

An exploration of what adolescent girls with ASC say helps them successfully  
navigate the social aspects of mainstream schooling.

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## Abstract

Historically, there has been presumed to be a male bias in the diagnosis of ASC, however recent research has started to focus on the possibility that some females with ASC may have a different phenotype to males and present with different characteristics, and therefore needs. Additionally, these girls may mask autistic traits, giving the external appearance of coping and risking girls not being diagnosed or not being given the support they need. Adolescence appears to be a particularly significant time for these girls as social interactions become more complex, impacting on friendships and learning. This study took a participatory approach to investigate what helps adolescent girls with ASC succeed in the social aspects of mainstream schooling. Five participants (Years 7-8) were recruited as co-researchers, choosing which areas of school to focus on during data collection, verifying analysis and making decisions about the dissemination of findings. Their recounts of their experiences at school were analysed using a deductive thematic analysis to identify and interpret what they considered helpful. Their ideas indicated their motivation for autonomy, competence and relatedness and reflected a desire to be understood and have a good fit with their environment. Relationships with others and clarity in expectations appeared key for creating a positive school experience. Some participants also indicated a use of personal insight and consideration of others' motivations in developing their understanding and ability to manage at school. Participants valued their role as co-researchers, indicating personal benefit and feelings of empowerment in their feedback. Evaluation of the procedure showed that participatory research with these students is feasible and successful and it will be beneficial to promote community participation in future research and school practice. It is hoped that these findings will contribute to this new area of research and inform support for girls with ASC at multiple levels.

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## **Table of Abbreviations**

Abbreviation	Term
ADHD	Attention Deficit Hyperactivity Disorder
APA	American Psychiatry Association
AS	Asperger Syndrome
ASC	Autism Spectrum Conditions
ASD	Autism Spectrum Disorder
CLASS	Communication, Learning and Autism Support Service
CYP	Children and young people
DECP	Doctor of Educational and Child Psychology
DfE	Department for Education
EP	Educational psychologist
IPA	Interpretative Phenomenological Analysis
PhD	Doctor of Philosophy
SEND	Special Educational Needs and Disability
ToM	Theory of Mind
UEL	University of East London
UNCRC	United Nations Convention on the Rights of the Child

## **Chapter 1: Introduction**

### **1.1 Introduction**

This chapter introduces the background and rationale for the research project. The concept of autism and Autism Spectrum Conditions (ASC) will be presented and new theories about the interaction of ASC and gender outlined, including the potential impact on the lived experiences of girls with ASC. Key terms will be defined and the national and local context presented. Finally, the researcher position will be elucidated and the research rationale explained.

### **1.2 The History of Autism and Associated Terms**

The National Autistic Society describes autism as '*a lifelong developmental disability which affects how people communicate and interact with the world.*', there are estimated to be around 700,000 individuals in the UK with autism (National Autistic Society, 2021). Autism was first described in 1943 by Leo Kanner, who emphasised the presence of '*autistic aloneness*' and '*obsessive insistence on the preservation of sameness*' in individuals with this condition (Harris, 2018). However, the definition, understanding and associated terms for autism have changed over time.

Wing (1981) introduced the idea of a spectrum of conditions, not necessarily associated with '*severe mental retardation*', and linked by difficulties with social interactions, communication and imagination (the triad of impairments). Sub-groups under the autism banner were introduced in the DSM-IV, including Asperger Syndrome (AS) which described higher functioning individuals with social communication difficulties (Harris, 2018). These sub-groups have now been eliminated and the current DSM-V refers to Autism Spectrum Disorder (ASD), a spectrum of conditions, characterised by deficits in the areas of

communication, language, flexibility of thought and social and emotional understanding (APA, 2013).

Autism Spectrum Conditions (ASC) is an alternative term which is considered more neutral and less stigmatising, being compatible with neurodiversity (normal variation in the developmental routes to adulthood) and autistic individuals possessing cognitive profiles that can be advantageous in some environments (Lai & Baron-Cohen, 2015). These terms appear interchangeably in the scientific literature and public domain and there is no consensus within the autistic community over which term is preferred (Kenny et al., 2016). For the purposes of this research the more neutral ASC and autism are preferred, however, other terms are used when reporting scientific literature.

### **1.3 A Female Phenotype for ASC**

ASC has historically been viewed as a condition primarily affecting males, with the most recent estimate being a ratio of 3:1 male to female (National Autistic Society, 2021). However, this gender bias has been increasingly questioned with alternative explanations proposed including different gender-specific ASC profiles, protective and compensatory factors in females and a gender bias in the existing referral and screening processes, including diagnostic criteria and tools (Egerton & Carpenter, 2016). A growing body of research has started to address these possibilities and recent reviews have pointed towards evidence for differences in the presentation of ASC in males and females (Hull et al., 2020; Lai et al., 2015; Wood & Wong, 2017). Wood and Wong (2017) and Hull et al. (2020) conclude that there is preliminary evidence suggesting a Female Autism Phenotype, although further substantiating research is needed to determine its exact nature.

Hull et al. (2020) propose that the Female Autism Phenotype represents similar underlying autistic traits to those currently associated with the diagnostic criteria for autism

(difficulties with social communication and interaction, restricted interests and repetitive behaviour, and unusual sensory responses) but expressed differently and accompanied by a co-occurrence of internalising disorders. These are discussed further below.

Females with ASC have been described as more socially motivated than males with ASC (Baldwin & Costley, 2016; Sedgewick et al., 2016), although Wood and Wong (2017) found evidence for different types of relationships rather than differences in motivation. Hull et al. (2020) proposed that autistic females may be more socially motivated than autistic males and have fewer social impairments but find it harder to maintain long-term friendships. Females with ASC may also have fewer stereotypic and repetitive behaviours and more socially acceptable intense interests such as celebrities or horses (Baldwin & Costley, 2016; Lai & Baron-Cohen, 2015). In addition, these interests tend to focus on topics with relational purposes such as animals, fictional characters, or psychology, be more age and gender appropriate, and may create fewer difficulties for individuals and their families, compared to the interests of autistic males (Hull et al., 2020).

Some studies have found that females with ASC may employ strategies to camouflage or mask their social difficulties and avoid standing out (Cook et al., 2018), using compensatory behaviours that include playing alone but in close proximity to others (Dean et al., 2017), deliberately learning aspects of social behaviour and communication (Baldwin & Costley, 2016; Bargiela et al., 2016; Livingston et al., 2019; Sedgewick et al., 2016) and consciously suppressing autistic traits (Cook et al., 2018). However, a recent review by Hull et al. (2020) found evidence for camouflaging behaviour in both males and females with autism, with inconsistent results in observational and reflective studies comparing rates of camouflaging behaviour in males and females. They conclude that further research is needed to determine if camouflaging is more common in autistic females compared to males and therefore whether



or not camouflaging behaviour forms part of the Female Autistic Phenotype (Hull et al., 2020).

Irrespective, it is still possible that the tendency to camouflage may contribute to the underdiagnosis of females with ASC (Livingston et al., 2019) and camouflaging behaviour is also associated with other costs for the individual. The deliberate use of learnt behaviour and social mimicry can be exhausting (Baldwin & Costley, 2016; Bargiela et al., 2016; Gould & Ashton-Smith, 2011) and leave individuals vulnerable to confusion about identity and manipulation by others through their wish to conform (Bargiela et al., 2016). There is a strong association between camouflaging behaviour and poor mental health outcomes, including anxiety, depression and suicidal thoughts (Hull et al., 2020) and the outward appearance of coping can also decrease the support offered (Cridland et al., 2014; Tierney et al., 2016).

Difficulties associated with social skills discrepancies and compensatory behaviour have been shown to increase with age, as social interactions become more complex and social expectations by others increases (Cook et al., 2018; Cridland et al., 2014; Dean et al., 2013). Tierney et al. (2016) identified the transition from primary to secondary school as a significant period when difficulties may become more apparent and extend beyond peer relationships. The social aspects of learning can cause girls with ASC to struggle, for example when engaging in group tasks which require the skills for group communication (Tierney et al., 2016). Social interactions with teaching staff can also be problematic with reports of secondary school teachers sometimes misinterpreting these girls' behaviour as 'rude' or 'lazy' (Bargiela et al., 2016). Additionally, the need to understand complex or ambiguous language during teaching input, coupled with the increased executive function demands of formal learning, can also cause girls with ASC to struggle in secondary school (Baldwin & Costley, 2016).

## **1.4 Gender**

Sex and gender are separate constructs with sex referring to the biological aspects of maleness and femaleness and gender including the psychological, behavioural and social aspects of maleness and femaleness (APA, 2013). Distinction between sex and gender is not inherent in autism research literature (Lai et al., 2015) and the papers included in this research appear to use the lived experiences of participants to make distinctions between males and females. For the purposes of this research, references to females and girls indicate individuals who perceive themselves to be female and live and act accordingly.

## **1.5 National Context**

The existence of a female phenotype for ASC raises the possibility that previous, inherently male-centric research on ASC may have reduced relevance for females with ASC. This leads to the potential for misdiagnosis or a lack of diagnosis within this population (Cook et al., 2018; Dworzynski et al., 2012; Kreiser & White, 2014; Lai & Baron-Cohen, 2015) and the existence of a significant number of females who may not be receiving support because they do not fit the established criteria for diagnosis (Young et al., 2018). Additionally, for those with a diagnosis, their different needs mean that recommendations for support for children with ASC may not always be appropriate (Kirkovski et al., 2013).

This has implications for the provision of education and social care for these individuals. Local authorities are required by the Special Educational Needs and Disability (SEND) Code of Practice (Department for Education (DfE), 2014) to support the offer of high-quality provision to meet needs and remove barriers to learning, and by the Children and Families Act (2014) to consider the extent to which provision is sufficient to meet the educational and social care needs of children and young people (CYP) with SEND. These requirements

cannot be met for females with ASC if their needs are not fully understood or identified, highlighting a need for greater understanding in this area.

## **1.6 Local Context**

Within the researcher's local authority, CYP with ASC are supported by CLASS (Communication, Learning and Autism Support Service). This service has recently reviewed their provision and identified support for girls with ASC and communication and language difficulties as an area for service-wide professional development, in part due to concerns that they are not identifying early signs that help is needed. In addition to increasing the knowledge of their own practitioners, CLASS are also developing training for schools to aid their support of these students. Consequently, it is likely that research into this area, especially at a local level, will make a positive and relevant contribution to both strands of their professional development process.

## **1.7 Researcher Position**

In conducting research, it is important for the researcher to recognise how their own background, experiences, values and beliefs shape their generation and interpretation of findings and to position themselves to acknowledge this and facilitate reflexivity, thereby minimising researcher bias (Creswell & Creswell, 2017; Willig, 2013). The researcher has therefore reflected on her prior experiences and values and their potential impact on this research project. This section will be written in the first person.

Prior to starting the DECP course at the University of East London (UEL) I worked in animal behaviour and welfare research, completing a PhD examining maternal behaviour and offspring development in sheep. This research sparked an interest in the influence of the environment on development which continued after I qualified as a primary school teacher. In my teaching role, I gained particular satisfaction in working with those children in my class

who struggled to fit in, socially or academically, and collaborating with them to generate support that was tailored to their individual needs. It was for this reason that I left teaching to apply for the DECP training.

An initial interest in focusing my research on girls with ASC was generated by completing a National Autistic Society online training course entitled ‘Women and Girls on the Autistic Spectrum’. The knowledge gained from this led to professional and personal insights and a desire to know more, including exploration of how to support this demographic group. As someone who does not feel confident in unfamiliar social situations, I felt affinity for this group of individuals and was also struck by a conclusion that specified these girls required support that differed from that currently available but did not go on to describe what it should look like.

I have a strong background in working for social change and since joining UEL have honed this through greater understanding of the shared values of autonomy, social justice and beneficence. During placement casework I have deepened my understanding of person-centred approaches and the value and facilitation of pupil voice. Coupled with the success I previously achieved when collaborating with my pupils as a teacher, this has steered me towards taking a participatory approach to this research.

## **1.8 Participatory Research**

Over the past 40 years, there has been a notable shift towards more collaboration with research participants and a participatory research approach (Aldridge, 2016). The aim of participatory research is to recognise and give credence to the voice of the individual or community of interest and to actively involve them in generating knowledge, rather than position them as objects of scientific investigation (Aldridge, 2016). Hart (1992) advocated for children’s participation in transformative projects whilst acknowledging the complexities

of this approach, including concerns over the competency of children to make informed decisions and the dangers of manipulation. He devised a ladder of participation against which projects could be evaluated, moving from manipulation, through tokenism towards varying levels of participation which increasingly placed children's voices at the centre of activity. True participation is achieved once children start being involved in decision-making and the ultimate objective is a project designed by the children themselves (Hart, 1992).

Aldridge (2016) also devised a participatory model, showing how participants move from passive to more active roles as their inclusion in decision-making increases, ultimately engaging in social change and transformation when they lead the process. This conveys an emancipatory purpose to the research (Aldridge, 2016). A participatory approach is therefore compatible with children's rights to be involved in decisions about their situation and future, as specified in the SEND Code of Practice (DfE, 2015), and their right to have their opinions listened to and taken seriously as specified in Article 12 of the United Nations Convention on the Rights of the Child (UNCRC, 1989).

## **1.9 Research Rationale**

There is evidence that some females with ASC may present differently to the more traditional, male-centric, model of ASC (Wood & Wong, 2017) and as a result may either remain undiagnosed (e.g., Kreiser & White, 2014) or have their needs misunderstood, once diagnosed (Kirkovski et al., 2013). Both scenarios are likely to result in CYP who are missing out on the support they need to thrive and achieve and there is a need for new knowledge in this area, highlighting their priorities and generating ideas for more effective and valid intervention for these girls (Egerton & Carpenter, 2016). The literature indicates that adolescence and the transition to secondary school is a time which may be particularly problematic for these girls as social interactions become more complex, affecting social and

academic engagement (Tierney et al., 2016). The aim of this research is therefore to investigate this further, establishing what is already known about the social experiences of girls with ASC in mainstream secondary education and identifying gaps in the knowledge of how they can best be supported. Social experiences are defined as any activity involving interaction with another person. The use of a participatory approach and the inclusion of individuals from the target community as co-researchers aims to increase the relevance and effectiveness of the subsequent research project and the information gathered.

## Chapter 2: Literature Review

### 2.1 Introduction

This chapter gives an overview of relevant literature related to the social experiences of adolescent girls with ASC in mainstream schooling. Experiences of both school and friendships have been considered to ensure a breadth and diversity of knowledge in this area. A systematic approach (Booth et al., 2016) was used to identify relevant peer-reviewed papers which were then critically assessed to identify gaps in the literature and inform the rationale for the current research.

#### 2.1.1 Review Strategy

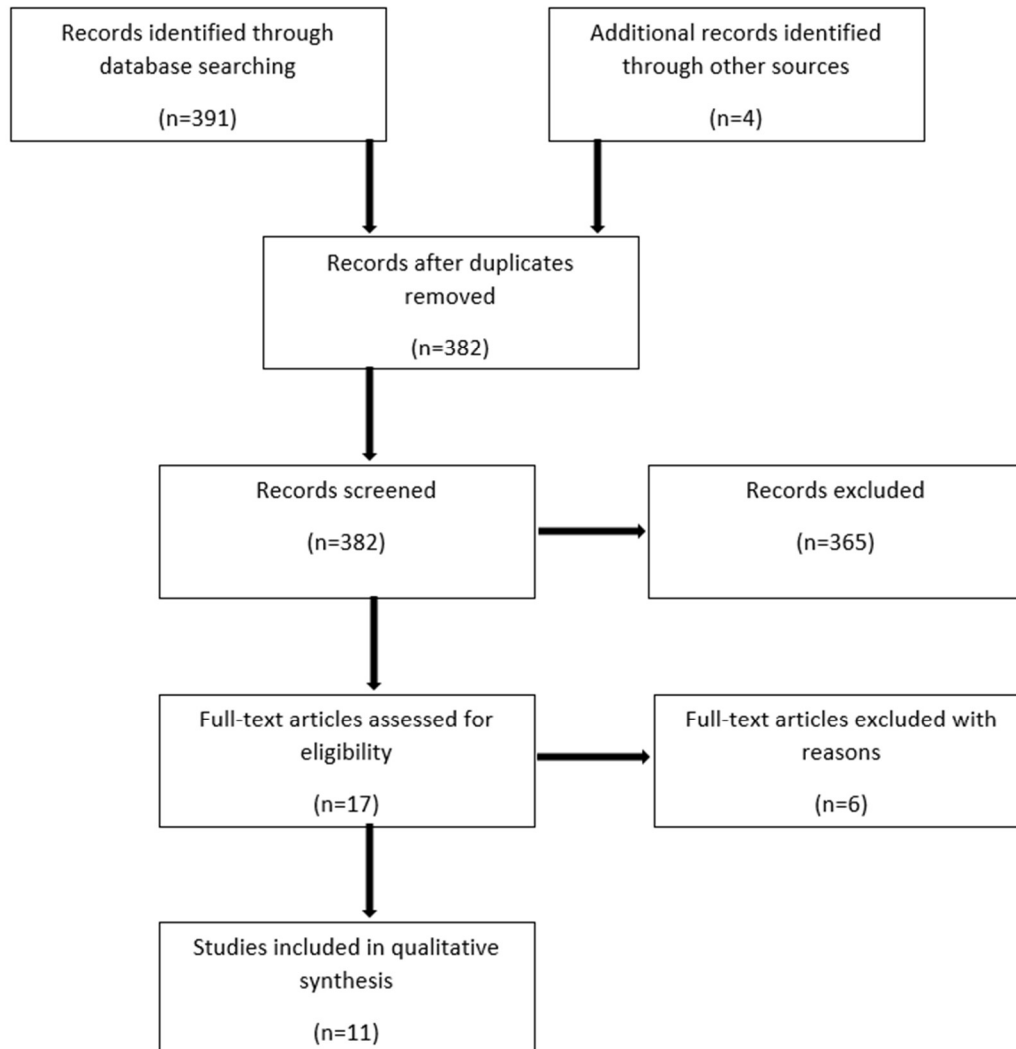
This literature search aimed to answer the question: what is currently known about the experiences of the social aspects of mainstream secondary schools for girls with ASC?

The search was conducted and completed on 22<sup>nd</sup> June 2020 and is outlined in Figure 2.1. Six databases were used and accessed via the EBSCO portal: Academic Search Complete, APA PsychArticles, APA PsychInfo, Education Research Complete, Education Abstracts and ERIC.

The search terms were informed by the researcher's experience of conducting a previous scoping review and the observation that a variety of terms were used to describe a diagnosis of autism in the literature. 'woman' was not used due to the expected age of participants. The search terms used were 'girl OR female' AND 'ASD OR autism spectrum disorder OR autism OR autistic OR Aspergers OR Asperger syndrome OR ASC OR autism spectrum condition' AND 'friend\* OR school'. To ensure relevance to the review question papers were filtered according to the inclusion and exclusion criteria described in Table 2.1. Due to the small number of papers, geographical location was not considered in the exclusion criteria but is considered in the critical analysis of the studies.

**Figure 2.1**

*Flow Diagram of the Literature Search Process.*



391 papers were initially identified by the search with 13 duplicates. Four additional papers were identified through other sources. The abstracts of 382 papers were therefore screened for inclusion in the literature review and 365 excluded. Seventeen papers were identified for full-text screening and a further six were excluded at this stage: four due to no separation of gender and two due to no description of experiences of friendship and social interactions. A total of eleven papers were included in the literature review and critical analysis and are detailed in Appendix A.



**Table 2.1***Inclusion and Exclusion Criteria*

<b>Inclusion Criteria</b>	<b>Justification</b>
Peer-reviewed articles	Weight of Evidence value
Date range of 2000-2020	Relevance to current theoretical views on females with autism
Full text available	Accessibility
English language	Accessibility
Age range of girls with autism during reported experiences 11-19 years	Relevance to review question focus of secondary school experiences
Diagnosis of autism spectrum condition or social communication difficulty	Relevance to review question
Participants are female or gender effects separated and identified	Relevance to review question
<b>Exclusion Criteria</b>	
Autism spectrum condition or social communication difficulty not main area of need	Not relevant to review question
Experiences of friendship or social interactions not described	Not relevant to review question
No separation of male and female data	Not possible to identify specific experiences of females
Educational setting not mainstream secondary school	Not relevant to review question

**2.2. Critical Review of the Existing Research**

Critical analysis was informed by Gough's (2007) Weight of Evidence framework and considered the integrity of each paper's evidence on its own terms, as well as considering its appropriateness for answering the review question and its relevance to the research aim. Each study was assessed at three Weight of Evidence levels: A, B and C (Gough, 2007). At level A, the coherence and integrity of the evidence in its own terms were assessed with reference to prescribed methods for data collection and analysis, and evaluation of adherence to these. At level B, the appropriateness of the design for answering the review question was assessed through consideration of fitness for purpose and the relevance of the design for generating appropriate data that reflected the views of adolescent girls with ASC. At level C,

the study's main focus (topic) and context were evaluated in relation to their relevance to the research aim, namely consideration of mainstream secondary school experiences and social interactions for adolescent girls with ASC within the UK education system. Assessment details for each study are included in Appendix A.

To facilitate the synthesis of findings, the papers were grouped into four categories according to their main research focus. These are 'Maternal Perspective', 'Experiences of Mainstream Schooling', 'Perceptions of Friendship' and 'Coping Strategies'.

### ***2.2.1 Maternal Perspective***

One paper explored the topic from the perspective of mothers raising daughters with ASD.

Cridland et al. (2014) aimed to investigate the experiences of adolescent girls with ASD, as previous studies of adolescents with ASD had largely focused on the male perspective or had not separated out the effects of gender. The authors used a qualitative design, conducting semi-structured interviews with two mothers of girls with ASD and three dyads of girls with ASD and their mothers (girls were aged 12-17 years). The rationale for including maternal perspective was to achieve a multifaceted understanding of the girls' experiences. Interpretative Phenomenological Analysis (IPA) of the transcripts identified seven key themes incorporating experiences of diagnosis, friendship, schooling, and development.

Three themes focused on school and friendship experiences: 'Being surrounded by boys', 'Experiences of High School' and 'Complexity of adolescent female relationships'. ASD being a condition traditionally associated with boys led to girls experiencing difficulties with fitting in or being offered traditional boys' activities during interventions and support services. However, there were some positives to this, as boys were identified as being easier

to get along with and there were possibilities for using shared interests as a basis for friendship. Experiences of schooling were positive and negative, with access to a broader range of subjects and a more structured environment being beneficial. Girls with ASD identified challenges in harder or uninteresting work, managing a larger school environment and making friends. Their mothers focused on difficulties with teachers' limited knowledge of ASD symptomology in girls and transition between primary and secondary schools. The introduction of new routines, such as having multiple teachers, was particularly problematic at this time.

The theme relating to friendships with other girls appeared to be largely constructed from the mothers' perspectives. They described difficulties resulting from the increasing complexity of female friendships, the experiences of relational aggression and a lack of shared interests with other girls, for example their daughters' disinterest in fashion. Sampled quotes also suggested a lack of the social skills needed to take part in sustained interactions with peers.

In terms of elucidating the experiences of adolescent girls with ASD, this study by Cridland et al. (2014) faces a significant limitation. Although the aim of the study was to provide a multifaceted understanding of their experiences, the maternal perspective predominates and three out of seven themes are described without any evidence from quotes by the girls themselves; across the whole analysis, 90% of quotes are maternal in origin. The focus of maternal quotes, especially those chosen for themes relating to social interactions, is often appraisal of their daughters' behaviour or experiences against their expected norm of adolescent behaviour in girls, and the identification of challenges or difficulties. However, without the inclusion of the girls' opinions, it is not possible to discern whether these are experienced as difficulties by the girls themselves or are deficits perceived by others in comparison to a social construct. This is further exacerbated by the chosen quotes giving

examples of the girls' behaviour, rather than their reactions to and feelings about social interactions and friendships. The paper does not explore the possibility that girls with ASD may have a different understanding of friendship compared to their mothers.

This study also has methodological limitations with the sample of participants lacking the homogeneity that is associated with an IPA approach (Pietkiewicz & Smith, 2014). The participant age range of 12-17 years encompasses a significant period of change in adolescence and the participants attended three different types of educational setting, increasing the likelihood that they were considering differing experiences in their recollections. IPA strives to seek depth rather than breadth of understanding but a heterogeneity in participants can dilute this. Additionally, the aim of IPA to elucidate meaning for individuals, rather than record occurrences, and the small number of participants further limits the ability for the findings to be generalised to the wider population, decreasing its value for answering the review question. The geographical location of Australia also reduces the value as the education system is likely to differ from that of the UK.

**2.2.1.1 Summary and Conclusions from Maternal Perspective.** This study provides insight into the maternal perspective of having an adolescent daughter with ASD. It highlights these girls lacking the social skills needed to access social situations with neurotypical peers and difficulties associated with mainstream schooling, including managing a larger school environment and lack of staff understanding. However, the subsidiary role assigned to the girls' opinions limits the ability to discern the lived experience of being an adolescent girl with ASD, limiting the ability of this paper to answer the review question.

### ***2.2.2 Experiences of Mainstream Schooling***

Four studies were identified as specifically exploring the experiences of mainstream schooling for girls with ASC.

**2.2.2.1 What Teachers Need to Know.** Jarman and Rayner (2015) aimed to explore the school experience of females with AS due to their perceived underrepresentation of females in previous studies examining the experience of having AS in a mainstream setting. To achieve this, they used an anonymous online survey and recruited participants via ASD and AS related websites. They identified two groups of participants: parents of girls with a diagnosis, aged 5-18 years, and adult females with a diagnosis. A total of 45 participants submitted surveys: 15 parents and 30 adults. The authors used an inductive reasoning approach to analyse the data and identified three themes: ‘Teacher recognition of AS in females’, ‘Lack of understanding about challenges associated with AS’ and ‘Helpful attitudes and actions of teachers’.

The first two themes related to a lack of understanding from school staff in terms of recognising the presentation of AS in females and taking into consideration the challenges associated with a diagnosis of AS. This led to reports of teachers not believing diagnoses or not being flexible in their approach to teaching girls with AS. Participants reported challenges related to the school environment and to accessing and engaging with schoolwork. Sensory sensitivities associated with AS made the school environment stressful and overwhelming and an inability to self-organise was often not understood. The extra effort to understand or complete work, difficulties in processing and following verbal instructions and problems with higher order thinking were also sources of difficulties. There were frequent reports of increased stress and anxiety resulting from the lack of appropriate support or consideration of these challenges.

An added complication was the tendency of females to mask their symptoms or maintain a façade of socially acceptable behaviour at school, which exacerbated the perception of teachers that they were coping and not experiencing difficulties. This tendency to mask also led to stress and anxiety. Participants proposed a need for teachers to receive

more education about AS in females and the potential for pupils to have diversity in their presentation of AS. However, the third theme highlighted more positive experiences and the potential for understanding teachers to make a difference. Among the teacher characteristics valued by participants were being flexible, demonstrating a positive and accepting attitude and identifying and addressing individual needs. Being made to feel valued, liked and welcome were particularly appreciated by participants.

A significant limitation of this study is that anonymous data collection meant eligibility had to be taken on trust and it was not possible to verify that participants were genuine. In addition, of the 30 adults answering the survey, 25 received their diagnosis in adulthood and would be unable to comment on teacher understanding of their AS diagnosis. As in the Cridland et al. (2014) study, the parent voice dominated; of the 43 quotes included in the analysis, only 11 or 26% were from female participants with AS. Although this limitation is lessened by parent quotes largely considering situations from their daughters' perspectives, it still results in second-hand recounts of their lived experiences.

When considering the review question, this study has limited relevance due to its focus on all schooling, not just secondary education, and a geographical location of Australia. In addition, there is a lack of direct reference to social interactions.

**2.2.2.2 Positive and Negative Experiences of Mainstream Schooling.** Rainsberry's (2017) study aimed to address the paucity of research describing the experiences of girls with autism in mainstream secondary schools, to identify the areas which require attention and action. She worked with three girls in Years 8, 9 and 11 to produce case studies of their school experiences over a one-month period. Data collection was agreed with the participants and took the form of written, illustrated diaries. These were collated into individual stories, with informal discussions between the author and participants to check interpretations and

agree the format. No explicit analytical method was specified but commonalities between the stories were identified, grouped and discussed under the following headings: 'Special friendships', 'Friendships and peers', 'Special interests', Teachers and school staff', 'Attitudes of staff', Subject lessons', 'Routine, structure and support', 'Environment and sensory issues', 'Diagnosis and disclosure' and 'Secondary school versus primary school'. Discussion of these areas mainly comprised descriptions of the positive and negative experiences with some interpretation of individual experiences.

The findings showed that these girls were motivated to have friendships and that these provided comfort, support and belonging for two of the participants. Attendance at secondary school also increased the propensity for friendships. There were some negative aspects to friendships, in particular, difficulty with the unpredictability of peer interactions and being able to read others' minds and body language. Special interests were a basis for social interactions and engagement in lessons. Teachers and staff played a significant role in how school was experienced by the participants and there were positive comments acknowledging differentiation, adjustment and being understood. However, there was also evidence that teachers misinterpreted needs as 'bad behaviour'. The participants valued support such as access to learning resource bases but sometimes felt support was imposed and not welcome. Aspects of the school environment such as corridors and the lunch hall could be sensorily overwhelming and participants indicated a desire to have personal space at points throughout the timetable such as breaktimes. All participants felt differently about their diagnosis, with one unaware she had one.

Participant voice was strong in this study, however the lack of interpretative analysis, for example thematic analysis or IPA, significantly affected the generalisability of the findings which were essentially, collated individual descriptions. This is a common critique of weak thematic analysis (Braun & Clarke, 2006). A small sample size of three participants,

also reduced the generalisability of the study and the fact that one participant was unaware of how she fulfilled the eligibility criteria raises questions over how the research was introduced and understood by participants. Therefore, although the study appeared to closely fit the review question, a lack of interpretative rigour limits its usefulness in answering it. Additionally, the study only partially fulfilled the aim of identifying areas in need of attention, limiting this to descriptions of negative experiences, identifying the need for greater understanding in schools and recommending activities that positively promote awareness of difference, but not making suggestions about how support for girls with autism could be developed.

**2.2.2.3 Experiences of School Exclusion.** Sproston et al., (2017) aimed to gain insight into the experiences of autistic girls in secondary school through exploring their experiences of school exclusion. The authors used a qualitative design and conducted semi-structured interviews with eight parent-child dyads, focusing on their current educational setting and their previous experience of mainstream education, including being excluded. Participants were aged between 12 and 17 years. The data were analysed using an inductive thematic analysis and three themes were identified: ‘Inappropriate school environment’, ‘Tensions in school relationships’ and ‘Problems with staff responses’.

