

***Doctorate in Professional Educational,
Child and Adolescent Psychology***

Programme Director: Vivian Hill



**School experiences of autistic girls who were
diagnosed in adolescence:
Views of young people and their parents/carers**

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*A thesis submitted in partial fulfilment of the Doctorate in Professional
Educational Child and Adolescent Psychology*

Student declaration

I, Lucy Colat-Parros declare that, expect where explicit attribution is made, the work presented in this thesis is my own.

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'In an ideal world the children would be kind and friendly... I would wish that they would be more understanding and amenable to 'strange' children like myself, without seeing it as pity or a duty. I would like if they invited me to hang out outside of school or to go to parties together' (Sas)

'I don't want people to go through what I did, and I know a lot of other people did, because it really does knock your self-esteem when you grow up... Not knowing that you, just all that's wrong with you, like not even what's wrong with you, is that you just have a different brain and that's why people treat you differently, it's not because you're a bad person or you're like making people's lives worse or like that you're doing it on purpose, it's just because your brain thinks differently... I know that a lot of a lot of arguments in my house, a lot of like, issues that I had with friends would have been solved so much more quickly if I had known this about myself earlier... But so yeah, I want to do stuff like this to sort of help hopefully, people in the future not have to deal with that like I do...' (Alex)

'I feel like something, something needs to be done because I think, I just think there must be so many young girls, particularly in the system... who struggle with their mental health and are being labelled with all sorts of things... '

(Alice's mother)

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I would like to dedicate this thesis to my Father, who always taught us the value of education – you would've been so proud I have finished the Doctorate (you were always there supporting me, proof reading and encouraging me). I miss you every single day and you have left a void in me that will never be filled...

Thank you for always believing and being there for me.

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List of Acronyms and Abbreviations

PCP	Personal Construct Psychology
EP	Educational Psychologist
CYP	Children and Young People
AGN	Autistic Girls Network
MSc	Master of Science
DEdPsych	Doctorate in Educational and Child Psychology
LA	Local Authorities
SENCOs	Special Educational Needs Co-ordinators
YP	Young People
GP	General Practitioner
IPA	Interpretative Phenomenological Analysis
UNRC	United Nations Convention on the Rights of the Child
CAMHS	Child and Adolescent Mental Health Services
EHCP	Education Health Care Plan
TA	Thematic Analysis
YP	Young People
DfE	Department of Education

Abstract

This research used a multi-informant approach and Bronfenbrenner's bio-ecological model (2005) as a lens to gather perspectives and experiences of autistic girls, alongside their parents, about their school experience and how this interacts with their pathways to diagnosis. There is limited academic research about these topics from the first-hand perspectives of the girls themselves. Semi-structured interviews and a personal construct psychology (PCP) tool ('the ideal/non-ideal school') were used to gather the experiences of eight girls and five of their parents, which allowed triangulation of data. A participatory and inclusive approach was taken throughout the research process to support the girls' participation. Data were analysed using reflexive thematic analysis and four themes were identified: (1) the environment plays a huge role in how I can learn; (2) people aren't predictable – navigating school relationships; (3) the journey to diagnosis – it didn't come from school and (4) adapting to my new identity. These themes told the story of the girls' journeys through school and how many environmental and relational elements had a huge impact on how they learnt and on their level of acceptance and comfort within school. Furthermore, their eventual diagnoses came not because of support from school or educational psychologist (EP) involvement but following intervention from external agencies. Being diagnosed during their adolescent years had an impact on the girls' rapidly deteriorating mental health during the later years of secondary school; a time when additional support could have been helpful in ensuring the girls adapted to their new identities.

Impact Statement

This study is the first to examine autistic girls' school experiences (across both primary and secondary) and their diagnosis journeys, and how these interacted in terms of school support. This research is key in supporting development of EP practice. There are currently nine academic papers in the literature that examine the school experiences of autistic females, but none of these examine all the elements included within this thesis, or use traditional and creative methods to gather and centre the girls' voices.

Four themes and five subthemes were identified from the girls (supported by their parents), with one individual subtheme from their parents. These themes described the autistic girls' journey through school and how their diagnosis unravelled. A range of negative experiences were described in the school environment, which affected the girls' abilities to learn, including the sensory impact of the classroom/school, social and friendship challenges, the unpredictable aspects of school life, and a lack of individualisation from teachers. When describing their diagnostic journeys, the girls explained how this did not occur from school and instead unravelled from mental health concerns that escalated. Outside support was then obtained with their parents' help.

Importantly, as a trainee EP, this study into autistic girls' educational experiences and their diagnostic journeys is significant due to the role of the EP, which involves improving outcomes for children and young people (CYP) aged 0-25 and ensuring that their voices are gathered and heard - as emphasised in the current SEND Code of

Practice, DfE, (2015) and the Children and Families Act DfE (2014). As EPs, we have the potential to bring parents/carers and school staff together during meetings such as consultations, in which we can actively and collaboratively provide support pre- and post-diagnosis. There are many implications from this research, and it is hoped that the recommendations shared from the girls can be utilised during consultations between EPs and school staff.

Furthermore, EPs can provide school staff with training regarding awareness and identification of how autism may present in girls, which could potentially support girls to gain access to diagnosis (and subsequent support) in a timely manner. Improved teacher training on autism is a priority for autistic individuals and their families (Crane et al., 2018).

Autistic individuals want research that will make an impact on their daily lives (Pellicano et al., 2014) and it is hoped that the current research supports this goal. This project was developed in consultation with the Autistic Girls Network (AGN), who found this topic to be priority. I hope this study will improve outcomes for the autism community and support the development of EP practice, so that it better serves autistic individuals and their families in future.

This study will make an important contribution to professional and academic knowledge. It is the first study of its kind examining autistic girls' school experiences and how it interacts with an adolescent diagnosis, gaining the girls' voices using interviews and a psychological inclusive tool. Data were gathered from the girls and their parents, whilst centring the girls' voices.

Chapter 1: Introduction

1.1 Rationale for this study

The idea for this study came from my personal interest in continuing research to support the autism¹ community (following my MSc and Year One DEdPsych research), alongside my professional experience as an educator for autistic CYP. I hope this study will improve outcomes for the autism community and support the development of Educational Psychology practice, so that it better serves autistic individuals and their families in future.

1.2 Statement of the problem

Throughout my Year One and Two trainee EP placements in various Local Authorities (LAs), Special Educational Needs Co-ordinators (SENCOs) raised concerns about the growing numbers of girls in secondary schools who show ‘signs of autism’ or ‘undiagnosed autism’. This topic is repeatedly raised during planning meetings and autism working groups within EP services, with common concerns surrounding girls in mainstream secondary provision, stemming from worries regarding their social, emotional, and mental health needs.

School can be a challenging place for autistic CYP (especially girls), due to factors such as challenging school environments, alongside a perceived lack of staff understanding and awareness of autism (Cook et al., 2018; Honeybourne, 2015; Jarman & Rayner, 2015; Moyse & Porter, 2015; Sproston et al., 2017). The transition

¹ Throughout this research paper I use identity-first language (i.e., autistic person) as opposed to person-first language (i.e., person with autism), which is preferred by members of the autism community (Bottema-Beutel et al., 2021)

from primary to secondary school may be particularly difficult (Zakai-Mashiach, 2022). While programs have been developed to support such transitions for autistic pupils, such as STEP-ASD (Mandy et al. 2016), access to these supports depends on a CYP having an autism diagnosis.

Several barriers to obtaining an autism diagnosis have been documented for girls. Traditionally, girls are diagnosed much later than boys (Whitlock et al., 2020) with the process of obtaining an autism diagnosis for girls not being straightforward and often involving lengthy delays (Bargiela et al., 2016; Leedham et al., 2020). Further, understanding and awareness of autism in girls can be scarce (Cridland et al., 2014; Honeybourne, 2015; Jarman & Rayner, 2015). Indeed, Gould (2017) notes that despite growing awareness of autistic girls, there is restricted support for schools with regards to their needs, and provision could be more refined.

There are several reasons why autistic girls are commonly not identified until secondary school (Bargiela et al., 2016; Leedham et al., 2020). One hypothesis is that the primary school environment is a more nurturing and supportive setting with executive demands lessened (e.g., with most of the school day taking place in one classroom and with the same peers). The somewhat calmer classroom environment of primary school contrasts with that of secondary school, which is normally large, loud, and busy, with multiple teachers accessed, and constant transitions taking place throughout the school day. These challenges can intensify anxiety (Goodall, 2015), which could disrupt an individual's learning (McAllister & Maguire, 2012).

An alternative hypothesis links to the social complexities of friendships that appear during adolescence (Hsiao et al., 2013; Sedgewick et al., 2016), becoming more evident during secondary school. Non-autistic girls may also struggle with the social complexities of friendships during adolescence (Sedgewick & Pellicano, p.126, 2019). However, the intensity of autistic girls' friendships may lead to greater instances of conflict, which they may struggle to recognise and/or manage (Sedgewick et al., 2016). We also know that during the early years, autistic girls tend to integrate with typically developing peers (Hiller et al., 2014; Sedgewick et al., 2016), while this lessens during adolescent years (McLennan et al., 1993; Ranson & Byrne, 2014).

Importantly, as a trainee EP, this study into autistic girls' educational experiences and their diagnostic journeys is significant due to the role of the EP, which involves improving outcomes for CYP aged 0-25. As EPs, we have the potential to bring parents/carers and school staff together during meetings such as consultations, in which we can actively and collaboratively provide support pre- and post-diagnosis. Furthermore, EPs can provide school staff with training regarding awareness and identification of how autism may present in girls, which could potentially support girls to gain access to diagnosis (and subsequent support) in a timely manner. Improved teacher training on autism is a priority for autistic individuals and their families (Crane et al., 2018).

1.3 Research Significance

To my knowledge, there is no academic research specifically examining the school experiences of autistic girls diagnosed during their adolescent years, with a focus on the voice of the young person and their parents/carers. Yet research about autistic

girls and their experiences in education is a priority area highlighted by the autism community (Pellicano et al., 2014). Furthermore, we are increasingly aware of the negative educational outcomes for autistic girls, such as exclusion (Gray, 2018; Sproston et al., 2017) and school non-attendance, both of which have been linked to a lack of a support. Moyses (2021) explains that an increasing number of autistic adolescent girls are stopping attending mainstream secondary schools in England, despite wanting to be in school, but they found the environment challenging and did not feel understood or supported.

This study will make an important contribution to professional and academic knowledge. It is the first study of its kind examining autistic girls' school experiences and how it interacts with an adolescent diagnosis, gaining the girls' voices using interviews and a psychological inclusive tool. Data were gathered from the girls and their parents, whilst centring the girls' voices. Regarding EP practice, psychological tools were used to elicit the autistic CYPs' voices, levelling the 'power balance' between the EP and the CYP.

1.4 Project Aim

The aim of this project was to gather perspectives and experiences of autistic girls, alongside those of their parents/carers, about their school experience and how this interacts with their pathways to diagnosis.

1.5 Researcher Background

Before beginning the DEdPsych and training as an EP, I worked as a Teaching Assistant, Primary School Teacher, SEN Teacher and SENCo, in various school settings (predominately in the Middle East). During my time in these roles, I worked extensively with autistic CYP and started to notice how presentations were different between autistic boys and girls. I also reflected on the training I received as a teacher, and how this tended to not focus on gender differences.

During my career, I became interested in autism, especially diagnostic pathways. I completed an MSc at UCL, and my dissertation focused on the autism diagnostic experiences of families of autistic children in Bahrain.

Upon starting the DEdPsych, I knew I wanted to continue researching autism. As I examined the existing literature and noticed a gap in the research eliciting autistic girls' voices to understand their experiences. As a Trainee EP on placement in various LA's, the topic of autistic girls kept occurring during SENCo planning meetings, typically in relation to 'recent' diagnosis or mental health concerns. I noticed that SENCos and school staff did not feel confident in their knowledge of autism in girls, nor did they know where to begin with strategies and support for these YP.

In Year Two of my course, whilst this thesis was being developed, I was able to utilise 'the ideal school' tool, to gather the voices of autistic YP (both boys and girls) in a secondary school in inner London, to support the schools' goal of making their school more autism friendly. This experience allowed me to pilot the ideal school tool; the success of which inspired me to use it within the current research.

Throughout my research, I recognise that I hold my own pre-existing views and have pre-existing experiences. I therefore aimed to be open to the voices of the YP involved in my research. According to Braun and Clarke (2013, p.9), to be a successful qualitative researcher, it is particularly important to have 'Qualitative sensibility', which includes, recognising our own assumptions and 'putting them aside', or 'bracketing them off', to ensure the 'research is not automatically shaped by these'.

As described later, I used 'reflexive thematic analysis' to analyse my data. Being reflexive involves examining our own position as a researcher, including our insider and outsider positions (Gallais, 2008). Therefore, it is important to mention that I share an insider link with the girls in my research as I am also female, and with the parent participants as I am also a parent. Yet I am also an 'outsider researcher', as I am not autistic myself, and do not have an autistic child.

It was therefore important for me to ensure that my research took as much of a participatory approach as possible (e.g., involving a neurodivergent parent of neurodivergent children), as well as obtaining first-hand experiences through eliciting my participants' voices in sensitive and respectful ways.

1.6 Research Questions

My research questions are, from the perspective of the girls (and supported by their parents/carers):

- 1) What was the girls' overall experience of school and school support like: what worked well, what improvements could be made, and did this change over time?²
- 2) What was the girls' pathway to autism diagnosis during their adolescent years: how did this interact with experiences of school support, what worked well and where could improvements be made?

² It should be noted that I originally had another RQ related to transition, but during the results analysis, my supervisor and I decided to merge this into RQ1 including it under 'school experiences' more generally due to the lack of data/emphasis from the girls and their parents/carers around this topic

Chapter 2: Literature Review

2.1 Chapter Summary

This literature review begins with a brief outline of autism and the current diagnostic criteria. The diagnostic process will be reviewed with a critical lens, examining whether it is truly fit for purpose for both sexes/genders³. The prevalence of autism will also be discussed, along with potential reasons for the widely reported sex/gender diagnostic bias. Next, the advantages of receiving a diagnosis in a timely manner will be briefly explored, highlighting why it is so significant for girls not to be disadvantaged in this regard. Then, the concept of camouflaging will be introduced, which could be a further hurdle to accessing a diagnosis. Following this background review, research surrounding autistic girls' overall educational experience is presented, including research that focuses on school staff and their understanding of autism in girls, as well as research on school transition (which may be particularly challenging for autistic CYP). Importantly, the relevance and significance of obtaining the voice of the CYP and their parent/carers is emphasised, both with regards to academic literature and EP practice. Finally, underpinning all this work, Bronfenbrenner's bio-ecological model (2005) is discussed.

2.2 Autism

Autism was first reported in the academic literature by Sukhareva (1925) who detailed the 'autistic features' of six boys she observed. Subsequently, autism was described by Kanner (1943) and Asperger (1944). Kanner (1943) described a group of eight boys

³This research uses the term 'sex/gender', as discussed by (Lai et al., 2015) to support the understanding that biological 'sex' and socially constructed 'gender' are not easily divided and the majority of individual's identities are linked to sex/gender.

and three girls, highlighting their solitary behaviours and inability to form contact with others, which he used to differentiate autism from childhood schizophrenia. Kanner (1943) viewed autism as a largely male condition. Subsequently, Asperger (1944) described four boys who had intense interests and social communication challenges, and felt no girls were 'affected' by the profile he identified. Autism was later described as a spectrum, including CYP with a wide range of IQ, from intellectual disability to very high IQ., and Wing (1981)'s research in which the term Asperger Syndrome was introduced.

Since this foundational work, our understanding of autism has developed considerably. Currently, autism is diagnosed behaviourally, using the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) or the International Classification of Diseases (ICD-11; World Health Organisation, 2020). Across both manuals, autism is described as a neurodevelopmental condition involving two fundamental qualities: 1) 'deficits in social communication and interaction' and 2) 'restricted, repetitive patterns of behaviour, interests, or activities' (DSM-5; American Psychiatric Association, 2013). Subgroups of autism have been taken out of the DSM-5 (2013) diagnosis, in favour of autism being a broad umbrella term that encompasses a very wide range of presentations. With regards to prevalence, autism affects approximately 1-2% of the UK population, varying according to demographic factors (Roman-Urrestarazu et al., 2021).

Diagnosis: Fit for Purpose?

Diagnostic criteria for autism have predominantly been designed based on the autistic presentation observed in boys and men (Kirkovski et al., 2013; Kopp & Gillberg, 2011;

Mattila et al., 2011). Yet we know that autism is a heterogeneous diagnostic category (Westwood et al., 2017) and presentations of the core autistic features can vary significantly from one individual to the next, with some indications of sex/gender differences. For example, there have been suggestions that autistic girls may have a different 'phenotype' or patterns of behaviours than autistic boys (Kirkovski et al., 2013; Van Wijngaarden-Cremers et al., 2014). Furthermore, Estrin et al. (2021) explain that the female autism phenotype is not recognised by the current autism diagnostic criteria and tools (McLinden & Sedgewick, 2022).

In terms of examining specific sex/gender differences in autism, these have been more commonly studied in relation to the non-social features of autism: restricted, repetitive patterns of behaviour, interests, or activities (RRBIs). Literature indicates that autistic girls potentially show fewer RRBIs (Kreiser & White, 2014; Rivet & Matson, 2011). Hull, Mandy et al. (2017) suggest that autistic females may experience very intense interests that go beyond the 'usual' common interests stereotypically seen in autistic people, which would mean they are eliminated from the diagnostic criteria completely. Further, Hull et al. (2017) explain additional sex/gender differences in other features linked to autism, such as internalising and externalising difficulties (e.g., behavioural problems and hyperactivity in males, versus depression and anxiety in females), which ultimately suggests that current diagnostic criteria could usefully be modified (Bargiela et al., 2016).

Autistic Girls

Historically, autism has been seen as a predominantly male diagnosis and autism research studies have traditionally recruited largely male samples (Watkins et al.,

2014). Global prevalence studies suggest a male-to-female ratio of 3:1 (Loomes et al., 2017), although this figure may reflect an under recognition of autism in girls. Reported reasons for disparities in access to diagnosis as a function of sex/gender include differences in behaviour and interests between the sexes (de Giambattista et al., 2021; Hiller et al., 2014; Hsiao et al., 2013; Mandy et al., 2012), lack of recognition of autism in women and girls (Kopp & Gillberg, 1992; Lai, Baron-Cohen, et al., 2015; Whitlock et al., 2020), genetics (Lai, Baron-Cohen, et al., 2015; Lai, Lombardo, et al., 2017), and an assessment bias towards males (de Giambattista et al., 2021; Gray et al., 2021; Russell et al., 2011).

Expanding on the above, behavioural and social differences as a function of sex/gender have been reported (de Giambattista et al., 2021; Hiller et al., 2014; Hsiao et al., 2013; Mandy et al., 2012). During the early years, autistic females tend to integrate with typically developing peers (Hiller et al., 2014; Sedgewick et al., 2016) but this integration lessens during adolescence (McLennan et al., 1993; Ranson & Byrne, 2014). Associated physical, psychological and social adjustments cause challenges in maintaining friendships (Hsiao et al., 2013) and navigating social disagreements (Sedgewick et al., 2016). As a result, autistic females are particularly susceptible to social isolation (Dean et al., 2014).

There is limited research surrounding the educational experiences of autistic adolescent girls. It is therefore important that, as EPs, we work closely with school staff and parents/carers to identify and support autistic girls from their early years and throughout school; working collaboratively to develop an understanding of autism that could potentially lead to more timely early identification and access to support.

