t catch as much information; I would just struggle.
It would just be too hard for me.
I need things broken down.

I can’t sometimes move on; I feel like that’s quite difficult-
that would get me worked up.
You’re just sat there like,
I don’t know what to do…

It makes you feel rubbish when you like,
don’t know what you’re doing.
So hard that you are really stressed.

Can you go over it?
And they’re like,
Weren’t you listening or summing like that?

I don’t like being at the front of the classroom,
Because they- you probably need the most help.
People are now going-
‘ha ha you don’t know what you’re doing.’

It’s normally the people who have low grades
are like the kind of people who say bad stuff about other people.

I don’t expect all subjects to be just like plain sailing,

I don’t feel like that’s reasonable,
I’m here at school to learn new things.

Don’t feel bad about self-
It just makes me feel lost.
Bit behind.

Sometimes I think, I’ll do that next lesson-
so, I’m not that bothered.

(Connor, Fresh, Richelle, Skyler & Wolf)

6.3.2.2. Punishment as failures. Participants identified punishments and trouble as part of being a bad student (see “A Troublemaker Type of Person.”) They also explored their own experiences of punishments and the negative effect these could have on their self-view. Four out of five participants reported that they would feel bad about themselves if they received a punishment or were ‘told off’ (Appendix Q).

These views were shown further in the poetic transcription “I Feel Horrible about Myself by Getting into Trouble.” The first stanza shows the range of interactions or behaviours within the classroom that can lead to such “trouble”. Participants discuss how receiving punishments could result in negative feelings and a desire to behave differently. As shown in stanza four, one participant states that eventually they had to learn to “forget about it” due to the volume of detentions received in a previous school year. Negative feelings, and a need to “forget about it,” may come from, as one participant suggests, detentions being seen as a “failure.” Negative feelings can also spring from the social impact of detentions, with feelings of loneliness and isolation springing from the loss of desired social time. Finally, one participant feels that after getting into trouble those teachers “hate me.” This suggests that they view getting into trouble for behaviour as resulting in staff having personal dislike towards them, one which continues after the event has occurred.

I Feel Horrible about Myself by Getting into Trouble

Teachers tell me off for talking,
refusing to listen to my teachers, refusing to do instruction.
They like shout at you for not listening;
they didn’t understand that I might look a different direction,
but I am still concentrating.
They didn’t understand where I was coming from.
I said they’re er not controlling the class right,
they didn’t take kindly to that.
That person is late and receives a break detention.

I normally stay out of trouble,
I had like a billion detentions.
I do like misbehave.

It kind of makes you feel bad,
you just wanna have not done it,
because it’s like you’ve failed.
I feel horrible about myself,
angry at myself, guilty,
by getting into trouble.

I’d probably forget about it-
because I learned to do that,
with how many detentions I got.
It was like yeh, another day.

I have gone a whole week without getting any detentions,
I am quite happy and relieved.

I feel lonely and isolated,

because I have break and lunch detentions all week-
I don't see my friends.
I'd rather go ahead and talk to everyone.

I have to stop misbehaving.

Teachers still hate me.

(Connor, Fresh, Harrison, Richelle & Wolf)

Participants therefore identified how struggling with work and receiving punishments could be part of the failures of a bad pupil, failures which could impact negatively on their self-view. In addition to these markers, grades achieved were an important element in determining if you were a good or bad student.

6.3.3. The Importance of Grades

Participants felt grades acted as markers of achievement, with a good student getting "good grades." Good grades were suggested to be high grades. The pressure participants felt to achieve good grades in examinations was discussed. This pressure was related to the felt importance of good grades for future achievement

Academic achievements were relevant to participant self-view. Richelle identified "bad grades at school" as part of her worst school day. Fresh stated that, "sometimes low grades drag me down, like I'm useless. Although high grades make me feel unstoppable as if I could do literally anything." Fresh felt that low grades can have a detrimental impact on the self-view, being associated with feelings of inadequacy and "useless[ness]." In contrast, high grades can boost confidence in tackling "anything." Harrison also chose "good grades" when asked by the researcher what, in a lesson, would make him feel good about himself whilst Lightning felt "when you've got like really good grades that'll make you feel the best." Fresh also chose good grades as one of the things that "motivate me when I am feeling down." Additionally, five participants agreed that bad grades can make you feel bad about yourself, whilst four agreed that good grades made you feel good about yourself (Appendix Q). Therefore, “good grades” were an important influencer on self-view.

Grades were also discussed in relation to target grades; grades participants were expected to work towards and to achieve. Fresh describes these as “nerve-racking” whilst Wolf described an image of a dartboard as representing target grades, where you must “aim for the centre because that’s the highest points.” Wolf suggests that this represents the “best education.” Lightning also considered target grades, and their impact on self-view, stating:

> Well, if someone has like er a high target it might make them feel good about themselves. That they’re good at that subject. They can like achieve a lot… if they’re too high and like unreachable and like make students think they’ll never get there.

Lightning suggests a high target can have a similarly positive impact as an actual grade as it implies skill, likely achievement and positioning as a good student. However, there was also a suggestion that some pupils may view this as setting up inevitable failure if “students think they’ll never get there.” For “someone of a lower target”, Lightning felt that they may view this as a sign they were “not as good” at a subject. Pupils may therefore be influenced by school targets alongside grades earned, where the concept of being high can represent achievement as a good student. In contrast, those targets viewed as lower mean they are “not as good.”

One place participants could receive good or bad grades were in their examinations, which were an opportunity to achieve or fail. Participant views on this are shown in the poetic transcription, “It’s Getting Your Grades.” The first three stanzas demonstrate the pressure and anxiety around exams, revealing that the source of this anxiety is the potential outcome. Stanza four shows the pride participants felt in achievement, whilst failure could result in feeling “not good enough.” Exams are a site of stress as you just “don’t know if you are going to get good or bad.” One participant focused on the possibility of improving. Although they felt they may view themselves as “not that good” if they got a bad grade, they also considered future improvement to reach their “target.” At the end of the poem, the pressure of exams is linked to the impact grades have on the future. Failure in exams is directly linked to a negative future- if you do not achieve your grades you are “stuffed.” In contrast, as Skyler commented, good grades can mean “a very good job.”

It’s Getting Your Grades
Worried, you get really anxious over exams,
you feel really stressed,
you’re probably really nervous,
you’re probably not prepared.

It’s getting your grades.
A lot of pressure.
Can I achieve here? How do I do it?

You don’t know if you are going to get good or bad,
and it could be anything.
Can I get the grade that I need to get?

I want to achieve and get good GCSEs.
I feel proud when I get good exams and grades results.
Well, if when you’ve got like really good grades,
that’ll make you feel the best.

Bad grades can mean disappointment,
I feel like I’m not good enough.
I’d think that I’m not that good-
but I might be able to improve.

If we don’t pass these exams, we are stuck.
We really haven’t got much of a future if we fail.
If you don’t get the grade, well you’re stuffed.

(Connor, Harrison, Fresh, Lightning, Richelle, Skyler & Wolf)

Participants therefore considered exams and grades as key for any next steps, whether that be further education, apprenticeships or job roles. This was summarised by Wolf who stated, “if you don’t have your GCSEs you can’t do anything.” Exams were viewed as crucial to progression beyond secondary school- a site of both current and future achievement or failure for the self. The impact of this perceived future self is shown further in all main study participants suggesting that, “Thinking they will have a bad future would/ not get a good job” would make them feel bad about themselves and four out of five viewed “feeling you can achieve in the future” as having a positive impact on their self-view (Appendix Q).

Grades are also reported on in school reports, which include both academic and effort (behaviour) grades. The worst school day for Richelle would be “bad scores” and “bad grades” on these reports. Trying to keep “good grades” was a focus mentioned repeatedly by Richelle. Lightning felt his reports were a positive influence as they summed up “good things…they think that you’ve you’re doing well overall. Or behaving well.” This contributed to him feeling that he was a “fairly good student.” Four out of five participants also felt that a good report would have a positive impact on their self-view and a bad report a negative impact on their self-view (Appendix Q). Therefore, school reports were shown as relevant to the self-view of participants.

In summary, participants identified examinations, reports, and target grades as providing evidence of being a good or bad student in relation to grades achieved. Participants viewed good grades as high grades, which could have a positive influence on their self-view. These grade-based achievements were also key for future success. Additionally, grades achieved could be evaluated through comparison with peers.

6.3.3.1. Comparing Achievements. When sharing experiences of comparing grades and achievements with their peers, participants focused on unfavourable comparisons, which placed them in a lower position. These comparisons generally resulted in negative feelings about the self although some participants utilised these comparisons with others as motivators to improve.

Four out of give participants suggested that comparison with others would have a negative influence on their self-view (Appendix Q). The impact of academic comparison is shown in the poetic transcription "I Sometimes Compare Grades." The first stanza suggests how being the *most* in comparison is important. This may be an aim to be the best academically but could also be athletically, physically or in rewards achieved. Indeed, several participants in the project (Fresh, Harrison & Lightning) suggested a need to be the top or most with reward credits. This suggests a competitive element to comparison with others. Yet, participants do not characterise themselves as the best in their comparisons. They focused on how lower grades or not being as good at a subject as others can impact on their self-view. They discuss how not being accepted in a subject which requires higher grades or not understanding or working as quickly as others can create negative views of the self. As shown in the fifth stanza, one participant felt that comparison could be a motivator to achieving more highly, by driving them to achieve the same as those others. In the final stanza, the statement "I aim to be the best I can" could imply a sense of competing with the self rather than with others. This participant wants to be the "best" version of themselves; the best that they personally can achieve.

I Sometimes Compare Grades
People try to be like the most something,
like the smartest or best at football or
the strongest or other things like most reward credits.

If we're doing a test and I don't do as well
as one of my friends, I like think that,
I am not as good at that.
I wish I was that good at like English as them.

If you have worse subjects than other people,
people might think they're not good enough;
it might make you feel bad about yourself.

It is a weakness because some people like,

get things straight away and then I’m like
“ah what are you supposed to do?”
I feel everyone’s ahead of me,
If they finish early it is like,
I am not as good as them.

I sometimes compare grades.
Sometimes it makes me work harder
to become like them.

I aim to be the best I can.

(Connor, Fresh, Harrison, Lightning, Richelle & Skyler)

In addition to evaluating and comparing their achievements, participants also considered what influenced them to achieve their grades.

6.3.3.2. Influences on Achievements. Participants considered good behaviour, effort, interest and motivation as key elements of the hard work required to achieve. Wolf suggested “it’s effort and interest” which allows people to achieve what they want. He felt that interest led to motivation and a desire to complete work, “if I’m not interested then it’s hard to be motivated to do it.” This was supported by Lightning who felt if he enjoyed subjects, “I would get on with them” and Connor, who felt that if you “enjoy it more” you are more likely to do homework. In contrast, Richelle focused more on the influence of behaviour on achievement, feeling that if you misbehave and receive either detentions or removal from the classroom, that this would impact negatively on grades achieved. To achieve you “have to stop misbehaving” to “get good GCSE.” Richelle therefore suggested that misbehaviour, and its resulting punishments, directly impacted on the achievements made at school.

Whilst Wolf felt that not achieving grades because of his own effort meant he would be upset with himself, he also showed an awareness of outside factors, such as the teaching received. Wolf felt that the teacher and the curriculum could play a part in student achievement, rather than this being purely dependent on the student's actions. If work was not individualised, he felt this contributed to student failure. He felt that by individualising work, you can "feel like you're achieving more" rather than "failing at everything you do" as it will be easier for that individual to understand.

Further to this, Skyler felt that praise was important to having "a positive mind-set about that subject especially if I find it hard" whilst Harrison suggested if he knew he was close to achieving in the school rewards system he "would work harder." This suggests rewards and praise can motivate pupil achievement. Skyler expanded on this when she stated, "a bigger variety of rewards…would give children in the school more motivation to work and crack on with what they are supposed to be." This captures how she felt that rewards can directly motivate student work rate.

In all, some participants demonstrated an awareness of outside factors which influence their achievement and subsequent position as a good or bad student. These included teacher praise and school rewards and how and what the teachers taught them.

6.3.4. Positioning the Self as a Good or Bad Student

As seen above, participants not only identified the characteristics of a good or bad student but also positioned themselves in relation to these roles, regularly discussing their own grades, work ethic, behaviour and any punishments or rewards within school. The scale in Figure 27 (below) shows where participants individually placed themselves in relation to being the best or worst student. Whilst no participant placed themselves at the extreme end of the scale, there are three students who placed themselves more towards best and two towards worst.

Figure 27

Participants' Positioning: Worst to Best Student

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N.B. Richelle was not in the group at this point so did not complete this task

Participants identified a range of characteristics that they felt placed them in their position on the scale. Work ethic and resilience, achievements, staff views and behaviour were considered markers of their position as a student. This is discussed in the poetic transcription “Not a Naughty Student.” The first three stanzas present reasons participants considered themselves good whilst the fourth and fifth stanzas present reasons for being placed as bad. Participants also showed contrasting views in how they wanted to be viewed by teachers or peers, shown in the final two stanzas of the poem. Participants did not want to be viewed as irritating by staff, by asking repeatedly when confused by a task. They felt this would lead to trouble, for not listening. Participants wanted to avoid characterisation as a bad student as staff are “more likely not to believe them” should they be accused of having misbehaved (Richelle & Skyler). They felt this placed them at a disadvantage as staff lose trust in them. However, participants also did not want to be at the top end of the scale either, it was important not to be an “annoying teacher’s pet” or a “try hard.” This may be why only two participants stated being seen as a good student would make them feel good about themselves (Appendix Q). Perhaps participants do not want to be seen as the type of good student who would be judged by others as a “teacher’s pet.” This may be why they do not place themselves at the top end of the scale.

Not a Naughty Student

I never back down from a difficult task.
A fairly good student,
Do quite well in numerous subjects,
have fairly high targets,
I do my homework.

Teachers say good things about me,
In parents’ evenings and things.

I am not a naughty student.
I normally stay out of trouble.

I don’t always finish all my work,
can’t keep on top of my homework.
I get on with my work-
after 10 mins.

I am an idiot but in a good way.
I can be disrespectful,
catch people out.

You don’t want to keep asking the teacher,
In case they shout at you for not listening.
You just don’t wanna come across as pesky do you?

I am not one of those annoying teacher’s pets,
teacher’s pet or a try hard,
where I will be their slave to get good grades.

(Connor, Fresh, Harrison, Lightning, Richelle, Skyler & Wolf)

6.3.5. Positioning as Student and Relationships with Staff

As discussed, participants felt that their positioning as a good or bad student could impact on how staff viewed and treated them. Staff no longer trusted such students, who may be presumed to have misbehaved even if they had not. This was summarised in Skyler’s words that “if I’m like good behaved they are more likely to believe somebody who’s not really in trouble.” Wolf also felt that after being in trouble with staff they now “hate me.” The sense of conflict surrounding rules was discussed by two participants, who concluded that you should follow the rules “to stop any- arguments happening” (Skyler & Wolf). Three participants also felt that conflict with teachers would make them feel bad about themselves, suggesting that some participants may avoid conflict with staff due to the negative impact this can have not only on their relationship with that staff member but also with their own self-view (Appendix Q).

Participants also suggested that feeling trust within their staff relationships may have a positive impact on their self-view. For instance, Harrison stated that if you were seated in a position which suggested staff trust, this would have a positive impact, "it can make you feel good about yourself if you're like- the teacher thought- like trusts you to put you with your friends or something." This was supported by four out of five main study participants agreeing that trust from teachers made them feel good about themselves (Appendix Q).

Therefore, participants considered their position as a student in relation to how this influenced their relationships with staff and how this impacted on their own self-view.

6.4. Control and Freedom of the Self

Participants suggested that school was a place where you change and "be sensible", where rules "need to be followed." As shown previously, this is particularly important if you are adhering to the role of good student.

As demonstrated in the poetic transcription, "Rules are Rules" participants considered the control of these rules and how this made them feel. Whilst they felt rules may be necessary to be "safe", participants also enjoyed breaktime and home time as an escape from the constraints of the rules and adult expectations they experienced in lessons, to "get away from it all," with friends who you "can be stupid" with. However, as shown in stanza six, breaktime is not a complete escape from control as you are still within school and "the same rules apply wherever you go." Participants could never fully remove the control of school rules when in the role of student, even in the breaks provided. If they tried to do this, they risked being characterised as a bad student who misbehaves.

Rules are Rules
Rules are rules, rules are for a reason,
they need to be followed,
no matter what.
Like make you feel safe;

To keep like people safe.

School have to be sensible at it.
Lessons, we have to be more polite.
Quiet. No chewing. No swearing.

Break time allows you to have a break from class.
I don’t get told to do stuff.
I don’t really have to do anything.
Relieve yourself from the hard work.

I get to spend time with friends.
Having fun. Run around. Be an idiot. Can be stupid.
Talk to everyone.
You can’t do that in lesson too much.
Read at breaks or something,
that calms me down,
be like oh yeh now you can go to your lesson.

You can relax from the stress
and get away from it all.

But that doesn’t mean you can do whatever you want.
The same rules apply,
wherever you go.

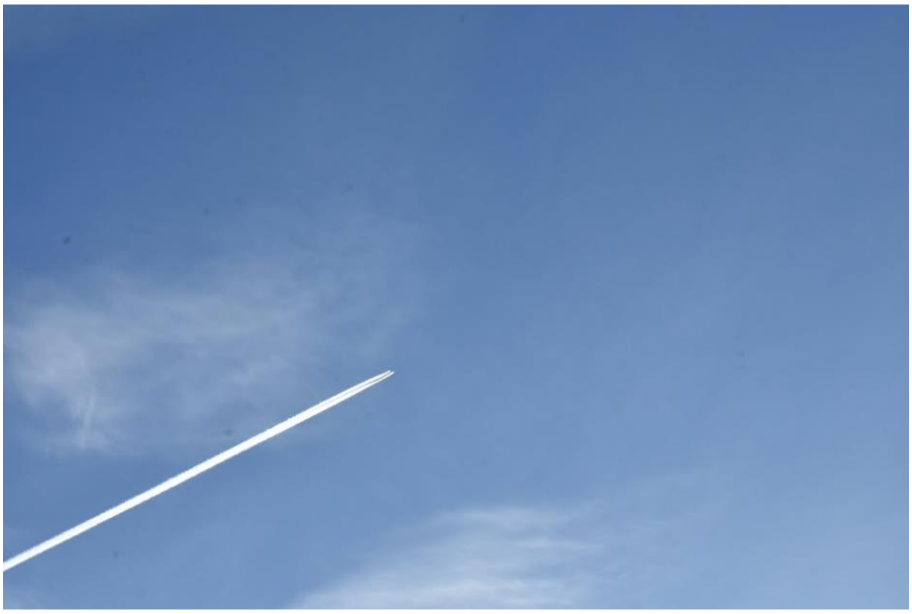
I like the end of the day.
I’ve done all my lessons and it’s time to go home
and relax.
You have time to relax.

(Connor, Fresh, Harrison, Lightning, Richelle, Skyler & Wolf)

Wolf also represented his desire for freedom in his photography (example below). He felt that this image represented that “I’d prefer to be up here. I’d prefer to be there.” He explained that he wanted to be flying the plane, rather than in school.

Figure 28

Wolf: School and Self Photograph



Participants therefore discussed their desire to be free from the constraints of the rules they faced within the school day.

In addition to considering school as an academic space, which positioned them as a good or bad student, participants also considered school as a social space and the influence of their interpersonal relationships within this on their self-view.

6.5. School and the Influence of Others: A Social Self

Participants identified school as an important social space, where sense of self could be influenced by a range of school others including teachers, TAs and support workers, and peers. School could be a place for friendship new and old, where supportive relationships could be formed with both peers and staff. However, as a key social space, school also contained negative social influences such as conflict with friends, negative judgements and bullying.

The importance of school as a site of social influence was summarised by Joe:

> School is important in determining how a person feels because it is where most of the people (outside their family) that a child knows are. Therefore, having a positive or negative experience of school can have a major impact on a child's wellbeing.

Joe suggested that school was a key social space, where pupils interacted with a range of people, who can subsequently impact on that person's self-view and their "wellbeing."

6.5.1. School as a Social World

Participants viewed school as a social world where you could meet new people and socialise with current friends. All participants chose friends as something they wanted to discuss in relation to their sense of self in school. Having and making friends in school was reported as a positive influence on the sense of self by all participants (Appendix Q). When I asked participants what would form a perfect school day, five chose friends and when I asked about the worst school day three stated falling out with, or not seeing, friends would be part of this.

The importance of interpersonal relationships within school is further represented in the poetic transcription "I Get to Spend Time with Friends". The second stanza shows how some participants enjoyed school as a chance to meet new people. This could happen when starting school, being put in different classes or being moved to a different seat. A seating plan could therefore be a positive as it could "make you make more friends." However, participants may still feel they "might not like the people I will be sat next to" and feel some discomfort about saying the "right things" to people they do not know. Introductions to new groups may not be comfortable for all participants, with one "scared to make new friendships." Breaktimes were an important opportunity to "spend time with friends." The importance to participants to have the chance to talk to friends is shown in the repetition of this within the poem. As shown in the final stanza, participants found it upsetting to miss these opportunities to talk and socialise.

I Get to Spend Time with Friends

What I like about school…

I could meet new people.
I still meet new people,
when I'm in different classes.
I like moving around the school,
you're with different people.
I've made quite a couple of friends,
from being put next to someone who I wouldn't usually,
have sat next to.

You feel uncomfortable,
when you move to another group,
say the right things to them,
might not like the people I will be sat next to.

I'm scared to make new friendships with people.

I really like breaktime
because I get to spend time with friends.
Have like a good time,
hanging around at break.
People to talk to.
It's good to talk to people.
Can be fun,
Seeing friends.

You get to sit round talking,
Talk to your friends
Or like arrange stuff for the weekend.

Missing what's happening in school with friends,
makes me feel sad.
I don't like it before school because my friends aren't really here.
I feel lonely and isolated.

(Connor, Lightning, Richelle & Skyler)

Participants discussed social groupings within school and the position of themselves within these social groups. Being part of a social group was mirrored in participants' literal position in spaces within the school, spending time in a certain area signified a group you belonged to. This is represented in the poetic transcription "People Separate Off." As shown in stanza one, social groups can be formed around how pupils positioned themselves. For example, those seen as "smart" or "sporty" joined together. Stanza two suggests that comfort can be found in similar selves and therefore people may prefer to be in groups with similar people. Spaces occupied in break and lunchtimes can also be characterised as *for* the groups of pupils associated with them, such as the library or field. Furthermore, a social grouping could be formed around appearance, as shown in Harrison's comment, "everyone has got those white trainers on. All the girls. So you just see gangs of them walking around." This suggests clothing can be used to form a group or "gang" that you must have the right attire to join.

As seen in 6.4, a positive element to being with a friendship group is a sense of freedom from the adult control. However, these groups do not always feel so free. Participants discussed how you could be in or out of a group due to conflict or differing ideas. This is shown in the final stanzas where participants discuss how one group member may control others' behaviour and position due to conflict and jealousy. Participants discuss how they may have to choose sides due to the conflict that has occurred, or they may be the one being pushed aside. This may lead to frustration at just wanting to be "friends with all of them” and with having to “act a certain way” to retain position in the group. This means participants feel “friendships can be quite complex” and that participants do not always have complete freedom within a group dynamic.

People Separate Off

Often like a load of smart kids get into a group,
go to the afterschool clubs and the library.
People that often like more sporty,
go out on the fields and play football.

People separate off.
They find it comfortable in what they like doing
and like get to know people similar to them a lot better.

She would control the group-
We would not speak to that person for three months.
Quite like controlling and like to me and the others.
I felt like an outsider for what-
two weeks.

You get in an argument,
and you get other people involved in it.
When you get jealous you can form like,
a troop or an army.

They bring me into their arguments.
I don’t like being in the middle.
If I walk away with it,
They’ll drag me back into it.

You might have to act a certain way,

to be part of a group.
At the moment,
I don't feel like I fit in with friends.

Friendships can be quite complex.
I just wanna be friends with all of them.

(Lightning, Richelle & Skyler)

Though they may experience conflict, as in Chapter 5, relationships could also be an important source of support for participants.

6.5.2. School Others as a Supportive Influence

Participants felt that teachers, support staff and school friends could be a supportive element, aiding in academic achievement and providing comfort for emotional issues.

The poetic transcription "Sort your Problems Out" demonstrates participant ideas around friends and school staff as an important source of academic and emotional support. When addressing a problem, Lightning suggests it is a more "easy like environment" when asking friends, so it may sometimes be preferable to ask friends for help. This is supported in stanza six, where friends are a source of positive reassurance due to having a similar point of view. As shown in stanza three, participants also feel that school staff create an environment where it is easy to discuss problems and that they feel that staff are open to listening to them. Participants therefore suggest that both friends *and* staff can be an important source of academic and social support but that these groups may offer support in different forms; it may "depend… on the situation" as to who is the best choice. Furthermore, whilst support from others can help position you as a good successful student, through helping you achieve academically, as shown in stanza 5, *offering* that support can position you as a good friend.

Sort your Problems Out

Teachers help you get past the exams.
Help you when you are struggling.
If you don’t understand something,
you can ask your teacher about it.
They might help you understand.

TAs try their very best to help us when we’re stuck.
Help me with the questions.
Explain the task clearly, so we can easily understand,
Get me to like get going quicker at my work.
When we have too much to do, they help us out,
helped with things that I needed to do.

Teachers are all willing to help you,
Erm sort your problems out.
They’re there for the pupils.
Teachers like if you want to come and speak to me,
my door’s always open, come and find me.
That actually make you alright to speak to that person.

A good friend could help along the way,
Homework and where and what to do on it.
If you’re stuck on something you can like,
ask them easily.
You can like ask them for help.
Friends who are doing well, they can show you through it better.

I’m a good friend,
because I help my other friends with what they are struggling with.

Help you in a different way to teachers or parents,
They’re more likely to be like in the same generation,

They can reassure you about different things.
Give you feedback that probably nobody else will be able to-
because they're a similar age.

I think adults would be able to understand a little bit better,
Sometimes it's the other way round-
depending on the situation.

I really want them to understand,
what I might need, relating to how I feel.

I would feel I am not alone.

(Fresh, Harrison, Lightning, Richelle & Skyler)

Another side to adult support is the perception of the self as a struggling student, who needs extra help. As previously discussed, being positioned as such may lead to negative comments from others. It would therefore be too simplistic to say support always has a positive effect.

6.5.3. Negative Interactions and Comparisons

Participants discussed a range of negative school-based interactions and comparisons, which could impact negatively on their self-view. When sharing experiences of bullying and judgement and comparing grades or appearance (as previously discussed), participants returned to a theme of being worth less, of being worse than others. This illustrates how these negative interactions and comparisons could lower self-esteem and impact negatively on self-view.

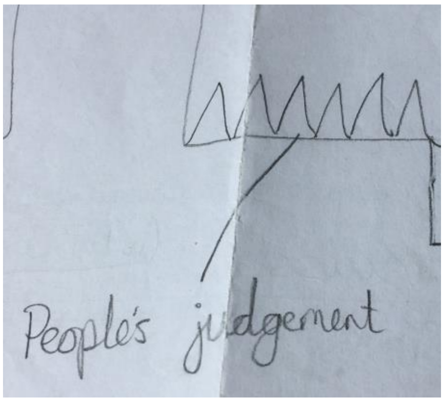
School as a space of judgement was discussed by Harrison who stated:

> In school you are surrounded by like all types of people and like that hate you or like you and erm so you can have lots of different judgements on how you look and so that's why you get more- it happens a lot in school.

Harrison felt that school was a space for participants to experience the judgements and comments of others; a place where you were "surrounded" by those who may have opinions on you and may comment on you as a person. Furthermore, Harrison felt judgement was something which "hurts you" and is "harder to avoid," represented in his drawing of spikes in his school videogame:

Figure 29

Harrison: School Videogame



Many participants discussed the negative impact of bullying on their self-view, feeling this made you seem "worth less than other people." This negative impact is demonstrated in the poetic transcription, "It Puts People Down." This represents the range of reasons for bullying that participants observed or experienced and how this can have a negative impact on self-esteem. The hurt of people's insults is further represented in Harrison's drawing of bullies as a videogame enemy, which illustrates the poem. As shown at the end of the poem, two participants discussed how they felt lucky that their school tackled these issues, in contrast to other schools where "they're just not bothered and don't help." These participants therefore showed awareness of how their experience of school attitudes to stopping bullying may be different to others.

It Puts People Down

Bad- bullying.

Bullies can hurt you.
Being hurt, hurtful words,
Insults from people.

Making fun of them,
What they like, what they look like,
bullying about people's appearances,
how they do things, how you act, what grades you get…
Making fun of autistic pupils;
easy target because of my autism.
People can be like mistreating you and like persuading
and manipulating you- just so you fit in with the group.

Get off my friend!
Seeing others being bullied,
makes me feel sympathetic.

They can make you feel bad.
Upset and angry.
It puts people down and makes people's self-esteem low.
You're worth less than other people,
empty inside.
It impacts on that person massively.

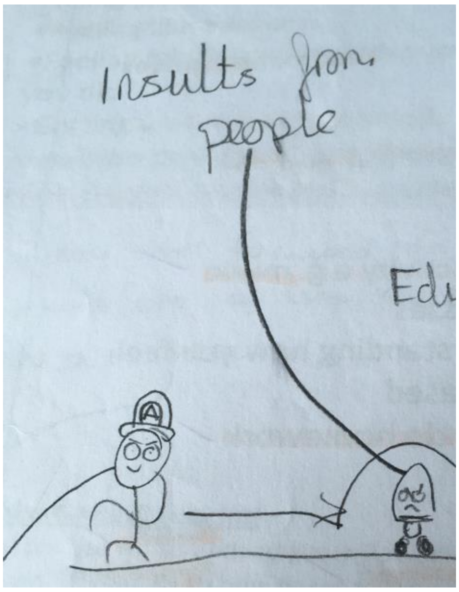
Nobody's gonna get like a good outcome-
out of bullying.

I think we're quite lucky,
Our school do things about these things.

(Connor, Fresh, Harrison, Lightning, Richelle, Skyler & Wolf)

Figure 30

Harrison: Bully Drawing



Participants had mixed views on the level of bullying they felt was experienced in their school. For example, whilst one felt people make fun of the “grades you get” others felt this “hardly” happened. Whilst some participants discussed a range of bullying, one felt that “I don’t think there was any like real bullies in our year but er some people do like make fun of other people sometimes.” This suggests that there were varying views on what constituted “real” bullying, with a differentiation between “being picked on all the time” and “friendly teasing”. There may also have been differing experiences of bullying for the participants themselves and in what they observed happening to their friends and peers. However, all participants agreed that bullying, being judged or made fun would make them feel bad about themselves (Appendix Q).

Participants also felt that if people treated each other with respect this could reduce negative interactions. This was shown in Skyler’s comment that “when people respect others and they get respected it is more likely that there is less arguments and bullying.”

Alongside increasing arguments, disrespect was considered to have a negative impact on how someone viewed themselves. This was seen in Harrison's statement, "it's like I don't know they don't think that you like deserve to be respected or something." This demonstrates a sense of worth in being deserving of respect and therefore, without this, an implicit suggestion that you are not worth being treated well.

In summary, participants felt that negative social interactions would have a negative impact on their self-worth. In contrast, supportive, positive social interactions would have a positive impact.

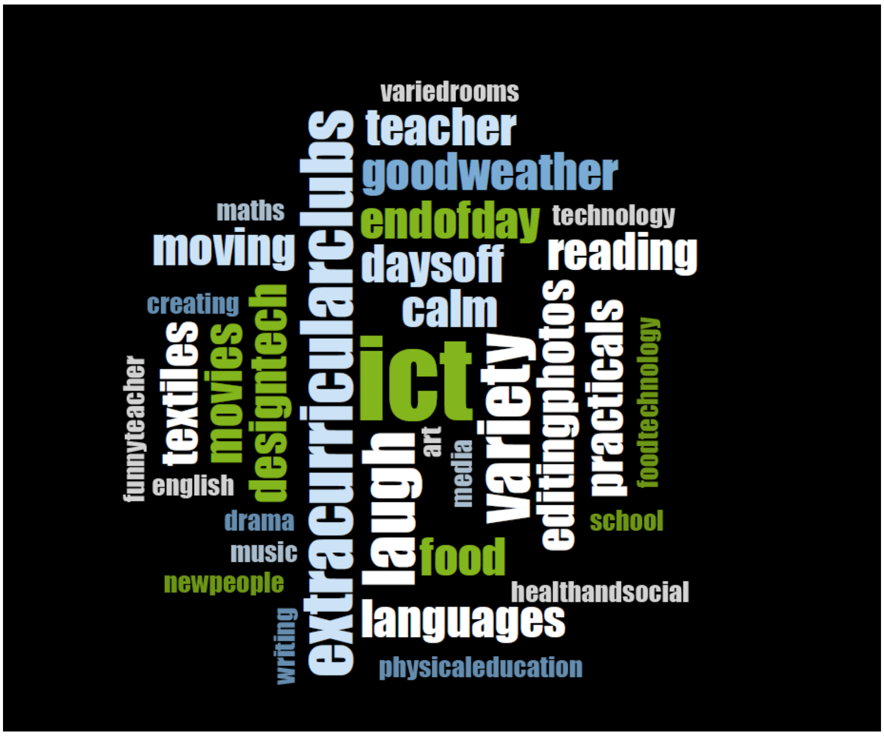
6.6. School Preferences and Interests

Participants discussed a heterogeneous range of school preferences and interests, including views on their perfect and worse school days. Whilst some participants had positive views of school, which they "love", others felt it was "rubbish."

The elements of school which participants enjoyed are represented in Figure 32. This demonstrates a wide range of subjects and learning preferences, alongside views on preferred "funny" teachers. Additionally, some participants preferred no school at all, with days off and the end of the day chosen by two participants as positive parts of the school experience.

Figure 31

School Preferences



6.6.1. Subject Preferences and the Future Self

Participants identified a range of reasons as to why lessons and subjects would be enjoyed and explored the relevance of subjects to the success of the future self. Subjects were therefore not just considered in terms of current enjoyment, but also what they could offer for the future.

Participants' preferences generally focused on practical, creative, technological or active subjects, with one participant describing creative subjects as a positive opportunity for self-expression. They often appreciated lessons which offered diversity, which were "different." In contrast, many participants did not enjoy subjects which were primarily sitting, writing, listening and looking at the whiteboard. This was represented by Wolf's photographs of a range of projector images. He stated that he took these to show "nowadays education is just look at the board this is this this is that"- a repetitive lesson style he did not enjoy.

Figure 32

Wolf's Projector Photographs

One participant did enjoy English and creative writing, and two did not like active lessons such as sport and PE. Whilst there may have been overriding trends, pupil preferences therefore showed heterogeneity across the group.

Some participants discussed their preferred focus on subjects which would be useful for their future selves. Richelle felt one of her favourite subjects, French, "helps later in life" and she did not like subjects which were "not as useful." Wolf stated, "you get to the point of thinking why am I- what am I doing with this?" He felt lessons should ask pupils to use technology more "we're surrounded by technology and we should start to embrace it more." He felt that lessons should prepare pupils for their future work by asking them to regularly use individual computers. Lightning wanted to achieve in subjects which would aid his future goals, such as maths, English and science, whilst subjects which "I'm not really going to do any jobs with that in the future" would be disregarded. Harrison also dropped a "favourite" creative subject to take scientific or technological alternatives, to aid with his future goals.

Therefore, even subjects which were most enjoyed could be left behind when planning the success of the future self. This emphasises the importance of achieving a desired future self, with participant choice not led by current preference, but by a wish for future success.

6.7. Summary

Returning to the key findings, I now summarise the main points from this chapter. As an interwoven component, I consider the key aspect ***both the academic and social sphere have an impact on the self-view*** throughout this discussion.

The autistic young people in my study considered ***the self as student as an academic role, in which you could be perceived as a good or bad pupil. Participants evaluated their own position in this role through academic achievements,*** or struggles***, and by school systems***, such as rewards, reports, or punishments. In this, school rules were an ever-present form of control, marking out whether participants were behaving as a good student or misbehaving as a bad student. ***Fulfilling some, or all, of the good student criteria could imbue pride and a positive self-view, whilst fulfilling that of a bad student could have a detrimental impact.***

Whilst some consideration was given to outside influences, the individual was generally accepted as the main cause of their achievements or failures. Participants therefore felt individual pressure to achieve academic success, ***which was deemed an important element in defining success in the future.*** This focus on the future-self influenced both participants' varied school preferences and impacted on their self-view. Moreover, achievements were often associated with being the highest or most in comparison with others. This links to the following key idea, how the self-as-pupil was considered in the social context.

The self as student was also considered as a social role. School offered a range of social elements which influenced how participants conceptualised and evaluated themselves, including interpersonal interactions, comparisons, and relationships. Participants desired supportive and trusting relationships with school staff and accepting friendships with peers. Social time in school, with these friends, could offer a sense of freedom from school rules and adult control. Belonging to a social grouping could be marked by similar interests or ability, appearance or physical location. However, there could be expectations to behave in a certain manner in these groups- and therefore the self was not necessarily completely free. Friendships could have a positive impact on how participants evaluated themselves. However, peers could also have a negative impact on the self-view, with negative judgements and bullying of concern. Such bullying could be a marker of being worth less as a person, having a detrimental influence on participants' sense of self. Of further negative influence were the unfavourable comparisons participants made between themselves and others, who they felt they were 'worse' than.

Links between the academic and the social self were made. Participants considered the interpersonal implications of being a good or bad student- how this may positively or negatively influence the perceptions of both staff and peers, and their subsequent treatment of that student. As such, conflict could be experienced between wanting to appear as a good student to staff whilst not wanting to be viewed by peers as the derided "teacher's pet."

This completes the presentation of the findings for school and the sense of self. The next chapter draws together these findings with those from Chapter 5, to consider the overall research question: how do autistic pupils negotiate a developing sense of self?

Chapter 7: Discussion: RQ1. Negotiating the Sense of Self

In this chapter, I discuss the first research question, drawing together data from Chapter 5 and 6, with relevant literature, to consider how autistic adolescents negotiate their sense of self. This includes a discussion of the influences on the conceptualisation, presentation, and evaluation of that self. Within this, the specific influence of the school setting is considered, contemplating how school can enable, or provide a barrier to, a positive self-evaluation. This addresses the gap identified in my review of current sense of self and autism research, where a lack of attention has been given to the full complexity and variety of the sense of self of autistic people and to the relevance of social environments, such as the mainstream secondary school, on the formation of that self-view.

In following a CAS approach, this chapter positions my findings as a critique of reductive deficit-focused and outsider-led constructions of the autistic sense of self. As such, I advocate for an insider-led approach, prioritising autistic adolescents' presentations and conceptualisations of the self. This chapter is therefore structured according to the elements that *participants* foregrounded in their self-description. Interests, preferences and strengths were a prominent and important feature for participants in how they wanted to be defined. Consequently, these aspects are discussed first. In contrast, the autism label was something which the young people in the study wanted to be distanced from. As participants did not elect for autism to be the leading feature in their self-description, I did not want to give this primary place in this discussion. Discussion of this is therefore placed towards the end of the chapter.

My research aims to consider how participants conceptualise, present and evaluate *all* aspects of their self-view. I therefore begin with the big-picture- an overview of how the participants conceptualised themselves, followed by a detailed discussion of each aspect. This aims to ensure that the comprehensive sense of self of participants is *fully* represented.

7.1. Autistic Adolescents' Self-View: Multiple Aspects and Influences

Reductive characterisations of an autistic person's sense of self have traditionally focused on what is claimed to be missing. In these deficit narratives, the self is defined through comparison with norms of development, and claims concerning lack of interpersonal affect, and impaired reflective ability (e.g. Farley et al., 2010; Hobson, 1990; 2002; Jackson et al., 2012; Lee & Hobson, 1998). The alternative methods employed in this study, however, enabled the autistic adolescents involved to share a comprehensive consideration of their complex and varied sense of self, reflections which highlighted the multiple ways in which their selves were conceptualised, presented and evaluated.

The complex range of elements included in participant self-description is evident in the themes presented in the two previous chapters. As part of their self-view, participants reflected on their interests and preferences, strengths and weaknesses, personality traits and unique aspects of themselves. They considered contextual selves, where they presented themselves differently, dependent on social role. In this, they highlighted how they may position themselves, to secure positive reactions and interactions in interpersonal relationships. Participants were aware of the aspects which could influence their position, particularly as a good or bad student, and how their achievements could enhance, or hamper, the future self they aspired to. Social influences were also prevalent in participant discussion of relationships with family, friends, peers and school staff, which were considered not only in relation to the importance of social contact and support but also in how these relationships and interactions could influence self-evaluations.

These multiple elements form a varied and complex self-description. This offers a more nuanced interpretation of the self, in contrast to the homogenous, singular, deficit description of autistic people, which has dominated diagnostic and research literature and the perceptions of non-autistic people (e.g. John et al., 2018). The findings of this study align with autobiographical autistic work, which often presents more complex, personal experiences than those found in autism research (MacLeod et al., 2013). My participants' presentation of a multifaceted, socially influenced self, counters claims of a non-reflective "primitive" self, which lacks social affect (Hobson, 1990, p.172). My data offers detailed reflections of autistic adolescents on the question of 'who am I?,' including their evaluations of that self, which demonstrate a self-view formed through a reflective I (Harter, 2012; James, 1892/2001). These self-reflections emphasise the heterogeneity- and complexity, of the sense of self in autistic adolescents.