The school environment was explored from the perspectives of positive and negative aspects of experienced school settings. Negative aspects included difficult sensory environments related to noise or large class sizes where girls felt that they had to fight for attention and access to support. There were also reports of a fear of judgement in mainstream classes which led to not asking for help. Attention to, and accommodation of, individual needs defined the positive aspects of school environments and participants valued smaller groups, staff being understanding and accommodating of differences and decreased pressure to remember things. School relationships included those with staff and peers and a sense of



feeling valued was common to making both a positive experience. Staff who showed an interest and checked in with participants facilitated them seeking help and they valued being listened to. However, threats to the pupil-teacher relationship arose from a lack of understanding from teachers which caused barriers, the internalisation of problems and avoidance of seeking assistance. Participants also reported problems with bullying and difficulties in peer relationships arising from social skills deficits. Problems with staff responses appeared to stem from a perceived lack of knowledge about autism by school staff. Participants reported that teachers did not understand their coping mechanisms, provided inappropriate support or withdrew or backtracked on promises of support.

In contrast with some previously reviewed studies, there was a fairly even balance of parent and pupil voice with 58% of quotes coming from the adolescents. However, limitations arise from a particular subpopulation and consequent difficulties with generalising the findings. All girls had been excluded from mainstream schools which implies a significantly negative experience of mainstream education. Furthermore, a lack of a comparison group, of either non-excluded girls with autism or excluded neurotypical girls, reduced the possibility of exploring the significance of having autism to their experiences, decreasing its value in answering the review question.

**2.2.2.4 What About my Voice?** Goodall and Mackenzie (2019) explored the experience of mainstream schooling for two girls with autism. The authors used multiple means of representation to access and represent the girls' different levels of experience, including semi-structured interviews, drawing activities and activities centred around statements to promote discussion. This multi-method was intended to allow triangulation in data collection and analysis. Data were analysed using inductive thematic analysis and the results focused on the impact of school on well-being, bullying and friendships, and the participants' views on inclusion. The two participants were aged 16 and 17 years, had

previously attended mainstream secondary schools, and were recruited as part of a wider study.

Both participants indicated negative feelings towards school and the experience of being in school having a negative impact on their well-being. At least part of this was related to sensory sensitivities associated with crowds and noise. Friendship worries and difficulties were also significant concerns and both young women stated that bullying was their top worry about mainstream education. A lack of close friendships and people to relate to led to feelings of isolation and this could be exacerbated by teacher-instigated activities such as being asked to find a partner during lessons. Feelings of being different and being judged for having autism were described by both young women and they stated that the condition made it hard for them to socialise. Both participants adopted compensatory and protective behaviours to camouflage their anxiety and isolation by withdrawing from social spaces within school or avoiding going altogether.

A major focus of this study was inclusion and seeking the young women's views on their experiences of and opinions about inclusion. Both stated that they did not feel included in school with a lack of awareness from others leading to them feeling invisible or unvalued. School ethos and teacher understanding were considered integral to promoting inclusion and the participants stated a desire for teachers to 'adapt their practice and attitudes to authentically include them'. Inclusion was viewed as more than just attending a mainstream setting, it required the acceptance and accommodation of individual needs and differences. In particular, the participants valued staff taking the time to listen and understanding the difficulties and problems they faced in school, including sensory issues and difficulties with friendships.

This study faces limitations in generalisability from a small number of participants who had both had negative experiences during mainstream schooling and subsequently left, resulting in a particular subpopulation. In addition, the relevance to the review question is further reduced by the geographical location of Ireland.

#### **2.2.2.5 Summary and Conclusions from Experiences of Mainstream Schooling.**

There were shared themes between studies and attendance in a mainstream school resulted in negative experiences and sources of stress and anxiety for all participants, especially in relation to the social environment. These commonly included sensory sensitivities to large groups and noise, and friendship issues arising from social skills deficits. However, it should be noted that all four studies have limitations that prevent confident generalisation, and this highlights a gap in the research; more studies are required to explore the experience of mainstream schooling for a range of girls with autism. Related to these negative experiences, a lack of teacher understanding about autism in females was raised as a significant concern across the studies and this was felt to lead to inappropriate or insufficient support for girls at school, consistent with the findings of Cridland et al. (2014). However, there were some reports of positive experiences with teaching staff and the identification and accommodation of individual needs was repeatedly cited as a way of making the school experience more positive. Feeling valued and experiencing a sense of belonging was also a shared theme across the studies. It would be beneficial to explore this further, especially in terms of successful examples, to aid the development of appropriate support for girls and young women with autism in mainstream secondary schools.

Masking and coping strategies were also described in three studies and were associated with negative outcomes for the girls. Maintaining a façade of socially acceptable behaviour or avoiding problem situations were sources of stress and anxiety and could also

prevent recognition of difficulties and the provision of support. None of the studies proposed solutions to the conundrum of how to support pupils who outwardly appear to be coping but are internalising their difficulties and struggling, and this is an area that would benefit from further investigation.

### ***2.2.3 Perceptions of Friendship***

Four studies explored the perceptions of friendship and social experiences by girls with autism.

**2.2.3.1 Understanding the Social Experiences of Adolescent Females on the Autistic Spectrum.** The aim of Foggo and Webster's (2017) study was to determine how adolescent girls on the autism spectrum understand and make sense of social expectations and what qualities they and their peers bring to social interactions and relationships. They used a phenomenological approach and created a semi-structured interview schedule which focused on various aspects of socialising including definitions of friendship, shared activities and conversation topics, conflict, and the emotional impact of social experiences. Seven girls aged 13-17 years old and attending mainstream schools took part, with six choosing to supply written answers and one taking part in a telephone interview. The authors used an inductive thematic approach for analysis and identified two primary overarching themes: 'Social interactions are important' and 'Social interactions are difficult'.

Participants were motivated to have friends and saw friendships as a positive part of their lives, conferring happiness and support as well as a sense of belonging and acceptance. They were able to describe the characteristics of friendship and list qualities that they valued in friendships such as trust, understanding, respect and the ability to be themselves without judgement. Descriptions of shared activities and conversation topics indicated a range of social interactions with friends congruent with those expected in adolescent friendships.

However, two findings stand out as being of potential significance. Firstly, participants gave diverse answers about what other girls talked about with their friends with three expressing uncertainty, two believing they discussed different topics to those they discussed with their friends and only two stating that they thought they talked about similar topics. This could indicate a lack of awareness of how others conduct friendships and social interactions or could indicate that girls on the autistic spectrum have a different perspective in relation to what constitutes a friendship. This is further indicated by the second potentially significant finding that the activities participants identified as favourite pastimes were those that they would tend to do alone such as artistic endeavours, spending time with animals and gaming, rather than the activities they shared with friends. This may be indicative of a different perspective on the function of friendships and social interactions in girls on the autistic spectrum. A follow up question linked to this was answered by three participants and indicated a need for time alone.

Difficulties with social interactions centred around managing conflict and group interactions and awareness of the perceptions of others. Overall, a lack of knowledge and certainty over how to behave in different social situations appeared to be the source of these difficulties, in particular knowing how to deal with and respond to the opinions of others. In a conflict situation, participants appeared to lack appropriate negotiating skills and a common response was to apologise even if they felt the source of conflict wasn't their fault. The perceptions of others were a source of uncertainty for participants with three saying they didn't know what others thought of them and four suggesting that others may view them in a negative light due to a lack of social conformity. All participants appeared to perceive other girls as having different interests to their own and referred to these interests as being indicative of greater maturity. Collectively, these comments suggest a feeling of being different to neurotypical peers and a struggle with awareness of the experiences and

expectations of neurotypical peers. Participants may also have tended to view themselves negatively when comparing themselves with neurotypical peers.

One limitation of this study is that most answers were provided in written form which removed the ability to develop understanding through prompts to discuss points further. Follow up questions were sent out in some cases but did not receive many answers. On this basis, the description of data collection through a semi-structured interview is inaccurate and misleading as topics were not explored beyond the initial questions. Another consequence is that although the data provide some rich insights into perceptions of friendships and social interactions, they also raise questions which could potentially have been answered in the traditional semi-structured interview format. The responses to a number of questions implied that these girls with autism are aware of differences between their friendships and those of their neurotypical peers and it would be beneficial to explore the significance of this to them further; to establish their understanding of friendship and to explore any impacts or perceived difficulties. Such information would be helpful in order to inform appropriate support for developing social skills and maintaining friendships in girls with autism.

As is inherent with a qualitative design, the small sample size limits generalisability and the geographical location of Australia may also reduce the relevance of the data in answering the review question. However, the results do give insight into the social world of girls with autism and as the focus is predominantly social interactions, rather than education, the decrease in relevance may not be as pronounced as in the studies investigating school experiences.

**2.2.3.2 Social Experiences and a Sense of Belonging.** This study by Myles et al., (2019) aimed to address the authors' perceived need to better understand the lived social experiences of adolescent females with autism at mainstream schools and to explore the

factors that add to and take away from their sense of belonging. Data were collected via semi-structured interview with eight girls aged 12-17 years attending three mainstream secondary schools in South West England. The interview schedule was developed using hierarchical focusing which involves giving prompts for topics of interest if these do not naturally arise during the conversation. The authors used thematic analysis and identified six themes: 'Reciprocal friendships', 'Feeling safe and supported', 'Encouragement and inclusion', 'Establishing and adhering to social expectations', 'Being on the periphery' and 'Feeling devalued'.

The first four themes were related to the ways in which girls felt that they belonged. Participants valued friendships and identified them as sources of happiness and support, both in terms of companionship and during social interactions with others at school. They were able to discuss the qualities associated with friendships and were motivated to engage in them. Many of the girls referred to the challenges of attending a large, busy school and connection with others was valued as a means of feeling safe and supported. Participants described the benefits of having quieter places to check in with staff and peers during the school day and feeling a sense of belonging when friends acknowledged them and made them feel valued. The personal qualities the participants identified as being involved in promoting belonging corresponded with social norms associated with female behaviour and tended to include references to verbal interaction skills, confidence and kindness. They also commented on the benefits of behaving in a socially acceptable way to ensure positive interactions with peers and one participant described mirroring or copying her friend's behaviour to ensure she was behaving acceptably.

More negative experiences during social interactions centred around difficulties with social skills and uncertainty in how to behave, which could lead to feelings of anxiety or even avoidance of social situations. Participants also reported feelings of not being able to join in,

which might arise from having different interests or priorities to peers or from deliberate exclusion by other girls ignoring them. Participants also described feeling devalued through not being listened to or feeling judged for their diagnosis. In addition, one participant described being misunderstood by teachers who didn't appreciate her difficulties and needs. Exploration of the social skills of participants revealed deficits in their knowledge of expected behaviour and difficulties with managing large groups of friends. Many participants expressed a preference for small social circles or one close friend and commented on the challenges of managing the complexities of female friendships such as arguments, jealousy and gossiping.

Although the generalisability of this study is limited by the small number of participants, its findings have high relevance to the review question and provide insight into the social world of girls with autism. The study did not extend to discussing potential ways to support girls with autism in managing social challenges and this would be a beneficial focus for future studies.

**2.2.3.3 It's Different for Girls.** Sedgewick et al., (2019) aimed to understand the nature of autistic adolescents' friendships in comparison to neurotypical peers and determine whether or not gender had an influence on experiences of friendship and conflict. The authors used a mixed methods design which comprised questionnaires and semi-structured interviews. A total of 102 adolescents, aged 11-18 years old, took part in the study: 27 autistic females, 26 autistic males, 26 neurotypical females and 23 neurotypical males. They completed the Wechsler Abbreviated Scales of Intelligence–2nd edition (Wechsler, 2011), the Friendship Qualities Scale (Bukowski et al., 1994), which assesses adolescents' perceptions of their best-friendship, and the Revised Peer Experiences Questionnaire (Prinstein et al., 2001) which assesses the frequency of overt and relational bullying behaviours that a participant both engages in and is subject to. Autistic participants also



completed Module 3 (10 participants) or Module 4 (41 participants) of the Autism Diagnostic Observation Schedule – 2nd Edition (ADOS-2) (Lord et al., 2012) at the beginning of the session. The parents of all participants completed the Social Responsiveness Scale - 2nd edition (Constantino & Gruber, 2012) which assesses social and behavioural difficulties associated with autism.

The semi-structured interviews focused on friendships and conflict using open-ended questions originally generated from the ADOS-2 ‘Friendships and Marriage’ section with additional questions to probe specific age-appropriate issues such as the contexts in which friendships were maintained. There was also discussion of critical incidents which comprised participants identifying two specific experiences with peers, one positive and one difficult, and elaborating on the participants’ emotional responses and meaning making during the experiences. 90 participants (27 autistic girls, 23 autistic boys, 20 neurotypical girls, 20 neurotypical boys) took part in semi-structured interviews. All measures were completed in one or two sessions, with the exception of the parent questionnaires which were returned by post.

The questionnaire data (total and sub-scale scores of each measure) were analysed using between-group ANOVAs with group (autistic, neurotypical) and gender (female, male) as factors in order to identify the influences of autism and gender on perceptions of friendship and any interactions between the two. The authors used inductive thematic analysis to analyse verbatim transcripts of the semi-structured interviews and identified three themes that were common to all participants, regardless of gender or group: (friends are) ‘People like me’, ‘Friends are there for you’ and ‘Spending time together’. However, there were also notable group differences with gender, rather than diagnostic status, being the differentiating factor.

The main finding of the study, inherent in both the quantitative and qualitative data, was that gender was a more significant influence on friendship experiences than diagnosis. The authors cited an absence of group interactions in quantitative data analyses as suggestive of the best-friendships of autistic girls being qualitatively more like those of neurotypical girls than those of autistic or neurotypical boys. This was congruent with the qualitative data in which female participants described close friendships based around emotional sharing, talking, and time together and male participants consistently discussed activity-focused, practical elements of friendship. Although there were differences between autistic and neurotypical individuals within the gender groups, the authors did not identify similarities across diagnostic groupings.

The authors identified three broad themes for the female participants: 'Nature of social networks', 'Conflict experiences' and 'Wanting to fit in'. All girls described similar definitions of friendships and conflict experiences and were consistent in the elements of friendship which they valued such as emotional and social support. However, autistic females described having fewer, more intense friendships, compared to neurotypical peers and were less socially aggressive and competitive. They described having friends as hard work, meaning that maintaining more than one or two close relationships would be difficult. Autistic females also appeared to be more frequent victims of relational aggressions and struggled more than their neurotypical peers in managing conflict, employing different resolution strategies; whereas neurotypical girls worked towards joint, reciprocal problem solving, autistic girls either took sole responsibility or ended the friendship entirely, an all or nothing approach that suggested that they struggled to identify how to resolve conflict situations through reciprocity. All girls discussed fitting in and seeking peer acceptance but achieved this through different means. Whereas neurotypical girls described dating boys to

look cool, autistic girls' descriptions of friends being people with whom you can be yourself were taken to imply that they felt that they must frequently control how they behave to fit in.

A key exception to the main finding was that autistic girls experienced more relational conflict than any other groups. The authors proposed two possible explanations for this: that autistic females might have higher levels of self-insight and social awareness than autistic males and therefore be more sensitive to relational aggression, or that the degree of conflict experienced by autistic females is elevated to such an extent that it has a significantly greater impact on them. This is an area that warrants further investigation.

This was mixed methods study that used both quantitative and qualitative data to explore friendship experiences and the findings are strengthened by the agreement between these data. The number of participants was also substantially higher than in traditional purely qualitative studies which increases the ability to generalise the findings. Furthermore, the study was conducted in the UK which increases its value and relevance to the review question. However, there are some limitations in terms of qualitative data collection. Autistic participants completed an additional test (ADOS-2 module) at the beginning of their session which had the potential to impact their answers in a couple of ways. Firstly, the extra test will have lengthened their session and may have impacted their performance, potentially making them more tired when they reached the semi-structured interview. Mean interview lengths were reported to be similar between the groups but this was not statistically analysed. Secondly, the interview questions were derived from the ADOS-2 and the authors acknowledged that there was repetition between the initial test and the interview questions for autistic participants. They felt this was compensated for by requests for elaboration but there is no evidence of checking for the possibility that participants did not repeat information from the initial test due to feeling that they had already supplied this information. This is especially significant for individuals with a diagnosis that is known to result in communication

difficulties and potential uncertainty about expectations (Jordan & Powell, 1995). Therefore, there is a possibility that autistic participants did not provide full answers during the semi-structured interviews and the data set is not as rich as it could be. Given that six individuals failed to reach the threshold for diagnosis in the ADOS-2 test but were still included - based on their clinical diagnosis, EHC plan or statement of Special Educational Needs specifying autism as their primary need and parental responses on the SRS-2 meeting the threshold for autism - its inclusion appears to be an unnecessary step and potential compromise of the data.

#### **2.2.3.4 Perceptions of Friendship Among Girls with Autism Spectrum Disorder.**

The final study looked at shared activities and friendship management, with the aim of elucidating how girls with ASD conceptualised friendship. Ryan et al. (2020), used a qualitative methodology with ten girls aged between 12 and 15 years old, interviewing participants in two focus groups of four and six girls respectively. A semi-structured moderator's guide was used to ensure coverage of several themes which focused on the meaning of friendship and friendship initiation and management. The authors used inductive thematic analysis to examine verbatim transcripts of the focus group discussions and identified four major themes: 'Establishing friendships', 'Friendship conflict and loss', 'Friendships and technology' and 'Gender differences'.

Having support to establish and maintain friendships through shared interests and opportunities to meet was highlighted by participants. School was the main physical context for forming friendships and shared interests increased the girls' confidence in approaching potential new friends as it made initiating a conversation easier. Having continued opportunities to meet up regularly was important for maintaining friendships. Participants also commented on the qualities of friendships, valuing trustworthiness, loyalty and reciprocity, and some emphasising the benefit of small number of friends over a larger social network. Exploration of conflict and loss within friendships showed that loss could occur for

a variety of reasons and caused distress for the participants; fears over loss stemmed from worries over isolation and loneliness. There were some reports of relational aggression such as gossip, social exclusion and the withdrawal of friendship, but participants also gave insight into viewing conflict as a normal process within friendships. Participants showed ambivalence over technology as a support for friendships. Online interactions were described as easier than real-life interactions, but participants unanimously expressed a preference for real-life friends. The authors postulated a sense that the girls found texting difficult and challenging, although this was not evidenced through quotes. Participants also showed mixed feelings about having boys as friends with some reports of positive feelings and some of feeling anxiety in relation to boys.

A limitation of this study is that the methodology may have constrained in-depth exploration of ideas because participants potentially found the focus group format challenging. The authors acknowledged that a focus group methodology could pose unique challenges for young people with autism, which is associated with communication difficulties, and reported that two of the participants contributed only brief comments despite efforts to reduce potential problems. Some insights from the participants raised further questions, and subsequent hypotheses about meaning in the discussion. For example, the authors hypothesised that shared interests may help initiate conversations that lead to friendship because they allow conversation to be object-oriented rather than immediately personal which individuals with ASD might find challenging. They also speculate about difficulties with texting and consequent lost opportunities for communication with peers. A semi-structured interview format with individuals, where the challenges of group conversation were removed, may have facilitated further discussion and elucidation of meaning for participants, reducing the need for conjecture in the findings. Another consideration for the suitability of using a focus group format is that previous literature shows

an association between social mimicry and conformity and the female ASD phenotype (e.g., Bargiela et al., 2016). This raises the possibility that the richness of the data was reduced through participants following others in the group, rather than sharing their own, differing experiences.

As with other qualitative studies, the generalisability of results is reduced by a small number of participants and particular subpopulation. Many of the participants attended all girls' schools which is likely to have affected their experiences of friendship, especially in relation to opportunities to socialise with boys. This is particularly pertinent as the participants reported school as the primary context for forming friendships and the insights into gender differences in friendships may therefore be limited in usefulness. The study was conducted in Ireland which may reduce its relevance for the review question, although the subject being friendship may make this less significant than with studies relating specifically to school experiences.

**2.2.3.5 Summary and Conclusions from Perceptions of Friendship.** In all four studies girls with autism were motivated to have friendships and saw them as positive parts of their lives. They valued friendships for the support they gave and described similar important qualities for friendships such as trust, reciprocity and the chance to be themselves. In addition, a common theme between studies was a preference for small friendship groups which could be linked to difficulties experienced in maintaining friendships. All studies made reference to some form of relational conflict and another common theme was difficulty in managing this conflict. This appeared to stem from uncertainty over how to behave and two studies described autistic females taking sole responsibility for conflicts, even if they didn't believe that they were to blame, as a way of resolving them.

Although participants were motivated to have friendships, another commonality was that friendships weren't straightforward and could be sources of uncertainty or anxiety. Individual factors implying this were different between studies and included not knowing how to behave in social situations, finding friendships hard work, feeling different to neurotypical peers, awareness of social conformity and changing your behaviour to fit in, and needing a context such as school to initiate and maintain friendships. These are consistent with the findings of other papers in this review. Some descriptions, particularly in the study by Foggo and Webster (2017), indicate a potential for autistic females to have a different understanding of friendship to neurotypical peers and this is something that could be explored further in the future. In order to provide appropriate support and guidance for social interactions, it will be beneficial to conduct in-depth exploration of how autistic girls feel about perceived areas of social difficulty and how, or if, they wish to be supported in resolving them.

#### ***2.2.4 Coping Strategies***

Two studies explored friendships and social interactions in autistic females with a specific focus on coping strategies.

**2.2.4.1 Looking Behind the Mask.** This study by Tierney et al., (2016) aimed to explore whether adolescent females with ASC use social management strategies, in particular masquerading, to hide socio-communication difficulties to enable them to fit in with peers. They used semi-structured interviews to gain the views of ten participants aged between 13 and 19 years old. To accommodate the girls' socio-communication difficulties, they elicited specific concrete examples and then explored these in detail, including asking for comparisons with how the participants felt neurotypical peers coped in the same situations. The authors used IPA to analyse the interview scripts and identified four superordinate

themes: 'Experience of social environments', 'Desire for friendship', 'Overcoming challenges' and 'Developmental tasks'.

All participants described a desire for friendships, but a recurring observation was that friendships were difficult, and the social environment and social interactions were challenging. The social environment was associated with negative experiences including sensory distress in crowded places, and uncertainty over social expectations. This led to participants feeling a lack of safety and rejection by peers, an inability to fit in and unintentional breaking of covert rules of which they were unaware. Some participants described friendships with boys as being more desirable due to more shared interests and a lack of emotionally based conversation. Many participants described social contact as exhausting and that making and maintaining friendships required considerable effort. In all cases external support had also been vital in making and maintaining friendships. Mutual misunderstandings in communication could lead to participants feeling confused and anxious in social situations and nearly all reported that group communication was difficult.

However, participants also reported the development of strategies to overcome these challenges. Some of these involved the participants' innate abilities such as strong empathising skills, observational skills and good memories being used to develop a social code that facilitated understanding implicit social conventions. Participants also described sophisticated levels of peer imitation, including copying facial expressions, topics of conversation and choices of interests, which was driven by a desire to fit in and not stand out as being different. Significantly, participants also tweaked this mimicry slightly to avoid being caught out which suggests an awareness of others' mental states which has previously been proposed to be deficient in individuals with autism (Baron-Cohen, 1995). Another strategy reported by all participants was masking negative feelings by pretending to be happy in social situations that provoked feelings of unhappiness and anxiety. These coping



strategies were not benign, requiring effort to maintain, and there were emotional consequences or even severe repercussions for sustained use. Participants reported anxiety and depression, and some had used self-harm as a way to cope with frequent rejections and miscommunications. A significant finding, in agreement with previous studies, was that some masking strategies were so successful, they resulted in others being unaware of the extent of the difficulties faced by the girls and this negatively impacted on their access to support. This highlights that although the strategies were enabling the girls to take part in their social environment, they were not removing the difficulties and therefore not providing a complete solution.

The transition from primary to secondary school was identified as the point at which difficulties emerged, with the changes in social expectations being a trigger. Adolescence was described as a time when there were multiple, major unspoken changes in social etiquette which led to confusion for participants and a decrease in their ability to abide by and understand new social norms. Consistent with other papers in this review, the increase in school size could also be problematic, with increased opportunities for sensory distress and extra demands on socio-communication skills, for example making new friends.

A limitation of this study, in common with the study by Cridland et al. (2014), is that it lacks the homogeneity in participants that is associated with an IPA approach (Pietkiewicz & Smith, 2014); participants were aged between 13 and 19 years which covers a significant period of adolescent development and potentially varied experiences. A further limitation is that generalisation to a wider population is reduced by a small number of participants and the use of IPA, as it aims to understand the meaning of experiences for individuals, rather than describe occurrences of behaviours or experiences.

**2.2.4.2 The Role of Masking.** Cook et al., (2018) chose to focus on the perspectives of girls with autism and those of their parents with the aim of exploring their experiences of learning, friendship and bullying in different school settings. They used semi-structured interviews to gain the views of eleven parent-girl dyads from mainstream and specialist provision schools; six of the girls attended mainstream schools and five girls attended specialist settings. The authors used inductive thematic analysis and identified three themes: 'Motivation to have friends', 'Challenges' and 'Masking autism'.

All girls reported being motivated to have friends but experiencing difficulties in achieving this. These could be due to lacking the social skills needed to form and maintain friendships or feeling different to neurotypical peers and struggling to fit in. In common with previous studies, there were reports of bullying and relational conflict, and difficulties with managing this. Social isolation and being on the periphery of groups was common. The sensory environment of school could also lead to girls feeling overwhelmed. An interesting finding was that most parents and some girls reported having different expectations for friendships compared to neurotypical peers. The authors noted that social exclusion, such as not being invited to parties, appeared to affect parents more than the girls themselves.

Both parents and girls reported that they copied the mannerisms of other girls and hid their autistic characteristics in order to fit in. Girls reported a reluctance to be labelled, and therefore a desire to conceal their differences, and this tendency to mask behaviour appeared to be more common in mainstream settings, functioning to prevent the girls being singled out. Masking was viewed as both a solution and a problem, facilitating conformity and acceptance but also hiding difficulties and negatively impacting on the provision of support or even diagnosis. This could lead to further problems such as falling behind in school and social difficulties. As in the previous study by Tierney et al. (2016), social mimicry was an

incomplete solution, offering a superficial and immediate solution during social interactions but potentially internalising problems and deferring difficulties to be dealt with later.

Interpretation of the data is limited by many of the findings being brief statements and naming occurrences without elaborating or explaining their meaning for the girls. An example is the statement that masking behaviour led to falling behind at school and further social difficulties; no specific examples were given to explain explicitly how masking affects schoolwork and the further social difficulties were not discussed. This leaves the reader needing to fill in gaps with inference and wondering what led to the authors reaching these conclusions. The lack of supporting evidence produces an incomplete picture and limits the ability of the study to inform future support for girls with autism experiencing difficulties during social interactions. Further limitations come through the small number of participants which is inherent in qualitative designs.

**2.2.4.3 Summary and Conclusions from Coping Strategies.** In agreement with other papers in this review, both studies reported that girls with autism are motivated to have friends but find achieving friendships challenging, arising from difficulties with social skills and fitting in. Both studies also reported that girls used social mimicry as a strategy to address difficulties but that this had negative implications; girls internalised problems which resulted in difficulties going unnoticed and girls missing out on appropriate support.

Whilst both studies identified that coping strategies are incomplete solutions to the difficulties autistic girls experience in association with social interactions, they did not explore alternatives or ideas for supporting these girls. This highlights a gap in the research knowledge and a potential area for further exploration in future studies.

## 2.3 Summary and Overall Conclusions

Several common themes were identified in this review of studies exploring how girls with ASC experience the social aspects of mainstream schooling. Findings showed that these girls are motivated to engage in the social environment and maintain friendships but find this a difficult experience that can cause anxiety and distress. Significantly, the studies examining general school experiences highlighted similar concerns to those specifically examining social interactions, suggesting that the social aspects of school are a significant source of difficulties for girls with ASC. Whilst the studies reviewed identified areas of need such as sensory sensitivities to large, noisy school environments and social skills deficits, they did not specifically explore ways in which these needs can be addressed or supported, reducing the ability for these studies to be used to inform interventions to support girls with ASC. Of particular concern is the repeated finding that some of the girls' own coping strategies, in particular masking, are incomplete solutions, not only resulting in internalising problems and potential mental health difficulties but also leading to needs not being recognised and resultant inappropriate or inadequate support. The pervasive invisibility of these needs mean that they are unlikely to be resolved without specific, focused investigation.

There were some inconsistencies between studies with some suggesting a substantially negative experience of the social environment and some highlighting positive and negative aspects. This could in part be due to the subpopulations chosen for participation in some studies and there is scope for further investigation, especially of the experiences of mainstream schooling for a variety of girls with ASC. Additionally, some studies pointed to the potential for girls with ASC to have a different perspective of friendship to neurotypical individuals. This is an important consideration when devising appropriate support for these girls and highlights a need to explore this further and to include their voice in such decisions. Exploration of positive experiences will also be of benefit in informing effective support as

they will elucidate successful support mechanisms. Finally, a lack of teacher understanding of the needs of girls with autism was raised in several studies, mainly those which included a parent voice, suggesting a need for better information for school staff. This is likely to be enhanced by including ideas for appropriate support as well as descriptions of needs.

Exploration of the female phenotype for autism is a new and developing area of research, as is demonstrated by most of these studies being published within the last 5 years. The conclusion of this literature review is that there is scope for further exploration of their lived experiences, their perceptions of friendships and the social difficulties they encounter during their school experiences, with a view to finding positive solutions to these difficulties and informing appropriate support. This study will address this through working with adolescent girls with ASC to explore relevant aspects of their school and social experiences and how positive solutions for difficulties can be achieved.

## **Chapter 3: Methodology**

### **3.1 Introduction**

This chapter describes the aims and purpose of this research, states the research questions investigated, and provides explanation and justification of the methodologies chosen. The ontological and epistemological positions are elucidated, followed by description of the research design and data collection procedures. In addition, ethical and confidentiality issues are considered, and the trustworthiness and validity of the project discussed in reference to potential threats and the measures taken to counter these.