Late Diagnosis

Advantages to receiving a timely autism diagnosis include the development of self-identity; access to support, services, and interventions; and improved developmental outcomes (Bryson et al., 2003; Filipek et al., 1999; Hurlbutt & Chalmers, 2002; Portway & Johnson, 2005; Ruiz Calzada et al., 2012; Russell & Norwich, 2012; Wong et al., 2015). Expanding on self-identity, accessing a diagnosis can support the cultivation of a positive autistic identity and sense of belonging in the autistic community (Giles, 2014; Parsloe, 2015). Furthermore, delayed diagnosis (or a lack of a diagnosis) could mean autistic people are not benefiting from available supports and interventions (Gray et al., 2021; Whitlock et al., 2020).

Regarding females, research indicates grave consequences for those whose autistic identity remains undetected (Whitlock et al., 2020), including being bullied, feeling socially isolated and feeling misunderstood (Bargiela et al., 2016; Portway & Johnson, 2003; Portway & Johnson, 2005; Punshon et al., 2009). Ultimately, studies show that autistic women feel that their lives would have been simpler if their autism had been acknowledged earlier (Bargiela et al., 2016; Harmens et al., 2022).

Bargiela et al. (2016) conducted semi-structured interviews with 14 women who received their diagnoses in late adolescence or early adulthood (between the ages of 19-30 years), to better understand the experiences of women who met diagnostic criteria for autism but were not identified early. Participants explained that during their early years, their difficulties had indeed been identified, but were not attributed to autism. Eight out of the 14 participants explained that their lives would have been simpler if they had received their diagnosis earlier. Participants claimed that a bias

occurred when dealing with front line health care professionals (e.g., General Practitioners, GPs) and educators, as they did not understand female-typical presentations of autistic behaviours, and associated autism with boys. Further, Bargiela et al. (2016) explained that the inclination for females to have internalising (e.g., anxiety) challenges, rather than externalising (e.g., hyperactivity/impulsivity) challenges, poses a barrier to diagnosis. The researchers propose that higher social motivation (Sedgewick et al., 2016) and more sophisticated non-verbal communication (Rynkiewicz et al., 2016) should be key factors for investigation when assessing a female for an autism diagnosis.

Despite Bargiela et al. (2016)'s study utilising a specific sample (e.g., females with above-average IQ based in the UK), the study highlighted important factors in relation to access to diagnosis for females, such as misinterpreted needs, continuous mental health challenges, camouflaging behaviours and ultimately, stereotyped understandings of autism impacting diagnosis. It was also the first study to examine the experiences of late diagnosis for autistic females. Yet this study did not make comparisons between male and females, nor did it consider other gender identities, so it is unclear to what extent these findings are unique to females.

Leedham et al. (2020) conducted semi-structured interviews with 11 autistic females in the United Kingdom, who were diagnosed during middle to late adulthood. The research took a participatory approach (Fletcher-Watson et al., 2019) as three autistic adults supported development of the interview schedule. The authors analysed their data using Interpretative Phenomenological Analysis (IPA) and identified four key themes. The first theme 'a hidden condition' covered trying to fit in, linked with mental

health concerns and mislabelling. The second theme, 'the process of acceptance', underpinned the girls different experiences and emotions whilst making sense of their new diagnosis and ultimately, living life through a new lens, in which for some a new perspective occurred instantly whilst for others it happened gradually over time. The third theme 'post diagnostic impact of others' included mixed preliminary reactions from others and stereotyped assumptions. The fourth and final, theme 'a new identify on the autism spectrum', encompassed navigating relationships, understanding of self and the implications of diagnosis. Similar to Bargiela et al. (2016)'s study, many of the females in this study discussed experiences of camouflaging their traits to 'blend in', which worsened their mental health difficulties. Furthermore, the study highlighted that the majority of autistic females expressed great relief post-diagnosis, and it allowed them to start a 'meaning making process'; as found by Baldwin and Costley's (2016), who examined the life experiences of 82 autistic women in Australia. Yet limitations of this research (and that of Bargiela et al., 2016) include a lack of a comparison group, a lack of inclusion of those who have intellectual disability and relying heavily on verbal interviews for data collection.

Camouflaging

Definitions of camouflaging are still evolving and this concept has also been referred to as compensation, masking and adaptive morphing (Cook et al., 2022). Camouflaging⁴ is a method used by autistic individuals to alter their usual social behaviours to acclimatise to, and cope within, the neurotypical (non-autistic) social world (Cook et al., 2021; Dean et al., 2017; Hull, Mandy, et al., 2017; Hull, Petrides, et

⁴ It should be noted that even though I use the term 'camouflaging', some autistic people prefer other terms (Cook et al., 2021a; Lawson, 2020; Pearson & Rose, 2021) and a participatory approach with the autistic community should be taken in regard to terminology going forward (Fletcher-Watson, et al., 2019).

al., 2017; Lai, Lerch, et al., 2017; Livingston & Happé, 2017). Common examples of camouflaging include preventing repetitive hand movements ('stimming'), sustaining eye contact, using scripts for conversation and using learned rules to reply to others' non-verbal behaviour (Cook et al., 2022). Due to the demands of camouflaging, it can result in exhaustion, anxiety and depression (Cage & Troxell-Whitman, 2019; Hull et al., 2021; Lai, Lombardo, et al., 2017; Tierney et al., 2016), as well as generating confusion about one's sense of self (Bargiela et al., 2016).

Camouflaging was introduced, largely in regards to autistic females, by Attwood (2007), and this work inspired a breadth of academic research examining the construct among autistic girls and women (Bargiela et al., 2016; Cridland et al., 2014; Tierney et al., 2016) as well as males and non-binary individuals (Hull, Mandy, et al., 2017; Livingston et al., 2019). In their recent systematic review on camouflaging, Cook et al. (2021) conclude that most studies indicate that autistic females show greater levels of camouflaging versus autistic males. Yet, as Cook et al., (2021) mention, camouflaging is indeed evident in autistic people who are not female (i.e., it is not a specific characteristic of autism in females).

Most camouflaging research has been conducted with autistic adult samples, but there is emerging literature examining camouflaging in autistic girls. Halsall et al. (2021) examined the potential camouflaging strategies (and the motivations, presentation, and implications of these behaviours) used by eight autistic girls (aged between 12-15 years old) who attended three different resources bases in mainstream secondary schools, across three different LAs. The authors used a multi-informant approach by conducting semi-structured interviews with the girls, their parents/carers and

educators. The variety of settings, locations and various participants gave diverse experiences to reflect upon and triangulate, providing a rich set of data. Furthermore, this research was unique in that it was the first to examine whether autistic girls in a resource base (attached to a mainstream school) used camouflaging strategies

Halsall et al. (2021) found that the girls in their study tried to use camouflaging strategies to mask both learning difficulties and their autistic characteristics, in both mainstream and resource base classes. Furthermore, the authors explained that all the girls experienced negative consequences because of camouflaging, including fatigue, anxiety, emotional pain, and self-identity worries. These findings have significant findings for EPs, who can support school staff to develop a greater understanding of camouflaging and offer evidence-based strategies and intervention. Indeed, the authors of the study produced a supplementary guide with ideas for school staff, including increasing knowledge of autism, supporting potential consequences, and the reducing stigma associated with camouflaging/autism. Additionally, they provided guidance on supporting girls' sense of 'fitting in' and friendships, which could prove useful to share with school staff such as SENCOs during EP school planning meetings or as part of further training.

2.3 Autistic girls' educational experience

There is emerging literature on the educational experiences of female autistic adolescents (Dean et al. 2014). Tomlinson et al. (2020) conducted a systematic review examining research on the school experiences of autistic females and found eight papers from 2014-2018 that met their criteria. Their main findings were divided into different levels: the 'school', 'classroom' and 'individual'.

'School level' findings included challenges with managing the setting (such as sensory difficulties); a lack of consideration from school staff; and difficulties with parent-school relationships (including misunderstanding the needs specific to autistic females) (Cook et al., 2018; Moyse & Porter, 2015).

With regards to the 'classroom level', themes included challenges with access to the curriculum, including teacher's instructions not being clear and the need for more diverse teaching approaches (Honeybourne, 2015; Jarman & Rayner, 2015; Moyse & Porter, 2015). Another aspect highlighted was the transition between primary and secondary School, as well as struggling with micro-transitions (e.g., between different lessons and teachers, from structured to unstructured play), (Cridland et al., 2014; Honeybourne, 2015; Moyse & Porter, 2015).

Lastly, regarding the 'individual level', key messages included an emphasis on positive relationships with school staff who understood autism (Jarman & Rayner, 2015), especially in girls (Cridland et al., 2014; Honeybourne, 2015; Jarman & Rayner, 2015). Furthermore, masking was common for the girls and, worryingly, reports of social isolation and alleged bullying were widespread (Cook et al., 2018; Cridland et al., 2014; Honeybourne, 2015; Moyse & Porter, 2015).

Reflecting on the results from the systematic review, some themes are not sex/gender specific and are simply characteristics unique to autism (e.g., struggling with transitions). Nevertheless, the findings are significant as they highlight important themes related to autistic girls' school experiences, which link with the broader literature, and add to existing research findings on female autistic samples. Indeed,

the authors of the systematic review note that research in this area is limited, with small samples.

Importantly, the review highlights that parents (versus school staff) are more likely to understand and interpret challenges their daughters are facing in the school environment, emphasizing the importance of a strong school-family relationship to provide better outcomes for autistic girls. This observation is significant for the EP role, as we can potentially bring together families and school staff during consultations, leading to a shared understanding of needs, a shifting of perspectives and awareness raising (and, ultimately, better outcomes). Yet Tomlinson et al. (2020) emphasise that few studies included within the review seek to understand school experiences from the perspective of the girls themselves, which is key for future research.

In one of the few studies to elicit the views of autistic girls, Sproston et al. (2017) conducted semi-structured interviews with eight autistic girls (aged 11-18 years) and their parents to investigate their experiences of mainstream schooling prior to school exclusion. The authors examined aspects such as whether alternative educational provision was provided, what the school exclusion process was like, and what the girls' current educational provision was. Thematic analysis was used to analyse data, and three key themes were identified: 'unsuitable school environments', 'strains in school relationships', and 'issues with staff responses' (including a misunderstanding of the girls' needs and an associated lack of support). These key themes are reinforced by prior research into autistic individuals' school experiences (Cridland et al., 2014; Humphrey & Lewis, 2008; Sciotto et al., 2012; Tomlinson et al., 2020) and a major finding was that the findings for autistic girls didn't really differ from findings in autistic

boys. Sproston et al. (2017) also highlight that future research should identify how to positively encourage and support autistic girls' educational journeys. The use of creative methods could be helpful in this regard; to ensure inclusivity to gather the views of a broad range of autistic young people, especially those who struggle to communicate their thoughts, feelings and emotions verbally.

Moyse (2021) used creative tools to understand autistic girls' school experiences, including school exclusion. She interviewed ten adolescent autistic girls using a variety of creative tools, such as the 'ideal school' (explained further in the 'Methodology' section of this thesis) and 'life charts' (where the girls produced a chart, identifying - chronologically – their positive and negative school experiences). Moyse's study took a mixed methods participatory approach: the author is autistic and an Autism Advisory Group was used to support study design/development. Moyse (2021) acknowledges that the study findings support previous literature, including the mental health impact of negative school experiences for autistic CYP, a lack of understanding from teachers about autism, and limited emotional and learning support received by the girls. Ultimately, she highlights that underpinning all her findings is the requirement to truly listen to the voice of the autistic young person.

Most recently, Zakai-Mashiach (2022) conducted a study to understand 'self-retrospective perceptions' of autistic women on their school experiences. She interviewed eight autistic women who were between the ages of 19-29 years of age, and asked them to reflect on their school years at mainstream primary and secondary schools in Israel. The participants were mainly diagnosed during their adolescent years, with two being diagnosed at an earlier age. Zakai-Mashiach explains that the

participants were all of 'high verbal and cognitive abilities'. The study utilised semi-structured interviews to gather experiences, and analysed data qualitatively. The results were presented in three parts to represent three phases of education: 'elementary' (primary school), 'middle' school and 'high school' (secondary school). In total seven themes were discussed under the above school levels. Under 'elementary school', themes included 'misunderstanding' (which caused the participants emotional distress at school) and 'classroom peers' (participants reflected on feeling lonely and unsuccessfully trying to make friends). Under 'middle school', themes included 'transition' (the change from elementary to middle, which was challenging due to new environments, peers and teachers), 'diagnosis' (this brought mixed experiences for participants) and 'relationships with teachers' (participants felt they lacked autism knowledge, didn't get to know them individually, and focussed on the girls' academic achievement over their needs). Lastly, under 'high school', themes included 'autism diagnosis disclosure' (participants were unsure what to tell their peers) and 'self-identity' (some felt it was an immediate positive experience during their school years, whilst others only felt acceptance post-secondary school). Amongst other limitations, the author states that it is important to recognise that some of the results from the study may also be common to autistic males, and furthermore, that a multi-informant approach would have provided a broader perspective.

Cohen et al. (2022) also conducted a recent study interviewing ten autistic adolescents and adults living in the United States (aged between 15-35) to understand how their primary and secondary school experiences (including their relationships with teachers and peers) shaped their identities. The findings discussed that as pupils they felt they received discriminating messages from teachers and peers regarding being autistic

(post-diagnosis), including their teachers viewing them from a restrictive 'autism lens'. Positively, participants discuss how they moulded their identities to the focus on a positive sense of self. The authors emphasise that their sample was limited and small, but nevertheless highlights the importance of an inclusive school environment, in which teachers hold positive views of autism and autistic pupils.

School Staff and Autism in Girls

School staff could play a key role in autism identification (Bargiela et al., 2016; Gray et al., 2021) as they see pupils daily, in social and non-social situations. Therefore, it is crucial that they understand how autism presents in different sex/genders. However, their understanding of autism can be restricted (Whitlock et al., 2020) especially regarding autism in girls (Hiller et al., 2014; Posserud et al., 2006). Research shows that some teachers report fewer worries with regards to girls' verses boys' behaviour (Hiller et al., 2014; Mandy et al., 2012) and that school staff believe that externalising behaviour has to be present for an autism diagnosis (Jarman & Rayner, 2015). It is therefore important that teachers fully understand autism, including the potential differences in presentation across sex/gender, as this helps identify CYP who need an autism assessment (Whitlock et al., 2020).

Whitlock et al. (2020) experimentally examined how 289 primary school educators identify autism. In their study, primary school teachers were shown four written vignettes that featured children with different clinical characteristics, and they were asked to rate the probability of (a) the child being autistic, and (b) them pursuing help for the child. Vignettes were designed using a participatory approach, as an autistic adult was consulted with regards to the development. As hypothesised, Whitlock et al.

(2020) found that their sample of educators were less sensitive to autism in girls, due to a lack of understanding of the 'female autism phenotype'. The authors also found a bias against autistic females with the female autism phenotype, but not for females with the male autism phenotype. These findings accord with those of Bargiela et al. (2016), whereby autistic women attributed their late diagnosis partially to professionals (e.g., teachers, GPs) not understanding the female autism phenotype.

Whitlock et al.'s (2020) study was the first study to examine whether primary school teachers (who play an important role autism identification and referral) show a gender bias when identifying autism in children. Limitations of the study include how a qualitative component could have been helpful, to understand the educators' responses further (Whitlock et al., 2020). Future research could also examine the same hypotheses with other gatekeepers to diagnosis, such as health care professionals (e.g., GPs), as previous research has indicated that they may fail to recognise different presentations of autism (Bargiela et al., 2016; Crane et al., 2018).

Whitlock et al. (2020) added that school staff were 'unlikely' to request further support from an EP or medical professional (which could potentially lead to diagnoses) after seeing the vignettes showing a female with the female autism phenotype. It is, therefore, crucial for EPs to support and develop understanding of the female autism phenotype, so school staff can better identify autistic girls and enable them to receive timely diagnosis and support. Importantly, the authors noted that school staff with personal experience of autistic individuals were better able to recognise autism, whereas autism training had little effect in this regard. Therefore, as EPs, we must try to ensure that support and training is valid, meaningful and impactful. As Whitlock et

al. (2020) explain, support and training could involve facilitating personal contact with autistic individuals.

Gray et al. (2021) conducted a UK-based study examining SENCOs' understanding of autistic girls in their LA. Data were collected through questionnaires, sampling 53 SENCOs across a mixture of Early Years, Primary and Secondary settings. The questionnaire was developed based on training on autistic women and girls from the National Autistic Society; a respected charitable organisation in the UK. Furthermore, parental voices were gathered via a group interview with three mothers of autistic girls. No fathers volunteered to participate in the study, which potentially would have provided a different perspective (Grebe et al., 2022). Gray et al. (2021) concluded that their SENCOs had an awareness of the typical male presentation of autism, but were not confident in recognising and supporting autistic girls. When asked about the foundations of their understanding of autism (not gender specific), 11% reported teacher training, and 79% reported work experience. Furthermore, 70% of SENCOs felt further training in this area would benefit them. Overall, this study highlights the importance of updating teacher training and ensuring continuous professional development for school staff (including SENCOs), who play a key role in a school in identifying and supporting autistic girls (Gray et al., 2021).

School transitions

The transition from primary to secondary school setting is a huge change for a young person, and can be one of the biggest hurdles in their educational journey (Zeedyk et al., 2003). While this transition can be positive, providing various opportunities (Coffey,

2013), it can also place considerable demands on an individual; socially, intellectually, structurally and emotionally (Zeedyk et al., 2003).

The transition can be especially challenging for autistic children, due to vast differences in the secondary school environment (versus primary) as well as the traits of autistic CYP (Makin et al., 2017). There are programs designed to support autistic children during this specific transition, such as STEP-ASD (Mandy et al., 2016). However, what happens to autistic CYP who are undiagnosed and lack access to such support?

The girls in this research were all undiagnosed during their major schooling transition (primary to secondary school). As such, they would not have 'benefited' from, or been supported in relation to, their autism diagnosis. To the best of my knowledge, no research has examined the school experiences of autistic girls undiagnosed when they entered secondary school, through gathering both the CYP's and their parent/carers' voices. Therefore, this research could potentially help EPs and schools develop awareness of what potential worries or needs for autistic girls could be and how they can address them.

Some academic studies have tried to unpick the elements linked to a successful primary to secondary school transition for those diagnosed as autistic. Limitations to these studies include, examining child (Mandy et al., 2016) or parent/carers (Dillon & Underwood, 2012) only; studies having small samples (Dann, 2011); examining experiences at one point in time (McNerney et al., 2015); or relying one specific type of methodology (Peters & Brooks, 2016).

Makin et al. (2017) conducted a mixed-methods study looking elements supporting a successful primary to secondary school transition in one LA in England, for a group of autistic CYP (13 boys, two girls). Pre-transition (final term of mainstream primary), the authors used semi-structured interviews; post-transition (the first term of secondary), they used questionnaires and interviews. Seven children transitioned to mainstream secondary, while eight transitioned into specialist provision. As well as gaining the CYP's views, they also interviewed their parents and teachers.

Results demonstrated that CYP felt the transition to be a negative experience (both in mainstream and specialist settings) and many discussed their general dislike of school, including ongoing challenges such as fears around losing familiar relationships from primary school. With regards to parental views, messages centred around striving for positive outcomes for their child yet struggling to get their children's needs met. From the teachers' perspective, timely preparation was key, including multiple visits to the new setting and potentially having a mentor to support CYP. Makin et al. (2017) conclude that the success of transition is strongly related to school and system level factors, such as communication between the two settings, timely school choice, and waiting for school placement.