This section has illustrated how the insider-led findings of my research challenge deficit characterisations of autistic adolescents' sense of self, offering new ways of understanding the experiences of autistic people. I now consider individual aspects of the self from the study, aiming to fully represent the detailed and varied views of the autistic participants and to counter reductive deficit narratives. This begins with interests, hobbies and preferences, which participants identified as a key defining feature of themselves.

7.2. Interests, Hobbies and Preferences: A Defining Self-Element

Interests, hobbies, and preferences were a prominent feature of how participants said they would define themselves to others. A wide range of these were communicated across the participant group. They were identified as a key marker of who a person was, acting as defining traits of individuality. The range of interests, hobbies, and preferences underlines the heterogenous views of the participants involved. Interests and hobbies were conceptualised as having a positive effect on how they viewed themselves- when they were considered to be a strength.

As in King et al. (2017), preferred interests and hobbies were a key distinguishing feature in participants' self-definitions. Deficit narratives would characterise the prominence of interest-based statements as a repetitive interest or excessive preoccupation, couching this in negative terms as an 'abnormal' excess (e.g. Farley et al., 2010). In contrast, the alternative methods employed in this study resulted in similar findings to King et al., that sense of self and interests for autistic adolescents go *beyond* this reductive representation. Like King et al., participants in my study viewed these interests as an important part of building and maintaining relationships. Interests were a shared activity around which bonds could be created, or improved, with family, friends, and new acquaintances. This meant that the participants in my study made links between their social self (relationships) and their active self (interests and hobbies). Rather than being an excessive focus, leading to isolation from others, their interests were an important component of social relationships. Participants discussed their interests and hobbies as a personal trait *and* in terms of their interpersonal value, considering how they could aid in the building of relationships (Harter, 2012). Moreover, whilst these interests and preferences may have been a prominent part of how they chose to *describe themselves* to others, they were keen to stress that they were not more important to them *overall* than their family bonds or home life. This highlights the importance of these social bonds to the autistic adolescents in this study.

These discussions emphasise how a focus on sharing active aspects of the self, does not in turn mean that that self is devoid of interpersonal influence, as was claimed by Jackson et al. (2012) and Lee and Hobson (1998). Instead, it illustrates how interests can act as an enabler in furthering social bonds.

Both general interests and school preferences were also linked to the future self. As with Molloy and Vasil's (2004) autistic adolescent, several participants aligned future career options with their current areas of interest, whilst school preferences also reflected a focus on their value for future employment. And like King et al. (2017), these interests were part of participants' sense of self-continuity, as something which would continue as part of their future self. In my study, interests and preferences were not only viewed as an enjoyable pastime but were perceived as a vehicle for enhancing the future self.

These findings reveal the reductive nature of framing interests in terms of repetitive focus. Interests and preferences have a range of important functions, influencing how participants define themselves, both in the present and the future, whilst also enabling social bonds and supporting future success.

7.3. Highlighting Strengths and Minimising Weaknesses: Enabling a Positive Self-view

Strengths and achievements were a frequent part of participant discussion when identifying how they would want to be defined as a person. They were important aspects of themselves, that they wanted others to focus on. Strengths and successes included hobbies or interests, competition wins, extracurricular success, and special talents. Participants also talked about leadership responsibilities, both inside and outside of school, and other school-based achievements, such as academic success and receiving praise and rewards. Finally, they described themselves in relation to positive personality traits, such as being friendly or loyal. Strengths and achievements were seen as instilling a sense of pride and confidence, having a positive impact on their self-evaluation. This illustrates how the autistic young people involved in the study emphasised positive elements when defining their sense of self; these were the areas that *they* wanted to be defined by.

In contrast, weaknesses or failures had a detrimental impact. A sense of being "weak" was associated with feeling "horrible" about yourself. Participants therefore did not want weaknesses to be a focus in the definition or presentation of the self. This did not mean they were unaware of areas of difficulty, identifying their emotional, physical, academic, behavioural, and social problems. In this, they evaluated both their inner, psychological, private self, and their outer physical and social selves (see Chapter 2 for commentary). Participants wanted to recognize these areas so they could be “tackle[d]” and “overcome.” However, they did not want others to define them through these issues, which had negative associations.

This foregrounding of strengths echoes the findings of Crabtree and Rutland (2001), whose study involved adolescents diagnosed with learning difficulties. These young people devalued domains of weakness, whilst prioritising those of success. Williamson et al. (2008) had similar findings with autistic young people, who also emphasised areas of competence and control, whilst minimising areas of less competence. This was further evident with the autistic young man, Lee, in Molloy and Vasil (2004) and Mark, in Baines (2012). Although Lee was aware of areas of difficulty in social arenas, he prioritised his academic achievements as a sign of value. This enabled a positive sense of self, based on pride in his areas of strength. Mark also emphasised his academic abilities, placing focus on how he sat within a smart narrative. Prioritising strengths/ success is therefore seen across a range of studies with autistic adolescents as well as in my own.

Crocker and Wolfe (2001) and Harter (2012) theorise that it is the domains that a person positions as important which can influence overall self-esteem. If the areas which are evaluated are aligned with competence, then those self-evaluations can be positive. In contrast, if areas of weakness are a focus, this can have an adverse effect on the sense of self. Therefore, if autistic adolescents prioritise the domains in which they succeed and minimise those in which they feel they do not, this could have a positive impact on their overall self-view- just as it did for Crabtree and Rutland’s (2001) participants. This may be a motivating factor behind my participants choice to foreground their strengths, due to the influence on a more positive self-evaluation. Participants in this study have shown their desire not to be defined through deficits. Perhaps this desire springs from a wish to avoid a definition where positive aspects are made “invisible” and a person is represented through weaknesses, which have a detrimental effect on their self-view (Brownlow, 2010, p.20).

In summary, participants have considered how strengths and weaknesses influence their sense of self. Of particular significance is their desire not to be characterised through areas of impairment, instead maintaining a focus on their strengths and abilities. This highlights how the autistic young people in my study are resisting the dominant framing of them as less able.

Such dominant framing is evident in previous sense of self research, which has focused on characterising the autistic sense of self as socially impaired (Hobson, 1990;2002; Jackson et al., 2012; Lee & Hobson, 1998). In challenge to such a narrative, I now discuss the relevance of the social world to the sense of self of the autistic adolescents involved in this study.

7.4. The Relevance of the Social World

This section considers the relevance of the social world, and the relationships within it, to the sense of self of autistic adolescents. This includes a focus on the social influence of peers within the school environment- a key site for such interpersonal interactions (Harter, 2012). In highlighting the varied ways in which the interpersonal context influences the sense of self of the autistic adolescents in the study, I counter deficit narratives, which characterise their sense of self as lacking in social affect. Instead, I argue that the social world is highly relevant to these autistic young people.

7.4.1. The Importance of Social Relationships

My data shows how social relationships were important to participants. These interpersonal interactions were valued for the support and enjoyment that they offered. They were also highly relevant to the self-view of the autistic participants involved.

Just like their wider peer group, a range of relationships were important to the autistic adolescents in my study (as also seen in King et al., 2017). These included friendships with peers, and relationships with family and school staff. Social time with both family and friends was valued, with some participants keen to create new connections. Though some viewed these “new people” as an unnerving prospect, one participant sought out such social experiences, viewing her social ability as a strength. All participants felt that socialising with friends and family was a fun and enjoyable experience whilst, as one participant stated, “it feels bad being alone.” These findings mirror the views of autistic adolescents in Molloy and Vasil (2004), who also desired friendship and felt that being alone resulted in unhappiness.

Family and friends were not only valued in terms of the company they provided but were also considered relevant to participants' self-view. The majority of participants chose to discuss family members and relationships when answering the question of 'who am I?' Being part of a family was viewed as key, a role which was associated with responsibility, such as being a role model for siblings. Participants also discussed responsibilities undertaken in other social roles, such as being a leader or helper in school or in extracurricular clubs. A focus on undertaking relevant responsibilities mirrors Goffman (1959/1990) and James' (1892/2001) assertion that social roles carry particular expectations, which impact on subsequent behaviour. Participants in the study highlighted such expectations and discussed their attempts to meet the responsibilities of their social roles. These roles and responsibilities had a positive impact on their self-view, imbuing self-confidence and feelings of being trusted and respected by others. This aligns with the findings of Harter and Whitesell (2003) that higher self-worth can be reported by adolescents who feel validated and approved of.

Being given such responsibilities was an achievement that participants wanted represented within their self-description. This implies a desire to be viewed positively, as a trustworthy person, by others. Many participants also attributed other positive social traits to themselves, such as being friendly, loyal, and funny. In this, humour was considered a particularly necessary social trait, identifying you as someone who was fun to socialise with. Participants therefore illustrated their awareness of key social traits and how these related to position, and friendship, with others. This was unlike Lee and Hobson's (1998) findings, that autistic children and adolescents presented traits in a categorical form e.g. just that you are "nice" (p.1139). In my study, traits were considered in terms of the interpersonal implications that they may have, judging how such traits would influence relationships with others.

Friendships were important as a sign of acceptance and as a positive influence on the self-view of participants. This aligns with the findings of Bauminger et al. (2004) and Humphrey and Lewis (2008), where friends were characterised as fostering a positive sense of self. One participant in my study stated that friends provide a sense of value, of being someone who is worth being friends with. Having friends suggests that others "like you" and view you as a "good person." This mirrors Mogensen and Mason's (2015) autistic adolescent, who also associated friendship with a sense of being “very valued” (p.264) as a worthwhile person, who was accepted by others. As Harter and Whitesell (2003) found, feeling approved of for who you are can enable a higher sense of self-worth. This may be why participants across my study associated friendship with a positive sense of self- these friends represented a sense of approval, acceptance and worth.

Relationships with friends and family offered an important source of support, countering negative emotional influences. These desired and supportive relationships challenge Hobson’s (2002) view of autism as a lonely world, devoid of the interpersonal relationships which fill the non-autistic sphere. Participants in my study referred to a myriad of important relationships in their lives. Rather than appearing “rudimentary” and limited in love, as Mayes and Cohen (1994, p.213) claim, my participants discussed the belonging, acceptance and support that could be gleaned from their relationships with others. The findings in this study therefore support Davies’ (2016) critique of the characterisation of an autistic person as being in a “world of their own” (p.132). My participants repeatedly demonstrated that various others were important to their social context, and that they had developed deep relationships with these others.

Relationships with understanding friends, teachers and support staff were also considered a crucial academic, social, and emotional support within the school environment. In this, further social ramifications were considered. Having “the most help” from school staff was viewed by some participants as leading to negative comments from others. Participants were also wary of how teachers might misinterpret constant requests for help as a lack of attention or engagement, resulting in trouble with those staff. Some participants identified conflict with staff as having a detrimental impact on their self-view, whilst trusting relationships with teachers would have a positive effect. Therefore, asking for help and support within a relationship had additional, social ramifications to consider.

The range of relationships presented here, considered both in relation to how participants define, present, *and* evaluate themselves, are of significance. These findings stand in counter to Lee and Hobson’s (1998) study, which found that social statements by autistic adolescents relate only to family, and that the sense of self, for autistic adolescents is a self focused construction. My study instead aligns with King et al.’s (2017) findings. It highlights the relevance of a varied social world to the sense of self of autistic adolescents, which they freely discuss, when employing alternative methods.

7.4.2. School as a Key Social World

I now discuss how this social self was considered by participants specifically in relation to the school environment.

Participants in this study identified school as a key site for social interaction and making new connections, mirroring the autistic adolescents' views in Skafle, Nordahl-Hansen and Øien (2020). My participants identified how the self interacts with, and is influenced by, a range of others in this social space, including both peers and educational staff. They experienced school as a place of valued social time *and* as an environment where comparison with others was undertaken, and judgements from those others were experienced. These social elements were all discussed in terms of the impact that they could have on the negative or positive self-evaluations participants made. Positive influences included friendships and supportive relationships with peers and staff, whilst harmful influences included bullying, negative judgements and comparisons (see below). This supported the findings of Williams et al.'s (2017) metasynthesis, which also identified unfavourable comparisons with others, and the negative perceptions and reactions of both peers and staff, as having a detrimental impact on the self-evaluation of autistic pupils. On the other hand, supportive friendships and peer acceptance were argued to have a positive influence on self-worth. Therefore, just as in Williams et al., participants identified the social world within school as highly relevant to their self-worth (Harter, 2012; 2015).

Within this social world, participants identified how separate social groups could be formed, to create different social identities. Friendship groups could be established around similar interests or roles, with group identity signalled in different ways, such as through all members wearing similar attire on non-uniform days, or by location, with certain areas marking out which group you belong to. For example, "sporty" students congregated on the field, to play football. Participants therefore considered how social identities can be formed in the school environment, and the elements which could mark out such groups. However, unlike Cooper et al.'s (2017) study, which focused on autism as a social identity, participants here discussed groupings based on interests, school abilities or appearance.

Participants in my study also discussed the freedom of social time spent in a friendship group, where they could escape the sense of doing “as you’re told” by teaching staff, and be free from the serious, responsible climate of the classroom. However, there were also negative dynamics in such social groups, including the precarious position one might occupy. Differing ideas, conflict or a controlling member may lead to you being out of the group. Thus, participants had to navigate negative reactions from the group. This can lead to frustration at the political requirements of the friendship group. This illustrates the complexity of social groupings, and the varying influences on how the group is not only defined as a whole, but also from the point of view of participants’ individual position within it. Discussion of the self within social groups contrasts Lee and Hobson’s (1998) finding that autistic adolescents did not conceptualise themselves in relation to such groupings. For the young people in my study, self-definition included a consideration of the social groups to which they belonged.

These findings reveal how participants characterised school as a social world, where separate social groupings can form. This is a social world with requirements and expectations, which can influence the self-view. I now consider, in detail, two key areas of social influence within school: comparison with peers and the judgements of those peers. This highlights how these are important elements of focus, due to the negative impact they had on participants’ self-view.

7.4.2.1. School as a Site for Peer Comparison. Participants in the study identified how comparing themselves with their school peers could have an impact on how they viewed themselves. These could be wider social comparisons, such as comparing appearance, or school specific comparisons, such as those made between academic achievements, or school rewards earned. This is like the autistic adolescents in Winstone et al. (2014), who compared physical attributes, personality, preferences and educational abilities or needs.

As in Winstone et al. (2014), comparisons with peers focused on points of difference. In identifying such differences, participants highlighted their distinctness from others. In considering this distinctness, participants made upward comparisons, emphasising how they were worse than their peers, not looking, or achieving as well as them (Festinger, 1954). There appeared to be a focus on being the most or best, illustrating a competitive driver when comparisons were made. These upward comparisons were discussed in detail in relation to academic achievement. Grades, a slower work speed, or rate of understanding, were all compared with others to evaluate their academic ability as lesser.

The prevalence of upward comparisons in this study contrasts with the autistic adolescents in Huws and Jones (2015) and MacLeod et al. (2013). Whilst these studies also found social comparisons were made, these were downward comparisons with autistic others, which can have a self-enhancing effect. Instead, my participants followed the findings of Williams et al.'s (2017) metasynthesis of research on autistic pupils in mainstream schools, focusing primarily on upward social comparisons, which increase a sense of negative difference. Although one participant employed academic comparisons as a motivator to improve, such comparisons were generally considered to have a negative impact on self-worth. Overall, participants identified upward comparisons as having an adverse effect on their self-evaluations, creating negative feelings about the self. This follows social comparison theory, which posits that comparisons with others can influence self-esteem (Festinger, 1954).

Furthermore, Williams et al. (2017) assert that upward comparisons emphasise things that non-autistic pupils do better; comparisons of difference readily available in mainstream settings (King et al., 2017). Whilst the participants in my study did not make an autistic/non-autistic distinction, they did make comparisons with those who they perceived as better than themselves. These comparisons were often centred around academic achievements, perhaps illustrating how the academic is prioritised in the educational environment (Bolic Baric et al., 2016). Capps et al. (1995) argue that a detrimental effect from such upward comparisons can be negated, by a perception that the position can be changed, for instance, that academic attainment could improve. Whilst no participant directly commented as such, one participant did share how academic comparisons, for him, were a motivator to improve and therefore he would attempt to change his position. However, even with this mindset, he still felt that achieving lower grades than another had a negative influence on his self-view. Perhaps here the perception that he *could* improve, was not enough to counteract the adverse effect of being in a lesser position.

In discussing the negative upward comparisons made with peers, participants have illustrated how school, as a site of social comparison, can have a detrimental influence on their self-view. This challenges claims of a lack of social relatedness in the sense of self, and self-evaluation, of autistic adolescents (Hobson, 1990; 2002; Lee & Hobson, 1998). This is evidenced further in participants discussion of the impact of peers' judgements on their self-view.

7.4.2.2. School as a Site for the Judgements of Others. Participants also highlighted the negative interactions that could occur within school as a social environment. School is a space where you are "surrounded" by the opinions and judgements of others. Therefore, unlike Camp et al.'s (2002) adult participants, these autistic young people could not avoid social contexts where they were devalued. In school, they could be subject to derogatory judgements on multiple aspects such as: their appearance, interests, behaviour, mistakes, fears, being autistic or different, or their success (or lack of it) as a student. Participants discussed how autism was a target for "mockery," not only in school but also on social media, where autistic was used as an insult (see 7.5.3). This mirrors the views of participants in Goodall (2018) and Baines (2012) that autism and autistic behaviour, such as stimming, could be a target for negative comments. Negative judgements on appearance were also considered. These could result in feeling "bad" or "worse" than others. Additionally, the judgements of peers could be experienced as part of more extensive bullying. As with other studies, such as Goodall (2018), Cook et al. (2016) and Zablotsky et al. (2013), autistic pupils in this mainstream setting also identified bullying and negative evaluations from peers as part of their experience. Therefore, similarly to McCauley et al. (2017), an awareness of the perception of others was demonstrated with the autistic adolescents in this study, with participants sharing a range of judgements, which had been made about them, and other autistic people, by their peers.

As McCauley et al. (2017) noted, the awareness of such peer disapproval was linked to participants' sense of worth. Negative judgements and bullying imbued a sense of being of lesser worth, having a negative impact on the self-view of the participants in my study who experienced this. This self-evaluation was linked to respect, with the behaviour of others marking out for participants whether you are worthy and deserving of such respect. These findings align with Bolic Baric et al. (2016) study, where participants also identified bullying as something which created a sense of being not “worthy as a person” (p.187). This suggests that victimisation can have a dehumanising effect, as it marks out your lack of worth as a human being, in the eyes of others.

It must be noted that, whilst detrimental comments and judgements were discussed, the autistic adolescents in this study did not share examples that were as extreme as the physical and sexual bullying found in Goodall (2018). Perhaps this is because, as one participant states “I think we’re quite lucky our school do things about these things.” This implies that although they feel that *their* school addresses the bullying experienced, this is not always necessarily the case. Of significance is that *all* participants in this study agreed that negative judgements and bullying had an adverse effect on their self-evaluation. This could be influenced by the desire of autistic adolescents for peer approval (as in as Williamson et al., 2008). For the participants in my study, this approval could be represented as lacking, in negative comments, which illustrate the lack of respect or appreciation of your worth that others have. In identifying such events as having a detrimental influence on their self-view, participants highlighted the influence of peer interactions on their sense of self.

This section has challenged claims that the sense of self of autistic adolescents is self-focused, and that self-understanding, and evaluation, is not based in social relatedness and interaction (Hobson 1990; 2002; Jackson et al., 2012; Lee & Hobson, 1998). A social self has been discussed by participants in relation to social traits, relationships, social groupings, roles and expectations, comparison with others and the perceptions of those others. These findings have revealed the range of interpersonal elements and implications considered as part of their self-definition and evaluation by the participants in this study.

7.5. Positioning of the Self within Social Contexts

This section considers the participants’ awareness of how the self can be presented and perceived within various social contexts. In this, they sought to be viewed in ways which avoided negative interactions and judgements, from peers and school staff. This illustrates how the autistic adolescents in this study were not only cognisant of the social implications of how they presented themselves, but that they actively presented a certain self, which aimed to solicit positive perceptions from others.

7.5.1. The School Self: A Need to Fit in

This active positioning was particularly evident in participant discussion of the self in the school context, which was contrasted with the self at home.

Many participants described home as an important, safe, and comfortable space. Some also discussed how they felt that the self in the home context could be freer from judgement. They reported that they did not need to fit in at home, a place of acceptance and unconditional support. In contrast, school was viewed as a place where change was essential to meet peer expectations and to fit in, by avoiding being seen as "strange." This demonstrates how, as in Harter and Monsour (1992), these adolescents identified a presentation of different characteristics, dependent on social context. These changing presentations were, in accordance with James' (1892/2001) theory, undertaken to ensure that they were viewed positively by the group.

In these views, participants were similar to the autistic adolescents in Humphrey and Lewis (2008), who characterised mainstream school as place to fit in by being 'normal,' to avoid the bullying that can spring from perceptions of abnormality (Bolic Baric et al., 2016). For my participants, being the "odd one out" could lead to mockery and negative peer views. They felt that there was a required positioning to fit in with accepted norms in interests, actions, behaviour, and conversations- a need to take on an appropriate "front" in school. They followed Goffman's (1959/1990) assertion that people present a "personal front" to manage the expectations, and subsequent reactions, of others (p.34). As in Davidson and Henderson (2010, p.156), they also felt a need to hide their differences, to "pass" as normal. Baines (2012) found that with autistic adolescents, social success can be achieved through the positive perceptions that can be maintained with peers, by employing an accepted front. For my participants, popularity and belonging in school social groups required adaptation to fit what is expected (Baines, 2012). There was a need to position yourself away from the different outsider, who is judged negatively by peers (Bolic Baric et al., 2016; Humphrey and Lewis, 2008). In this, autistic young people feel a need to adapt and change how they present the self, aiming to avoid any negative treatment by appearing 'normal' (Williams et al., 2017). This was evident in both my own study and in the findings of Baines (2012) and Humphrey and Lewis (2008).

It is worth noting that two adolescent males in my study did not feel that they engaged with required norms, such as social media, or in adapting their behaviour within the school environment. The extent to which the autistic young people ‘hid’ elements of themselves was therefore not present across the entire group. Furthermore, whilst there were differences which were “strange,” and by implication, wrong there was also a sense of a right kind of difference, that could be shared with peers, rather than hidden away. These differences were those which were viewed favourably by both the self and by peers, unique elements, respected roles, or special talents. Such valued differences were also reported in Winstone et al. (2014), where unique knowledge and social responsibility were identified by an autistic adolescent as positive differences, based on his own perception and the feedback from adults in the community. An autistic adolescent in Mogensen and Mason (2015), also reframed difference as a point of pride due to the positive views of peers, who he felt admired his mystery and unusual knowledge. Differences which have positive interpersonal implications therefore have no need to be masked as they are not associated with unaccepted abnormality.

What is particularly significant about these findings is the illustration of the ways in which autistic young people actively construct the self. They are aware of what constitutes social value and which behaviours will result in ridicule. This leads to deep consideration of how the self is presented outside the home environment. Whilst negative difference may be masked and hidden away, elements which were associated with the *positive* reactions of others could be happily shared. These choices acted as protective strategies, presenting elements which could be viewed positively, and have a constructive impact on self-evaluation, whilst hiding those which were perceived negatively, having a detrimental influence on the self-view.

7.5.2. Positioning as School Student

Participants discussed how they were positioned within the specific role of student. They considered their academic self, how they defined themselves as pupil, and related this to the social context, considering how the self-as-pupil was perceived, and subsequently treated, by their peers and by school staff. Their position as good or bad pupil was therefore influenced not only by academic achievement but by judgements on their achievements and behaviour. This self-as-pupil was evaluated by participants, further influencing their appraisal of the self.

7.5.2.1. The Good or Bad Student Role. Participants offered their characterisations of both a good and bad student, identifying their own position within these roles. A good student was characterised as one who continuously works hard to achieve their best and behaves well, obtaining good grades and school reports, receiving many school rewards, and being a good role model, who is respectful and helps others. A bad student was characterised as “naughty,” with a lack of work ethic and low grades achieved. They appear as having little care for school, breaking rules, missing deadlines and being unpleasant to their peers. The good or bad student could be further identified by their adherence to, or breaking of, the uniform rules.

Being a good student was viewed as enabling a sense of confidence and pride. As discussed, participants aligned good grades with being a good student. Good grades were identified as “high” grades, with many participants also sharing the pressure they felt to achieve their grades in examinations. Achieving such good grades was associated with a sense of pride and a positive sense of self. This discussion aligns with the autistic young men in both Baines (2012) and Molloy and Vasil (2004), whose academic achievement also enabled a sense of pride and a positive self-view. Conversely, failing to achieve was considered to have a negative influence, with one participant associating low grades with being “useless.” As well as actual grades received, the grades given as targets by the school could affect the self-view. High targets could act as a marker of skill and likely achievement in the subject, boosting the self-esteem of a pupil. However, should these targets prove “unreachable,” this could have a negative impact. This mirrors Capps et al.’s (1995) argument for upward comparisons, with self-evaluations dependent on whether a change of position is viewed as achievable. Grades were therefore discussed by participants not only in relation to their self-definition as a student but also considered in terms of their influence on their subsequent self-evaluation.

School rewards and reports were evaluated as markers of being a good student, representing staff recognition, and appreciation, of good work or behaviour. Receiving rewards was identified as a positive influence on self-view, with participants feeling these rewards marked out your hard work- that you are “doing well” as a student. Again, the discussion of these rewards showed a focus on obtaining the highest or most possible. School reports, which contained academic and effort grades, could also be an influence. A positive impact resulted from a report which characterised you as a good student and a negative effect sprang from a report which presented failure as a bad student.

Being unable to maintain good behaviour resulted in punishment and participants identified where they sat within this, sharing the areas they perceived themselves as having failed in. This included receiving punishments and difficulties with schoolwork. Punishments generally had an adverse effect on participants’ self-view, perhaps acting as a distinct sign of failing as a bad pupil. Although, one participant, on receiving a high volume of detentions in the previous year, had learnt to “forget about it” and treat it as a norm, just “another day.” This could be because they had become used to these punishments, however, it could also be indicative of a protective strategy. This participant may have devalued this domain of academic life, minimising this as a site of failure. Rather than constantly reflecting on the negative implications of these punishments, which would have an adverse effect on their sense of self (Crabtree & Rutland, 2001).

Participants therefore identified a range of markers, which indicated whether they were meeting the expectations of the good or bad pupil. Consequently, this study stands in contrast to McCauley et al.’s (2018) narrow focus on assessing the ‘accuracy’ of an academic self-concept in mathematics and reading, compared to actual grades received. Here, participants illustrated the complexity of the self-as-pupil, sharing a wide range of features that they evaluated to gauge their position. This included: schoolwork, examinations, grades, rewards, reports, teacher views, and punishments. They also identified the burden of achieving and the competitive pressure to strive for the best high grades. They discussed not only whether they were meeting the good or bad pupil criteria, but also how these various elements could impact on their self-view. Participants therefore evaluated themselves within the academic domain, evaluations which had a subsequent impact on their self-esteem (Harter, 2012; 2015).

It must be noted that, in such evaluations, the good pupil role was not without issue, with participants highlighting the pressure that may be felt to maintain such an image *and* the negative views peers may have of a "try-hard." One participant commented that a good student may have to maintain the "smile" of a positive demeanour, hiding how they really feel whilst a bad student's "cocky" confidence might hide difficulties, low self-esteem, or negative emotions. Both roles may therefore require the maintenance of a 'front' (Goffman, 1959/1990) and the masking of thoughts and feelings. Therefore, no one escapes from a need to 'mask' their internal reality, whether they be positioned as a good or a bad student.

7.5.2.2. Positioning as Pupil: Influences and Ramifications. In considering their own position as a good or bad pupil, participants also discussed the impact of such a position on their relationship with, and subsequent treatment by, peers and teaching staff.

With teachers, participants were aware of how struggling with work, and asking for help, may be misconstrued as lack of attention (see 7.4.1). This mirrors the considerations of participants in King et al. (2017), who discussed the interpersonal implications of being good or bad at sports in school. Here, a participant referred to how teaching staff will not like you for your lack of effort. A participant in my study also stated how, after getting in trouble, those teachers "hate me." This illustrates the detrimental impact on the teacher-student relationship he perceives after such an event. In addition, participants suggested that being positioned as a "naughty" student was a difficult role to escape, with a subsequent lack of belief in innocence, due to the expectations of such a naughty student. In contrast, being a good pupil engendered trust and belief from teaching staff, due to an assumption that they would not be in "bad situations." Participants also identified trust from teachers as having a positive impact on how they viewed themselves (Harter & Whitesell, 2003). It could be that being positioned as a good student by teaching staff has a positive impact on the self-view, due to the trust it implies those staff will have in that student. Rather than the autistic stereotypes discussed in Goodall (2018), the participants in my study have considered the homogenisation that can be associated with being positioned as a good or bad student. This includes how this position can impact on subsequent treatment and expectations from teaching staff.

Although participants showed a desire not to be viewed by staff as a “naughty” student and, as in King et al. (2017), wanted good relationships with teaching staff, they also did not want to be perceived as a “teacher’s pet” or a “try-hard.” This was exemplified when participants placed themselves on a scale representing their position between the best and worst student. No participant placed themselves at the far end of the scale, with results skewed around the mid-point. This perhaps represents the conflict between the two social contexts, between the desire to be trusted by staff, as a good pupil, and the need to avoid the negative peer perceptions of those who are ‘too good.’

Participants therefore linked the academic and social self within the school setting. The self-as-pupil was considered in relation to interpersonal implications- how such a self influences others’ response to you (Hart & Damon, 1988; Harter, 2012). This aligns with the participants in Baines (2012) who positioned themselves within a smart narrative, with peers and teachers who they felt respected this, and presented themselves as an entertainer, with those peers who responded more positively to such a position. Thus, autistic adolescent pupils in both Baines and this study have demonstrated their consideration of how their academic self, the self in the role of pupil, influences their social relationships and interactions in the school environment. Both my participants, and those in Baines, thought that academic success or ability might need to be downplayed with peers to prevent negative reactions. This perhaps implies that the social takes precedence here, that the views of others are more important than emphasising academic strength. These findings highlight the relevance of the social domain to the self-as-pupil presentation of the participants in my study.

Achieving as a good student or failing as a bad student also had ramifications beyond present school relationships. Participants aligned the self-as-pupil with the future self; a prevalent feature in participants’ discussion. Participants highlighted the importance of grades for their future aspirations, with good grades required for a “very good job” and a future to be “proud” of. These grades were placed as key for *any* route of progression beyond secondary school. Therefore, examinations were aligned not only with current achievement or failure but also with what can be achieved by the future self. This resulted in pressure and anxiety, with participants concerned that they may not achieve their required grades. This discussion illustrated participant consideration of self-continuity and their expectations and aspirations for their future self. Participant awareness of how the actions of the present self could impact the achievements of a future self accords with the autistic adolescents in King et al. (2017) and counters Jackson et al.'s (2012) claim that autistic people do not consider the broader chronological context as part of their self-view. Of further note is Harter's (2012) assertion that it is *later* adolescence when interest in the future self, and careers, increases. Following Harter's age ranges, all my participants would be classed as early to middle adolescence. Therefore, my participants illustrated this preoccupation from an *earlier* age. Perhaps this was due to the connection between examinations and their future opportunities, which were consistently focused on in *all* years of the secondary school curriculum. This possibly brought the future self more prominently into present consideration- as participants keenly felt how present actions could impact on their future goals.

Participants in my study felt that if their perceived possible future self did not represent a desired successful outcome, that this would have a negative influence on their self-view, whilst, if they felt they could achieve in the future, this could have a positive effect. A good future was mostly aligned with a good job that earned “a decent wage.” Although one participant moved away from this career emphasis, highlighting how being “married,” “settling down,” and not being alone, were his aims for the future. For this participant, the focus was more on the security of the home unit. However, overall, a bad future was associated with not “getting a job,” not only because of the money earned but also due to the status afforded to those who are employed. Therefore, participants' views of a good future may have been influenced by how they would be perceived by others, should they not achieve suitable employment. As with Winstone et al. (2014), the alternative methods employed in this study resulted in a detailed discussion of the future self. Participants not only identified what their imagined future would be but also their justification for desiring such a future; a justification including personal aims and social implications. This further challenges Jackson et al. (2012) as participants were not focused purely on the present and considered both the chronological aspects of the self in the future, and the social context that this may place them within.

The responsibility for being positioned as a good or bad student, and for achieving or failing in the future, was mainly placed on the student themselves. Achievement was associated with personal work ethic, resilience, behaviour, and academic success, gained from the student's effort and hard work. There was less discussion of how the school environment or staff might be responsible for pupil outcomes. As Richelle commented *you* "have to stop misbehaving" to achieve. There was some discussion of how interest, enjoyment, and teaching style, must be considered, alongside effort, in pupil achievement. For instance, Wolf discussed at length how personalised learning was important to enable students to succeed. A need for the school to increase the possibility for rewards to be attained by *all* was also identified to increase pupil motivation. Additionally, there was some discussion of the negative influence of peers, and how this can pull a young person into "their type of way." Therefore, there was some sense of outside influence on being a good or bad student, however, the focus for changing such a position still lay with the person themselves. School was a place where *you* change, the self must be controlled, you must be "sensible," follow the rules, and be a good student (Hodge et al., 2019).

These findings have revealed the complex range of considerations involved in the self-as-pupil role; a role which can influence the self-evaluation of autistic adolescents. Of particular significance is the connection between the academic and social self. When considering their position as a good or bad student, participants evaluated themselves within the academic domain *and* considered how this position could impact on their relationships with others. This link was further evident in participant discussion of a successful future self; a success dependent on academic achievements and characterised by positive social ramifications. This again highlights the relevance of the social world to participants' reflections on their self; a social influence considered here in terms of the present *and* future self.

Finally, I consider how autistic pupils positioned themselves in relation to the autism label. As discussed, this was something participants avoided placing as a key feature of the self-description- it is therefore placed in this latter position, representing participants' desire for their self-description not to be defined by this aspect.

7.5.3. Positioning the Self: the Autism Label

Participants in the study distanced autism from the self; they did not choose to include this as part of their self-description. Except for one participant, autism was only discussed in relation to the sense of self when prompted by me. This could imply that participants did not want to include autism in their self-presentation. Similarly to some of the autistic adolescents in Molloy and Vasil (2004), they may not have wanted to be defined by their diagnosis, or they may not have felt that autism was a critical part of their identity. When autism was discussed it was characterised as a difference. Whilst this difference could include positive aspects, such as special talents, it could also entail difficulties with communication, anxiety, and fitting in. Participants' mixed views on autism also echoes the findings of both Molloy and Vasil and Berkovits et al. (2020), where autistic adolescents discussed negative social aspects and positive creative and cognitive skills as associated with autism.

As in Baines (2012) and Johnson and Joshi (2016), participant distancing from the autism label may relate to the negative associations with autism, experienced within the social context. Participants identified mockery, insults and bullying specifically linked to autism. As in Finlay and Lyons (2000), my participants had an explicit awareness of the negative judgements which can be based on the autism label. This is similar to the societal stigma discussed by autistic adults in Johnson and Joshi (2016); a stigma driven by the lay perceptions of non-autistic others (John et al., 2018). In my study, such stigma and negative views were experienced not only in the school setting but also through electronic communication (Gergen, 2000). As these experiences occurred not only in the school environment, but also on social media, this may possibly emphasise how autism can lead to negative interactions in wider society, not just in their own school. This may have led to participants' desire not to identify with autism as part of their identity. Cooper et al. (2017) found that such identification can influence the self-esteem of individuals, an influence which correlates with how such a group is perceived (Brown, 2000; Tajfel, 1974). With the participants in my study experiencing negative out-group views of autism, perhaps distancing from the label was necessary as a protective strategy, separating themselves from perceptions which could have a detrimental influence on their self-view (Ellemers et al., 1999; Finlay & Lyons, 2000).

To separate themselves from such perceptions, the autistic young men in Baines (2012) would supress autistic behaviour, which was perceived as “crazy” (p.551); a suppression also evident with the autistic adolescent males in Carrington and Graham (2001).The autistic young people in my study also gave examples of how they hid their diagnosis and attempted to “blend in” to avoid negative views and the “different” treatment that can be experienced, when you are identified as autistic (Davidson & Henderson, 2010). Being treated differently, and a desire to not be treated as such, echoes the concerns of the autistic adolescents in both Humphrey and Lewis (2008) and Saggers (2015). This desire can lead to autistic adolescents choosing to hide their diagnosis from both peers and school staff- as seen in this study and in the findings of Humphrey and Lewis and Stevenson et al. (2016). It was therefore not only peers who were of concern to participants, but also the views and reactions of school staff. In this, the participants in my study mirrored Goodall (2018), where one autistic young person stated their concerns over staff judgement, every time they “couldn’t keep myself together properly” (p.9). For the participants in my study, distancing from the autism label could perhaps protect them from such judgements from school staff.

Participants were, however, willing to reveal their autism diagnosis to those who could offer help and support, and who might need to understand their difficulties to prevent “trouble.” They also had to be “trustworthy.” As discussions around hiding a diagnosis referenced a desire to avoid differing treatment, perhaps trusted others were those who would not alter how they acted towards, or treated, autistic young people upon learning of their diagnosis. Discourses around trust mirror those in Davidson and Henderson (2010), where autistic adults also debated who could be trusted to know their diagnosis.

Of further interest is one participant’s view that issues with non-autistic others can spring from a lack of empathy on the part of their non-autistic peers. This consideration of the role of others in negative interactions is found in Lee, in Molloy and Vasil’s (2004) study, who attributed bullying experiences to issues with the bullies, not with himself, and in Finlay and Lyons (2002) where participants suggested the issue was with those who stigmatised others. However, whilst this may have been noted, the participants involved in my study still seemed to feel it was their need to change, to hide, to adapt, to prevent such treatments and to protect themselves. It was not for their non-autistic peers to address. This may be because, as Hodge et al. (2019) argue, school staff, and the interventions undertaken by autistic young people, can perpetuate the message that it is the autistic pupil who needs to change and appear ‘normal’ in the school environment (Shyman, 2016). Such continued messages can emphasise to pupils that to be autistic is to be an abnormal other, who needs to change and fit in (Bagatell, 2007; Brownlow, 2010; Goodley, 2016). As discussed in 7.5.1, fitting in was a concern for many of the autistic pupils in the study, who were highly aware of how the wrong kind of difference made you an outsider in the school community and, therefore, that they needed change to avoid such treatment.

There was, one exception in my study, Wolf, who did not feel his diagnosis should be hidden from anyone and that it was widely known amongst the people he interacted with. He described autism as an intrinsic part of himself; interwoven with his sense of self. He aligned with those autistic pupils in the study of Humphrey and Lewis (2008) who accepted autism as an important part of themselves. However, he did not clarify whether his openness about autism was a choice or whether it was simply something he could not hide. In saying everyone should know he was autistic, this could suggest that he had had positive experiences of sharing this knowledge or that he believed everyone would know regardless as it was an inherent part of his “entire life.” Although, it must be observed that autism was not an aspect of the self that he prioritised. When answering ‘who am I,’ the aspects of the self he presented focused on his interests, achievements, roles and responsibilities, and unique experiences. Therefore, whilst he did not want to hide his autism diagnosis from anyone, he wanted to focus on other self-descriptors when defining his sense of self.

Some aspects of autism, such as special talents or observational skills, had a positive influence on how participants viewed themselves. Strengths or talents made you stand out in a “good” way and feel “proud” of who you were. This identification of strengths aligns with the autistic adolescents in Berkovits et al. (2020), Molloy and Vasil (2004) and Mogensen and Mason (2015), who identified cognitive and creative strengths as positive aspects to autism. Participants in my study celebrated the elements of autism they viewed as strengths- as positive social capital. However, the autism diagnosis- which could produce an adverse response from peers and wider society- was disguised, separated from the self as presented. Unlike autistic adults in Brownlow (2010) and Bagatell (2010), my participants did not attempt to challenge discourses of normality or celebrate differences which were viewed negatively by others. Instead, they emphasised their socially accepted strengths and continued to hide those elements which resulted in a negative response. Like the autistic adolescents in Baines (2012), they masked negatively perceived traits and foregrounded accepted abilities, aiming to place themselves within a different narrative to that of autistic pupil. Perhaps the participants in my study felt that the autism label would “drown…out” the strengths they wished to be prioritised in their self-description as Runswick-Cole (2016, p.26) suggests. Furthermore, they may have been trying to protect themselves from the negative impact on self-esteem that identification with a devalued or stigmatised group label can have (Crabtree et al., 2010).

These findings reveal participants’ awareness of the social ramifications of the autism label, and their desire to distance themselves from negative, stigmatised aspects of autism. However, aspects which can be viewed as *strengths* were celebrated as socially accepted areas of pride. Within such considerations, debates formed around who could be trusted to know about a diagnosis, with an aim to prevent differing treatment. It must be noted that, in avoiding such stigmatised and differing responses, it was the autistic adolescent who had to change or hide, not the non-autistic peer or school staff member. The participants in this study have therefore demonstrated the complex deliberations and choices they undertake, in opting for a certain position, in relation to the autism label.