### **3.2 Aims and Purpose of the Research**

#### ***3.2.1 Research Aims***

This research aimed to address the issues identified in the literature review in Chapter 2. One conclusion of this review was that the social aspect of school appears to be a significant source of difficulty for adolescent girls with ASC. However, most research to date has been descriptive and not explored solutions for appropriate support. The primary aim was therefore to explore ways to support adolescent girls with ASC during social interactions in school. This was achieved through taking a positive psychology approach (Seligman et al., 2005) and asking participants to reflect on what was already working well in helping them to navigate the social aspects of school. A participatory approach was also used with participants recruited as co-researchers and involved in decisions about data collection, analysis interpretation and dissemination of findings, promoting the relevance of the findings to the participant community.

An additional issue identified by the literature review was concern around a lack of teacher knowledge about the female phenotype for autism. Through documenting experiences and focusing on positive ways to offer support, the research also added to the existing

knowledge of the school experiences of adolescent girls with ASC and generated information to support teacher understanding.

### ***3.2.2 Research Purpose***

Research can be classified as explanatory, exploratory, descriptive or emancipatory (Creswell, 2007; Robson 2002) and the primary purposes of this research were exploratory and emancipatory. Exploratory research is concerned with finding out more, particularly in little-understood situations, and seeking new insights or assessing phenomena in a new light (Robson, 2002). This is congruent with understanding of the female phenotype for ASC being a new and developing area of research and with the complexities associated with offering appropriate support that arise from some girls masking and hiding their autism.

The use of a participatory research approach gave the research an emancipatory purpose through creating opportunities for engagement in social action (Robson, 2002). In accordance with the principles of emancipatory research discussed by Stone and Priestley (1996), the research process directed data collection towards topics of relevance to the lives of the research participants and focused on removing barriers, rather than identifying deficits. The positioning of participants as co-researchers aimed to avoid creating feelings of passivity within them and the promotion of anti-oppressive practices.

### **3.3 Ontological and Epistemological Position**

The underlying ontology and epistemology of this research project were those of critical realism, reflecting the complex and multifaceted nature of the research subject and the exploratory and emancipatory research purposes. Whilst an empirical approach is often reductionist, classifying reality as observable events, a critical realist perspective recognises that reality is constructed through underlying, and interacting, causal mechanisms which produce experiences and observable events (Danermark et al., 2002). Such mechanisms can

be physical, biological, physiological, psychological, socio-cultural and normative, amongst others, and interact at different levels and within context to generate multiplicity and complexity (Bhaskar & Danermark, 2006). Critical realism acknowledges that experiences are influenced by the context, including social structures, in which they are experienced and are therefore not inevitably consistent or predictable (Danermark et al., 2002).

For adolescent girls with ASC, their experiences of the social aspects of school will result from interactions between multiple mechanisms such as the social and communication difficulties they experience due to being autistic, the expected norms for the social activities they engage in, their understanding and interpretation of these norms, and the context within which these social activities occur. A further consideration is the complexity that results from some girls with ASC masking and copying behaviour to fit in, giving the appearance of coping but internalising stress and anxiety. Consequently, these mechanisms could not be discerned through observation alone and a critical realist perspective facilitated exploration of how these various mechanisms interact to produce the girls' experiences of the social aspects of school. As the aim of this research was to explore positive ways to support girls with ASC, it was essential to have a multi-level understanding of their reality, from their perspective, and to not prioritise outward appearances. Congruent with the research aims, a focus on what produced an observable event or experience enabled understanding of how to offer support, as well as description of that event (Bhaskar & Danermark, 2006).

In addition, as the participants' subjective experiences required their interpretation to be known, the epistemology of this research was reliant on an interaction between the researcher and the participants to discover and reveal their experiences. This led to qualitative methods that were dialogic in nature, requiring transactional discourse that took context into account. Qualitative data analysis facilitated reporting the complexities of the situation and the interpretation of meaning for the participants (Creswell & Creswell, 2017).



Bhaskar and Danermark (2006) state that a critical realist perspective allows for ontological pluralism and the accommodation of insights from other metatheoretical positions. In this research the emancipatory purpose introduced elements of the transformative paradigm, providing a voice for participants and including an agenda for positive change (Creswell & Creswell, 2017). In addition, there was recognition that as well as being created by multiple mechanisms, reality is also socially constructed by all those involved and consequently there can be multiple versions of reality (Mertens, 2007). To promote social justice and effect change for the participants, it was essential to give priority to the reality defined and experienced by the participants and this was facilitated by using a participatory approach that positioned them as experts in their own experiences.

### **3.4 Participatory Research**

A participatory research approach involves planning and conducting the research process in collaboration with those people whose experiences are under study (Aldridge, 2016; Hart, 1992). Including participants as co-researchers enabled a joint process of knowledge production and decision making, facilitating new insights and positive changes being achieved for those involved (Bergold & Thomas, 2012). Within this project participants directed the research by identifying which social activities and experiences they felt were important to focus on and deciding what to reflect on during their personal data gathering. This prioritised their concerns and inherent expertise in understanding their circumstances and experiences, rather than external suggestions from the researcher.

The participants were also involved in verifying the themes identified by the researcher during thematic analysis of the collated data and the interpretation of their reflections on what helped them to successfully navigate the social aspects of schooling. Participants were not involved in the process of identifying themes across the data set due to

logistical considerations and potential impact on their learning. The time required to learn the principles of thematic analysis, read and analyse five transcripts and engage in subsequent group discussion to identify themes would have resulted in a significant commitment during the school day and time away from learning. Consequently, a compromise was reached whereby the participants' involvement in decision making was balanced against their time commitments. A role in verifying the thematic analysis and the opportunity to propose changes was felt to maximise ownership of the research whilst minimising the impact on their learning.

A key premise of participatory research is effecting change with participants and true participation in research should go beyond contact with researchers during data collection (Pain & Francis, 2003). Therefore, once analysis was complete, the participants were also involved in decisions over how to disseminate the findings and how they could be used to inform changes in the support offered by their schools.

#### ***3.4.1 Assessing the Impact of Taking Part in the Research***

Several aspects of the research design gave the potential for participation in the project to have an impact on participants. Previous studies have found that identifying and reflecting on personal successes can have a positive impact on attributes such as well-being and happiness (Seligman et al., 2005), and the act of reflection on experiences and making sense of what happened can provide a structure for learning from experience (Gibbs, 1988). In addition, the emancipatory purpose of the research gave the potential for feelings of empowerment and raised self-esteem. The potential impact of taking part was investigated through asking the participants to reflect on the overall experience of participation in the project and analysing their experiences.

### **3.5 Research Questions**

Three research questions were identified:

- 1). What social aspects of mainstream schooling do adolescent girls with ASC consider to be relevant focus areas for those offering support?
- 2). What do adolescent girls with ASC say helps them successfully navigate the social aspect of mainstream schooling?
- 3). What do adolescent girls with ASC think about participating in research and analysing their social experiences in school?

### **3.6 Research Design**

#### ***3.6.1 Qualitative Design***

A qualitative design was used to explore and understand the meaning ascribed by the participants to their experiences (Creswell & Creswell, 2017). This was in keeping with a critical realist perspective, as it allowed elucidation of the underlying mechanisms producing the experience, and with an emancipatory purpose as the participants' voices were given credence. Additionally, a qualitative approach facilitated exploration of a new and understudied area (Creswell & Creswell, 2017).

#### ***3.6.2 Selection of the Qualitative Method***

A data set was created by gathering the views of five adolescent girls with ASC in different schools across the researcher's local authority. Data collection was based on individual semi-structured interviews (or equivalents) with participants. In this way, the research aimed to increase the range of experiences gathered, and richness of the data set, and to avoid the potential limitations of focus groups, as discussed in relation to the study by Ryan et al. (2020) in Chapter 2. A semi-structured approach facilitated flexibility and allowed

participants ownership over which information to share. Data were analysed using a thematic analysis approach (Braun & Clarke, 2006).

The interpretation and analysis of subjective experiences can be achieved using various different approaches, including IPA, grounded theory and thematic analysis. Consideration was given as to which approach would best answer the research questions and aims which sought to identify positive solutions and outcomes, as well as understand the experiences that lay behind them. The in-depth focus of IPA on discerning how individuals make sense of their experiences (Pietkiewicz & Smith, 2014) was felt to be too narrow for answering the research questions and to place a limitation on the ability to discern how context influenced situations and the identification of outcomes. In addition, a grounded theory approach, which seeks to generate a theory from the data to explain phenomena (Robson, 2002), was inappropriate for elucidating outcomes and solutions. Thematic analysis was chosen as it complements a critical realist perspective and is a method that can both reflect reality and unpick the mechanisms underlying it, including the influence of context (Braun & Clarke, 2006).

### ***3.6.3 Thematic Analysis***

Thematic analysis involves identifying and analysing repeated patterns of meaning or themes across a data set (Braun & Clarke, 2006). The analysis form varies according to the purpose of the research and the claims that will be made about the data. It can range from providing a broad, rich description of the whole data set that gives a sense of important themes, to providing a detailed account of a particular area that addresses a specific question or topic of interest. Themes can be semantic in nature and provide collated surface descriptions of the data, or analysis can include interpretation and attempts to theorise the significance of patterns and broader meanings, producing latent themes. Themes may also be

identified inductively in direct response to the data, or deductively, under the direction of a specific area of interest and question framework (Braun & Clarke, 2006).

Analysis involves a six-step process outlined by Braun and Clarke (2006):

- 1) familiarisation with the data, through repeated reading of the data and active seeking of meaning and patterns.
- 2) generation of initial codes for features of the data that appear interesting and related to the area of interest.
- 3) search for themes through the sorting of codes into potential themes and examining the relationships between codes and potential themes.
- 4) review of themes and refinement to ensure internal homogeneity and external heterogeneity.
- 5) definition and naming of themes, including identifying the essence of themes and determining which aspect of the data each theme captures.
- 6) producing a report that includes evidence of the themes from within the data, an analytical narrative that goes beyond description and makes an argument in relation to the research question.

The data on school experiences were analysed using a primarily deductive approach that aimed to identify what participants considered helpful in successfully navigating the social aspects of school. However, to maximise the scope of the findings, the researcher also remained open to inductive understanding of the transcripts, identifying other areas of significance for the participants. Analysis was interpretive, producing latent themes, to examine the mechanisms underlying the experiences of the participants and gain a deeper understanding of why experiences were successful. After step 5), the analysis was discussed

with participants, who were asked to give feedback on, and verify, the researcher's interpretations of their shared ideas and identification of common themes.

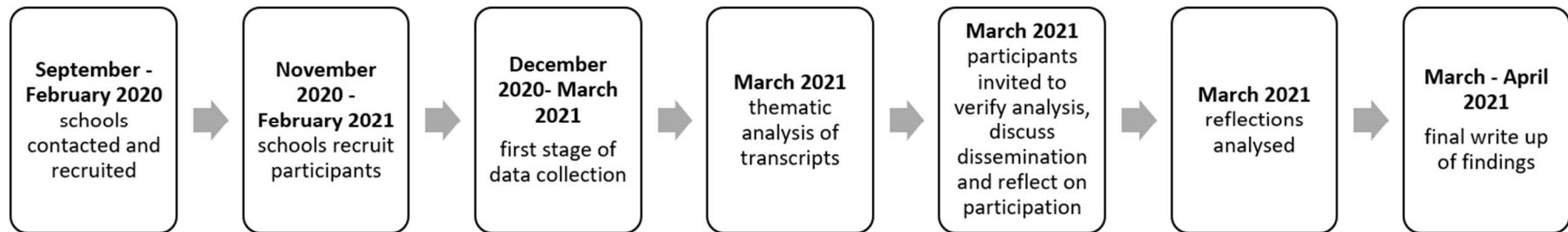
The participants' reflections on taking part in the research project and evaluating their experiences (research question 3) were analysed using an inductive approach to allow insight into the emancipatory nature of the research project and identify the meaning of the process for the participants. Analysis was informed by Braun and Clarke's (2006) method, but data were too brief to conduct a full thematic analysis.

### **3.7 Research Procedure**

The research was conducted in the Autumn and Spring terms of the 2020-2021 academic year. Due to the Covid-19 pandemic, the original intention of face-to-face data collection was not possible and interactions between the researcher, participants and supporting school staff were conducted remotely using Microsoft Teams. Participants were supervised by an adult. The following procedure was used: schools were initially recruited, then asked to recruit eligible participants. The researcher met virtually with individual participants to introduce the research project and to establish which social activities each participant wanted to focus on during data collection. The participants were also given training in reflection and decided on their method of data collection in this meeting. Following a two-week experimental focus period, the researcher and participants collected data via their preferred method. Once data from all participants had been collated, the researcher used thematic analysis to identify themes and interpret their shared experiences. Participants were then invited to verify the findings and suggest amendments as necessary. This was also an opportunity to suggest ways to disseminate the findings and to reflect on taking part in the research project. Further analysis was conducted to explore these reflections. A timeline for the research procedure is given in Figure 3.1.

**Figure 3.1**

*Timeline of the Research Procedure*



### ***3.7.1 Recruitment of Settings and Participants***

Participants were recruited through their school setting. Mainstream secondary schools across the local authority were approached to increase the diversity of participants and their school experiences. Recruitment of schools was via their link EP, CLASS practitioner or direct contact by the researcher, four schools agreed to participate. The researcher initially contacted a link member of staff to agree the details and logistics of running the project and data collection within the school. The schools were then asked to pass on recruitment information to any girls that were eligible to take part and their parents (Appendix B). This information included a description of the research project and an invitation to contact or meet the researcher to discuss any questions. Once participants and their families had agreed to join the research project, written consent was obtained from both the parents and the girls (Appendix B).

### ***3.7.2 Eligibility to Participate***

To focus the study on the experiences of females with ASC, participants were recruited from girls with an ASC diagnosis, including AS and high-functioning autism (Lai & Baron-Cohen, 2015), and no additional diagnoses such as Attention Deficit Hyperactivity Disorder (ADHD) or social anxiety; ASC can be comorbid with other diagnoses (Lai & Baron-Cohen, 2015). This was due to the experience of having an additional diagnosis having the potential to impact on the participants' experiences of school in additional ways and thus influence the data collected, decreasing the ability to interpret it purely in terms of the influences of having ASC.

Potential recruits were invited from Years 7-10, due to Year 11 students being likely to be engaged in GCSE mock exams during the data collection period. This not only had the potential to have an impact on the girls' experiences of being in school and reduce the ability



to interpret the data in terms of the influence of having ASC, it also raised concerns about adding pressure to the participants during a time associated with high workload.

### 3.7.3. *Participants*

Five girls from three schools were recruited to the project, aged between 11 and 13 years (Table 3.1).

**Table 3.1**

*Participant Information*

<b>Pseudonym</b>	<b>Age</b>	<b>Year group</b>	<b>School</b>	<b>Data collection method</b>
Una	13	8	A	Interview
Phoebe	12	8	A	Journal
Zelda Hyrule	11	7	A	Interview
Molly	12	8	B	Interview
Sabre	11	7	C	Interview

### 3.7.4 *Data Collection*

**3.7.4.1 Identification of Relevant Social Activities.** During the initial meeting with a participant, the researcher outlined the background and aims of the project and participants had the opportunity to take part in discussion about these. The co-researcher role was explained and the research questions discussed, with emphasis placed on the focus for collecting data that were relevant and appropriate for offering support. The participant and researcher collaborated in identifying which aspects of the social side of school were important to focus on, with the participant taking the lead and the researcher facilitating but avoiding directing. The participants were encouraged to consider social activities that they found challenging but that were also associated with positive examples of success. However,

participants were also informed that they could report and reflect on difficult situations that did not have a positive outcome, if they thought that this would be useful. Participants produced a list of identified social activities that included the option ‘other’ to facilitate reflection on social events within the data collection period that they felt were relevant but had not initially identified. A diagnosis of ASC can be associated with literal interpretation and rigid thinking (Jordan & Powell, 1995) and there was a possibility that participants might not include reflections on significant events because they had not been agreed with the researcher in the initial meeting. The inclusion of ‘other’ aimed to avoid ambiguity over following ‘the rules’ and maximise the participant’s ownership over their data production.

**3.7.4.2 Training in Reflective Practice.** Participants also received training in using Gibbs’ reflective cycle (Figure 3.2) (Gibbs, 1988) during the initial meeting to facilitate their recollections of social activities and expand the depth and breadth of their data. It was anticipated that using a structured reflective process would enhance the participants’ ability to identify and verbalise the mechanisms that contributed to their experiences of the social activities they reported on. Emphasis was placed on the first four stages (description, feelings, evaluation and analysis) as the research had a descriptive and interpretational focus. Training involved the researcher explaining the purpose and meaning of each of the stages, and the cycle as a whole, demonstrating its use with a generic example and then providing scaffolded support for a practise example of the participant’s choosing. The script for this is included in Appendix C. Participants were also given an information pack to aid reflection (Appendix D) which had been emailed to their schools before the initial meeting.

**3.7.4.3 Data Collection from School Experiences.** Participants were asked to actively reflect on their chosen social activities over a two-week focus period agreed during the initial meeting. A specific focus period was chosen, over general reflections on school

**Figure 3.2**

*Gibbs' Reflective Cycle*



experiences, for the following reasons: firstly, the use of a reflective framework is supported by the identification of specific events. In addition, a diagnosis of ASC can be associated with difficulty in the personal episodic part of the autobiographical memory, meaning that autistic individuals can have difficulties in remembering themselves performing actions or experiencing events without a cue (Jordan & Powell, 1995). A defined period of experimental focus, with specific events to reflect on, was used to provide a structure to facilitate participants creating their own cues to aid their recall of personal memories. A two-week period was chosen to allow enough time for a range of events to occur, whilst allowing events to be sufficiently recent that memories could still be detailed for those choosing to take part in semi-structured interviews.

To facilitate involvement and promote autonomy, participants chose how to collect their data (Table 3.1). Due to the social communication difficulties associated with ASC, there was a possibility that participants might find a semi-structured interview format for data collection inhibiting. Participants were therefore offered a choice of different data collection options, including reflective journals, voice or video recordings, semi-structured interviews or their own method. Four participants chose semi-structured interviews, and one participant kept a reflective journal.

The timing of data collection was affected by events related to the Covid-19 pandemic, with some participants needing to be interviewed more than two weeks after their initial interview. As near as possible to the final day of the two-week experimental focus period, the researcher and participants completed data collection. For those participants who had chosen a semi-structured interview, the researcher and participant met via remote videocall and the participant was asked to have their list of specified social activities and a copy of Gibbs' reflective cycle in view to aid recall. The participant was encouraged to take the lead in recalling events, with the researcher giving prompts as needed. The interview was recorded and the researcher made notes as a backup. The participant who had chosen to keep a journal passed this over via their school reception. All participants were debriefed (Appendix E) and given the opportunity to ask questions or report concerns.

**3.7.4.4 Follow-up Contact with Participants, including Reflection on Participation.** Following thematic analysis of the data, the participants were contacted for a follow-up with three purposes: to verify the themes identified by the researcher, to discuss ideas for how to disseminate the findings and to reflect on taking part in the project, their role as co-researchers and the experience of analysing their experiences of social activities. This follow-up was less in-depth than intended as it was restricted by school closures due to the pandemic and the need to offer an option for written responses. (Appendix F). To collect their

reflections, participants were asked four questions, based on Gibbs' reflective cycle (Gibbs, 1988), about their experiences during the research project. Three participants responded to this invitation with one taking part in a third remote interview and two choosing to submit written answers.

**3.7.4.5 Acknowledgement of the Researcher's Position.** To acknowledge the researcher's position and any potential influence of this on data analysis, the researcher reflected on each meeting with participants and recorded their initial thoughts and interpretations of the participants' comments and experiences. Focus was placed on identifying shared experiences and feelings of affinity with the participants which might lead to the researcher projecting their own values on the participants' experiences. These entries were referred to during subsequent analysis.

### ***3.7.5 Data Analysis***

**3.7.5.1 Thematic Analysis of School Experiences.** All data with verbal content were transcribed by the researcher and written data were copied verbatim (including graphic features) and typed into a format that facilitated coding and the referencing of evidence; data organised in numbered rows (examples in Appendix G). During these processes, data were checked for identifying information, and omissions made. Transcription by the researcher facilitated the start of familiarisation with the data.

The researcher continued familiarisation by reading the transcripts three times, using a different order for each cycle, and actively seeking references to successful outcomes and associated events, thoughts, actions and contexts. The researcher also remained open to inductive interpretation of the data. Initial codes were identified and notes made on their potential meaning and implications for the experiences of the participants (example of a coded transcript in Appendix H). These were then examined and sorted according to the

relationships between them. The researcher's reflective diary was used at this stage to monitor and moderate reflexivity.

Once potential themes had been identified, these were reviewed and refined to ensure internal homogeneity and external heterogeneity. Definitions and names for each theme were generated and extracts of transcripts identified as evidence for the themes from within the data.

**3.7.5.2 Verification of Interpretation and Identified Themes.** Participants were invited to verify the themes identified by the researcher and to discuss the interpretation of meaning and implications in the follow-up contact. The researcher collated the themes and interpretations in a list which was emailed to the participants, via school, with an invitation to respond in writing (returned by email) or via a remote video interview (Appendix F). Participants were asked to indicate if there were any interpretations they disagreed with and to supply alternative ideas. They also had the opportunity to ask questions and discuss their thoughts on the findings.

**3.7.5.3 Analysis of Reflections on Taking Part in the Research.** The analysis of participants' reflections on taking part was informed by thematic analysis, however the amount of the data collected meant this was limited to interpretative description. The participants' answers to the four questions were analysed with reference to the impact of taking part, changes in thinking or behaviour and feelings of empowerment and emancipation.

### **3.8 Ethical Considerations**

A number of ethical issues were considered, including informed consent, confidentiality and data protection, potential for emotional distress and the participants' experiences of taking part in the research. Prior to commencing, the research project received

ethical approval from the University Research Ethical Committee (Appendix I). The change to remote data collection caused by the Covid-19 pandemic necessitated amendments to the ethical application (Appendix J).

### ***3.8.1 Informed Consent and Right to Withdraw***

Participants and their parents received an information letter that fully explained the background, purpose and aims of the project, including plans for dissemination of findings after the project (Appendix B). Written consent was required from parents and participants before any part of the project was started and participants were made aware of their right to withdraw as co-researchers at any stage of the project and that their data could be withdrawn prior to analysis. Participants also received a debriefing letter after the initial data collection which contained a reminder of their right to withdraw (Appendix E).

### ***3.8.2 Confidentiality and Data Protection***

A data management plan was completed and approved as part of the research registration process and updated in response to the Covid-19 pandemic (Appendix K). Confidentiality was ensured by participants choosing pseudonyms and being asked to refrain from referring to their school or location names which could identify them during data collection. Interview recordings were transferred to the UEL OneDrive immediately after recording and the recordings deleted from the Microsoft Teams stream. Other electronic data were also stored on the UEL OneDrive. All data were transcribed for data analysis and any information that could have identified participants or school staff omitted. The verification of themes and analysis with participants involved generalised findings with no personal references that would identify other participants.

### ***3.8.3 The Potential for Emotional Distress***

Although the research had a positive focus, aimed at identifying successful events, there was some potential for emotional distress to arise from the process of reflection. Accordingly, participants were made aware during the initial meeting of a designated contact within their school who would be able to offer advice or direct them to appropriate support. Participants were also debriefed after data collection and reminded of the designated member of staff (Appendix E). A familiar adult was available during the remote meetings with participants.

### **3.9 Reflexivity**

Reflexivity is essential to minimise researcher bias and requires the researcher to be aware of how they contribute to the construction of meaning throughout the research process, including when generating the research questions and design, and analysing and interpreting the data (Willig, 2013). As a female who lacks confidence in unfamiliar social situations, the researcher had her own opinions about which social aspects of school might be challenging for girls with social and communication difficulties and there was a need to take steps to limit potential researcher bias at each stage of the process. To enact reflexivity and elucidate personal influence on the research process, the researcher engaged in critical, personal reflection throughout the process.

The use of a participatory approach, in which the data collection was driven by participants, facilitated the generation of research questions that were open-ended and a research design that prioritised the participants' opinions and experiences. Participants chose which data to collect and were encouraged to lead the dialogue during data collection. Any scaffolding by the researcher was carefully considered to minimise the use of leading questions and suggestions that reflected the researcher's opinions about the situation being



discussed. Additionally, as language has a constructive dimension, not merely reflecting reality (Willig, 2013), the researcher made considered choices when phrasing discussion about the project to convey a neutral position.

The potential for researcher bias during the analysis and interpretation of data was addressed by keeping a reflective diary and notes throughout the research project. These were used to identify the researcher's own feelings about the topics raised by participants and to acknowledge these during interpretation and identification of themes. Following analysis, the researcher's interpretation was also verified by participants.

### **3.10 Validity and Trustworthiness of the Research**

The trustworthiness or reliability of qualitative research relates to the overall impression of quality of a research endeavour and the validity is linked to the accuracy of the findings and their fidelity to the standpoint of the researchers, participants and consumers (Rose & Johnson, 2020). Qualitative research can be perceived as less rigorous than quantitative research as it cannot be subject to the same criteria for objectivity and consistency such as the use of controls or the ability to replicate the experiment directly (Braun & Clarke, 2006, Robson, 2002). However, there are techniques to increase trustworthiness and validity and counter concerns (Robson, 2002; Rose & Johnson, 2020) and these were followed in this research project.

Reliability, the soundness of the research, was promoted through the selection and justification of appropriate methods and a consistency in approach with consideration of reflexivity and subjectivity (Rose & Johnson, 2020). Consistency during thematic analysis was achieved through accurate definitions of codes and themes that facilitated reliable application of meaning across transcripts (Rose & Johnson, 2020). Braun and Clarke, (2006) caution that the value of thematic analysis can be threatened by weak or unconvincing

analysis which consists of mere description of the data with little or no interpretation. This was countered by the application of a theoretical framework that directed and anchored the analysis and subsequent claims (Braun & Clarke, 2006). Internal generalisability of the results was facilitated by transparency over how many participants agreed with the identified themes (Gibbs, 2007), however it should be noted that the small numbers involved in qualitative research limit its power for external generalisation (Robson, 2002).

Validity of the research was facilitated through member checking (verifying the themes with participants following analysis), critical reflexivity throughout the research process, and the seeking of rich, thick description through the use of Gibb's Reflective Model (Gibbs, 1998) (Rose & Johnson, 2020). This increased the sense of realism and embeddedness in the field of the data collected (Rose & Johnson, 2020). The use of a participatory approach promoted catalytic validity and the ability of the research to promote positive change by working with participants on their interests and concerns (Rose & Johnson, 2020).

Participatory approaches have been criticised for lacking objectivity due to the closeness of participants and researchers (Bergold & Thomas, 2012), threatening the reliability of data. However, closely involving participants in the research process has also been found to have a positive impact on the community involved, creating trust and acceptance of the research and keeping projects grounded and focused on benefits for the community (Staley, 2009). The threat to reliability is therefore balanced against a promotion of community validity. Within the current research, the use of critical reflection and reflexivity was used to minimise this particular threat to the reliability of the data.

### **3.11 Summary**

This chapter has outlined the purpose and aims of the research and set out the underpinning ontological and epistemological positions. The selection of methodology has been explained and justified, with reference to a critical realism framework and the exploratory and emancipatory purposes of the research. The research procedure has been described in detail, including participant selection and recruitment, the use of a participatory approach during data collection, analysis and dissemination, the thematic analysis approach, and ethical and confidentiality considerations. Finally, trustworthiness and validity have been considered with reference to the steps taken to promote these within the project.

## **Chapter 4: Findings**

### **4.1 Introduction**

This chapter will present the findings from the data analysis process described in the previous chapter. Exploration of the female phenotype for ASC is a relatively new field of research and this project aimed to add to the existing knowledge by working with adolescent girls to explore relevant aspects of their school and social experiences and what was already working well.

The findings are organised according to the three research questions:

- 1). What social aspects of mainstream schooling do adolescent girls with ASC consider to be relevant focus areas for those offering support?
- 2). What do adolescent girls with ASC say helps them successfully navigate the social aspects of mainstream schooling?
- 3). What do adolescent girls with ASC think about participating in research and analysing their social experiences in school?

### **4.2 What Social Aspects of Mainstream Schooling do Adolescent Girls with ASC**

#### **Consider to be relevant Focus Areas for Those Offering Support?**

This research question was primarily investigated by asking the participants which aspects of school they would like to discuss in their data collection. This information was supplemented by analysing their transcripts and identifying any additional topics which were included in their discussions of their experiences. Table 4.1 shows these results.

All participants considered break and/or lunchtimes and interactions with friends and school staff as relevant areas to focus on. Three participants chose working with others and all participants named specific lessons. These were chosen by Una and Phoebe because they

**Table 4.1***The Social Aspects of Mainstream Schooling Discussed by Participants.*

<b>Participant</b>	<b>Topics identified for discussion</b>	<b>Additional topics covered during discussion</b>
Una	Talking to the teacher (about learning and asking for help), talking to friends in lessons, talking to friends in tutor time, having lunch, breaktime (inside and outside), partner work in science, other	Moving around school
Zelda Hyrule	Tutor time, breaktime, technology classes, PE classes, other	Talking to friends, moving around school, online learning, opportunities to meet other students (e.g., older pupils), pastoral support
Molly	Teachers helping in class, tutor time, talking to friends, science lessons, lunchtimes, going to the Key, working with others, other	How I find classes (support) and supply teachers, both added at the beginning of the interview
Phoebe	Arriving at school, geography lessons, talking to friends, talking to staff in Learning Support, breaktime, lunchtime, teacher talking to me, working with other people, other	Phoebe commented on lessons in other subjects
Sabre	Learning support group, homework club, teachers checking in, having friends, teachers making allowances, other	Pastoral support, including access to animals, activities during breaks, maths lessons

were favourite lessons whereas Molly, Zelda Hyrule and Sabre chose to talk about lessons in which they had experienced difficulties. All participants discussed pastoral support outside the classroom. Moving around school was included as it was discussed within a social context and appeared significant to Una and Zelda Hyrule.