2.4 Parent/carer voice

A key part of an EPs role is eliciting both the CYP and the parent/carers' voice. Considering Bronfenbrenner's ecological systems theory (2005), eliciting voice would encompass the 'mesosystem', by establishing, building rapport and a trusting relationship between parents/carers and school staff (for example to facilitate CYPs' needs, staff understanding, develop appropriate strategies and reduction of stress).

Academic literature highlights differences in how autistic girls navigate school versus home. As discussed previously, Tomlinson et al. (2020) conducted a systematic review of autistic girls' school experiences, identifying differences between the perspectives of school staff and parents/carers. These differences were evident in their 'school level' findings, which included difficulties between parents and schools linked to misunderstanding the specific needs of the girls (Cook et al., 2018; Moyse & Porter, 2015). As well as building strong relationships between parents/carers and school staff, understanding and awareness of how autism presents across sex/gender is key, as autism is commonly viewed as a 'male condition' by school staff (Tomlinson et al., 2020). Therefore, it is important to ensure strong positive relationships are built between parents/carers and school staff, to lead to better outcomes for autistic girls.

2.5 Pupil voice

The United Nations Convention on the Rights of the Child (UNCRC), Article 12 (United Nations, 1989, p.5) states that 'Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child'. This position is also reflected in England through the Children and Families Act (Department for Education, 2014) and the SEN Code of Practice (Department for Education, 2015), which place a duty on Local Authorities, to regard the 'views, wishes and feelings of children and their parents and young people' (Children and Families Act, Section 19, p.2). Consequently, all CYP should be given the chance to express their views, feelings and thoughts, yet autistic individuals are still routinely omitted from decision making (Pellicano et al., 2014).

Ensuring children's views are represented is empowering and supportive of mental health (Smillie & Newton, 2020). Yet most research on the educational experiences of autistic CYP is gained through the views of parents and professionals (Sproston et al., 2017), who may not directly represent the lived realities of the autistic people they support (Billington, 2006; Calder et al., 2013; Mackay & Parry, 2015).

Positively, there have been increasing examples of autistic CYP having their voices heard in academic research. As previously discussed, Moyse (2021) examined the experiences of autistic girls excluded from education, with her study being particularly significant due to the historical lack of research using autistic girls' voices to gain first-hand experiences regarding their schooling. Encouraging and supporting participation from autistic individuals has the potential to improve their lives (Fletcher-Watson et al., 2019). Additionally, as per ecological systems theory (Bronfenbrenner, 1979; 1989; 2005), it is crucial to gain CYP's experiences to support the development of school practice at the 'microlevel'.

Creative and diverse methods may be particularly helpful to gain autistic CYP's voices, as traditional methods, such as standard interviews, may not be suitable (Winstone et al., 2014). Academic research has begun to use various tools to enable CYP to express their views (Greathead et al., 2016; Harrington et al., 2014; Hill et al., 2016; Moyse, 2021). Talking mats, visual supports, schedules, and tangible activities have aided autistic pupils to express their educational experiences and ambitions (Cameron & Murphy, 2002; Dann, 2011; Hill et al., 2016, p. 201; Winstone et al., 2014).

Recent research has used a multi-method approach (interviews and a creative tool) to elicit autistic individuals' views. Specifically, Cunningham (2020) extracted the voices of 11 autistic pupils (eight males, three females) on what they felt an 'autistic friendly' primary school should consist of. The author used a two-step approach, initially using a group interview to explain the study and the 'three houses approach' to subsequently elicit the autistic pupils' views. The 'three houses approach' allows individuals to record their thoughts in a house of good things, a house of worries and a house of dreams (Cunningham, 2020). For most of the pupils, Cunningham scribed, and a few wrote their own responses, which helped if pupils were anxious. Indeed, it is important to offer flexibility when conducting research with vulnerable populations. Overall, Cunningham's (2020) approach was successful in gaining autistic pupils' views and it aimed to use their views as a stimulus for change, inevitably informing practice (in this case, how to make a primary school more autism friendly).

2.6 Bronfenbrenner's Ecological Systems Theory and Bio-ecological Model

As discussed in Chapter 2, the autism diagnostic criteria frames autism as a 'within child series of deficits. Evans (2017) explains that a deficit-focused definition reflects more on the society that has created it, than about the CYP it intends to describe. As EPs, we aim to look beyond 'within child' factors, and examine the whole environment, including the interacting systems that the CYP is embedded in. We commonly use Bronfenbrenner's ecological systems theory (1979, 1986) and, more recently, his bio-ecological model (2005) as a lens, encompassing strength-based approaches through which to support CYP and their families.

Bronfenbrenner's (1979, 1986) original ecological theory of development suggested that a person's development and social understanding was a consequence of their environment, which encompass a complex array of interacting systems. The model features the individual in the centre of the 'microsystem', which includes their distinct personalities, day-to-day setting, and key relationships (including at home and school). The next layer is the 'mesosystem', which links with the 'microsystem', through the relationship between home and school (for example, via communication between families and school staff). The 'exosystem' includes the connection between multiple environments and focuses on more indirect participation, such as wider country level aspects that do not necessary directly interact with the CYP. The 'macrosystem' is a larger system involving culture and politics (for example, country-wide policies on diagnosis and public views on autism). Lastly, the 'chronosystem' encompasses changes longitudinally, which could involve experiences across a lifespan (Bronfenbrenner, 1979, 1986). Due to the crucial links between these elements, it is important to ensure that as EPs we take a full systemic approach when examining the educational journeys of autistic girls, to improve their overall experience and support the girls and their families.

Bronfenbrenner updated his model in 2005, and developed 'the bio-ecological model', which can be used to understand the systems that influence an individual's development and actions. The bio-ecological model (Bronfenbrenner, 2005) includes four principles: Process, Person, Context and Time, or PPCT. Further, the model suggests guidance for each principle and their collaborations (see Figure 1).

Comparing both models, the systems from the ecological theory of development (1979, 1986) are expressed in the context principle of the bio-ecological model (2005), which puts the influence of each system alongside the impact of individual factors and time. Reflecting on the present research, the exchanges between the autistic girls and their parents, and the systems surrounding them (such as the school), would be called 'proximal processes'. Bronfenbrenner (1989) suggests that the more proximal, multifaceted, and constant the experience of an environment, the more likely it will influence development. This idea will be considered in the research, as the girls may have experienced multiple school settings.

Furthermore, the bio-ecological model (2005) distinguishes the influence of individual elements of an individual's traits. This view emphasises that the autistic girls and their parents/carers in my study will be impacted by their individual traits and resources, including biological, social, emotional and cognitive factors.

The final part of the updated model examines the influence of time on development, and how this interacts with the other systems. Examining this aspect from an individual level, as the sample comprises adolescent and young adult girls and their parents, thought must be given to the impacts of this period of their lives. Figure 1 applies Bronfenbrenner's bio-ecological model (2005) to the systems investigated for this study.

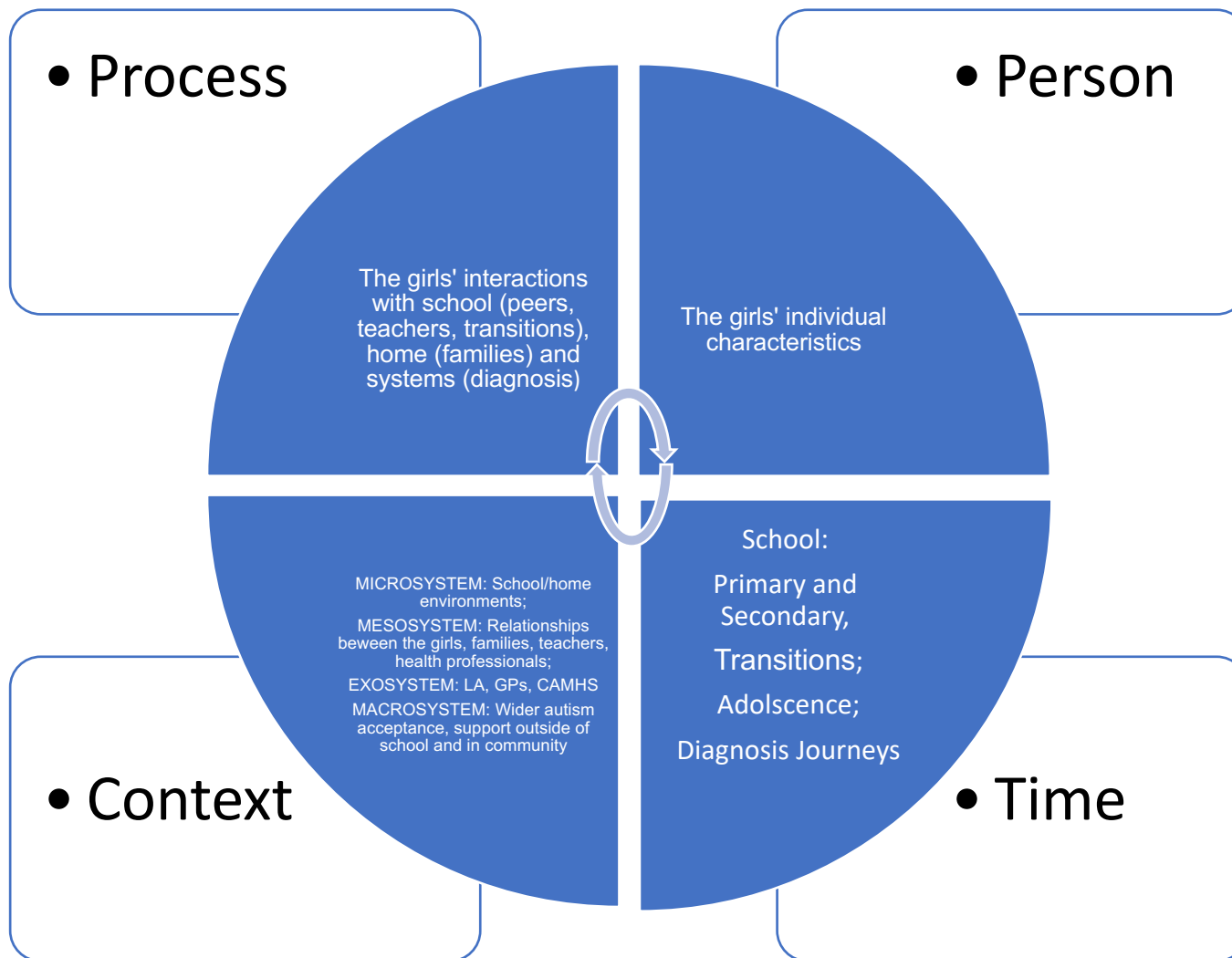


Figure 1: Applying Bronfenbrenner's bi-ecological model (2005) to this study

2.7 Research Aims and Questions

As discussed in Chapter 1, the main aim of this research is to understand the school experiences of a group of autistic girls who were diagnosed in adolescence, from the perspectives of the girls themselves (supplemented by narratives from their parents/carers). This research will further examine the girls' pathways to diagnosis and how this experience interacts with support received. Specifically, I will seek to address:

- 1) What was the girls' overall experience of school and school support: what worked well, what improvements could be made, and did this change over time?
- 2) What was the girls' pathway to autism diagnosis during their adolescent years, and how did this interact with experiences of school support: what worked well and where could improvements be made?

Chapter 3: Methodology

3.1 Introduction

This chapter begins by examining the research from a theoretical perspective, and discusses the epistemological and ontological position of the research. Following this introduction, the chosen research design is examined and justified, and the specific methods used are discussed. Next, the details of the participants and how they were recruited are explained, followed by the data collection process. Following this, the materials and ethical considerations are outlined. Finally, the 'pilot' study is explained, and the data analytic process is discussed in depth.

3.2 The researcher's approach

Theoretical Perspective

This research adopted a multi-informant approach, examining the school experiences of autistic girls and their parents/carers using Bronfenbrenner's ecological systems theory and model (Bronfenbrenner, 1979; 1986; 2005) as a theoretical lens. This theory was chosen as the research examines school experiences at multiple levels, whilst considering the interrelated systems around the girls themselves.

Epistemology and Ontology

Braun and Clarke (2013, p.29) explain that 'epistemology is about the nature of knowledge'. As this research considers the experiences of girls and their parent/carers at multiple levels (as per Bronfenbrenner's eco-systemic model), the research takes a 'social constructionist' stance and epistemological position⁵. The chosen position

⁵ Given that this research is adopting the constructionist epistemological position, it is important that as a researcher I acknowledge my own understanding of the world, see 4.5: Researcher background

implies that the world and knowledge is socially constructed and common values are generated by groups, individuals and cultures via our collaborations (Fox, Martin & Green, 2007). Research that holds this epistemological perspective recognises different ways of constructing social experiences, to investigate their circumstances and explore their consequences for human experience and society (Willig, 2008). As the current research is exploratory and examines the experiences of a specific sample of autistic girls and their parents/carer using their own voices, it was deemed the most suitable stance.

Ontological positions in research detail the connection 'between the world and our human interpretations and practices' (Braun & Clarke, 2013, p.27). Willig (2008) explains that the ontology of a study can be either 'relativist' or 'realist', with Braun and Clarke (2013) explaining that most quantitative research has a realist ontology. The current study takes a 'relativist' ontological approach, as it examines individual experiences and data consist of a variety of interpretations. Braun and Clarke (2013, p27) explain that relativism 'argues there are multiple constructed realities', which aligns with the social constructivist epistemological position of this research. Furthermore, this approach and position align with the methodology used in this research. For example, constructionist methods of gaining pupil voice, namely personal construct psychology, were used with participants (see Section 3.4).

3.3 Qualitative research design

The aim of this research was to gather autistic girls' lived experiences in relation to their school journeys, and to examine how this links with their diagnosis, with the view to understand where potential improvements could be made. By using a multi-

informant approach (i.e., also eliciting the views of parents/carers), I aimed to provide further context for the girls' experiences (considering Bronfenbrenner's eco-systemic model, which examines systems around an individual).

I considered gaining the perspectives of teachers/school staff, but due to the ongoing repercussions of the COVID-19 pandemic, such as high absentee rates in schools and extra pressure on school staff, this was felt to be unreasonable. Furthermore, it was likely to be difficult to identify one teacher to participate in relation to each participant: each young person would have left primary school a while ago, and there is often a broader range of teachers in secondary school.

As discussed previously, EP practice involves ensuring that the CYP's voice is gathered and heard, as emphasised in the current SEN Code of Practice (DfE, 2015) and the Children and Families Act (DfE, 2014). This research therefore gathered first-hand experience from the girls and their parents/carers, allowing an understanding of the girls' educational experiences and how this links with pathways to obtaining an autism diagnosis. Parents likely played a crucial role in accessing a diagnosis (Crane et al., 2016). Therefore the inclusion of the parents' voices (to supplement the girl's experiences) allowed any gaps to be filled.

Considering the focus of this research on the autistic girls' experiences, alongside the social constructionist stance and epistemological position, a qualitative methodology therefore supports the overall research aims. Braun and Clarke (2013, p6) explain that in qualitative research 'there are multiple versions of reality – even for the same person

– and that these are very closely linked to the context they occur in’. Throughout this research, we are considering the girls’ (and their parents/carers’) versions of reality.

Qualitative researchers must be very conscious of their biases and influences on their data. Braun and Clarke (2013) discuss how qualitative research is a ‘subjective’ process, as we naturally bring our own backgrounds, history, views, values and experience to our research, as do the participants (see Section 1.5). As such, researchers need to be reflexive throughout the research process, for example, by keeping a journal or being explicit about one’s positionality. The steps I took to uphold these principles are discussed further in Section 3.9.

Interviews

Data were collected using semi-structured interviews, which was deemed appropriate, as this research investigates an ongoing situation (the girls’ and parents/carers’ experiences and views); not experimental, controlled circumstances.

Participants were recruited across England to understand experiences across the country. As such, an online interview seemed most feasible. An online interview involves the same method as an in-person interview and asks participants to explain their experiences about a particular aspect (Salmons, 2014). More specifically for autistic individuals, an online interview enables the external environment to be managed, e.g. sensory overwhelm can be controlled, or the impact of in-person social communication energy consumption can be reduced (Blume, 1997; Müller, Schuler, and Yates, 2008).

Gathering the girls/parents' voices

As well as semi-structured interviews, a psychological tool ('the ideal/non-ideal school') was used, which is based on personal construct psychology (PCP) – see page 55 for a detailed description. It was important to choose an inclusive tool to gather the girls' voices, to ensure they could express their thoughts, feelings and experiences as comfortably as possible. This approach also gave girls the choice of the medium in which to tell parts of their stories.

In the academic literature, a variety of tools are evidenced by EPs to gain CYP's voices. Harding and Atkinson (2009) examined how EPs obtain CYP's views by conducting a focus group in a LA and identified five main practises:

- Discussion-based methods (including direct questioning using the CYP's SEN statement – now referred to as an Education, Health and Care Plan or EHCP)
- Task-related procedures (such as sentence completion tasks or questionnaires such as *Myself as a Learner*, Burden, 1998)
- Therapeutic-based approaches (e.g., PCP, solution focussed methods such as scaling, Beaver, 1996)
- Indirect methods (e.g., Asking family or referring to children's writing)
- Measures for CYP with additional/language communication needs that use visual prompts to elicit views (e.g., *Bears Cards*, St Luke's Family Care, 1997 and *All about me profile*, NSPCC, 2008)

In Harding and Atkinson's work, various factors influenced participants' decisions on which technique to use, such as time limitations, or features such as the age or type

of need that the CYP was identified with. This finding mirrors my observations of main grade EPs, and I would normally make a professional judgement in collaboration with my supervisor with regards to the specific tool deemed most suitable for case formulation.

A more recent study by Smillie and Newton (2020) surveyed 73 Welsh EPs in their practice. Therapeutic-based approaches were most frequently used frameworks for exploring pupil views. However, as EP practice is influenced by a variety of factors, including time and financial constraints, the methods used may not be representative of the 'best' methods of achieving participation.

As a trainee EP, I have commonly used evidence-based therapeutic-based approaches, specifically PCP methods ('the ideal/non-ideal school'), with autistic CYP. For example, Attwood (2006) stated that PCP is suitable for autistic individuals and Moran (2006) supported the use of PCP to elicit autistic children's views, as described further below. Furthermore, with regards to structured drawing tasks, literature shows that autistic children can and do use drawings throughout structured activities to explain what they know, and are reliable in what they recognise about their drawings post-activity (Allen, 2009). Therefore, I felt that a PCP approach would be most suitable for the current research.

PCP was first proposed by Kelly (1955), who explained that we build our own unique understanding of reality (a construct system) from our own experiences. Each construct within a system is a basic unit of interpretation and is binary e.g., good/bad, worst/best. PCP methods are widely discussed in the literature, and Ravenette (1999)

was prominent in using drawings with CYP to elicit their construct systems. Moran (2001, 2006) expanded this work, developing the widely used 'ideal self-drawing technique' to explore self-identity (Moran, 2001). In this task, an individual draws their non-ideal self and then contrasts this with their ideal self. The perception of self is then explored using scales developed in the task, for example if a characteristic of non-ideal is 'lonely' and ideal is 'sociable' then this would constitute a construct that the individual can rate themselves against. It is then possible to explore what the individual and others can do to make changes or move up the scales. The facilitator acts as a scribe during this task, which takes pressure away from the individual, allowing them to focus purely on the drawing activity. This tool also supports CYP to feel empowered, and to recognise that their views are important (Moran, 2001; 2006).