Throughout this section, the participants in my study have illustrated the varying storylines they have had to position themselves within (Baines, 2012; Harré & Moghaddam, 2003). This includes the self at home, the social self at school, aiming to fit in, the self-as-pupil, the future self, the self in relation to the autism diagnosis and the right and wrong kinds of different self. In these various positions, participants aimed to fit in with societal norms, to promote trusting and accepting relationships and to avoid negative judgements and interactions. This highlighted their awareness of the interpersonal implications of how their self was presented to others. These findings emphasise how, rather than being devoid of interpersonal awareness (Hobson 2002), these autistic participants demonstrated a skilled assessment of, and response to, social requirements, aiming to maintain positive interpersonal responses. In this, the responsibility for participants’ positioning was placed squarely with their own behaviour and, if necessary, their responsibility to change. These findings reveal the complex social considerations made by autistic adolescents, when choosing how to present themselves to others.

7.6. Conclusion

Drawing together the findings discussed in this chapter highlights the variety and complexity of the reflective self-view of the participants involved. This offers a rarely seen, but richly textured account of the multiple ways that autistic young people negotiate the development and presentation of the self. This self is conceptualised through interests and preferences, strengths and weaknesses, personality traits, points of difference, active, and physical elements, the possible future self, and the self-as-pupil.

When conceptualising, presenting and evaluating the self, multiple social elements were considered. This included a wide range of interpersonal relationships and interactions, social groupings, and roles and responsibilities. The self was actively presented according to social context, with participants demonstrating a nuanced awareness of the changes that may need to be made to meet the expectations of different social groups and roles. In this, the focus was upon engendering acceptance and positive reactions and avoiding negative judgements. This entailed positioning the self apart from abnormal differences and towards accepted strengths and behaviours. Such positioning relates to protective strategies, with autistic young people acting to shield their self-evaluation from negative social reactions.

A key site of such social interaction is the school environment, with participants considering how they defined and evaluated their position as a good or bad pupil. This position was marked by academic achievements and school systems; a position which could further influence how they were treated by others. Their position as pupil therefore related to both academic *and* social spheres. Participants self-evaluations were adversely influenced by social aspects such as the negative judgements of, and upward comparisons with, their peers, and the worthless feelings that could arise from experiences of bullying. In contrast, having friends, being trusted with responsibilities, and rewards and praise from teachers could have a positive effect. Focusing on strengths and achievements also had a positive influence, whilst focusing on weaknesses had a detrimental impact on the self-view.

Consequently, to protect their self-view, participants wanted to minimise areas of weakness in their self-description and to focus on strengths and achievements.

Finally, participants considered themselves in the present *and* the future, sharing the socially acceptable future success they wanted to achieve. This future self was linked to the present, with academic achievements and current interests considered as enablers of such a future. In addition, interests were viewed as a key marker of individuality and a vehicle for maintaining and enhancing social bonds. In their discussion of the future self, and their multi-faceted discussion of the importance of interests, participants therefore challenged reductive, deficit discourses of ‘repetitive’ interests and a lack of future thinking.

In summary, this self-conceptualisation, presentation and evaluation challenges deficit, homogenising characterisations of the autistic adolescents’ sense of self. By using alternative methods, the autistic adolescents in my study were able to communicate their complex and varied self-view, which included a wide range of social self-aspects, their awareness of interpersonal implications and their desire to be positioned in a particular light within the social context. In this, they emphasised their wish not to be defined through impairments or to be characterised by abnormal difference. This builds on and extends the small number of studies which also use alternative methods, to enable autistic young people to challenge impairment narratives of the self (e.g. King et al., 2017; Winstone et al., 2014).

This chapter has generated new knowledge on how autistic adolescents’ present, conceptualise and evaluate their sense of self, from an insider point of view. It has addressed a gap in research by considering how this sense of self is influenced by the specific social environment of the mainstream secondary school. This has included a detailed consideration of how social aspects, such as interpersonal relationships and social expectations, can impact the self-view. My study has therefore moved beyond a focus on academic achievement or the autism label, to consider a complex network of elements, which form the self-concept, evaluation and presentation.

Chapter 8: RQ2: Participant Evaluation of the Participatory Process

In this chapter, I draw together findings and relevant literature for the second research question, which focused on pupils' views of the participatory research methods employed. The chapter therefore offers a detailed evaluation of the participatory process, from the insider perspective of the autistic participants involved. This offers reflections on a research process not previously undertaken in sense of self and autism research, evaluating the *choice* of a range of creative and traditional methods, which could then be *further adapted*, to meet preferred modes of communication. Due to the distinctiveness of the research process, comparisons to current literature are often to assertions researchers have made, rather than research findings. This literature is drawn together with my own data, to offer insights for future participatory research.

RQ2. data includes findings from the questionnaires completed to evaluate the project, which asked participants' views on the participatory process; the choices given; the research topic, methods, and environment; and on working with me and their peers. It also includes participants' choice preferences in the research activities and their explanations for these choices. From this data, the key findings are:

- Participants have diverse preferences, which researchers should appreciate *throughout* the participatory process.
- A choice-based methodology can increase comfort, confidence, enjoyment, motivation, freedom, and sense of equality. This can enhance the fullness of participant response.
- The research topic must be considered as an influence on difficulty and discomfort.
- Participants desire respectful and supportive relationships with the researcher, where trust is maintained.
- Participants had particularly positive views of the enrichment club format of the project, with social opportunities and freedom of choice key aspects of this.

To provide the big picture of the analysis, on which the key findings are based, the chapter begins with the thematic map for RQ2.

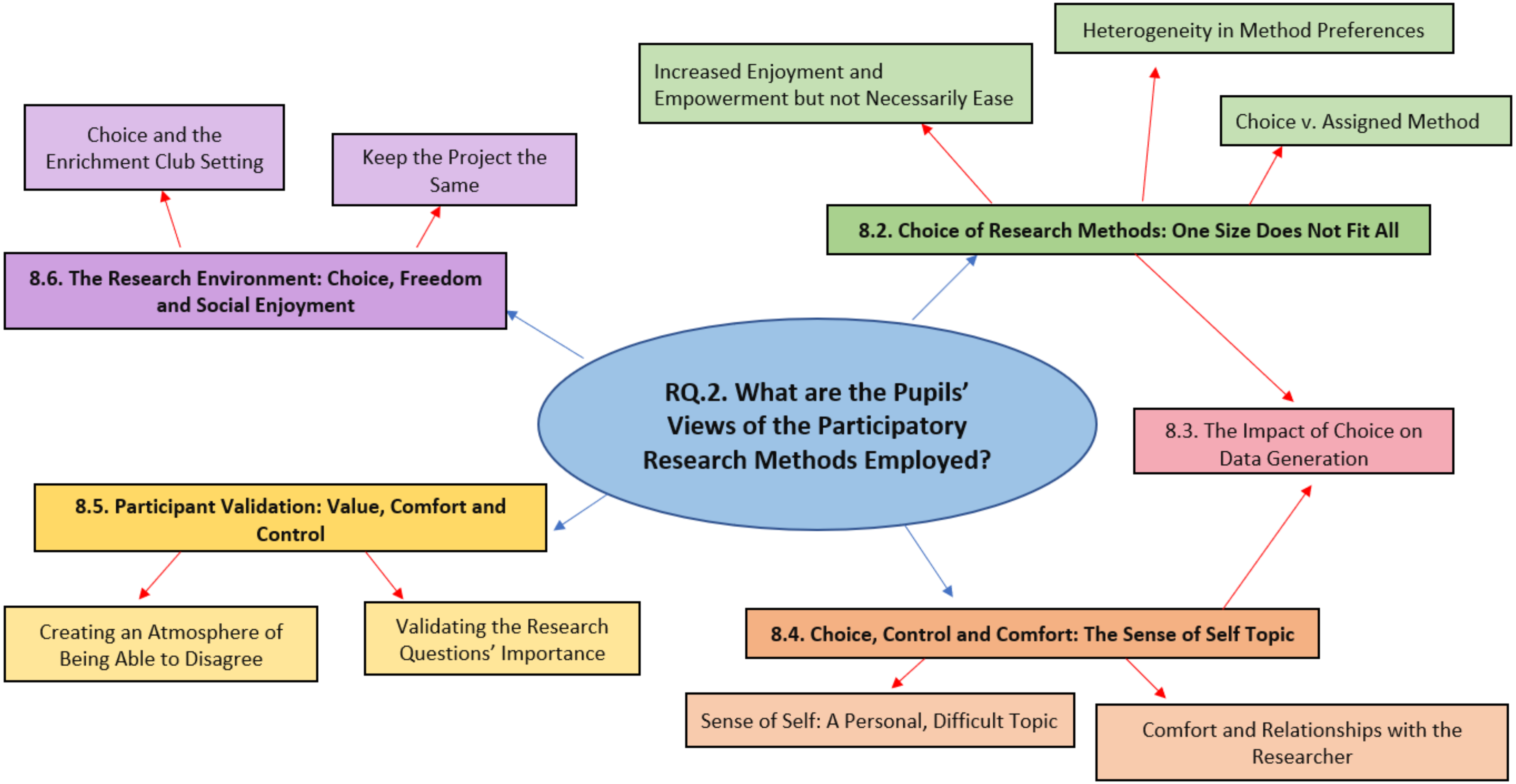
8.1. Overview of Themes

In the thematic map (Figure 33), overarching themes radiate from the central idea of views on the participatory elements employed. These are represented by a blue arrow and are broken down into subthemes, using a red arrow.

As discussed in Chapter 4, main themes were researcher-led, and were based on the participatory and inclusive design concepts I asked participants to evaluate. However, I remained open to participant-led sub themes, which emerged from the data. For example, issues around what was “too personal” to share and how choice can enhance enjoyment came entirely from participant comments made.

Figure 33

Thematic Map: RQ. 2

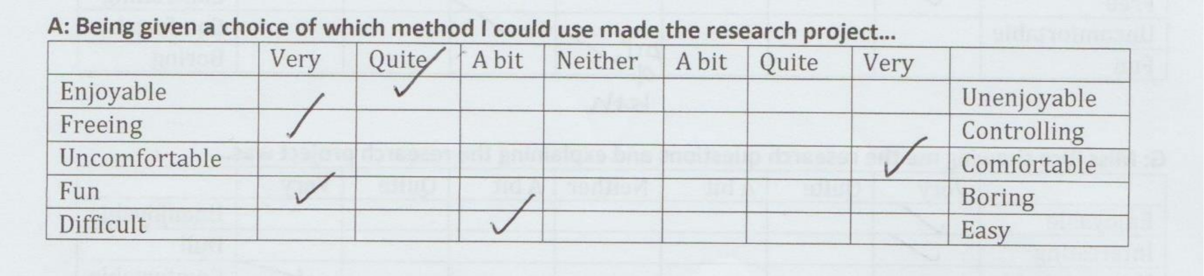


Note. Numbers refer to the main sections of this chapter.

I now examine each theme, considering my data alongside relevant research literature. Data is presented through poetic transcription and quotation (as in Chapter 5 and 6). As, participants' evaluation questionnaires included semantic differential scales (see 4.4, Chapter 4), frequency scores from this activity are included. Full questionnaires can be found in Appendix K. Figure 34 shows the semantic differential scale process.

Figure 34

Semantic Differential Scale



A: Being given a choice of which method I could use made the research project...

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Enjoyable		✓						Unenjoyable
Freeing	✓							Controlling
Uncomfortable							✓	Comfortable
Fun	✓							Boring
Difficult			✓					Easy

The raw data for these scales can be found in Appendix R. Throughout the chapter, adjectives chosen from these scales are denoted in italics.

The chapter now moves through the key themes of the thematic map, following main themes, in a clockwise direction. As such, the chapter begins with participant evaluations of the choice of methods and modes of communication available.

8.2. Choice of Research Methods: One Size Does Not Fit All

Participant evaluations of the research methods suggested that 'one size doesn't fit all' and that variety and choice was key, due to the different ways that these young autistic participants wished to express themselves. Variety could be seen both across and within participant method choices, and choices varied over the time span of the project. Participants also felt that being able to choose from a range of response methods and communication modes enhanced enjoyment, comfort and a sense of freedom from control, thus supporting the participatory aim of empowering participants.

8.2.1. Increasing Enjoyment and Empowerment but Not Necessarily Ease

Participants' evaluations suggested that having a choice of method in which to respond to RQ1. was a predominantly positive experience. Evaluating the methods employed, participants were asked to choose adjectives for the statement, "being given a choice of method I could use made the research project…" Participants mainly chose the positive adjectives of *enjoyable, freeing, fun* and *comfortable*. This may imply that having a choice of research methods enhanced enjoyment and feelings of freedom from control in the research process.

Participants also evaluated the specific method they used in the research, such as photography or talking with prompts. Responses again showed the predominant participant view was that the method chosen was *enjoyable, fun, freeing* and *comfortable*. Harrison also stated that he was more comfortable "when I'm making my own thing." Participants therefore endorsed the choice of methods in their positive evaluations of this process, feeling that it afforded a sense of *freedom* and *comfort*, and increased their *enjoyment* in taking part. This supports the assertion that active involvement in the research process decreases the power imbalance for participants, through the methods employed (Macaulay, 2017; Searle et al., 2019). Additionally, comfort and enjoyment were important as anxiety may prevent autistic children and young people from wanting to take part in research (as in Beresford et al., 2004; Preece & Jordan, 2010).

However, whilst participants found having a choice of method made the research project more fun, it did not necessarily make it easier. Eight out of fourteen participant responses reported this process as *difficult,* and six out of fourteen responses identified their specific method as *difficult*. This suggests that even though a method was chosen it was not always easy to complete for all participants.

Whilst choosing a method to complete increased enjoyment and comfort, it did not make it easier for *all* participants to provide their views.

8.2.2. Variety in Method Choices

Throughout the project, participants provided their views on the specific response method available to them. They identified their preferred methods at the start of the project, and then evaluated the subsequent use of those methods. Analysis shows that there was not one oral, visual, or written form which suited all participants. No single method was preferred. As shown in Table 10, a range of methods, across visual and word-based forms, were favoured by some participants and yet were a least preferred choice for another.

Table 10

Most to Least Preferred Method (ordered 1-11).

	Connor	Fresh	Harrison	Joe	Lightning	Richelle	Skyler	Wolf
Photography	6	4	4	11	5	3	3	1
Drawing	6	10	3	5	11	11	7	11
Collage	5	7	2	10	4	2	1	
Cartoon	5	9	3	4	9	11	5	11
Film	2	2	8	6	10	6	1	2
Video Game	2	1	1	9	9	11	10	2
Write/ Type	3 (Type)	6	2	2	2	1 (Type)	1 (Type) 11 (Write)	1
Story	6	8	5	1	11	6	2	6
Talking	4	5	3	7	2	2	1	8
Talking with Prompts	4	3	3	8	1	1	1 or 2	6
Numbering/ Ordering	5	11	3	3	3	1	9	2

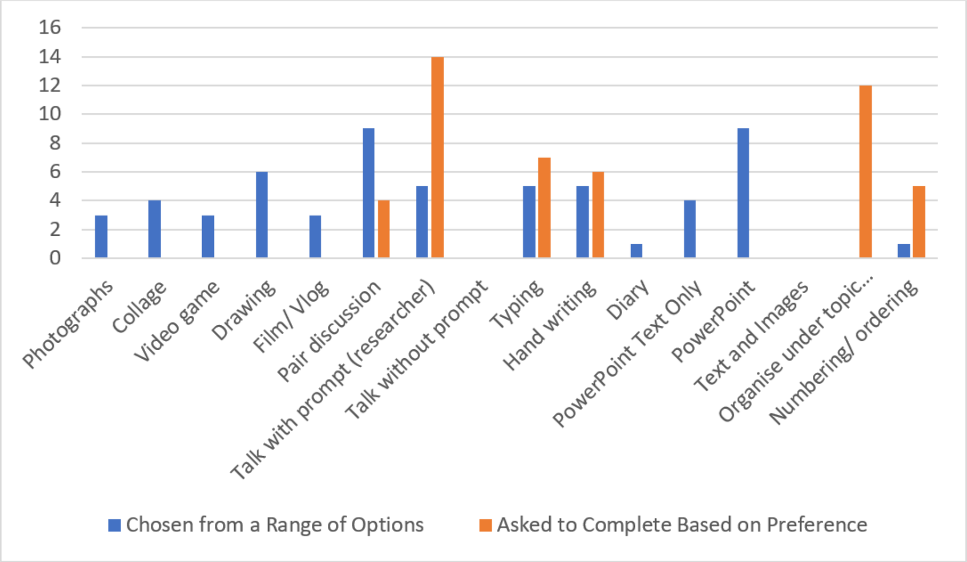
🟦 Participant's Top Three Choice- Preferred Method

🟧 Participant's Bottom Three Choice- Least Preferred Method

Participants also ranged in the activities that they subsequently chose to employ throughout the project (Figure 35). In this, PowerPoint was a popular choice, chosen from outside my original method suggestions. This illustrated how participants may wish to make additional choices, beyond those that the researcher has considered.

Figure 35

Frequency of Method Completion



Overall, these findings indicate, that to meet the preferences of even a small group of autistic participants, range and variety was required- ‘one size did not fit all’ for my participant group.

Whilst participants may have had different views on which method they preferred, there were parallels shown in the reasons given for these preferences. As discussed below, participants preferred methods that they enjoyed, that they felt effectively represented their views or experiences and which they felt comfortable employing. Participants also preferred methods they felt they were good at and avoided those they felt they were bad at. Therefore, in making the method accessible and easier, participants could feel they were good at employing these formats by succeeding in their completion. Their views on each specific method are set out below. This makes clear the complex diversity in participant views, further illustrating how one set method is not appropriate for all.

8.2.2.1. Word-Based Methods. Participants evaluated both oral and written forms, varying on their preferred word-based forms. Some particularly enjoyed talking with prompts- either with the researcher or with peers, whilst others much preferred typing to discussion. Most participants felt prompts were helpful to support discussion and considered typing an easier, preferred option when writing.

Participant's views on word-based forms are represented in the poetic transcription "I Can Talk about Something." The first stanza shows how some participants preferred writing whilst others preferred talking. For some participants, as stanza two shows, prompts were an important starting off point, making the discussion process easier- and they liked having these available. This supports Carter and Ford's (2013) assertion that prompts can be helpful "triggers" when considering a research topic (p.98). Rather than being an element of control, participants who wanted to speak to the researcher directly welcomed some structure to this discussion. Perhaps this is because, following a participatory approach, I used participant created prompts, organised by the young people themselves. In this way, discussion was directed by participants choice of which prompts to discuss, in which order (Danker et al., 2017; King et al., 2017). These prompts could act as a helpful memory cue (Preece & Jordan, 2010), and support conversing on the complex, abstract topic of the self (Gauntlett, 2007). However, as they were not led by the researcher's focus or area of interest perhaps this enabled them to be seen as helpful, rather than as an aspect of control (King et al., 2017).

The second half of the poem focuses on participant views on using words in a typed or written form. Participant preference for typing is shown in the number of responses using this. This may be because "it takes too much effort" to hand write whereas typing is enjoyable and "easier" to do. Perhaps as Saggers' (2015) autistic adolescents discussed, handwriting longer responses can be a site of difficulty, anxiety and stress. Alternatively, participants preference for typing may be because computers are a familiar form, with which young people are comfortable (Danker et al., 2017).

As shown in stanza five, one participant felt typing was preferable to direct verbal discussion. Typing gave them time and space to clearly convey their views, particularly with people they did not know as well, due to the discomfort verbal discussion would cause them. Typing was therefore viewed as easier than the discomfort of speaking directly to the researcher. Perhaps this was because computers offered a safer form of interaction, away from the anxiety of another person's judgement- as is present in face-to-face conversation (Wegerif, 2004). These typing preferences contrast with another participant who felt "us talking is quite comfortable." Therefore, even within participants who preferred a word-based form, views varied on whether they would prefer to talk or type.

I Can Talk about Something

I like to write or speak to someone.
Us talking is quite comfortable.
Writing it directly,
and the same with talking,
it's more easy to like show it,
rather than like through pictures.
Words can give more detail.

I can talk about something,
If I get a topic to talk about,
with prompts would be easier for me.
I can't usually go on about something,
that I come up with myself.

I like to know what topics she wants me to talk about,
especially if I am helping someone by sharing it.

Writing or typing is easy to ask questions,
Typing because that's easier than writing it down.

I love to type and use computers.
I prefer typing.
I would really prefer to type than write.

I find it easier to type,
rather than directly communicating to someone.
I find talking to people,
especially those who I am not familiar with,
extremely hard.
Writing things down allows me to get my opinions across,
better than talking.

I would be good at writing stories of my experience.
I'm not that good at really writing a story.
I do not like making a story.
I'd find making a story quite hard.

Don't like writing; it takes too much effort.

(Connor, Harrison, Joe, Lightning, Richelle & Skyler)

King et al. (2017) and Winstone et al. (2014) argue that the traditional interview process is a barrier to autistic participation. Considering this assertion, it is interesting that some of my participants did not want to avoid interviews, with four placing talking in their top three preferences of methods to employ. It was *within* the interview process that participants chose a range of adaptations, including prompts, notation, talking with peers or typing their conversations, rather than undertaking unstructured, face-to-face conversation. Two participants also chose to have contemporaneous notes written, instead of audio recording. This mirrors the work of Winstone et al. (2014), who also adapted their interviews to be based around creative activities, enabling participants to provide their views and opinions more effectively. My participants also took part in a variety of preferred, adapted interview forms, which facilitated them in sharing their views. This illustrates how research with autistic participants should not be avoided over fears of a method, such as an interview, being a barrier but that the researcher can consider preferred adaptations to a conversational form.

Overall, adaptations to the traditional interview were a valuable tool to meet the range of participant preferences, in undertaking word-based responses.

8.2.2.2. Visual Methods. There were also varied responses to the use of visual methods. Some participants placed methods, such as film or photography, as their top preferred choice whilst others recorded them as least preferred (Table 10). Moreover, some preferred to create their own images whilst others preferred using ready-made images to create collages or PowerPoint slides. Participants who enjoyed one visual method, such as photography might not enjoy another, such as drawing, to the same extent. They also had mixed views on how effectively they felt images could convey their opinions and experiences. Furthermore, discussion of visual methods illustrated participants' preference for a method they were good at and a desire to avoid those that they felt they were bad at.

These views are represented in the poetic transcription "Finding and Using Images." Each stanza shows participants' contrasting views on visual methods. Whilst one person may "really like" something another may not feel the same way. Positive views on visual methods sprang from feelings of enjoyment or passion for that method, alongside a belief that this form would effectively represent their views or experiences. For example, one participant felt that photographs can "show emotion" and "are like time machines. They make photographers remember what happened that day." Although, they also felt that "only the photographer really knows what they were feeling." Even though this participant chose to take photographs, they felt that the observer or audience of those images could never fully access the emotions the participant was feeling at that time. As discussed in the poetic transcription "I Can Talk about Something," other participants also felt images could not accurately represent their "personal experiences." Therefore, participants had mixed views on how effectively they felt images could convey their feelings and experiences to others.

Negative views of a method were often linked to ability. Drawing was regularly discussed by participants in terms of being “bad” at it, and this was given as a reason why they would not undertake this method. In contrast, if a participant felt a method was a strength, they would be keen to complete it. For example, photography expertise led one participant to choose to take photographs. This illustrates how participant views of how “good” they are at something influenced their use of a method.

Finding and Using Images

Finding and using images is fun;
I love putting together collages.
I don’t really think that I could find suitable images,
to describe my own personal experiences.
They are quite hard to show what you are talking about.

I like making games;
I would like making a game about something;
I am currently expanding my knowledge on programming.
I don’t really like video games;
I don’t like video games either.
I’m not really into video games and ‘inventing’ one.
I would not enjoy completing the task in this way.

I like watching films; love Vlogs,
I really like filming and editing. I love doing it.
I am not really good with showing through films,
I don’t think I am good at like making them myself.
I wouldn’t like filming me doing something.

I run a photography company.
People are able to show emotion through images effectively.
Photographers are able to take images with emotion,

but only the photographer really knows what they were feeling.
I do not like taking photos.
I'm not really sure about how I could take photographs,
to represent my opinions.

I do not like drawing images, I don't like drawing pictures.
I can't draw, I'm not a good drawer,
Well, I'm not that good at drawing pictures,
I also hate drawing images,
because I am very bad at drawing.

(Connor, Fresh, Harrison, Lightning, Joe, Richelle, Skyler & Wolf)

Two participants showed the need to retain visual methods as an option, even if this had not been previously stated as preferred. Harrison particularly enjoyed drawing and chose to employ this on a regular basis. He also requested "More activities like drawing. It's more fun," in his methods evaluation. However, drawing was not placed as his top choice in the initial ordering of methods. A similar pattern emerged with Fresh, who chose to take photographs, even though this was also not in his top three choices originally. This demonstrates the need for options to remain available as participants' preferences may differ over the course of the project.

8.2.2.3. Ordering or Numbering. Participants completed ordering activities, such as sorting topic prompt cards by influence on self-view or by importance to the self-definition (see Chapter 4 for detail). This was undertaken by all participants on my request.

They reported mixed views on ordering or numbering, predominantly choosing *difficult* to describe ordering activities yet also reporting that they were sometimes *fun* and *enjoyable*. Three participants stated that these methods made it "easier" to provide their views, one felt it would be "enjoyable" and another stated this is "how I prefer to show things" (Joe, Lightning & Richelle). In contrast, two participants felt "using numbers to give my opinion while putting them in order" was "tedious" so they would "rather not" (Fresh & Skyler).

This method further showed how participants may prefer adaptations to a method. Skyler did not mind organising topic cards into an order but wanted to avoid using numbers. Wolf was happy to number or order topics as long as he did not have to organise by importance to sense of self whilst Fresh was happy to use symbols but did not want to colour-code. This shows that certain adaptations of a method may improve motivation to complete. For example, participants may be unhappy numbering from one to ten but enjoy placing topic cards in order from favourite to least favourite.

Two participants found the ordering method to be *controlling* and *uncomfortable*, even when adaptations were available. This may be due to this being completed at my request, rather than a method chosen by the participant. Whilst adaptations were available, with the option not to complete the activity should they so choose, this assigned method still resulted in some participants feeling discomfort and a lack of control.

8.2.2.4. Working with Others. Most participants were happy to collaborate with peers, with several participants particularly enjoying this. Peers were therefore a key part of the project. Preferences for working with others were shown by those who chose to complete paired discussion (Figure 35). One participant requested “more group collaboration” and “more group projects” whilst two agreed that they preferred working with a friend or partner to working alone (Connor, Harrison & Wolf). Participants primarily preferred to work with a peer. However, Skyler enjoyed working with peers and adults whilst Fresh primarily preferred to work with myself or the TA. Here, Fresh stated he wanted to work alone, depending on “topic difficulty,” being given the option to ask for adult help if he wanted it. Overall, though participants often wanted to work with others, be that peers or adults.

Participants predominantly evaluated working with peers as a *fun, free* and *enjoyable* experience. They enjoyed “collaboration,” “working as a team,” “seeing how others worked,” and having the “chance to work with people wouldn’t have” (Skyler & Wolf). They also enjoyed joining together to discuss views and experiences with people they may not have interacted with previously. Participants’ sense of freedom in peer working perhaps supports Niemi et al.’s (2018) argument that conversations with peers enhance a sense of control, by removing the adult researcher's influence on the discussion. In addition, one participant felt that the commonality, of discussion with those who had the same difficulties, added comfort to share within the peer group (RD, Session 16). This may be why, as Sloper and Beresford (2014) claim, working with peers can reduce feelings of inhibition.

Participants particularly enjoyed the opportunity to socialise with their peer group, to build or maintain friendships with those peers (as in Holland et al., 2010). These friendships could add additional comfort in the research process of being with "people I know" (Connor & Harrison). Over time, participants built relationships which they felt were supportive and without judgment. For example, Skyler became more comfortable sharing with peers as the project progressed. By the end of the process, she felt:

> Everyone was supportive of each other's opinions, and nobody judged you for the decisions that you made in that I felt comfortable. I didn't want to be a sheep and follow everyone else. I just wanted to say what I thought about something. Everybody's choices were respected by everyone in the group.

This contrasted her preference at the start of the research project, where comfort would come from being "Private. Just me and Miss Rice." This illustrates how social time was important to participants feeling at ease with peer discussion around personal issues, by building such respectful relationships. Indeed, half of participants evaluated group or pair work as a *comfortable* experience, however, two did suggest there may be some *discomfort* within this setting.

Finally, participants were split on whether working with others was a *difficult* or *easy* process. When considered alongside their enjoyment, this suggests that whilst something may be *difficult*, it does not necessarily mean it is *unenjoyable*. Therefore, rather than forgoing collaborative options, it may be that some researcher support may be needed- to facilitate the structure and recording of such a process. This was evident in my project with two participants requesting such support for their pair discussion. In addition, participants required my assistance in mediating conflicts with peers, conflicts which may account for the difficulty participants ascribed to this approach. This aligns with Niemi et al.'s (2018) research with Finnish primary age pupils, where they were also required to intervene in a conflict, within a peer interview. Just because there may be some difficulty with a method, does not necessarily mean that participants should be denied it as an option. Whilst the adult may withdraw from the research aspect, giving participants control over the questions and discussion focus, they may still be needed for social support, for aspects which impact on participant wellbeing, such as conflict with peers. The researcher may also need to ensure that quieter pupils are not dominated by more confident peers, and that they have equal opportunities to provide their views (as in Holland et al., 2010). The adult in a support role was also evident with Fresh, who preferred to begin work independently, asking for adult help if a task was found to be difficult. This illustrates how participants appreciated working with others, but that it was important to have variety, and supportive adaptations, to enable their preferred options.

Positive views of pair and group work do not mean that independent work should be disregarded. Working independently was evaluated positively by three out of four participants as *enjoyable, comfortable* and *freeing*, with two finding it *fun* and *easy*. However, one participant did feel it was *quite boring* and *quite difficult*. One participant, Wolf, enjoyed taking a hybrid approach, completing his personalised “tailored” tasks, which were set to his “skill level” whilst working alongside, helping, and being helped by, others, with “Everyone… set their individual work” but “everyone’s still working together to help each other out.” Wolf suggests that he enjoyed having “tailored” work that made it easier to provide his views and opinions but that an atmosphere of collaboration and support could still exist alongside this. This illustrates the varied forms desired by participants, with a range of pair, group and independent work preferred.

Participant views again emphasise the importance of choice in working styles, with participants varying on their preferences for working with others.

8.2.3 Choice and Variety: Accessible Adaptations

Participant evaluations have therefore highlighted the variety of preference in modes of communication, ranging *across* visual, oral, and written forms. Those which were a top preference for one participant were often a least preferred method for another. This diversity was also evident *within* the chosen methods, particularly in the modes of communication. Differences were seen in conversational choices, with varied preferences in who participants wanted to converse with and in their choice to either type their responses or to speak face to face. Additionally, participants could prefer one visual form, such as photography, but not necessarily enjoy another visual method, such as drawing. Some participant preferences changed dependent on the context in which they were undertaken. For example, Richelle did not want to be recorded conversing with the researcher, but later completed a recorded conversation with a peer. This highlights how participants' preferences may fluctuate, suggesting that they should not be constrained by the initial choices made. Some participants chose PowerPoint, which was not originally offered by me. In so doing, they emphasised the importance of open choice, with the option to identify modes of communication not originally considered by the researcher. Like Preece (2002), these findings illustrate the heterogeneity of choice across even a small group of autistic adolescents. This supports Scott-Barrett et al.'s (2018) assertion that we should not make assumptions about how autistic young people may want to communicate in a research study. Instead, the researcher should appreciate the variety of ways autistic participants may wish to communicate (Nicolaidis et al., 2019). As Ellis (2017) states it is "not a matter of one size fits all" (p.23-24); a range of methods may be necessary to meet the varied needs and strengths of the participants involved (Clark, 2010).

The importance of enabling such participant involvement was underlined by Joe, "the best way to show that someone's opinions are valued is to allow them to participate in all activities and tasks." To allow someone to "participate in all activities," it may be important to offer choices and adaptations within the activities available, to ensure *all* of them are accessible for participants. As discussed above, a range of adaptations were therefore undertaken by participants, particularly to conversational forms and to rank ordering topics. When implementing such accessible adaptations, Skyler and Richelle's comments must be considered. They discussed that, "just because I have a disability doesn't mean I need to be treated like a two-year-old" and that "I don't want them [the researcher] to treat me differently." This suggests that participants may view unequal or different treatment as infantilising, with Skyler agreeing that she did not appreciate being treated as incapable. Participants' views therefore align with Alderson's (2008) assertion that the researcher should avoid infantilising younger participants, through assumptions of incompetence. Whilst it may be important to ensure that participants can partake fully in research, adaptations should therefore not be employed in a way that leaves participants feeling patronised. Perhaps here, participant choice is again key, with adaptations offered as *their* choice, rather than automatically being implemented through an assumption of incapability. Just as Bourke (2009) and Spiel et al. (2017) warn against enforced participation in *all* areas of the participatory research process, it may be that the researcher also needs to be wary of enforcing method adaptations. A presumption of competence should be in place for autistic participants with the option of adaptations present (Biklen, 2005; Scott-Barrett et al., 2018). There is a need to be aware of the risk of inadvertently removing power and control from the participant, by making them feel demeaned through enforced support.

Adaptations were implemented when participants were asked to rank order topics. As previously discussed, some participants felt *uncomfortable* and *controlled* undertaking this activity. Perhaps this is due to these activities being completed by everyone at the request of the researcher, to provide comparable data. This demonstrates how, even with accessible adaptations, and options not to complete areas of the activity on request, the act of *specifying* a method increased a sense of discomfort and a lack of control.

To conclude, participants adopted a range of adaptation strategies in the project-adaptations which could support participant enjoyment, comfort and ease in sharing their views. Such adaptations were viewed as helpful, *when* utilised in ways which did not patronise participants or for activities which reduced their control within the process.

8.3. The Impact of Choice on Data Generation

Participant evaluations of the choice of methods available in the project have highlighted the variety and richness of preference in modes of communication. Of further consequence, were participant reports of how having a sense of freedom and choice could *increase* the breadth and fidelity of the data arising from the project. They felt that the enjoyment and freedom experienced in such choices resulted in an increased motivation to complete an activity, producing a fuller and truer representation of their views. In contrast, feeling unequal and controlled would make them be unwilling to contribute as fully.

The importance of choice and freedom in the research process is represented in the poetic transcription “It Helps us be Free from Control.” This demonstrates participants’ positive views on choice, which creates a sense of freedom and enhances enjoyment, mirroring the semantic differential scale data on method choices discussed above. Drew et al. (2010) also found that the fun perception of their photography method encouraged adolescents to take part. My participants moved this finding a step further, by explaining *how* pleasure in a method can influence participant contribution levels, motivating them to provide their complete views on the topic discussed. This was evident when Wolf reviewed the researcher’s initial findings. Here, he agreed that he would be more motivated by something he enjoyed, including if it were linked to his passions.

In contrast, as shown in stanza 4, if a method were too difficult or unenjoyable, participants felt they would “rush it and not do it as properly as I would normally.” Participants also reported that if they were given an undesired method then I “might get different results” as they “might say something else,” counter to what they truly felt, to bring the process to a close as quickly as possible. This implies that, if participants were asked to complete a method which was too unenjoyable or difficult, the data produced may be less detailed or even be “something else,” a “lie,” which may not fully represent what the participant truly feels. An activity being enjoyable therefore not only serves the purpose of having a positive impact on participant feelings during its completion but may also have an impact on the data generated as well. This is in accordance with Preece (2002), who found that autistic children and adolescents may give inaccurate answers to escape the discomfort of an interview. However, my participants did not necessarily attribute this desire to escape to anxiety, as in Preece. Instead, they equated wanting to escape with a sense of being controlled or with a lack of enjoyment. Both my study, and Preece’s, illustrate how the sharing of a participant’s views may be curtailed due to their desire to escape.

It Helps us be Free from Control

Make own choices;
It’s easier to show thoughts.
Make our own decisions;
It helps us be free from control.

Got to do what I wanted.
All of the decisions were your choice.

If I’m not interested in it,
then it’s hard to be motivated to do it,
because you just don’t want to complete it.

If a person was made to do a task,
in a way that they didn’t want to do it,
they may not put as much effort or enthusiasm into the task.
I’d probably like rush it and not do it as properly,
as I would normally.
Then it might get different results;
I might say something else.
If don’t like spotlight might lie.

Being told what I COULD do,
rather than what I SHOULD do,
gives a break from the rules and orders.
It makes me hopeful,
That there will be a choice that I could agree to.

I like to express myself.

(Fresh, Harrison, Lightning, Joe, Richelle, Skyler & Wolf)

Continued consideration of control is seen in Fresh, Richelle, Skyler and Wolf's discussion of how "shar[ing] decisions equally" would contribute to them giving fuller responses. If the researcher did not include them in decision making, they would think they were "bossy" and "won't like them," leading participants to feel "differently about answering." These contemporaneous notes, from group discussion, highlighted that, if participants felt controlled by the researcher, they may not wish to answer that researcher's questions. On the other hand, if they felt decisions were shared, and they were treated as equally important, they would not "be afraid to show my opinion" (Harrison). The importance of creating an atmosphere where participants felt open to answering is encapsulated in the final line of the poetic transcription, "I like to express myself." This shows how participants enjoy expressing their views and opinions. It is therefore important that they feel "free from control" and able to do so. These findings illustrate how a sense of researcher control, and a lack of value in the process, can influence participant response. This aligns with Milton's (2014) assertion that a voice which feels devalued may cease to be shared, due to a lack of trust in researcher and their process. Furthermore, this data highlights how the adolescents in my study appreciated the participatory paradigm and valued equality in the research relationship.

Finally, participants felt that undertaking a method that they were good at would increase their confidence, also enabling a wider contribution. My study therefore supports Rose's (2016) assertion that confidence is found in using existing skills. Moreover, as seen previously in "Finding and Using Images," participants would avoid methods they thought they were bad at as they felt they would fail in attempting these. In Mannay's (2016) reflection on her use of creative methods, fear of failure, of being rubbish at drawing, led one adult woman to not only avoid completing this method but to also leave out elements that she felt she could not draw. My participants, like Mannay's, showed that a lack of confidence in a method can result in an avoidance of completion. As Mannay asserts, this can lead to crucial elements of a participant's experience being rendered invisible. In contrast, for my participants, choice of method positively influences self-confidence, enjoyment and motivation, which work together for a fuller contribution. This supports Beresford et al.'s (2004) argument that playing to an autistic participants interests, and strengths, can enhance enjoyment and, in doing so, produce a richer response. Enabling this deeper response was important in meeting my participants' desire for their opinions to be heard.

The impact of choosing their own methods, on the richness of participant contribution, is further evident when comparing this with an assigned method. This is now discussed.

8.3.1. Completing an Assigned Method: An Unenjoyable Difficulty

Similarly, to Winstone et al.'s (2014) use of a comparative traditional interview, my participants also completed an assigned method at the start of the project, to compare with the choices that followed. This enabled participants to offer their views on undertaking an assigned method, perspectives considered in this section.

At the start of the project, all participants were asked to complete the Twenty Statements Test (TST)-a prevalent method in sense of self research. This is a structured method for researching self-definition, which asks participants to independently provide twenty I am.. statements, answering the question of 'who am I? (as devised by Kuhn & McPartland, 1954). Participants were then asked to evaluate this method. The difficulty of a compulsory, non-adapted method was shown in participant responses (as illustrated in Table 11), with the majority unable to independently complete the twenty statements. Only two of the eight participants could produce a full set of twenty statements about themselves. Four participants managed to respond with around half the requested number of statements (9-12), whilst two produced a quarter or less (2-5). Therefore, whilst the TST may have been suited to some participants, it was much more difficult for others. This emphasises the need for a range of options to enable *all* participants to engage.

In using the TST, I also considered the influence of adaptations to an assigned method. After the initial attempt, participants worked on their original TST lists in pairs or groups. Sharing ideas, and accessing support from peers, enabled participants to improve their total number of who am I statements. Working in isolation made the TST more difficult as participant responses increased when they were able to work with others in the group or myself.

However, working with others still only enabled one more participant to create a full set of twenty statements. Whilst some participants could produce a full response using this set method, many could not, even with additional support. These views on difficulty were further evident in participant evaluations of the TST, with four main study participants feeling that this was *difficult* and two feeling it was *easy*. Pilot study participant Lightning also called this a “hard” task. One assigned method may therefore pose difficulty for some members of the group, even when adaptations for support are made. This suggests that there is a need for participants to first make a *choice* of method, which is *then* adapted for accessibility, to enable a full response. Merely adapting an assigned method, did not have the same effect as the adapted choices which followed, and resulted in the rich and complex sense of self data presented in Chapters 5 and 6.

Table 11

TST Total Participant Responses

	C	F	H	J	L	R	S	W
Total Spontaneous Statements- Created Individually.	5 (3 the same).	9	20	20	2	11	11	12
Total Statements after Working as a Pair/ Group.	13	11	20	N/A	15	15	20	14

🟩 20　🟧 13-17　🟦 8-12　🟨 0-5

Note. Joe worked independently only.