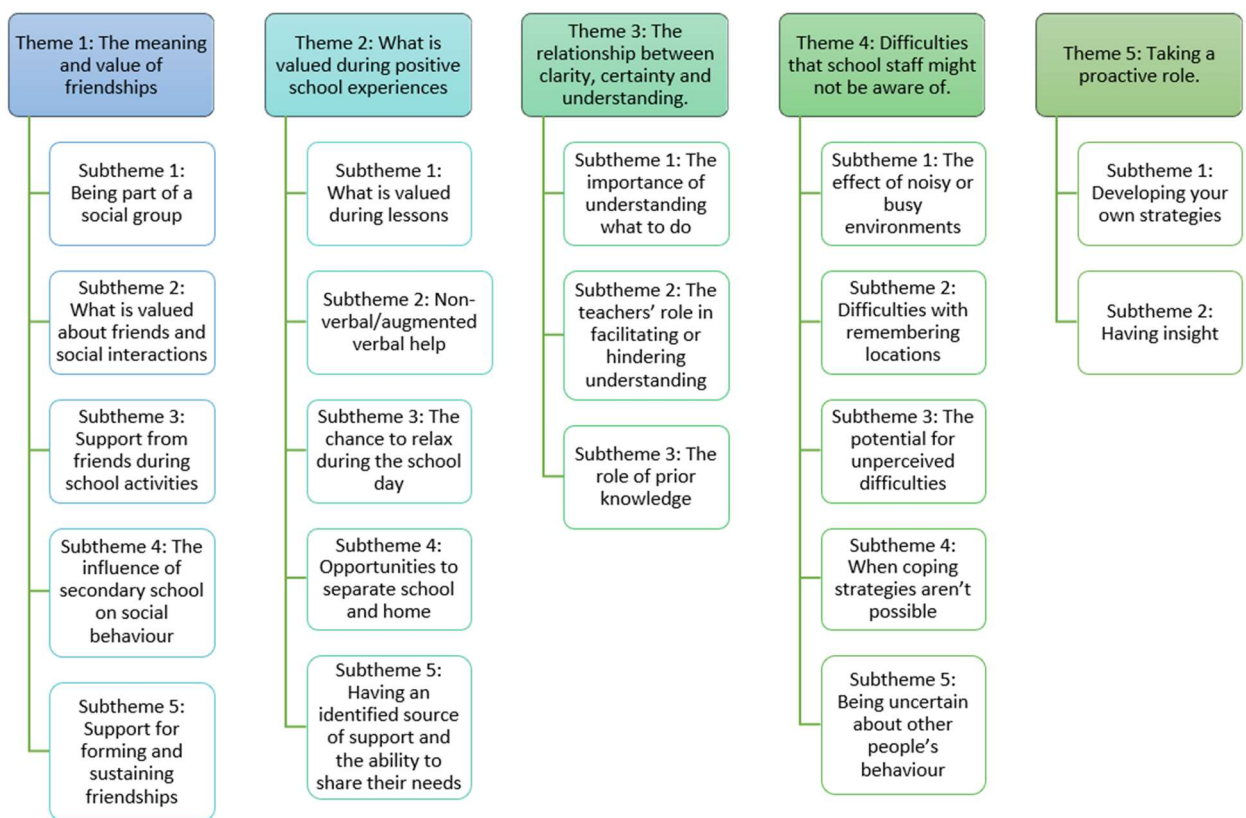
### **4.3 What do Adolescent Girls with ASC Say Helps Them Successfully Navigate the Social Aspects of Mainstream Schooling?**

This research question was explored through a primarily deductive thematic analysis of the transcripts of four semi-structured interviews and one reflective diary (Appendix G), directed by a focus on exploring influences on the participants' ability to succeed in school

and their perception of social experiences. Five main themes were identified: ‘The meaning and value of friendships’, ‘What is valued during positive school experiences’, ‘The relationship between clarity, certainty and understanding’, ‘Difficulties that school staff might not be aware of’ and ‘Taking a proactive role’. Several subthemes were identified within each of the main themes and these are shown in the thematic map in Figure 4.1.

**Figure 4.1**

*Thematic Map*



**4.3.1 Theme 1: The Meaning and Value of Friendships**

All participants referred to friends and social activities during their interviews or diary entries and three chose to specifically discuss talking to friends in their list of relevant areas. This theme encompassed the participants’ understanding of friendships, their participation in

social groups and activities, the value they placed on interactions with friends, including the support they received from friends, and indications as to how the development and maintenance of friendships can be supported. There were five subthemes: 'Being part of a social group', 'What is valued about friends and social interactions', 'Support from friends during school activities', 'The influence of secondary school on social behaviour' and 'Support for forming and sustaining friendships'.

**4.3.1.1 Subtheme 1: Being Part of a Social Group.** All participants showed evidence of being socially motivated and having a set of friends which they enjoyed spending time with at school. Una described a good day at school as '*seeing friends and having fun lessons*' (Una, line 330), and Phoebe described one break as '*fun and with friends*' (Phoebe, line 38). This was reinforced through references to negative experiences that resulted from not spending time with friends, for example Molly showed disappointment that her friends would be absent: '*however recently, one of my friends hasn't been in ..., so I've been sitting with my other friend...she's now going to be at home so I'm going to be alone for the last few days sadly.*' (Molly, lines 408-410). Phoebe also described a breaktime as '*weird bcc I didn't stand with my friend...*' (Phoebe, line 46) following a disagreement with her friend.

The closeness of participants to their friendship group was shown through seeking them out at breaktime, regardless of whether or not they had been together in the previous lesson: '*...sometimes me and my friends don't have the same lessons together, so we meet up again at breaktime*' (Zelda Hyrule, lines 143-144) and this being a pre-agreed action: '*we meet in the spot that we have to go to*' (Una, line 102). Sabre also referred to maintaining connection with friends in other classes during lessons: '*...our base classes are like really close to each other and so we can like see each other and where we can like see each other, we often just like smile at each other...*' (Sabre, lines 267-269) indicating attachment.

There was also a sense of group identity in participants' descriptions of their friendship groups, for example Molly referred to her friends as '*...our like pack of three...*' (Molly, line 238) and Zelda Hyrule's description of a typical breaktime used repetition of the word 'we': '*normally I talk to my friends, sometimes we play games, things like that, um, and often we like move across the playground a lot...*' (Zelda Hyrule, lines 132-133), suggesting that she felt like an integrated part of the group. Sabre commented on the longevity of her friendship group: '*...my other friends, I've known them forever, so they've known me forever, so they're the ones who are here and they're just good...*' (Sabre, lines 250-252), suggesting an established and secure sense of belonging.

#### **4.3.1.2 Subtheme 2: What is Valued about Friendships and Social Interactions.**

All participants referred specifically to interactions with friends during school and spoke positively about these opportunities. Sabre and Una stated that they 'hung out' with friends and talking with friends was a frequent topic which appeared to be valued, for example Molly commented: '*well, I would just say it's nice to make conversation, even when I'm eating, I feel like awkward when we're not making conversation...*' (Molly, lines 405-406). Some participants referred to discussing personal information and enquiring about how friends were in these conversations: '*...it's nice to walk over and see them and ask them how they are and things like that...*' (Zelda Hyrule, line 134) and: '*I find it's like a good time to relax and talk to my friends and just like overall talk about how I've been feeling through the day or just anything in general really.*' (Molly, lines 186-187).

Molly's reference to the opportunity to talk about how she'd been feeling suggests that she appreciated this, and other participants also referred to the emotional support friends could give. Zelda Hyrule indicated that talking things through with friends was beneficial for helping her feel settled: '*...we talk to our friends and we talk about what our next lessons are*



*going to be, I feel a bit more settled in before we move to the lessons.*’ (Zelda Hyrule, lines 113-114).

Emotional support arising from their friends’ understanding of personal circumstances appeared key for some participants. Sabre described her friends as *‘...all really good as they understand...’* (Sabre, lines 24-25) and Una stated that her friends were good because *‘they know me’* (Una, line 336), agreeing that it was important to have people who understood her and adding that *‘they know everything [about me]’* (Una, line 340), including what she is interested in and how to spot if she is happy or sad. Participants appeared to experience emotional safety with their friends and saw them as a source of comfort or security.

Some participants also referred specifically to getting enjoyment and experiencing fun with their friends. Molly described sharing amusing experiences during conversations: *‘...when we discussing something funny that happened in class...’* (Molly, line 262) and elaborated on the pleasure that this could give:

*‘That it’s keeping me happy and it’s making me feel happy and like it just makes you feel over amazing, being able to have that really happy feeling where not all the time you can feel that happy and laughing just gives you a break from any normal emotions that you might feel...’* (Molly, lines 271-273).

Sabre specifically referred to enjoying spending time with a friend who made her laugh: *‘I have this other friend called C and she’s in the same class as me and she’s like, she’s my jokey around friend and she’s like yeah...and I like to hang around with her.’* (Sabre, lines 271-272).

Collectively, the participants’ descriptions of conversations and interactions with friends suggest that their friendships involve personal connection, shared experiences and emotional support and that talking is an integral part of maintaining friendship bonds.

**4.3.1.3 Subtheme 3: Support from Friends During School Activities.** Friends also appeared to be sources of support to participants during the school day and an aid for negotiating potential challenges inherent in the timetable. Examples include helping them find their way around school: *‘...he said she’s lost and he figured out where I was meant to be and that sorted that out...’* (Zelda Hyrule, lines 296-297) and exchanging information about lessons:

*‘...then also like, let’s say that there’s a really bad substitute teacher who’s like really strict, we can warn each other... so let’s say like in my science class and I’m a bit ahead from her group so I can like, if there’s something to tell her about, that like a video, that may seem like that may make her feel not too good I can warn her...’*  
(Molly lines 195-199).

Una and her father indicated that she likes to be guided by others in social interactions, agreeing that *‘You just do what other people do.’* (Una, line 123), and this was consistent with Una’s answers during the initial introductory interview where she explained that her friends often choose the topic of conversation when she doesn’t know what to say.

Participants also indicated that friends were good to work with and a source of support in lessons: *‘...I couldn’t really remember like how we were making it and I would have to ask my friends...’* (Zelda Hyrule, lines 196-197). Familiarity in these interactions appeared key with Molly explaining: *‘...If it is like someone who I know and I’m like kind of alright with then they will most likely at least like attempt to help me...’* (Molly, lines 100-101) and Zelda Hyrule indicating she would prefer to ask a friend when she was feeling uncertain:

*‘...but with the people in my group I would ask what’s going on and usually, since I know so many people, I’d have at least one person, if we were like working in like*

*team sports, I'd have at least one person that I can ask so I know what we're doing...'*  
(Zelda Hyrule, lines 338-340).

Una stated that a good partner in science was '*...a friend*' (Una, line 201), agreeing that it was helpful to sit next to friends in lessons and that they were easier to talk to because '*they understand*' (Una, line 62). Sabre described her closest friend supporting her in lessons by sharing experiences: '*...she's just like, whatever I do, she does if she doesn't like it either so if I [puts hands over ears] she just does that to make me feel like I'm not the only one doing it...*' (Sabre, lines 248-250) and Phoebe appreciated the chance to choose who to sit next to during a science test: '*Science did a test but got to sit next to anyone I wanted...*' (Phoebe, line 46).

Participants therefore appeared to have benefited from working with people who know them and with whom they share a connection, especially when facing a difficulty during a lesson. It seems likely that the familiarity that came from friendship and knowing each other reduced the negative nature of the situation and provided reassurance if they needed to seek help.

In most of the discussions, and in line with the questions asked, participants referred to the support they received from friends, rather than mutual support. However, Molly referred to providing emotional support for a friend: '*...and yeah, sometimes she's been feeling a bit sad, she does seem to be someone who is a bit emotionally vulnerable and she likes having us around to comfort her and just make her feel all out better.*' (Molly, lines 241-247) indicating that she saw friendship as a reciprocal act where she offered support as well as receiving it. This is an area that was not specifically explored in the current research and the lack of evidence from other participants does not preclude that they also saw their friendships as reciprocal and mutually beneficial.

#### **4.3.1.4 Subtheme 4: The Influence of Secondary School on Social Behaviour.**

Molly and Zelda Hyrule referred to the difference attending secondary school had made to their opportunities to make friends and their interest in other people. For both, the increased number of people to be with was a positive change from primary school and Zelda Hyrule elaborated to explain:

*‘...I found it really nice because in the schools that I’ve been at before, erm, they weren’t incredibly diverse, being smaller schools so being with loads of other people, I’ve just become more interested in all these other people and what they look like.’*  
(Zelda Hyrule, lines 77-79)

Molly also indicated that the secondary school environment had influenced her propensity to spend time with friends:

*‘...I remember in Year 7 I would try and get some time alone but now I’m in Year 8 I’ve noticed that I’m not really going to get that alone time so I may as well spend it with my friends’* (Molly, lines 444-446).

Her matter-of-fact description implied that she didn’t view the loss of alone time in a negative way and there was evidence that the change in environment may have scaffolded the change in her social interactions and friendships; she now spoke warmly of sharing conversations and funny stories with her current friends, having also described being content to spend a lot of time alone at primary school:

*‘...I would play alone and then all the teachers would like think that there was something wrong with me and would be like are you ok? And I would be like no I’m fine because I would be as happy as I can be’* (Molly, lines 426-428)

**4.3.1.5 Subtheme 5: Support for Forming and Sustaining Friendships.** Enquiries about support for friendship did not occur in all discussions but analysis revealed some

aspects of school life that appeared to have a positive influence on the interactions between participants and their friends and therefore could have the potential to support these friendships. Molly, Una and Zelda Hyrule all referred to having friends within their tutor groups suggesting that this is an important aspect of school life for creating friendship opportunities.

The chance to talk to friends throughout the school day was also a frequent topic during discussions and it appeared that these opportunities were valued by participants. Given the importance of conversations in their friendships, these opportunities could also be important in sustaining friendships. Tutor time was a popular time to talk and Molly explained: *'So normally we spend that time talking because at lunch we're eating our food so we don't really make much conversation at lunch...'* (Molly, lines 208-209) indicating that conversation was important to her but not always possible to fit in at other times. Zelda Hyrule referred to tutor time as an opportunity to talk to friends: *'...when we go to tutor time and we talk to our friends...'* (Zelda Hyrule, line 113) and Una named talking to friends in tutor time as a relevant focus area, agreeing that it was a good opportunity to share experiences from outside school.

Breaktime was valued by participants as a time to see friends and there was also specific mention of the start of the day as being a time to see friends and catch up, for example Molly explained: *'...Maybe before school we're all waiting out by the entrance, just chilling, talking and like...'* (Molly, lines 245-246). Una also named meeting people before school as a relevant focus area and stated this was good due to *'seeing friends'* (Una, line 245), agreeing that this was a chance to catch up. Meeting before school appeared to be a way for participants to set up a positive start to the day, as well as a chance to see friends, although their friends were integral in this positive start.

There was also evidence of participants valuing external support for forming or developing friendships. Zelda Hyrule described her tutor setting up activities to promote friendship at the start of the year: ‘...*the teacher like encouraged us to talk to each other and we’re given like activities to talk about so that helped us, sort of form friendships, yeah.*’ (Zelda Hyrule, lines 65-66), and Molly referred to her discovery of social media as a catalyst for spending less time alone in primary school: ‘...*Cos even in primary school, even though I had friends I just preferred way more to just play alone and stay out of the drama. Until really at the end, that’s when I started picking up social media...*’ (Molly, lines 420-422). She also referred to using texts to keep in touch with friends who were absent due to the pandemic which implied that this continued to be a useful way to communicate.

**4.3.1.6 Summary of Theme 1.** The discussion of evidence within this theme has shown that participants were motivated to engage in social interactions with peers and identified as members of friendship groups. Their understanding of friendships included spending time with others, sharing experiences and emotional support, and using conversation to maintain friendships. Friends were also integral to working successfully during lessons and their presence appeared to help reduce the impact of negative situations. Having opportunities to connect with friends throughout the school day was valued and likely contributed to the maintenance of friendships.

#### ***4.3.2 Theme 2: What is Valued During Positive School Experiences***

This theme was identified through looking specifically for references participants made to things going well or their experiences of enjoyment. Five subthemes were identified: ‘What is valued during lessons’, ‘Non-verbal/augmented verbal help’, ‘The chance to relax during the school day’, ‘Opportunities to separate school and home’ and ‘Having an identified source of support and the ability to share their needs’. Not all of these subthemes

related directly to social aspects of the school experience but were included as they satisfied the secondary research aim of increasing teacher knowledge about the needs of girls with ASC.

**4.3.2.1 Subtheme 1: What is Valued During Lessons.** Fun was a word used by most participants in their descriptions of positive experiences during lessons, and engagement and enjoyment appeared to be something they prioritised and valued. Phoebe's diary entries were brief but her comments about lessons generally referred to whether or not she had enjoyed them, and she occasionally named activities she had found engaging e.g.: *'Maths: sooo much fun we did this really funny maths quiz'* (Phoebe, line 51). Una described a good day as *'seeing friends and having fun lessons'* (Una, line 330), and answered that the good thing about drama was that *'it's fun'* (Una, line 297). Molly also valued fun activities and explained that consideration of this was influencing her decisions about GCSE subjects:

*'I like wanted to take it because of the education factor, to get that extra information but I've now decided that I don't think I'm going to take that because there are other lessons that are more funner than just education.'* (Molly, lines 341-343).

The opportunities to take part in activities and work creatively appeared to be integral to lessons being engaging with participants naming creative and practical subjects such as art as valued experiences, for example Phoebe recorded: *'Art: was super fun and the best bcc I love this lesson'* (Phoebe, line 38). Molly elaborated on why she found these subjects fun:

*'Well, I find art and cooking and sometimes DT [fun], only sometimes cos the teacher in it, makes us do a lot of writing and as much as I can be a quick writer, it's like when you're copying it down and you have like a certain amount, because you're being told to write that specific thing in that much detail when you could very easily write something down way shorter but you have to write down that sort of thing, it's*

*just not that, it's just not really that fun but when we're doing practicals it's much better because we're actually able to do work and do the things...*' (Molly, lines 347-352)

It is possible that the sense of achievement in completing activities was what made these lessons engaging and this is reinforced by Molly's caveat that DT wasn't always fun due to frustrations over writing. Phoebe also indicated that the opportunity to be creative countered the negative experience of having a test: *'Science: test stayed 1 hour silent wasn't fun but it was ok bcc we got to make a poster and anything we wanted'* (Phoebe, lines 29-30).

Interest in a subject and the chance to develop existing knowledge was also important to Molly who made multiple references to such lessons being engaging e.g., *'...I found that I was able to pick up the information easy because I wanted to know more about it.'* (Molly, lines 319-320) and *'...it's a really good lesson and I know I'm learning something else about something I originally really like.'* (Molly, lines 311-312). This could have been linked to increasing confidence and self-esteem as she also explained that *'...kind of knowing more facts about them, kind of made me feel that I was an expert about them...* (Molly, lines 334-335).

Positive interactions with supportive teachers during lessons were also specifically mentioned by some participants. Sabre appreciated teachers checking on her and monitoring how she was coping with lessons and appeared to find this reassuring, for example:

*'...like my geography teacher, he mentioned a test and then he saw the look on my face and he just said it's ok, you don't have to worry, it's not a very important test, we're just going to see how you're doing so he's very supportive like that...*' (Sabre, lines 178-181)



Molly attributed her sense of success in English to the behaviour of her teacher: '*...I especially find that I do best in my English with my teacher, Mr X, I find I work better in that class. I normally get down like loads of paragraphs...*' (Molly, lines 31-33), adding '*...But I just find that I work like better in that class with him, because he is a supportive teacher as well.*' (Molly, lines 38-39). The feeling of having a personal connection with teachers therefore appears to benefit participants, emotionally and academically, and facilitates their success in learning. This is reinforced by Zelda Hyrule's description of feeling distressed in technology lessons when she thought her teacher didn't like her:

*'...I found it so stressful, um I had sort of thought that the teacher didn't really like me because she had thought, she had misunderstood and she'd thought that I was just chatting to my friends... ...But then when we emailed my teacher I realised that she hadn't really thought that and I realised that I had sort of made up this thing in my head so it wasn't, wasn't really real and so... yeah... it really helped when I realised that.'* (Zelda Hyrule, lines 209-215).

A personal approach by teachers could also be demonstrated through their teaching input and behaviour management. Sabre valued being allowed to fiddle during lessons: '*...so teachers don't tell me off, they tell some people off but you know, just don't tell me off, they don't tell me off when I'm like fiddling with something...*' (lines 36-37), acknowledging that it was a special dispensation that showed teachers understood her needs: '*Like I said, they let me fidget and they don't get angry with me and I'm always having to move and it looks like I'm in some circumstances like I'm not concentrating...*' (lines 225-226).

Teachers making adjustments in their interactions with the whole class in response to participants' needs was also welcomed, for example Zelda Hyrule appreciated a whole class approach in response to her distress during food technology lessons: '*...and what they did is,*

*they stopped urging people to be quicker...*’ (Zelda Hyrule, line 200-201). It was possible that these actions helped participants feel included in their class and held in mind by their teachers, as shown by Sabre’s description of teachers indirectly acknowledging her when addressing the whole class:

*‘...but another thing that teachers do that I like is that when they’re er, they don’t anymore when I’m in there, they don’t say you’re talking non-stop, cos last time I wasn’t talking and they say it’s a real shame that some of you are talking but there are some that aren’t and you’re wasting their time as well as mine. And so they’re not including us in...’* (Sabre, lines 38-41).

**4.3.2.2 Subtheme 2: Non-verbal and Augmented Verbal Sources of Help.** In describing receiving support, participants indicated that sometimes verbal directions were insufficient, and it helped for these to be augmented with physical resources or actions. Molly reported that videos or animations of learning topics could make things easier to understand: *‘...I can also find having like videos on, like animated things help explain it can also help explain it in a way that the teacher can, like cannot.’* (Molly, lines 301-302) and also described how examples of the expected work helped her to know what to do:

*‘Well, I know we had, like an example on the board which I found quite pretty good and in the front of our books we had a sheet of all the things we needed to do, as well as examples. And I think that I would probably have struggled a lot more if we didn’t have that.’* (Molly, lines 56-58)

Sabre also described how making written plans or notes with the teacher could help her organise her thoughts before starting a piece of work as she could be overwhelmed by all the different aspects of the task:

*'Sometimes people like, making out a list of it all, like not like write it out but it helps like that, like just write it down. It helps me because I'll be focusing on how big I want my handwriting to be, how fast I need to take it, how long it has to be and how many things I have to include in it, it stresses me out and I can't think about the actual thing.'* (Sabre, lines 100-103).

It likely that the physical resources helped to reduce the cognitive load of the task and facilitated task completion through having less information to hold in mind and recall.

Una and Zelda Hyrule both said that adults showing them where to go when they were lost was helpful and Zelda Hyrule explained that this was due to being unable to remember verbal instructions:

*'...they gave me directions and then another teacher came over and I, um, I couldn't remember the directions and so they said do you want me to walk with you and that really helped immensely because if they show me then I find it easier to remember, instead of just trying to remember the words that they said.'* (Zelda Hyrule, lines 267-270).

These descriptions suggest that concrete information, rather than abstract references that require further cognitive processing, can be helpful, especially in situations associated with potential anxiety such as being lost, learning something new or working out the expectations of a task.

**4.3.2.3 Subtheme 3: The Chance to Relax During the School Day.** Tutor times and breaktimes were specifically mentioned by some participants in relation to affording opportunities to relax and this appeared to be valued as a chance to recuperate after lessons. Una indicated that breaktimes were a chance to *'forget about the lesson'* (Una, line 138)

rather than talk about it and Zelda Hyrule used the analogy of computer games to explain why she valued them:

*‘so, um, I like break time because often in lessons that I find a bit more stressful, like PE and things like that, I find it really helpful to be able to um sit with my friends, and often if I find it, if I struggle to get through a lesson I just try to remember that I’ve got break time soon and that it’s nothing to worry about. But you know check points in video games, it’s kind of like that but in real life. (laughs)’ (Zelda Hyrule, lines 124-127)*

The lack of structure within tutor time appeared to aid relaxation and, as previously discussed, opportunities to talk to friends were also valued e.g.: *‘... So most of the time it’s quite chilled, we get to relax and talk to our friends...’ (Molly, lines 174-175).*

**4.3.2.4 Subtheme 4: Opportunities to Separate School and Home.** Tutor time was also considered as affording the opportunity to transition between home and school for some participants. This was dependent on when tutor time occurred in the participant’s timetable but transition in both directions was described as beneficial. Zelda Hyrule described why it was good to have a chance to prepare for the day:

*‘...when we first get in to school for the day, just before tutor time, like it’s still... like I’m, still not really prepared for school so then when we go to tutor time and we talk to our friends and we talk about what our next lessons are going to be, I feel a bit more settled in before we move to the lessons.’ (Zelda Hyrule, lines 111-114)*

Molly explained the benefits of having a cool down period at the end of the day:

*‘Well, I don’t find that if we go home feeling more chill and not like all stressed out with the schoolwork that’s just happened then we’re able to relax more but if we’ve*

*come home after doing like schoolwork, we're kind of in that mindset...* (Molly, lines 216-221)

It appeared that moving between school and home required a form of mental adjustment and that time to process this was a beneficial part of the school day and a way to counter stress. Related to this, although Sabre did not refer to a transition between school and home, she did discuss her difficulty with merging the concepts of school and home during homework. She named a homework club as a valued part of school which would help her to manage this:

*'...we have a homework club, also not open because of the corona virus but I know that would help me if I'm allowed into it because I really struggle with homework, especially at home because I can't handle the concept of school coming into my home.'* (Sabre, lines 6-8).

**4.3.2.5 Subtheme 5: Having an Identified Source of Support and the Ability to Share Their Needs.** All participants referred to using some form of pastoral support and four named a learning support facility. Having an identified source of support appeared to be valued by the participants with Sabre and Una naming them as preferred teachers to approach for help and Zelda Hyrule explaining: *'...it was just so comforting to know that there's like that there's someone there that works really hard to get what I've lost and look after me.'* (Zelda Hyrule, lines 311-313).

The assistance offered by these members of staff appeared to have a focus on emotional rather than academic support per se. Sabre gave many examples of valuing specific teachers who checked in on her, including her tutor, year head and deputy year head, for example: *'...Mrs X is the one I do like calls with and she like occupies me and sometimes she has other stuff to do and Miss Y can reassure me...'* (Sabre, lines 149-151) and Una used learning support for daily checking in about how she was feeling. Phoebe sometimes

described attending different lessons in learning support in ways that suggested it helped her to cope e.g.: *'PE: in ls it was fine 😊'* (Phoebe, line 36) and *'Music: wasn't in in ls was calm'* (Phoebe, line 64).

Having a connection with home through this support was also important. Una named ringing her parents as the sort of help that might be offered by learning support and Zelda Hyrule said that the feeling of support was increased through an association with home:

*'...also she knows my mummy so that and since I found that she knows her, I've found it a lot more comforting to be around her because I know that she's not a complete stranger and that she knows my mum as well.'* (Zelda Hyrule, lines 318-320).

Sabre indicated that her year head and mother were in close contact and commented on the joy her mother had experienced in hearing this teacher describe an example of looking out for her: *'...But my mum really loves it because Mrs X says, no you're not moving my Sabre and my mum really likes that because it was MY Sabre.'* (Sabre, lines 153-154). These descriptions suggest that close communication between home and school, with shared knowledge of their needs, is beneficial for participants.

Participants also valued being able to tell teaching staff their needs. This could be directly during lessons or with the help of others such as parents or school staff. Una referred to teachers as a source of help on several occasions and Molly's explanation of why her English teacher was supportive included reference to his approachability: *'I would go up to him and like tell him, and say like I'm not feeling comfortable like, that I'm like struggling with him, with it, and he would come and help us.'* (Molly, lines 44-45).

The ability to communicate needs and then see a change in approach appeared reassuring for participants. Zelda Hyrule described the positive emotional impact of having her needs acknowledged and responded to:

*'...I think I've relaxed a bit more with technology because um we had sent an email to the teacher about how I was finding it a bit stressful and we've sorted it out and my teacher has changed, has sort of changed their behaviour to sort of accommodate me which is really helpful...'* (Zelda Hyrule, lines 189-192).

Sabre also spoke about her year head fighting for her on multiple occasions, giving the impression that she knew she was a reliable source of help:

*'Yeah and so she's the one that fights for me for homework club and all the other stuff and she also fought for me for forest school or something so I could just get space...  
...she also fought about that and she really helped me.'* (Sabre, lines 156-158).

The use of the verb 'fight' also implied that she felt protected by this relationship. It is likely that these teacher responses helped the participants to feel heard and the knowledge that teachers were approachable, open to listening to participants' concerns and willing to adjust or advocate for them appeared integral to creating a positive school experience.

**4.3.1.6 Summary of Theme 2.** Participants indicated that a positive experience in school could be supported in a variety of ways. A common feature that linked the subthemes was their emotional impact on the participants, either helping them engage with learning, recharge and relax after busy lessons or providing reassurance when difficulties were encountered. School staff were also integral in their facilitation of these opportunities, either directly through being available and approachable in lessons, or less directly through the built-in contact opportunities during the participants' timetables.

### ***4.3.3 Theme 3: The Relationship Between Clarity, Certainty and Understanding***

This theme encompasses the ability of participants to understand what is happening during lessons, in particular during teaching input and the delivery of verbal direction. Participants frequently referred to the ability to understand in a variety of contexts and it

therefore stood out as a significant consideration for them. There are three subthemes: ‘The importance of understanding what to do’, ‘The teachers’ role in facilitating or hindering understanding’ and ‘The role of prior knowledge’.

**4.3.3.1 Subtheme 1: The Importance of Understanding What to Do.** Concern over not understanding what to do or not being able to follow instructions easily was evident in the discussions with three of the participants. Sabre expressed concern that she frequently came away from teaching input with a lack of certainty:

*‘...the teacher says go off and do a task, especially on online learning and I struggle to do that and it’s the same with homework because it’s all like, I know everything and then I’m not sure, I’m not sure what I’m going to do when I get home and then also when I’m in online lessons and I’ll be like I’ve been amazing in the chat and then I’m like I don’t know what to do. That happens a lot.’* (Sabre, lines 91-96)

Molly described being frustrated by insufficient instructions as this impacted on her ability to complete work: *‘...it wasn’t really explained to the point where you could fully understand it and understand how to do it quickly which made mine not actually able to be complete.’*

(Molly, lines 355-357) and Zelda Hyrule also commented on the stress caused by not having enough information to work things out herself: *‘...I would sort of get a bit stressed because I couldn’t work through it because I didn’t know what to do...’* (Zelda Hyrule, lines 198-199).

This could also result in fear of getting things wrong:

*‘...I didn’t know what we were meant to do and I found it quite scary because erm I didn’t know how long I was meant to run for and I didn’t know the specific rules for it and I would find myself doing something wrong...’* (Zelda Hyrule, lines 328-330)

It was apparent that these situations could be sources of distress and that being confident in how to proceed, through gaining a clear understanding of what to do during the initial



direction and teaching input for tasks, was important to participants in allowing them to access the lesson and work independently. Molly's statement that her teacher '*...explained it clearly and I er, I understood what to do and I was able to crack on.*' (Molly, lines 138-139) showed the significance she placed on being able to complete her work independently and the role of her teacher in setting this up for her.