The 'ideal school/non ideal school' was later developed by Williams and Hanke (2007) in collaboration with Moran, based on the 'ideal self drawing technique', and is used widely by EPs in their work with CYP. Williams and Hanke (2007) initially produced the tool to conduct research to obtain the views of fifteen autistic pupils in mainstream school with regards to what is important for them in a school. They concluded that the tool was valuable for the CYP in the study, allowing all involved to express their views. Further, school staff provided positive feedback about the activity, with many specifically highlighting the benefit of the 'open-ended nature' of the task.

Given the above, it was decided that a PCP tool, 'the ideal/non-ideal school', would be a supportive, accessible and inclusive method for my participants (see Appendix 13). Additionally, the tool aligns with a social constructionist perspective, as the girls

are describing their 'ideal' and 'non-ideal' classroom and school, allowing their voices to be centred using different methods (interviews and the PCP tool).

Participatory approach

Fletcher-Watson et al. (2019) define participatory autism research as, 'incorporating the views of autistic people and their allies about what research gets done, how it is done and how it is implemented'. It is important to note that there is no 'one right way' of conducting participatory research as fundamentally 'participatory experience is not simply a method or set of methodologies, it is a mind-set and an attitude about people' (Sanders, 2022, p.1). For this research, I have taken steps towards using a participatory approach. Initially, meetings took place between myself, my supervisor and the CEO of the Autistic Girls Network (AGN), Cathy Wassell, (CW), who is a neurodivergent parent of neurodivergent children), to co-construct the project; discussing the current gaps in the literature regarding autistic girls, and issues that were arising among their large network. These priorities were used to ensure that the project was guided by the priorities of the autistic community. AGN is a charity that aims to support autistic girls and their families, including signposting to relevant support networks and providing support through their active private Facebook group. Additionally, AGN actively campaigns for recognition and diagnosis of autistic girls. CW and I liaised during the data collection phase, and we had reflexive discussions surrounding the themes and subthemes; whether these reflected the experiences of the broader network and what the implications of the findings were. Importantly, this research was time-limited and, ideally (if there were no time constraints), I would have sought an autistic panel to support my study and review the research as it unfolded.

3.4 Materials

Interview schedules were developed by reviewing previous literature and through conversations with CW (see Appendix 6 and 7). The interviews included mainly open-ended questions and a few closed questions [note: the closed questions were mainly used in ‘Part B: Demographics’]. The interview schedules were structured into five parts:

Section	Summary
1) <i>Part A: Briefing and rechecking consent</i>	The interview began with a brief introduction about the research, expressing gratitude for participation, checking their completed consent form, providing an overview of the structure, reminding participants of ethical implications and the consent traffic light cards, and ensuring participants were comfortable to begin.
2) <i>Part B: Demographics</i>	‘Part B’ involved gathering simple demographic information – such as the type of secondary schooling provision attended.
3) <i>Part C: Schooling experience</i>	Part C involved discussing school experiences, which began with questions relating to the ‘ideal school activity’ and then moved onto open-ended questions.
4) <i>Part D: Autism Diagnosis</i>	Part D aimed to understand the pathway to diagnosis.
5) <i>Part E: Ending</i>	‘Part E’ involved checking whether there were any further questions and thanking those involved for their participation.

As well as the interview schedule, the girls were provided with the 'ideal/non-ideal school' activity (see Appendix 13) in advance of the interview. This activity allowed the girls to draw (or write), about a school 'they would not like to go to' and a school 'they would like to go to'. This process included thinking about how the school looked, the adults and children in the school, and what they would be doing in this setting. Using this tool allowed the girls to explore their thoughts around the research topic in their own time.

During the interview, the girls used the 'ideal/non-ideal school activity' to structure their responses and reflect on the activity. Interestingly, when asked about the activity, seven participants said they preferred to write their responses rather than draw and only one participant said they liked drawing. Furthermore, five participants said they found the activity 'easy', and Sas commented, 'it was fairly easy but it did bring up strong emotions'. One participant had recently used the tool during other research. It was interesting to gather these data, as the ideal/non-ideal school is a tool that I use in EP practice with CYP (both autistic and non-autistic); see also Appendix 14.

Following the interview, the girls were asked if they wished to share their drawings/writing from the 'ideal/non-ideal school activity' and all were willing to share. Most of the girls decided to write (and not draw), therefore the drawing parts of the activity was used to facilitate discussion and conversations during interviews; it was not 'analysed' per se.

3.5 Participants

The aim was to recruit 10-12 autistic girls and their parents/carers. Autistic girls can be difficult to recruit as some may lack a formal diagnosis (Gould & Ashton-Smith, 2011). Initially, the sample was to be obtained through networks such as the AGN, Ambitious about Autism Youth Network, Autistica and through SENCOs/EPs in my current LA on placement. However, I began recruitment on the AGN's social media pages (with CW's permission) and the sample was obtained using these adverts and then snowballing (e.g., word-of-mouth from other participants). While I initially approached other networks, the advert was not circulated through these routes especially as other organisations posed barriers with regards to sharing the advert (e.g., some met capacity with helping promote research).

Recruitment of autistic girls

Participants were chosen through purposeful and convenient sampling methods, on the basis that they had received an autism diagnosis in adolescence, were aged 16-25 years of age, were born female and resided in the United Kingdom. The target age of 16-25 years was felt to enable participants to reflect on their schooling across the entirety of secondary school. This age range excluded individuals who had disrupted Secondary school education due to the COVID-19 pandemic (e.g., school closures, limited access to services and family support during lockdowns; Pavlopoulou, Wood & Papadopoulos, 2020). Importantly, the study was open to those who were born female but did not necessarily identify as female at present. The reason for this decision was that autistic people are more likely than neurotypical individuals to identify outside of the gender binary (Strang et al., 2020). One participant who enrolled for the research noted on their demographic form that they identified as non-binary.

To respect their wishes to participate and to ensure inclusion in the study, I felt it was important that they were still eligible to participate. I therefore use the term 'girls' throughout this thesis (in keeping with the recruitment materials), but it is important for me to acknowledge that this term may not resonate with all my sample.

Recruitment of parent/carers

Parents/carers were chosen based on the understanding that they had a daughter who was diagnosed during their adolescent years and currently 16-25 years of age. They were also required to provide consent for their daughter's participation if their daughter was under the age of 18 years.

3.6 Data Collection: A two-step Approach

An advertisement was circulated that contained information about the study, along with a weblink and QR code that linked to the online survey platform Qualtrics (see Appendix 1). The Qualtrics link allowed participants to register their interests and featured information sheets (Appendix 2 and 3) and a consent form to sign (Appendix 4 and 5). Interested individuals were sent an introductory email with my One-Page Profile (See Appendix 12). The participants were also given three options of how to participate: interviewed by me, by their parent/carer, or by writing their responses (see Figure 2).

Once participants specified their preference, they were sent the interview schedule (see Appendix 9 and 10) in advance, alongside the 'ideal/non-ideal school' activity (see Appendix 13) and a set of traffic light consent cards (for participants to show their

readiness during interview; see Appendix 11). Ultimately, the cards provided the autistic girls and their parents/carers with another tool to express their wishes/consent.

If the participant was under 18 years of age, consent had to be obtained from a parent/carer before proceeding. All the girls were asked if they wished for their parent/carer to be interviewed at a different time point after their interview.

Figure 2: Data Collection Process

- 1) Participants read the information sheets and completed a consent form online via the advert link/QR code.
- 2) I received and reviewed the consent form and contacted the interested participant. I introduced myself, sent my one-page profile and described next steps. I also check with regards to the girls' ages (if under 18, their parent/carer needed to give consent for them to proceed).
- 3) I also asked girls if their parent/carer wished to participate; if so, they were asked to complete the consent form and I contacted them directly for an interview after the girls' interview was completed.



The participant then chose whether to:

- 1) Be interviewed virtually by me
- 2) Be interviewed by their parent/carer (this would be recorded and sent securely to me)
- 3) Write their responses

If they decided to be interviewed by me, they completed the 'ideal school activity' before we met.

If they decided to be interviewed by their parent/carer, then this needed to be recorded and shared with me later for transcription purposes.

If they decided they did not want to be interviewed, but would rather write their responses to the questions, these were completed and sent back to me.

Final sample

In total, 64 people registered their interest. Of these, two were outside of the age range and five were outside the UK, so these participants were ineligible. I contacted all other interested participants and followed up with friendly reminder emails to see if they wished to participate. Some participants who initially expressed interest did not respond further when initial contact was made; others changed their minds about participating; and others had conflicting priorities in their lives at that point in time. In total, 13 participants decided to take part.

The 13 participants comprised eight girls and five parents (two mothers, one father and one couple who attended the interview together to share their experiences). Half of the girls had their parents participate. Of the girls, four chose to attend a virtual interview and four decided to write their responses in their own time. All parent participants chose a virtual interview. All girls were assigned a pseudonym, some chose these whilst others wanted me to choose. As discussed earlier, it should be emphasised that the objective of this study is to hold the girls' voice at the centre, and the parents' interviews are a supplement to their experiences.

At the time of the study, the girls ranged in age from 16-25 years of age, and all had attended mainstream school, apart from one participant who was home-schooled for their final two years of school. All participants were white, born female, clinically diagnosed as autistic during their secondary school years, and attended secondary school in the United Kingdom (see Table 1).

The girls' interviews varied between 33 minutes and 1 hour 19 minutes. The parents' interviews were between 27 minutes and 1 hour 32 minutes. Participants were given the option to turn off their cameras during the online call. It is worth noting that all participants seemed to enjoy the process of contributing to the research, and their dedication and advocacy was evident.

Following the participants' input, I sent a thank you email to all involved, and I asked if they would like to receive a copy of the thesis when it was completed, which they enthusiastically requested.

Table 1: Participant Information⁶

Pseudo name	Gender	Age	Ethnicity	Schooling	Age received diagnosis	Diagnosis: Were school involved?	Interviewed or Wrote Responses	Parent/carer participation
Girl 1 'Alice'	F	18	White	Mainstream	15	Started from CAMHS referral, then went Private	Interviewed (Virtual)	Yes (Alice's mother) – interviewed virtually
Girl 2 'Alex'	Non-Binary	18	White	Mainstream	17	Started from CAMHS referral and diagnosed by CAMHS	Interviewed (Virtual)	No
Girl 3 'Adalyn'	F	16	White	Mainstream	(Secondary School)	Went Private	Wrote responses	Yes (Adalyn's mother and Adalyn's father) – interviewed virtually
Girl 4 'Gemma'	F	25	White	Mainstream	17	Guidance counsellor supported assessment	Wrote responses	No

⁶ All participants were assigned female at birth and now identify as female except for one participant who was assigned female at birth but now identifies as non-binary (and uses they/them pronouns).

Girl 5 'Harriet'	F	18	White	Mainstream	17	Parents advocated and got diagnosis when diagnosed with chronic illness	Interviewed (Virtual)	Yes (Harriet's father) – interviewed virtually
Girl 6 'Kirsty'	F	18	White	Mainstream	18	CAMHS/Family supported diagnosis, went privately	Interviewed (Virtual)	No
Girl 7 'Rebecca'	F	17	White	Mainstream then home-schooled from Year 10 onwards due to anxiety	(Secondary School)	CAMHS	Wrote responses	Yes (Rebecca's mother) – interviewed virtually
Girl 8 'Sas'	F	22	White	Mainstream	16	Mother supported diagnosis, obtained privately	Wrote responses	No

3.7 Ethical approval

Ethical approval was obtained via the Department of Psychology and Human Development at IOE (See Appendix 31). The British Psychological Society Code of Ethics and Conduct was followed, BPS (2021).

Prior to participation, each participant was briefed on the study through a comprehensive, yet accessible, information and consent sheet (see Appendix 2 and 3) and was given a consent form to sign (Appendix 4 and 5). Participants were given ample time to review the documents, ask questions and they were provided with my supervisors' contact details.

Furthermore, participation was voluntary, and all could withdraw from the interview at any point. They were also informed that the information provided would be anonymised, and any data recordings destroyed at the end of the project. As per UCL GDPR policies, anonymised research data is kept on file for at least ten years.

At the beginning of the interview, participants were reminded of the ethical considerations, including that they were not obliged to answer any question they were uncomfortable with, that data would be anonymised, and that they could stop the interview at any time they wished to. Further, if participants demonstrated anxiety in response to questioning, they were told they could use the consent traffic light cards (see Appendix 11) and were reminded of avenues of support. Additionally, participants were informed that confidentiality would only be breached if there was a safeguarding

concern or child protection risk; if this occurred, I would contact my supervisors immediately.

The girls who participated could have been vulnerable, as we know autistic CYP frequently encounter co-occurring mental health concerns (Stadnick et al., 2022). I am a qualified primary school teacher, have DBS approval and have worked extensively with CYP for the past 14 years, which meant I felt confident in working with this group. All research tools were discussed and 'piloted' in collaboration with the Head of the AGN (see Section 3.8) to ensure they were suitable for autistic CYP. I tried to ensure all tools were designed in line with best practice for the participation of autistic people in research (see Section 3.3).

Data were gathered using a Dictaphone. If the girls chose to write their replies, they could return them securely via email or by post, based on personal preference. All participants chose email, and none chose to be interviewed by their parent/carer.

Once data were transcribed and anonymised for subsequent analysis, original recordings were deleted. All data gained for this research was obtained with full consent of the participants, not altered in any form and transcribed word-for-word (see Appendices 16, 17 and 18 for example transcripts).

3.8 Piloting discussion

To ensure the study was ready to be disseminated and supported by the autistic community, initially I sent the outline of my planned study to the Head of the AGN (see

Appendix 15). We then agreed on a date for a 'pilot' study and discussion after I received ethical approval. Due to time constraints, it was decided that reviewing the interview with CW was all that was practical, but helpful as she herself is neurodivergent, female, and with extensive experience of supporting families of autistic girls (in a personal and professional capacity).

During the 'pilot', we jointly reviewed the information sheet and consent forms, and a few changes were suggested around terminology on the demographic form, to ensure they were inclusive and clear (e.g., adding in other schooling options such as home-schooling, alternative provision).

We then discussed interview schedules, and CW encouraged me to edit the questions slightly to ensure 'context' was fully explained and that examples were given, so the girls could fully understand what was being asked of them. One example included using a checklist with examples of transition support, as CW emphasised that most girls probably would not have had any support or know of different types of support. Additionally, with regards to the 'ideal/non-ideal school activity', CW suggested providing an example of a completed version, so participants would have an example to follow if needed.

As another suggestion following this conversation, I originally planned to send out the packs by mail, but CW encouraged me to think about offering a virtual option that the girls could access. Furthermore, CW explained that her autistic daughter would not like to be interviewed by someone else or her parent, so she suggested adding in another option: that the girls could write their responses and share them with me. This

option proved popular, and 50% of the sample chose to write and return their responses.

Original interview schedules are in Appendices 6 and 7, and modified versions are in Appendices 8 and 9.

3.9 Data Analysis

Thematic analysis (TA) is 'a method for developing, analysing and interpreting patterns across a qualitative dataset', that encompasses 'systematic processes of data coding to develop themes'. It is these themes that are 'your ultimate analytic purpose' (Braun & Clarke, 2022, p.4).

TA was selected as the analytic method as data were qualitative and as this research involves examining participants' life experiences and views. Braun and Clarke (2017) explain that TA is the ideal method for identifying patterns within and across this type of data. Furthermore, as previously discussed, this thesis holds a social constructionist position, which emphasises the importance of each individual's experiences and view of the world.

Reflexive TA

The specific approach used for analysis was 'reflexive' TA, which differentiates the method from other TA (Braun & Clarke, 2019). Reflexive TA is 'not just one approach' (Braun & Clarke, 2022, p9) as each researcher's approach and study aims will be unique. Furthermore, as a researcher using reflexive TA, our orientations can change

as analysis progresses. Ultimately, being reflexive means taking a 'critical reflection on your role as a researcher, and your research practice and process' (Braun & Clarke, 2022, p5), throughout the entire process.

Before undertaking reflexive TA, it was important to consider how to be a reflexive researcher. Braun and Clarke (2022) suggest that journaling can help to engage with personal reflexivity, which includes social positioning, personal background, life experiences, and political and ideological commitments. I therefore acknowledge that the themes could be influenced by own experiences (see Section 1.5), and journaled throughout the process (see Appendix 20). By sharing the transcripts and working alongside my research supervisor throughout data analysis, we were also able to openly question my choices in relation to my positionality during coding.

Stages for analysis

Data analysis followed Braun and Clarke (2022)'s six stage analytic process. Braun and Clarke (2022, p6) emphasise that these six stages are not 'the method' – the phases enable you to make sense of the data, but the method consists of the process plus surrounding 'values, assumptions and practices'. Such 'values, assumptions and practices' can be explained under the umbrella term 'qualitative sensibility', which Braun and Clarke (2022) explain as being able to create research questions suitable for qualitative research.

In terms of my position as a researcher and my experience with qualitative research, I previously used TA methods (Braun & Clarke, 2006; Braun & Clarke, 2013) in my

MSc dissertation (on parents' views on autism diagnosis and post-diagnosis support in the Kingdom of Bahrain) and my Year 1 doctoral project (on parents' experiences on home-schooling a child with autism during the 2020/2021 COVID-19 lockdown in England). As their TA method and approaches have evolved since then, I used Braun and Clarke's 'ten core assumptions of reflexive TA' (2022, p8) to inform my analysis (see Appendix 30).

It should be noted that this study takes an inductive exploratory approach, and not a theoretical deductive one, therefore the coding process and themes are strongly connected to the data (Braun & Clarke, 2006; Braun & Clarke, 2022). This approach was reflected during the interview process and data collection; as parents and girls were interviewed, I was cautious to listen for their 'open story', which Braun and Clarke (2006) emphasise the importance of.

Braun and Clarke (2006) also explain that codes and themes can be compiled into two groups, semantic or latent. Braun and Clarke (2022) more recently describe semantic and latent levels as 'two ends of a spectrum' (Braun and Clarke, 2022, pg. 57), noting that both can be linked in one analysis, rather than choosing one level. This research has codes predominately at a latent level, as the research philosophy does not predominantly concentrate on a precise ideology but tries to explore descriptively the school experiences of girls and their parents, which is a developing area. Essentially the analysis aims to find meaning at the more implicit level, rather than the explicit (Braun & Clarke, 2022).

In terms of the qualitative framework, Braun and Clarke (2022) describe two types: experiential and critical. This thesis takes an experiential qualitative framework, in which the analysis tries to explore individual's perspectives (the girls and their parents' experiences).

Lastly, Braun and Clarke (2022) describe a final variation of reflexive TA, in terms of theoretical frameworks: realist/essentialist versus relativist/constructionist. As previously noted, this research takes a social constructionist stance, which links to Braun and Clarke's view that a relativist/constructionist analysis tries to understand realities described in data; in this case, the girls' and their parents' first-hand experiences.

Next, I consider how Braun and Clarke's six stages of thematic analysis apply to my own analytic process:

Phase 1: Data familiarisation

I transcribed each interview verbatim (see Appendices 16, 17 and 18 for examples⁷); listening repeatedly and becoming deeply familiar with the content of the interviews. I printed each interview and re-read them with the audio transcript. Alongside this process, I made notes about any insights related to each data item and the broader data set.

⁷ For confidentially purposes, I have not provided a full transcript.