In addition, predominant participant views were that the TST was not *enjoyable* or *fun*, with half the participants choosing *boring* or *unenjoyable* to describe the TST. Half the participants also felt it was *controlling*. As a sense of control was previously identified by participants as resulting in less desire to contribute fully, this may have impacted on the statements provided here. However, four out of six did feel *comfortable* with the TST, so not all opinions were negative. Additionally, two participants added positive comments, that the TST was "interesting" and "good because people will know facts about yourself" (Richelle & Skyler). Therefore, a positive element to the TST method was the opportunity to share information about yourself with others.

Comparing the TST evaluations with those of the chosen methods further illustrates participants' views. In terms of ease, sense of freedom and enjoyment, the TST was evaluated less favourably than the chosen methods participants later employed.
Chosen research methods were evaluated as more *enjoyable* and *fun* (10/13 and 11/13 responses) compared to the TST, with only 1/6 responses identifying this as such. As discussed previously, enjoyment can impact on the detail participants provide- a lack of enjoyment and motivation may have influenced the number of participants who did not complete a full twenty TST responses. Additionally, half of the participants identified their chosen research method as *easy*, compared to a third for the TST. This suggests that a chosen research method was perhaps easier than the TST. However, with only half choosing such a response, the chosen research method was not necessarily a solution to difficulty for *all* participants. Other factors may need to be considered such as the difficulty of the topic discussed. It may be that "it's quite hard to describe" yourself no matter which method is employed (Lightning). This will be discussed in the following 8.4.

Overall, the TST supports the assertion that an assigned method can increase difficulty and decrease participant enjoyment, resulting in a reduced participant response. The TST demonstrated how assigning a method may hamper participant engagement, reducing the amount of data generated. In considering the TST, alongside the wider choice of methods and adaptations employed, this study builds on Winstone et al. (2014). It not only finds that a change to method can increase the contribution of autistic adolescents, but it also provides insider participant views on *why* this fuller contribution may occur. Participants have not only considered the ease of the method as an influence on their contribution but also identified comfort, enjoyment, motivation, self-confidence, and feelings of being valued and free from control, as relevant to the fullness of their communication. This study has shown the range of methods which are required to enable such a response, illustrating the impact a methodology which offers a choice in research methods can have. These participant evaluations perhaps therefore stand as a counter to research where methods are assigned, or removed, based upon researcher assumption, actions which may not necessarily align with the varied preferences or needs of the autistic adolescents involved.

To conclude, participant preferences have emphasised the importance of eschewing a ‘one size fits all’ research method, which, as previously discussed, can be a barrier to participant response and perpetuate deficit narratives (see Chapter 4). In taking an alternate approach, with a choice of methods and communication modes available, participants experienced increased enjoyment, motivation, confidence, and a sense of control which, in turn, resulted in a fuller contribution. This supported the participatory aims of enabling equality in the research relationship, with autistic insider voices fully heard- aims which were endorsed by the autistic participants involved.

8.4. Choice, Control and Comfort: The Sense of Self Topic

In the second theme of the method evaluation, participants provided their views on the sense of self research topic. Evaluating participant views on the research topic was important because, as Lightning stated, it may be “quite hard to describe” yourself, no matter which method is used. This, as Gauntlett (2007) asserts, can be due to the complex array of aspects which form a person’s conception of who they were, are, or who they want to be; a complexity evident in the sense of self findings from this study (see Chapter 7 for discussion).

Participants felt that being able to choose which topic areas they wanted to consider could make it easier to provide their views and experiences on this difficult topic. In contrast to choosing a research method, more participants felt this made the research project *easier* to partake in. Three participants felt these choices made it *easy* to provide their views and experiences whilst only one felt it was *difficult*. This contrasts with completing their chosen research method, where views were equally split with regards to *ease* and *difficulty*. This implies that control over *what* you discuss may be as important as choosing *how* you discuss it. Therefore, control over areas of discussion may also need to be included, when enabling autistic adolescents to contribute to a research project. As with the research methods, having choices over the aspects of the self discussed also increased enjoyment and a sense of freedom from control, enhancing the participatory aims of the project. Participants predominantly evaluated having the option to choose which sense of self and school topics to discuss as *enjoyable, fun* and *freeing*.

In addition, discomfort around the topic should be considered. More participants expressed *discomfort* when choosing topics than when choosing methods, indicating that the topic itself may increase discomfort, even when choices are available. Such discomfort was reiterated in participant evaluations of discussion of elements that made them feel good or bad about themselves, which was predominantly evaluated as *uncomfortable* and *difficult.* Whilst some participants found this *enjoyable* and *freeing*, some found it *unenjoyable*, and half found it *controlling*. This shows how sensitive topics, such as those which focus on positive or negative impacts on self-view, can make participants feel *uncomfortable* and can be *difficult* to share. This could be because elements which made them feel bad represented weaknesses, an area which participants did not want to focus on (see Chapter 7). Participants can feel *controlled* when asked to discuss this, however, half also found it *freeing* to provide these views- showing the diversity of opinion on discussion of the research topic.

Difficulty and discomfort did therefore not necessarily mean that participants wanted to avoid the sense of self topic. Instead, they suggested that it was important for the researcher to respect what was “too personal” to share, whilst simultaneously creating a comfortable atmosphere to discuss what they should wish, especially if a sensitive area was to be discussed. Further to this, they emphasised the importance of supportive relationships in aiding a sense of comfort. They felt that building trust in these relationships was important. They also wanted to retain control over what was shared and be able to trust the researcher to maintain the confidentiality, anonymity and privacy they had requested.

Participants felt this would all contribute to making them feel more comfortable in exploring difficult and sensitive topics.

8.4.1. Sense of Self: A Personal, Difficult Topic

Participant views on the discussion of such personal or difficult topics will now be considered in more depth. Participants regularly highlighted their concerns around what was "too personal" a topic to share- with me or with peers. Views about the difficulty of the topic were mixed in the participant group, some participants found the sense of self easy to discuss, others found knowing yourself, and subsequently describing that self, a difficult task. Some suggested that it was easier to describe others than themselves. However, participants still predominantly *enjoyed* discussing the sense of self topic. Therefore, even though it may have been difficult, and debates may have circled around what was "too personal" to share, participants still enjoyed the opportunity to provide their views on their sense of self.

Views on the personal nature of the topic are represented in the poetic transcription "Deciding what is too Personal." When asked about the bad points of having to discuss themselves, giving away "personal" information was identified as a negative aspect. As shown in stanza three, participants therefore chose at times to take the frequently reiterated option to not answer or give a no comment response, particularly for questions which they felt would reveal information they would rather keep to themselves. One participant also preferred some elements not to be shared with the group but did not "mind sharing my personal experience with Miss Rice." Therefore, although pair work was preferred overall by participants, some sensitive topics may be best discussed individually.

This corroborates Bourke's (2009) findings from a study with those who have had breast cancer. In my study, participants also felt that personal subject matter should not be shared with others in the research group. Whilst Bourke's (2009) participants were wary of the negative impact of their views being shared with their healthcare professionals, my participants may have been concerned over their sensitive information being shared by peers with other pupils, from outside of the group. Having control over which topics were discussed, and with whom, perhaps enabled greater comfort; participants could choose not to discuss particularly sensitive points, whilst still sharing their desired views on sense of self and school. As discussed previously, if participants felt unequal and controlled, they may not share as fully as if they felt that it was their choice to do so. Therefore, choice of which discussion elements are shared, and with whom, should form considerations of participant comfort and control. Additionally, the researcher needed to respect that some participants may never feel comfortable sharing "things that are very personal." Finally, one participant asked for reassurance on "what Miss would use my answers for." This highlights the need to ensure participants fully understand what their data will be used for and that they can choose to remove this data should they wish, allaying any anxiety a participant may have.

Deciding what is too Personal

It's hard, deciding what is too personal.

A downside to having to create something,
was giving away some slightly personal information.
Some of these things may be quite private and personal to me.
We all need our privacy.

I feel uncomfortable,
When I am asked very personal questions.
I would like to keep this private.
Can I just not talk about this please?
No comment. No comment.

It depends what the topic is.
If it is something negative,
I don't like other people listening or knowing.
I don't mind Miss Rice seeing,
I don't mind sharing my personal experience with Miss Rice,
But I wouldn't want others in the group to,

Even though they are all very nice and understanding.

I feel anxious as to why and what Miss would use my answers for.

I did feel comfortable;
I didn't put things that are very personal.

(Connor, Fresh, Harrison, Richelle & Skyler)

Participant views on the difficulty of the sense of self topic were further evident in their evaluation of the statement "talking about yourself has been…" Here, two participants found it *easy* to talk about themselves as a topic, whilst four felt it could be *difficult*. Participants stated that, "it's quite hard to describe myself," "sometimes I don't know how I feel about myself," I "do not like talking about myself" and "I don't know myself. You don't really know yourself" (Connor, Lightning & Wolf). This shows how some participants found it difficult to discuss and describe their self-view, with one feeling they "don't really know" themselves to be able to do this. Wolf also differentiated on the elements of self which were difficult to discuss, "saying what I do is easy" but "speaking about my personality is hard." Although speaking about his personality was something he was able to do, it was something he found more difficult. This shows how certain elements, such as actions, may be easier to discuss than others, such as "personality" traits.

Lightning, felt it was "easy to just pick out details in general that people think of." He preferred to discuss how he felt his peers or people generally might think, feel or describe themselves. He found it more difficult to describe his own specific self-view or to define how he was unique from others, even though he felt that you know yourself the best. Further to this, both Lightning and Harrison found it easy to describe what their friends or peers were like, with Harrison helping Connor to expand his 'who am I' statements at the start of the project. The ease that these participants found in describing others may be because, as Lightning agreed, they notice what others do but may not always spend a lot of time reflecting on themselves. Wolf also stated he prefers to "focus on other things" over his self-view, such as his hobbies and passions. This may suggest difficulty in describing himself came from a desire not to focus on the self, and therefore having avoided self-reflection, rather than difficulty in undertaking such reflection. In contrast, reflecting on others may not be avoided in the same way, so they are easier to describe. Difficulty here may therefore reflect a participant who *chooses* not to spend time on introspection, rather than an inability to self-reflect as argued by Hobson (1990;2002).

Others had less difficulty in discussing themselves, with one stating “you have lots of ideas because you know about yourself” and two others agreeing that they found this an easy task (Harrison, Richelle & Skyler). Participants also predominantly felt it was an *enjoyable* and *fun* process to discuss themselves and their self-view. Therefore, just because it may be difficult to discuss themselves personally as a topic, this may not mean that participants would not enjoy the opportunity to do so. Instead, it should be considered how they can be made comfortable in sharing their views.

In summary, the sense of self topic can be difficult to discuss, particularly when considering personal, sensitive aspects. Choice and control within these topic discussions can be helpful. In addition, relationships with the researcher, or with peers, can influence the level of comfort participants feel. Working with peers was discussed in 8.2.2.4. I now consider participants’ views of their relationships with myself-as-researcher.

8.4.2. Comfort and Relationship with the Researcher

Participants linked their feelings of comfort during the research process with the relationship they had with myself-as-researcher. They trusted me to retain any agreed confidentiality, privacy and anonymity. Supportive relationships, in which they could speak freely when they wished, enhanced their feelings of comfort and the sense of being part of a team. When evaluating my role, participants reported this as a *supportive* and *encouraging* relationship. They suggested that trust and relationships were built with both myself and the group over time and that comfort increased with a sense of being with “people I know.” However, one participant suggested that the teacher’s role may have had an inherent control that, they felt, could not be counteracted. Therefore, whilst most participants felt *free*, one individual felt my control as teacher was unavoidable.

Views on participant comfort are represented in the poetic transcription, "I Felt Comfortable to Give My Opinion." The first stanza shows the importance of participants' relationship with the researcher. A sense of trust and being supported was important in enabling participants to feel comfortable sharing their views. When evaluating the statement, "Working with Miss Rice, I have felt…", participants further appraised this relationship, predominantly feeling *free*, *part of a team, encouraged, comfortable, supported* and *happy*. Feeling supported may have enhanced the sense of being part of a team as participants identified being "here to help" and being "supportive" as part of a teammate's role (Fresh & Richelle). Participants' views that a teammate should offer help and support are of interest. Some participants asserted that the team should "work with others need," with help coming from an adult *or* from peers. In this, it was felt that I should also "encourage us to be supportive to our other teammates" (Fresh & Skyler). If offering help is part of a team approach, then this could suggest that making adaptations to help the young people to contribute did not automatically create an unequal power relationship of the teacher helping the student. Instead, it was an expected part of being in an equal team. Perhaps this is why, even with the varying adaptations I put in place, participants predominantly felt *free* and *comfortable* when working with me. They did not align with Ellis' (2017) concerns that such adaptations added a layer of control to the process. Moreover, participants' feelings of freedom could possibly suggest that the power differential, of adult and adolescent, of teacher and pupil, or of researcher and participant had been depleted (Holland et al., 2010; Kim, 2012).

However, as seen in stanza four, my position as the teacher in the group could not be fully escaped. One participant felt that this role had an inherent control, that could never be left behind, stating "teachers have a massive control" and choosing *very controlled* to describe working with me. This suggests that, with the format of the research process placing me in the teacher role, even with my attempts to counteract this, this participant still felt controlled. Whilst most participants felt free in the process, this participant felt that a sense of control from a teacher was inescapable- my label as teacher-in-control could not be shed. Furthermore, one participant felt *uncomfortable* "just sometimes" but could not elaborate on why this was the case. Therefore, whilst most participants felt *free* and *comfortable* with me as researcher, further attention may be needed for all to feel this way.

Moreover, respect for confidentiality and requested privacy was important to participants' comfort, reiterating the ideas presented in "Deciding What is too Personal." Participants wanted to have control over what was known about them and would feel discomfort over it being "leaked to anyone unwanted" (Skyler). As part of a respectful relationship, participants wanted to be able to trust that I would retain the confidentiality and privacy that had been agreed, which enhanced their comfort with me. This was a process which went beyond meeting standard ethical protocols, aligning with my participatory aim to create an equitable partnership. Participants felt that in not sharing anything they wished to keep to themselves I was undertaking an equal team approach. As in the participatory research projects Nicolaidis et al. (2019) completed with autistic adults, my participants felt it was important to build and maintain trust within the research partnership. As seen in Chapter 4, my commitment to not breaking such trust, including around confidentiality, was therefore a *continuous* process, in both working with participants *and* in the presentation of data.

Stanza two also illustrates the importance of creating an atmosphere of freedom to speak "when I wanted to." Whilst participants may have wanted the opportunity to keep "private" certain views or experiences, it was equally important that they feel comfortable to talk freely when they should wish. Supportive relationships, where participants felt free to speak when they so wished, added a sense of comfort and of being in a team. As seen above, participants predominantly evaluated their relationships with me-as-researcher as *supportive* and *encouraging*; they felt *comfort, part of a team* and that they were *free* from control. Such an atmosphere made them feel more secure in sharing their views and opinions. This supports Scott-Barrett et al.'s (2018) argument of the importance of building rapport with autistic participants, to enable them to fully contribute.

I Felt Comfortable to Give My Opinion

I feel comfortable using my opinion,

when I talk to someone I trust.
I did feel comfortable because,
I could trust Miss Rice.
I felt comfortable to give my opinion,
as no matter what I said,
Miss Rice listened and supported me with it.

It was easy to express my opinions,
And I could talk freely when I wanted to.
Miss Rice was supportive of what I had to say
and prompted me when I was struggling with topics.

I felt comfortable.
When I know what I say is going to be confidential,
Unless I want other people to know about it.
Miss Rice didn't tell anyone else what you said,
unless you asked her.
She won't do anything I don't want.
It was private.

It felt uncomfortable. Just sometimes.
Teachers have a massive control.

(Connor, Fresh, Joe, Lightning, Richelle, Skyler & Wolf)

The level of comfort felt by participants may also change over time. In addition to Skyler's increasing comfort with peers, as discussed previously, Wolf also moved from stating he could not disagree with me because "it takes a lot of time," to feeling he could do so comfortably by the end as "it was private." This shows how building trust and relationships, with the researcher or peers, made participants feel more comfortable to provide their views once they felt they were with "people I know" (Connor & Harrison). This mirrors the findings in Scott-Barrett et al. (2018) that a longer-term project can enable relationship building between participant and researcher, whilst becoming a ‘known adult’ can increase the comfort felt by the young people involved in a study (Clark & Moss, 2005). This perhaps highlights how time to build such relationships may be necessary in a research project (Scott-Barrett et al., 2018).

To conclude, participants evaluated their relationship with myself-as- researcher. The importance of building trusting relationships over time was evident. Participants wanted to form respectful relationships, where they could rely on the researcher’s adherence to ethical principles: maintaining their desired confidentiality, and not pushing them to reveal what they may not be comfortable to do so. They also wanted me to be supportive, aiding them in communicating what they wished to share. Such actions were viewed by participants as enabling the building of an equitable team, who supported each other, without judgment. Overall, participants gave positive evaluations of their relationship with me. However, although most felt *free* and *supported* in this relationship, one warned that I could never completely escape the inherent control of the role of teacher, even within the participatory approach employed.

8.5. Participant Validation: Value, Comfort and Control

The fourth theme was participants’ evaluation of their validation of the research questions and my initial interpretations of their data. Participant questionnaire responses gave a predominantly positive evaluation of these aspects, identifying them as *enjoyable*, *useful*, and *interesting*. When discussing the project foci, participants had varied views on which research areas were of most importance to them. In this, they considered immediate personal benefits, such as research as a cathartic exercise, and longer-term wider benefits, such as school issues being identified and subsequently addressed. When considering my initial interpretations of the data, participants showed a willingness to disagree and to clarify their views, something which was evident throughout the project. However, some participants felt controlled by, and uncomfortable with, the participant data summaries, which provided my initial interpretations, even if they still felt comfortable to disagree. Whilst this process may have enhanced the accuracy of representing participant views, it did not necessarily enhance feelings of control and comfort for all.

8.5.1. Validating the Research Questions

Participants felt positively about being able to provide their views on the research questions. Whilst some responded in neutral terms, participants mainly considered this a *useful, interesting,* and *enjoyable* process. Providing views on the research questions was therefore predominantly evaluated as a positive aspect of the research study. Participants valued the opportunity to "validate" the research project focus (Chown et al., 2017, p.727).

In group discussion, all proposed research questions were categorised as most important or relevant by one or more participants. This validation process therefore enabled a realisation of the participatory ideal, that research questions should be considered relevant and worthy by the autism community (Chappell, 2000; Macauley et al., 1999). However, participants expressed a *range* of perspectives, with some choosing all the research questions, whilst others selected only one or two as most important (Figure 36). Validation of the research focus again illustrated the heterogeneity in participants' views, emphasising how, even within a small group of autistic adolescents, varied views were held as to which research foci were most crucial to them. Participants' views on my proposed research questions highlighted the need to validate the research focus, hearing the views of a *range* of autistic young people, who may differ in the areas of research they wish to see undertaken.

Participants in my study provided insights on why the research questions were important to them. They felt that there was a need to research how autistic people feel and view themselves, including how outside influences, such as the school environment, can impact this. They discussed the importance of emotional aspects, feeling that I should research "things that influence the person's feelings" and "if we are happy and that matters" (Connor, Harrison & Lightning). They also felt that it was important to identify "whether or not a person is enjoying school, as well as how school is affecting them" as this was a place that does "affect how we feel" (Fresh, Joe, Richelle, Skyler & Wolf); a place that can "make… you feel bad about yourself" (Connor & Harrison). They felt it was important to identify these issues *and* to "take them away if negative" whilst trying to "use them if positive" (Connor, Harrison & Lightning). For participants, the research needed to not only identify issues but to also play a subsequent role in addressing such challenges. They therefore wanted this information to be utilised beyond the study, to address negative influences and to promote positive effects for autistic pupils. Like the autistic adults in Pellicano et al. (2014b), they wanted research to focus on how services (in this case school) can improve day-to-day difficulties for autistic young people.

Some participants also commented on the positive impact the research process could personally have, with a focus on such research questions giving them the chance to get “off their chest” things which, if “kept inside” would make them “more upset” (Fresh, Richelle, Skyler & Wolf). Participants viewed the opportunity to answer these questions as a cathartic exercise in sharing their difficulties. They therefore considered both personal benefits, with research involvement as a cathartic process, and wider benefits, with the research project’s responsibility to enable changes for autistic pupils. As such, participants aligned with participatory and emancipatory ideals, feeling that research should be facilitating improvements in the day-to-day lives of autistic people, addressing the challenges they may face (Chown et al., 2017; Walmsley, 2001).

Secondly, participants felt it was important to appreciate how different people may be, think or want to express themselves. I should know how they “prefer to answer questions and talk about themselves” as people “think different things” and have “different ways of expressing how they feel” (Fresh, Lightning, Joe, Richelle, Skyler & Wolf). They felt that being able to give their views on the research methods employed was important in recognising the differing ways they preferred to express themselves.

Overall, no research question emerged as the singularly most important. What is considered important to one autistic adolescent might not be the same for another; this community did not have homogenous views on which areas of research should be undertaken (Durham Community Research Team, 2011; Macauley et al., 1999). Green (2015) warns that emancipatory research that affiliates itself tightly with *one* perspective within the disability community can exacerbate the marginalisation of those who do not follow that same point of view. In so doing, these differing voices can be silenced from the research process. As every question had some participant validation, all research questions were therefore considered in the project, with an awareness of the benefits that participants wished such research to provide maintained.

Figure 36

Participant Views: Importance of the RQs

	C	F	H	J	L	R	S	W
Q1. How do you answer the question of ‘who am I?’	🟦	🟦		🟦				🟦
Q2. What influences how you see yourself and answer ‘who am I?’ How you feel about yourself?	🟦			🟦	🟦		🟦	
Q3. How does school make you feel positively (good) or negatively (bad) about yourself?	🟦		🟦	🟦	🟦			🟦
Q4. How successful is the way I ask for people’s opinions? Do they feel included in the decision making? Do they like or dislike the ways I have gotten their opinion?	🟦			🟦	🟦	🟦		

Note. Questions shown are the participant friendly versions, which were given alongside the official research questions.

8.5.2. Creating an Atmosphere of Being Able to Disagree

Participants also evaluated the third participatory step: offering their agreement, or disagreement, with my initial interpretations of their RQ1. data (see Chapter 4, 4.4 for details). These evaluations offered a more mixed response than those provided for validating the research questions. Commenting on my initial data interpretations (provided in individual participant summaries), chosen adjectives illustrate that this was mostly *enjoyable, interesting, useful* and *free*. However, there were several *neither* responses in participants' semantic differential scales, perhaps indicating some indifference to this format. Furthermore, five out of thirteen responses evaluated this process as a *bit uncomfortable*. The discomfort participants felt is of concern.

This discomfort was not necessarily due to having to disagree with the researcher. Participants discussed whether they felt comfortable to disagree with my initial interpretations, and in the research project overall. Six participants discussed how they could disagree with me if they had a different opinion. Participants stated that, "if I wasn't comfortable with something I could say", "it was quite easy to disagree" and that "I could disagree" (Fresh, Harrison & Richelle). They demonstrated their willingness to disagree in their individual data summaries- every participant disagreed or partly disagreed with findings at several points, subsequently correcting this interpretation, so that it accurately represented their views (Table 12).

Table 12

Participant Disagreement with Findings

	C	F	H	L	R	S	W
Disagree	1	1	2	2	3	2	3
Agree/Disagree (Partly)	8	3	1			19	3

It was important to be explicit about my position here, making clear the opportunity to disagree throughout the project, without fear of criticism or reprisal. This feeling was exemplified in Lightning's statement, "I could disagree as I was told I could at any time without question if I had a different opinion."

Participants' willingness to disagree perhaps suggests that participants felt comfortable to question the researcher, who did not automatically 'know better.' They were happy to disagree with my interpretations if needed. This could imply that they did not feel constrained by viewing me as the teacher 'expert,' with whom they must agree (Bakx et al., 2015; Kim, 2012).

An alternative consideration for participants' discomfort in reading my initial interpretations of their data is suggested by Holland et al. (2010). They found that the children and young people in their study were uncomfortable seeing their painful memories on paper. My participants may also have felt discomfort reading back my interpretations of their personal thoughts, and possibly difficult experiences, after the initial discussion had passed.

Four participants also identified this process as *controlling*. Whilst participant comment on initial interpretations may have meant that views were more accurately represented, the format employed was therefore not ideal in terms of participant comfort and control. My individual participant summaries followed Vincent et al.'s (2017) argument of decreasing the volume of text to enhance accessibility, by using bullet points. However, participant evaluations would suggest this was not appropriate for *all*. This mirrors the findings of the researcher Kenny (Scott-Barret et al., 2018), who employed an alternative visual form, a cartoon, to feedback to children with complex communication needs. This set form also resulted in mixed responses on understanding and enjoyment. Based on this, and my own approach, it could be implied that reducing the volume of text into an assigned alternate format is perhaps not the solution for feeding back interpretations. As Spiel et al. (2017) assert, it may be better to use a variety of forms, to cater for participant preference. As shown with participant views on the choice of methods given in my study, a sense of control, and comfort, could perhaps have been improved by offering more varied options to feedback on the initial findings, rather than employing a standardised findings' summary form.

Overall, participants positively evaluated the experience of validating the research questions but provided more mixed views on the findings' summaries. Discussing the research questions highlighted varied perspectives on which areas research should focus upon, illustrating how a homogenising approach may risk silencing those with differing views. The risks of a standardised format were further emphasised with the findings' summaries, which raised issues of discomfort and, for some, a sense of control. To address this, variety and a wider degree of choice may need to be implemented when accessing participant views on researcher interpretations.

8.6. The Research Environment

The final theme is concerned with participant's views on the enrichment club environment and on being part of a research project. In this, I consider how the school setting, timetabled lesson slot, and my teacher role, may have influenced my participatory aim- of participant empowerment.

Participants evaluated both the enrichment club aspect and the research project elements as being predominantly *enjoyable* and *fun*. These positive feelings were linked to the sense of choice and freedom participants felt, along with their appreciation of being able to socialise with peers. When comparing the enrichment club format and the research project, participants' felt the research elements were more *difficult* and *uncomfortable*. This is perhaps due to the discomfort participants previously identified around the personal, sensitive research topics discussed. In addition, whilst some participants felt "honoured" to have been chosen for the club, others felt that this meant they had an obligation to stay. Participant evaluations were largely positive, with several of the participants feeling they "wouldn't change anything." For those who desired changes, these were focused on having more of something they had undertaken rather than changing the process followed.

This section now focuses on participant views on the enrichment club, concluding with perspectives on the research project elements involved.

8.6.1. Choice and the Enrichment Club Setting

The enrichment club environment was predominantly evaluated positively, with the club being viewed as *enjoyable, fun* and *comfortable*, although some did find it *difficult* at times. Participant views on why the club was evaluated in a positive manner are represented in the poetic transcription “Are We Doing This Club Next Year?” The first stanzas illustrate how the club moved away from the pressures felt in other lessons. Participants enjoyed the option to make choices or “change[s]” based on their preferences. This sense of freedom was part of what led participants to feel that they were not in “a lesson.” This possibly illustrates that the participatory, choice-based format of the club diminished the control of the structured lesson, dominated by the teacher in charge and the school rules that they enforce (Thornberg, 2009). My hope is that this differing atmosphere somewhat countered the sense of “schooled docility,” which can exist within the school environment (Gallacher & Gallagher, 2008, p.506). Additionally, they enjoyed the social aspects of the club, such as getting to talk to “other people,” like the adolescents in Holland et al.’s (2010) project. These positive feelings led one participant to ask on several occasions, “are we doing this club next year?”

It must be noted that a sense of freedom from control was not necessarily present for *every* participant with regards to their choice in joining the club, as shown in the final stanzas. Whilst it was reiterated at several points that they could leave at any time; participants may have felt obliged to take part due to being “chosen” for a place in the club. Indeed, Harrison felt he had missed out on another option due to being “promised a guaranteed spot” in my enrichment group. The reiteration of being able to leave at any time may have therefore not have been sufficient, with participants feeling obligated to take part. Feelings of a “guaranteed spot” meant they had to partake. The first session, which clarified participants’ choice was perhaps too late. Harrison already felt obliged to be part of the group.

This case exemplifies Holland et al.'s (2010) warning, that the researcher needs to be wary of only seeing when a participant actively resists, missing those who feel they must follow expectations. I was explicitly aware of another participant, Richelle being sent back to the club by other school staff to finish her work after the second term. For this participant, I was able to offer direct support in moving against such a requirement whereas, as Holland et al. warn, Harrison's sense of having to follow his obligation was missed until his final evaluation. Participants remaining in the club may also have been influenced by the school context and its rules, where changing enrichment clubs was frowned upon by school staff, regardless of the researcher's reassurance about being able to leave. Even though I followed the researcher Kenny's comment (in Scott-Barrett et al., 2018) to offer consistent reminders, the school environment may have overridden this. In terms of leaving the club, a sense of "schooled docility" could have remained (Gallacher & Gallagher, 2008, p.506).

However, for Skyler, being invited to the club was a positive; she felt "honoured" to have been "picked", whilst Richelle was comfortable to state her desire to leave after two terms to undertake a different club. These mixed views illustrate how the process of invitation and withdrawal was clear and effective for some, but not for others, emphasising the heterogeneity of research processes needed for this group.

Are We Doing This Club Next Year?

It almost feels like it's not a lesson.
It doesn't even feel like a lesson.
It's just a chill lesson; it's like it's not even a lesson.

You're just like talking to other people,
And it's the only lesson pretty much,
Like had a chance to change it.

The club is very open,
and it doesn't force anyone to do anything.
If someone doesn't want to do something,

No one is willing to force anyone to do anything.

Are we doing this club next year?

Well there wasn't really that big of an option choice was there.
You haven't chosen it.
I didn't pick this enrichment.
No one did; we all got chosen.
I couldn't do snooker
Because we were promised a guaranteed spot.

She could've picked anybody,
but she chose to pick us.
I feel honoured, like I've been picked,
like I've been chosen for this.

(Connor, Harrison, Skyler & Wolf)

8.6.2. Keeping the Project the Same

Being part of a research project was also seen as predominantly *enjoyable* and *fun*. In contrast to the enrichment club environment, it was evaluated as more *uncomfortable* and *difficult*. As discussed earlier, participants had identified both the sense of self topic, and sharing personal information, as *difficult* and *uncomfortable*. This is perhaps why they perceived the research project, which focused on these topics, in the same way.

These views did not necessarily mean that participants wanted the research process to be changed, as shown in the poetic transcription "Keep it the Same." At the end of the process, most stated that they would not alter how we had completed the research project- there were not "any bad things" and everything was "within reason," as shown in stanzas one and two. Participants felt the choices available and the freedom they experienced were a positive element. Alongside this, the opportunity to socialise, and "having a laugh" were positive features, illustrating the atmosphere of humour and enjoyment present in the project. This could suggest that I met my aim of enabling a culture which moved away from the room controlled by the authoritarian adult, to being a researcher who creates a fun and free relationship (Corsaro & Molinari, 2008). Moreover, participants appreciated being part of something "important" and helping me with the research, showing the value participants could feel in taking part. One participant also felt I had contributed to their knowledge as "I also learned some things." The poem then moves to explore any changes participants wanted to see. These changes were methods or groupings we had undertaken, that they wanted to see more of, rather than altering the format of the study. This perhaps illustrates their satisfaction with the way the process was undertaken.

Keep it the Same

There aren't any bad things.
Change nothing- everything was OK,
Nothing- I am alright with it how it is.
Nothing- I feel that everything in the project is within reason.
I wouldn't change anything about the research project.
I wouldn't change a thing.

Nothing- I was free to choose anything I wanted,
and any method of explaining my opinions for research,
and the project felt comfortable and free.
I didn't feel restricted.
I understood what everything was about.

Having fun in it, having a laugh,
My best mate being in it- cool people,
Being able to add in a pun,
every now and then.

You get to be part of something,

made me feel part of something important,
I have some ideas about myself that others don't,
which can be used to help Miss Rice.
I also learned some things.

Do more filming and PowerPoints,
more activities like drawing,
computer room more often,
increase class size and sample size,
and more collaboration.

Being part of the project felt good.

(Connor, Fresh, Harrison, Lighting, Richelle, Skyler & Wolf)

Overall, participant evaluations of the club and the research process were positive, but did identify some areas of improvement, which would enhance participant comfort and control. Positive aspects were socialising with peers, fun, enjoyment and humour, the sense of freedom from control and being involved in something important. Whilst there was some discomfort or difficulty with the research topic, this did not mean participants wanted to change the way the project was undertaken. They had a predominantly positive experience. However, an awareness of the feelings of obligation of a school-based research project, possibly from others beyond the researcher themselves, was highlighted as an area of concern.

Having considered all areas of participant evaluation of the participatory process, I now conclude with the key findings, for RQ2.

8.7. Conclusion

A high level of sensitivity was needed to ***address the heterogeneous range of method choices/ modes of communication required to meet autistic young people's varied***

research preferences, to ensure accessibility for all. ***Appreciating this complex variation throughout the research process***, and therefore enabling maximum participant involvement, is an essential element in meeting participatory and emancipatory aims. This suggests an evolving process of adaptation sensitive to participants' diverse needs. In this, participant views illustrate how ***a choice-based methodology can enhance participant contribution by increasing comfort, confidence, enjoyment, motivation, freedom, and a sense of being valued as an equal partner,*** which was important to the participants involved. Avoiding assumptions, particularly those which infantilise participants, further supports participant equality and empowerment.

A difficult or personal research topic does not mean that participants want to avoid sharing their views. These barriers do not mean that autistic adolescents' voices should be excluded from involvement in a study. Instead, the insider evaluations presented here provide insights into how control over which areas of the research topic are discussed, and with who, can further increase participant comfort. This sense of comfort is also enhanced through ***respectful, trusting and supportive relationships***, which build over time, enabling autistic adolescents to be comfortable when sharing their views. To enhance ease of response, it was therefore evident that choice over *what* was discussed, and with *who*, was as equally important as *how* this was discussed.

In addition to research methods and topic, participants also evaluated the research environment. The ***club environment was a positive influence on participants' experience. Enabling desired social opportunities and freedom of choice***, which supported my aim to break down the power differential of teacher-student in the school environment. However, participant evaluations suggest that this was not completely successful and that contextual influences contributed to a sense of diminished control, highlighting the influence the context can have on participatory aims.

A participatory element that was a particular area of success was the validation of the research questions. This again emphasised the heterogeneity of autistic participants' views on which topics should be focused on, whilst commonality was seen in their desire for such research to enable improvements for autistic people. Participants also had varying views on the set format in which they provided input on researcher interpretations. This further emphasised the need for a ***choice of varied forms across all areas of the research process.***

In summary, participants highlighted how a high level of sensitivity, respect and evolving adaptation is necessary to address the ***complex variation*** in autistic young people's research preferences. This is ***a heterogeneity that needs to be considered across the research process,*** to enable maximum participant involvement. Participants' evaluations suggest that such a rarely taken, participatory, choice-based approach can have a positive impact on their research experience, where "everything in the project [was] within reason." This increased comfort and enjoyment can improve participant motivation to provide their views. Comparison with traditional, assigned methods further evidenced how a choice-based methodology could enable a fuller response, and, in so doing, challenge deficit narratives around the sense of self. This supported the argument that traditional methods constrain autistic participants, perpetuating deficit narratives, particularly those around sense of self.

This chapter has offered insider insights on a seldom employed research approach, with autistic participants choosing from a *range* of research methods, which were *further* adapted to meet their communication preferences. These detailed evaluations have addressed the dearth of insider, participant perspectives on the participatory research process for autistic young people. This builds on previous studies, which have focused on the researchers' evaluation of working with these groups (Ellis, 2017; Scott-Barrett et al., 2018). This insider approach is important, due to the disconnect which may be seen between researcher and participant perspectives on the research process (Pellicano et al., 2014a). The chapter has therefore provided insights for future participatory research with autistic young people, which can support autistic voices to be prioritised in following research.

The dissertation now draws together the implications for future practice and research from both discussion chapters, in my concluding chapter. This following chapter considers the limitations present in this research, alongside the overriding contributions to knowledge obtained.

Chapter 9: Conclusion

In this chapter, I provide the final reflections for the project, drawing out the key findings from the study and considering their implications for future practice. Dissemination plans are discussed, which, in line with participatory and emancipatory approaches, aim to enable positive change in practice for autistic adolescents. The limitations in fully meeting my research aims are considered. Within this, I discuss the adaptations and foci for future research, which would address such limitations. The chapter concludes by reiterating the contribution to knowledge offered by this research.

9.1. Key Findings and Implications

This section clarifies the global findings for each research question, considering their further implications for practice.

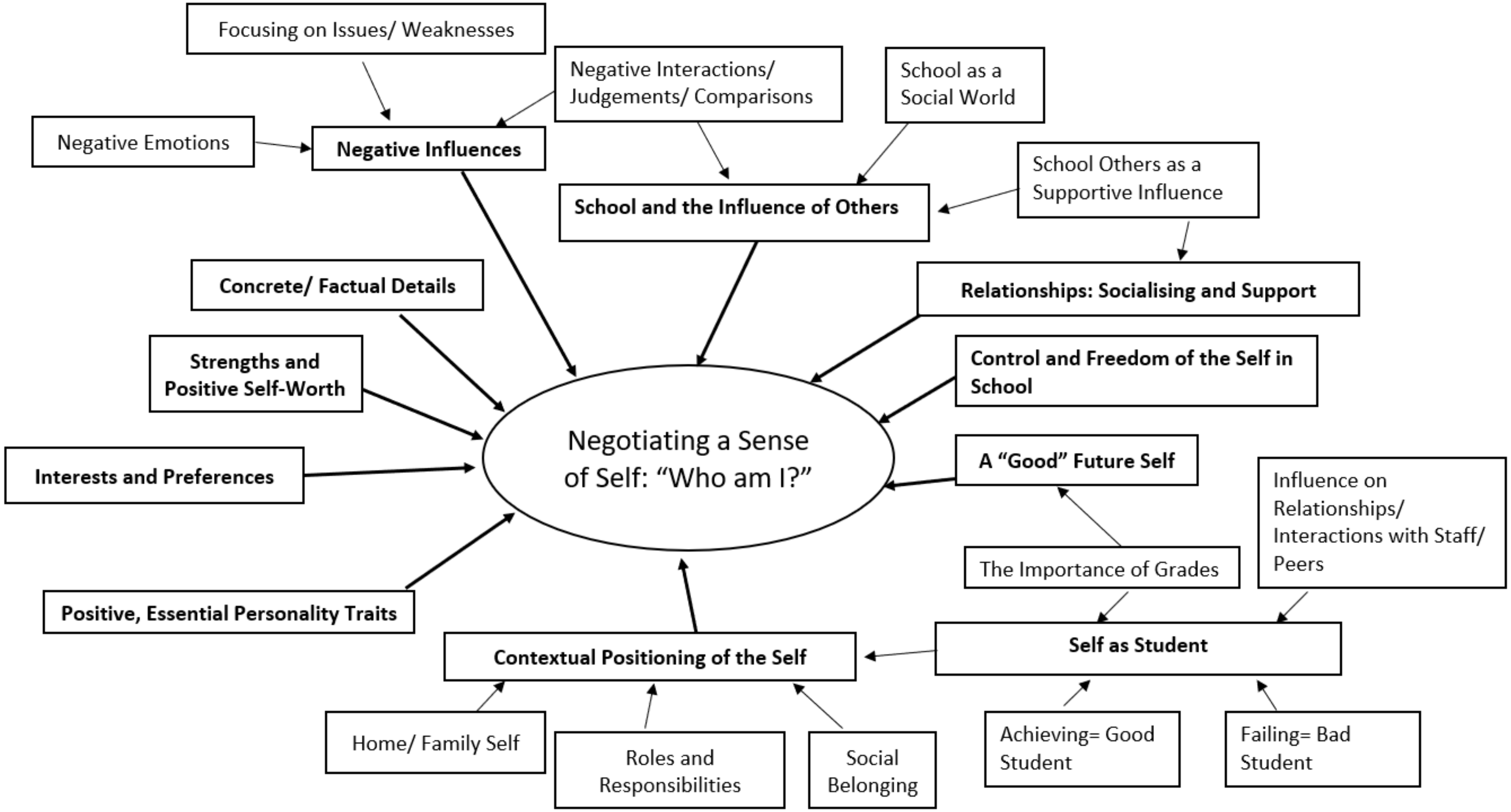
9.1.1. RQ1. How do Autistic Pupils Negotiate a Developing Sense of Self?

RQ1. considered how autistic adolescents' present, conceptualise, and evaluate their sense of self, from an insider point of view. Within this, I addressed a gap in research, by considering *how* this sense of self is influenced by, and presented in, the specific social environment of the mainstream secondary school.

The findings for RQ1. highlighted the complexity of the reflective self-view of the autistic adolescents involved. This is represented in Figure 37, which illustrates the multiple aspects considered by participants, when reflecting on the question of 'who am I?'

Figure 37

Autistic Adolescents' Complex Sense of Self



Participants demonstrated a reflective and evaluative sense of self, which considered self-distinctness and continuity as well as physical, active, psychological, and social aspects. Social influences included interpersonal relationships and interactions and the expectations associated with the various social roles that these participants fulfilled. These discussions illustrated how the autistic adolescents involved actively presented themselves according to the social context. Participants demonstrated a nuanced awareness of the changes that may need to be made to meet social expectations and aimed to promote the acceptance of others. This could entail positioning the self away from ‘abnormal’ differences and towards socially accepted strengths and behaviours, protecting themselves from negative social reactions.