#### **4.3.3.2 Subtheme 2: The Teachers' Role in Facilitating or Hindering**

**Understanding.** Teachers appeared to have a key role in facilitating understanding through clear explanation. Una identified her teachers as the source of understanding what to do in lessons: '*...the teacher will tell us.*' (Una, line 213), and indicated that she preferred to wait for a teacher's help over working out a problem with a partner. She also stated that a good teacher was '*someone who's good at explaining things*' (Una, line 228), following a list of options. Molly also described gaining confidence through her teacher's ability to explain what to do:

*'so, when he was helping me, I was kind of felt like I was getting it and understanding it and I kind of like, kind of, even when he started explaining it, I felt like I knew where I was going and knew what to do.'* (Molly, lines 143-145)

Teachers taking a personalised approach was also beneficial for promoting understanding. Sabre appreciated a teacher being available during lessons: '*...another thing that teachers help me with is my teacher, Mr Z, in maths he like comes into the lesson and he like listens with me and he helps me.*' (Sabre, lines 203-204) and Zelda Hyrule appreciated teachers in her old school checking existing knowledge:

*'...at my old school, the teachers were really nice, if you didn't know what you were doing, they were really helpful and they would sort of, at the start of the lesson they would, I think they still do at my school now, but they would say "who knows how to*

*play this?” and then we’d put our hands up and then they’d say, ok, so the people who don’t know how, and then they’d actually explain the rules a bit. But that happens quite rarely in our PE...’ (Zelda Hyrule, lines 382-386).*

However, participants also referred to circumstances where a teacher could hinder understanding. Teaching input being too quick to follow was identified as a source of confusion for Zelda Hyrule: *‘...I found it a bit hard because everything was really quick and I didn’t remember what we were making for our food tech so I couldn’t really remember like how we were making it...’ (Zelda Hyrule, lines 194-196)* suggesting that having sufficient processing time is important when learning something new. Sabre described how unclear teaching input reduced her understanding and also created distress through not knowing how to respond and ask for help:

*‘...sometimes I get scared and also sometimes it’s their fault, well not their fault but they’re the reason why I feel stressed so I wouldn’t say oh yeah you are making no sense in what you’re teaching us about, I would just never do that.’ (Sabre, lines 189-191).*

Zelda Hyrule referred to uncertainty arising during online learning and the negative emotional impact of not having the ability to ask clarifying questions in the moment:

*‘...sometimes for online learning lessons that aren’t live, sometimes I find that a bit more difficult because the teacher just sets the work and leaves us to it and that makes me more stressed because if I don’t understand something then I ask them a question and sometimes they’ll take a while to see it and I have to sort of wait there looking stressed and I don’t really move on to the next bit like most people...’ (Zelda Hyrule, lines 394-398).*

Her acknowledgement of not being able to move on in her work due to uncertainty highlights the distraction and barrier to working that not knowing can be in some situations. Overall, it was apparent from these descriptions that uncertainty can be a barrier to starting work and completing it independently and that the teacher has a key role in providing reassurance over what to do and how, congruent with Una's preference to wait to ask a teacher when she is stuck.

Teacher confidence also had an influence on the reassurance gained from asking for support. Molly explained that having a confident teacher helped her soak in information: *'well, firstly having a confident teacher... like having a confident teacher who can explain it clearly, that firstly allows me to be, like to be able to be focused and do it...'* (Molly, lines 299-300). In contrast, supply teachers lacking confidence in their subject knowledge were a source of uncertainty:

*'...But if it's someone who doesn't know then they'll need to go onto Google and look that up which takes more time and if it was a teacher who knew a bit or at least had some kind of like GCSEs in that subject they would at least be able to attempt to answer the question and give me an answer good enough.'* (Molly, lines 78-81),

It is possible that Molly equated a lack of subject knowledge with a lack of reliability in delivering a correct answer: *'...if they're not a qualified teacher I will most likely not understand it.'* (Molly, lines 88-89).

Zelda Hyrule also described supply teachers as lacking confidence and implied that this added to her own anxiety: *'...so supply teachers are a bit panicky as well and they don't know exactly like, they don't know what the routine is for every class...'* (Zelda Hyrule, lines 260-261). Participants therefore appeared to place importance on having a teacher who can

provide reassurance and certainty in situations where they themselves are lacking in confidence.

**4.3.3.3 Subtheme 3: The Role of Prior Knowledge.** Prior knowledge of a subject appeared valuable in aiding understanding. This could be related to having context to place the new knowledge within and the ability to make links with existing knowledge, for example Molly explained: *'...if I don't know enough about it then I find I'm just sitting there and sometimes I can't soak in the information properly.'* (Molly, lines 295-297). Zelda Hyrule also described PE lessons becoming easier over time as they became more familiar:

*'...but it has gotten a bit easier because I've gotten used to what we're doing and there hasn't really been anything new lately so I found it a bit easier because it's the same thing so I don't have to worry about that.'* (Zelda Hyrule, lines 333-335)

It is likely that prior knowledge reduced the cognitive load of the situation and this also appeared to aid coping with non-academic difficulties as well as aiding understanding. Zelda Hyrule explained that familiarity with a sport could make it easier to manage the busy social environment of a PE lesson:

*'...so the sports that I do understand, it's a bit easier because I don't have to worry about the people getting competitive with me because I know what I'm doing and like get, like not understanding the rules because I do know the rules and then that sort of takes away the stress of it a bit, like the overstimulation, yeah.'* (Zelda Hyrule, lines 387-390)

There was also evidence that participants' awareness of already knowing something about a subject increased their engagement with lessons and their confidence in expecting to understand. When discussing PE lessons, Zelda Hyrule described the reassurance of having knowledge from previous experience: *'yes and cos I played hockey at my old school quite a*

*bit and um, that was quite helpful because I knew that I didn't need like that much help and I was less stressed about it, um.*' (Zelda Hyrule, lines 378-379), suggesting that knowing she wouldn't need to ask for help was beneficial in making the experience more positive.

Prior knowledge of situations or circumstances was also valued for helping participants to cope with their school day. Molly described tutor time as a good time to share information about lessons: *'...then maybe like talk about how their lessons have been like, sometimes I remember my friend would say like talk to me about how they found their substitute teacher and stuff that went on in the lesson...'* (Molly, lines 191-193), and went on to explain that a good reason to have tutor time in the middle of the day was that it gave them the ability to *'...warn each other about substitutes...'* (Molly, line 229). This is significant as Molly was finding substitute teachers hard to cope with.

Zelda Hyrule also discussed the benefit of knowing about new situations in advance, feeling that her friends had an advantage when they started school because they had attended open evenings:

*'and some of er my friends, I thought it, right at the start of it, I sort of felt that I didn't know what the school looked like and I sort of felt that they had an advantage over me because they had been on some of the open evenings before and they knew what the school was like and for me... ...and then it was, like it was so big and it was so scary and I hadn't memorised anything of what was going on...'* (Zelda Hyrule, lines 539-546).

It was apparent that having some knowledge of what to expect in a situation could reduce the negativity of the experience, even if the event itself remained the same.

**4.3.3.4 Summary of Theme 3.** Understanding of, and certainty about, what to do was a significant concern for participants and was discussed in relation to a variety of

contexts. Participants indicated that teachers played an integral role in facilitating their understanding but could also inadvertently be involved in hindering their certainty about what to do and development of their understanding. A lack of certainty and clarity could lead to distress and also appeared to increase the cognitive load of a situation, reducing their ability to cope or make progress in their learning. Confident teachers and prior knowledge of subjects or situations were valued by participants in helping increase the certainty of a situation.

#### ***4.3.4 Theme 4: Difficulties that School Staff Might Not be Aware of***

In the course of discussing their school experiences, participants referred to needs and difficulties that they appeared to be trying to cope with themselves and may therefore not be immediately obvious to others in their environment. This fourth theme is a collation of these potentially unperceived difficulties and includes five subthemes: ‘The effect of noisy or busy environments’, ‘Difficulties with remembering locations’, ‘The potential for unperceived difficulties’, ‘When coping strategies aren’t possible’ and ‘Being uncertain about other people’s behaviour’.

**4.3.4.1 Subtheme 1: The Effect of Noisy or Busy Environments.** Three participants spoke about noisy or busy situations affecting their ability to think clearly during schoolwork. Molly described the difficulty of working in a noisy classroom: ‘...it’s harder to concentrate because there’s so much noise going around...’ (Molly, lines 67-68) and Sabre included her busy homelife in her explanation of why she found homework hard to complete: ‘...so much going on and I’m... I find it really hectic and I just can’t handle it really.’ (Sabre, lines 88-89). Zelda Hyrule included more detail, describing how a busy PE lesson affected her decision-making:

*‘...I just find that really tricky because I have to focus on that but then they’re also saying that so I don’t know what I’m doing so it’s sort of so I’ve got the ball now and I can’t remember what I’m doing now...’* (Zelda Hyrule, lines 355-357).

She also described a similar experience in busy corridors during transitions between lessons: *‘...because there were so many people, I was just getting distracted...’* (Zelda Hyrule, lines 251-252).

It appeared that noisy and busy environments could increase the cognitive load for participants, and they found it hard to filter out distractions and focus on specific tasks, to the detriment of their ability to engage in learning tasks. It may also be notable that Phoebe referred to some lessons as being calm, suggesting that this was something she valued.

**4.3.4.2 Subtheme 2: Difficulties with Remembering Locations.** Two participants, Una and Zelda Hyrule, spoke about difficulties with getting lost and navigating their way between lessons when they first started at secondary school. Zelda Hyrule indicated that this could be hard to cope with, especially as a familiar source of help was unavailable:

*‘...because at the start of school I didn’t have the same [timetable as my sister] and I found that really difficult to get through because I didn’t know where I was going and I couldn’t ask my sister where I was because she didn’t know so I found it very difficult to learn where all the classrooms were...’* (Zelda Hyrule, line 165)

This suggests that learning the layout of the school is something that can take time and that participants appreciate help in achieving this. Una gave it as one of her examples of seeking help from teachers: *‘When I started at school, I didn’t know where I was going so they helped me.’* (Una, line 14).

**4.3.4.3 Subtheme 3: The Potential for Unperceived Difficulties.** Some participants spoke about the negative effects of internal distractions on their ability to focus or engage

during the school day and their description suggested that these were not necessarily situations that would be obvious to people in their vicinity. Phoebe described having other things on her mind during lessons, for example, '*Geography: I'm in ls this lesson I got a pl bcc I answered a question but I keep dozing off and getting distracted and stressed.*' (Phoebe, lines 6-7) and '*Morning was meh because I had clothes issues bcc they didn't feel nice 😞*' (Phoebe, line 23) and it is conceivable that this would have affected her ability to engage in learning.

Other participants discussed negative experiences during transitions due to the high cognitive load of having lots to think about. Sabre described nearly forgetting her school bag due to having too much to think about in the morning: '*I'm thinking about I have to catch the bus, is my ticket out, I should have that, and then...*' (Sabre, line 114), and Zelda Hyrule talked about losing belongings between lessons due to thinking about other things: '*...I found losing belongings very difficult because I erm I don't notice cos I'm so focused as I leave the class on where I need to go for my next class and I er, I found that quite difficult and quite scary...*' (Zelda Hyrule, lines 305-307).

Organising equipment and moving between lessons are inherent activities within the normal secondary school routine and there is therefore a high chance that the normal expectations of school life have the potential to be a source of stress.

Sabre also spoke about not being honest when teachers asked her if she was ok:

*'the teachers always check on me and make sure I'm ok. Sometimes I don't, I don't be honest in my answer, but I know they're trying to help and that does help. I do try to be honest but sometimes I'm too scared to.'* (Sabre, lines 12-14).



Although this might not immediately appear to be a distraction, the fear that Sabre experienced in this situation created the potential for a negative experience that teachers could dismiss, due to previously being told that everything was ok.

In all of these situations it was possible that other people may not have been aware of these internal factors and this highlights the potential for participants' negative experiences to sometimes arise from unseen factors. This will have implications for the support offered and it will be beneficial for school staff to be open to this possibility when offering assistance.

**4.3.4.4 Subtheme 4: When Coping Strategies Aren't Possible.** Several participants referred to having coping strategies to help them manage anxiety, but some also described becoming aware that these were not appropriate for a secondary school environment. Molly described a fidget toy that she had made for herself to aid feeling calm but recognised that it was not appropriate to use this in school due to other people's perceptions:

*'It's basically like a recorder cleaner with a ribbon on which I can wave it and my eyes will be like attracted to it [demonstrated the action]. And like my eyes get satisfied and it like allows me to like enter my own world almost and I would do that like every day but I would notice that I would get like quite a lot bullied for it so that's why I kind of stopped. I always have it in my bag though because I can like get it out after school and to also have as a comfort.'* (Molly, lines 453-457).

Zelda Hyrule repeatedly referred to a coping strategy of talking to friends to distract herself from feeling stressed but also described how it could be inappropriate during certain lessons, causing teachers to assume she was misbehaving:

*'...she had misunderstood and she'd thought that I was just chatting to my friends although I was trying to... like um even if I wasn't talking about what was going on it*

*was so I was trying to distract myself from what I was stressed about and it was like a coping mechanism.* ' (Zelda Hyrule, lines 210-213).

Even outside of school, there could be conflict between secondary school expectations and the ability to use coping strategies when participants were set homework. For Sabre this arose from school pressure following her home which she regarded as her place to recover:

*'Well, I always think of home as my safe place, where I can be like, where I like can be me but when it brings homework into it and it creates pressure on me to do this thing and I just can't handle it...'* (Sabre, lines 85-86)

For Zelda Hyrule conflict arose from time pressures and ambivalence over her ability to engage in calming activities:

*'Yeah, the only thing about my art is that I find it a bit hard to do that as much as I want to because I've got homework and things and I need to recharge the batteries so sometimes when I'm recharging I don't have time to do my art and then I worry about not doing my art which is weird because my art is the thing that's meant to make me not worry anymore.'* (Zelda Hyrule, lines 518-521)

This is significant as the inability to use existing coping strategies mean that these girls will need to develop new, more feasible strategies and it will be beneficial for staff to be aware of this need and the potential impact on the girls to cope, at least in the short term.

#### **4.3.4.5 Subtheme 5: Being Uncertain About Other People's Behaviour.** Zelda

Hyrule and Phoebe both described feeling upset due to difficulty with understanding other people's behaviour. This could be associated with conflict within friendships, as indicated by Phoebe's diary entry and her distress at not understanding why her friends were being hostile:

<i>Break</i>	<i>Lunch</i>
<i>Was weird bcc I didn't stand with my friend so I stood with my other friend and they ignored me for the whole lunch and break</i>	← same  <i>And they gave me mean looks even though I didn't do anything 😞 so I felt hurt she was angry [can't read]</i>

(Phoebe, line 46)

However, it could also occur during everyday interactions with others. Zelda Hyrule described distress caused by being unable to interpret her conversations with peers in lessons:

*'I don't know how to describe it but they jus, they act in that way and sometimes, although some others might find that like people talking normally, sometimes I just sort of think are they angry at me? Or are they upset? I can't really tell. Cos normally I don't really struggle with things like that but sometimes, people it's in the tone of their voice, that how they make me feel, it makes me feel up..., they make me feel like upset but they might have just said something completely normally, and I might have just taken it as passive aggressive.'* (Zelda Hyrule, lines 342-348)

This distress appeared, at least in part, to be related to her awareness of not knowing for sure if she had understood the other person's intention. She also experienced similar uncertainty over interactions with a teacher and described her relief at realising it had been a misunderstanding on her part:

*'...But then when we emailed my teacher, I realised that she hadn't really thought that and I realised that I had sort of made up this thing in my head so it wasn't, wasn't really real and so... yeah... it really helped when I realised that.'* (Zelda Hyrule, lines 213-215).

Zelda Hyrule's comments highlight her awareness of the potential for her reaction to be different to other people's and this suggests that she recognised that they might not be aware that she had reason to become upset. Using personal insight is discussed further in Theme 5.

**4.3.4.6 Summary of Theme 4.** This theme comprised a collation of difficulties for the participants that appeared quite internal in nature and therefore potentially unperceived by other people. The participants' descriptions also suggested that they attempted to cope with most of them alone, further decreasing the likelihood of these difficulties being apparent to others. Although this research attempted to take a positive approach, inclusion of these difficulties is important to increase understanding of the participants' lived experiences and expand the potential for offering support.

#### **4.3.5 Theme 5: Taking a Proactive Role**

As can be seen in the previous theme, participants took an active role in coping with school life and there was evidence that they used their own strategies to make school a positive experience. This theme relates to the participants' discussion of their own responses to their school experiences and comprises two subthemes: 'Developing your own strategies' and 'Having insight'.

**4.3.5.1 Subtheme 1: Developing Your Own Strategies.** Molly, Zelda Hyrule and Sabre talked specifically about strategies they had developed to help them cope with some of the negative aspects of their school experiences. Molly countered her anxiety over not understanding a topic through asking others and comparing the answers:

*'...I don't know what it means, I could ask them and if they don't know what it means and they give me an example of what they think it means and then I can compare what*

*I think it is to what they think it is and see if they kind of match up.* ' (Molly, lines 105-107).

Sabre talked about the stress caused by not getting everything right on a test and the self-talk she used to cope with this: *'Sometimes I'll try to say positive things in my head like this time you can do it again and sometimes that works but sometimes it doesn't...'* (Sabre, lines 168-169) and Zelda Hyrule described a number of strategies for coping with stress, for example talking to others to distract herself or using a mindfulness technique:

*'...sometimes, I just try to look at what's going on and I just try to, I try to slow down what's going on, I try to, I dun know, look at my shoes, look at something that's around me, something that I know isn't going to change and that sort of helps me ground myself a bit more.'* (Zelda Hyrule, lines 490-492).

It was apparent that participants were attempting to cope independently with personal problems and their development and use of their own strategies conveys a sense of self-reliance and autonomy.

The use of strategies could also be proactive and involve planning ahead. Zelda Hyrule described using strategies at home, including having 'hibernation' at the weekend to help her manage the busy social aspect of school:

*'...stay away from people and I don't know, watch my favourite films something like that, I find that a good coping mechanism and it's just, it's just a way of recharging my social battery for when I get to the next week.'* (Zelda Hyrule, lines 510-512)

This also highlights the self-awareness involved in developing personal strategies and the exploration of own behaviour and reactions to familiar situations needed in order to know which strategies will be successful. This is discussed further in subtheme 2.

**4.3.5.2 Subtheme 2: Having insight.** As seen in subtheme 1, some participants spoke about their experiences in ways that suggested that they had insight into their behaviour and the way they reacted to some situations. This self-awareness appeared to be useful in helping the participants make sense of situations and make decisions about how to act. Molly described deliberating over asking for help during a lesson:

*...I think at the time I was a bit nervous cos, about like asking but kind of most of me was thinking well if I don't ask then I'm just going to get in trouble for not doing anything so I may as well ask. ' (Molly, lines 152-154)*

This appeared to be a positive rationalising process, rather than indecision, with her conclusion being: *'Yeah, and that's what gave me the confidence to like go straight ask.'* (Molly, line 158). Zelda Hyrule also described similar reasoning when making new friends and the help it gave her in overcoming fear:

*'...If I'm a bit scared of it I try to think that there isn't anything that bad that's going to happen, they're not going to run away screaming at me just because I asked to be their friend. I think that helps me make friends.'* (Zelda Hyrule, lines 177-179).

The assessment of negative and positive aspects in a situation therefore appeared to be a conscious action that benefitted participants by boosting their confidence in knowing how to act. It is possible that the courage to overcome negative feelings came from knowing that they were making an informed decision.

Participants' insights could also involve consideration of the way they thought and recognition of how their brains work. Sabre referred to this in terms of learning maths:

*'I'm good at maths in some situations but some maths I'm really bad like algebra, brackets, I don't understand it, all that squared, all that weird stuff. I understand fractions and... it did take me 2 years to do fractions, that's how my brain works, it*

*has to really get used to it. I hope it doesn't take me another two years to understand algebra!*' (Sabre, lines 198-201)

and Zelda Hyrule reflected on her general approach to thinking about situations:

*'...I think I call it over-analysing cos I just try to put into words everything that I know and then sort of, often I realise that I've been over-thinking about it, just trying to translate it into words. But yeah, I do sort of have that understanding of myself... yeah...'* (Zelda Hyrule, lines 418-420).

In both descriptions, there was a sense of self-acceptance and a recognition of the benefits of knowing how they thought. Sabre's comment also implied the use of hindsight and learning from previous experience and this was also evident for the other participants. Zelda Hyrule indicated that her reflections on struggles with online lessons showed that she could have taken a different, more successful approach: *'...if I had tried to like work a bit harder instead of actually getting scared that I don't know it then I would have actually found what had gone wrong and then I can sort that out.'* (Zelda Hyrule, lines 402-405) and Molly predicted that she would be ok when her friends were away from school by considering her primary school experiences:

*'...well I think I'm going to be quite alright because in primary school I mostly spent most of my time alone so yeah I think just going back to those years won't be that bad and after all, I can always text them after school and we always had that home time to socialise.'* (Molly, lines 416-418).

This self-knowledge therefore appeared empowering for the participants, facilitating their potential to cope and identify positive strategies.

**4.3.5.3 Summary of Theme 5.** This theme showed that some of the participants were actively reflecting on their own behaviour and using it to understand situations, make

decisions and use coping strategies. In general, this reflection and self-awareness appeared to be positive and aided managing difficult experiences and learning for future scenarios.

#### ***4.3.6 Verification of the Thematic Analysis and Research Findings and Ideas for Dissemination***

Following the initial thematic analysis of the data, the participants were asked to verify the proposed findings, as outlined in Chapter 3. Three participants responded and indicated that they agreed with the findings, with no suggested changes. The analysis reported above is the version agreed with these participants. One participant did not have any ideas for disseminating the findings and another participant suggested that the research ideas could be shared with her school via a school assembly or an article in the school newsletter. This could have been due to the wording of the question or it could indicate that she felt it would be beneficial for the whole school community to develop their understanding of supporting girls with ASC. The third participant wanted to encourage other schools to have a version of her learning support facility where students would feel welcome and supported, with the opportunity to talk to a supportive adult. This would be available at lunch and break and also an option for lessons that they knew would be stressful, such as when they were being taught by a substitute teacher.

#### **4.4 What do Adolescent Girls with ASC Think About Participating in Research and Analysing Their Social Experiences in School?**

Three participants responded to the questions about participating in the research project and all three indicated that taking part had been a positive experience which they had found useful. Phoebe said that participating had made her think differently but did not elaborate on how, other than saying that thinking about work was bad but thinking about friends was good. For Molly, having someone to talk to who was interested in seeing things



from her point of view was appreciated: *'I quite like having someone to talk to who kind of understands it and kind of like wants to learn about, kind of like, how I see the world and whatnot.'* (Molly, feedback interview). She also described the usefulness of thinking about her experiences in a different way: *'Cos it really made me look into, like really made me think and look into how I see it and kind of really think about how I've been feeling about all that stuff and whatnot'* (Molly, feedback interview) adding that the experience helped develop her understanding: *'...because it's let me look at things that I've mostly not told other people and yeah, I've just kind of explained it.'* (Molly, feedback interview).

Zelda Hyrule explained that talking to someone about her school experiences helped her to process what happened and realise that the negative experiences weren't as frequent as she had been assuming: *'I realised that although I thought lots of negative things happened at school, there weren't really many to think of.'* (Zelda Hyrule, feedback questionnaire). The experience also helped her to realise that over the long-term, the negative emotions weren't that memorable: *'It was nice to realise that I often couldn't remember much of the memories that had made me embarrassed or upset.'* (Zelda Hyrule, feedback questionnaire). This suggests that although she had described using self-reflection during her initial interview, she experienced a different form of insight when verbalising her thoughts aloud to another person. Therefore, for both Molly and Zelda Hyrule, the opportunity to talk about their school experiences developed their understanding of themselves and appeared to provide additional clarity. Both of the adults associated with these participants also commented on how much they had enjoyed and appreciated the opportunity to talk through their experiences.

#### **4.5. Summary of the Research Findings**

The participants explored a variety of aspects of schooling in their discussions, including friendships, interactions with peers and school staff, positive experiences in lessons

and school, potential areas of difficulty, and their own role in making school a positive experience. These findings add to the existing knowledge of the experiences and needs of adolescent girls with ASC and also provide information that can be used to inform the support offered to them. It was apparent that the participants were socially motivated and valued their friendships for the shared experiences and support that friends could give. Participants also valued supportive teachers and school staff who were approachable and adapted their practice to accommodate the participants' needs. Some of the participants indicated that they valued autonomy and independence in their approach to school life and discussed ways that this could be promoted or hindered, either through the actions of others or their own reactions or use of strategies. Those participants that responded found participating in the research project to be a positive and useful experience that benefited them personally. These findings will be further discussed and their implications for practice explored in the next chapter.

## **Chapter 5: Discussion**

### **5.1 Introduction**

This chapter will further explore the study findings in relation to answering the primary and secondary aims of the research and investigating links to the existing literature. This will include interpretation of the findings to inform future support, indication of how the findings will be disseminated and consideration of the implications for practice within schools and Educational Psychology. There will also be critical evaluation of the research design and methods used. Finally, there will be consideration of the potential for future research and useful directions in which this area of knowledge can be further developed.

### **5.2 What do Adolescent Girls with ASC Consider Helps Them Succeed in Navigating the Social Aspects of Mainstream Schooling?**

The primary aim of this research project was to take a participatory approach to exploring what can help adolescent girls with ASC navigate the social aspects of school. The first two research questions were relevant to this aim, firstly establishing which aspects of school were relevant to focus on and secondly exploring examples of what was already working well. As their co-researcher role enabled participants to discuss any experiences they felt to be relevant, data collection also generated reflection and discussion on a wide variety of experiences in school, not just positive social interactions. These reflections contributed to answering the research questions and also fulfilled the secondary aim of adding to the existing knowledge about the experiences of adolescent girls in mainstream schooling.

#### ***5.2.1 The Aspects of School Considered Relevant for the Research Focus***

The participants identified a variety of aspects of school to focus on during their discussions including their interactions with friends, peers and staff and activities inherent in the timetable such as named lessons, tutor time and break and lunch times, congruent with

previous studies (e.g., Rainsberry, 2017). A common theme throughout their discussions was a focus on describing the direct interactions they had with others during these experiences, usually on a one-to-one basis or within a small group. This was apparent in their reflections on formal learning experiences and on more informal activities such as tutor and break times. It therefore appeared that participants considered close interactions with others to be significant for achieving a positive school experience and this is explored further in relation to the second research question.

Whilst some participants described the impact of being in larger groups within school, for example the difficulties caused by noisy and busy environments, there was very little discussion on taking part in larger group activities such as group working in lessons, contributing to class activities or joining in with extra-curricular groups. It is possible that this was due to the restrictions on social mixing caused by the Covid-19 pandemic and the lack of opportunities to experience joining groups. However, participants would still be taking part in some group activities and this finding could indicate that participants considered the opportunity to have a close connection with others to be integral to their group participation. This is reinforced by their references to the support they received from friends and teachers during lessons.

### ***5.2.2 What Contributes to a Positive School Experience?***

Participants chose to discuss a wide variety of school experiences and generated many ideas for what contributes to a positive school experience and helps them successfully navigate the social aspects of schooling. It was notable that each participant described unique experiences, choosing different lessons to discuss and focusing on different aspects of their relationships with others. However, as can be seen from the themes generated and explored in Chapter 4, there were commonalities in their experiences and ideas. A key finding was the

prominence and importance of relationships for the participants and the significant influence that interactions with others could have on their experience of school. Participants were also able to identify aspects of the school environment that could help or hinder their ability to engage with learning and cope with school expectations and many, but not all, of these were discussed in relation to social contexts. Some participants also indicated that they were motivated to take on a pro-active role and generate their own ideas for managing school. These findings are now discussed in relation to their ability to inform future support and their contribution to the secondary aim of the research of adding to the existing knowledge base.

**5.2.2.1 The Importance of Relationships and Interactions with Others.** It was apparent that the participants were motivated to interact with others during their school experiences and valued the relationships they developed with both friends and staff. The contributions of relationships with others were discussed across the themes and influenced the participants' engagement with lessons, their ability to cope with the expectations of the school day and their enjoyment of school. This is significant as some authors suggest a diagnosis of autism results in low motivation to interact with others and form relationships (Chevallier et al., 2012) and this can be a commonly held belief in the public domain (personal observation). Although there were some reports of difficulties with understanding the behaviour of others and some occasions when participants found the social environment overwhelming, for the participants contributing to this study, relationships with others were integral to creating a positive school experience and a sense of belonging. The comfort, support and sense of belonging supplied by friends has previously been shown to be integral to a positive school experience for teenage girls with autism (Myles et al., 2019; Rainsberry, 2017).

All participants were motivated to have friends, as seen in previous studies (e.g., Cook et al., 2018; Sedgewick et al., 2016) and described being members of friendship groups.

Belonging to a friendship group gave participants the chance to have fun and share experiences and they valued the emotional support that friends offered in and out of lessons, in agreement with the findings of Sedgewick et al. (2019). It appeared that the familiarity of working with friends could reduce the negativity of some situations and ‘hanging out’ with friends at break gave opportunities to relax and reset during the busy school day. Myles et al. (2019) and Foggo and Webster (2017) also found that girls with autism valued friendships for the happiness and support they offered. Opportunities to talk and ‘hang out’ enhanced the feeling of connection with friends and these were a valued part of the timetable. Talk has also been found to be a significant element of friendships for girls with autism by Sedgewick et al. (2016) and Ryan et al. (2020) reported that opportunities to meet up regularly were important for maintaining friendships for girls with autism. There were elements of attending secondary school that facilitated the formation of friendships, in particular participation in tutor groups and tutor-led activities, and the wider diversity of potential friends.

A sense of belonging could also be achieved through the relationships developed with school staff. Access to an identified source of support, in the form of a regular check in or the offer of an open door by pastoral staff was highly valued and a source of reassurance for participants. Developing a trusting relationship with a key, supportive adult is proposed to be beneficial for children with a history of trauma, in part, by allowing them to relax sufficiently to be open to learning (Bombèr, 2017). It is possible that the certainty that support was available provided a similar function for participants in this study who were navigating the potentially uncertain and anxiety-provoking school environment. A similar situation was also seen within lessons with supportive teachers also providing reassurance and some participants describing the negative effect that a lack of teacher reliability could have on their emotional well-being and certainty about their learning. In agreement with the findings of

Sproston et al. (2017) some participants reported that staff showing an interest in them and checking in facilitated them in seeking help.