Phase 2: Coding

I read through all transcripts, line by line, and started to write codes and code labels (descriptions) on the transcripts. I looked for parts of the data that were 'interesting, relevant or meaningful' (Braun and Clarke, 2022, p.35), and that broadly related to the research questions. I then re-read my transcriptions after noting codes and code labels, to ensure I had a 'fresh perspective' on the data (Braun & Clarke, 2022, pg. 70). Alongside highlighting the transcripts, I drew an initial spider diagram of the codes (see Appendix 22), to help me be reflexive whilst both journaling and drawing the codes from the participants' stories. Importantly, Braun and Clarke (2022) emphasise that the process is not about decreasing data, but about being analytic and systematic.

I started by coding two of the girls' interviews (one written, one verbal) and one parent interview, drafting first codes and sub-codes, and sharing these with my supervisor (see Appendix 19). Originally, I considered inter-rater reliability, but learned that in reflexive TA having only one coder (the researcher) is standard practice (Braun & Clarke, 2022). It is not recommend to use several coders (as other methods of TA do), to gain 'accurate' analysis, as the process of reflexive TA is subjective. Despite the above, Braun and Clarke (2022) mention that having more than one coder can be helpful to have deeper and more multifaceted insights into the data.

I continued with the next ten transcripts and, once I had coded these individually (as per Appendix 19), I refined these into two more precise documents: one for the girls and one for the parents (see Appendix 21). This process allowed me to look deeper at the codes and I met again with my supervisor for a discussion. Following this

meeting, I felt ready to progress onto the next stage of the process, in devising initial themes.

Phase 3: Generating Initial Themes

There are various ways of conceptualising themes, but specifically for reflexive TA, 'a theme has to capture a wide range of data that are united by, and evidence, a shared idea' (Braun & Clarke, 2022, p.77). Braun and Clarke (2022) add that when conducting reflexive analysis, it is important not to simply use a 'topic summary' as a theme, as they explain that these do not identify 'a shared meaning or idea'. Instead, a reflexive TA theme is a 'pattern of shared meaning organised around a central concept' (Braun & Clarke, 2022, p.77). Therefore, as I was reviewing and re-reading my codes and code labels, I tried to not just consider my research questions, but think about what message and story was coming through from the participants and their shared experiences.

Braun and Clarke (2022) acknowledge that this phase will involve developing initial themes that could change as analysis progresses. Braun and Clarke (2022) further discuss how this process specifically includes looking at the codes to find 'similarities of meaning' (p.79), and 'clustering together potentially connected codes' (pg. 79) to make candidate themes, all while reflecting on how they are linked to the research questions and the broader analytic process. I was cognisant that if interesting ideas were repeated by an individual participant but not across the data, they were individual experiences. Such experiences are not considered 'patterned meanings' and are therefore not a basis for a theme.

For initial theme development, I cut out each initial code I identified (see Appendix 23) and started to assemble them on a large sheet of paper (see Appendices 24 and Appendix 25). This process allowed me to explore and cluster codes into general patterns, all of which contributed to a central concept and linked to my original research questions.

I started to merge the initial codes into initial themes (see Appendix 26), and I met with my supervisor to discuss. My supervisor advised me to reflect on the girls' story and what was important to them, without focusing too narrowly on organising ideas around the research questions. I felt these suggestions fit well with Braun and Clarke's (2022) process of reflexive TA, in which they explain the process is an ongoing one, noting how the themes will shift and change at this early phase.

Braun and Clarke (2022) recommend drawing 'thematic maps' at this stage, which help to start to tell the story of the data and how the themes link to one another. In the first draft of the (girls) thematic map, the three core ideas (or themes) are in circles, and they are 1) 'The environment plays a key role in how I learn', 2) 'My relationship to the world' and 3) 'Adapting to a new identity'. Additionally, potential subthemes are in the rectangle boxes, with single or double lines depending on how 'important' they are to each theme. As can be seen from Appendix 27, the ideas all connect in some form, and start to tell a story of the data. As Braun and Clarke (2022) emphasise, this activity allows the researcher to start to understand the potential layers in the analysis and suggest using different lines to highlight these layers (single, double etc.). They emphasise that this is a working map, which will change and fluctuate, and the themes

(specifically, candidate themes) are all tentative at this stage of the analysis. I repeated the exercise of visual mapping for the parent data.

Braun and Clarke (2022) recommend between two and six themes (including sub-themes) for a report of 8,000 words. However, if writing a thesis above 10,000 words, more themes could be considered. Either way, a 'large number of themes can result in a thin and underdeveloped analysis' (p.91).

Phase 4: Developing and reviewing themes

Phase 4 involves expanding on the themes developed in Phase 3, by reviewing all the coded data and the full dataset. Ultimately, it is about ensuring any patterns can be further developed and that a 'validity check' is carried out whilst reviewing the tentative themes. Successful TA involves developing themes that centre on an individual main idea (and are not topic outlines); are rich and different; are not too multi-faceted; and each theme is unique (Braun & Clarke, 2022).

I produced more refined Thematic Maps for the Girls and Parents (see Appendix 28). Following discussion, my supervisor suggested merging the two sets of data onto one thematic map, so that the parents' data (in yellow) supports that of the girls, and that the girls' themes are central (see Appendix 29).

Phase 5: Refining, defining and naming themes

Braun and Clarke (2022) describe this phase as expanding on the current themes and undertaking more refined analytic work. They emphasise that this process should include writing 'theme definitions', which they describe as 'an abstract for the theme – outlining the scope, boundaries and core concept of the theme' (p.108).

I therefore re-listened to recordings, re-read the data and original codes, and reviewed the current Thematic Map (Appendix 29). I looked at each potential theme, and mapped it out with the codes and data, ensuring I could write a brief theme definition for each. As an example, for 'Theme 1: The environment plays a huge role in how I learn', I summarised this with regards to the barriers and impact of how the school environment (in the classroom and building) can affect and block the girls' ability to learn. This process allowed me to ensure that each theme told the girls' stories. I also found there were some codes that could be 'let go', which Braun and Clarke (2022) emphasise is important.

After completing this process, I revised the Thematic Map (see Figure 3 in Section 4), considered the names of each theme, and included the parents' subtheme (in yellow on Figure 3), supporting the girls' subthemes (in blue).

At this stage, I met again with CW (Head of AGN) to review my themes. We reflected and discussed the themes and subthemes, alongside the data gathered.

Phase 6: Writing Matters for Analysis

As Braun and Clarke (2022) emphasise, during this process the researcher is effectively writing up alongside each stage of the methodology (see Appendices 19 and 20). Ultimately, this phase is about putting the girl's stories together and telling those journeys.

Chapter 4: Results

4.1 Introduction

This chapter presents the findings from the analysis of 12 interviews, with the girls' interviews (n=8) being the 'central voice', and the parents' interviews (n=5) supporting these. Data were analysed using reflexive TA (Braun and Clarke, 2022), in which I developed four themes, including five subthemes from the girls' data (supplemented by the parents' data) and one subtheme exclusively from the parents' data (see Figure 3). These themes and subthemes are presented next.

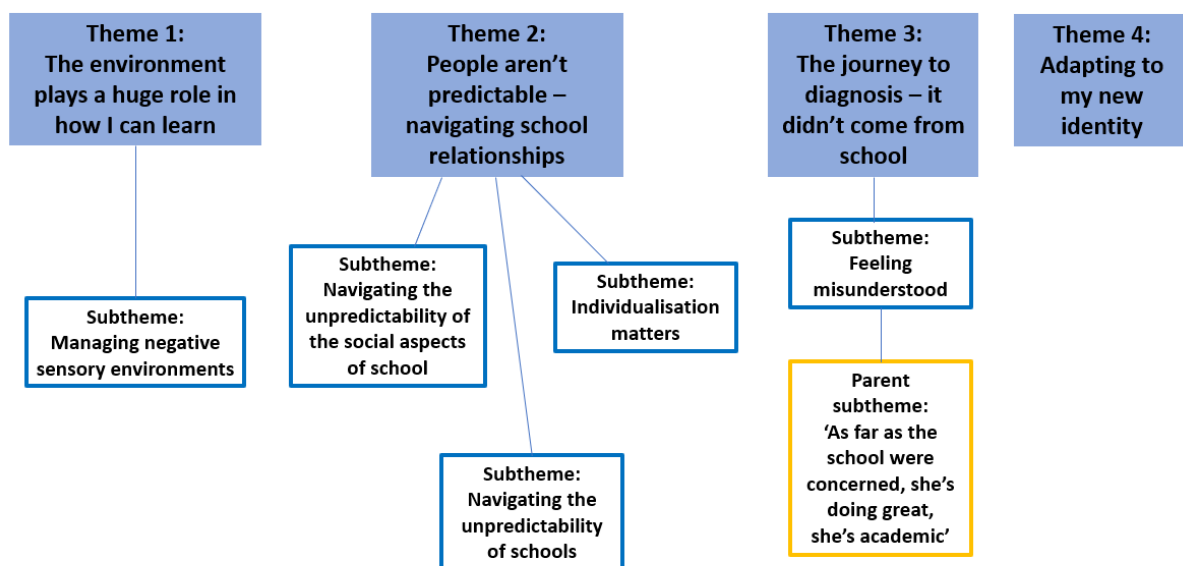


Figure 3: The 'Final' Thematic Map

4.2 Theme 1: The environment plays a huge role in how I can learn

Theme 1 includes the girls' reflections on how the school environment (e.g. the school grounds, the classrooms) played a crucial role in how they felt and therefore, could learn. The girls describe how the physical environment and sensory elements (such

as, proximity to people, bright lights, and sensitivities to noise) influenced their entire learning experience.

'I've been done a disservice by the environment I've been put in because I know sort of what I'm able to achieve and what I can do in the classroom setting and then to have an environment where I just can't cope and I can't focus... I'd been kind of let down a little bit by that... (Alice).'

The girls emphasised that it was physical environment, rather than the schoolwork, that they struggled with:

'I never particularly found schoolwork that hard but because of my surroundings and because of the people, it made it that much more stressful to do work and to like, feel as though I could actually have a decent education because of the surroundings... it was very anxiety filled for me... (Alex).

Harriet described her 'ideal school' with a supportive environment that enabled her to focus on learning:

'[In my ideal school drawing] I've got headphones on and I'm smiling, a little stick figure (laughs)... I feel like my well-being would be supportive... I'd be thriving...I'd be able to access my strategies. I'd be content because I really enjoy education and learning things, but it's just the environment in which that's happening can be very difficult.... it drains all the energy you would have to learn - by existing in the environment to learn...' (Harriet).

Subtheme: Managing negative sensory environments

The girls described aspects of the sensory environment that impacted their daily experience at school, which included proximity to people, bright lights, and sensitivities to noise.

Having too many pupils in classrooms and sitting close together, was reported to be difficult. The girls added that close proximity in the classroom could be distressing:

‘Very cramped classrooms is another thing. I hate... where we're sort of all shoulder to shoulder... not got enough room to properly write and it's been like everyone's looking over your work all the time... not a fan of that... very stressful for me.’ (Alice)

This negative experience with proximity to others also extended to difficulties when moving around the wider school environment:

‘[My non-ideal school would have] lots of students.... And I guess, like those schools which are really not designed to be schools and that have like tiny classrooms, and tiny corridors and then like, everyone ends up in the corridors and then it's like, between lessons and that was like super overwhelming...’ (Kirsty).

Harriet added that their ‘ideal school’ would avoid sensory overload caused by proximity to others by having lots of ‘exit points’:

‘[In my ideal school] I also put an outdoor space in the centre of the school... because then it's accessible from different points and you're not walking out into a big crowded amount of people - there's different ways that you can get to that outdoor space...’.

The girls also discussed how lighting within the school - particularly the brightness of lights – could affect their ability to learn. Kirsty noted how fluorescent lighting and bright smart boards (which are present in most modern classrooms) affected her ability to learn: ‘They were so bright, and it was just, it was a real barrier for me... it's like - physically hurting my eyes!’. She further explained that using daylight could be a solution: ‘[My ideal school would have] lights which are like not ridiculously bright and like they try and use daylight rather than, like, umm fluorescent lights’.

Likewise, Harriet reported that she wore glasses to avoid overstimulation from the lights: ‘I actually got these glasses, these are just normal glasses prescription tinted, because I kept having seizures from getting overstimulated, from the bright lights in the classrooms...’.

Finally, noise at school was reported to be a major issue by the girls, with several girls using the word ‘loud’ when describing their non-ideal school. Alex explained how the wider school layout, such as narrow corridors, had an impact on their mental health, as this meant the noise was amplified: ‘I definitely struggled with even just like moving around the school because the corridors quite like narrow but there was a lot of people and it was always really noisy and it made me really anxious’.

The girls also described how classroom noise during lessons made it difficult to learn. For example, Alex noted that: '[Non-ideal would be] very loud, very busy... and having sort of adults that aren't particularly patient with some people. I struggled a lot. I'm like very like noise sensitive... I struggled a lot with like people shouting out'. As Rebecca elaborated: '[The non-ideal school classroom would have] an open door with loud noise outside'. Further, Sas explained that she did not need a completely silent workspace, but just some adaptations: 'I would like a classroom that provides a quiet, familiar, easy going, non-stressful learning environment... and the sound didn't echo around'. It was felt that teachers had a role to play in managing noise too. As Harriet discussed: '[I found teachers] interactions with kids [at primary] quite difficult, quite loud. Not ideal'.

To summarise the how much of an impact that sensory elements had on the day-to-day school experience, Harriet explained:

'There was a quote in a book that I read about autistic girls and it said, 'Everyday life can be a trauma - referring to the light and the experiences of noise and the social interactions' and that specifically stuck with me'.

4.3 Theme 2: People aren't predictable – challenges with navigating school relationships

Theme 2 includes the girls' and parents' reflections on their relationships with peers and school staff throughout primary and secondary school. The girls described how challenging the social aspects, specifically friendships, were for them throughout their school experience. They also discuss challenges around unexpected changes or

unpredictability that would occur at school, and subsequently upset their entire day of learning. These challenges included supply teachers, off time-table special events, or changes of classrooms. The girls' also explain how teachers can be unpredictable with fluctuating personalities or sporadic behaviour management. Ultimately, they also felt that their learning was not personalised, and that school relationships were not individualised.

Subtheme: Navigating the unpredictability of the social aspects of school

Girls reported that both primary and secondary school were challenging socially. Adalyn explained: [primary school was difficult due to] friendships' and '[Secondary school was difficult due to] everything from socialising, classrooms and assemblies to uniform, teachers and noise'. Kirsty specifically elaborated on primary school friendship challenges, including making friends and having a large group of friends: '[In primary] I know I struggled socially... I struggled with making friends... I have one friend. I would never have like a group of friends or anything...'.

Parents shared their daughters' experience of friendship difficulties unravelling during primary school. Alice's mother explained:

'[Year Three onwards] she started having problems with friendships. And I think life started to get a bit more complicated, there were lots of issues of friendships, fear of teachers... but you know, mental health was going downhill and you know, she didn't really have friends and she would stay in a playtime instead of going out with everybody else'.

Likewise, Harriet's father explained how hard it was for her to retain friendships during this time:

'She would tend to have one person that she was very close to for a while and then that wouldn't be so close and then there would be another person, rather than lots of friends... I think there was a lot of girls that were like really keen to be friends with her and it was only a matter of time before they weren't interested anymore' (Harriet's father).

Harriet's father explained that inconsistency around constant friendships continued into secondary school for his daughter:

'I think she found it quite difficult again [in secondary] she found friend groups a bit more difficult... she never had a big group of friends, which she did have like, you know, one or two good friends that she changed...'.

The girls explained how their friendship difficulties, and 'feeling different', resulted in bullying. They specifically described how bullying occurred at the beginning of secondary school: 'I was bullied quite a lot in year seven, because I hadn't yet caught up to the masking point yet, because I hadn't really had too...' (Alice). Rebecca explained how she was bullied specifically because she was autistic: 'In Year 7, [I was] bullied by another child, being told I had numerous disabilities, including autism'. Alex upon reflection, also felt they were bullied due being autistic:

'I think people need a lot more awareness... the things that are typical things that teenagers tend to bully other teenagers are autistic traits. And I got a lot of, like people were just like very mean to me... about certain things that I did, that looking back on now, everything they made fun of me for were my autistic traits and were the things that I did because I was, I don't know, I was struggling or I was trying to cope...'

Gemma explained how this experience added to secondary school being a very negative time: '[What difficulties were there in secondary?] essentially everything – overcrowded school, struggled to make friends, was bullied, very alone and isolated'. Isolation occurred because of feeling alone, and Sas felt she could not go and eat lunch in the hall:

'At one point I didn't eat anything for lunch or just ate things I could take from the edge of the lunch hall easily, such as bread rolls and fruit, because it was too embarrassing and scary to sit at lunch alone'.

Adalyn's mother said that their daughter never went to the playground due to her friendship worries, 'She never spent a day on the playground... field. Never in her entire secondary school experience.... did she spend any time on the field...'

Alice's mother linked her daughter's secondary school friendship difficulties to her rapid mental health decline:

'When we moved into Year 11 and things just very rapidly went downhill with her mental health, very rapidly... and she wasn't coping, being in school... and she wasn't, I think a lot of it was to do with the fact that she wasn't coping in friendship groups, because she was feeling like she needed to withdraw herself and then they couldn't understand that and she just was struggling just to cope with everything. It was just a point of complete overwhelm...'

The girls felt that their peers were not understanding of their differences, specifically in secondary school, and thus misunderstood them. Alice explained: 'Going from quite a small primary to quite a decent size high school. And suddenly the things that were like... different about me, weren't alright anymore'. This lack of understanding caused difficulties in friendships and socialising, especially as the girls described how they found it challenging to 'fit in' due to not understanding 'how to act'. Alice explains:

'But it was learning that realising the things that I could and couldn't say, that was probably the most difficult part of high school because it was so you know what girls like... It's just so nuanced. And it was all these things that I'd be like, why are we doing that? Why are you saying that? Can I not just.... Can I not just say this or do it? And it's no, you can't you can't do that.... (Laughs) But um yeah that's probably the worst part of Secondary School... (Laughs)'

Alex elaborated how feeling misunderstood by their peers was challenging:

'I had a lot of issues with people that just didn't get why I was the way I was.... I had a lot of issues that people just didn't like, like difference... I hated drama.

I hated all of the petty like, teenage girl stuff that went on.... And I couldn't, I couldn't understand why it was such a big deal to them... It wasn't to me... which it made it quite hard to stick with friends because they expected me to act like them and think like them when I really didn't...'

This same participant also reported that having autistic traits such as fixated interests, made her feel very different:

'Throughout the whole of secondary it was like that... I used to get made fun of, for just talking about things that I was interested in, because I would get so passionate about it, because it would be something that, you know, it was my special interest or that I was like, fixated on at that point... And people would just be like, 'Why are you so obsessed with it?' And I didn't understand...it became like what helped me get through the day sometimes... And having people around me that wouldn't let me talk about it, and would ridicule me for talking about it, was really, was really hard....'.

Alice felt her friendships and ability to socialise developed when she learnt *how* to socialise, 'I found it kind of alright to make friends once I kind of learned the Social Code'. Consequently, Kirsty felt that school effectively is an environment where everyone should act the same, 'I think there was definitely like, definitely an expectation for everyone to be the same or like the idea that like different is bad'. Sas felt that more inclusivity was needed in school and in the wider environment:

'In an ideal world the children would be kind and friendly... I would wish that they would be more understanding and amenable to 'strange' children like myself, without seeing it as pity or a duty. I would like if they invited me to hang out outside of school or to go to parties together'.