School was a key site of such social interaction. Participants considered their role as pupil as an academic *and* social role. Whether they were viewed as a good or bad pupil was marked by academic achievements and school systems. This position could entail social expectations, judgements, and particular treatment from others in the school setting, based on how they were viewed. The negative judgements and comments of others, and the upward comparisons made with better peers, had a detrimental impact on the self-view of autistic adolescents. In contrast, accepting friendships with peers and trusting relationships with teaching staff could have a positive effect. Of further importance was the positive influence of focusing on strengths and achievements whilst focusing on weaknesses had a detrimental impact on the self-view. This led participants to protect their self-view, by minimising areas of weakness in their self-description and focusing on strengths. School was associated with the future self, with academic achievements considered important for a successful future. This future could also be based on current interests, which were viewed as a marker of individuality and as a vehicle for maintaining and enhancing social bonds.

Participants’ self-conceptualisation, presentation and evaluation therefore challenges deficit, homogenising characterisations of the autistic adolescents’ sense of self. By using alternative methods, the autistic adolescents in this study were able to communicate a reflective, complex, and varied self-view, which was influenced by a wide range of social aspects. Participants were aware of how their self-presentation influenced interpersonal interactions, identifying what constituted social value and which behaviours would result in ridicule. Of particular significance are the ways in which autistic young people actively construct the self, deeply considering how the self is presented in the social context, with an aim to be positioned in a positive light. This challenges deficit discourses, which argue that autistic people lack interpersonal affect in their sense of self (e.g. Hobson, 2002; Jackson et al., 2012; Lee & Hobson, 1998). Participants' discussion of the future self, and their multi-faceted discussion of the importance of interests, also challenges reductive, deficit discourses of repetitive interests and a lack of future thinking (Farley et al., 2010; Jackson et al., 2012). Participants emphasised *their* wish not to be defined through such impairment narratives or to be characterised by 'abnormal' difference.

RQ1. led to the following implications for practice:

- Characterising autistic adolescents through homogenising, deficit stereotypes is neither consistent nor favourable with their self-view.
- Emphasising impairments has a detrimental impact on self-esteem. Autistic adolescents prefer to focus on their strengths, something which could be followed in educational practice (Berkovits et al., 2020).
- Interests can form both an important social enabler and the basis for an aspirational future self. Interest based social groups could therefore be offered in school (Saggers, 2015).
- Positive relationships with peers and staff can enable a sense of value and acceptance. Staff trust can be demonstrated through the responsibilities autistic pupils are given.
- Bullying and negative judgements from peers can heighten a sense of worthlessness. This is of relevance due to the prevalence of such bullying in mainstream secondary schools (Williams et al., 2017; Zablotsky et al., 2013). It would therefore be helpful to address the perceptions and actions of non-autistic peers, moving the focus away from the autistic adolescent, who can often feel it is their responsibility to change and fit in (Hodge et al., 2019; Saggers, 2015)
- Differing treatment is a concern for autistic pupils. They can feel pressure to mask aspects of themselves to fit in. Challenging abnormal discourses may be important to

counter this need to change, by celebrating all forms of difference as the ‘right’ kind (Bagatell, 2007; Hodge et al., 2019).

- Being a good student can enhance a sense of pride. This position may seem unobtainable if associated with top grades and rewards, which are never achieved. If stuck in a negative position viewed as unchangeable, this can have a negative impact on self-view (Capps et al., 1995). It is therefore important that autistic adolescents do not feel trapped in a bad pupil stereotype, receiving only regular punishment, and have a range of opportunities to achieve and be rewarded or praised.
- Academic, grade focused conditions emphasise an alignment between examination success and the future self. They also form part of the upward comparisons autistic adolescents make, which have a negative impact on their self-view. A sensitivity to the impact of competitive, grade-centric educational environments on self-esteem would be helpful.
- Autistic adolescents may have varying views on who their diagnosis is shared with and they may not want this to be the focus of their self-description. Whilst strengths and positive social aspects may be celebrated, there is also stigma and negative judgements to be avoided. Autistic adolescents may not feel able to claim autism as a positive part of their identity, until such societal views are addressed with their non-autistic peers (Williams et al., 2017).

These findings extend the small number of studies which have used alternative methods to counter impairment narratives of the autistic young person’s sense of self (e.g. King et al., 2017; Winstone et al., 2014). This meets my CAS aims to challenge dominant, deficit focused constructions (Orsini & Davidson, 2013). These findings have also supported my aim to enable the autistic voice to inform the development of school practice, by highlighting areas of the school experience which can have a negative or positive influence on the self-view of autistic adolescents. Within this, a sensitivity to the changes which may need to be made to school systems, and the work which could be undertaken with staff and peers is key. As shown in participants’ views, the autistic adolescent often feels it is *their* responsibility to change to meet social and academic expectations (Hodge et al., 2019). In enabling a positive sense of self for autistic adolescents, it is important to counter the sense of being the one with the ‘abnormal’ impairment, which needs to be altered, as this can have a detrimental influence on the self-view of autistic adolescents (Bagatell, 2007; Mogensen & Mason, 2015).

9.1.2. RQ2. What are the Pupils' Views of the Participatory Research Methods Employed?

RQ2. evaluated the participatory research methods employed, focusing on the autistic participants' views of these methods. This evaluation offered insider insights on a seldom employed research approach, with autistic participants choosing from a *range* of research methods, which were *further* adapted to meet their communication preferences.

Participants' views illustrated how the use of inclusive, alternative methods could enable autistic young people to communicate in ways which challenged deficit narratives around sense of self. This built on King et al. (2017) and Winstone et al. (2014), providing autistic participants views on *how* an alternative approach could enable a fuller response. These participant evaluations highlighted that a choice-based methodology, where participants have control over *how* they give their views, *what* they give their views on and *who* they share their views with, can enable increased comfort, enjoyment, motivation, confidence, and a sense of being valued as an equal partner. In contrast, autistic young people's responses could be curtailed by traditional, assigned methods, which do not support varied communication preferences. Dependant on the method employed, differing narratives about autistic adolescents' sense of self could be perpetuated- due to the influence of those methods on the depth of response that can be shared. This has clear implications for future practice, emphasising the significance of enabling comfortable communication for autistic participants- to ensure that they can fully share their insider point of view.

Ensuring such communication is of further importance when considering the desire of the participants to be heard, even on a difficult or sensitive topic, and for their views to be used to improve practice for autistic young people. Instead of considering areas of difficulty as barriers to autistic adolescents' involvement, this study highlights how participant choice and control, and respectful and trusting team relationships, can enable autistic adolescents to share their views. These team relationships included both me as researcher *and* their peers, who participants valued the opportunity to both socialise and work with on the research project. These social aspects again emphasised the researcher's role in addressing, rather than avoiding, barriers, with participants appreciating adult researcher support with mediating conflicts and with ensuring that quieter voices were heard (Holland et al., 2010; Niemi et al., 2018).

These findings highlighted the danger of assuming a lack of competence or social interest, of prescribing a best form of communication, and of presuming that autistic adolescents will not be able to access, or be comfortable to discuss, difficult or sensitive topics. RQ2. illustrated how a high level of sensitivity, respect and evolving adaptation was necessary to address the complex variation in autistic young people's research preferences. This was a heterogeneity that needed to be considered *across* the research process, to enable the participatory aim of full participant involvement in the process.

RQ2. led to the following implications for practice:

- It is best to avoid assumptions about how autistic adolescents may wish to communicate, imposing methods based on these assumptions can hamper participant response and reduce participants' sense of control (Scott-Barrett et al., 2018).
- There is not a 'one size fits all' option for research methods and modes of communication with autistic adolescents; a range of visual, oral and written forms may be required to meet varied communication preferences (Ellis, 2017).
- Motivation, enjoyment, confidence and comfort in methods can influence participant contribution, alongside feelings of freedom and being valued in the research process (Beresford et al., 2004; Mannay, 2016; Milton, 2014).
- Adaptations to chosen methods can be helpful in increasing accessibility, but must avoid infantilising participants, through assumptions of incompetence (Alderson, 2008).
- Reforming traditional interviews as conversations, with adaptations such as typing, prompts, working with peers or talking around an activity can aid in overcoming interview barriers for autistic participants (Winstone et al., 2014).

- Difficulty and/or discomfort with a research focus can be eased through participant choice and control over which topic areas are discussed, and with who.
- Trusting, supportive and respectful relationships with the researcher, and with peers, are important, relationships which often need to build over time (Scott-Barrett et al., 2018).
- Autistic adolescents may find working with peers enjoyable. In this, they may appreciate adult researcher support with mediating conflicts and ensuring that quieter voices are heard (Holland et al., 209; Niemi et al., 2018).
- A club can offer an enjoyable social space within which research can be undertaken. If in a school environment, the researcher may have to be wary of contextual expectations, which can influence a pupil's freedom of choice (Gallacher & Gallagher, 2008).
- Validating RQs, whilst retaining an appreciation of the heterogeneity of views which may exist within the autistic community, is a valuable participatory step (Chown et al., 2017; Durham Community Research Team, 2011).
- Variety and choice of approach can be extended to the participatory step of participant input on the interpretation of data (Spiel et al., 2017). An appreciation of the discomfort seeing difficult experiences re-presented may entail is also helpful (Holland et al., 2010).

As discussed, participants wanted their views to have a positive impact on practice for autistic adolescents. This aligned with my own stance, influenced by participatory and emancipatory approaches, which focuses on improving the lives of the community, through an insider perspective (Chown et al., 2017; Macaulay et al., 1999). I now discuss how I aim to achieve this- through dissemination.

9.2. Dissemination

To have impact on practice, my research needs to be accessed by a *range* of stakeholders and research users, many of whom are outside of the research community (Lakey et al., 2014; Morton, 2015). Stakeholders include parents, educational staff, and practitioners from outside of the school setting. Dissemination therefore needs to be accessible, to ensure these research users can act on findings, and disseminate to others, to further inform knowledge and understanding and policy and practice changes (Morton, 2015; Ross & Morrow, 2016).

Consequently, my findings are disseminated through poetic transcription and word clouds, which provide accessible, affective and engaging forms (Carroll et al., 2011; VanWyk et al., 2012; Viégas et al., 2009). Dissemination will be direct to research users, and through knowledge brokers, such as professional bodies or lobbying groups (Lakey et al., 2014). For example, I have already disseminated my work to trainee teachers and learning support staff, to autistic and non-autistic academics, parents and young people at the Scottish Autism conference and to parents and teachers at a special school event. In this dissemination, I have involved participants in the progress I have made, providing them with updates on this (see Appendix S). This aimed to make clear my commitment to their wish, that their views have a positive impact for autistic young people.

Whilst disseminating my findings, I am committed to CAS aims, focusing on fostering empathy and understanding, challenging deficit narratives, and advocating for autistic pupils, highlighting the barriers they face. As part of this, the interpretative validity of the disseminated findings must be considered. With regards to the robustness of thematic analysis, I followed a defined, methodical and transparent system led by Braun and Clarke (2006) and Attride-Stirling (2001)- as set out in Chapter 4. I ensured internal validity through a rigorous system of participant validation for the initial interpretations of their data (Cohen, Manion & Morrison, 2011). To meet my aim of achieving a reciprocal research relationship, it was vital that my interpretations be validated by the insider participant rather than by another outsider researcher. The choice of illustrated poetic transcription also enabled the presentation of all data on a theme, so that *every* participant who had contributed was included (Madill & Hopper, 2007). This provides the full story of participants' views, including any data which departs from the dominant narrative, thus providing transparency on heterogeneous ideas or experiences (Braun & Clarke, 2006; Gasson et al., 2015). Additionally, I maintained a detailed reflection on my influence on the research process and my participants (Cohen, Manion & Morrison, 2011), including in relation to meeting my participatory aims. The limitations within this are now considered.

9.3. Limitations

I now summarise the limitations to meeting my research aims, considering the implications of this for further participatory or CAS research.

9.3.1. 'Full' Participation

The participatory ideal of full participation (Bourke, 2009) was a limitation in my research project, which varied in the levels of participation achieved.

Whilst RQs were validated by the autistic participants involved (Chown et al., 2017), the initial creation of the RQs and topic focus was by me (see Chapter 4). In future research, I would want to include autistic participants at the primary stage of RQ *creation*, to enhance their control over this stage of the process.

Participants did have extensive control over the research methods employed and over *what* was shared and with *who.* They also approved my initial interpretations of their data and evaluated the effectiveness of the process (RQ2). However, in these stages, a wider choice of communication modes could have been implemented. Whilst the summaries of my initial interpretations enhanced accessibility and reduced demands on time, some participants reported that they felt *controlled* and/or *uncomfortable* in this process. The semantic differential scales, completed for RQ2, also imposed one singular form of communication. In future research, I would want to consider how the wide range of choices present in the collection of data could be available for participants in analysing data *and* in evaluating the research process. It would be worthwhile investigating whether the comfort and control that participants experienced due to the choices available in the collection of data would also extend to data analysis and research evaluation, if completed in the same form.

Participants have also not been involved in the dissemination of findings. This was due to my complex consideration of participant anonymity (see Chapter 4). I was aware of participants' desire not to share their autism diagnosis with certain groups, and to be in control of who could be trusted with this information. In respecting this decision, it would not be appropriate to ask participants to align themselves with the research project in dissemination activities, which could out their diagnosis to groups from which they wished this to be kept. I was also aware of Fletcher-Watson et al.'s (2019) assertion that not all autistic people may want to become advocates or activists for their community. Participants may wish the researcher to advocate for them as an ally, utilising the data as support for this. However, as Bourke (2009) argues being participatory entails participants *choosing* their preferred level of participation. In future research I would want to make clear the implications of dissemination to autistic pupils, gauging more clearly *their* preferences on being involved in the dissemination process.

In aiming for full participation, participatory research focuses on the enablement of participant power and control (Bourke, 2009). This was considered in relation to the contextual power dynamics of my project. In my position as lead of the enrichment club, I took the role traditionally filled by a teacher. As discussed in Chapter 4, I therefore had to counter the expectations of such a role, focusing on breaking down the expectation of pupil docility to the expert teacher (Gallacher & Gallagher, 2008). Participant evaluations suggested that I was somewhat successful in addressing this power-differential, with most feeling *free* and *supported* in their relationship with me. Although, one participant warned that I could never completely escape the inherent control of the teacher, even within the participatory approach I employed. Whilst my enrichment club did succeed in somewhat breaking down the control of a traditional lesson, it was evident that to empower participants within the school setting meant also considering the influence of others, such as peers and/or school staff, and the pre-existing power asymmetries within these relationships. Although, some benefits were seen in the school context, including the support of, and enjoyed socialisation with, peers and the environment acting as a helpful memory cue, which also provided a higher possibility of 'catching' immediate events for discussion (Holland et al., 2010). As such, further research comparing such an approach in *differing* locations, and the effect of these locations on participant power and comfort, would be worthwhile.

Finally, in taking a CAS approach, I felt conflict between my position, of prioritising the autistic voice, and my research project being undertaken by a non-autistic adult. This thesis has set out the varied methods which aimed to address this issue, by empowering participants and reducing my control in the process. As discussed in Chapter 1, I would not claim this solved the problem, or fully relieved the unease I continued to feel. However, not undertaking this research, due to being unable to adhere to an ideal of 'full' participation, would have resulted in the voices of *these* autistic young people, at this time, in this situation not being heard. Whilst I would want autistic researchers involved in leading *every* aspect of the process in future research, moving sense of self and autism research towards emancipatory levels of control, I still see value in my role in this project. Throughout, I was driven by a commitment to advocating for the young people involved, based on the needs and barriers that *they* identified. In taking a position of participatory facilitator, I enabled participants to share their experiences, within a mutually respectful research relationship (Cargo & Mercer, 2008). This was a positive relationship built on respect for participants *as* young people, rather than as objectified “monkeys in a zoo” (Pellicano et al., 2014a)- a relationship which enriched the experience for both me *and* the young people involved.

9.3.2. Contributing to a Heterogenous Picture of Autism

The small sample size, with six participants in the main study and two in the pilot, offered a richly detailed account of the sense of self of these pupils. It provided a comprehensive picture of the self-view of the pupils involved- based on their context, in their age range, at that moment in time. This small, specific sample would be problematic to generalise beyond this group. However, the heterogeneity evident in this group of 8 young people does suggest that further research, which promotes the autistic person’s chosen presentation of their sense of self, would be valuable- to enable the full appreciation of their varied and complex personhoods. Williams et al. (2017) asserts that research into the sense making experiences of autistic children in school should consider a wide range of cultures, school phases and forms. My study focuses on autistic adolescents in a mainstream UK secondary school. As such, further value could be gleaned from undertaking similar studies in different contexts and principalities, broadening consideration *beyond* the social context of this group, to include a wider array of insider perspectives.

This thesis provides autistic adolescents’ evaluations of a rarely used methodological approach. It would be valuable to obtain insider insights on this from a wider *variety* of autistic participants. For instance, my sample could all articulate themselves verbally, if necessary. It would be worthwhile investigating the value of this approach for those autistic people who cannot communicate in such a manner and who may have differing communication preferences to those involved in my study.

9.4. Key Contributions

This study has generated new knowledge on autistic adolescents' presentation, conceptualisation and evaluation of their sense of self, prioritising the identity that *they* choose to present from their insider perspective. In so doing, this study has challenged reductive deficit narratives, which suppose a homogenised, unreflective, anti-social self-view. Participants have revealed the complexity of their developing sense of self, which considers its continuous and distinct nature, is comprised of active, physical and psychological qualities, *and* which negotiates a wide range of social influences, with the self actively presented according to social context. This entails autistic young people positioning themselves away from 'abnormal' differences and towards accepted strengths and behaviours, protecting themselves from negative social reactions. This highlights autistic adolescents desire not to be defined through impairments or to be characterised by 'abnormal' difference.

This study has also addressed a gap in insider-led research which considers *how* this sense of self is influenced by the social environment of the mainstream secondary school (Williams et al., 2017). This moves beyond a focus on academic achievement (McCauley et al., 2018) or the autism label (Berkovits et al., 2020), to consider how the self-as-pupil is presented, conceptualised and evaluated as a complex social and academic role. As such, this study brings together *all* the elements of the sense of self of autistic pupils in a mainstream secondary school.

Of final significance is the methodological approach, which offered a high degree of participant choice in how data was collected, with initial choices made, which could then be further adapted to meet participant preference. This was a continuous, evolving process with adaptation made throughout. This process was evaluated by participants, to offer an insider-led evaluation of this rarely taken research approach. This offers knowledge on the benefits and challenges of a participatory choice-based study, influenced by the tenets of CAS, and undertaken with autistic adolescents. These detailed evaluations address the dearth of insider, participant perspectives on the participatory research process for autistic young people- offering insider insights for future research, which undertakes a participatory or CAS approach.

This study therefore contributes to fields of research relating to both its subject matter *and* its methodological practice. In prioritising autistic voices, the study has offered valuable insights not only in sense of self, autism, and mainstream schooling research but also for research practice. It has illustrated how an alternative choice-based approach can enable empowered respectful participation for autistic young people- an approach which could be replicated across an *array* of subject matter. This offers a key contribution to the methodological field: participatory research with autistic young people.

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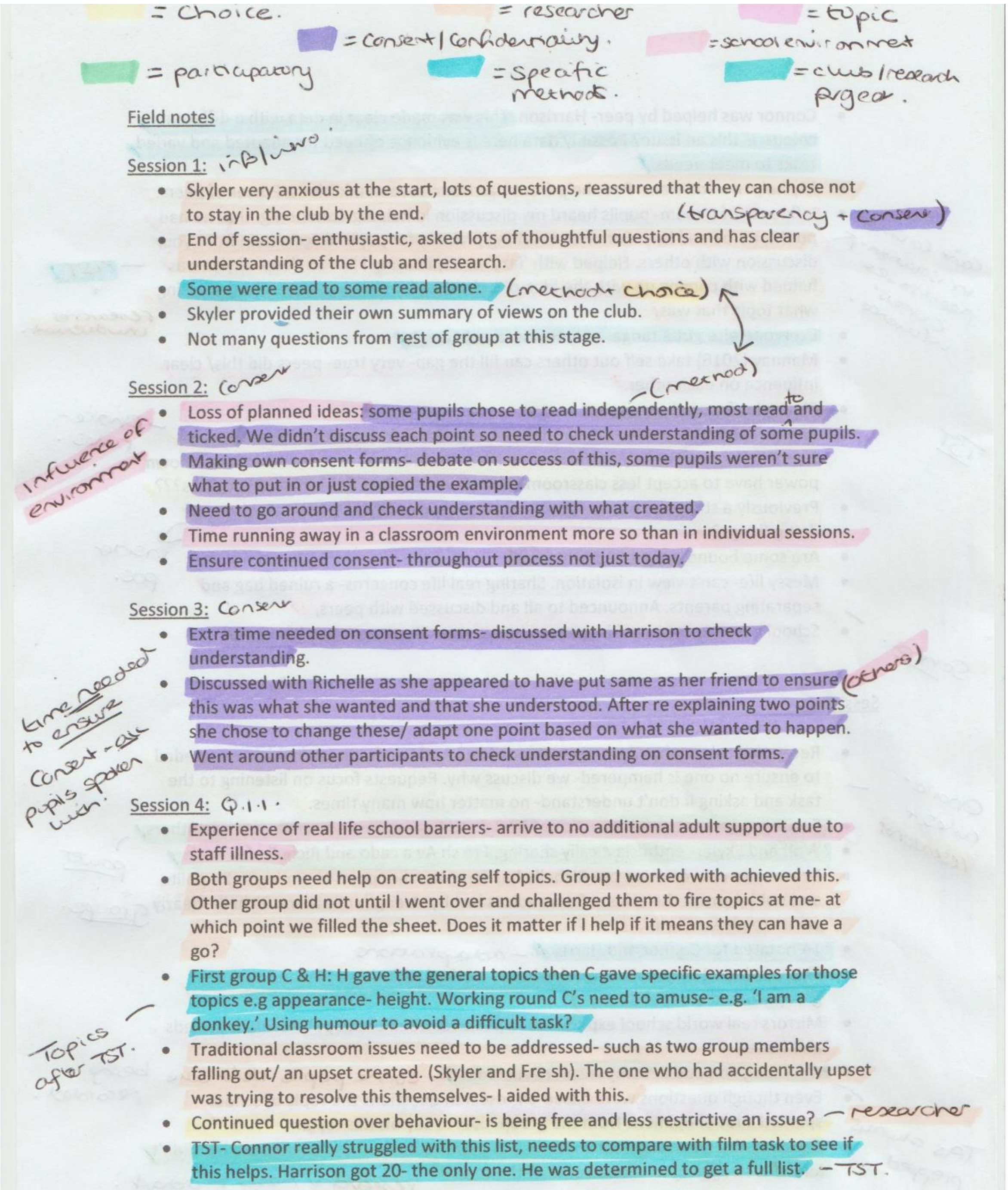
APPENDIX A

Sample of research diary reflections- typed field notes were created after each session. Colour-coding and additional handwritten notes added at the end of the project for further reflection on the process. The sample below provides examples from the start, middle and end of the project.

Figure A1.

Research Diary Example- Start of Project



🟨 = choice.
🟧 = researcher
🟪 = topic
🟪 = consent / confidentiality.
🟥 = school environment
🟩 = participatory
🟦 = specific methods.
🟦 = club / research project.

Field notes

Session 1: intro.

- Skyler very anxious at the start, lots of questions, reassured that they can chose not to stay in the club by the end. (transparency + consent)
- End of session- enthusiastic, asked lots of thoughtful questions and has clear understanding of the club and research.
- Some were read to some read alone. (method choice)
- Skyler provided their own summary of views on the club.
- Not many questions from rest of group at this stage.

Session 2: consent

- Loss of planned ideas: some pupils chose to read independently, most read to and ticked. We didn't discuss each point so need to check understanding of some pupils. -(method)
- Making own consent forms- debate on success of this, some pupils weren't sure what to put in or just copied the example.
- Need to go around and check understanding with what created.
- Time running away in a classroom environment more so than in individual sessions.
- Ensure continued consent- throughout process not just today.

influence of environment

Session 3: consent

- Extra time needed on consent forms- discussed with Harrison to check understanding.
- Discussed with Richelle as she appeared to have put same as her friend to ensure (others) this was what she wanted and that she understood. After re explaining two points she chose to change these/ adapt one point based on what she wanted to happen.
- Went around other participants to check understanding on consent forms.

time needed to ensure consent - all pupils spoken with.

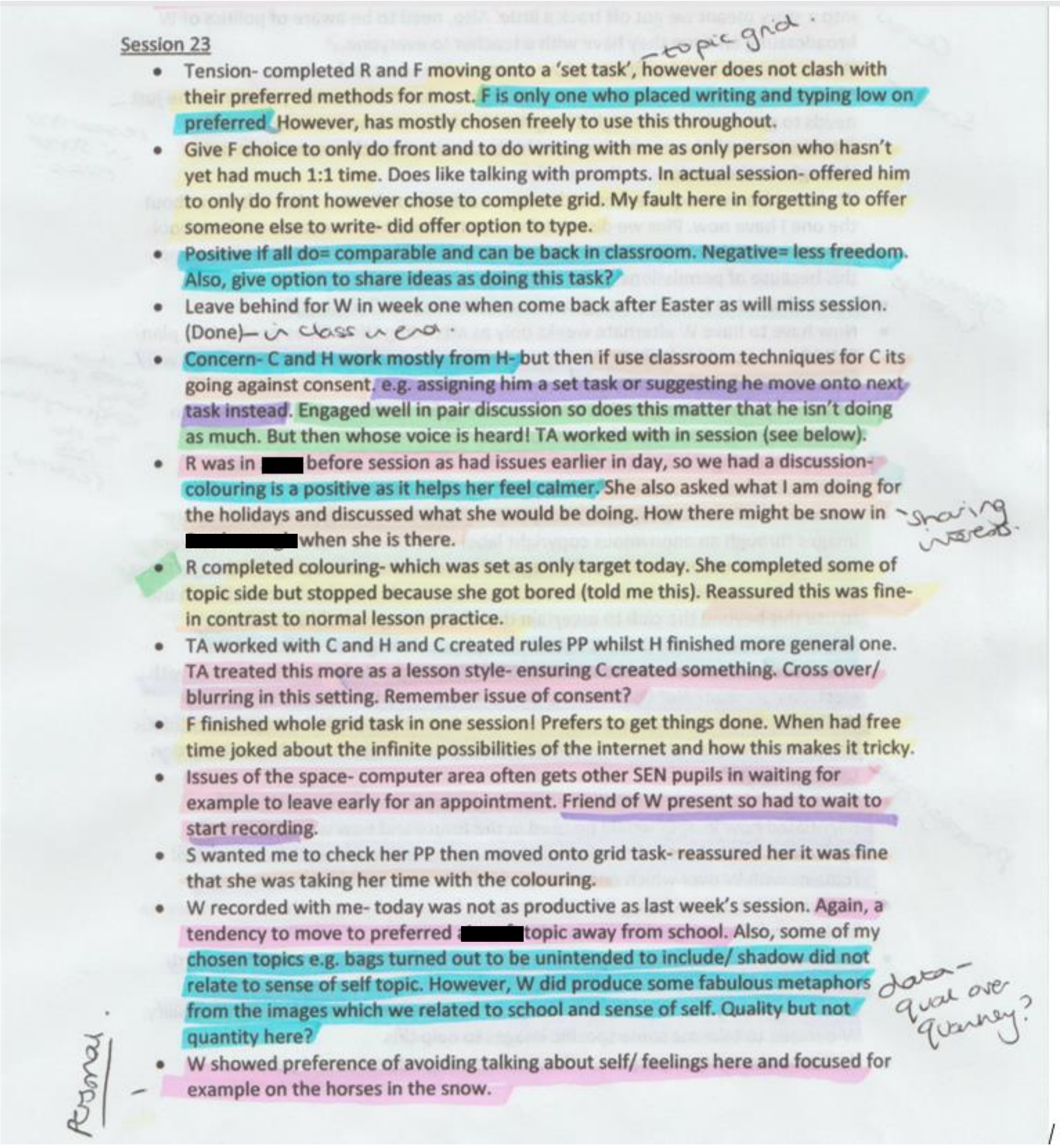
Session 4: Q.1.1.

- Experience of real life school barriers- arrive to no additional adult support due to staff illness.
- Both groups need help on creating self topics. Group I worked with achieved this. Other group did not until I went over and challenged them to fire topics at me- at which point we filled the sheet. Does it matter if I help if it means they can have a go?
- First group C & H: H gave the general topics then C gave specific examples for those topics e.g appearance- height. Working round C's need to amuse- e.g. 'I am a donkey.' Using humour to avoid a difficult task?
- Traditional classroom issues need to be addressed- such as two group members falling out/ an upset created. (Skyler and Fre sh). The one who had accidentally upset was trying to resolve this themselves- I aided with this.
- Continued question over behaviour- is being free and less restrictive an issue? — researcher
- TST- Connor really struggled with this list, needs to compare with film task to see if this helps. Harrison got 20- the only one. He was determined to get a full list. — TST.

Topics after TST.

Figure A2.

Research Diary Example- Middle of Project



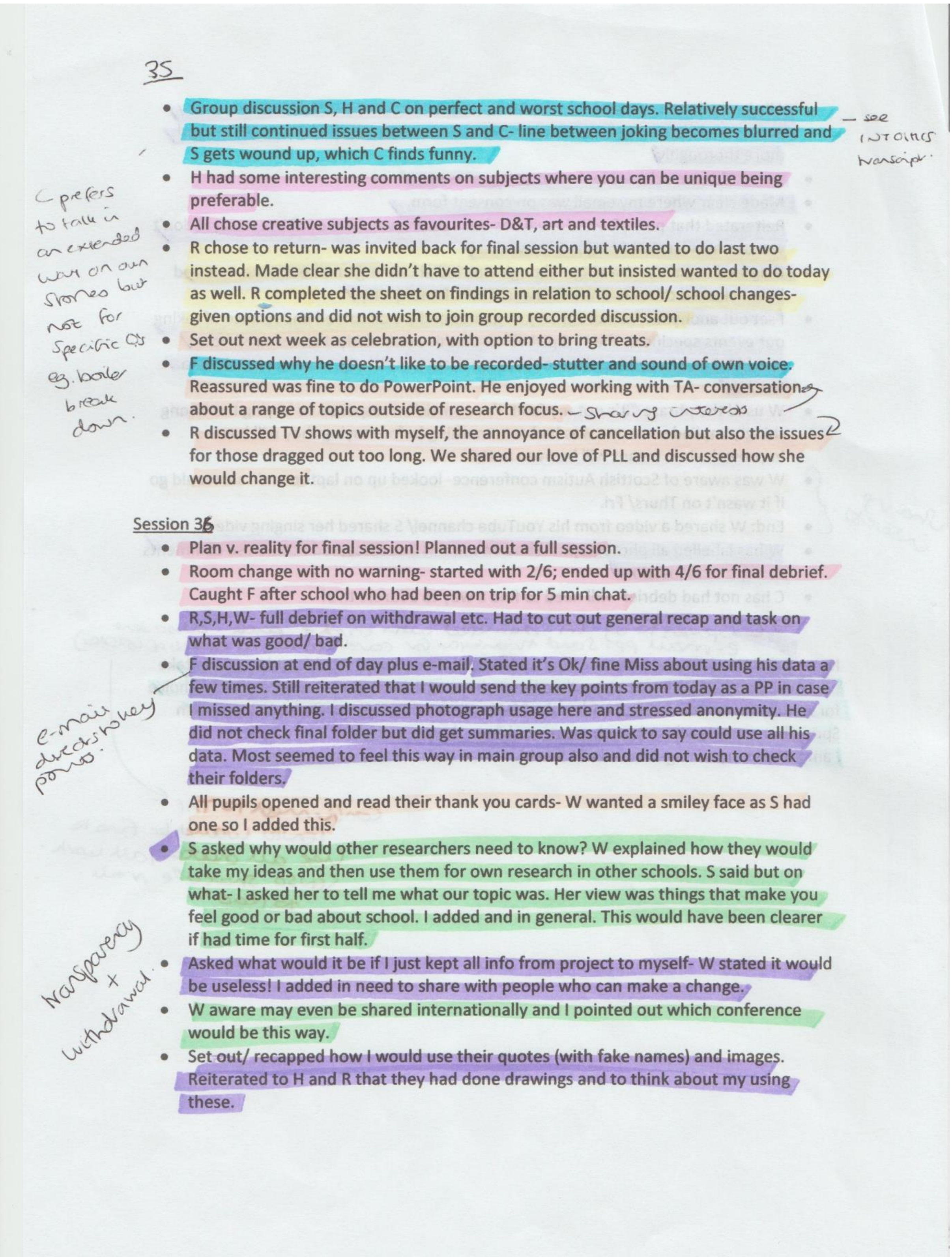
Session 23 – topic grid .

- Tension- completed R and F moving onto a 'set task', however does not clash with their preferred methods for most. F is only one who placed writing and typing low on preferred. However, has mostly chosen freely to use this throughout.
- Give F choice to only do front and to do writing with me as only person who hasn't yet had much 1:1 time. Does like talking with prompts. In actual session- offered him to only do front however chose to complete grid. My fault here in forgetting to offer someone else to write- did offer option to type.
- Positive if all do= comparable and can be back in classroom. Negative= less freedom. Also, give option to share ideas as doing this task?
- Leave behind for W in week one when come back after Easter as will miss session. (Done)– in class in end .
- Concern- C and H work mostly from H- but then if use classroom techniques for C its going against consent, e.g. assigning him a set task or suggesting he move onto next task instead. Engaged well in pair discussion so does this matter that he isn't doing as much. But then whose voice is heard! TA worked with in session (see below).
- R was in [redacted] before session as had issues earlier in day, so we had a discussion- colouring is a positive as it helps her feel calmer. She also asked what I am doing for the holidays and discussed what she would be doing. How there might be snow in [redacted] when she is there. – sharing interests.
- R completed colouring- which was set as only target today. She completed some of topic side but stopped because she got bored (told me this). Reassured this was fine- in contrast to normal lesson practice.
- TA worked with C and H and C created rules PP whilst H finished more general one. TA treated this more as a lesson style- ensuring C created something. Cross over/ blurring in this setting. Remember issue of consent?
- F finished whole grid task in one session! Prefers to get things done. When had free time joked about the infinite possibilities of the internet and how this makes it tricky.
- Issues of the space- computer area often gets other SEN pupils in waiting for example to leave early for an appointment. Friend of W present so had to wait to start recording.
- S wanted me to check her PP then moved onto grid task- reassured her it was fine that she was taking her time with the colouring.
- W recorded with me- today was not as productive as last week's session. Again, a tendency to move to preferred [redacted] topic away from school. Also, some of my chosen topics e.g. bags turned out to be unintended to include/ shadow did not relate to sense of self topic. However, W did produce some fabulous metaphors from the images which we related to school and sense of self. Quality but not quantity here? data – qual over quantity?
- W showed preference of avoiding talking about self/ feelings here and focused for example on the horses in the snow.

Personal

Figure A3.

Research Diary Example- End of Project



35

- Group discussion S, H and C on perfect and worst school days. Relatively successful but still continued issues between S and C- line between joking becomes blurred and S gets wound up, which C finds funny. — see [illegible] transcript.
- H had some interesting comments on subjects where you can be unique being preferable.
- All chose creative subjects as favourites- D&T, art and textiles.
- R chose to return- was invited back for final session but wanted to do last two instead. Made clear she didn't have to attend either but insisted wanted to do today as well. R completed the sheet on findings in relation to school/ school changes- given options and did not wish to join group recorded discussion.
- Set out next week as celebration, with option to bring treats.
- F discussed why he doesn't like to be recorded- stutter and sound of own voice. Reassured was fine to do PowerPoint. He enjoyed working with TA- conversations about a range of topics outside of research focus. – sharing interests
- R discussed TV shows with myself, the annoyance of cancellation but also the issues for those dragged out too long. We shared our love of PLL and discussed how she would change it.

C prefers to talk in an extended way on own stories but not for specific Q's eg. boiler break down.

Session 36

- Plan v. reality for final session! Planned out a full session.
- Room change with no warning- started with 2/6; ended up with 4/6 for final debrief. Caught F after school who had been on trip for 5 min chat.
- R,S,H,W- full debrief on withdrawal etc. Had to cut out general recap and task on what was good/ bad.
- F discussion at end of day plus e-mail. Stated it's Ok/ fine Miss about using his data a few times. Still reiterated that I would send the key points from today as a PP in case I missed anything. I discussed photograph usage here and stressed anonymity. He did not check final folder but did get summaries. Was quick to say could use all his data. Most seemed to feel this way in main group also and did not wish to check their folders.
- All pupils opened and read their thank you cards- W wanted a smiley face as S had one so I added this.
- S asked why would other researchers need to know? W explained how they would take my ideas and then use them for own research in other schools. S said but on what- I asked her to tell me what our topic was. Her view was things that make you feel good or bad about school. I added and in general. This would have been clearer if had time for first half.
- Asked what would it be if I just kept all info from project to myself- W stated it would be useless! I added in need to share with people who can make a change.
- W aware may even be shared internationally and I pointed out which conference would be this way.
- Set out/ recapped how I would use their quotes (with fake names) and images. Reiterated to H and R that they had done drawings and to think about my using these.

e-mail directs to key points.

transparency x withdrawal.

APPENDIX B

Parental information and permission documents- school information anonymised.

Figure B1.

Parental Information Sheet

Sheffield
Hallam
University

PARTICIPANT PARENT/CARER INFORMATION SHEET

Title of project: Sense of self and autism: the mainstream secondary school experience.

This is a PhD study that will identify what children and young people experience as barriers to the development of a positive sense of self for children and young people with autism in a mainstream secondary school. The project takes a participatory approach and will hear the opinions and voices of these children and young people in order to identify ways to enable a positive sense of self in the mainstream secondary school setting. The project will promote reflective self-awareness and a positive self-image and identify ways to counter any barriers to this. Please consider the information below and decide if you would like your child to have the opportunity to take part.

Why have you asked my child to take part?

All children and young people with autism at X are being given the opportunity to take part in the research project. No voices will be disregarded. Any pupil who chooses to take part in the research project will be included.

What will my child be required to do?

The PhD study will run alongside the enrichment club and so your child will be working on the 'Story of me' project. This is a biography style project, which will comprise of producing drawings, collages, photographs and narratives about themselves.

If your child chooses to take part in the research, once they have produced their visual materials and narratives, they will take part in an interview with the researcher. This will be audio recorded.

In addition, they will learn about the research process, creating interview questions/ surveys and getting the opportunity to disagree with and criticise current research about autism and the self. They will also be given the opportunity to evaluate the usefulness of the research methods employed.

Where will this take place and for how long?

The project will take place in the enrichment classroom at X. All visual and narrative productions will be undertaken as part of the lesson. Interviews will aim to be conducted during the enrichment lessons, however, some may need to take place in free time if the pupil is willing to do so.

The project will run for the yearlong enrichment sessions. However, if your child wishes to leave the research project, but remain in the club, this is not a problem.

When can I discuss my child's participation?

Any questions can be sent, at any time, to my e-mail address: b6036529@my.shu.ac.uk
Alternatively, if you would prefer to discuss this, please feel free to send a request for me to call you at a convenient time.

When can I and my child review the findings of the study?

Pupils will be able to see summary findings after their interviews. This will allow the opportunity to further inform the researcher's interpretation of their comments or their visual and narrative productions.

A debriefing meeting will be open to parents at the end of the school year. A summary of the overall findings of the study will be available. If you would prefer, these findings can be emailed to yourself (please send an e-mail request to the email address above).

How long is the whole study likely to last?

The study itself will be completed by the end of the PhD process (around October 2019).

How will you use what you find out?

The data collected will form part of the PhD thesis. In addition, this will be used for papers in academic journals. However, as one of the main outcomes of the project is to improve the experience for pupils with autism in mainstream schools the data could be used in any of the following ways:

- offering seminars or training to schools, local authorities and special needs bodies.

-presenting findings within training institutions to new teachers, ensuring that the new generation of educators promote a positive sense of self

- producing a ‘handbook’ for schools and parents on the findings about the sense of self and the interventions which can be put in place.

- working with The Autism Centre at Sheffield Hallam University to host a conference for people with Autism and practitioners to share findings

Will anyone be able to connect my child with what is recorded and reported?

The study will be anonymised so that your child cannot be directly connected with the findings. Therefore, no names of the children, the school, the staff or identifiable information about the people, school or area will be included. In addition, no images that the pupils produce which show identities, or contain information which allow them to be identified, will be reproduced. Interviews will be typed up and the audio deleted. These typed up versions will only be available, to anyone other than me, in a form where any identifiable information is also removed.

How can I find out about the results of the study?

If you would like to see a summary of the PhD thesis, which will be produced from the study, please send an e-mail request to the researcher’s e-mail address.

What will happen to the information when this study is over? Who will have access to it?

Any data which your child has requested not to be included in the study will not be available and will be destroyed. Audio files of the interviews will be deleted. Any data which could identify the child attached to it will be kept by myself for three years, to be analysed for other academic papers but **never** printed in these papers. It will then also be destroyed.