**5.2.2.2 The Importance of Being Understood.** Although peers and staff played different roles in creating a sense of belonging and offering support, a feature common to both types of relationship was the other person's understanding of the participants and their situations. All participants showed a desire to be understood and commented on the positive effect that understanding from both friends and staff had on their experiences. It appeared that the ability for others to take a personalised approach during interactions, and make offers of support based on individual needs, was reassuring and instrumental in helping participants to engage with school and friendships.

Having the ability to understand needs was also a key feature of teachers described as being supportive within lessons. This could be manifest through teachers taking time to talk individually to participants or by acting on communication about their needs and making adjustments in the delivery of lessons or behaviour management. The physical enactment of changes in behaviour to accommodate needs was a clear sign that participants had been heard and validated and appeared to add to their sense of acceptance and promote feelings of belonging.

Teacher understanding of individual needs and flexibility has previously been shown to be valued by girls with autism, contributing to a positive school experience (Jarman & Rayner, 2015; Sproston et al., 2017) and generating reports of an enjoyable school experience comparable with that of neurotypical peers (Dillon et al., 2016). Promoting a feeling of being understood was one of the recommendations made by Honeybourne (2015) to improve the school experiences of girls on the autistic spectrum and teacher understanding has been considered integral to inclusion as it requires acceptance and accommodation of individual

needs (Goodall & Mackenzie, 2019). It was significant that in the current study, reports of experiences where teachers did not appear to understand individual needs such as coping strategies led to feelings of anxiety at not fitting in and doing the wrong thing.

**5.2.2.3 The Importance of Certainty.** The importance of being certain about their understanding of what was going on was also discussed widely by participants. In particular, anxiety could arise from not understanding what other people meant during social interactions and this was especially pertinent during lessons and when receiving teaching input. In many cases this could be due to the nature of the information and the way it was delivered with participants indicating that fast delivery, insufficient detail or unclear language hampered their ability to process the information. This led to frustration at not being able to complete work independently and anxiety over making mistakes. Concern over clarity in what is being asked of them has previously been reported by girls with Asperger's (Stewart, 2012) and difficulty with understanding complex or ambiguous language and the increased executive function demands of formal learning has also been associated with a difficult experience in secondary school for girls with autism (Baldwin & Costley, 2016).

However, the participants in this study also talked widely about positive examples where their cognitive processing and understanding was supported. Teachers checking previous knowledge and filling in knowledge gaps helped participants to feel confident about their ability to understand new learning and participants recognising themselves that they already knew about a topic was reassuring. The use of visual examples or physical demonstrations to supplement verbal instructions was valued and appeared to reduce cognitive load through not having to remember long instructions. Teachers who were able to deliver clear, unambiguous explanations and directions were described as supportive and, interestingly, some participants commented on the negative impact of teachers lacking confidence in their delivery of information. Teachers who convey instructions in a clear and



concise manner have previously been portrayed by autistic secondary school students as more helpful than teachers who were inconsistent in their delivery or digressed (Dillon et al., 2016). In addition, a teacher's inability to provide a definitive answer can sometimes be perceived by autistic individuals as indicative of lacking competence (Ripley, 2015). It was apparent that at least one of the participants interpreted some teachers' behaviour in this way and this appeared to be associated with a view of those teachers being less reliable and supportive. Lack of certainty was a particular problem when being taught by supply teachers.

It is notable that the identified methods of support are reflective of attuned, guiding and clarifying approaches to teaching (Aelterman et al., 2018). Attuned teachers are those who attempt to make learning more engaging through personalised understanding of the student, provide explanations that are meaningful to the students and accept negative affect by trying to understand the student's point of view. Guiding teachers are those who scaffold learning through monitoring existing knowledge and provide the steps necessary for task completion, thereby enabling students to work independently. Clarifying teachers are those who communicate clear and unambiguous expectations, providing an overview of what to expect in the lesson and monitoring of the student's progress towards this. An attuned and guided approach to teaching has been found to relate to the most adaptive pattern of outcomes for teachers and students (Aelterman et al., 2018) and it appears that participants in this study also found these approaches beneficial.

A more general sense of certainty over what to expect in future events was also valued by participants with reports that having prior knowledge about lessons or other events was an advantage. This did not necessarily change the nature of the event but the knowledge of what was coming appeared to allow participants to prepare and to reduce the negative impact. Predictability and familiarity in routines, with adequate preparation for transitions and change is already a recognised way of supporting autistic students within schools

(Ripley, 2015). Within this study, participants indicated that such knowledge could also be gained by sharing experiences with friends and this was named as one way that friends could offer support. It is also indicative of the participants' own contribution to managing their school experiences which is discussed below.

**5.2.2.4 The Facilitation of Coping.** All participants indicated that there were aspects of school life that they found challenging, although the positive focus of the data gathering meant that these were not widely discussed. In common with other studies, the examples given included finding noisy and busy environments overwhelming and these negatively impacting on their ability to concentrate and process information (e.g. Cook et al., 2018; Honeybourne, 2015; Sproston et al., 2017), difficulties with understanding others (Foggo & Webster, 2017), finding the executive function demands of secondary learning stressful (Baldwin & Costley, 2016) and a desire to separate the concepts of school and home (Dillon et al., 2016). Some participants also talked about more personal reasons for finding it hard to cope, such as feeling uncomfortable in their clothes or having other things on their mind.

Inherent in discussions of difficulties were references to how coping could be facilitated. This has already been discussed in relation to the role of others providing support, understanding and reliable help but participants also highlighted other sources of support for coping. Opportunities to relax and have respite from formal teaching throughout the timetable were valued and these breaks often involved the chance to connect with friends or check in with pastoral support. One participant described the breaks using a computer game analogy and indicated that they provided a chance to recharge or reset. The concept of a window of tolerance within which individuals are able to function optimally is increasingly being used in recommendations for supporting emotional regulation (e.g., Knightsmith, 2019). Staying within this window is dependent on an individual's emotions not fluctuating too widely and entering either hyper-arousal or hypo-arousal where the individual is unable to cope. It is

proposed that this can be aided by chances to rest and/or reset, congruent with the descriptions of participants in this study.

For some participants there was suggestion that transitioning between home and school required cognitive adjustment and the facilitation of separating home and school also helped with reducing stress and anxiety. Suggestions comprised less formal transition periods at either end of the school day or homework clubs. Difficulties with tolerating homework have previously been discussed in relation to literal thinking by autistic individuals and the fact that homework blurs the boundaries between school and home (Dillon & Underwood, 2012). Although only one participant reported a similar strength of feeling about homework, there were other suggestions that some participants were seeking a distinction between school and home and appreciated a chance to make this cognitive adjustment a part of the school day.

Some participants also described having personal coping strategies that helped them reduce anxiety and stress through calming their minds or distracting themselves from thinking about the stressful stimulus. The benefits of others understanding needs has already been discussed and one participant specifically commented on appreciating her teachers allowing her to use her coping strategies in class. However, participants in the other schools experienced difficulties and distress as a result of realising their preferred methods were inappropriate for a secondary school environment and could even lead to misunderstandings about their behavioural conduct. Misinterpretation of behaviour by teachers was also reported by Bargiela et al. (2016), causing distress through accusations of ‘rudeness’ or ‘laziness’. This highlights the necessity for developing understanding of autism in schools and the need to be open to the various adaptations students will need to make when they move to secondary school, not just in terms of getting used to a new routine and navigating a new

building (although that was also apparent) but also in terms of the way they manage their stress and anxiety.

**5.2.2.5 Taking a Proactive Role in Managing School Experiences and the Role of Personal Insight.** The final theme examined the role the participants themselves took in managing their school experiences and increasing the chances of them being positive. Some participants described developing their own strategies to facilitate taking part in school life and reduce the negativity they experienced in some situations. Previous studies have described girls with autism as camouflaging or masking their behaviours in order to fit in at school, which has involved developing personal strategies. Some girls reported deliberately learning social skills and strategies (Baldwin & Costley, 2016), copying acceptable phrases and facial expressions (Bargiela et al., 2016; Tierney et al., 2016) and deliberately suppressing autistic traits (Cook et al., 2018). Others used observational skills to develop social codes that helped them understand social conventions (Tierney et al., 2016). It was unclear how the strategies described by the current participants related to fitting in, but their descriptions have parallels with the previous studies in that they were attempts to cope independently and counter negative experiences without the help of others.

The strategies participants employed demonstrated self-awareness that appeared to result from reflection and the development of personal insight. Whilst the research protocol was designed to facilitate reflection during data collection, their descriptions revealed that some participants already used reflection and personal insight in their daily experiences. Participants referred to the thought processes involved in analysing their behaviour, rationalising the situation, deepening understanding and coming to a conclusion which could also include a decision about how to act. This process appeared to be empowering, helping them to identify ways to cope or ways to learn from a situation and reduce the negativity in the future.

The use of reflection and insight was not just confined to descriptions of their own role. There was evidence of participants using insight across the themes, in their discussions of what they valued about friends, in their recognition of what helped or hindered them in lessons and in their awareness of how others might view their behaviour. Such discussion involved acknowledgement of the other people's understanding of a shared situation and some analysis of this, including speculation that others' understanding might differ from their own or recognition that people changed their behaviour in response to different circumstances. For example, one participant commented on peers probably not realising she was upset because she had misinterpreted their vocal tone and another participant observed that teachers made personal allowances for her in lessons but would reprimand others for the same behaviour. Participants also used phrases like 'that's how my brain works', 'in that mindset' and 'I feel a bit more settled in', indicating consideration of how their own mental processes were involved in their experiences and the influence these could have on how events transpired.

The ability to attribute mental states to yourself and other people is known as Theory of Mind (ToM) (Premack & Woodruff, 1978). A deficit of ToM in those diagnosed as being on the autistic spectrum has been a central tenet in autism research for some time, explaining social and communication difficulties through an inability to understand the mental states of others (Baron-Cohen, 1995; Baron-Cohen, 2000; Frith 2001). However poor performance on ToM tasks is not seen in all individuals with an autism diagnosis (e.g., Livingston et al, 2019) and critical discussion around the theory is developing (e.g., Gallagher, 2004; Gernsbacher & Yergeau, 2019; Hickok, 2014). Gernsbacher and Yergeau (2019) critique the empirical validity of ToM studies, citing a lack of specificity and universality for autistic individuals, a lack of convergent validity between various means of assessing ToM and a lack of predictive validity in these measures. The authors argue that tasks designed to test ToM are contrived

and heavily dependent on participants understanding the language of the question (Gernsbacher & Yergeau, 2019). Happe and Frith's (2020) review of the concept of autism acknowledges that this topic is much debated. The authors refer to differences between explicit and implicit ToM, proposing that individuals with autism lack spontaneous, automatic implicit tracking of mental states in others. Some studies (e.g., Livingston et al., 2019) suggest that autistic individuals who 'pass' ToM tests use sophisticated compensatory strategies that existing tests lack the sensitivity to detect.

Hickok (2014) advocates for moving away from deficit models and proposes that social difficulties may arise through a lack of opportunity to practise and develop social skills, rather than an inherent lack of ToM. His 'Intense World Theory' proposes that the emotional intensity of social interactions causes autistic individuals to avoid these interactions or approach them differently, decreasing their opportunities to learn how to act. In support of Hickok's proposal, emerging research focused on ToM indicates that it is multi-dimensional, involving cognitive and affective elements, and does not spontaneously emerge but must be learnt through early interactions with others (Westby & Robinson, 2014). This developmental trajectory is described as a series of stages: stages 1 and 2 are pre-ToM, the infant first engages with others and then develops a sense of self. Stage 3 involves first order ToM in which they reflect on others' thoughts and feelings, and stage 4 involves second order and higher ToM where the individual predicts what one person is thinking about another person's thoughts. Higher order ToM is necessary for understanding figurative language, sarcasm and recognising lies (Westby & Robinson, 2014). It is therefore possible to think about individuals being at different stages of developing ToM, rather than being in a binary present/absent state.

The emerging research around a female phenotype for autism also raises questions about ToM deficits in some individuals with autism. A pertinent finding is the tendency of

some females with ASC to camouflage or mask autistic traits (Baldwin & Costley, 2016; Bargiela et al., 2016; Livingston et al., 2019) with the aim of fitting in socially and avoiding standing out (Cook et al., 2018). Such a mindset requires that individuals have established that others perceive they are different, have ascertained what the incongruent personal quality is and have taken steps to change this to be more similar to equivalent personal qualities in those they wish to be accepted by. This complex process involves awareness of both their own and others' mental states and a desire to be aligned and connected with others; they care about what other people think about them. To give a direct example: participants within the study by Tierney et al. (2016) reported tweaking social mimicry to avoid being caught out. This adjustment would be unnecessary if they were unable to anticipate the thoughts of others and did not place importance on what others thought about them. The current study also indicates that at least some individuals with a diagnosis of ASC do consider their own and the mental states of others in making sense of their experiences and deciding how to act. It is not denied that this can be a source of difficulty and their observations indicate that the process does not always produce satisfactory answers, however evaluation of thought processes does seem to be a significant part of their coping toolkit and it will be important to be open to this possibility when offering support to this demographic of students.

### ***5.2.3 Difficulties that School Staff Might Not be Aware of***

As already discussed, all participants indicated that there were aspects of school life that they found challenging and some of these were collated separately in Theme 4, describing difficulties that school staff might not be aware of. Whilst this theme is incongruent with a positive psychology focus and research questions aimed at identifying successful strategies, it was included as it satisfied the secondary aim of adding to existing knowledge about the experiences of adolescent girls with ASC in mainstream schooling. Having identified these difficulties during analysis and having recognised the potential

positive impact of school staff having awareness of, and being able to accommodate these needs, the researcher felt a moral obligation to report them and further contribute to the existing knowledge base.

#### ***5.2.4 Overview of the Findings and Consideration of Psychological Theory***

**5.2.4.1 The Desire for Relatedness, Autonomy and Competence: Psychological Well-being and Self Determination Theory.** Inherent within the participants' descriptions of their school experiences was an expectation to take part and be integrated into school life, and a desire to be independently successful, indicating parallels with the desire for relatedness, autonomy and competence explored in Self Determination Theory (reviewed by Ryan & Deci, 2019). Self Determination Theory proposes that autonomy, competence and relatedness are basic psychological needs, the satisfaction of which is congruent with psychological well-being (Ryan & Deci, 2019). It is possible to map all three of these psychological needs onto the analysis of the current study, both in the goals participants were seeking for themselves and in the areas they identified as being supportive of them succeeding at school.

Relatedness was represented by their social motivation and the value they placed on personal connection with teaching and support staff. Participants repeatedly referred to the importance of relationships with others in facilitating positive experiences at school and staff described as supportive were also those reported to show a personalised approach. The knowledge that there was an identified source of support was also key. The participants' desire to understand what was going on and receive enough information to work independently reflected both autonomy and competence, as did their development of their own strategies using self-awareness. Ryan and Deci (2019) point to a critical role for self-awareness in facilitating autonomous functioning through promotion of integration and volition, both apparent in the descriptions in the present study.



Other factors that participants identified as helpful for facilitating autonomy and competence included engaging lessons and chances to be creative, non-verbal and augmented verbal help, confident teachers who were able to give clear explanations, the ability to communicate needs and teachers adapting accordingly, and prior knowledge about a subject or event. Conversely, some factors that reduced the ability of participants to act with autonomy and experience competence included noisy and busy environments, personal distractions, uncertainty over the behaviour of others and the inability to use coping strategies. Facilitation of coping across all areas of school life was a more generalised way of supporting autonomy by enabling participants to feel capable of managing the challenges of school life. Consequently, it appears that taking an approach that is informed by Self Determination Theory and aims to promote autonomy, competence and relatedness will be beneficial to this demographic of students.

**5.2.4.2 The Influence of Environmental Fit and The Social Model of Disability.** It was also apparent that participants' experiences were dependent on context and outcomes could differ according to a variety of external factors. These included teaching style, behaviour management methods, work partners, noise levels and the 'social busyness' of a situation. For example: teachers checking prior knowledge was reassuring whereas teachers who made assumptions could provoke anxiety; noisy classroom environments negatively affected cognitive processing. In general, where participants experienced more optimal conditions or a better environmental fit, they also reported greater success and less distress. The influence of the environment and the interaction between need and context is considered within the Social Model of Disability which proposes that disability is a culturally and historically specific phenomenon that changes with context (Shakespeare, 2006). By thinking about a person's needs in the context of their environment, it is possible to identify barriers to them taking part and acting autonomously and to work to remove those barriers, shifting the

location of the problem from the individual to the barriers and attitudes that prevent them from participating (Shakespeare, 2006). Within the current study, this was illustrated by the significant benefit participants gained from being able to communicate their needs and have teaching staff adapt accordingly. In these cases, it was the environment that was changed, not the individual, and this resulted in participants reporting increased autonomy and facilitation of feelings of competence and relatedness.

Many of the examples and ideas shared by participants involved describing optimal conditions that promoted positive affective state or removed barriers to successful cognitive processing. Crucially, participants also acknowledged the interaction they experienced with their environment, which could be their physical and/or social context, discussing the way it made them feel and, in some cases, indicating that the accommodation of their needs stopped them feeling like a problem. It appeared that successful experiences were linked with an accepting and inclusive ethos that could accommodate needs and make a place for the individual. The Social Model of Disability was instigated in response to discrimination against individuals with physical disabilities and it has faced criticism for being a blunt tool that is too simplistic and can neglect to acknowledge the full extent of impairments, especially as a barrier free utopia is an unlikely achievement (Shakespeare, 2006). However, for the purpose of this study, it helps to highlight the importance of holistically examining why a person is experiencing difficulties and moving away from locating the problem within the individual. Considering the individual within the context of their environment and unpicking how the perception of a problem has arisen facilitates an inclusive ethos that sees barriers not people as the problem. It won't always be possible to remove barriers but acknowledgement of them changes the narrative and can help promote self-esteem (Shakespeare, 2006). Therefore, it appears that considering environmental fit and identifying

barriers to autonomy and independence will also be beneficial when facilitating support for these students.

### ***5.2.5 Summary of Key Findings and Implications for Informing Support for Girls with***

***ASC.*** The primary aim of this research was to work with girls with ASC to identify positive solutions to the difficulties they encounter in mainstream schooling and use this information to inform appropriate support for this demographic of students. The key findings can be summarised as follows:

- Positive relationships with school staff and friends are important and provide a sense of belonging and support. Having an identified source of guaranteed support is highly valued, as are chances to talk and connect with friends throughout the day. Friends can provide emotional and academic support.
- It is important to be understood by friends and school staff, including others having knowledge of personal difficulties and being receptive to communications about needs.
- It is important to be certain about what is happening and what is needed to complete a task or activity. This certainty reduces anxiety and facilitates an ability to be independent.
- Understanding during learning can be facilitated by teaching style and participants' prior knowledge.
- Attuned, guiding and clarifying approaches to teaching are regarded as supportive and motivation can be facilitated by engaging lessons and the chance to be creative.
- Participants do find school challenging but their ability to cope can be facilitated. In addition to the adjustments described above, it is helpful to have chances to reset during the school day, opportunities to separate school and home and for school staff to be open to hidden personal concerns.

- Participants are motivated to find their own strategies to manage school and use insight and awareness of others' motives to inform their thinking.
- Participants value autonomy, competence and relatedness and environments that facilitate and support their ability to achieve these.
- Participants value a good fit with their environment and the identification and removal of barriers which can prevent them from feeling included.

These findings are not intended to be a comprehensive list for schools to follow. Some items reflect the participants' values, some reflect broad overarching concepts, and some include more practical considerations. As shown by the heterogeneity of shared experiences, every individual has unique needs, and a lack of specific direction is deliberate. It is hoped that these findings will have more use as a starting guide from which schools can develop their understanding of these students' needs before beginning discussions with individuals about what will work for them.

### **5.3 What do Adolescent Girls with ASC Think About Participating in Research and Analysing Their Social Experiences in School?**

The third research question focused on the participatory nature of the study and asked participants about their experience of taking on a co-researcher role and examining their school experiences. The three participants that responded to this question indicated that it had been a useful experience and that taking part had changed the way they thought about school and themselves. For two participants, the exercise had deepened their understanding and provided further insight, above that which they had already gained through their independent reflections. Reflection on previous experience can be a source of learning and prompt for change (Gibbs, 1988) and this appeared to be true for these participants. It was also postulated before data collection that such reflection had the potential to raise well-being

through a focus on the positive aspects of experiences. The data collected for this research question were insufficient to provide a measure of this, but it was notable that one participant stated that the process had helped her positively recalibrate her perception of the frequency of negative experiences and gain reassurance through this, congruent with the principles of a positive psychology approach (Seligman et al., 2005).

There was evidence that the opportunity to talk in a forum where their knowledge was given precedence was perceived as empowering by two of the participants. Adults associated with these participants both commented on the value they gained from the opportunity to talk and one participant commented directly on benefitting from knowing someone else wanted to understand how she saw the world. Both participants showed enthusiasm for sharing the findings with others in a position to make changes for school provision and one participant's decision to disseminate the findings through writing an article for her school newsletter was a direct example of the process facilitating her voice. Participatory research is intended to have an emancipatory purpose that promotes engagement in social action (Aldridge, 2016; Robson, 2002). The current study shows that this opportunity was valued by some girls with ASC and that they welcomed the chance to contribute their voice to their wider community.

#### **5.4 Dissemination of Findings**

One objective of this research was to generate information which can be used to inform the support offered to adolescent girls with ASC and social and communication difficulties. To enhance the potential for impact, the findings will be disseminated at multiple levels: in the participants' schools, across the researcher's local authority and, potentially, in the autism research literature. As part of the research design, participants were involved in decisions about what would be included in the disseminated findings and how it would be shared with their own school. One participant has chosen to contribute an article to her school newsletter

and this is planned for the summer term. The participant will be taking the lead in producing the article, with contributions from the researcher as requested and directed.

The researcher will take the lead in writing a briefing paper for their local authority to disseminate the findings across the local education community. This will include a summary of the findings agreed with the participants and the additional contribution from one participant who wished to encourage all schools to have a learning support facility that was available to students during break and lunch times and during lessons which they found challenging. The researcher will refer to her rationale in explaining why this is a valuable resource. In addition to the summary of findings, the briefing paper will include an explanation of the participatory and collaborative nature of the research and the value gained from giving precedence to pupil voice. It is hoped that this will not only encourage schools to use the information generated in the current research but to also encourage them to use a more collaborative and participatory approach with pupils when producing support and intervention plans and school policies in the future.

The researcher also intends to investigate publishing the findings in the wider scientific literature. This will not only widen the potential impact of the findings but also fulfil the secondary aim of the research in adding to the existing knowledge about the experiences of adolescent girls with ASC in mainstream schooling.

## **5.5 Evaluation of the Participatory Design**

As described in Chapter 1, participatory research is a continuum, the aspiration of which is the participant-led emancipatory generation of information which can be used to effect social change (Aldridge, 2016). In evaluating the current project against the principles of participatory research, it is possible to place it within the higher end of Aldridge's (2016) Participatory Model, mostly within 'Participant as actor', and between Levels 5 and 6 of

Hart's (1992) Ladder of Participation. Hart (1992) describes Level 6 as the first stage where true participation is seen as children are involved in decision making within adult initiated projects, whereas in Level 5 they act as consultants. Although this project prioritised participant decisions about data collection and content, the analysis and write-up were researcher-led and participants acted as consultant verifiers at this stage. They also had a limited role in the dissemination of findings. This was partly due to logistical considerations and the time involved in these stages, as outlined in Chapter 3, and the constraints of collecting data during a global pandemic, as outlined below. However, there was also a consideration that the analysis and interpretation of findings in regard to the psychology literature is a role which requires a certain type of knowledge and prior experience. This created a tension between the dual aims of placing participants at the centre of the process and producing information that went beyond description of individual lived experiences and, through analysis and interpretation, could be used to contribute new understanding and insight about social issues (Aldridge, 2016). Aldridge (2016) acknowledges that this tension can mean it is not always possible to work at a truly emancipatory level. It is possible to evaluate this project as being collaborative, with the participants contributing expertise on their lived experiences and evaluation of the support they receive and the researcher contributing knowledge of psychological theory and analysis to facilitate the ability to generalise their shared knowledge.

Steps were taken to maximise the degree of participation within the limits outlined above. The researcher reflected on the notion of 'participant voice' and the needs of the participants which might affect their ability to convey this authentically, endeavouring to use a design that promoted placing participant voice centre-stage (Aldridge, 2016). Participants made their own decision about how they wished to share their data, facilitating their communication needs, and, beyond the stated aim of the research questions and the suggested

use of a guiding reflective framework, the researcher attempted to make minimal direction about the content of data shared. In that way, participant voice was afforded credence and the experiences included in analysis were chosen by the participants.

The emancipatory aspect was elevated through the demonstration of participants gaining new insights and positive changes through their participation (Bergold & Thomas, 2012) and analysis and discussion that focused on the identification and removal of barriers (Stone & Priestley, 1996). The commitment of the researcher to using the findings to pursue positive social change at multiple levels also promoted the emancipatory potential of the project. Finally, the interpretative analysis of the findings, with reference to psychological theory, demonstrated a commitment to developing and advancing participatory research through applying rigour and promoting the credibility of these findings (Aldridge, 2016).

## **5.6 Limitations of the Research**

Although the data gathered were successful in fulfilling the primary and secondary aims of the research project, it is important to acknowledge the limitations of the data set and the implications these have for generalising the findings for use by the wider community. Some of these limitations were inherent in the design and some were imposed by the Covid-19 pandemic restrictions and the consequent changes to data collection methods and the experiences of the participants.

### **5.6.1 Research Design and Implications for Generalisability**

The most significant factor of the research design affecting generalisability was the small sample size that is inherent in a qualitative analysis protocol. This limits the breadth of experiences included in the data and thus their relevance and pertinence for the wider community of adolescent girls with ASC. The recruitment of schools from across the local authority and the inclusion of three different schools was a step to acknowledge and counter



this and broaden the diversity of school experiences. However, the small number of recruits and similarities in age and school catchment areas still placed a limit on diversity and mean that it may be difficult to extend these results to schools with different demographics.

Another potential limitation is the positive focus of the data collection and the emphasis on what was already working. Although this was a deliberate part of the design, aiming to identify support which was already known to be useful, there was also an inherent danger that difficulties would be overlooked, and the impression given that the participants did not find school challenging. Additionally, this approach necessitated the identification of students judged by school staff to be succeeding in school and thus excluded the voices of other girls with ASC who were experiencing difficulties and may have potentially different needs. The intention of this research was never to produce a definitive list but a guiding framework which could initiate exploration of potential support for girls with ASC. It is therefore hoped that these findings will provide a starting point which can lead to further exploration with different groups of girls with ASC.

### **5.6.2 Covid-19 Pandemic Restrictions and Implications for Generalisability**

In March 2020, social distancing measures and restrictions were imposed by the Government in response to the global Covid-19 pandemic. These had various impacts on the current study and the nature of the data collected due to changes in the way schools operated and the way data could be collected.

Schools were closed for extended periods, in the spring and summer of 2020 and the winter of 2021, limiting the time available for recruitment and data collection. In addition, schools were required to follow social distancing protocols that limited the mixing of students between and within year groups. These measures changed the experience of school for participants over the short and long term, giving them a disjointed experience of school with

periods of home-learning in the months preceding the data collection period and an untypical experience of school when they were present. This has the potential to further limit the ability to generalise the findings once restrictions are lifted. However, it should be noted that the experiences described by participants appeared subjectively applicable to learning experiences in general and there is no certainty about how long social distancing restrictions will need to be kept in place. It is possible that social mixing will not return to pre-pandemic levels, reducing concerns over the applicability of the present findings.

Due to the restrictions on social mixing, all interactions with school staff and participants, including data collection, had to be changed to remote methods as described in Chapter 3. This was felt by the researcher to be a limitation on the ability of some of the participants to contribute, especially those who found talking to others difficult. Two participants in particular appeared to find talking via Microsoft Teams difficult. The opportunities to build rapport and offer alternative ways of sharing ideas were severely curtailed by the need to communicate through a screen and although both girls did contribute ideas that informed a number of themes, it would have been preferable to have more flexibility in how their participation could have been facilitated. As discussed above with the positive focus, this raises the possibility that the opinions of more socially confident individuals dominated and were not necessarily applicable to all participants.

### **5.7 Researcher Reflection and Reflexivity**

This reflective section will be written in the first person. The experience of conducting this research was overwhelmingly positive, despite many frustrations, and it was a privilege to work with such inspiring young women. Taking on a participatory project was a daunting prospect, especially having come from a more traditional research background where I was the expert owner of the research. It was necessary to engage in critical reflection

to evaluate how I was positioned by myself and others and to maintain confidence in the ability of the process to produce valuable data. My personal interest in the topic also meant that I needed to maintain awareness of my voice in data collection and analysis. As discussed in Chapter 3, I took steps to ensure that my own views and interest in the topic were not biasing my interpretation of answers or causing me to ask leading questions. In addition, as the data collection proceeded, I began to identify common experiences that were shared by participants and I needed to extend this monitoring to ensure that I did not inadvertently steer the interviews with later participants towards topics identified by their co-researchers. Monitoring of both was achieved through keeping a reflective diary and notes on each interview and engaging in reflection-in-action (Schon, 1983) during interviews and analysis to check why I was about to ask a particular question or why I had responded/interpreted in a particular way. I found open questioning particularly difficult when speaking with the participants who found talking to others challenging, especially when this appeared to make them feel uncomfortable. I was able to draw on knowledge from the teaching on the DECP training and my experiences working on placement to alleviate these tensions.

There were a number of frustrations that arose during the data collection, some as a result of the Covid-19 pandemic and the subsequent changes to the research schedule and data collection methods. This led to compromises in the number of participants recruited and disappointment that planning to counter some of the research limitations could not be followed through. The added complexity of remote connection with participants also meant that I was more reliant on the help of school staff in setting up meetings and interviews with participants. Coupled with the complications of school closures once data collection had started, this resulted in the follow up stage being less in-depth than intended and a more superficial exploration of research question 3. As discussed above, conducting the data collection remotely also affected the ability to build rapport with participants and it was

necessary to work hard within interactions to position us both as equal directors of the data collection. Overall, I felt that the need to communicate remotely restricted the level of participation achieved and necessitated me to take on more of a leadership role than I had originally intended, especially towards the end of the project.