Parents explained how their daughters tended to have either younger friends, or much older ones, even adults. Adalyn's mother and father explained how their daughter relied heavily on adult/teacher relationships from a young age:

'[Adalyn] would very much cling to adults... and she did it all through pre-school as well.... And that carried on into primary school and she did find that positive...' and 'Even in preschool, she didn't really have really good relationships necessarily with her peers but she picked out one adult, a key worker and we're still friends with her now today. She can build really strong attachments to adults...'.

Contrastingly, Rebecca's mother observed her daughter preferring to socialise with younger peers:

'Before she left primary school, the teacher actually pulled me in to talk to me, as it was at this point she realised she was going to struggle, as she was in Year 6, but she was actually playing with kids in probably Year 4, so she wasn't playing or interacting with kids of her own age, she was playing with kids, two years younger or so...'

Parents also explained how they felt their daughter found friendships easier with other autistic YP:

‘(Harriet) is really good at seeking out other neurodivergent people. She's got like a radar and she, she finds them and she gets on with them immediately. And she's really good at that... she got to kind of like Sixth Form College, she got some really good friends there... You know, and I think is it called ‘double empathy’ or something like that when autistic people get on really well with autistic people.... she's great at communicating that...’ (Harriet’s father)

‘You know, if she was to meet up with more girls with autism, like her, then she wouldn’t have this issue with friendships, that she's got’ (Rebecca’s mother).

Subtheme: Navigating the unpredictability of schools

The girls’ discussed various challenges around unexpected changes or unpredictability that would occur at school and teacher’s fluctuating personalities. Adalyn explained how: ‘[Primary was difficult due to] communicating with teachers, assemblies, special days, change in routine’. Alex went into detail about how a ‘simple’ change for others at school, could affect their school day deeply:

‘If I would turn up at school and walk to where I had to line up, and if it was a different teacher than my usual teacher like a supply teacher or whatever, I used to like sob because I couldn’t deal with the unexpected change...’.

Parents agreed with the girls and emphasised how school staff did not consider how school events would affect some CYP:

‘So when there was big learning days off, you know off curriculum kind of stuff, you know the communication from the school to the SEND department basically didn't happen. And then the SEND department just has all these children who can't cope, descending on them. And it's like you could have got these children ready for it or giving them dispensations... It's just really poorly handled...’.

Harriet reflected on key differences between primary and secondary school, which centred around unpredictability, such as routine (the lessons being taught by different teachers in different classrooms) and differences in classroom management (perhaps linked to different teachers and therefore teaching styles):

‘[The thing I found most difficult about secondary was] ... probably the inconsistency... a lot more routine was predictable in primary, whereas when you get all young teenagers in a big building together, there's going to be a lot more unpredictability. It might be a productive classroom might be people throwing glue sticks on the ceiling, it might be quiet getting your work done, it might be chaotic, loud, people are fighting. You never know what's going to happen with the day to day and I found that very stressful and very difficult to navigate because it was just quite sudden’.

Harriet also described how daily classroom changes that occurred at her secondary school, were difficult and had an impact on her mental health:

'it used to really stress me out, so we had in my high school... we had a lot of science teachers who just kept leaving constantly... So we ended up having a science lesson in maths or in history, and it would just really throw me off because it's an entirely different environment, the science buildings, they have high stools, they have stuff for science experiments... And then if you suddenly put that in a new environment with little warning with teachers absences as well, of not knowing until you're meant to already be there...'

Continuing the theme of unpredictability, the girls mentioned that they struggled when their teachers had personalities that changed from one moment to the next, and not being able to 'read' their mood or know what to expect next. As Alex explained:

'If they [teachers] were quite unpredictable, like one minute they were angry at you or one minute they were like trying to be happy and playful with the students... I really didn't like that because I didn't know where I stood with them...'

Harriet also shared how teachers' who had fluctuating personalities was very difficult for her:

'The thing of being loud and I've had a lot of experiences in the past of teachers prone to start shouting at the class and get silence and that can be quite without warning... so unpredictable.... Quite prone to yelling and not giving precise information about tasks and things, being quite brief in what's happening in the classroom, because then you want to ask questions, sometimes you'll get

yelled at for asking the questions and it just makes the entire experience more difficult...’.

The girls also described challenges when teachers demonstrated a lack of behaviour management/control over the classroom, which led to them feeling stressed in these unpredictable environments. Alice described her non-ideal school classroom as, ‘Very kind of unorganised and the teachers don’t have much control over the classroom. I find that very, very stressful’. She went on to further elaborate on the teachers, ‘...People who teach us who can’t they can’t control the class they can’t you know, if people are kind of, you know, not obeying the rules or, or talking back, they can’t kind of squash it or anything...’.

Gemma also struggled when teachers appeared to lack control of the classroom: ‘[Non-ideal school would have teachers who] can’t take control of the class and [Non-ideal school would have students who] make lots of noise and disrupt the lessons’. Rebecca also echoed this view in their ideal school description, ‘[In my ideal school] teachers would control the class and be approachable and understanding’.

Subtheme: Individualisation matters

Girls felt that most teachers (in primary and secondary) did not personalise their learning experience to support them and their individual needs. Alex felt that it was difficult for teachers to understand them throughout school, ‘I had quite a difficult time with getting teachers to understand me’. They added that having an understanding teacher really matters, ‘I had a lot of problems, all right up into you into like, year five, year six.... Year six was the only year that I ever got support and that was because I

had a different teacher'. Harriet additionally shared how she felt misunderstood by school staff and unsupported in primary:

'[The thing I found most difficult about primary]... the teachers mostly, I was undiagnosed for quite a long time. And they didn't get it.... Of it was just, the general interactions of assuming everyone was on the same wavelength and stuff.... I actually got pranked by teachers several times'.

Kirsty summarised her thoughts towards the importance of individualisation when describing her ideal school, '[My ideal school would be] small enough for you to be an individual rather than just like a number...'. Adalyn shared that having a supportive teacher relationship in secondary school was very important to her, '[The best part of secondary was] a relationship with one particular staff member'.

The girls also reflected on what could have helped them feel understood and supported at school, which included their teachers taking the time to get to know them as individuals:

'I think it's very important that you go and speak to the individual on their own. You've got to build up a rapport with them enough that you feel like you can go and say, so what would you want from me? What can I do to help you make the environment more comfortable for you?' (Alice).

'Consider everyone's needs and like see everyone as an individual, and know when to recognise when someone's feeling uncomfortable when something's not right, and know what they can do to support everyone individually... [I'd

feel] much more like ready to learn... More supported... I'd be much more able to engage in lessons and learn stuff'. (Kirsty).

Kirsty added how it was unhelpful to think that every autistic person has the same needs and if school staff had understood her individual needs, she would have been supported and able to access the learning:

'...a lot of the time, people assume that every autistic person struggles with eye contact, or every autistic person struggles with loud noises, whereas like, that's not necessarily the case. Like for me, auditory processing is like a really big deal. But for a lot of people that wouldn't even be something that would be an issue... if you're aware that you have autistic students in your class, have that conversation with them, ask what you can do to make things easier...'

Alex reflected on how they now feel supported at college by staff and added why feeling understood matters:

'I have support at college. I know that I feel a lot better about going in... even if I end up having a meltdown and I get overstimulated, because I have people I can go to and I have the understanding from teachers that you know, it's not because I don't want to be in the school or it's not because I don't want to learn it's just kind of hard for me to do that right now.... And that as soon as I am calmed down and I'm better, I will be back and ready to learn because I do, I do enjoy learning about new things... And I think that that's just, that's the most

important thing is knowing that a teacher actually cares what they're doing and what how they're impacting children...'.

The girls also shared how if simple differentiation was put in place to cater to their individual needs, this would have changed their ability to access learning, such as understanding their auditory processing needs and how simple modifications could have been made to support them:

'I had a lot of teachers that would say something and I have quite an issue with auditory processing, so I always needed someone to say it and write it down so that I have those two things so I could get it into the brain properly.... And a lot of teachers didn't do that. Even though I asked some of them they still didn't do it...' (Alex).

The girls also discussed further other ways in which they needed individual differentiation to access learning, such as clear verbal or numbered written instructions:

'[In my ideal school] the tasks they'd have very clear instructions for them... Being able to do the tasks with very clear like numbered instruction... so if you forget them, you're not going this has been too fast, you're able to process it at your own speed.... And you can do your best you can ask for help with the teacher in the centre of a room, if you need a break – you can take it... just being able to work with your own time management...'. (Harriet)

Lastly, Alex explained how teachers were not always direct about what they wanted the pupils to do, which resulted in them shouting at pupils for not understanding their instructions. The girls felt this experience could have been eliminated by the teachers giving clearer instructions and recognising the different needs within their class:

‘A lot of teachers that I had would want you to do something but not tell you directly and then shout at you for not doing the thing, but they never told you directly to do it, they just expected you to know that you have to do (laughs) and which obviously I didn’t.... Like yes, so shouting at me and it made it a lot more stressful...’ (Alex).

4.4 Theme 3: The journey to diagnosis – it didn’t come from school

In relation to diagnosis, the girls described a journey which spiralled from mental health concerns. Upon reflection of their early years and general feelings around school, the girls felt their mental health was always a concern. Alice and Alex remembered their early strong attachments to their mothers and the impact this separation into school had, ‘I’ve always been very attached to my mum having quite a maternal sort of, teaching experience was quite beneficial when I was younger...’.

‘I was always a very anxious child... when I first started I struggled with, like leaving my mum. I used to cry every single morning going into school. And I used to have meltdowns quite easily.... I found it very difficult to like transition into school and actually get there...’.

Parents also recalled their daughters experiencing severe separation anxiety in the early years and primary school: 'We really felt the alarm bells started ringing in Year Two, she had a really lovely Canadian teacher... she left and went back to Canada. And (Adalyn) had an over the top reaction for that, it was like grief...' (Adalyn's mother). Alice's mother also recalled how difficult her daughter's separation anxiety was for her and her daughter when she started school:

'She did morning's only [pre-school] and it wasn't good. It didn't go terribly well. Because she suffered very much with what we thought was separation anxiety. So it was a quite traumatic thing... I did know it was gonna be like this because she'd always struggled at playgroup and play school... Any of those places. I couldn't leave her... I used to have to sit in an office in the back and occasionally move to my car for half an hour and then I'd have to come back in again (laughs)... I think it also traumatised her a bit that daily event of separation...it remained difficult for quite a long time. And she would umm go into school it would all be very, very upset and this went on for a couple of years'.

More generally some of the girls reflected on how school was generally an anxiety triggering environment, 'I was, like, always anxious at school... just stressed out...' (Alex) and 'I felt alone, anxious, depressed [at school]' (Gemma). Sas remembered specific school events that would trigger anxiety, 'Remembering to complete homework, or to bring in items needed for class, it was a big source of anxiety for me [in primary], that I would get into trouble because I didn't mean to do this'. She also reflected on this during the non-ideal school activity, '[In my non-ideal classroom] I am the only person the teacher can call on despite not having my hand up. It makes sense

as I had a lot of social anxiety about talking in class and getting answers wrong'. Lastly, Adalyn shared how she generally felt low at school, 'I felt Isolated, upset and angry [at school]'.

Parents also recalled the anxiety and unhappiness their daughter's felt at school. Adalyn's mother specifically described her daughter's anxiety in primary school and how difficult this was, as school did not understand or support their daughter's mental health difficulties:

'It was in year three, she had a very no nonsense kind of teacher who she really, really disliked very actively. And at that point, we were going in and out for school. I was getting phone calls saying Adalyn's tummy aches, she's coming in and out of assembly saying she had tummy ache... she was finding assemblies very hard... And I would go and collect her from school. She'd be sat down with a bowl and it's like I can see as her mother, she's not got tummy ache, there's something going on that, you know, it's obviously a child's way of expressing that she was anxious... she was very worried and didn't want to take part in anything that was going to be a surprise or different. And that's where we started to get a little bit... it was anxiety...' (Adalyn's mother).

Rebecca's mother described how she felt her daughter's anxiety ruined her entire secondary school experience:

'It's quite hard to try and find something positive about secondary school (laughs)... she was just so scared of getting things wrong and being told and getting the detention... I'm not sure how strict it was, but in her head was very

strict... it was just you name it, she used to worry about it, she would worry about everything, anything and everything.... and if she got to school and she'd forgotten something, well then she'd be, she'd get herself into a real state, if she forgot her P.E. kit or, or her food for her food tech or something like that, she would just be in this horrendous meltdown state, because she was gonna get into trouble because she forgot something, so yeah, anxiety was just through the roof really!

Alice's mother tried to unpick her daughters' anxieties, and found this stemmed from her initial separation anxiety and fears she felt:

'So when we talk to her about it, a lot of it was to do with the fact that she was scared that I wouldn't be able to get to school to pick her up or wherever she was to collect her. That was a big part of what was behind the fear of, of the weather'.

Subtheme: Feeling misunderstood

The girls reflected on how their autism diagnosis journey seemed to begin when their mental health was declining rapidly, and they were referred to CAMHS. Alex described a rocky journey with their mental health and initially felt dismissed by CAMHS when they were referred: 'I'd got first referred to CAMHS in year nine. And then they said that school had to deal with it, because they didn't really listen to me and said that it was only friendship issues...'

Alex also went on to describe further interactions with CAMHS and being referred for CBT despite having done that privately and feeling it was not helpful:

‘So I got re-referred in Year 10 I think yes.... And then I don’t think any anything came of that either... then I got re-referred again in year 11... I had to do 10 weeks of CBT on CAMHS even though I’d told them that it didn’t work for me... The 10 weeks kept getting pushed back as well...’.

Parents shared how therapies such as CBT did not have an impact for their daughters:

‘She struggles to engage with CBT, mindfulness.. Everything like that, she really can’t handle that...’ (Adalyn’s mother), and ‘[CAMHS] did CBT therapy for her for a long time and it didn't work, it didn't do anything for her...’ (Alice’s mother).

Ultimately, after a long process of feeling dismissed, autism was finally discussed. For Alex, it led to almost instant diagnosis after assessment:

‘I had a meeting with my CAMHS worker and I said, ‘Look, I don’t think that this is just anxiety, I do have anxiety, but I don’t think that, that’s the cause of all of the other stuff that’s happening that I’m dealing with, and I was like something’s going on’... And then she was like, yeah, and she talked to my mum as well - Have you ever thought that she might be autistic?. And my mum was like, I hadn't because like my son's autistic and he’s like, very different... and then she brought it up to me as well. And I said, I think it’s ADHD, okay, well, we’ll do the autism thing... because I was adamant that it wasn’t autism because the way that I saw autism in other people, I was like, that’s not me... And then I got

referred for, to be put on the waiting list for the assessment... and then I got my assessment in August of 2021 and got diagnosed the same day...’.

Alice also explained how the interactions with CAMHS were what initially led to her diagnosis, but due to long waiting lists she sought a private assessment:

‘ I think like a month after I went for a private assessment because the CAMHS nurse, he said himself, he said ‘You wouldn’t get diagnosed on the NHS because of the diagnostic criteria, the way they did the assessments, you just wouldn’t and the waiting list is too long anyway...’ so fortunately, we were able to go privately... So within a month, I had my diagnosis....

Harriet shared how her autism diagnosis unravelled, and that she believed her struggles with mental health and illness over the years led to her also developing chronic illness:

‘My autism diagnosis came around because I was spending a lot of time in hospital, I got diagnosed with chronic illness, and they thought that masking was affecting and making it worse... it was massively driven by me and my family rather than the school... the chronic illness that I’m diagnosed with is functional neurological disorder that generally is triggered by a trauma or an illness. And there wasn’t anything specific - it was from my masking. The trauma was built up from 17 years masking without a diagnosis. And that’s how I ended up having paralysis and seizures and things because it went so long unrecognised...’.

Harriet also explained how the school were not involved with her autism diagnosis, 'It was not with the school, it was entirely driven by us... I had a whole team with a Paediatrician and it was them who were driving the diagnosis'. Kirsty also described how school did not support her diagnosis and she endured a lengthy journey with CAMHS, which led to her family ultimately paying privately to get a diagnosis faster:

'I didn't get my diagnosis until I was 18... school weren't involved. I've been under CAMHS since I was like 12... We had the conversation with CAMHS, but this conversation happened when I was 18... I think the adult waiting list was three years long... So I ended up going privately, and I got the diagnosis probably like two or three months after we first had the conversations...'

Rebecca's mother explained how her daughter was not able to access counselling for her declining mental health, as her school felt there were others with higher needs:

'When she first got to the school, she was really struggling, her anxiety was really high. I tried to get some counselling because I'd actually been to the doctors about it and the doctors said 'Oh no, you can only get counselling through the school', so I went to the school and they decided no, she's not high enough priority... because she's not self-harming, basically...'

The girls often first heard the word autism in relation to themselves, as part of their lengthy diagnosis journeys, during this secondary school years, and usually towards the end of their education:

'[I first heard the word autism relating to myself] in 2016, when I got my diagnosis. I knew I was a bit different but no one had said anything to me before this. [The school] had to fill in a form sent by the psychiatrist to provide more information on me but that was it... For me it was instantaneous practically as my mum booked the appointment privately', [Length it took to get diagnosed] about 6 months from when first interested (we went to a private practice)', (Sas).

The girls reflected on the frustration they felt about being misunderstood at school and hypothesised that if school staff had understood how autism presents in girls, perhaps things would have been different. As Alice explained:

'I think if you're clued up enough on how different it is and all these, all these things that can present and how it can look, especially in girls who are forced to conform, otherwise, they're completely ostracised... it makes for such a healthier person really... That's the key, is to just teach them everything that they can know about it...'

Alex also felt like they 'slipped under the radar' at school and that due to their internal presentations, no one identified their needs:

'It seems that it's very based on people having diagnosis and like not actually searching for people that are struggling, that might need help... There's a lot of people that get lost like, I got very lost in the system. Because I was quiet. And I struggled very internally with all of my issues...No one sort of paid attention

enough to really realise that there was something that I needed help with that...’.

Harriet’s father also felt that if someone had flagged up his daughters’ anxiety earlier on, she would have not masked and suffered from mental health difficulties for prolonged periods:

‘The main thing is... had there been someone at the school who had recognised (Harriet’s) autism at that stage, it would have been a huge thing for us, because when (Harriet) had like, all kinds of sort of like mental health issues, at sort of like 16... and she started with her neurological disorder. We think a lot of that was because she had been masking you know, until then, and found life very, very stressful and very, very difficult, which led to all kinds of anxiety issues’.

Finally, Sas reflected on how schools could better identify autistic girls in their settings:

‘I get the sense that in some schools there is a way to help diagnose girls through the school, rather than having to seek help privately. So perhaps to finetune this in-house process to better pick up on autistic symptoms in girls, and to account for masking when trying to diagnose pupils’.

Parents described their daughters actively declining mental health, self-harm incidents and suicide attempts during secondary school. Alice’s mother described how things became so bad for her daughter that she was crying out for help but the school were not taking this situation seriously enough:

'In Year 10, she started to talk to me about how she sometimes got quite sad... towards the end of year 10, [she] talked to me more fully about it and said that she was feeling very bad and I advised her to contact the school counsellor, which she did...She was on a waiting list and one day things were so bad and I've got phone call from school to come and collect her, because she'd gone to student support and she told them that she felt suicidal and didn't want to be here anymore. So obviously they had called me I went down and collected her and it wasn't the first time at this point... and she just begged me to help her...'
(Alice's mother).

Adalyn's mother also shared their daughter's experience of self-harm, which continued on school premises, adding how they felt let down and dismissed by the school:

'She was starting to self-harm by cutting herself often with things that she found in school like pencil sharpener blades and things like that. And she was doing it on school sites and often even doing it in the [NAME] centre. And they didn't put in a risk assessment. There was no care plan for her nothing... she'd go to school, break a protractor in half and use that so she wasn't really being adequately cared for in school...It's terrifying. We felt really stigmatised that they never used the word suicidal, they said things like, she didn't want to be here... they're not accurately portraying, the state these autistic girls are getting themselves too.'