Anonymized data may be stored on the University repository. Here, it can be requested by other researchers. To ensure anonymization and confidentiality, I will only include the following in this access form:

- Transcripts (typed up versions) of interviews, with all answers which could be linked to your child removed.
- Photographs of your child's pieces, which do not include pictures of themselves or people they know, or information which could identify your child.
- The summary of findings which have been agreed upon by your child (again only containing abstract data which cannot be linked to your child's identity).
- My own field notes. These will only contain my own ideas, not comments on individual pupils.

If you would prefer your child's data to not be available to other researchers, please tick the box on the consent form.

What if I do not wish my child to take part?

Participation in the study is entirely voluntary and has no impact on your child's place in the enrichment club. Therefore, anyone who does not want to take part does not have to be part of the study.

What if I or my child changes their mind during the study?

Your child is free to withdraw from the study at any time, without having to leave the enrichment club and with no consequence from the researcher. Your child can also choose to withdraw any individual pieces of data, for example if they no longer want a drawing/ collage or answer to a question included. This can occur up to two weeks after I have discussed the summary of findings with your child, which each child will be provided with after their interviews.

Do you have any other questions?

Please feel free to email me with any questions at any time. The supervisors for the project are also listed below. If you would prefer, you can also contact X, the Head teacher or the SEN department of the school.

Details of who to contact with any concerns.

Researcher: E Rice- b6036529@my.shu.ac.uk

Supervisors: Professor N Hodge- **:** n.s.hodge@shu.ac.uk

Dr. L Reidy- ssllr@exchange.shu.ac.uk

Figure B2.

Parent Consent Form

Sheffield
Hallam
University

PARTICIPANT PARENT/CARER CONSENT FORM

TITLE OF RESEARCH STUDY: Sense of self and autism: the mainstream secondary school experience.

Please answer the following questions by ticking the response that applies

	YES	**NO**
1. I have read the Information Sheet for this study.	☐	☐
2. I understand that I may ask further questions at any point by using the email address provided. I have asked any questions I want answered at this point.	☐	☐
3. I understand that I am free to withdraw consent for my child’s participation from the study at any time, without reason, however, data can only be withdrawn up to two weeks after summary findings are given.	☐	☐
4. I understand that withdrawing my child from the research study will not entail them being asked to leave the enrichment club.	☐	☐
5. I agree to my child providing information to the researcher under the conditions of confidentiality set out in the Information Sheet.	☐	☐
6. I wish to give consent for my child to participate in the study under the conditions set out in the Information Sheet.	☐	☐
7. I consent to the use of images (drawings or photographs) **not** containing identifiable information to be printed as part of this research study.	☐	☐

8. I consent to anonymised data to be included in future publications, including but not restricted to conferences, journal publications and training events. ☐ ☐

9. I agree for my child’s anonymised and unidentifiable data to potentially be accessed by future researchers. ☐ ☐

10. I understand that giving my consent does not entail any obligation for my child to take part in the study. Consent is given for my child to be allowed to take part should they so wish. ☐ ☐

Parent’s/ Carer’s Signature: ____ Date: ___________

Parent’s/ Carer’s Name (Printed): _____________________________________

Contact details: ____

Researcher’s Name (Printed): Emma Rice

Researcher’s Signature:

Researcher's contact details:

Miss E Rice
Graduate School
Faculty of Development and Society
Sheffield Hallam University
Unit 9, Science Park
City Campus
Sheffield S1 1WB

E-mail: b6036529@my.shu.ac.uk

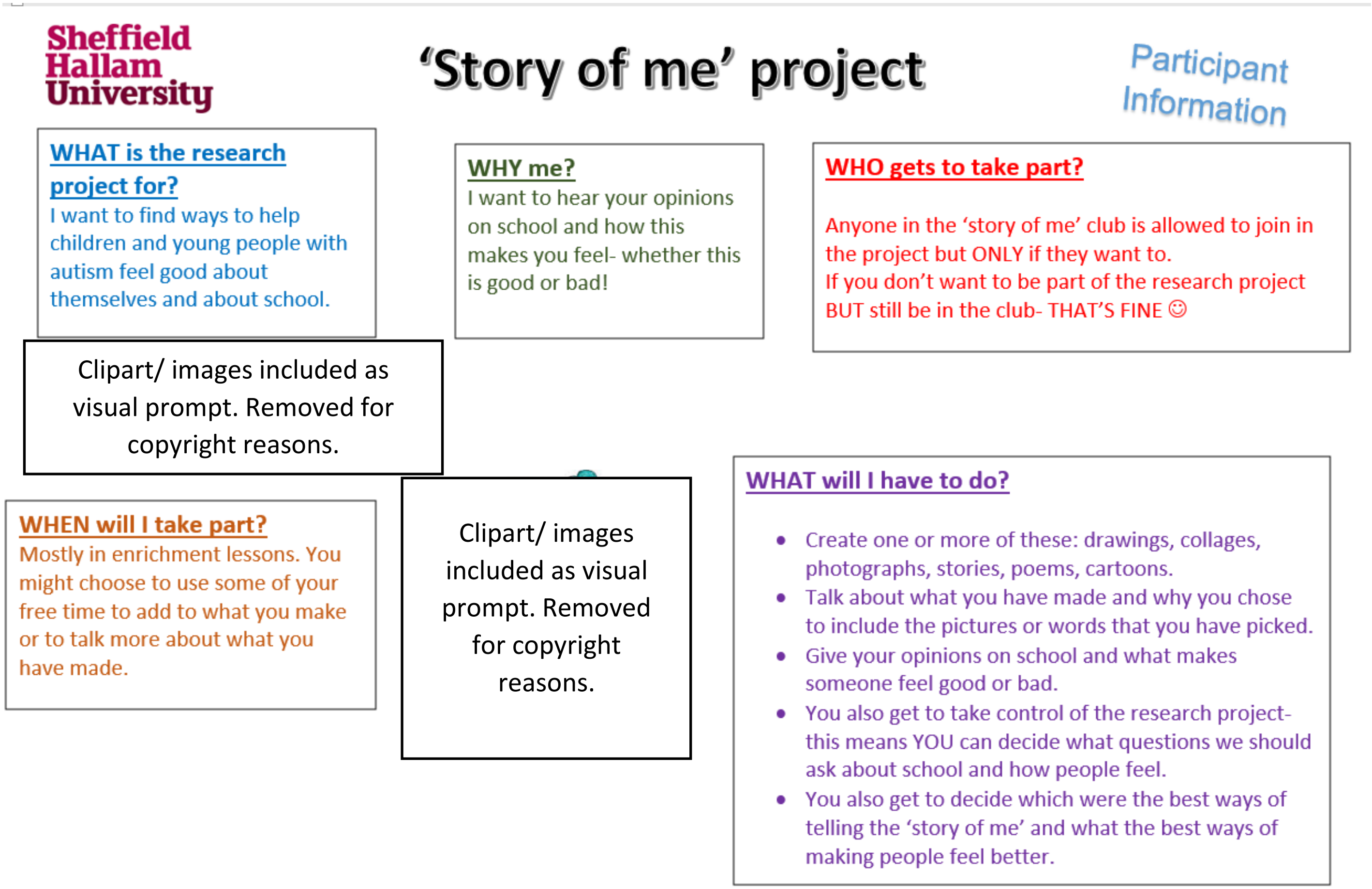
Please return one copy of the consent form and keep one for yourself.

APPENDIX C

Accessible participant information sheet- anonymised to remove school information.

Figure C1.

Participant Information Sheet- Page 1



Sheffield Hallam University

‘Story of me’ project

Participant Information

WHAT is the research project for?
I want to find ways to help children and young people with autism feel good about themselves and about school.

WHY me?
I want to hear your opinions on school and how this makes you feel- whether this is good or bad!

WHO gets to take part?

Anyone in the ‘story of me’ club is allowed to join in the project but ONLY if they want to.
If you don’t want to be part of the research project BUT still be in the club- THAT’S FINE ☺

Clipart/ images included as visual prompt. Removed for copyright reasons.

WHEN will I take part?
Mostly in enrichment lessons. You might choose to use some of your free time to add to what you make or to talk more about what you have made.

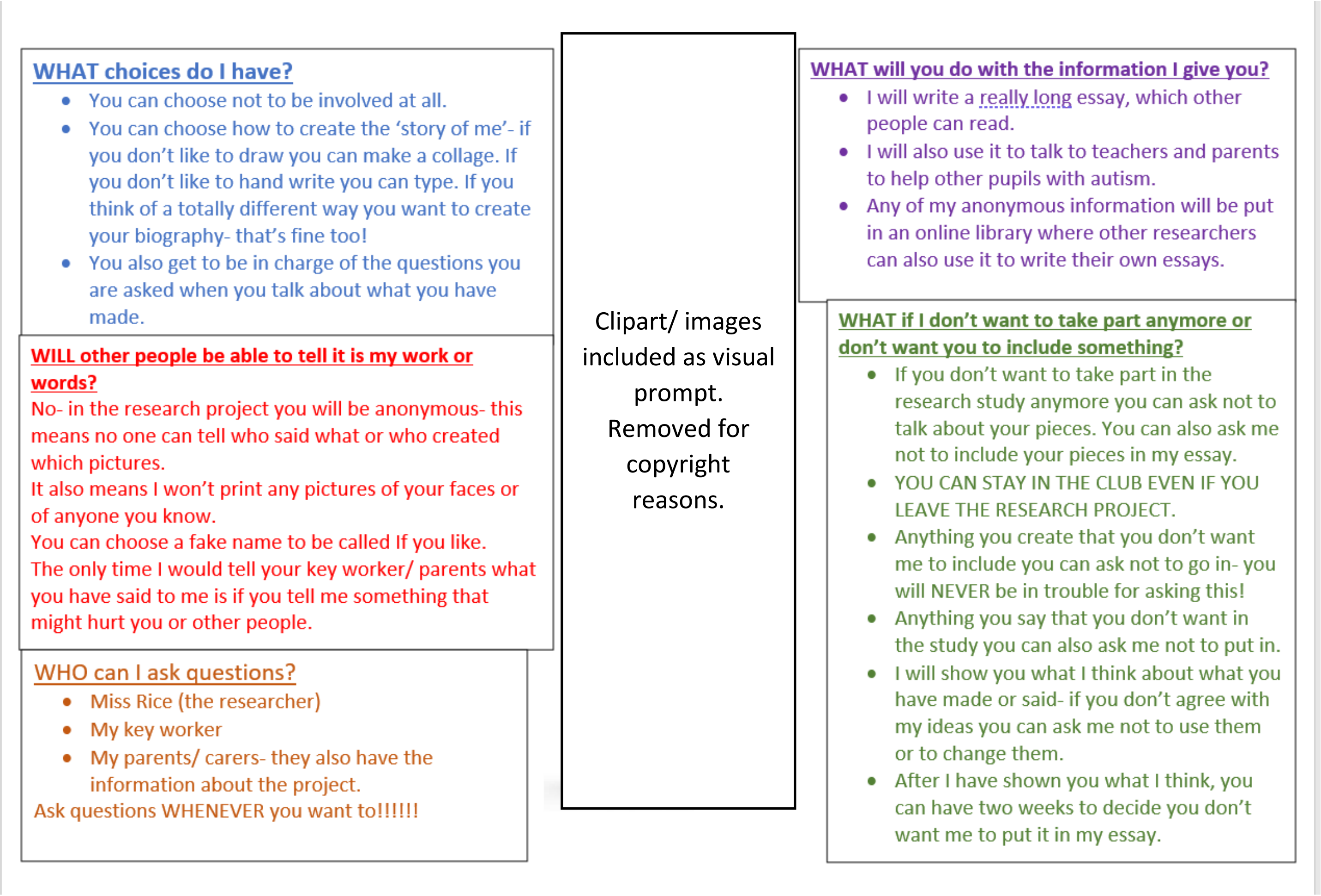
Clipart/ images included as visual prompt. Removed for copyright reasons.

WHAT will I have to do?

- Create one or more of these: drawings, collages, photographs, stories, poems, cartoons.
- Talk about what you have made and why you chose to include the pictures or words that you have picked.
- Give your opinions on school and what makes someone feel good or bad.
- You also get to take control of the research project- this means YOU can decide what questions we should ask about school and how people feel.
- You also get to decide which were the best ways of telling the ‘story of me’ and what the best ways of making people feel better.

Figure C2.

Participant Information Sheet- Page 2



WHAT choices do I have?

- You can choose not to be involved at all.
- You can choose how to create the ‘story of me’- if you don’t like to draw you can make a collage. If you don’t like to hand write you can type. If you think of a totally different way you want to create your biography- that’s fine too!
- You also get to be in charge of the questions you are asked when you talk about what you have made.

WILL other people be able to tell it is my work or words?

No- in the research project you will be anonymous- this means no one can tell who said what or who created which pictures.
It also means I won’t print any pictures of your faces or of anyone you know.
You can choose a fake name to be called If you like.
The only time I would tell your key worker/ parents what you have said to me is if you tell me something that might hurt you or other people.

WHO can I ask questions?

- Miss Rice (the researcher)
- My key worker
- My parents/ carers- they also have the information about the project.

Ask questions WHENEVER you want to!!!!!!

Clipart/ images included as visual prompt. Removed for copyright reasons.

WHAT will you do with the information I give you?

- I will write a really long essay, which other people can read.
- I will also use it to talk to teachers and parents to help other pupils with autism.
- Any of my anonymous information will be put in an online library where other researchers can also use it to write their own essays.

WHAT if I don’t want to take part anymore or don’t want you to include something?

- If you don’t want to take part in the research study anymore you can ask not to talk about your pieces. You can also ask me not to include your pieces in my essay.
- YOU CAN STAY IN THE CLUB EVEN IF YOU LEAVE THE RESEARCH PROJECT.
- Anything you create that you don’t want me to include you can ask not to go in- you will NEVER be in trouble for asking this!
- Anything you say that you don’t want in the study you can also ask me not to put in.
- I will show you what I think about what you have made or said- if you don’t agree with my ideas you can ask me not to use them or to change them.
- After I have shown you what I think, you can have two weeks to decide you don’t want me to put it in my essay.

APPENDIX D

Figure D1.

Participant Accessible Research Question Sheet

Clipart/ images included as visual prompt. Removed for copyright reasons.

These are the research questions I started with. However, I am not sure that all of them are important. What do you think of my questions? Which of these are important to you?

Throughout the sessions we are ALWAYS allowed to give our opinion on what we would add, change or remove.

1. How do autistic pupils negotiate the developing sense of self?

   How do you answer the question of ‘who am I?’

2. What do the pupils identify as having an impact on this sense of self?

   What influences how you see yourself and answer ‘who am I?’ How you feel about yourself?

3. What are the pupils’ views of the school’s enablers or barriers on this developing sense of self?

How does school make you feel positively (good) or negatively (bad) about yourself?

4. What are the pupils’ views of the participatory research methods employed in the sense of self study?

How successful is the way I ask for peoples’ opinions? Do they feel included in the decision making? Do they like or dislike the ways I have gotten their opinion?

Strangely, my hardest question is at the top so let’s go backwards!

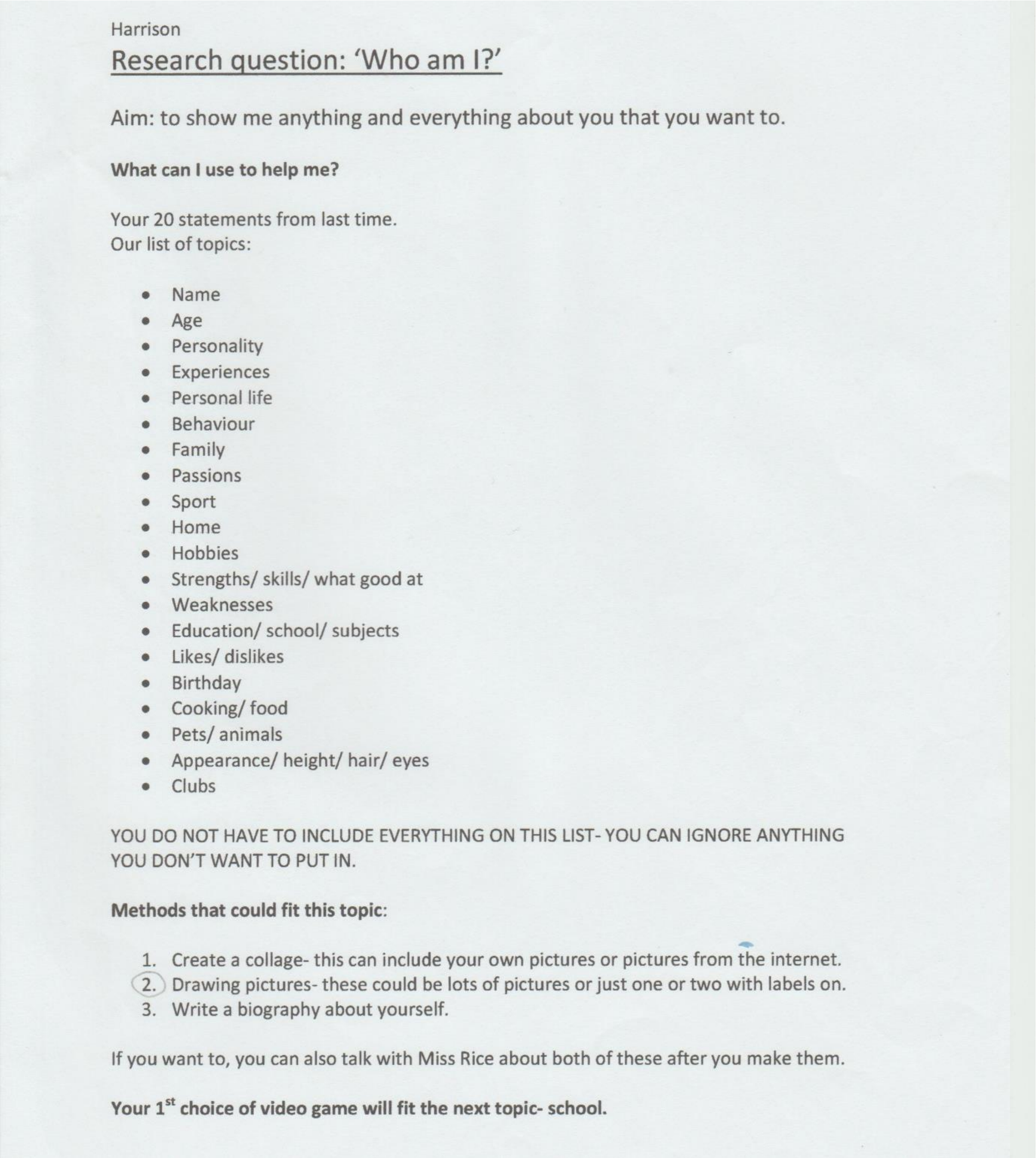
Clipart/ images included as visual prompt. Removed for copyright reasons.

APPENDIX E

Sample of suggested choices for methods given to participants to start with- based on preferences previously given. This sheet also recapped the participant-created list of possible topics to discuss when considering the sense of self.

Figure E1.

Harrison's Method Support Sheet



Harrison

Research question: 'Who am I?'

Aim: to show me anything and everything about you that you want to.

What can I use to help me?

Your 20 statements from last time.
Our list of topics:

- Name
- Age
- Personality
- Experiences
- Personal life
- Behaviour
- Family
- Passions
- Sport
- Home
- Hobbies
- Strengths/ skills/ what good at
- Weaknesses
- Education/ school/ subjects
- Likes/ dislikes
- Birthday
- Cooking/ food
- Pets/ animals
- Appearance/ height/ hair/ eyes
- Clubs

YOU DO NOT HAVE TO INCLUDE EVERYTHING ON THIS LIST- YOU CAN IGNORE ANYTHING YOU DON'T WANT TO PUT IN.

Methods that could fit this topic:

1. Create a collage- this can include your own pictures or pictures from the internet.
[✓ 2.] Drawing pictures- these could be lots of pictures or just one or two with labels on.
3. Write a biography about yourself.

If you want to, you can also talk with Miss Rice about both of these after you make them.

Your 1st choice of video game will fit the next topic- school.

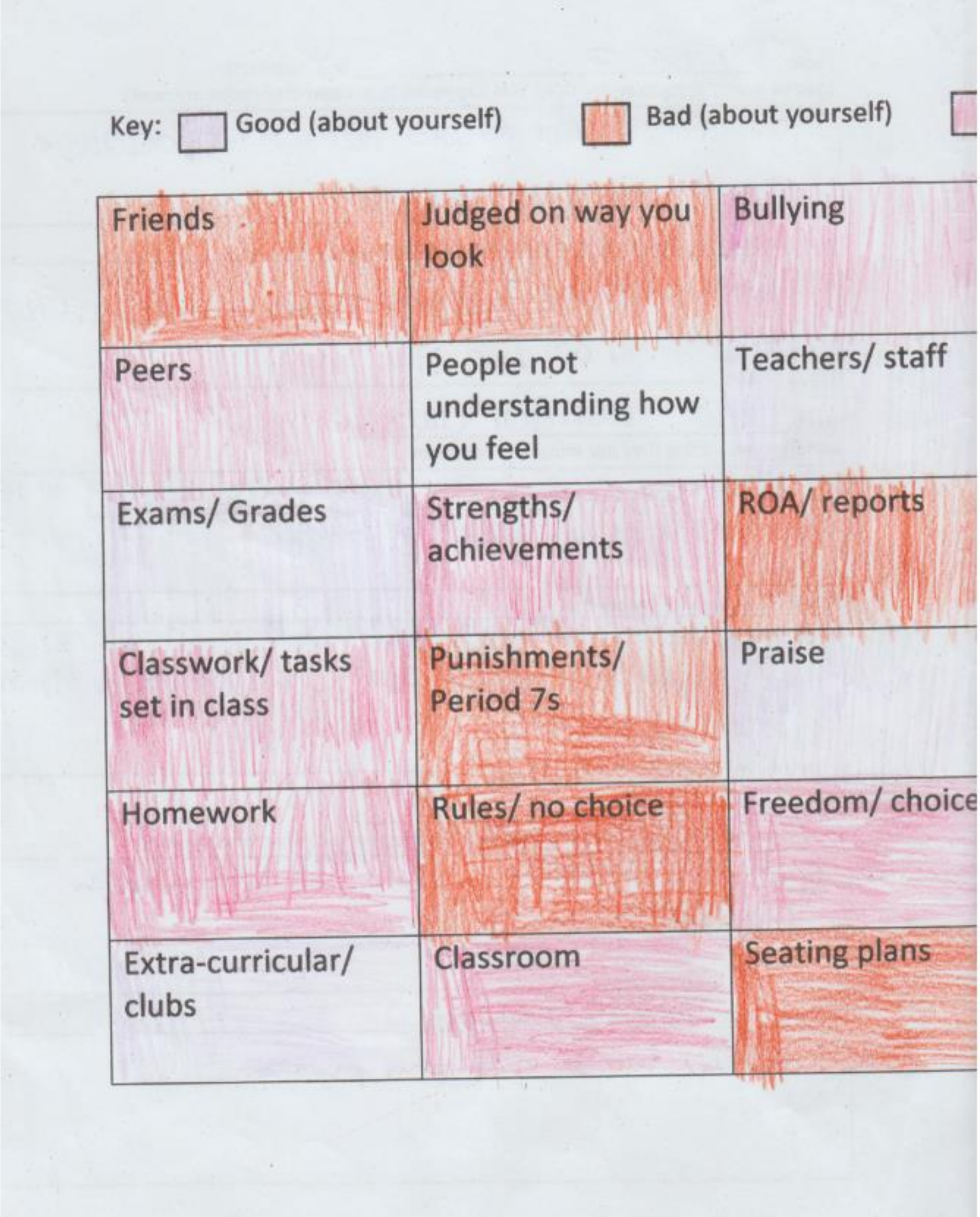
Note. Harrison circled his choice- drawing- from the three suggestions made by me, based on the preferred methods he had previously identified (see Chapter 4).

APPENDIX F

Example of school topic sort- colour-coded to show opinions.

Figure F1.

School Topic Sort: Page 1

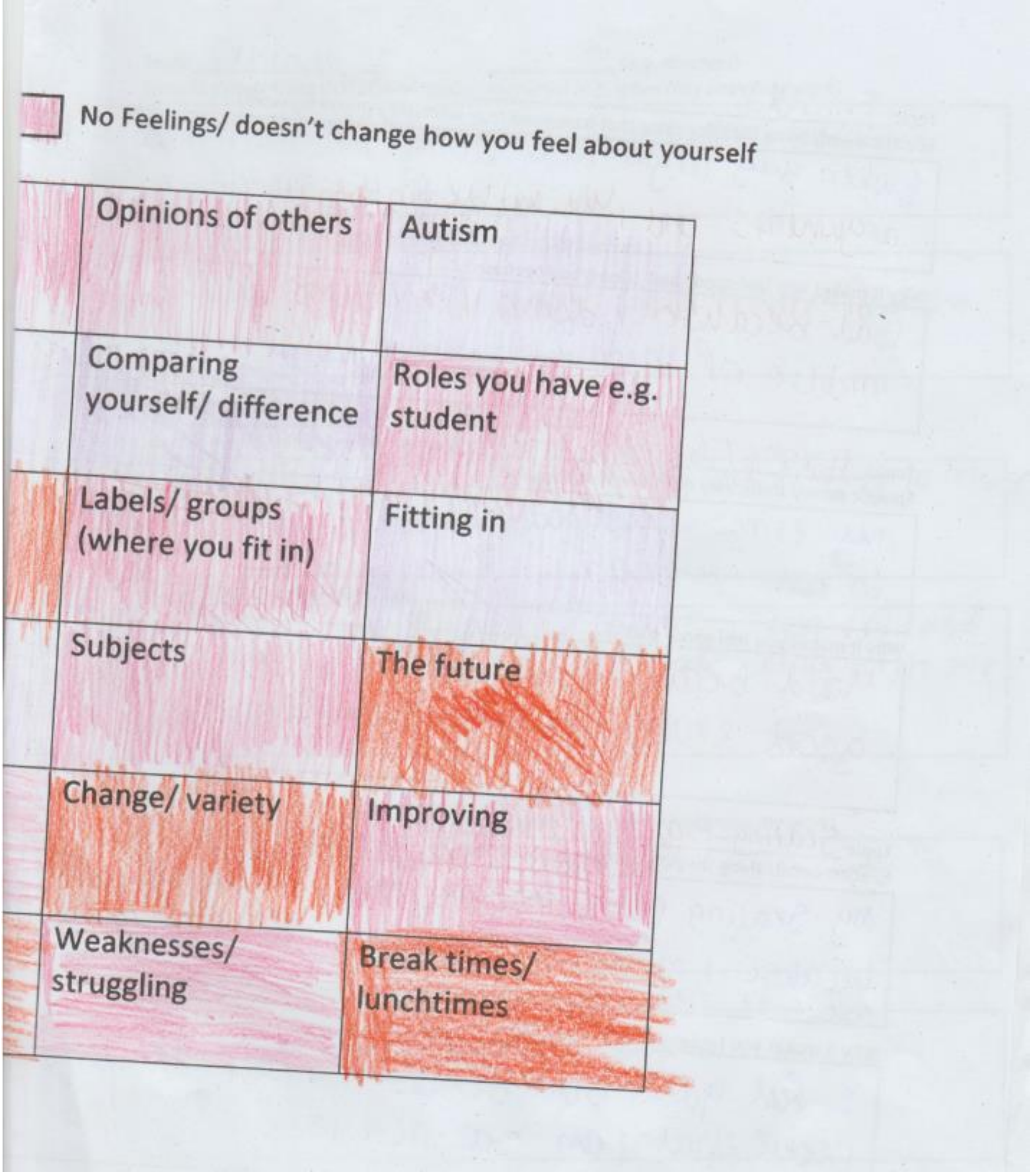


Key: ☐ Good (about yourself) 🟧 Bad (about yourself)

Friends	Judged on way you look	Bullying
Peers	People not understanding how you feel	Teachers/ staff
Exams/ Grades	Strengths/ achievements	ROA/ reports
Classwork/ tasks set in class	Punishments/ Period 7s	Praise
Homework	Rules/ no choice	Freedom/ choice
Extra-curricular/ clubs	Classroom	Seating plans

Figure F2.

School Topic Sort: Page 2

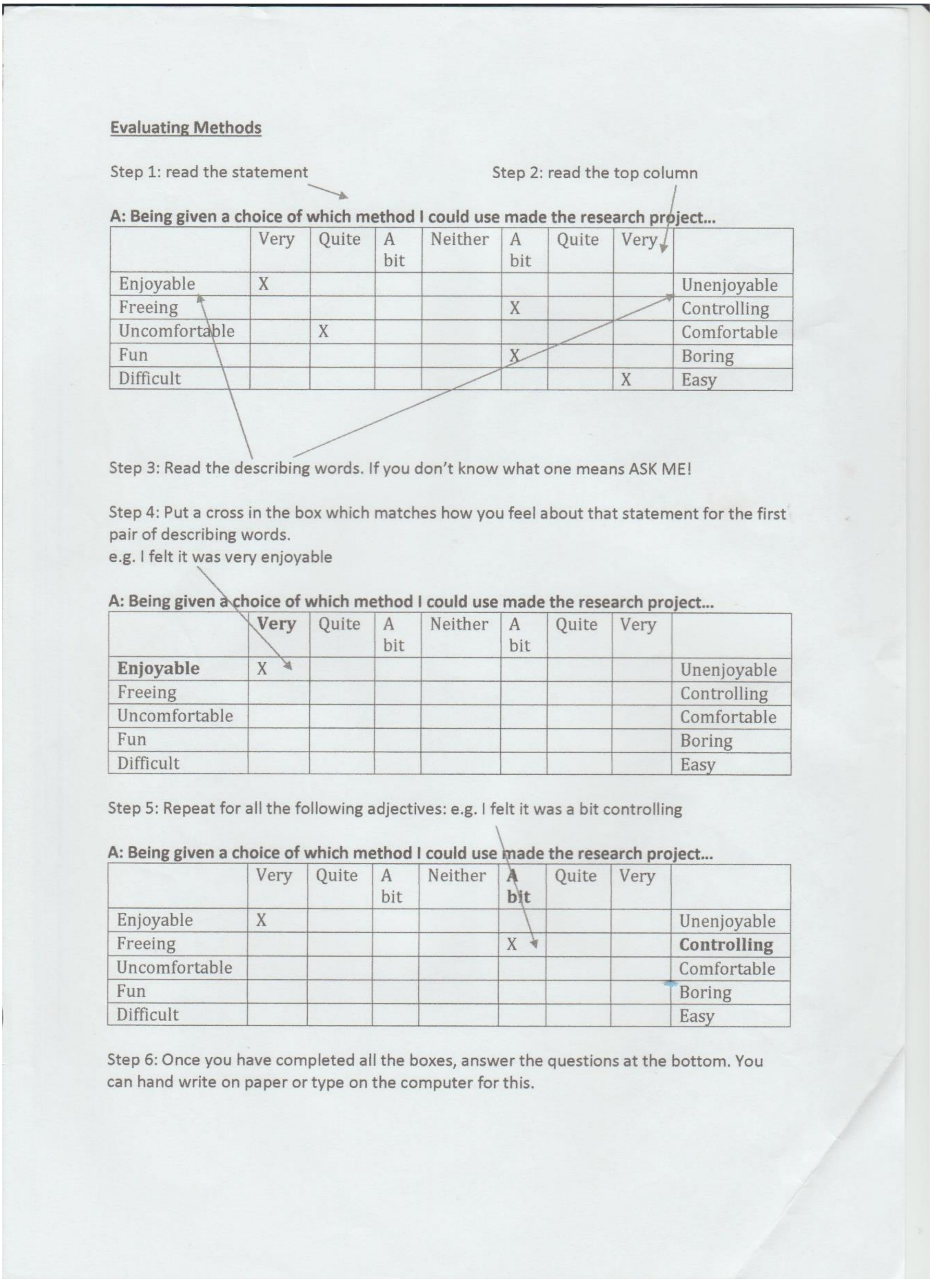


🟥 No Feelings/ doesn't change how you feel about yourself

Opinions of others	Autism
Comparing yourself/ difference	Roles you have e.g. student
Labels/ groups (where you fit in)	Fitting in
Subjects	The future
Change/ variety	Improving
Weaknesses/ struggling	Break times/ lunchtimes

APPENDIX G

The instruction sheet below was provided to support participants with completing their semantic differential scale evaluations of the participatory research process.



Evaluating Methods

Step 1: read the statement

Step 2: read the top column

A: Being given a choice of which method I could use made the research project…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Enjoyable	X							Unenjoyable
Freeing					X			Controlling
Uncomfortable		X						Comfortable
Fun					X			Boring
Difficult							X	Easy

Step 3: Read the describing words. If you don't know what one means ASK ME!

Step 4: Put a cross in the box which matches how you feel about that statement for the first pair of describing words.
e.g. I felt it was very enjoyable

A: Being given a choice of which method I could use made the research project…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Enjoyable	X							Unenjoyable
Freeing								Controlling
Uncomfortable								Comfortable
Fun								Boring
Difficult								Easy

Step 5: Repeat for all the following adjectives: e.g. I felt it was a bit controlling

A: Being given a choice of which method I could use made the research project…

	Very	Quite	A bit	Neither	**A bit**	Quite	Very	
Enjoyable	X							Unenjoyable
Freeing					X			**Controlling**
Uncomfortable								Comfortable
Fun								Boring
Difficult								Easy

Step 6: Once you have completed all the boxes, answer the questions at the bottom. You can hand write on paper or type on the computer for this.

Appendix H

The tables below detail the data participants submitted for **RQ1**- broken down by sub question.

Table H.1.

Participant Data: RQ 1.1.

	Visual	Word-based		Organising topic cards
		Oral	Written	
Connor	Video- added to a PowerPoint (1 clip- 1 minute 38 seconds) plus images and text (4 slides). Autism is/ good/bad things about autism/ who should know someone is autistic- PowerPoint- text and images (3 slides).	1 x Elicitation interview- Connor chose the slides he wanted to discuss in detail. Discussed with his key worker who typed his response.	Twenty Statements Test.	Organising sense of self topic cards into importance to self and good/bad influences on the self-view- discussed reasons for choice with researcher, who made contemporaneous notes. Connor also discussed with Harrison Harrison's good/bad choices in this task (20 minutes).
Fresh Avocado	30 photographs plus 2 images from the internet.		Twenty Statements Test. 1 x Photo-elicitation interview- Fresh chose the images he wanted to discuss in detail.	Organising sense of self topic cards into good/bad influences on the self-view- discussed reasons for choice with adult, who made contemporaneous notes.

	PowerPoint- additional photographs (15) and text (12 slides).	Commented on his top 3 (most important) and bottom 3 (least important) photographs- instead of doing the organising topic cards task. Autism is/ good/bad things about autism/ who should know someone is autistic- PowerPoint- text only (6 slides).	
Harrison	Collage- self-drawn (18 images). Autism is/ good/bad things about autism/ who should know someone is autistic (15 drawings).	Twenty Statements Test. 1 x Elicitation interview- Harrison chose the images he wanted to discuss in detail.	Organising sense of self topic cards into importance to self and good/bad influences on the self-view. Discussed reasons for good/bad choice with a peer (Connor) (20 minutes). Top three and bottom three importance provided as a written response.
Joe		Twenty Statements Test. Based on Twenty Statements Test: Written response- most or least	

			important statements to describe the self, plus elements from the list which make him feel good or bad about himself. Response to structured questions: list of everything anyone thinks about to answer who am I/ what adolescents/ adults/ autistic adolescents focus on/ feel is most important to describe themselves.	
Lightning		Interview with prompts- (1 hour 15 mins).	Twenty Statements Test.	
Richelle	PowerPoint- images (23) and words (7 slides).	Conversation on importance of chosen slides to self (top and bottom 3)- researcher taking contemporaneous notes.	Twenty Statements Test. 1 x Elicitation interview- Richelle chose the slides she wanted to discuss in detail.	Organising sense of self topic cards into importance to self and good/bad influences on the self-view. Discussed reasons for importance with researcher, who made contemporaneous notes. 7 of these topics were chosen by the participant for further explanation as to why they made her feel good/bad. This was provided as a written response.

Skyler Greenthief	PowerPoint- images and words (4 slides- including one collage with 13 images).		Twenty Statements Test. 1 x Elicitation interview- Skyler chose the slides she wanted to discuss in detail. Autism PowerPoint- text only (4 slides).	Organising sense of self topic cards into importance to self and good/bad influences on the self-view- discussed reasons for choice with researcher, who recorded the conversation (10 minutes).
Wolf	60 Photographs	2x Elicitation interviews with the researcher- Wolf chose the photographs he wanted to discuss in detail (1 hour total).	Twenty Statements Test. 1 x Photo-elicitation interview- Wolf chose the photographs he wanted to discuss in detail. Autism PowerPoint- text only (4 slides).	Organising sense of self topic cards into good/bad influences on the self-view- labelled with reasons for choice (3x Good; 1x Bad). Notes also made on how each topic would be photographed and why.

Table H.2.

Participant Data: RQ 1.2.

	Visual	Word-based		Organising topic cards
		Oral	Written	
Connor	Videogame design- text and images (2 slides).	40-minute group discussion on school with Harrison, Skyler and Wolf. 2 x peer discussion with Harrison- 40 minutes total (based on topic prompts). Perfect/ worst school day group discussion with Skyler and Harrison (20 minutes). Good/bad student- discussed with researcher who wrote down responses.	Best to worst student scale- labelled with reasons for choice. PowerPoint- Good/bad things about school (2 slides).	Organising sense of self and school topics into good/bad influences on the self-view (colour-coded). 6 of these topics were chosen by the participant for further explanation as to why they made him feel good/bad. This was dictated by to the researcher, who wrote contemporaneous notes.

Fresh Avocado	PowerPoint- images and words (5 slides). Videogame design- images (4) and words. Created on word (3 pages).		Good/bad student- bullet point response. Best to worst student scale- labelled with reasons for choice. Perfect/ worst school day- PowerPoint- text only (15 slides). Discussed with TA whilst creating.	Organising sense of self and school topics into good/bad influences on the self-view (symbols). 6 of these topics were chosen by the participant for further explanation as to why they made him feel good/bad. This was provided as a written response.
Harrison	Videogame design- images and labels (Plan- A3 hand drawn; final- PowerPoint with 6 images). Good/bad student- drawn and labelled.	40-minute group discussion on school with Connor, Skyler and Wolf. 2 x peer discussion with Connor- 40 minutes total (based on topic prompts). Perfect/ worst school day group discussion with Skyler and Connor (20 minutes).	Best to worst student scale- labelled with reasons for choice.	Organising sense of self and school topics into good/bad influences on the self-view (colour-coded). 6 of these topics were chosen by the participant for further explanation as to why they made him feel good/bad. This was provided as a written response.

Joe		E-mail response to structured question: Is school important to how someone feels about themselves?	
Lightning	Interview with prompts- (1 hour). Perfect/worst school day- discussed with researcher who typed as contemporaneous notes into a table of: what would happen/ how would feel and why.		
Richelle	Pair discussion with Skyler- 40 minutes (based on topic prompts).	Diary- 3 entries. Perfect/worst school day- listed as bullet points.	Organising sense of self and school topics into good/bad influences on the self-view (colour-coded). 6 of these topics were chosen by the participant for further explanation as to why they made her feel good/bad. This was provided as a written response.

Skyler Greenthief	Vlog based on topic prompts- (30 mins). Perfect/ worst school day PowerPoint- collage of 10 images plus 1 slide of text. What could school do/ stop doing to make autistic pupils feel better about themselves PowerPoint- images (5) and text (5 slides).	40-minute group discussion on school with Harrison, Connor and Wolf. Pair discussion with Richelle- 40 minutes (based on topic prompts). Perfect/ worst school day group discussion with Harrison and Connor (20 minutes).	Best to worst student scale- labelled with reasons for choice. Good/bad student- bullet point response.	Organising sense of self and school topics into good/bad influences on the self-view (colour-coded). 6 of these topics were chosen by the participant for further explanation- which was provided to the TA, who wrote contemporaneous notes.
Wolf	50 Photographs	40-minute group discussion on school with Harrison, Skyler and Connor.	1 Elicitation interview with the researcher- Wolf chose the photographs he wanted to discuss in detail (40 mins total). Best to worst student scale- labelled with reasons for choice.	Organising sense of self and school topics into good/bad influences on the self-view (symbols used). 6 of these topics were chosen by the participant for further explanation as to why they made her feel good/bad. This was provided as a written response.

Note. For RQ2, data included: all participants' questionnaires, as described in Chapter 4 (see 4.4.2). For main study participants this was after completing RQ1.1 *and* after completing RQ1.2. For pilot study participants, only Lightning completed this- at the end of his sessions. All participants also provided their views on their top 3 and bottom 3, when choosing their preferred methods, explaining why they did, or did not, like these (See Chapter 4, 4.3.1.).

APPENDIX I

Coding Chart: Q1.1- colour-coded to align with the thematic map (Chapter 5).

Table I1.

Coding Chart Q1.1.