A further frustration arose through awareness and appraisal of my own research abilities. Transcription allowed reflection on my own contributions to the conversations, and I often found myself thinking of better questions or responses that might have led to deeper exploration of a topic. Although this did not have the potential to affect my questioning in this research project, I have noticed that it has positively influenced my use of questioning during casework and extended my ability to place pupil voice at the centre of my assessments.

## **5.8 Unique Contribution**

This research has contributed to an emerging area of research. Many of the findings have shown parallels with existing knowledge, in particular the motivation of girls with ASC to have friends, their understanding of friendships and their experiences of mainstream schooling, adding weight to this growing body of evidence. However, the research set out to extend knowledge too, and unique contributions have been achieved through a focus on identifying ways to support adolescent girls with ASC and a participatory approach which prioritised the knowledge of the target community and increased the authenticity of the findings.

Whereas previous studies have described the difficulties girls with ASC face in school and highlighted a need to offer support, the main outcome of the current findings has been a description of what this support could look like and the provision of ideas for ways that various aspects of the school environment can be adapted to facilitate autonomy and

independence. Rather than adopting a deficit orientated approach that problematises girls with a diagnosis of ASC, this research has examined their values and motivations and explored ways that they can be empowered through removing barriers to participation and inclusion. Confidence in the relevance and efficacy of these approaches has been achieved through the use of a participatory approach in which the target community specified which areas of school should be a focus and a positive approach which sought out what was already known to work.

In reference to the reviewed literature, taking a participatory approach with this demographic of students is also a new development of this research area. The repositioning of the participants within the research from objects of examination to authors of their own story has given the opportunity for deepening insight into their lived experience, including exploration of their use of insight and awareness of mental states in generating their own understanding of their experiences. In addition, the ability to map the ideas the participants generated onto established psychological theory and existing models of teaching style has endorsed their validity, increasing confidence in the efficacy of this approach. Therefore, a further unique contribution of the research has been to show the usefulness and credibility of taking a participatory approach with these students.

## **5.9 Implications for School and Educational Psychology Practice**

This research has high relevance for the practice of schools and Educational Psychology Services, given its focus on how girls with ASC can be offered support to succeed in school. The direct implications for informing the support offered to these students have been discussed in the summary of findings for research questions 1 and 2, but there are further implications which come from a more general consideration of the findings.

### **5.9.1 Knowledge and Understanding of Needs**

Participants showed a strong desire to be understood and also experienced a positive impact of a good fit with their environment and teachers accommodating their needs. This means that schools, and the educational psychologists (EPs) supporting them, will need to ensure that they have a good understanding of the general presentation of ASC in girls and that they keep up to date with this new and developing area of research. However, as seen in previous studies (e.g., Dillon & Underwood, 2012), the individual specific needs of the participants in this study were heterogenous, indicating a need to establish tailor-made support through collaboration with their students.

EPs will have an additional role in advocating for the students they work with, drawing attention to the need to identify barriers to participation and inclusion and the benefits of working to change the environment. Viewing difficulties as a manifestation of an individual's inherent condition can lead to teachers feeling powerless to effect change through teaching, regarding a young person as unteachable because of their 'label' (Hodge, 2016). In helping teaching staff understand needs from an environmental fit perspective, rather than an individual deficit perspective, EPs have the potential to empower teachers and build their capacity to effect change through quality first teaching and appropriate intervention.

### **5.9.2 Promotion of Self-awareness and Self-advocacy**

A key finding of this study was the use of self-awareness and personal insight by some participants in making sense of their experiences and managing their ability to cope at school. Combined with the benefits participants found from being able to communicate their needs, this raises the possibility that schools should be aware of this phenomenon and be open to including the promotion or facilitation of self-awareness and self-advocacy when

offering support to these students. EPs should also be open these possibilities when working directly with students, either during assessment, by giving credence to pupil voice, or when offering intervention work.

### **5.9.3 Pupil Voice and Pupil Participation**

The SEND Code of Practice (DfE, 2014) specifies that young people and their families should be placed at the heart of decision making about their needs and provision. This research has shown the value and credibility of information gained by directly asking this target community, and subsequently indicates that schools have much to gain by seeking pupil participation in devising many aspects of schooling, from intervention plans to whole school policies. EPs will again have an advocacy role in promoting the value and credibility of pupil participation and are also well placed to provide signposting and training for ways to achieve true participation by these students.

### **5.10 Future Research**

Many different avenues for future research arise from consideration of the findings and limitations of this project. Some concern specific topics for investigation and others concern more holistic ideas around the approaches taken in researching this subject area.

The main limitation of this study was the small and relatively homogenous group of participants included in the data collection. Given that the exploration of how these students can be supported in school is a new branch of this area of research, it will be beneficial to conduct further studies with more diverse groups, for example those with different cultural, geographical and socio-economic backgrounds. It will also be essential to devise ways to include harder to reach participants for example those who are struggling in school to the point where they find it hard to engage with or access mainstream learning.

A question that arose from the literature review concerned the perception adolescent girls with ASC have of friendships and how this may differ from the perceptions of their neurotypical peers. However, the participant-led data collected did not provide sufficient information to explore this in detail, although one participant did refer to the reciprocal nature of her friendships and providing support for others. This therefore remains an area that could benefit from further investigation as a deeper understanding of what these students gain and expect from friendships has potential to inform support and lift barriers to inclusion in the future. For example, in the current study some aspects of the school timetable were beneficial to establishing and maintaining friendships and participants valued being able to work with friends.

The use of personal insight and consideration of thought processes or mental states is another area that warrants further exploration. For the current research focus, this can be linked to elucidating ways to promote autonomy and self-advocacy within the mainstream schooling system. Additionally, direct consideration with autistic individuals of how they think about themselves and others is likely to add to the knowledge and debate around ToM and its role in the social and communication difficulties experienced by autistic people. Pellicano (2020) discussed the usefulness of including autistic individuals in work examining the fundamental building blocks of autism, involving them in interpretive debate and asking for a comparison of their lived experiences and the experiences predicted by lab-based experiments, extending the concept of peer-review.

This research has shown the usefulness and validity of taking a participatory approach with adolescent girls with ASC, highlighting what is most useful for them, and this is something that should be considered in future research projects. Pellicano (2020) also called for more participatory research with the autistic community, proposing that this was a way to produce more effective basic autism science that can be applied to produce tangible benefits



for their community. There is known to be a disparity between UK patterns of funding in autism research and the priorities of autistic individuals and their families, with the majority of funding focusing on the underlying causes and biology of autism rather than more practical areas such as interventions, support and services (Pellicano et al., 2014). Future research should therefore be directed at involving the autistic community in elucidating what will be useful in facilitating positive lived experiences.

## **5.11 Conclusion**

This research fulfilled a primary aim of using a participatory approach to discover what adolescent girls with ASC say helps them successfully navigate the social aspects of mainstream schooling and provide ideas that can be used to inform future support for these students. The ideas shared by participants indicated their motivation for autonomy, competence and relatedness and reflected a desire to be understood and have a good fit with their environment. The parallels with existing literature and psychological theory gave credence to these findings and it is hoped that they will provide a guiding framework which will help schools to deepen their understanding of the needs of adolescent girls with ASC and facilitate their exploration of tailor-made support with individual students. This information should also provide an impetus to explore ways to support other adolescent girls with ASC from different demographic backgrounds who potentially have different needs.

A secondary aim of adding to a new and emerging research area was also fulfilled with findings replicating and developing existing ideas around the motivation for friendship and school experiences of adolescent girls with ASC. The findings also deepened understanding through the participants' discussion of their use of personal insight and their independent consideration of their own and others' mental states when trying to understand their experiences. This suggests that it may be useful to engage in more interpretative

dialogue with these students in the future, giving credence to their expertise in their lived experiences.

Evaluation of the research process, including feedback from the participants, also allowed elucidation of the suitability of using a participatory approach with these students. The study showed that participants valued their roles as co-researchers, gaining personal benefit from taking part and reflecting on their experiences, and indicating feelings of empowerment in their feedback. Combined with the credibility of the findings generated by this method, this shows that participatory research with these students is feasible and successful and it will be beneficial to promote community participation in future research and school practice. As Molly concluded, participating in this research: *'...let me look at things that I've mostly not told other people and yeah, I've just kind of explained it.'*

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**Appendix A**  
**Literature Review Papers**

<b>Authors, date and title</b>	<b>Publication</b>	<b>Focus of the study</b>	<b>Methodology and analysis</b>	<b>Main Findings</b>	<b>Assessed Quality</b>
Cook, A., Ogden, J., & Winstone, N. (2018). Friendship motivations, challenges and the role of masking for girls with autism in contrasting school settings.	European Journal of Special Needs Education	An exploration of the experiences of learning, friendship and bullying for girls with autism in different school settings.	Qualitative design. Semi-structured interviews with eleven parent-girl dyads from mainstream and specialist provisions. Data were analysed using inductive thematic analysis.	<ol style="list-style-type: none"> <li>1. Participants were motivated to have friends but experienced difficulties in achieving them, due to a lack of social skills or struggling to fit in.</li> <li>2. Participants reported concerns over social isolation.</li> <li>3. Participants used strategies to fit in, including coping peers and hiding autistic traits and this was more common in mainstream settings.</li> <li>4. Masking hid difficulties to such an extent that it negatively impacted on the provision of support.</li> </ol>	<p>Level A: A limitation is that interpretation of the data lacked depth and reported brief description of occurrences rather than explanations of meaning for the participants.</p> <p>Level B: The semi-structured interview design was appropriate for answering the review question.</p> <p>Level C: The topic and context were relevant to the research aim.</p>
Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2014) Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum	Journal of autism and developmental disorders	An investigation of the experience of adolescent girls with ASD.	Qualitative design. Semi-structured interviews with two mothers of girls with ASD and three dyads of girls with ASD and their mothers. Data were analysed using IPA.	<ol style="list-style-type: none"> <li>1. Participants found friendships difficult due to increased complexity at this age and a lack of social skills.</li> <li>2. Experiences of school were both positive (access to a broader range of subjects and a structured environment) and negative (more challenging work, managing the school environment and making friends.)</li> <li>3. Teachers have a limited knowledge of ASD symptomology in girls.</li> </ol>	<p>Level A: This study lacked the homogeneity of participants required by IPA analysis.</p> <p>Level B: The use of IPA and a predominance of the maternal voice reduced the appropriateness of the design to answer the review question.</p> <p>Level C: The topic fitted closely with the research aim, but the context of Australia limited its</p>

<b>Authors, date and title</b>	<b>Publication</b>	<b>Focus of the study</b>	<b>Methodology and analysis</b>	<b>Main Findings</b>	<b>Assessed Quality</b>
disorders during adolescence.					applicability to girls in the UK education system.
Foggo, R. S. V., & Webster, A. A. (2017) Understanding the social experiences of adolescent females on the autism spectrum.	Research in Autism Spectrum Disorders	An investigation of how adolescent girls on the autistic spectrum make sense of social experiences.	Qualitative design. Semi-structured interview schedules used for a phenomenological approach to gather the views of seven adolescent girls. Data were analysed using inductive thematic analysis.	<ol style="list-style-type: none"> <li>1. Participants were motivated to have friends and saw friendships as a positive part of their lives.</li> <li>2. Participants listed the qualities they valued in friendships, including trust, understanding and the ability to be themselves without judgement.</li> <li>3. Participants also indicated that they found friendships difficult, especially when managing conflict.</li> </ol>	<p>Level A: A limitation of the design was that most answers were submitted in written form, removing the opportunities for further questioning normally afforded by a semi-structured approach.</p> <p>Level B: The phenomenological approach, prioritising participant voice, was appropriate for answering the review question but the actual delivery of the approach created limitations as outlined above.</p> <p>Level C: The topic of social interactions was relevant to the research aim and countered the decrease in relevance arising from a geographical location of Australia.</p>
Goodall, C., & MacKenzie, A. (2019) What about my voice? Autistic young girls' experiences of	European Journal of Special Needs Education	An exploration of the experience of mainstream schooling for girls with autism, with a focus on feelings of inclusion.	Qualitative design. Multiple methods of data collection, including semi-structured interviews, drawing activities and scaffolded discussions with two	<ol style="list-style-type: none"> <li>1. Participants reported negative experiences at school due to crowds and noise, and feelings of being different and judged.</li> <li>2. Participants found friendships difficult and reported concerns about bullying and feelings of isolation.</li> </ol>	<p>Level A: This study used an appropriate interpretative analytic method for the focus and participant group.</p> <p>Level B: The multi-method design, prioritising authentic participant voice, was appropriate for answering the review question but</p>

<b>Authors, date and title</b>	<b>Publication</b>	<b>Focus of the study</b>	<b>Methodology and analysis</b>	<b>Main Findings</b>	<b>Assessed Quality</b>
mainstream school.			adolescent autistic girls. Data were analysed using inductive thematic analysis.	3. Participants adopted compensatory and protective behaviours to camouflage their anxiety and isolation. 4. Teachers could make a positive difference by understanding individual needs and adapting practices and attitudes to authentically include them.	the small number of participants placed limitations on generalisability. Level C: The topic was highly relevant to the research aim but the context of interviewing girls who had left school due to negative experiences limited generalisability as they were a very specific subpopulation. The geographical location of Ireland also reduced the relevance of the context for the research aim.
Jarman, B., & Rayner, C. (2015) Asperger's and girls: What teachers need to know.	Australasian Journal of Special Education	An exploration of the school experience of females with AS in a mainstream setting.	Qualitative design. Anonymous online survey completed by participants recruited via ASD and AS related websites (parents of girls with AS and adult females with AS). The data were analysed using an inductive reasoning approach.	1. Teachers could influence school experiences positively (by being flexible, accepting and addressing individual needs) and negatively (through lack of understanding about needs and not taking these into account). 2. A tendency for girls with AS to mask their symptoms and attempt to fit in exacerbated their needs going unnoticed and not being met. 3. The school environment presented challenges through being overwhelming, an increased requirement to self-organise and increased complexity of verbal instructions and work expectations.	Level A: A significant limitation was that participants were anonymous, and it was not possible to verify eligibility to participate. Level B: The parental voice predominated, reducing the appropriateness of the design to answer the review question but this was countered to some extent by consideration of situations from their daughter's perspectives. Level C: The relevance of the topic to the research aim was limited through consideration of all schooling and a lack of direct reference to social interactions and

<b>Authors, date and title</b>	<b>Publication</b>	<b>Focus of the study</b>	<b>Methodology and analysis</b>	<b>Main Findings</b>	<b>Assessed Quality</b>
Myles, O., Boyle, C., & Richards, A. (2019) The social experiences and sense of belonging in adolescent females with autism in mainstream school.	Educational & Child Psychology	An investigation of the lived social experiences of adolescent females with autism in mainstream schools.	Qualitative design. Semi-structured interviews with eight adolescent girls. Data were analysed using thematic analysis.	<ol style="list-style-type: none"> <li>1. Participants valued friendships and viewed them as a means of support for dealing with the challenges of mainstream schooling, especially through fostering a sense of being valued and belonging.</li> <li>2. Participants reported consciously acting in socially acceptable ways to fit in, for example copying the behaviour of others.</li> <li>3. Participants also reported difficulties with social skills and uncertainty over how to behave, which could lead to anxiety, being unable to join in or even avoiding social situations.</li> </ol>	<p>the context of Australia limited its applicability to girls in the UK education system.</p> <p>Level A: This study used an appropriate interpretative analytic method for the focus and participant group.</p> <p>Level B: The semi-structured interview design, prioritising participant voice, was appropriate for answering the review question.</p> <p>Level C: The topic and context were highly relevant to the research aim.</p>
Rainsberry, T. (2017) An exploration of the positive and negative experiences of teenage girls with autism attending mainstream	Good Autism Practice	An investigation of the school experience of females with autism in a mainstream setting.	Qualitative design. Case studies with three adolescent girls, producing written and illustrated diaries. No explicit analytical method specified, commonalities were identified and discussed.	<ol style="list-style-type: none"> <li>1. Participants were motivated to have friendships but experienced some difficulties with peer interactions.</li> <li>2. Teachers could influence school experiences positively (by being understanding and adjusting for individual needs) and negatively (through misinterpreting needs as bad behaviour).</li> <li>3. Aspects of the school environment could be sensorily overwhelming.</li> </ol>	<p>Level A: A significant limitation was the lack of interpretative analysis of data.</p> <p>Level B: The case study design, prioritising participant voice, was appropriate for answering the review question.</p> <p>Level C: The topic and context were highly relevant to the research aim.</p>



<b>Authors, date and title</b>	<b>Publication</b>	<b>Focus of the study</b>	<b>Methodology and analysis</b>	<b>Main Findings</b>	<b>Assessed Quality</b>
secondary school.					
Ryan, C., Coughlan, M., Maher, J., Vicario, P., & Garvey, A. (2020) Perceptions of friendship among girls with Autism Spectrum Disorders.	European Journal of Special Needs Education	An investigation of how girls with ASD conceptualise friendships through exploring shared experiences and friendship management.	Qualitative design. Two focus groups with ten adolescent girls using a semi-structured moderator's guide. Data were analysed using inductive thematic analysis.	1. Friendships were supported through shared interests and opportunities to meet up, particularly in school. 2. Participants valued trustworthiness, loyalty and reciprocity in friends. 3. Participants also reported experiencing conflict but viewed it as a normal part of friendship.	Level A: The data collection and analysis followed expectations but faced limitations in their appropriateness (see below). Level B: As acknowledged by the authors, the use of focus groups potentially limited this study as some participants may have found them challenging experiences, inhibiting their ability to share ideas. Level C: The topic was relevant for the research aim but the context of a geographical location of Ireland potentially reduced relevance for girls in the UK education system.
Sedgewick, F., Hill, V., & Pellicano, E. (2019) 'It's different for girls': Gender differences in the friendships and conflict of autistic and	Autism	An investigation of the nature of autistic adolescents' friendships in comparison to those of neurotypical peers.	Mixed methods design. 102 participants (27 autistic females, 26 autistic males, 26 neurotypical females and 23 neurotypical males) engaged in semi-structured interviews and	1. Gender was a more significant influence on friendship experiences than diagnosis. 2. Autistic girls reported having fewer, more intense friends, compared to neurotypical peers and reported difficulties with managing conflict. 3. There was evidence that autistic females were aware of the need to behave in an acceptable way to fit in.	Level A: Data collection and analysis for both methods were appropriate and agreement between the qualitative and quantitative results strengthened the findings. Level B: The use of relevant questionnaires and semi-structured interviews were appropriate to answer the review question and the high number of participants increased generalisability.

<b>Authors, date and title</b>	<b>Publication</b>	<b>Focus of the study</b>	<b>Methodology and analysis</b>	<b>Main Findings</b>	<b>Assessed Quality</b>
neurotypical adolescents.			completed questionnaires. Quantitative data were analysed using between-group ANOVAs and qualitative data were analysed using inductive thematic analysis.		Level C: The topic and context were highly relevant to the research aim.
Sproston, K., Sedgewick, F., & Crane, L. (2017) Autistic girls and school exclusion: Perspectives of students and their parents.	Autism & Developmental Language Impairments	An investigation of the experiences of school for autistic girls who have been excluded from mainstream schools.	Qualitative design. Semi-structured interviews with eight parent-child dyads. Data were analysed using inductive thematic analysis.	1. Participants reported negative school experiences including a lack of teacher understanding of needs and coping mechanisms, noise and large class sizes causing the school environment to be overwhelming, and fear of judgement which led to not asking for help. 2. Participants also reported positive school experiences, including accommodation of individual needs, smaller group sizes and a sense of being valued and having positive relationships with peers and staff.	Level A: This study used an appropriate interpretative analytic method for the focus and participant group. Level B: The semi-structured interviews and even balance of parent and participant views were appropriate for answering the review question. Level C: The topic was highly relevant to the research aim, but the context of interviewing girls who had been excluded limited generalisability as they were a very specific subpopulation who were likely to have had significantly negative school experiences.

<b>Authors, date and title</b>	<b>Publication</b>	<b>Focus of the study</b>	<b>Methodology and analysis</b>	<b>Main Findings</b>	<b>Assessed Quality</b>
Tierney, S., Burns, J., & Kilbey, E. (2016) Looking behind the mask: Social coping strategies of girls on the autistic spectrum.	Research in Autism Spectrum Disorders	An exploration of the use of social management strategies to hide socio-communication difficulties.	Qualitative design. Semi-structured interviews with ten adolescent girls with ASC. Data were analysed using IPA.	<ol style="list-style-type: none"> <li>1. Participants were motivated to form friendships but found them challenging due to uncertainty over social expectations and unintentional rule-breaking.</li> <li>2. Participants described social contact as exhausting and requiring considerable effort.</li> <li>3. Participants developed strategies to overcome the challenges of social interactions, including developing their own social codes and imitating peers in order to fit in and also pretending to be happy.</li> <li>4. Masking strategies were associated with anxiety and depression and misconceptions that they were coping and so not receiving support.</li> </ol>	<p>Level A: This study lacked the homogeneity of participants required by IPA analysis.</p> <p>Level B: The semi-structured interviews and prioritisation of participant views were appropriate for answering the review question.</p> <p>Level C: The topic and context were highly relevant to the research aim.</p>

## Appendix B

### Recruitment Information for Participants and Parents



#### Participant Information Letter

Exploring what adolescent girls with ASC say helps them successfully navigate the social aspects of mainstream schooling.

You are invited to take part in a research study exploring the experiences of girls with ASC in mainstream secondary schools. Please could you take some time to read the information below before considering whether or not you would like to take part.

#### Who am I?

My name is Helena Pickup and I am a trainee educational psychologist in X local authority, studying at the University of East London. I am doing some research as part of my studies for a Doctorate in Educational and Child Psychology.

#### What is my research about?

I am exploring what support girls with ASC find beneficial in helping them navigate the social side of school. To do this, I am taking a positive approach and looking at what is already working. I am also running my project using a participatory model and asking anyone who takes part to help in choosing which information to collect.

This project has been approved by the School of Psychology Research Ethics Committee and therefore follows the research standards set by the British Psychological Society.

#### What will you be asked to do?

If you decide to take part in this project, you will be asked to be involved in a series of activities that will enable us to collect recounts of your experiences of the social side of school over a two-week period. All discussions will take place in school via Microsoft Teams.

Firstly, we will discuss which aspects of school you think it is important to include in the research and we will make a list of these focus areas. We will also discuss different ways for you to record your recounts and you will choose a method that you feel comfortable will and manageable.

Then we will choose a two-week period in X for data collection. At the end of that period I will collect your recounts or record an interview with you of approximately 30 minutes if that is your chosen method.

To help you describe your experiences, I will talk you through a reflection model called Gibbs' reflective cycle which asks you to think about an event in the following way: 1) describe what happened, 2) think about how you felt, 3) evaluate the good and bad points, 4) analyse if there is anything else you can make of the situation. I will send you information about this to take away.

I will analyse your recounts and then ask you to confirm that I have made an accurate assessment of what you were trying to say. If you don't agree, I will make changes according to your instructions.

Once the results are written up, you will have the opportunity to help decide how they can be used to improve the support you receive at school. At the end of the project I will ask you to do a final reflection on your experience of taking part in the project and collaborating in the research.

I will not be able to pay you for participating in my research, but your participation would be very valuable in helping to develop knowledge and understanding of my research topic.

#### Confidentiality and safety.

All of your data will be held securely and kept confidential by using a pseudonym of your choice to identify it. All electronic data will be stored on my secure UEL Onedrive.

Your privacy and safety will be respected at all times and I will not tell anyone else what you have shared in your recounts. You will not have to answer any questions or recount any experiences that you do not want to. You are also free to withdraw from the project at any time.

This project has a positive focus and I will only be asking you to tell me about what is going well at school. However, if thinking about any of the events makes you feel worried or unhappy, Ms X has agreed to be someone you can find to talk to. I hope that taking part in the research will be a positive experience and you will be able to benefit by helping me report back the results to your school and helping to improve the support you receive.

#### What will happen to the information you give me?

I will analyse your recounts along with the recounts of other participants and look for similar ideas about what helps you all succeed in the social aspects of school. If you wish to, we will collaborate in deciding what you would like to feedback to your school to help develop the support they offer.

I will also use the information to write a thesis for my qualification as an educational psychologist. This will not contain any personal details that can link the work to you, your school, or this local authority.

I will also prepare a general article to go out to schools across XLA to inform them of our findings but again, this will not contain any personal details that can link the work to you or your school.

Finally, as this is a new and emerging area of research, I will investigate having the project published in a psychology journal but this will not contain any personal details that can link the work to you, your school, or this local authority.

What if you change your mind?

You are free to leave the project at any point, even after your data has been collected. You do not need to give a reason or explanation. If you do not wish for anything you have told me to be included, I will be able to remove your data from the analysis up until the end of X, when I will need to write my thesis.

Contact details:

If you have any questions or want to know more, please contact me or ask X at school to get in touch. I am very happy to come in and talk to you at school.

Helena Pickup

If you have any questions or concerns about how the research will be conducted please contact the research supervisor Miles Thomas. School of Psychology, University of East London, Water Lane, London E15 4LZ, (Email: [m.thomas@uel.ac.uk](mailto:m.thomas@uel.ac.uk))

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas, School of Psychology, University of East London, Water Lane, London E15 4LZ.  
(Email: [t.lomas@uel.ac.uk](mailto:t.lomas@uel.ac.uk))



### Consent to participate

An exploration of what adolescent girls with ASC say helps them successfully navigate the social aspects of mainstream schooling.

I have read the information sheet about the above research project and have retained a copy for future reference. I am confident that the research project has been explained to me and any questions have been answered fully. I understand my role in the project and the various activities I will be asked to do.

I understand that my privacy will be prioritised and only the researcher will know what I have personally said. I understand that I will be involved in any decisions about how to feedback any information to my school. I understand how the information will be used after the project has been completed.

I freely and fully consent to take part in this research project.

I understand that I have the right to withdraw with no explanation at any time and that I have the right to withdraw my data at any point up until X.

Name

Signature

Researcher name

Researcher signature

Date



### Parent Consent Form

Exploring what adolescent girls with ASC say helps them successfully navigate the social aspects of mainstream schooling.

Your daughter's school is currently taking part in a research project run by trainee educational psychologist, Helena Pickup. The project aims to explore what support girls with ASC find beneficial in helping them navigate the social aspects of schooling. The possibility that girls with ASC have some different needs to those traditionally associated with ASC is a new area of research and it is hoped that this project will be able to contribute to knowledge that can be used to improve the support offered to girls with ASC. The project will take a positive approach, asking the participants to report what is already working well. It will also use a participatory framework and ask participants to be involved in key decisions about the data collected.

Your daughter has been invited to take part and has been given a detailed information sheet about the project. If they agree to participate, they will be asked to choose the areas of school life that they feel are important to the research project. They will also decide how to collect information about their experiences and to choose a method that they feel comfortable with and that they consider to be manageable. This might take the form of a reflective diary (written or verbally recorded) or a semi-structured interview with the researcher which will be recorded and transcribed. All participants will be asked to recount their experiences from a two-week period in X. Due to the Covid-19 restrictions, the researcher will not be able to visit your daughter in school and all meetings will take place via the school Microsoft Teams account. This will be organised and supervised by a member of staff.

Once the recounts have been analysed, the girls will be asked to verify the researcher's interpretations. At the end of the project they will be given the option to collaborate in feeding back the results to their school.

Your daughter will be asked to give written consent to participate but will be made aware that she is free to leave at any point during the project. She will also be able to withdraw her data at any point up until X. All data will be stored securely and anonymously with no personal details that can be used to identify your daughter or their school. The data will be used to feedback to your daughter's school, if she wishes, and to write a thesis that is necessary for my qualification as an educational psychologist. I will also use it to write a general article to share with schools across the local authority and will investigate having the findings published in a psychology journal. However, none of these documents will contain any information that will link the work to your daughter or their school.



If you have any questions or would like further information please contact me, I am very happy to talk to you on the telephone or via Teams:

Email:

If you have any questions or concerns about how the research will be conducted please contact the research supervisor Miles Thomas. School of Psychology, University of East London, Water Lane, London E15 4LZ, (Email: [m.thomas@uel.ac.uk](mailto:m.thomas@uel.ac.uk))

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas, School of Psychology, University of East London, Water Lane, London E15 4LZ.  
(Email: [t.lomas@uel.ac.uk](mailto:t.lomas@uel.ac.uk))

I give permission for my daughter to take part in this research project

I do not give permission for my daughter to take part in this research project

Signed

Date

## Appendix C

### Script for Initial Meeting

Hello,

Thank you so much for helping me out with my research. I hope that you will enjoy taking part and that we get to learn some useful ways to help provide support in schools. This project is about looking at what is already working well for you and also about you telling me what's really important for you in school. General 'getting to know you' and invitation to ask questions and discuss research.

We have a few things to do today:

- Choose your pseudonym so that I can anonymise your data and maintain confidentiality
- Choose the social aspects of school that you would like to think about. These should be the areas that you think it will be useful for someone offering you support to know about. They could be areas that you sometimes find difficult but also which you can think of some good examples for too. (If examples are needed: tutor time, break time, talking to friends, partner work, teachers helping in class, specific lessons). Make sure 'other' is on the list and explain the importance of being able to talk about anything that they think is important.
- Decide how you are going to collect your ideas. we will agree a two week experiment period and there are different ways that you can collect your ideas during this time. You can keep a dairy, you can make recordings, we can have another meeting where we can talk about your ideas (this will be recorded) or you can suggest your own idea.
- Practise using a reflection model called Gibbs' reflective cycle which asks you to think about an event in the following way:
  - 1) describe what happened,
  - 2) think about how you felt,
  - 3) evaluate the good and bad points,
  - 4) analyse if there is anything else you can make of the situation.

You have a picture of it on the pack I sent to school. We will talk about it together and have a practise so that you can ask questions and feel confident about how to use it. We will mostly just use steps 1 – 4 but if you want to think about 5 and 6, that's ok.

Work through list.

Practising Gibbs' reflective cycle:

Here is my example to help you understand how it works:

1. Description – at break, I sometimes walk into the room and everyone is talking in groups. If I don't know who to talk to, I might pretend to look in my bag for something so that people won't notice I'm not talking to anyone. When my friend looks over and smiles at me, then I feel able to join her group.
2. Feelings – at first, I feel a bit of panic because I'm on my own and everyone else is talking, I might be thinking that everyone would think I was shy and boring. Then I feel a bit better because I did something that stopped me standing out and it helped me to calm down and feel less stressed. I feel happy and relieved when my friend smiles at me as I think that might mean she was pleased to see me and would be happy for me to join her.
3. It was good that I found something to do and that my friend noticed me and smiled. It felt bad to have a panic and to not know what to say.
4. I know that some people are better at talking than others and that everyone is different. I like to be with people but don't always want to say anything. I think my friend understands this and it's good when people accept you for who you are.