Unsurprisingly, parents shared how their daughters reached burnout towards the end of secondary school, and could not cope any longer:

'...she was in the bathroom and saying 'I can't go in, I can't do this, I want it to end... But the point is, why did they not put her or refer her to CAMHS or the school nurse or anything? A long, long time ago when she was self-harming on school premises? There was no early intervention for her at all. So it was only ever gonna get to this point'. (Adalyn's mother)

Parents discussed how due to COVID-19 lockdowns and schools being temporarily closed, this worked to their daughters' advantage and they thrived learning at home. Adalyn's mother explains how this was very positive for their daughter:

'...she was super happy during lockdown, that's her happy place because obviously she wasn't at school and she doing her own interests around learning... So now we've moved her from the school, she's finished her GCSEs, she actually did manage to sit every single one... and all because she went in for the exam, came home, in for the exam, came home... So she had no social, which was difficult, but actually she reflects on it and says what a good idea it was...'

Alice's mother also shared how home-schooling helped her daughter get through her GCSEs:

'We went into lockdown in the early March of her Year 11. And I think it was the only thing that saved Alice because she wasn't coping in school, it was getting

worse and worse and I was struggling to get her in. I don't know how she'd have done in her GCSEs if it had been a normal year....'

Rebecca's mother described how they took the decision to home-school their daughter and reflects on how this was the best choice they could've made, as her mental health improved rapidly:

'Year 10 was the start of her GCSEs and she just fell apart, I couldn't get her into school... not really through choice, it was more we've got to do something, I can't just leave you... You know, that was how come we went into home education, it was never really something that crossed my mind, so she would have been just turned 14 when I pulled out of school but then she had two years at home... Home education time, her mental health improved no end... with hindsight and how much better she was, once she was out of the school system, I wish we had done it earlier'.

Parents subtheme: 'As far as the school were concerned, she's doing great, she's academic'

Parents felt that potentially due to their daughters' academic nature, their needs were overlooked. All girls in the sample were deemed academically bright: 'Like in primary, she was in top and then middle set' (Adalyn's mother); 'She was a high achiever, so everything was pretty much good' (Alice's mother); 'I would say that she did well at primary... she was always doing well at classes... She was academically doing well [in secondary]' (Harriet's father).

Yet Alice's mother remarked on how her external presentation did not align with her internal one:

'She was academically very, very bright.... pretty much at the top of the tree. Nobody thought there were any issues and they just assumed that what was being displayed was some kind of, well like I say, a separation anxiety... that she was just a clingy child really...' (Alice's mother).

Rebecca's mother felt similarly, that due to her daughters' academic nature, her internal state was overlooked:

'As far as the school were concerned, well she's doing great, academically she's doing well, she's turning up on time, she's bringing the right kit... you know as far as the school were concerned, she's perfect, she's been you know, star pupil sort of thing, because she does everything right. But inside, she was not in that state...'

Similarly, to the girls, the parents felt incredibly let down that none of the school staff were able to spot or flag their daughter's autism. Adalyn's mother felt let down that the school's EP wasn't informed of their daughter, 'And so the EP never saw Adalyn in school'. She emphasised how if Adalyn had actually been referred by the school, they would have noticed things:

'Let's face it, anyone, an EP and OT, or anyone would've know more about what Adalyn is going through, than what the SENCo did at school, they would

have come in and taken one look at that child and been able to provide more support that she was currently getting...’.

Adalyn’s mother felt school staff were not picking up their daughter’s needs due to autistic girls’ presentations being more internalised than externalised:

‘They deal with the extrovert children, the ones who are standing on the tables and swearing, but the little girls who are sitting there kind of going like this [buries head in hands] because they’re so terrified of all this noise and all this danger around them... get really ignored...’.

Adalyn’s father emphasised how other medical professionals immediately flagged concerns that school missed, ‘I mean the GP had one look at her and referred her...’. Harriet’s father reflected on how things could have been very different for their daughter if her autism had been recognised,

‘The main thing I would like is that if someone had said to us, at sort of year seven, okay, we think Harriet you know, possibly neurodivergent, that would have made a huge difference to her life.... there’s all kinds of concessions that now in retrospect, would have helped her an awful lot. So things like the, the over stimulus of kind of the dining halls, like big noisy areas, things like that have always been very stressful too her.... So, if there was an awareness of that, that would have really helped’.

Parents described how they felt let down by school, feeling that the provision of support came from them:

‘I mean all of this, all of this, it’s been pushed from us. It all came from us... I mean the school hasn’t been proactive in helping her at all... They were doing absolutely nothing to support her and they had no idea and everything that’s been implemented has come from us and her psychologist... they hadn’t tried different things or anything at all... we truly believe if it was left to the school and we hadn’t intervened and paid a lot of money to try and sort this out, she couldn’t have done her GCSE’s this year, she would have been complete refuser of school. She may even have been in hospital... (Adalyn’s father)

Additionally, some of the parents paid for private psychological or therapeutic support which supported the school to adapt the environment, but they felt let down that the school did not put this in place beforehand:

‘Again, privately paid for, we got her in [the OT] and one day she spent with Adalyn and she picked up immediately on some of the things that would make her life easier in the classroom environment, more comfortable for her, even things like ‘dimming the lights and putting her on a consistent seat’, which Adalyn wanted all along... ‘ (Adalyn’s mother).

The parents emphasised the inequalities of access to diagnosis and support and even how perhaps this meant the school did not ‘push for them to get diagnosed’:

'It's only because we're paying... we would never have this otherwise [diagnosis experience] and that's the that's the worst thing... We're lucky aren't we... but what about all the people that didn't have that? And is that why the school weren't referring us because they knew... and they keep coming back to, 'She wouldn't have met the threshold for CAMHS, she wouldn't have met the threshold for an EHCP...' (Adalyn's mother).

Parents explained how they found it hard to understand their daughter's needs, and therefore school support/advice would have been very important. Adalyn's mother explains how they did not have concerns surrounding autism, as the way they understood the condition was not how their daughter was presenting:

'[Primary school] she's meeting all the developmental milestones at that point. We didn't have any worries about her at all... socially she was able to maintain eye contact... And because we didn't know about the way autism presents in girls, we didn't know anything about masking... So you think of your children in terms of not being able to maintain eye contact or not having great verbal skills... She was playing piano, she was in top set for everything. We just.... I sound really apologetic, but I feel like I feel kind of embarrassed that we just didn't know...'

Likewise, Alice's mother explained how they felt their daughter was different, but they were not sure it was autism:

'...We'd say, 'do you think she's autistic?' And we'd go no... she can't be.... a bit like everybody else, she's got friends... the cliches... she copes well at school, on the whole, she copes with her work. she does socialise, okay, she hates parties, but a lot of kids cling to their parents at parties. And so you kind of second guess yourself... And come out at the end of it thinking no...'

Similarly to the girls, the parents emphasised that external health professionals (CAMHS, psychologists, counsellors and GPs) were the first to flag autism, not the school. Alice's mother explained how a counsellor first mentioned autism: 'This particular counsellor unbeknownst to me, at the end of it said she needed to be referred to CAMHS and sent a report to CAMHS, and in that, she queried whether she was autistic...'. She then explains how after this counsellor querying autism, it was a CAMHS nurse who said 'This screams autism'.

Rebecca's mother experienced a lengthier diagnosis with CAMHS, and it took them getting to know her daughter over time before they queried autism:

'I went to the doctor because of her mental health... eventually she got a referral to CAMHS... They put her for an initial assessment for autism and she didn't tick enough boxes for diagnosis to go any further at this moment in time. So, we carried on with a bit more CBT and things...but it was only through her going through to CAMHS, that they decided they were going to put her up for this autism diagnosis again, because obviously through talking to her, they had decided that actually it probably is autism'

Lastly, Adalyn's father explained their daughter was trying to understand herself with the support of a private psychologist:

'During lockdown, she was seeing the psychologist... I think she was trying to find herself, find a home for herself... She was looking online she said she might be ADHD... You know she was even putting on symptoms, you know, rocking, shaking... doing what, what you might expect from symptoms, of that and then she turned to us and you know, and I think the psychologist supported it as well... And said, 'I would really like to go for a diagnosis to see if I am autistic because I think I am' and at that point we kind of said...yeah...'

4.5 Theme 4: Adapting to my new identity

The final theme revolves around the transition process for the girls, themselves understanding their new identity and those around them understanding it. The girls reflected on how their diagnosis helped them understand themselves:

'I loved the day I got my diagnosis. I had a great day... my assessment was fantastic... the more I got talking, the more I was like, 'yeah, no, I do that. Oh, my God!' and nobody had talked to me in this way before... so it was great'
(Alice)

'I thought that it was me as a person being a problem. And then when I got diagnosed, it was like, 'Oh, so it's not me. It's just how my brain works'... I was like, 'okay, yeah, this is good... I'm happy that this has happened because I understand myself more'... (Alex).

With regards to post-diagnosis support at school, the girls explained how nothing really changed. For example, Adalyn explained how support came from her and not school, 'I had a student passport beforehand and after I sought out resources like a time-out pass and communication cards. Nothing was given or suggested'. Alice felt that she now 'understood' why they had given her a timeout card prior to diagnosis:

'Well, by that point, I'd already sort of had like... I had a timeout card that I could just show and then leave my lessons and I could go to the Student Support Office and go and sit in the library or, you know, do whatever I needed to do... Then sort of like a formal reason for having that as opposed to just I can't cope in lessons, but I've got, now I've got an actual reason'

Harriet felt very let down as there was not felt to be support specifically for her autism:

'[Did the school put in post-diagnosis support?] They did not... when I asked for autistic related assistance and support, I didn't really get it because it wasn't a priority at the time with the pandemic... I'd said – 'are there any quiet rooms I can go to?' – No, we're coming back from a pandemic, we do not have any quiet rooms available – they are all busy... ugh!'

Lastly, Sas reflects on how support provided was different depending on the teacher:

'I got my extra time back, which was the original purpose of the diagnostic appointment. I don't think I received any further official support from the school... I'm sure far more could have been done by the school, as evidenced

by the fact that I was friends with another autistic girl who went to the same school, who was diagnosed far younger than I was and she had a lot more support in place’.

Frustratingly, some of the girls could not understand why their teachers/school staff reacted with shock when they announced their diagnosis, and they did not find this helpful. Alice explains:

‘The issue for me, was that it was such a shock to all my teachers when I got diagnosed, you know, they had absolutely no idea... (Mother) sent the report in, that teacher was just like, ‘really...?’, she was honestly... and this is somebody who has known me since Year 7 but was, was completely shocked...’

Alice emphasised how individuals should be careful how they react when they hear about someone’s autism diagnosis:

‘Be completely open minded about what autism could look like... definitely don’t ever rule anything out. I think it put me off and it still kind of upsets me sometimes if I’m speaking to somebody and they go ‘Oh I never would’ve known’ or ‘You really don’t seem like it’ and I’m like well, that what are you doing by telling me that... apart from saying that you know, I’m not I’m not as autistic as the rest or whatever... when my teacher, she shared how surprised she was, that I’d been diagnosed - that wasn’t helpful at all... I think just never, just never being surprised if you come across a kid who is diagnosed with it, no matter

what you thought autism did look like or you thought that they didn't have any traits of it...'

Parents also discussed the external shock experienced from individuals around them, including the school and their wider family. As Alice's mother explained:

'I went back to school with the diagnosis had another meeting with the SENCo and again was met with shock that she had been diagnosed, and every teacher I spoke to, was disbelieving. I went back to [the Head] and told them about her diagnosis and they were shocked...They couldn't believe it'...I don't think I met a single person who went 'Oh, really!'... Not in education anyway'

Parents also discussed their own fears and worries related to the diagnosis:

'We've also had that slight fear of is that going to follow her around? Does that follow her through life is that gonna be on her medical records? There were those kind of slight kind of niggly feelings.... is this something that's going to cause a problem for employment you know, all of those kind of early fears about okay, how much do we want this to follow her around and stigmatise her...'
(Adalyn's mother).

'I questioned it myself you know, many times.... You know, even when she had the assessment and the diagnosis, I would find myself sometimes thinking, 'but is she though, is she?'.. you know I was still like... and part of it though, I think

was a lack of acceptance on my part, that kind of a fear... accepting that diagnosis and what that would mean for her going forward'. (Alice's mother).

Parents discussed their experiences amongst wider family with regards to their daughters' diagnosis. Harriet's father felt confused and questioned the wider family's reactions:

'There's so little understanding, I still think about female autism... but like within my family when I told people that (Harriet) was autistic, I got no response and people didn't even reply to messages and things. And I thought, oh that's really weird.... so I don't know if it was like that people didn't quite believe that she was autistic or just they didn't know what to say ?'

Rebecca's mother also described how her partner perceived the diagnosis differently:

'I was just expecting an autism diagnosis, because the more I'd read about autism and girls, the more I thought, well Rebecca just sits in that box completely. My partner on the other hand just thinks she's being awkward a lot of the time... He doesn't get it... So I actually think, if there could have been some help with awareness... as far as he's concerned, Rebecca is spoilt and that's the reason why...'

With regards to the girls, parents described how their daughters felt relieved during the diagnosis process:

'[Clinician] just went Alice, how would you feel about being assessed to see if you were autistic? And she went, 'Yes, please, that would be great'... And I just thought, Oh my God (laughs) and she just said, 'Yeah, definitely, I know, I'm different and I know there's something different and I don't work in the same way as my friends...' (Alice's mother).

Like the girls, the parents discussed the limited post-diagnosis support at school when their daughter returned. As Harriet's father explained:

'At school really not much [support]... they were still like, well, you know, we can't provide a quiet room for Harriet to go to because there isn't a quiet room in the college'.

Alice's mother described how schools needs to have procedures in place to support autistic girls' diagnoses:

'...[secondary schools] need to have something in place when... when they're informed that a kid has been diagnosed as autistic, there needs to be a set procedure in place as to what they can then do...how they can support... There was nobody in school I think who had an understanding of, of being autistic and was able to sit and say so, you know, how do you feel about the diagnosis? What do you feel this means to you in school and what do you feel going forward with that, you know, what we can do to, to assist...Why was there no one there at Year 10 and 11 when she was diagnosed to say, we need to do an assessment on her needs then to see what we can support her with at

school...Why is there not at that point? Why is it only there when she's going to university? It makes no sense...'

Similar to the girls, parents emphasised how university has been a more supportive environment than school:

'The one thing that I think is really key to say is that I think it's absolutely appalling that I knew she would get more support when she started university than she's had through her whole secondary career... they just seem to have a greater understanding of divergent needs'. (Alice's mother)

'Without a doubt college is so much better than school... they are super supportive... Much more flexible... I mean she's got counselling at college really easily, I mean she just has to email them and usually within two weeks she'll have a counselling appointment, she's got the support there... I think school is just a production line. I think you're a person at college, whereas at school you are a number...'. (Rebecca's mother)

The girls emphasised how being an advocate for others is very important to them, especially to create awareness regarding autism in girls. Alex explains, 'I like talking about autism, I think that it's an important thing to talk about, especially in girls, because we're not really known about it...'. They further explain the detrimental impact of having a late diagnosis:

‘I don’t want people to go through what I did, and I know a lot of other people did, because it really does knock your self-esteem when you grow up... Not knowing... that you just have a different brain and that’s why people treat you differently, it’s not because you’re a bad person or you’re like making people’s lives worse or like that you’re doing it on purpose, it’s just because your brain thinks differently... I know that a lot of a lot of arguments in my house, a lot of like, issues that I had with friends would have been solved so much more quickly if I had known this about myself earlier... I want to do stuff like this to sort of help hopefully, people in the future not have to deal with that like I do...’.

Harriet discussed how she is advocating for autistic girls, and how important it is that people hear autistic CYP’s first-hand experiences:

‘There needs to be more support for people like me in this exact position and I can be that support for someone else... I can be in that place. I can be making those leading steps and I can be helping because I’m fascinated with all of it’.

Lastly, Alice highlighted that autistic individuals should be the one’s giving training in schools and essentially, advocating:

‘I think some schools kind of give talks to the teachers on what autism is like, but I think it cannot be done by someone who doesn’t have it. And I think that’s the key... I would be, and I’ve said this to people before, it... (laughs) literally just give me a call (laughs)... I’ll come and talk to you about it because I feel

very passionately about people who don't have the issues, preaching about them...'.

The parents supported the girls and highlighted how they felt advocating was very important to them. Adalyn's mother explained, 'She wanted to do psychology, she wants to be an advocate for autistic girls and you know so do this [research]... '. Rebecca's mother also highlighted how her daughter was enthused to participate in this research:

'Lucy, fabulous, I'm really pleased you're doing this and I'm really interested in it. I mean, I think it was Adalyn who originally who found it and said 'Yes, I'm going to do this and I want to be in this, because this is really important'.

Chapter 5: Discussion

5.1 Introduction

The aim of this research was to examine the school experiences of autistic girls who were diagnosed during their adolescence years, and how this intersected with their diagnostic journeys. This aim was achieved by interviewing autistic girls to gain their voices and experiences, using interviews and a PCP tool, 'the ideal/non-ideal school'. Some of the girls' parents were also interviewed, and their voices and experiences used to support the girls' experiences.

Data were analysed using reflexive thematic analysis. Four themes and five subthemes were identified from the girls (supported by the parents' experiences). A further individual subtheme from the parents is discussed. These themes described the girls' journey through school and how their diagnosis unravelled. A range of negative experiences were described in the school environment, which affected the girls' abilities to learn, including the sensory impact of the classroom/school, social and friendship challenges, the unpredictable aspects of school life and a lack of individualisation from teachers. When describing their diagnosis journeys, the girls explained how this did not occur from school or their support and instead unravelled from mental health concerns which escalated and outside support was obtained with their parent/carer's support.

This chapter will discuss the results in relation to the research questions and the wider academic literature.

5.2 Research Question 1: What was the girls' overall experience of school and school support like: what worked well, what improvements could be made, and did this change over time?

This research aimed to understand autistic girls' first-hand experiences of school and (any) support received during their school years. Tomlinson et al. (2020) conducted a systematic review and found eight papers (2014-2018) that focussed on the school experiences of autistic females. Yet it is important to note that only four of these studies were conducted in the UK; two in Australia and two in the USA. Most of the studies were conducted in mainstream educational settings, with two being in SEN or both mainstream and specialist settings (Cook, Ogden and Winstone, 2018; Sedgewick et al., 2016). Only one of these studies used semi-structured interviews, and none used a creative method alongside a more traditional method. Furthermore, the study in the UK that used semi-structured interviews (Sedgewick et al., 2016) focussed predominately on social motivation and friendships experiences in specialist settings. Most recently, Moyse (2021) examined the school experiences of autistic girls who stopped attending school, using a mixed methods participatory approach, and using creative tools (PCP and 'life charts'), to gain their voice, and Zaki-Mashiach (2022) reported on the retrospective accounts of autistic women who attended mainstream schools using semi-structured interviews. Yet it is important to note that Zaki-Mashiach's study was not participatory or multi-informant like this study or that of Moyse.