Theme	Sub-theme	Code
Interests as Enablers		Hobbies Interests Passions Clubs Sport Music Food Celebrity Inspirations Favourites/ likes Freedom
Strengths and Positive Self-worth		Achievements School achievements Good at
“Good” Future Self		Jobs Money Future
Relationships: Socialising and Support		Friendship Family Pets Support Argument Socialising
Contextual Positioning of the Self	The Safety of the ‘True’ Home self	Family Self Home Place Live
	Roles and their Responsibilities	Family roles School roles Roles- other Behaviour Leader Responsibility Trusted Helper of others
	Social Belonging: Fitting in v. Difference	Fitting in Putting on a front Change self Popularity Normality Comparing

		Difference Autism Experiences Uniqueness
Negative Influences	Negative Others and their Judgements	Teasing Judged Other's views
	Focusing on Issues	Problems Difficulty Not good at/ weaknesses
	Negative Emotions	Worry Stress Guilty Fears Annoyances Dislikes Feeling bad
Positive, Essential Traits		Personality Humour
Factual Details		Name Age D.O.B Nationality Religion Humanness Physical states Physical appearance

APPENDIX J

Coding chart for Q1.2.- colour-coded to align with the thematic map (Chapter 6).

Table J1.

Coding Chart for Q1.2.

Theme	Sub-theme	Code
Positioning the Self as Student	The Importance of Grades	Exams Targets Grades Good at Failure Comparing Grades Pressure Reports Future
	Achieving as a ‘Good’ Student	Achievements Effort Motivation/Interest Personalised Specialised Work Ethic/ Attention Getting Better Determination Top Position Rewards Praise “Good Behaved” Good Student
	Failing as a ‘Bad’ Student	Deadlines Homework Punishment Trouble Misbehave Peer Pressure Not Doing Well Falling Behind/ Keeping Up Subjects Find Hard Questions/Tasks Mocking Weakness Worthless Regret Unkind Fighting Careless

		Idiot Refusal Bad Student
	Positioning and Relationships with staff	Trust Classroom Position Staff conflict
Control and Freedom of the Self		Rules Sensible Relaxing Choice Freedom Break Lessons
School and the Influence of Others: a social self	School as a Social World	New People Friendship Socialising Groups Seating Plan Arguments
	Negative Interactions and Comparisons	Bullying Judging Appearance Peers' views Dis/respect Niceness
	School Others as a Supportive Influence	Support Help Understanding Teaching Assistant (TA)
School Preferences and Interests		Like/Dislike School Dislike/ Bad School/ Classroom Environment Teaching Style Laugh Days Off Sleep Disturbance Calmness/ Peace Food

	Subject Preferences and the Future Self	Subjects Work Preferences Perspective Learning/ Teaching Styles Variety New Things Preparation Practical Technology Unique Writing

APPENDIX K

Sample evaluation sheet- personalised to the chosen methods of Skyler Greenthief.

Figure K1.

Evaluation of Methods for Q1.1.

Evaluating Methods- S

Task 1: put a cross in the box to show your opinion.

Remember at the start we ordered our methods (e.g. story writing, talking with prompts, ordering, collage, writing etc.) by what we preferred to use to give our opinion.

A: Being given a choice of which method I could use made the research project…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Enjoyable								Unenjoyable
Freeing								Controlling
Uncomfortable								Comfortable
Fun								Boring
Difficult								Easy

Please give your opinions on the methods you used:

B: Writing twenty statements about myself (starting with 'I am...') was…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Free								Controlling
Uncomfortable								Comfortable
Fun								Boring

C: Creating a PowerPoint to answer the question 'Who am I?' was…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Free								Controlling
Uncomfortable								Comfortable
Fun								Boring

D: Putting things in order was….

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Free								Controlling
Uncomfortable								Comfortable
Fun								Boring

Please now give your opinion on some of the things Miss Rice did:

E: Miss Rice asking me to explain what I put in my PowerPoint/ importance/ opinions was…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Free								Controlling
Uncomfortable								Comfortable
Fun								Boring

F: Miss Rice asking me what makes me feel good/bad was…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Free								Controlling
Uncomfortable								Comfortable
Fun								Boring

G: Miss Rice showing me the research questions and explaining the research project was…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Enjoyable								Unenjoyable
Interesting								Dull
Uncomfortable								Comfortable
Useful								Useless

H: Being given the reflections/ findings summary was…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Enjoyable								Unenjoyable
Interesting								Dull
Uncomfortable								Comfortable
Useful								Useless
Free								Controlling

I: Having our own individual task sheet was…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Enjoyable								Unenjoyable
Interesting								Dull
Uncomfortable								Comfortable
Useful								Useless
Free								Controlling

J: Working with Miss Rice, I have felt….

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Part of a team								Not part of a team
Frustrated								Encouraged
Free								Controlled
Uncomfortable								Comfortable
Happy								Sad
Unsupported								Supported

Finally, give opinions on your own experience:

K: Talking about yourself has been…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Uncomfortable								Comfortable
Fun								Boring

L: Being in the enrichment club has been….

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Uncomfortable								Comfortable
Fun								Boring

M: Being part of a research project has been…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Uncomfortable								Comfortable
Fun								Boring

Task 2: Please answer these questions as honestly as you can:

A: Were there any good/ bad things about being involved in the research project?

Good/bad things were…
because…

B: Were there any good/ bad things about having to create something about yourself?

Good/bad things were…
because…

C: Did you feel comfortable to give your opinion? And to disagree with Miss Rice if you had a different opinion?

I did/n't feel comfortable because…
I could/n't disagree because…

D: If you could change anything about the research project what would you change?

I would change…
because…

Figure K2.

Evaluation of Methods for Q1.2.

Evaluating Methods- S

Task 1: put a cross in the box to show your opinion.

Remember at the start we came up with methods and school-based topics as a group. Then we chose the methods and topics we wanted to include using our **A3 planning sheet.**

A: Being given a choice of which method I could use made the research project…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Enjoyable								Unenjoyable
Freeing								Controlling
Uncomfortable								Comfortable
Fun								Boring
Difficult								Easy

B: Choosing which school- based topics I wanted to include was…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Enjoyable								Unenjoyable
Freeing								Controlling
Uncomfortable								Comfortable
Fun								Boring
Difficult								Easy

Please give your opinions on the methods you used:

C: Completing a video diary/ Vlog about school and how it affects how I feel about myself was….

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Free								Controlling
Uncomfortable								Comfortable
Fun								Boring

D: Taking part in a pair discussion about school and how it affects how I feel about myself was….

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Free								Controlling
Uncomfortable								Comfortable
Fun								Boring

E: Working in a pair/ group was….

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Free								Controlling
Uncomfortable								Comfortable
Fun								Boring

F: Working independently was….

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Free								Controlling
Uncomfortable								Comfortable
Fun								Boring

Please now give your opinion on some of the things Miss Rice did:

G: Miss Rice asking me what in school makes me feel good/bad about myself was…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Free								Controlling
Uncomfortable								Comfortable
Fun								Boring

H: Miss Rice asking me to explain specific things in school which make me feel good/ bad about myself was… (A3 topic grid)

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Free								Controlling
Uncomfortable								Comfortable
Fun								Boring

I: Working in a group/ pair to discuss what the research question means was….

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Enjoyable								Unenjoyable
Interesting								Dull
Uncomfortable								Comfortable
Useful								Useless

J: Being given the reflections/ findings summary was…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Enjoyable								Unenjoyable
Interesting								Dull
Uncomfortable								Comfortable
Useful								Useless
Free								Controlling

K: Having our own task sheet (for task on school changes) was…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Enjoyable								Unenjoyable
Interesting								Dull
Uncomfortable								Comfortable
Useful								Useless
Free								Controlling

L: Working with Miss Rice, I have felt….

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Part of a team								Not part of a team
Frustrated								Encouraged
Free								Controlled
Uncomfortable								Comfortable
Happy								Sad
Unsupported								Supported

Finally, give opinions on your own experience:

M: Talking about myself and school has been…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Uncomfortable								Comfortable
Fun								Boring

N: Being in the enrichment club has been….

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Uncomfortable								Comfortable
Fun								Boring

O: Being part of a research project has been…

	Very	Quite	A bit	Neither	A bit	Quite	Very	
Difficult								Easy
Enjoyable								Unenjoyable
Uncomfortable								Comfortable
Fun								Boring

Task 2: Please answer these questions as honestly as you can:

A: Were there any good/ bad things about being involved in the research project?

Good/bad things were…
because…

B: Were there any good/ bad things about having to create something about yourself?

Good/bad things were…
because…

C: Did you feel comfortable to give your opinion? And to disagree with Miss Rice if you had a different opinion?

I did/n't feel comfortable because…
I could/n't disagree because…

D: If you could change anything about the research project what would you change?

I would change…
because…

APPENDIX L

Sheffield Hallam University

Our Ref AM/RKT/385-RIC

7th June 2017

Emma Rice
[redacted]

Dear Emma

Request for Ethical Approval of Research Project

Your research project entitled "**Sense of self and autism: the mainstream secondary school experience**" has been submitted for ethical review to the Faculty's rapporteurs and I am pleased to confirm that they have approved your project.

I wish you every success with your research project.

Yours sincerely

[redacted]

Chair
Faculty Research Ethics Committee

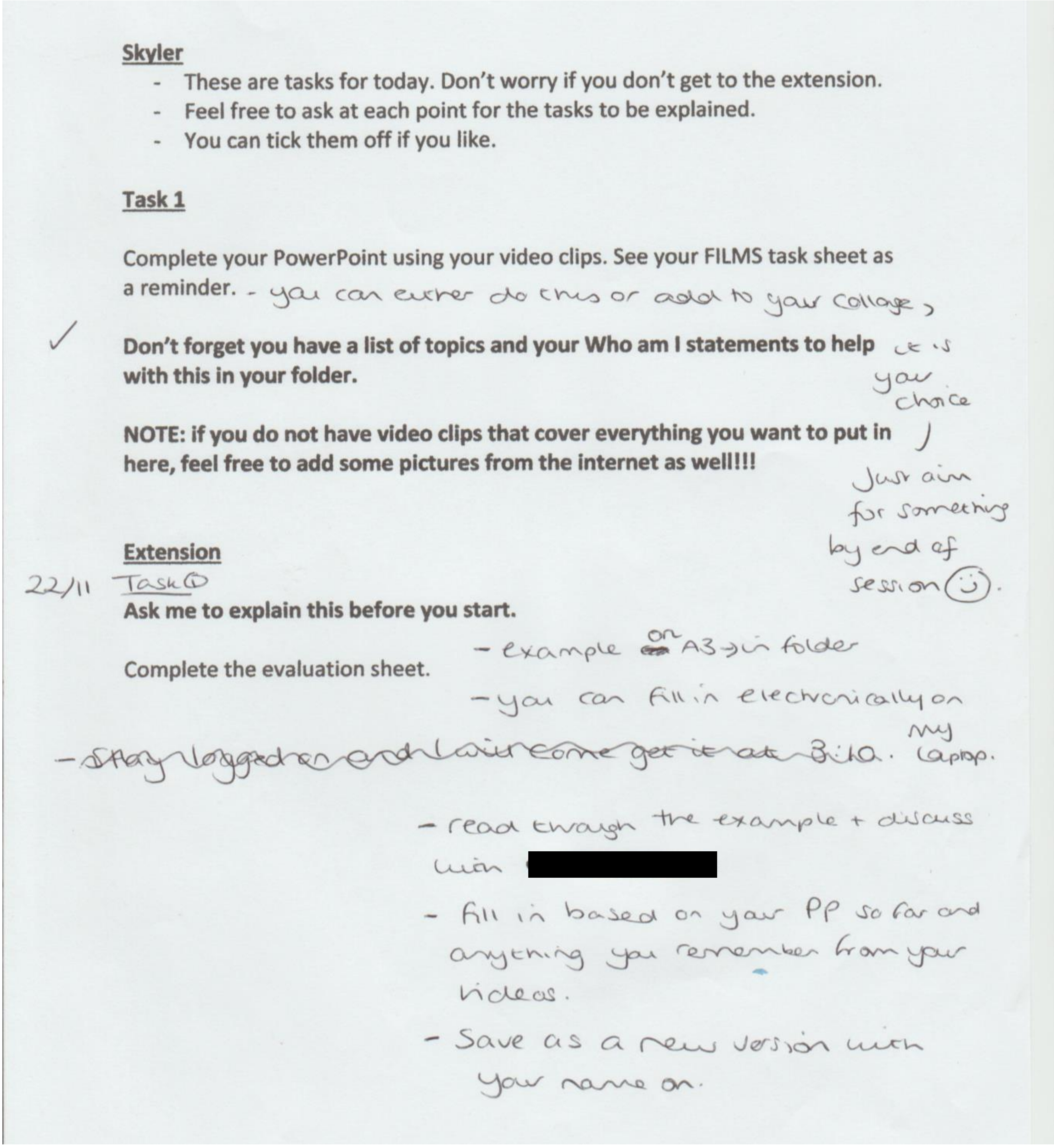
Office address :
Business Support Team
Faculty of Development & Society
Sheffield Hallam University
Unit 4, Sheffield Science Park
Howard Street, Sheffield, S1 1WB
Tel: 0114-225 3308
E-mail: DS-ResearchEthics@shu.ac.uk

APPENDIX M

Individualised task sheet provided to support participants with their individual method choices- focus was on recapping where they got up to the previous week/ ensuring they had transparency on what may follow/ support with organisation.

Figure M1.

Individualised Task Sheet for Skyler



Skyler

- These are tasks for today. Don't worry if you don't get to the extension.
- Feel free to ask at each point for the tasks to be explained.
- You can tick them off if you like.

Task 1

Complete your PowerPoint using your video clips. See your FILMS task sheet as a reminder. - you can either do this or add to your collage, (it is your choice)

✓ **Don't forget you have a list of topics and your Who am I statements to help with this in your folder.**

NOTE: if you do not have video clips that cover everything you want to put in here, feel free to add some pictures from the internet as well!!!

Just aim for something by end of session ☺.

Extension

22/11 Task ②

Ask me to explain this before you start.

Complete the evaluation sheet.

- example on A3 → in folder
- you can fill in electronically on my laptop.
- ~~stay logged on and I will come get it at 3:10.~~
- read through the example + discuss with [redacted]
- fill in based on your PP so far and anything you remember from your videos.
- Save as a new version with your name on.

APPENDIX N

Participant views on importance to the self and influence on the self- of the varying topics identified by the group, in relation to sense of self/ the question of ‘who am I?’

Figure N1.

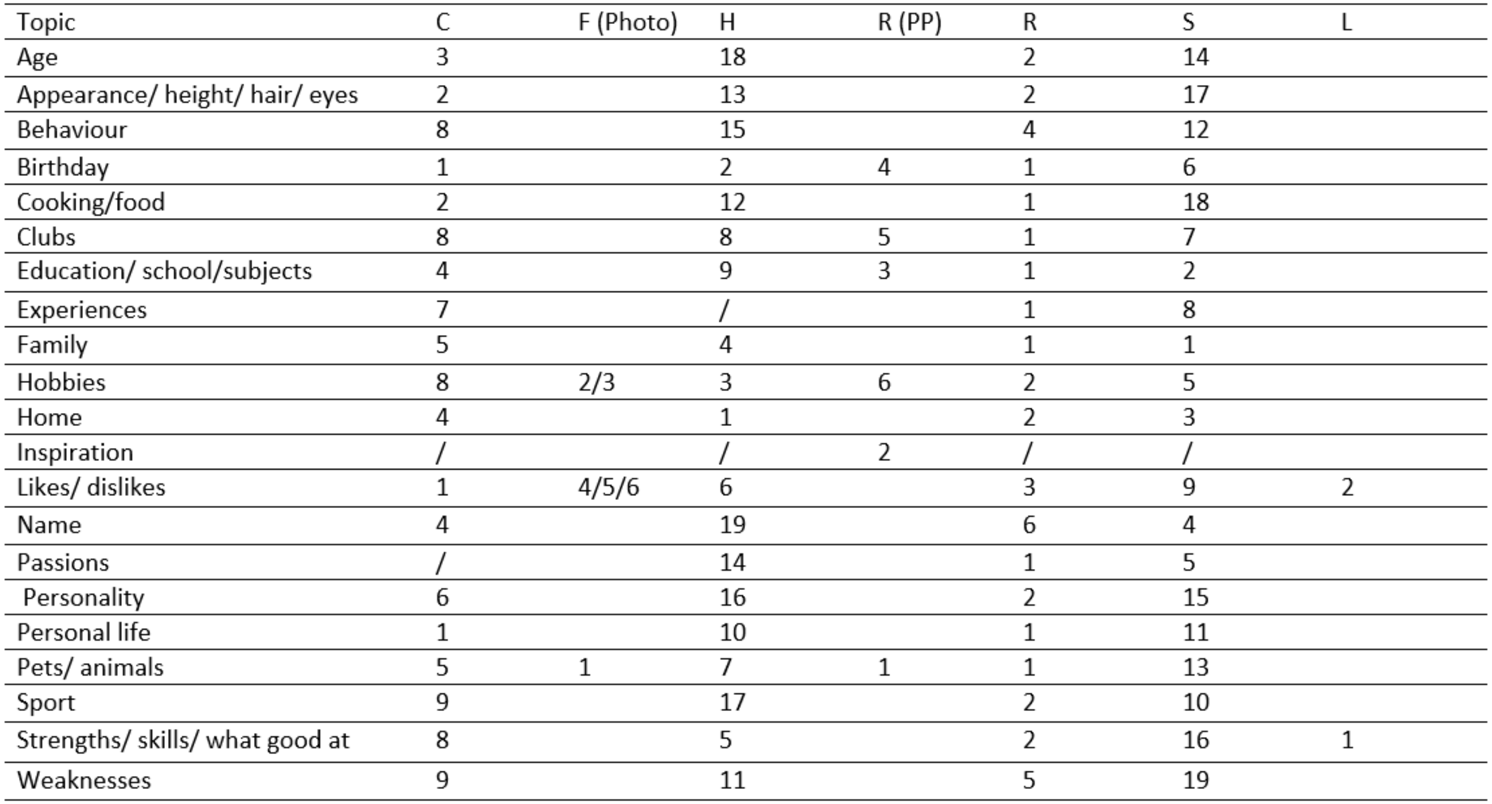
Matrix Displaying the Feelings Associated with Participant Created Sense of Self Topics

Topic	C	F	H	R	S	W	L	Good	Bad	Both
Age	🟪	🟩	🟪	🟥	🟪	🟩	/	3	1	2
Appearance/ height/ hair/ eyes	🟪	🟥	🟪	🟪	🟪	🟩	/	4	1	1
Behaviour	🟥	🟪	🟪	🟩	🟪	🟩	/	3	1	2
Birthday	🟪	🟪	🟪	🟪	🟪	🟪	/	6	0	0
Cooking/food	🟪	🟪	🟪	🟪	🟪	🟩	/	5	0	1
Clubs	🟥	🟩	🟪	🟥	🟩	🟩	/	1	2	3
Education/ school/subjects	🟥	🟩	🟪	🟪	🟩	🟩	/	2	1	3
Experiences	🟥	🟪	🟪	🟥	🟩	🟪	/	3	2	1
Family	🟪	🟪	🟪	🟪	🟪	🟩	🟪	6	0	1
Hobbies	🟪	🟪	🟪	🟪	🟩	🟪	/	5	0	1
Home	🟪	🟪	🟪	🟩	🟪	🟩	/	4	0	2
Likes/ dislikes	🟩	🟩	🟩	🟪	🟩	🟩	/	1	0	5
Name	🟪	🟪	🟪	🟥	🟪	🟩	/	4	1	1
Passions	🟥	🟪	🟪	🟩	🟪	🟪	/	4	1	1
Personality	🟪	🟪	🟪	🟪	🟪	🟩	/	5	0	1
Personal life	🟪	🟪	🟪	🟪	🟪	🟩	/	5	0	1
Pets/ animals	🟪	🟪	🟪	🟪	🟪	🟪	/	6	0	0
Sport	🟥	🟥	🟪	🟪	🟩	🟩	/	2	2	2
Strengths/ skills/ what good at	🟥	🟪	🟪	🟪	🟪	🟪	🟪	6	1	0
Weaknesses	🟥	🟥	🟥	🟥	🟥	🟥	🟥	0	7	0
Total								74	20	29

Good 🟪 **Bad** 🟥 **Good/Bad** 🟩

Figure N2.

Participant Views on the Importance of the Sense of Self Elements



Topic	C	F (Photo)	H	R (PP)	R	S	L
Age	3		18		2	14	
Appearance/ height/ hair/ eyes	2		13		2	17	
Behaviour	8		15		4	12	
Birthday	1		2	4	1	6	
Cooking/food	2		12		1	18	
Clubs	8		8	5	1	7	
Education/ school/subjects	4		9	3	1	2	
Experiences	7		/		1	8	
Family	5		4		1	1	
Hobbies	8	2/3	3	6	2	5	
Home	4		1		2	3	
Inspiration	/		/	2	/	/	
Likes/ dislikes	1	4/5/6	6		3	9	2
Name	4		19		6	4	
Passions	/		14		1	5	
Personality	6		16		2	15	
Personal life	1		10		1	11	
Pets/ animals	5	1	7	1	1	13	
Sport	9		17		2	10	
Strengths/ skills/ what good at	8		5		2	16	1
Weaknesses	9		11		5	19	

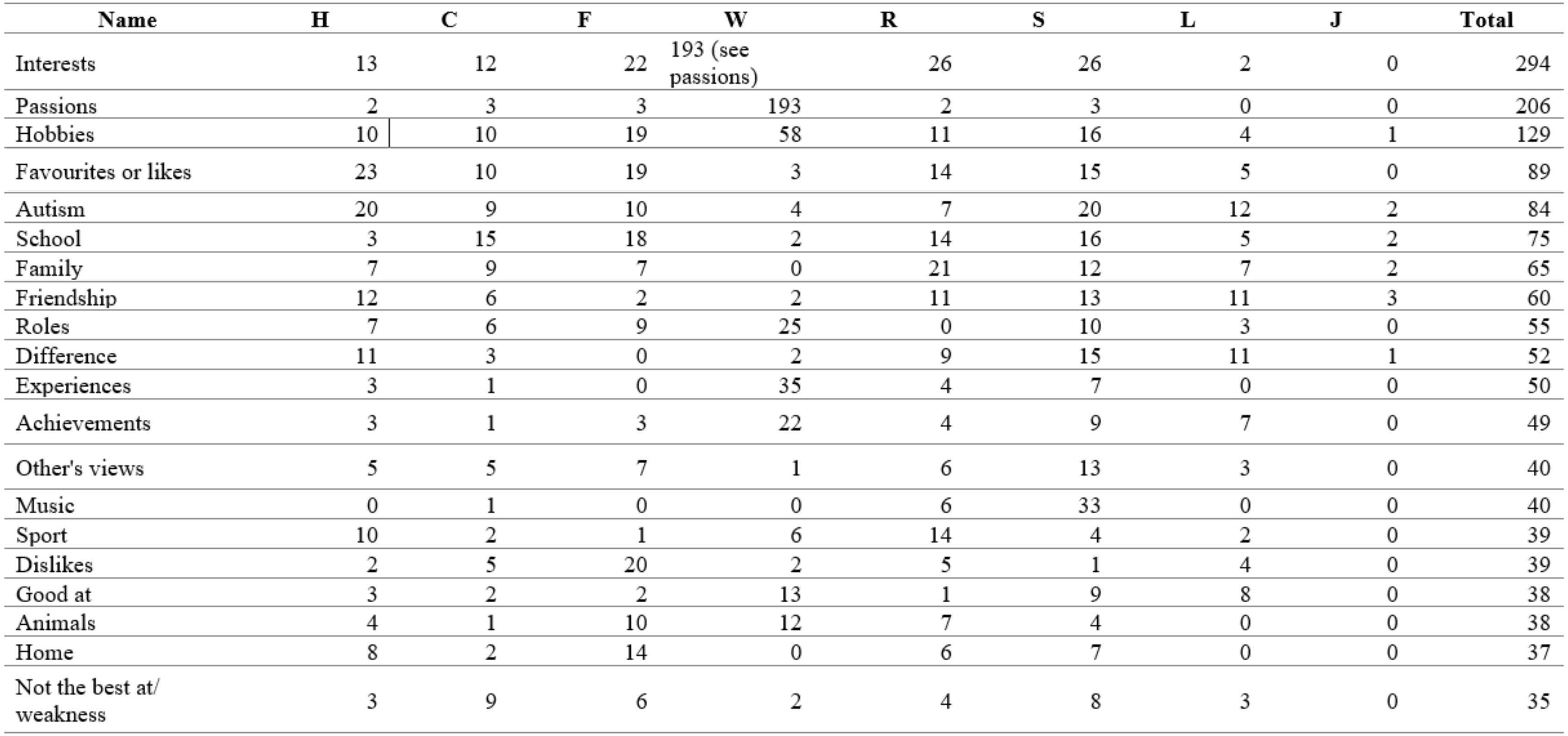
Note. Wolf and Joe chose not to organise by importance. Fresh organised his photographs rather than all the topics. Richelle organised both her PowerPoint slides *and* the topic cards. Lightning organised self-created post-it notes- as part of the pilot study approach.

APPENDIX O

Most frequent codes for Q.1.1 data- table below displays the twenty most frequently used codes when analysing this data.

Table O1.

Frequency of Codes- Top Twenty for Q.1.1.



Name	H	C	F	W	R	S	L	J	Total
Interests	13	12	22	193 (see passions)	26	26	2	0	294
Passions	2	3	3	193	2	3	0	0	206
Hobbies	10	10	19	58	11	16	4	1	129
Favourites or likes	23	10	19	3	14	15	5	0	89
Autism	20	9	10	4	7	20	12	2	84
School	3	15	18	2	14	16	5	2	75
Family	7	9	7	0	21	12	7	2	65
Friendship	12	6	2	2	11	13	11	3	60
Roles	7	6	9	25	0	10	3	0	55
Difference	11	3	0	2	9	15	11	1	52
Experiences	3	1	0	35	4	7	0	0	50
Achievements	3	1	3	22	4	9	7	0	49
Other's views	5	5	7	1	6	13	3	0	40
Music	0	1	0	0	6	33	0	0	40
Sport	10	2	1	6	14	4	2	0	39
Dislikes	2	5	20	2	5	1	4	0	39
Good at	3	2	2	13	1	9	8	0	38
Animals	4	1	10	12	7	4	0	0	38
Home	8	2	14	0	6	7	0	0	37
Not the best at/ weakness	3	9	6	2	4	8	3	0	35

Note. The researcher specifically asked about autism- rather than this being spontaneously discussed by participants. Only Joe shared this, without prompt, as part of his identity (see Chapter 5, 7).

APPENDIX P

Matrix Demonstrating Participant Views on the School and Sense of Self Topics- considering the effect of these elements on the valence of participants' self-evaluation.

Figure P1.

Participant Views on the School and Sense of Self Topics

	C	F	H	R	R (extra)	S	W	GOOD	BAD	NO
Autism	🟥🟨	🟥	🟪🟥	🟪		🟪🟥	🟨	3	4	2
Friends	🟪	🟪	🟪	🟥	🟪🟥	🟪	🟪	6	2	
Peers	🟨	🟨	🟨	🟨		🟪	🟨	1		5
Teachers/ staff	🟪🟨🟥	🟪	🟨	🟪		🟨	🟨	3	1	4
Judged on way look	🟥	🟥	🟪🟥	🟥		🟥🟨	🟨	1	5	2
Bullying	🟥	🟥	🟥	🟨		🟥	🟥		5	1
Opinions of others	🟪🟨🟥	🟪	🟪🟥	🟨		🟪🟥	🟨	4	3	3
People not understanding how you feel	🟥	🟥	🟨		🟥	🟥	🟨		4	2
Comparing/ difference	🟥	🟥	🟪🟥	🟪	🟥	🟥	🟨	2	5	1
Fitting in	🟪🟨	🟥	🟪	🟪	🟥	🟪🟥	🟥	4	4	1
Labels/ groups (where you fit in)	🟨	🟪	🟨	🟨	🟪🟥	🟪🟥	🟨	3	2	4
Classwork	🟥	🟥	🟪🟨	🟨	🟪	🟨	🟨	2	2	4
Homework	🟥	🟥	🟨	🟨	🟪	🟨	🟥	1	3	3
Subjects	🟨	🟨	🟨	🟨	🟪	🟨	🟨	1		6
Rules/ no choice	🟨	🟨	🟨	🟥		🟥🟨	🟪	1	2	4
Freedom/choice	🟪	🟪	🟪	🟨		🟪	🟪	5		1
Change/variety	🟨	🟪	🟪	🟥		🟪🟥	🟨	3	2	2
Reports	🟥	🟪	🟪🟥	🟥		🟪🟥	🟥	3	5	
Exams/grades	🟥	🟪	🟪🟨	🟪	🟪🟥	🟪🟥	🟨	5	3	2
Praise	🟨	🟪	🟪	🟪		🟪	🟨	4		2

Detention/ punishments	🟥🟨	🟥	🟨	🟥		🟥	🟥		5	2
Strengths and achievements	🟪🟨	🟪	🟪	🟨	🟥	🟪	🟪	5	1	2
Weaknesses/ struggling	🟥	🟥	🟥🟨	🟨	🟥	🟥	🟥		6	2
Improving	🟪🟨	🟪	🟪	🟨		🟪	🟪	5		2
Roles e.g. student	🟨	🟨	🟨	🟨		🟪	🟪	2		4
Classroom	🟥	🟨	🟨	🟨		🟨	🟨		1	5
Seating Plans	🟥	🟥	🟨	🟥		🟥🟨	🟥		5	2
Breaktime/lunchtime	🟪	🟨	🟨	🟥		🟨	🟪	2	1	3
Extra-curricular clubs	🟨	🟨	🟪	🟪	🟪	🟪	🟨	4		3
The future	🟪	🟥	🟨	🟥		🟪	🟨	2	2	2
Total								72	73	45

🟪 Good about yourself 🟥 Bad about yourself 🟨 No feelings/ does not change how you feel about yourself

APPENDIX Q

Matrices displaying results from participant reflection on whole group data- relating to school and its impact on a positive or negative self-view.

Figure Q1.

Matrix Displaying Participant Views on Positive Influences on the Sense of Self with a School Focus

Feel good (happy/proud/ like) about themselves	C	F	H	R	S	I feel this way	Other autistic pupils	Disagree
Feeling you have achieved something in school.	🟧🟦	🟧	🟧	🟧	🟧	5	1	
Feeling you can achieve in the future e.g. job/college/grades.		🟧	🟧	🟧	🟧	4		
Feeling you have achieved outside of school.		🟧	🟧	🟧	🟧	4		
Getting good grades (targets/ high grades/ compared to others.	🟧	🟧	🟧	🟦	🟧	4	1	
Improving/ getting better at something.	🟧	🟧	🟧	🟨	🟧	4		1
Praise from teachers (or parents).	🟦	🟧	🟧	🟧	🟧	4	1	
Trust from teachers.	🟦	🟧	🟧	🟧	🟧	4	1	
Being seen as a good student.	🟦	🟧	🟦	🟦	🟧	2	3	
Compliments from friends and peers.	🟧	🟧	🟧	🟧	🟧	5		
Having/making friends.	🟧	🟧	🟧	🟧	🟧	5		
Supportive friends.	🟧	🟧	🟧	🟧	🟧	5		
Focusing on strengths.	🟧	🟧	🟧	🟨	🟧	4		1
Doing well in a piece of class or homework.	🟧	🟧	🟧	🟧	🟧	5		
Getting a good report.	🟧	🟧	🟦	🟧	🟧	4	1	
Getting reward credits.	🟧	🟦	🟧	🟧	🟧	4	1	
Supportive teachers/ TA (who listen to your problems/ help).	🟦	🟧	🟧	🟧	🟧	4	1	
Being given important roles/ responsibilities.	🟧	🟨	🟧	🟧	🟧	4		1
Having a skill or talent that nobody else has.	🟧	🟧	🟧	🟦	🟧	4	1	
Focusing on a hobby/ talent/ skill.	🟧	🟧	🟧	🟧	🟧	5		

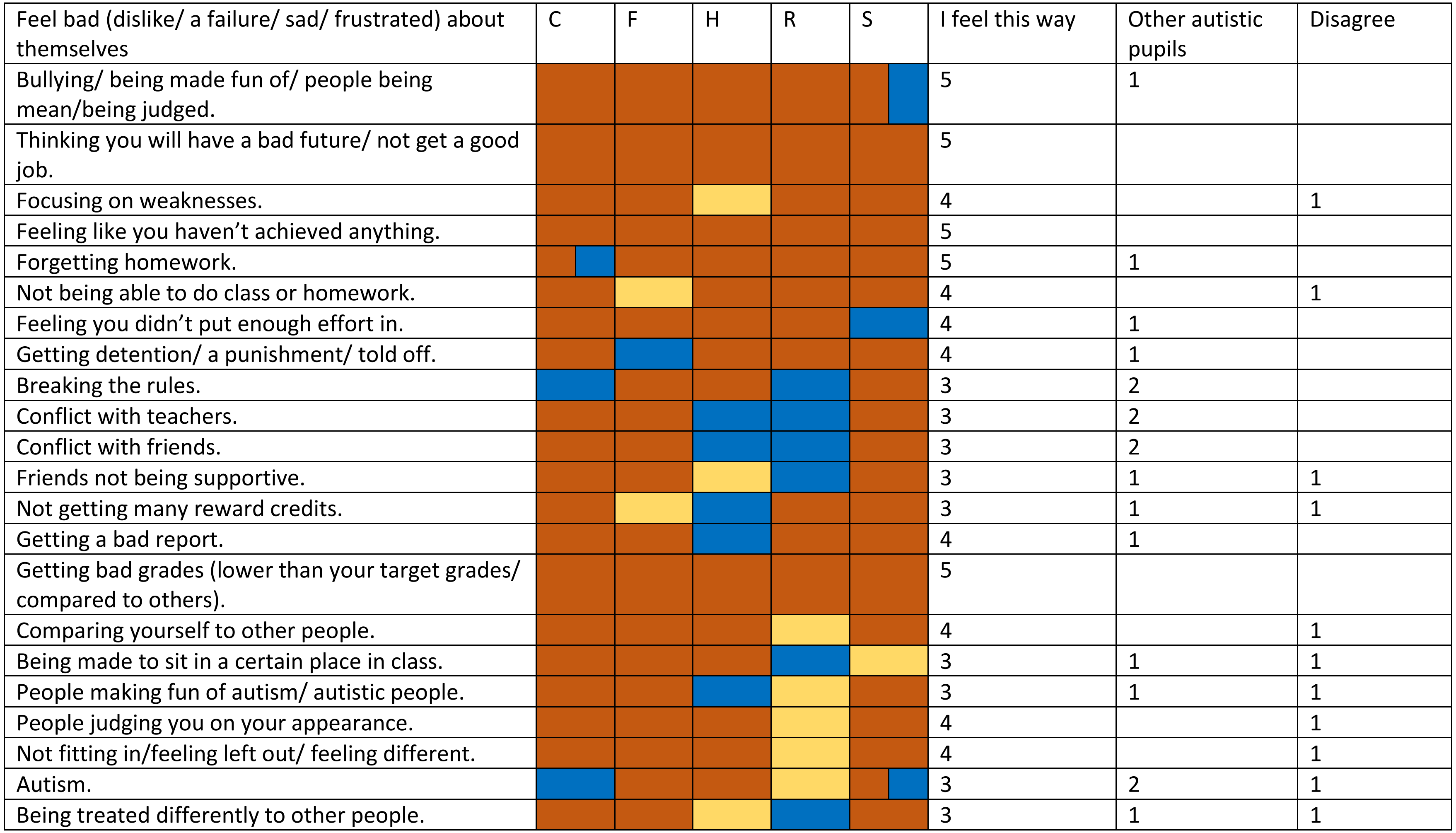
Getting a break/ the chance to have a laugh.	🟧	🟧	🟧	🟧	🟧	5		
Autism.	🟦	🟨	🟦	🟧	🟧🟦	2	3	1
People liking you for who you are.	🟧	🟧	🟧	🟨	🟧	4		1
Being respected.	🟧	🟧	🟧	🟧	🟧	5		
Completing a difficult task successfully.	🟧	🟧	🟧	🟦	🟧	4	1	
Being healthy/ exercising.	🟧	🟧	🟧	🟧	🟧	5		
Feeling like you fit in.	🟧	🟧	🟧	🟧	🟧	5		
Supportive parents.	🟧	🟧	🟧	🟧	🟧	5		

🟧 Agree- I feel this way 🟦 Agree- other autistic pupils feel this way 🟨 Disagree

Note. White boxes indicate where a participant chose not to answer. Wolf was absent from the project for the last couple of sessions and so did not complete this task.

Figure Q2.

Matrix Displaying Participant Views on Negative Influences on the Sense of Self with a School Focus



Feel bad (dislike/ a failure/ sad/ frustrated) about themselves	C	F	H	R	S	I feel this way	Other autistic pupils	Disagree
Bullying/ being made fun of/ people being mean/being judged.	🟧	🟧	🟧	🟧	🟧🟦	5	1	
Thinking you will have a bad future/ not get a good job.	🟧	🟧	🟧	🟧	🟧	5		
Focusing on weaknesses.	🟧	🟧	🟨	🟧	🟧	4		1
Feeling like you haven't achieved anything.	🟧	🟧	🟧	🟧	🟧	5		
Forgetting homework.	🟧🟦	🟧	🟧	🟧	🟧	5	1	
Not being able to do class or homework.	🟧	🟨	🟧	🟧	🟧	4		1
Feeling you didn't put enough effort in.	🟧	🟧	🟧	🟧	🟦	4	1	
Getting detention/ a punishment/ told off.	🟧	🟦	🟧	🟧	🟧	4	1	
Breaking the rules.	🟦	🟧	🟧	🟦	🟧	3	2	
Conflict with teachers.	🟧	🟧	🟦	🟦	🟧	3	2	
Conflict with friends.	🟧	🟧	🟦	🟦	🟧	3	2	
Friends not being supportive.	🟧	🟧	🟨	🟦	🟧	3	1	1
Not getting many reward credits.	🟧	🟨	🟦	🟧	🟧	3	1	1
Getting a bad report.	🟧	🟧	🟦	🟧	🟧	4	1	
Getting bad grades (lower than your target grades/ compared to others).	🟧	🟧	🟧	🟧	🟧	5		
Comparing yourself to other people.	🟧	🟧	🟧	🟨	🟧	4		1
Being made to sit in a certain place in class.	🟧	🟧	🟧	🟦	🟨	3	1	1
People making fun of autism/ autistic people.	🟧	🟧	🟦	🟨	🟧	3	1	1
People judging you on your appearance.	🟧	🟧	🟧	🟨	🟧	4		1
Not fitting in/feeling left out/ feeling different.	🟧	🟧	🟧	🟨	🟧	4		1
Autism.	🟦	🟧	🟧	🟨	🟧🟦	3	2	1
Being treated differently to other people.	🟧	🟧	🟨	🟦	🟧	3	1	1

Struggling with a problem alone.	🟧	🟧	🟨	🟧	🟧	4		1
Making a mistake.	🟧	🟦	🟦	🟧	🟧	3	2	
Not appreciating something nice someone did/ saying thank you.	🟧	🟧	🟧	🟧	🟧	5		
Needing a lot of help from the TA/ teacher to do work.	🟧	🟧	🟦	🟧	🟧🟦	4	2	

🟧 Agree- I feel this way 🟦 Agree- other autistic pupils feel this way 🟨 Disagree

Note. White boxes indicate where a participant chose not to answer. Wolf was absent from the project for the last couple of sessions and so did not complete this task.

Appendix R

The bar charts below represent the semantic differential scale data for the participant evaluations of the participatory process. They align with the sample scales seen in Appendix I and relate to the data described in Chapter 8.

Figure R1.

Participant Views on Being Given a Choice of Method

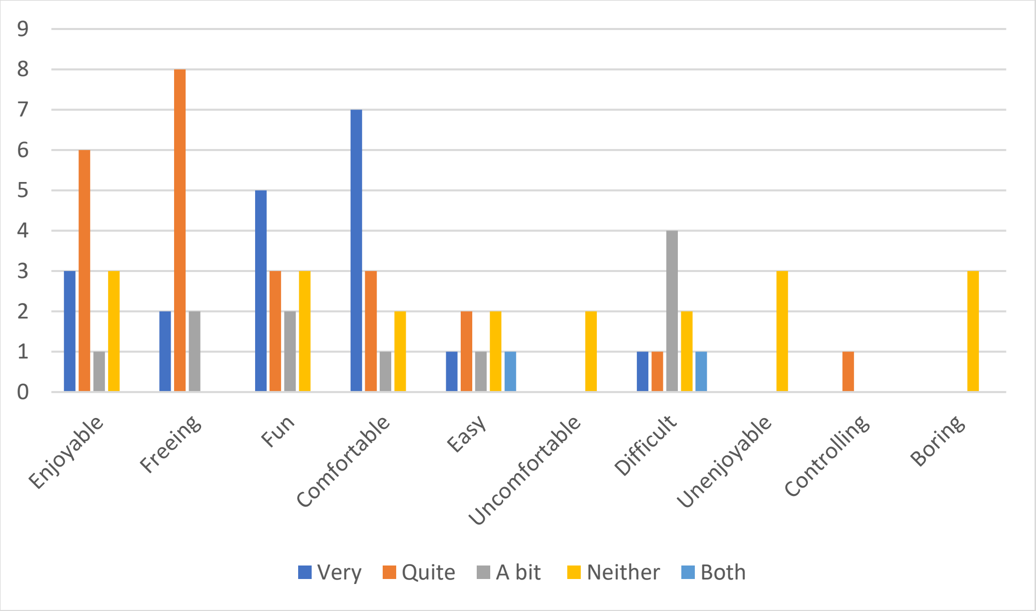


Figure R2.