Do you want to practise using one of your examples?

How would you like to collect your ideas?

When would you like to collect them?

Do you have any questions?

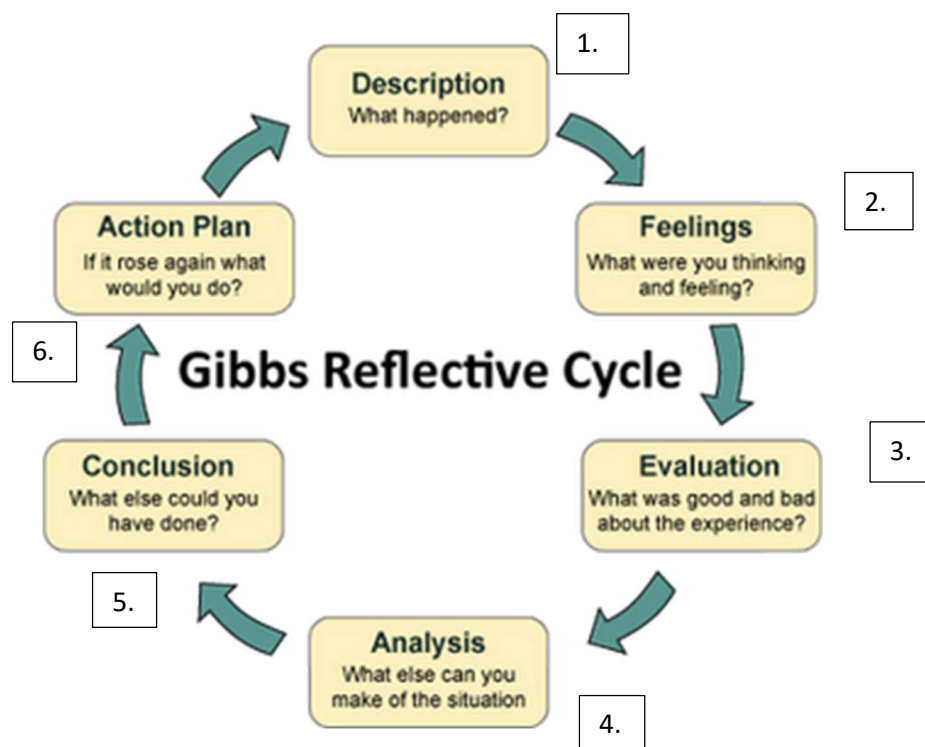
Thank you, I'll set up a meeting with Ms X and see you again on X

## Appendix D

### Information Pack for Participants

Hello, thank you so much for helping me out with my research. I hope that you will enjoy taking part and that we get to learn some useful ways to help provide support in schools.

This is a diagram which I hope will help you think about your experiences in school. We will talk about it together and have a practise so that you can ask questions and feel confident about how to use it. We will mostly just use steps 1 – 4 but if you want to think about 5 and 6, that's ok.



#### Example

1. Description – at break, I walked into the room and everyone was talking in groups. I didn't know who to talk to and pretended to look in my bag for something so that people wouldn't notice I wasn't talking to anyone. Then my friend looked over and smiled at me and I felt able to join her group. I wasn't sure what to say so I listened carefully to find out what they were talking about and get some ideas.
2. Feelings – at first, I felt a bit of panic because I was on my own and everyone else was talking, I was thinking that everyone would think I was shy and boring. Then I felt a bit better because I did something that stopped me standing out and it helped me to calm down and feel less stressed. I felt happy and relieved when my friend smiled at me and I thought that meant she was pleased to see me and would be happy for me to join her.

3. It was good that I found something to do and that my friend noticed me and smiled. It felt bad to have a panic and to not know what to say.
4. I know that some people are better at talking than others and that everyone is different. I like to be with people but don't always want to say anything. I think my friend understands this and it's good when people accept you for who you are.

I am going to think about the following things that happen in school:

## Appendix E

### Participant Debrief Letter

Thank you for participating in my research study on what girls with ASC say helps them succeed in the social aspects of school. This letter offers information that may be relevant now that you have taken part.

What will happen to the information that you have provided?

The following steps will be taken to ensure the confidentiality and integrity of the data you have provided. Your data does not contain any personal details that can link it to you or your school. Your data will be identified using your chosen pseudonym and will only be viewed by the researcher or her tutor who will be unable to link it back to you or your school. All data will be stored securely in the researcher's home and all electronic data will be stored on the UEL OneDrive. Once the study has been completed, data will be kept securely for the time period necessary to investigate having the findings published. Once the data is no longer required for publication it will be destroyed. You are free to withdraw from the project at any time and may withdraw your data up until X.

What if you have been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been upset by anything that has come up in the course of this project please be aware that support is available from school staff. Ms X is involved in this project and is available to listen and give support if needed. If you would like external support, this is available from Childline.

For Childline call 0800 1111 or get in touch online at [www.childline.org](http://www.childline.org).

You are also very welcome to contact me or my supervisor if you have specific questions or concerns.

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Helena Pickup,

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Miles Thomas. School of Psychology, University of East London, Water Lane, London E15 4LZ, (Email: [m.thomas@uel.ac.uk](mailto:m.thomas@uel.ac.uk))

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas, School of Psychology, University of East London, Water Lane, London E15 4LZ.  
(Email: [t.lomas@uel.ac.uk](mailto:t.lomas@uel.ac.uk))

## Appendix F

### Follow-up Invitation and Summary

Hello,

Thanks again for taking part in this research, I've really enjoyed working with you all. I've had a look at everyone's great ideas and made the list below. I would now like to ask you to do a few short tasks to finish off the project, they can all be completed by typing your answers on this document and then sending it back to me or we can arrange another meeting on Teams:

- Please could you read through the list and tell me if there's anything that you disagree with and what you think it should be changed to. (Please type any changes next to the bit that you disagree with.)
- Please could you also tell me how you felt about being part of the research project and thinking about your experiences at school? (Please type your answers next to the following questions):
  - How did you feel when you were thinking about school?
  - What was good and bad about thinking about school?
  - Was it useful?
  - Has it made you do anything differently?
- Finally, do you have any ideas about sharing your ideas with your school? Please type them here:

Your list of ideas:

Friendships:

- Friends are really important to all of you and you have a social group that you feel part of.
- Secondary school has changed your friendship opportunities as there are more people to be friends with.
- You enjoy talking to friends, having fun and sharing experiences.
- It's beneficial to work with friends in lessons as they understand you and can offer you support.
- Some of you talked about friends offering other types of support such as helping you find your way around school or deciding what to do when you're hanging out.
- Your friendships can be supported through chances to talk during the school day, using social media, tutors setting activities that promote friendly gestures and your own individual ideas.

What you value about school:

- Most of you talked about liking engaging lessons and having fun activities to do. Some of you named favourite lessons.
- All of you talked about valuing opportunities to be creative in lessons.
- You valued the chance to relax during the school day, either during break time or tutor time.
- Some of you talked about the benefits of school staff using visual examples or showing you how to do things, rather than just telling you in words. You said this helped you to



understand more easily or helped with the fact that you can forget long instructions, especially when you are stressed.

- You all seem to value having a place or person to go to where you know you will get help. This tends to be non-academic help such as help with finding lost things or people checking how you are feeling. It can help to know there is a connection with home.
- Most of you also appeared to value being able to tell teachers and other school staff about your worries and appreciated it when they helped you or made changes in lessons.
- Some of you valued a chance to have a time to transition between home and school and adjust to being in a different place. This could be in the morning, getting settled into school or at the end of the day when you're getting ready to go home.
- Some of you find doing schoolwork difficult at home and value having a homework club that means you can work at school instead of home.

What helps you to understand what you need to do:

- Some of you talked about it being important to you to be sure about you're doing, especially in lessons, and this helps you to work independently.
- You appreciated teachers checking what you already know and explaining things really clearly, with examples. You also value teachers who are confident and know lots about their subject.
- Sometimes teachers can make it hard to understand in lessons by going too quickly, assuming you already know about a subject or not being very confident about the subject or school routine. This is especially a problem with supply teachers.
- Some of you talked about how helpful it was to already know a bit about a subject as this decreases the stress and increases the chance of you understanding. It can also help to have prior knowledge about new things such as supply teachers (from friends) or new schools (through open evenings).

What teachers might not know, but it would be helpful if they did:

- Noisy and busy environments can make it hard for you to concentrate and stay focused on what you are doing.
- Some of you talked about it being hard to remember your way around school, especially when you first started.
- Sometimes you might be distracted by other things you have on your mind, such as uncomfortable clothes, being tired, thinking about what you have to do next or worrying about not having had an answer to a question. You might be worried if you haven't got everything right in a test.
- Some of you have coping strategies that aren't easy to use in school, such as fidget toys or talking to friends to distract yourself from being stressed.
- Some of you don't always ask for help, even when it is offered. However, it's reassuring that people do ask so you don't want them to stop asking in the future.
- Sometimes you can feel unsure about why other people are acting the way they are, or you may misinterpret what they do, and this leads to stress.

The things you do yourself:

- Some of you talked about the strategies you have developed yourselves to help out during the school day. These help you to do things like talk to teachers in lessons, manage your stress and worries or make friends.
- Some of you seem to value thinking about what you do and the experiences you have. You use these thoughts to help you understand what is going on or how you learn, and this helps you feel more confident about school.

Thanks again and please let me know if you have any questions.

Very best wishes,

Helena

## Appendix G

### Examples from an Interview Transcript and a Diary Transcript

Transcript for Molly, 16.12.2020, via Teams

H: can you remember what we're going to do today?

M: umm, I may have forgotten (smiling)

H: (smiling), that's ok, do you remember about two weeks ago we made a list about the things you thought were important to talk about at school?

M: (nods)

H: ok, and do you have the list?

M: yes, that's what's on this (shows paper), that's slowly dying in my bag

H: (laughs) brilliant. And do you remember that we talked through that cycle of how to think about things?

M: that's on the other side.

H: ok, so what I thought it would be useful to do, what we could do is work through all of the things on your list and you can tell me about them and think about what went well in them and what really helped you and if there's anything else that you think about that you want to talk about, for example you were telling me about your maths lesson and the teacher that really helped, anything like that, that's ok to talk about too.

M: ok

H: ok, is that ok?

M: yep

H: I'm going to mostly let you talk so it's lots of your ideas, but I might ask you some extra questions, is that ok?

M: ok,

H: ok, or you ask me questions if you have any (nods)

M: ok

H: ok, off you go

M: well (looks at list), shall I start with the ones I came up with at home?

H: yes, that would be good

M: ok, so the first one I did was like, how I find classes, so... mostly like, I find most of my classes alright. The ones I especially do quite well in is English and history I think...

H: ok

M: I do alright in Maths and the other subjects I do alright in I especially find that I do best in my English with my teacher, Mr X, h, I find I work better in that class. I normally get down like loads of paragraphs. Like I remember one time, we were doing this special study with everybody about Charles Dickens, and I hadn't been in the following day but when I came in the next day, I managed to get down five paragraphs which I found quite good.

H: wow! And do you know what helped you to do that.

M: umm, I don't really know. I did like have a sheet there helping me to know what to write down and what not. But I just find that I work like better in that class with him, because he is a supportive teacher as well

H: so what makes him supportive?

M: well, he really does explain things, he gives like ideas to help us and what not and he lets us share our work if we feel comfortable... and yeah...

H: ok, so if you didn't feel comfortable, what could you, how would you let him know

M: I would go up to him and like tell him, and say like I'm not feeling comfortable like, that I'm like struggling with him, with it, and he would come and help us

H: ok, umm, would you say that to him at the beginning of the lesson or during the lesson?

M: yeah, I'd tell him at the beginning.

H: yep, can you think of a lesson that you've had recently with Mr X?

M: umm, if I was to check my timetable because that would help me remember. (checks timetable). Let's see... umm... I had it, I had him on Monday... and on Tuesday... yeah, Tuesday last lesson is the latest I've had him

H; ok, and did anything good happen in that last lesson?

M: umm... well I managed to get like a lot of work done and like, I was able to use, like lots of powerful description, an yeah...

H: great, can you remember anything that was helping you in that lesson?

M: umm. Well, I know we had, like a example on the board which I found quite pretty good and in the front of our books we had a sheet of all the things we needed to do, as well as examples. And I think that I would probably have struggled a lot more if we didn't have that.

H: great, and is there anything that Mr X did that helped, the way that he was talking to you, or explaining that helped?

M: he explained it quite clearly, so we knew what to do, and yeah....

H: Great, so, is there anything else you want to say about English?

M: not really that I can think of.

H: ok, did you have anything else on your list from home?

M: yes I do, so (looks at list), I put down support, which we kinda covered already, and supplies I put down because I've been finding it really hard with supplies, becau.. because the rest of the class get really loud and I'm just trying to get down and get my work down but it's harder to concentrate

because there's so much noise going around and you can't hear the supply and in our recent science lesson that we had yesterday, we had a supply who didn't really know anything about science, and didn't even know the answers to the question, and was having to use Google a lot. Which I found that, kind of it would have been better if we had had a supply who A, could control the class more and B, like understand the work more and actually know a bit about the subject and what not.

H: ok, so if we were to flip that, are you saying that if a teacher knows a lot about the subjects, does that help you?

M: yeah...

H: yeah... do you know why?

M: I think it's because they know what they're talking about if they know, like about what about the subject and they would know the answers to a question. But if it's someone who doesn't know then they'll need to go onto Google and look that up which takes more time and if it was a teacher who knew a bit or at least had some kind of like GCSEs in that subject they would at least be able to attempt to answer the question and give me an answer good enough.

H: ok, and so how do you feel when you don't get a good enough answer?

M: well, if I don't really put down and like, an answer that I kinda like... it's depends kinda like, on what... if it's like in English and I don't put down a most detailed explanation answer, then like I don't really feel like I've really done it good enough. Yeah, but normally I wouldn't like get the time to like try and redo it but if it's a question like in science or maths, where kind of, I know it's most likely not right or something like that but I've given it go then there's nothing I can really do cos I don't know it and at least in maths sometimes the teacher can help me like at least explain it better but still if they're not a qualified teacher I will most likely not understand it.

H: ok... so I'm trying to think how to summarise what you just said? So I'm wondering if it helps you... sometimes you feel that you haven't done a question as well as you could and it helps you to have someone to talk it through with? To help you to explain it more in your own words...

M: yeah...

H: but if a teacher doesn't really know the subject then they can't support you in that?

M: yeah

Phoebe, diary, kept between Friday 4<sup>th</sup> and Thursday 17<sup>th</sup> December 2020

Day 1: overall mood 😊

4<sup>th</sup> December Friday

Spanish: I'm in LS for this lesson so I will do some work probably homework I'm doing Hegarty maths 😊

Geography: I'm in LS this lesson I got a p1 bcc I answered a question but I keep dozing off and getting distracted and stressed

PE: didn't go but my pen burst on me and my iPad 😞 😊 but it's fine

Science: gone to this lesson

Had a good day

Day 2: overall mood 😊

Monday 7<sup>th</sup> December

All of year 8 had day off because someone had COVID-19 so I slept and watched TV

I had no difficulty bcc I was at home and I helped a car find its mummy

Had a good day

Day 3 overall mood 😊

Tuesday 8<sup>th</sup> December

Morning was meh because I had clothes issues bcc they didn't feel nice 😞

Maths: didn't go very tired but did do a bit of English and technology

English: really good I thought that I had a test but I didn't I drew a demorzel

Drama: didn't go I was in LS

Technology: good had a test but it was ok and it was fine

Science: test stayed 1 hour silent wasn't fun but it was ok bcc we got to make a poster about any thing we wanted

Had a good day

## Appendix H

### Example of Initial Coding of Transcripts

200 did take me 2 years to do fractions, that's how my brain works, it has to really get used to it. I hope it  
201 ~~doesn't take me another two years to understand algebra!~~ *missile*

202 H: ok, so lots of practise?

203 S: but another thing that teachers help me with is my teacher, Mr Z, in maths he likes comes into the  
204 lesson and he likes listens with me and he helps me *} teacher*

205 H: ok, so can you ask him questions when he's listening with you?

206 S: yeah

207 S: actually, cos whenever he thinks he can leave me and I'm doing really well, then 2 seconds later  
208 I'm like I don't understand and um...

209 H: ok, that's good

210 S: not that I don't understand it, I do actually understand it but then they're talking around it and I'm  
211 like yeah, lost it again...

212 H: so you think you've got it, and they move on and you're lost again?

213 S: [nods]

214 H: yeah? Ok so erm, is there anything else about teachers that you wanted to talk about?

215 S: erm, yeah, there's one more thing, my science teacher, I just had him this morning and he was  
216 dissecting a sheep's heart and he was very like you don't have to watch it if you don't want, you *recog  
needs*  
217 ~~have lots of options~~

218 H: ok, can you explain a bit more about that?

219 S: well, he says, um you could leave the call, you could just go on the slides and find all the  
220 information about, just the information without all the pictures and erm you can go on BBC Bitesize  
221 and watch this thing about donating organs, that's what we were learning about... organs

222 H: ok, good, so that's good to have the choice?

223 S: [nods]

224 H: yep, ok, so anything else about teachers?

225 S: like I said, they let me fidget and they don't get angry with me and I'm always having to move and *adapting  
to needs*  
226 ~~it looks like I'm in some circumstances like I'm not concentrating but I'm must be doing something~~  
227 ~~with my feet, or my hands but... sometimes I have to do this [demonstrates] and under the desk...~~  
228 ~~yeah, I just move a lot, even though sometimes I'm really interested in the lesson and I...~~

229 H:ok

230 S: I move a lot, and I know and I...

231 H: great, and do you know why you need to move a lot?

232 S: it's not like I'm feeling unsafe, it's like just like, I'm always, I always need something to do, even if  
233 it's the most interesting thing, I'm still like this [demonstrates] or... or be like.... Anything that's just, *} coping  
strategies*  
234 it's not just to... myself it's just to keep my body busy, my brain's busy and my body is just like, what  
235 about me? I have to keep up...

## Appendix I

### Initial Ethical Approval

#### School of Psychology Research Ethics Committee

### NOTICE OF ETHICS REVIEW DECISION

#### For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

**REVIEWER:** Sonya Dineva

**SUPERVISOR:** Miles Thomas

**STUDENT:** Helena Pickup

**Course:** Professional Doctorate in Educational and Child Psychology

**Title of proposed study:** An exploration of what adolescent girls with ASC say helps them successfully navigate the social aspects of mainstream schooling.

#### DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.
3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

#### DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY

*(Please indicate the decision according to one of the 3 options above)*

**APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES**

**Minor amendments required (for reviewer):**



- Question 9.4. - Please make sure that you provide your supervisor with a copy of the written permission from the schools involved once they agree to take part in your study.

**Major amendments required** (*for reviewer*):

**Confirmation of making the above minor amendments** (*for students*):

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name (*Typed name to act as signature*): H E Pickup  
Student number: U1825080

Date: 27<sup>th</sup> November 2020

*(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)*

**ASSESSMENT OF RISK TO RESEACHER** (*for reviewer*)

Has an adequate risk assessment been offered in the application form?

YES

**Please request resubmission with an adequate risk assessment**

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

HIGH

**Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.**

MEDIUM (**Please approve but with appropriate recommendations**)

LOW

**Reviewer comments in relation to researcher risk (if any).**

**Reviewer** (*Typed name to act as signature*): Sonya Dineva

**Date:** 04 Feb 2020

*This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee*

**RESEARCHER PLEASE NOTE:**

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

## Appendix J

### Ethical Amendment

UNIVERSITY OF EAST LONDON  
School of Psychology

#### REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

#### FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

**Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.**

Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Tim Lomas (Chair of the School Research Ethics Committee).

#### HOW TO COMPLETE & SUBMIT THE REQUEST

1. Complete the request form electronically and accurately.
2. Type your name in the 'student's signature' section (page 2).
3. When submitting this request form, ensure that all necessary documents are attached (see below).
4. Using your UEL email address, email the completed request form along with associated documents to: Dr Mark Finn at [m.finn@uel.ac.uk](mailto:m.finn@uel.ac.uk)
5. Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
6. Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

#### REQUIRED DOCUMENTS

1. A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
2. Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form

etc.

3. A copy of the approval of your initial ethics application.

Name of applicant:	Helena Pickup
Programme of study:	Doctorate in Educational and Child Psychology
Title of research:	Exploring what adolescent girls with Autism Spectrum Conditions say helps them successfully navigate the social aspects of mainstream schooling.
Name of supervisor:	Dr Miles Thomas

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
Change face to face meetings with supporting school staff to telephone, Skype for Business or Microsoft Teams meetings.	To remove the chance of transmitting Covid-19 during the continuing pandemic.
Change face to face meetings with participants to telephone, Skype for Business or Microsoft Teams meetings. These meetings are still expected to take place during school hours, whilst participants are in school and will use school technology.	To remove the chance of transmitting Covid-19 during the continuing pandemic.

<b>Please tick</b>	<b>YES</b>	<b>NO</b>
--------------------	------------	-----------

Is your supervisor aware of your proposed amendment(s) and agree to them?	Yes	
---	-----	--

Student's signature (please type your name):

Date: Helena Pickup

<b>TO BE COMPLETED BY REVIEWER</b>		
<b>Amendment(s) approved</b>	<b>YES</b>	<b>NO</b>
<b>Comments</b>		
Changes agreed as ethically sound.		

Reviewer: Dr Miles Thomas

Date: 16 September 2020

## Appendix K

### Data Management Plan

## UEL Data Management Plan: Full

Completed plans must be sent to [researchdata@uel.ac.uk](mailto:researchdata@uel.ac.uk) for review

*If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).*

Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts, prototypes, and multimedia objects that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects.

Administrative Data	
PI/Researcher	<b>Helena Pickup</b>
PI/Researcher ID (e.g. ORCID)	<a href="https://orcid.org/0000-0001-6280-7625">https://orcid.org/0000-0001-6280-7625</a>
PI/Researcher email	U1825080@uel.ac.uk
Research Title	An exploration of what adolescent girls with ASC say helps them successfully navigate the social aspects of mainstream schooling.
Project ID	
Research Duration	15 months starting April 2020

Research Description	This will be an exploratory, qualitative study which will gather information about the girls' experiences of the social aspects of school by asking them to reflect on their experiences over a specified data collection period. A deductive thematic analysis will be used to examine patterns and themes in their recounts. The participants will be involved in decisions about data collection, data interpretation and data dissemination giving an additional emancipatory purpose to the research design.
Funder	Part of a professional doctorate degree
Grant Reference Number (Post-award)	N/A
Date of first version (of DMP)	26 <sup>h</sup> November 2019
Date of last update (of DMP)	17 <sup>th</sup> September 2020 v.2 updated to reflect change in interview methodology due to Covid-19
Related Policies	<a href="#">Research Data Management Policy</a> <a href="#">UEL's Data Backup Policy</a>
Does this research follow on from previous research? If so, provide details	no
<b>Data Collection</b>	
What data will you collect or create?	Written diary entries, verbal or filmed blogs, recorded interviews on the telephone or UEL's Microsoft Teams or transcripts of verbal recordings (electronic and hard copies). There are 10 participants, choosing their own data collection method from the choices above. The data collected will be reflections on their experiences during social situations in schools. It will not contain any sensitive data around health and I will discourage the participants from including any personal data that might identify people or their school. Any personal references will be anonymised once the data are received by the researcher.

<p>How will the data be collected or created?</p>	<p>Participants will create their own written diaries and verbal or filmed blogs. I will record interviews on a Dictaphone (telephone conversations) or via the record function on Microsoft Teams. I will transcribe all verbal recordings, including the interviews.</p> <p>Participants will use their own devices to record blogs and I will transfer the files to my laptop and then on to OneDrive for business. The blogs will be personal recordings and will only contain footage/recordings of the participants themselves. Recordings will be initially made on a Dictaphone or Microsoft Teams and then transferred immediately to OneDrive for Business, recordings on Teams will be transferred to OneDrive to Business, and erased from the Dictaphone or Microsoft Stream. Transcripts will be typed up in Word documents. I will not be using software to analyse the data.</p>
<p><b>Documentation and Metadata</b></p>	
<p>What documentation and metadata will accompany the data?</p>	<p>There will be consent forms, information sheets and debrief sheets. There will be a list of pseudonyms. I will keep a research diary and make supervision notes following meetings with my research supervisor. My diary will be handwritten but will not contain any identifying information or personal information about participants or their schools.</p>
<p><b>Ethics and Intellectual Property</b></p>	
<p>How will you manage any ethical issues?</p>	<p>All participants will be asked for written, informed consent, be aware of their right to withdraw at any point and be debriefed after data collection. If a participant decides to withdraw, they will be made aware that their data will be removed up until the point where the data has been analysed.</p> <p>All participants will be made aware of in-school support, should any emotional distress occur during the data collection period. This will be re-enforced in the debrief letter and details of external support agencies also provided.</p> <p>In order to ensure confidentiality, all data will identified by pseudonyms chosen by the participants and only the researcher will be involved in analysis. Participants will only view and check data interpretation relating to their own data.</p>



<p>How will you manage copyright and Intellectual Property Rights issues?</p>	<p>The participants will own their blogs and I will own the transcripts that I make for analysis purpose. My copies of the blogs will be retained until my thesis has been examined and then destroyed. The transcripts will be retained as described below.</p>
<p><b>Storage and Backup</b></p>	
	<p>Electronic recordings of interviews and blogs will be stored on an encrypted memory stick, which will be stored in lockable storage in the researcher’s home. Electronic copies of transcripts of interviews and blogs will be encrypted and stored in my personal folder on my LA network, which is password protected.</p> <p>All hard copies of data (printed transcripts of interviews, printed transcripts of blogs and participant reflective diaries – used for the analysis process) will be stored in a secure drawer in my house. Data will be identified using pseudonyms and a list of pseudonyms will be kept separately from the data in a secure locker at my local authority office where I will be on placement until August 2021. Once the thesis has been examined, the pseudonym list will be destroyed.</p> <p>Consent forms will be collected electronically, via secure school email and saved to a separate folder on UEL’s OneDrive for Business .Electronic recordings of interviews and recordings of blogs will be backed up as encrypted files on my personal space on the UEL OneDrive. Encrypted and see above regarding the separation of pseudonymised data and personal data.</p>
<p>How will you manage access and security?</p>	<p>Recorded data will be transferred to my laptop and then to the encrypted memory stick immediately after collection and then deleted from the recording devices. Data will be stored as described above and only I will have access to passwords and keys. If it is necessary to show selected data to my supervisor for advice purposes, there will be no identifying information on the data and I will not refer to names of participants or schools. Hard copies of the data will be shared during these tutorials and retained by myself.</p> <p>The memory stick will be stored in lockable storage and data will be securely deleted after my thesis has been examined, following guidance from IT Services.</p>

<b>Data Sharing</b>	
How will you share the data?	<p>Data may need to be shared during research tutorials or during viva examination. I will share hard copies of any data that is necessary to share and I will retain this hard copy at the end of the tutorial or viva examination.</p> <p>Transcripts and scanned reflective diaries (identified by pseudonym) will be deposited in the UEL repository, and advice from UEL Library and Learning services will be followed. Consent will be sought from participants on initial consent forms for deposit and sharing of data.</p>
Are any restrictions on data sharing required?	See below, data will be retained for publication purposes.
<b>Selection and Preservation</b>	
Which data are of long-term value and should be retained, shared, and/or preserved?	The electronic copies of transcripts and hard copies of the written diaries are of long-term value for publication purposes.
What is the long-term preservation plan for the data?	<p>The hard copies of written diaries will be scanned to create electronic copies and then all electronic copies will be stored in the UEL data repository to enable publication opportunities. This will be reviewed after 5 years for transfer or deletion. Consent for deposition and sharing will be sought on initial consent forms. An embargo on data sharing of initially 3 years will be put in place to allow publication opportunities. This will be lifted (or extended) in accordance with the progress of publication. Once lifted, data will be available to be shared openly with a creative commons license.</p> <p>[retain a copy for yourself]</p> <p>“Personal or sensitive data must be anonymised where it is appropriate for release in other respects.... The UEL Data Protection Officer provides advice and guidance on what is inappropriate for general release”. (UEL Research Data Management Policy)</p>

<b>Responsibilities and Resources</b>	
Who will be responsible for data management?	I will be responsible.
What resources will you require to deliver your plan?	I already have an encrypted memory stick, a secure drawer and secure locker
<b>Review</b>	<b>Update plan re deposit of data and contact <a href="mailto:researchdata@uel.ac.uk">researchdata@uel.ac.uk</a></b>
	<b>Please send your plan to <a href="mailto:researchdata@uel.ac.uk">researchdata@uel.ac.uk</a></b>  <b>We will review within 5 working days and request further information or amendments as required before signing</b>
Date:17/09/2020	Reviewer name: Penny Jackson Research Data Management Officer

## Guidance

Brief information to help answer each section is below. Aim to be specific and concise.

For assistance in writing your data management plan, or with research data management more generally, please contact: [researchdata@uel.ac.uk](mailto:researchdata@uel.ac.uk)

### Administrative Data

#### Related Policies

List any other relevant funder, institutional, departmental or group policies on data management, data sharing and data security. Some of the information you give in the remainder of the DMP will be determined by the content of other policies. If so, point/link to them here.

### Data collection

Describe the data aspects of your research, how you will capture/generate them, the file formats you are using and why. Mention your reasons for choosing particular data standards and approaches. Note the likely volume of data to be created.

### **Documentation and Metadata**

What metadata will be created to describe the data? Consider what other documentation is needed to enable reuse. This may include information on the methodology used to collect the data, analytical and procedural information, definitions of variables, the format and file type of the data and software used to collect and/or process the data. How will this be captured and recorded?

### **Ethics and Intellectual Property**

Detail any ethical and privacy issues, including the consent of participants. Explain the copyright/IPR and whether there are any data licensing issues – either for data you are reusing, or your data which you will make available to others.

### **Storage and Backup**

Give a rough idea of data volume. Say where and on what media you will store data, and how they will be backed-up. Mention security measures to protect data which are sensitive or valuable. Who will have access to the data during the project and how will this be controlled?

### **Data Sharing**

Note who would be interested in your data, and describe how you will make them available (with any restrictions). Detail any reasons not to share, as well as embargo periods or if you want time to exploit your data for publishing.

### **Selection and Preservation**

Consider what data are worth selecting for long-term access and preservation. Say where you intend to deposit the data, such as in UEL's data repository ([data.uel.ac.uk](http://data.uel.ac.uk)) or a subject repository. How long should data be retained?