Participant Views on the Specific Method they Employed

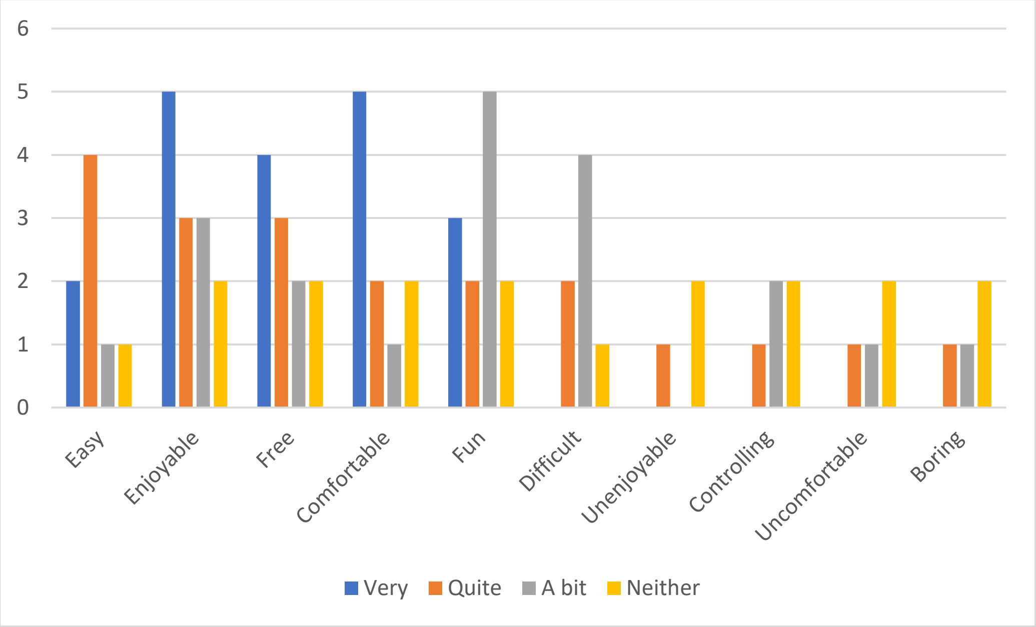


Figure R3.

Participant Views on Working in a Pair or Group

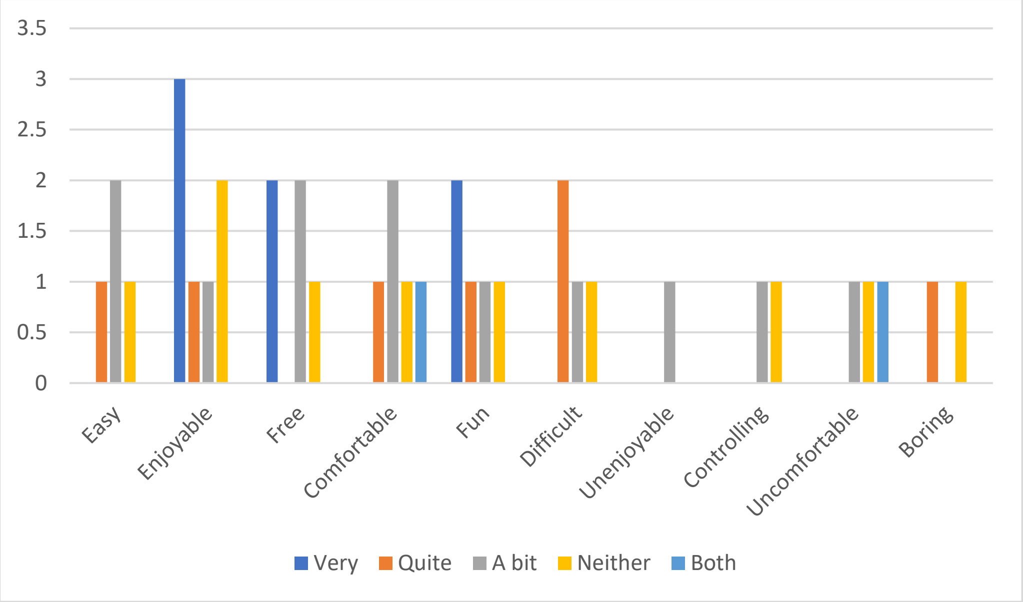


Figure R4.

Participant Views on Working Independently

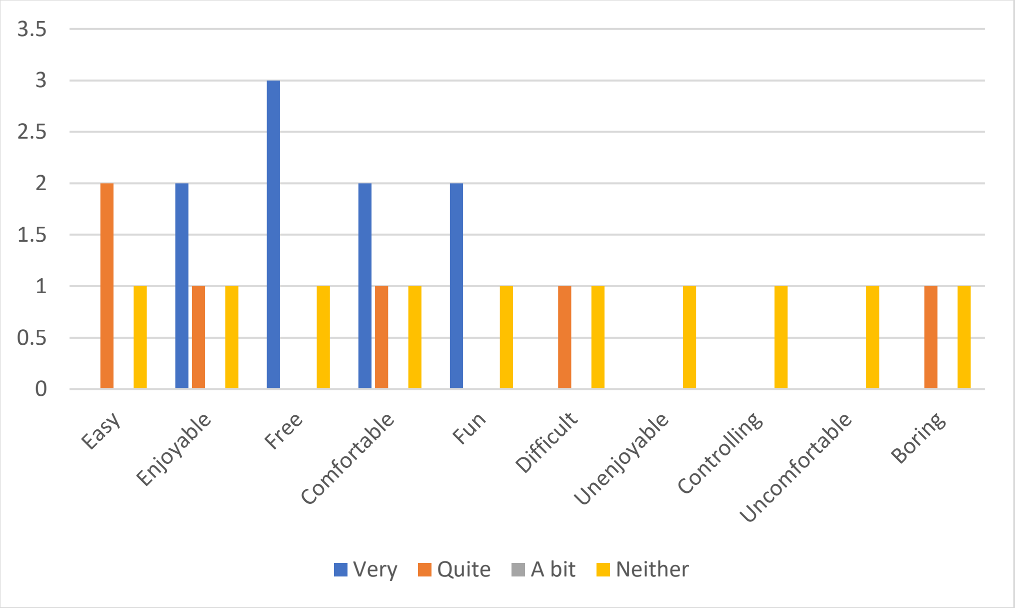


Figure R5.

Participant Views on Putting Things in Order

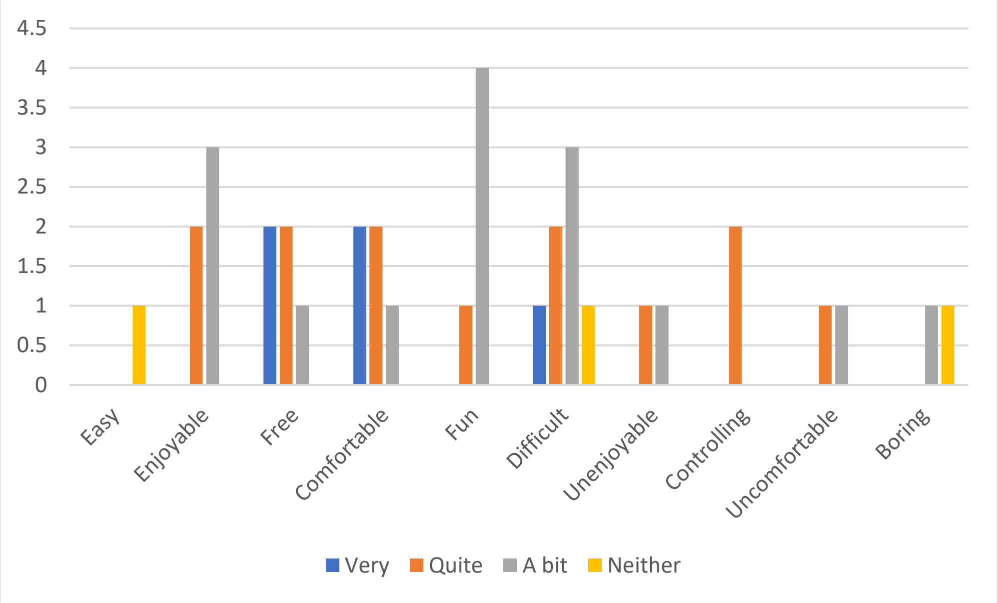


Figure R6.

Participant Views on Choosing which School-based Topics to Discuss

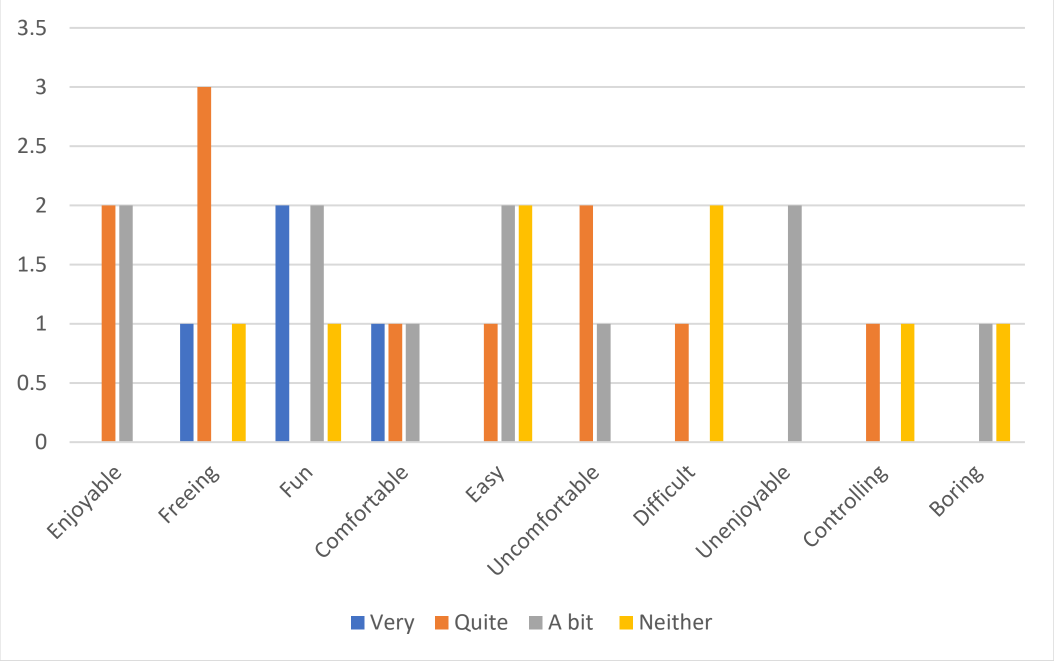


Figure R7.

Participant Views on being Asked to Explain Specific Elements, which Made them Feel Good or Bad

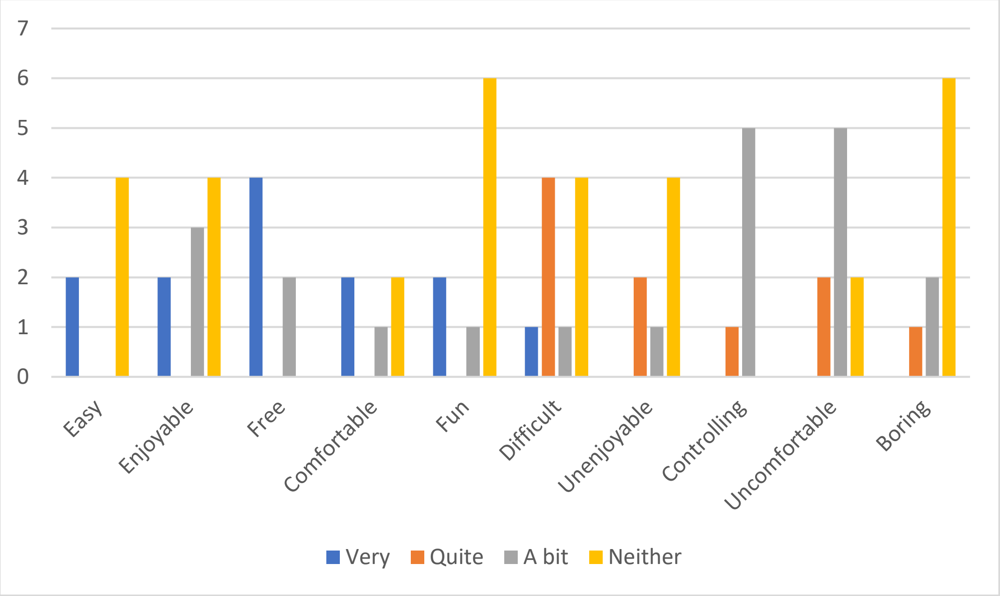


Figure R8.

Participant Views on Discussing the Self/ Themselves

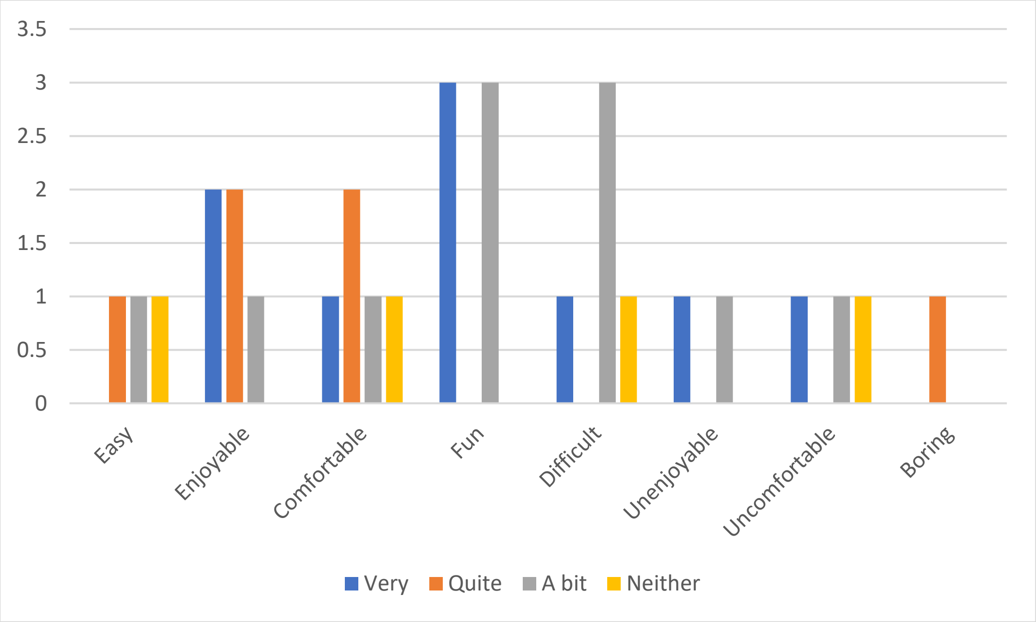


Figure R9.

Participant Views on Working with the Researcher

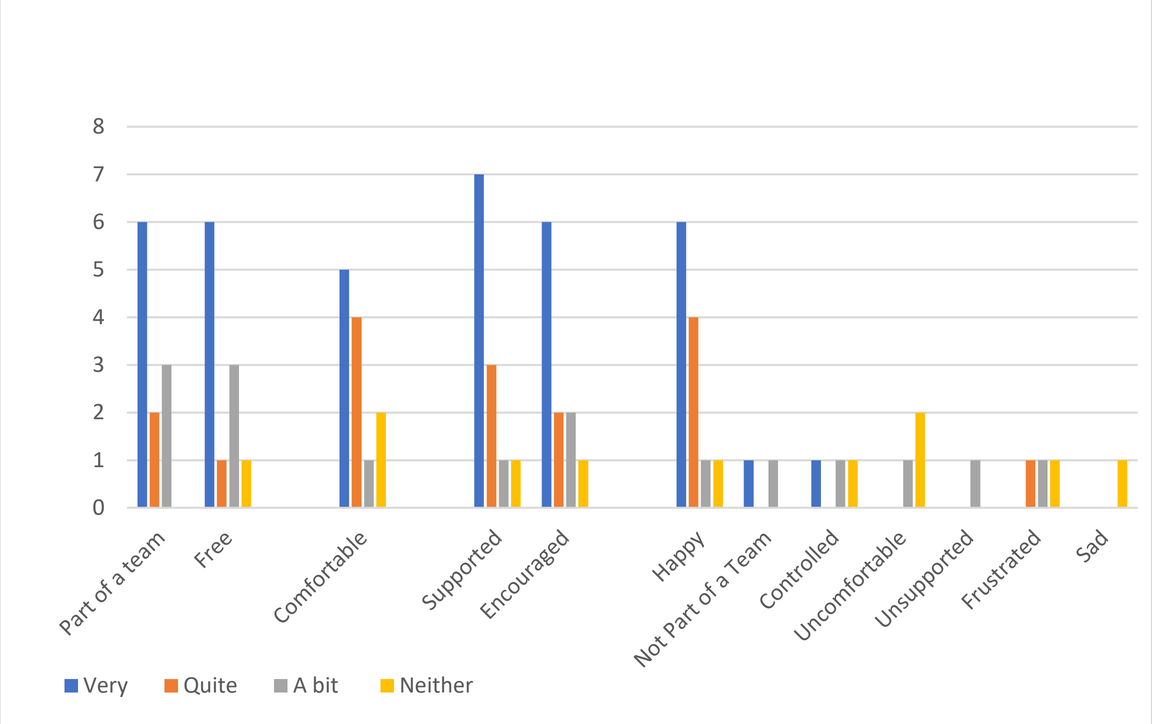


Figure R10.

Participant Views on the Twenty Statements Test

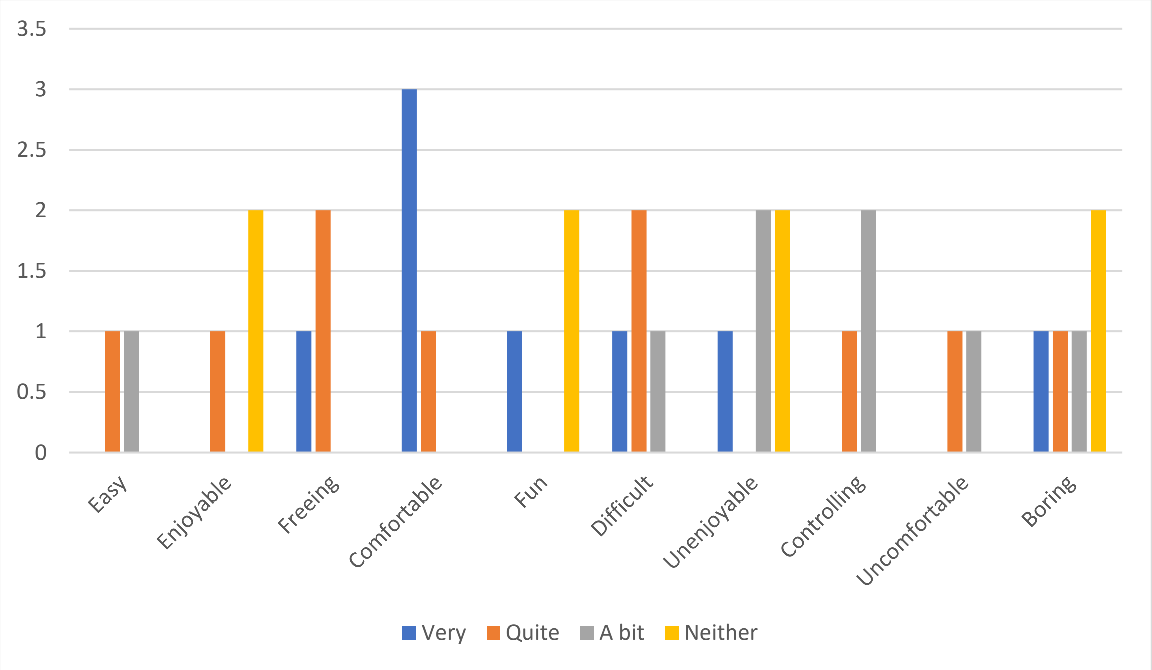


Figure R11.

Participant Views on Discussing the Research Questions

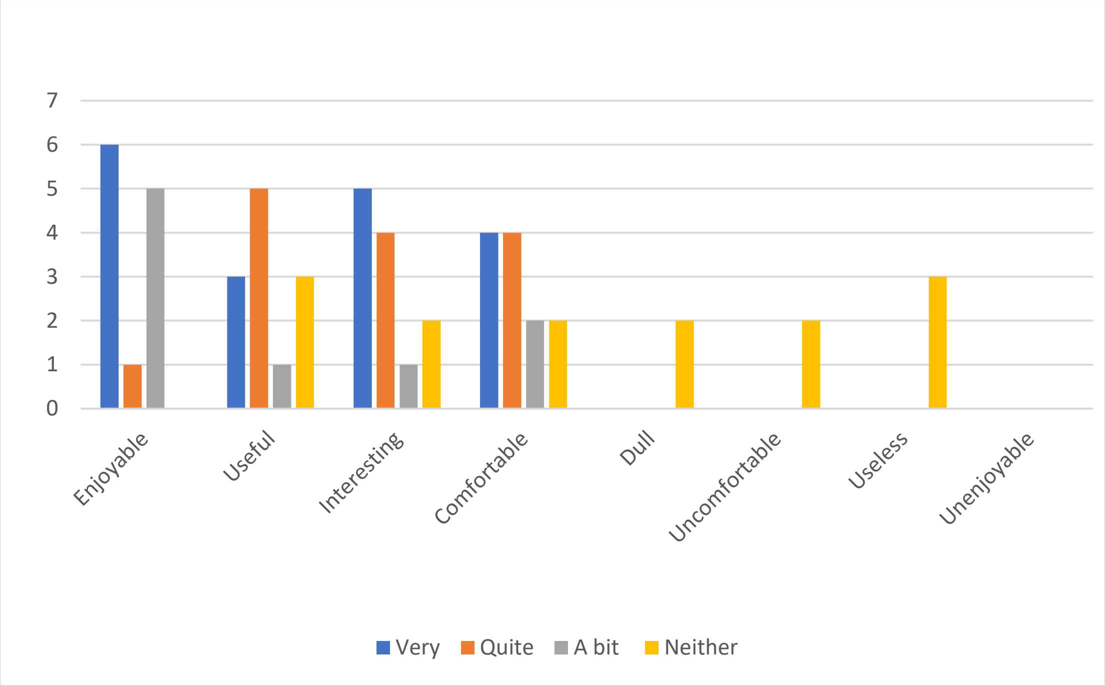


Figure R12.

Participant Views on Findings Summaries

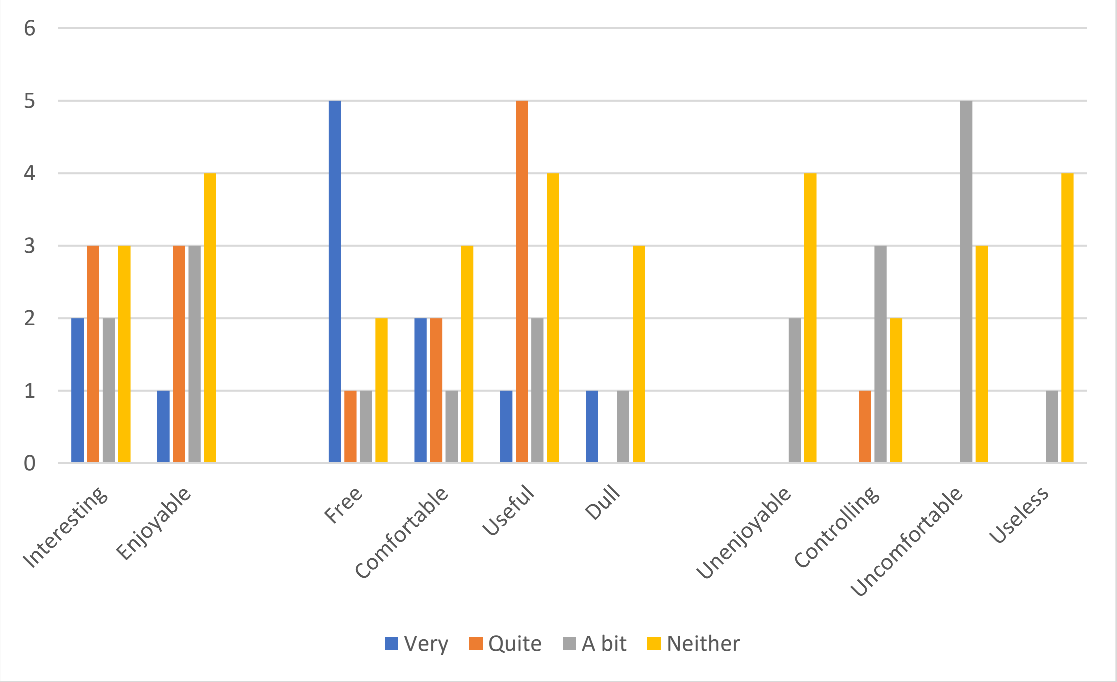


Figure R13.

Participant Views on the Enrichment Club Format

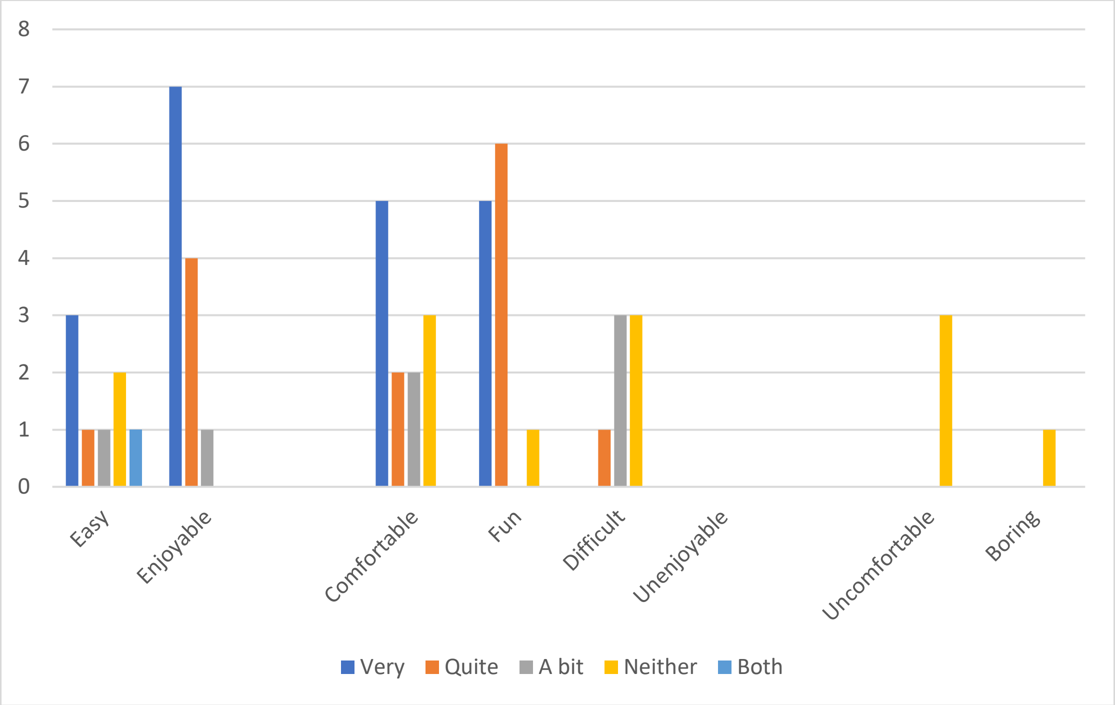
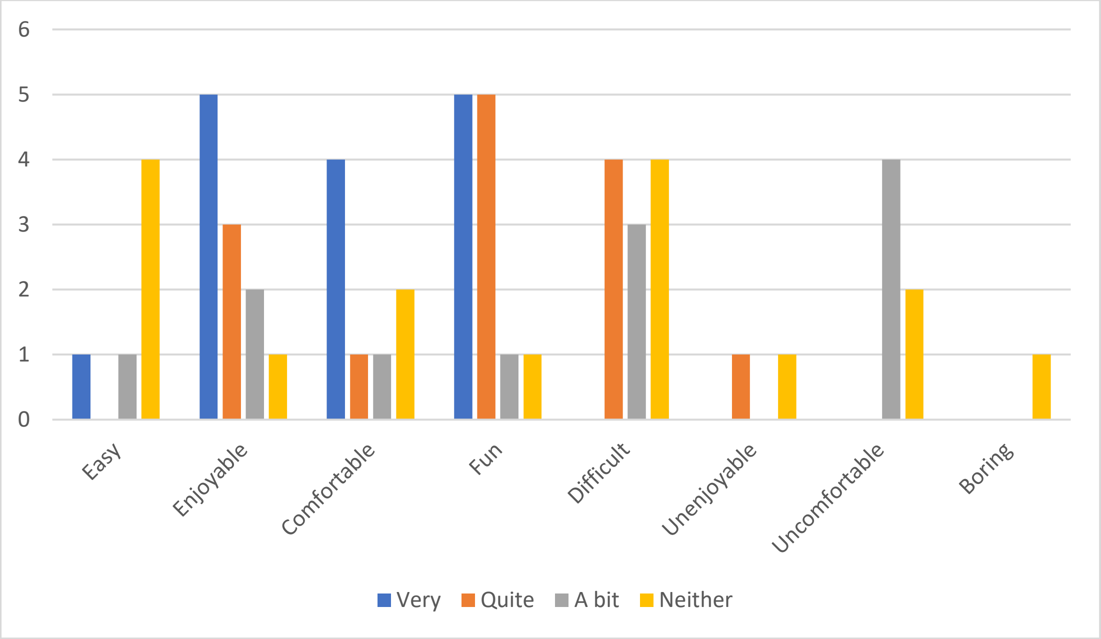


Figure R14.

Participant Views on Being Part of a Research Project

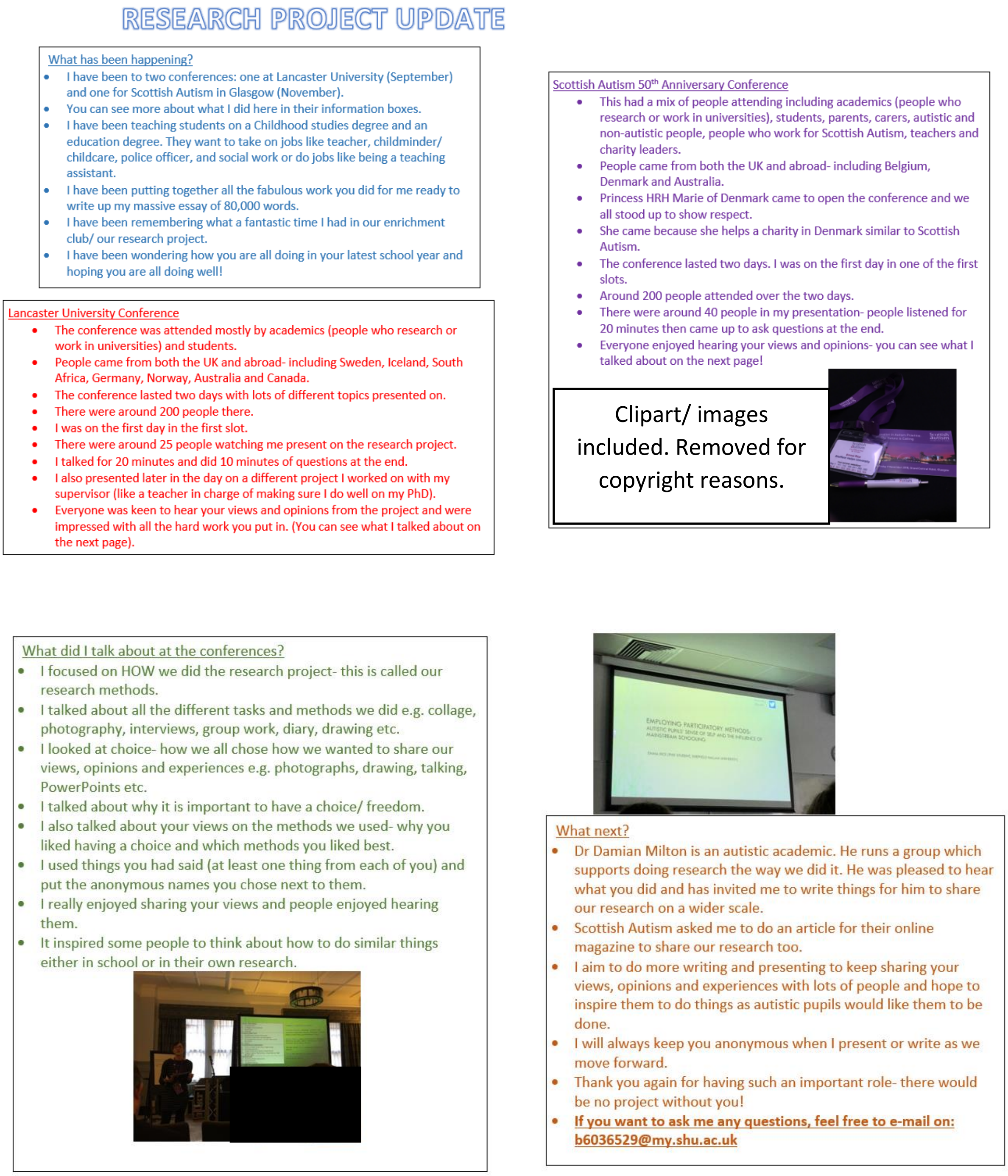


APPENDIX S

Dissemination updates provided to the participant group.

Figure S1.

Update 1- November 2018



RESEARCH PROJECT UPDATE

What has been happening?

- I have been to two conferences: one at Lancaster University (September) and one for Scottish Autism in Glasgow (November).
- You can see more about what I did here in their information boxes.
- I have been teaching students on a Childhood studies degree and an education degree. They want to take on jobs like teacher, childminder/ childcare, police officer, and social work or do jobs like being a teaching assistant.
- I have been putting together all the fabulous work you did for me ready to write up my massive essay of 80,000 words.
- I have been remembering what a fantastic time I had in our enrichment club/ our research project.
- I have been wondering how you are all doing in your latest school year and hoping you are all doing well!

Lancaster University Conference

- The conference was attended mostly by academics (people who research or work in universities) and students.
- People came from both the UK and abroad- including Sweden, Iceland, South Africa, Germany, Norway, Australia and Canada.
- The conference lasted two days with lots of different topics presented on.
- There were around 200 people there.
- I was on the first day in the first slot.
- There were around 25 people watching me present on the research project.
- I talked for 20 minutes and did 10 minutes of questions at the end.
- I also presented later in the day on a different project I worked on with my supervisor (like a teacher in charge of making sure I do well on my PhD).
- Everyone was keen to hear your views and opinions from the project and were impressed with all the hard work you put in. (You can see what I talked about on the next page).

Scottish Autism 50th Anniversary Conference

- This had a mix of people attending including academics (people who research or work in universities), students, parents, carers, autistic and non-autistic people, people who work for Scottish Autism, teachers and charity leaders.
- People came from both the UK and abroad- including Belgium, Denmark and Australia.
- Princess HRH Marie of Denmark came to open the conference and we all stood up to show respect.
- She came because she helps a charity in Denmark similar to Scottish Autism.
- The conference lasted two days. I was on the first day in one of the first slots.
- Around 200 people attended over the two days.
- There were around 40 people in my presentation- people listened for 20 minutes then came up to ask questions at the end.
- Everyone enjoyed hearing your views and opinions- you can see what I talked about on the next page!

Clipart/ images included. Removed for copyright reasons.

What did I talk about at the conferences?

- I focused on HOW we did the research project- this is called our research methods.
- I talked about all the different tasks and methods we did e.g. collage, photography, interviews, group work, diary, drawing etc.
- I looked at choice- how we all chose how we wanted to share our views, opinions and experiences e.g. photographs, drawing, talking, PowerPoints etc.
- I talked about why it is important to have a choice/ freedom.
- I also talked about your views on the methods we used- why you liked having a choice and which methods you liked best.
- I used things you had said (at least one thing from each of you) and put the anonymous names you chose next to them.
- I really enjoyed sharing your views and people enjoyed hearing them.
- It inspired some people to think about how to do similar things either in school or in their own research.

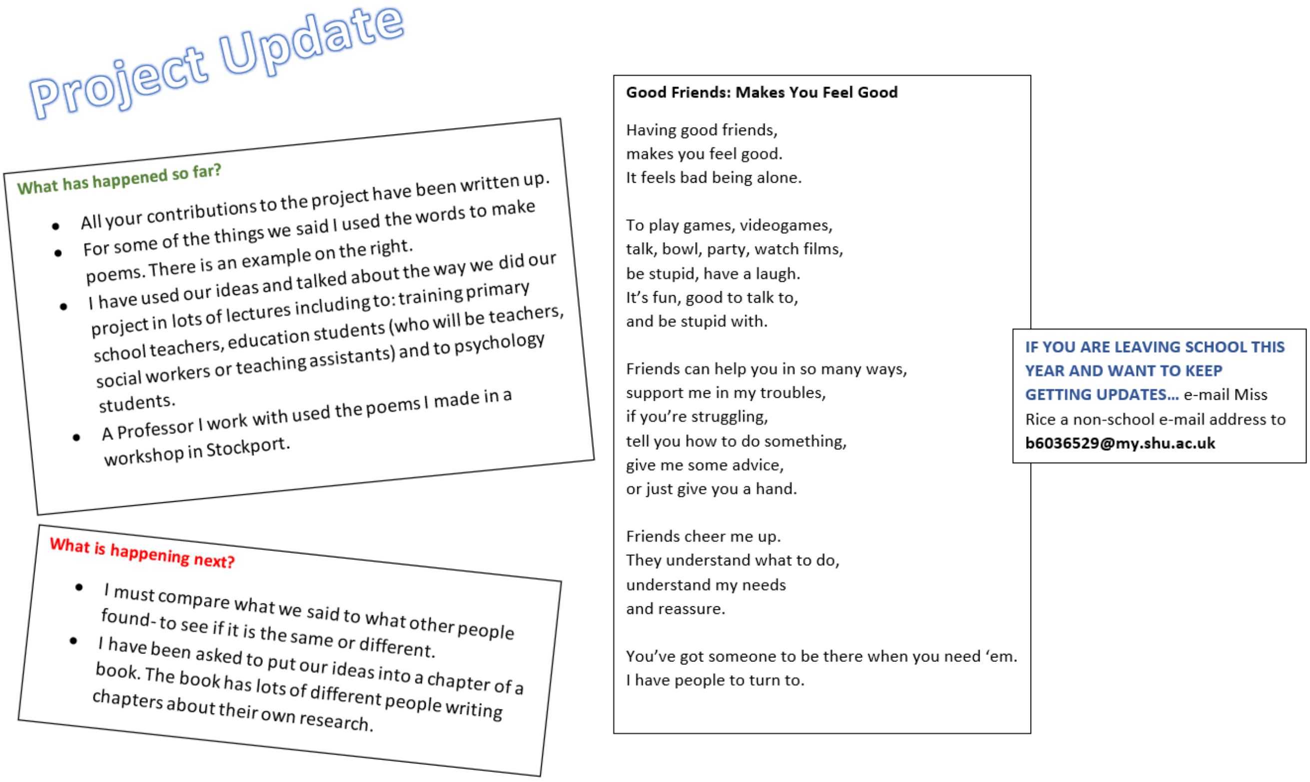
[redacted]

What next?

- Dr Damian Milton is an autistic academic. He runs a group which supports doing research the way we did it. He was pleased to hear what you did and has invited me to write things for him to share our research on a wider scale.
- Scottish Autism asked me to do an article for their online magazine to share our research too.
- I aim to do more writing and presenting to keep sharing your views, opinions and experiences with lots of people and hope to inspire them to do things as autistic pupils would like them to be done.
- I will always keep you anonymous when I present or write as we move forward.
- Thank you again for having such an important role- there would be no project without you!
- **If you want to ask me any questions, feel free to e-mail on: b6036529@my.shu.ac.uk**

Figure S2.

Update 2- March 2020



Project Update

What has happened so far?

- All your contributions to the project have been written up.
- For some of the things we said I used the words to make poems. There is an example on the right.
- I have used our ideas and talked about the way we did our project in lots of lectures including to: training primary school teachers, education students (who will be teachers, social workers or teaching assistants) and to psychology students.
- A Professor I work with used the poems I made in a workshop in Stockport.

What is happening next?

- I must compare what we said to what other people found- to see if it is the same or different.
- I have been asked to put our ideas into a chapter of a book. The book has lots of different people writing chapters about their own research.

Good Friends: Makes You Feel Good

Having good friends,
makes you feel good.
It feels bad being alone.

To play games, videogames,
talk, bowl, party, watch films,
be stupid, have a laugh.
It's fun, good to talk to,
and be stupid with.

Friends can help you in so many ways,
support me in my troubles,
if you're struggling,
tell you how to do something,
give me some advice,
or just give you a hand.

Friends cheer me up.
They understand what to do,
understand my needs
and reassure.

You've got someone to be there when you need 'em.
I have people to turn to.

IF YOU ARE LEAVING SCHOOL THIS YEAR AND WANT TO KEEP GETTING UPDATES… e-mail Miss Rice a non-school e-mail address to **b6036529@my.shu.ac.uk**