This thesis took a broader perspective – building on the limited existing academic studies and exploring autistic girls school experiences (in both primary and secondary school) and their diagnosis journeys. Steps were taken to incorporate a participatory

approach, using interviews as well as PCP methods to gather the voices of the girls and their parents. This work therefore represents a unique contribution to the literature. In terms of the findings, the girls expressed how important the physical school environment was and the impact that this could have in terms of facilitating/hindering their learning. This finding is similar to that of previous research, which found overall challenges for autistic girls in managing school environments (Honeybourne, 2015; Jarman and Rayner, 2015; Moyses and Porter, 2015). In this thesis, sensory elements (proximity to others; bright lights and sensitivities to noise) stood out to the girls as being important, yet overlooked, in relation to their school experience. This finding aligns with that of Jarman and Rayner (2015), whose survey of autistic girls found that the girls felt that teachers did not understand the sensory sensitivities that made their school experience demanding and overwhelming.

In the current study, the girls felt that if they were supported to make adjustments, such as utilising headphones to control noise levels or wearing glasses to block the light rays from the interactive smart board, they would have been able to better access the learning. Where this was not implemented, they felt misunderstood and experienced sensory overload, which meant they could not focus or access learning. Likewise, Jarman and Rayner (2015) found that when school staff in their study supported autistic girls to make modifications to the sensory environment, their stress and anxiety was reduced. This solution resonates with the findings of my study, where the girls reported needing support to manage the sensory aspects of the environment.

Another key theme that the girls in my study discuss was the impact of relationships, whether this be with peers, teachers, or school staff. These relationships were felt to

affect their entire school experience (across both primary and secondary school). With regards to peers, struggles ranged from feeling left out of friendship groups, difficulties making friends and feeling different to others. Worryingly, the girls recounted bullying taking place, because they appeared 'different' (e.g., having fixated interests), and these experiences led to them feel isolated and alone during school. These findings align with existing literature, with several studies identifying social isolation and bullying as common occurrences for autistic girls at school (Cook, Ogden and Winstone, 2018; Cridland et al. 2014; Honeybourne, 2015; Moyses and Porter, 2015; Zakai-Mashiach, 2022). These friendship challenges were found to result in the girls learning to 'mask', to externally cope, which had negative consequences for their mental health. Corroborating this finding, Bargiela et al. (2016) and Leedham et al. (2020) both found that their samples of late-diagnosed autistic women had similar experiences to the girls in this study, such as camouflaging their traits to 'blend in', which worsened their mental health difficulties.

The parents who participated in this research also shared the impact of peer relationships on their daughters' school experience. They reflected on their daughters' struggles with friendships, which started in primary school, and which they felt contributed to their daughters' gradual mental health decline. The parents discussed similar experiences to the girls', such as fluctuating friendships, being left out of friendship groups, not having age-appropriate friendships, and preferring to be around adults rather than children their age. The parents hypothesised that their daughter's preferred adult relationships due to their daughters' feeling safe, secure, and predictable in these encounters; as opposed to the instability and vulnerability that comes with childhood and adolescent friendships. Autistic girls in this study were also

found to prefer spending time with other autistic girls. In the broader literature, Cook, Ogden and Winstone (2018) and Sedgewick et al. (2016) also highlight that autistic girls tended to form friendships with other girls with SEN, in mainstream and specialist settings, which they hypothesise could be due to having related interests.

Interestingly, despite some previous literature finding differences between primary and secondary settings (Hiller et al., 2014; Sedgewick et al., 2016; McLennan et al., 1993; Ranson & Byrne, 2014), the girls (and their parents) in this research reflected on both settings being difficult with regards to friendship groups and peers. It is important to note that Hiller et al. (2014)'s study used teacher and clinician reports, with teachers reporting fewer concerns with regards to friendships; a finding linked to their understanding of autism being more external presenting and 'male-centric'. Additionally, Sedgewick et al's (2016) study used an adolescent sample from SEN settings. These differences in design may account for the subtle differences in findings between my work and that reported in previous literature.

A further subtheme that was identified regarded challenges around unexpected changes or unpredictability that would occur at school and consequently upset the girls' entire day of learning. These changes in routine included off-timetable special event days, having supply teachers or having changes of classroom at short notice. One of the girls reflected on how these situations were exacerbated in secondary school, such as having lessons in different rooms at the last minute (e.g. an English lesson in a Science lab). This finding is similar to the work of Cridland (2014), in which mothers report their autistic daughters struggling with the changes of classes and teachers in secondary school. Moyse and Porter (2015) and Honeybourne (2015) also

report the challenges of transitions during the school day, such as structured lessons to playtime. Clearly, this unpredictability represents a major challenge for autistic girls. With regards to further unpredictable aspects of school, the girls' reported finding it challenging when their teachers had unpredictable personalities, which would fluctuate and create stress for them; for example, not knowing where they stood with their teacher as one day they were angry and one day they were friendly. The girls also reflected on teachers' not being consistent with behaviour management, which meant the classroom environment would often not be conducive to learning, despite the girls emphasising how much they wanted to learn. This is a novel finding, which could be related to obtaining the girls' direct experience.

A final subtheme with regards to relationships to others was the emphasis of individualisation. The girls felt that their teachers did not personalise their learning experience to support their individual needs, with girls feeling completely misunderstood by most school staff, throughout both primary and secondary school. Mainstream school staff's misunderstanding of the presentation of autism in girls and its negative implications have been highlighted in the literature (Cridland et al, 2014; Honeybourne, 2015; Jarman and Rayner, 2015; Zakai-Mashiach, 2022). The girls recommended that if school staff had simply tried to get to know them on an individual level, they could have understood what exactly would have made their learning environment more comfortable. Some of the girls reflected on their current experience in college/university and how they feel a lot more supported, as they have key staff they can reach out to. Importantly, the girls' discussed how it is important for school staff to understand that autism is not a 'one size fits all' approach, and every autistic person has different needs. These needs were felt to be best understood by talking to

the girls and eliciting strategies to best support them, for example, catering to auditory processing needs by simply writing down instructions. Similarly, in the literature, Honeybourne (2015) and Jarman and Rayner (2015) highlight the requirement for clear instructions and differentiated teaching styles, to enable autistic girls to access the curriculum fully.

The parents echoed the girls' sentiments, explaining how it seemed that teachers did not fully understand their daughter's needs, or the presentation of autism in girls. The parents added that this lack of knowledge and understanding resulted in their daughter's not being identified as autistic until later than was necessary. Consequently, parents felt extremely let down by the school. It was down to the parents to seek outside support and obtain a diagnosis; and parents were clear that those with less resourcing would likely struggle to navigate such a process alone. This finding is similar to that of Moyse and Porter (2015), who found that parents' views on their daughters' needs was not considered, and school staff were questioning their daughter's diagnosis and overall level of need. Furthermore, a review by Tomlinson et al (2020) found that misunderstandings were linked to school staff considering autism to be a predominantly male condition.

5.3 Research Question 2: To examine the girls' pathway to autism diagnosis during their adolescent years, and how this interacted with experiences of school support; what worked well and where could improvements be made?

This research aimed to understand autistic girls' first-hand experiences of an autism diagnosis (during their adolescent years), and if/how school were involved. We know

that there is a diagnostic bias against autistic females (Whitlock et al., 2020). Therefore, it is important that EPs work closely with school staff and parents/carers to identify and support girls from their early years and throughout their school journey who may be (subtly or overtly) struggling with aspects of school. By working collaboratively to develop understanding of autism in girls, this could lead to more timely identification, and – ultimately – fewer mental health consequences for the girls. Bargiela et al. (2016), and more recently Leedham et al. (2020), both conducted interviews to understand late-diagnosed women’s autism diagnostic journeys. This thesis builds on these limited academic studies by exploring autistic girls’ diagnostic journeys, and also by taking steps to utilise a participatory approach (via interviews and PCP methods) to gain the girls’ voices (complemented by their parents).

With regards to their diagnostic journeys, the girls described their experience being one that did not come from school advocacy or EP involvement. Instead, their journeys to diagnosis all stemmed from ongoing mental health concerns. Reflecting on their early years, the girls were able to identify ‘flags’, such as anxiety, attachment worries, depression, isolation, and difficulties with transitions. Yet despite these ‘clues’, autism was never mentioned by school staff or health professionals until much later (during their adolescent/secondary school years). Bargiela et al. (2016) similarly found that autistic women had difficulties identified during their earlier years, but these were not attributed to autism. Their sample also expressed concerns that health professional and educators did not understand female-typical presentations of autism. Similarly, Whitlock et al. (2020)’s study supports previous research highlighting a bias against autistic females, as their sample of primary school educators showed a gender bias in recognizing autistic children. This work links to the reports of girls in this study,

who reported that their delays in accessing a diagnosis were due to school staff not understanding the presentation of autism in girls.

The girls in the current study reflected on how their mental health declined across their school years, and that their autism diagnosis journeys began effectively when they were referred to CAMHS, because of persisting mental health concerns. For most of the girls, this referral to CAMHS came from external counselling or from a GP visit – all facilitated by their parent/carer. Additionally, the diagnosis was not a simple journey; CAMHS did not identify that they were autistic immediately, and many of the girls went through counselling or programs such as CBT initially, which went on for long periods of time.

Ultimately, the girls felt their autism was not being identified in a timely manner, especially by those who saw them daily – school staff. Some participants explained their diagnosis came from their parents researching and bringing their own findings to CAMHS. The girls all shared how they felt they were struggling for many years internally, and that no-one tried to understand them individually. As such, they slipped under the radar. In Moyse (2021)'s study, the girls highlighted that if their schools had prioritised their mental well-being, rather than their academic progress, they would have felt more respected and secure at school. The current findings certainly seem to echo Moyse's (2021) conclusions.

The parents interviewed in the current study also supported the girls' reflections on their diagnostic journeys, and discussed the mental health concerns (e.g., anxieties, phobias, fear) that began in their early years and then increased across their school

lives. Worryingly, parents described their daughter's reaching burnout, and commented on self-harm and suicide attempts in secondary school. In the literature, studies highlight the elevated levels of stress and anxiety (Cook, Ogden and Winstone, 2018) and experiences of depression (Honeybourne, 2015) faced by autistic girls during their school years. This is corroborated by high levels of both self-harm and suicidality in autistic people generally (Cassidy & Rodgers, 2017; Cassidy et al., 2020). Action is clearly an urgent priority for this extremely vulnerable group.

Similarly to the girls, the parents in this sample reflected on the girls' autism potentially being missed due to their external presentations of being high-achieving and academic, and their tendency to internalise their feelings at school. These experiences led parents to feel let down by the lack of school support. Moyses and Porter (2015) also found that parents reported their daughters' needs to be misinterpreted by teachers who lacked knowledge of autism in girls and did not fully understand how to modify their teaching in relation to the girls' needs (see also Cook, Ogden & Winstone, 2016). Moyses (2021) suggests that autistic girls with internalising challenges, could be missing out on early intervention or diagnosis, so it is essential for staff to 'dig deeper' in terms of identifying girls who may be struggling with aspects of school.

The final theme identified in this thesis surrounded the girls' developing autistic identities. The girls' felt they could better understand themselves following their diagnosis and began a journey of self-acceptance. Similarly to other studies (e.g., Baldwin & Costley, 2016; Bargiela et al., 2016; Leedham et al., 2020), the girls in this study felt great relief post-diagnosis and started to understand themselves and their new identity in a positive sense. With regards to post-diagnosis support, the girls did

not feel like anything significant changed for them at school, and they reported that this was disappointing. If any support was put in place, it was felt not to be specific to autism and/or their needs. An important issue the girls highlighted was the shock they received from those who they felt knew them best, ranging from school staff to family members, regarding their autism diagnosis, which was not helpful to them. The girls emphasise that if those around them had been open and accepting, they would have felt more supported.

The parents in the current study similarly reflected on the response of school staff response to their daughters' diagnosis and how unhelpful their shocked response was. Jarman and Rayner (2015) also discuss how parents reported that they struggled to convince teachers that their daughter's had Asperger's Syndrome. Ultimately parents reflected on how university or college has been more of a supportive environment than school. It will be essential for future work to consider the good practices identified at a university or college level, and to reflect on how these practices could be implemented at earlier stages of the girls' educational journeys.

Lastly, the girls and their parents discussed how advocacy has been an important part of the girls' journeys post-diagnosis, and how they could act as advocates in training school staff about autism in girls. Jarman and Rayner (2015) emphasised how important awareness of autism in girls is for school staff, as most relate autism to externalising behaviours, whereas autistic girls may show more internalising behaviours (as found in the research presented in this thesis). Whitlock et al. (2020) also echo how training on autism for school staff in the UK may need refining to reflect understanding of autism in girls. Additionally, they emphasise it is key to ensure school

staff have personal contact with autistic people to help teachers understand the training in real context.

Overall, the findings from this thesis provide important information about how best to support autistic girls; in identifying that they are autistic, and in implementing appropriate support so that they can thrive in school. The findings closely echo existing research, but also provide an important new perspective, especially around considering how unpredictable aspects at school (such as teachers having unpredictable personalities or being inconsistent with behaviour management) can affect autistic girls' entire learning and school experience. Furthermore, previous literature found differences between primary and secondary settings with regards to autistic girls' difficulties with friendships and peers, and the sample in this study emphasised that both environments were challenging.

Chapter 6: Conclusion

6.1 Introduction

This chapter will examine the strengths and limitations of this research and then discuss recommendations for future research. Following this overview, implications of the research for schools and EP practice are outlined. Finally, the girls' own recommendations for making school a 'better place' for autistic girls will be presented.

6.2 Strengths of the research

Autistic individuals want research that will make an impact on their daily lives (Pellicano et al., 2014) and it is hoped that the current research supports this goal, by looking at the educational experiences and diagnosis journeys of autistic girls and highlighting areas for potential improvement. Furthermore, (as discussed in Section 3.3), this project was developed in consultation with the AGN, who found this topic to be a priority.

This research took a multi-informant approach whilst, crucially, centring the voice of autistic girls themselves. This approach allowed the girls to detail their experiences, and their parents, who also shared their experiences separately, which allowed a richer picture combining and a linking of their experiences. The girls and their parents experiences did overlap considerably, but this might be indicative of how the girls chose to have their parents involved, so it may have been those with the strongest relationships with their parents (who discussed experiences at length) that opted for this option.

A further strength of the research is that it took steps towards being a participatory project. The research was developed in line with Cathy Wassell (the Head of the AGN), who herself is neurodivergent and has a neurodivergent daughter. The project was developed with her support, cross-checking the development of the materials and reviewing the results and findings. Furthermore, the thesis took into consideration the girls' needs and tried to ensure they could share their experiences in the most comfortable manner. These approaches included using inclusive methodologies such as different methods for interviewing, providing consent cards, utilising an evidence-based PCP tool suitable for autistic CYP, and ensuring they felt prepared and informed in advance (e.g., by sharing one-page profile of myself and providing interview questions in advance).

Lastly, this study is the first to examine autistic girls school experiences (across both primary and secondary) and their diagnosis journeys, and how these interacted in terms of school's support. This knowledge is key in terms of development of EP practice.

6.3 Limitations of the research

When considering the limitations of this research, there are aspects of the sample which must be discussed. Firstly, the sample size would typically be considered small compared to quantitative research (n=30), but it is worth noting that smaller sizes are valued in qualitative research, as the purpose is obtain a 'rich, in-depth understanding', rather than a 'generalisable understanding' (Braun and Clarke, 2022, p.6).

The sample recruited were all white, which does not represent the United Kingdom as 82% of the UK population in the UK is White but 18% consists of Black, Asian and other ethnic minorities (Gov UK, 2021). The sample was also cognitively able and none of them had attended a SEN school during their school years. It is important to aim to recruit a more diverse sample in further studies to better reflect the autistic population. Furthermore, reflection on why some communities do not participate in research and what could be done to engage with them would be beneficial to support wider, diverse samples. It would also be interesting to carry out a further study with autistic girls who are of different academic abilities and who attend a SEN setting.

With regards to the parent sample, potentially it could have been helpful to have all of the parents participate (the final sample consisted of five of the girls' parents – one couple, and three individual parents), to triangulate results. Yet it is important to mention that it was key to have the girls' experiences and voices at the centre of the research. Autonomy was also key, with the girls asked if they wanted their parents involved, and the girls' wishes were respected in this regard.

A further reflection would have been if teachers/school staff were recruited, gathering their perspectives to generate even richer data. Yet it was decided that it was challenging to recruit the girls' teachers from schools. For instance, the relationships with teachers may not be positive (thus affecting the girls' participation), and logistically this may be challenging (due to potential staffing changes from primary to secondary school, and the girls' going to different schools at different times).

Another limitation was being unable to fully pilot the study with autistic girls, or having an autistic advisory board of autistic girls (aged 16-25), who could have reviewed the

materials and participated in pilot/mock interviews. While I was fortunate to have the expertise of the Head of the AGN, the involvement of those at the centre of this work could have been hugely beneficial.

Lastly, the use of a measure of autistic symptomatology may have been useful in more clearly mapping out the characteristics of my sample. For example, the Social Responsiveness Scale (Constantino & Gruber, 2005) is a parent-report 65-item questionnaire that assesses social and behavioural difficulties associated with autism in children and adolescents. On each item, parents are asked to rate their child's behaviour over the past six months using a 4-point scale ranging from 'not true' (score of 1) to 'almost always true' (score of 4). The SRS has excellent reliability (Cronbach's $\alpha = 0.95$) and strong predictive validity. This measure could have been helpful to understand the sample further, and to allow for understanding how diverse the sample was in terms of their cognitive ability. This measure was not used due to the constraints of the DEdPsych thesis (e.g., cost) but could have added a helpful dimension to the data collected.

6.4 Future research

Following on from the current study, further research should be conducted with more diverse samples of autistic girls', examining their school experiences and autism diagnosis during their adolescent years, to build on the limited research in this area. Nevertheless, the current work represents an important foundational step in the field.

6.5 Implications for EP practice

As discussed at the start of this thesis, the research uses Bronfenbrenner's bio-ecological model (2005) as a lens for considering the girls' school experiences and diagnostic journeys. EPs use Bronfenbrenner's models and theories to guide their practice, when considering the systems and factors around a CYP. Next, I consider how the model applies to the results of my research.

To recap, Bronfenbrenner's bio-ecological model consists of four sections: Process, Person, Context and Time (see Figure 1). In terms of 'Process', this underpinned the girls' and their parents' personal narratives and experiences surrounding their primary and secondary school experiences and unique diagnostic journeys. Examining the girls' themes, there is also a seemingly clear journey that involved sensory and environmental struggles at school; ongoing social challenges; unpredictability and difficulties with transitions; and persistent mental health concerns that exacerbate, spiral and lead to an autism diagnosis. Therefore, as EPs it is important that we are working alongside SENCOs to ensure early identification occurs, to ensure girls are not 'slipping under the radar', and that 'flags' are identified before situations spiral to mental health concerns, such as self-harming or suicidal ideations. We could achieve this goal by supporting schools to ensure girls are accessing the correct mental health support (and liaising with external agencies, such as CAMHS, in a multi-disciplinary manner), as many of the girls went through many types of therapy before feeling heard/understood.

In terms of 'Person', the girls shared similar experiences yet also had unique stories to tell, and this finding links into the girls' feelings shared around 'individualisation'.

The girls explained how if their teachers/school staff had tried to understand them personally and on a one-on-one level, this would have enabled them to have an overall better learning experience. In a wider sense, this finding also translated to the girls feeling misunderstood by their teachers/schools, and the fact that their autism diagnosis did not come from school. As EPs, we can work individually and systematically with schools, to support them in developing their knowledge around autism in girls, which hopefully supports faster identification. One of the ways to achieve this goal could be providing them with information such as the White Paper 'Autistic Girls Network: Autism, Girls and Keeping It All Inside' (2022) (highlighting the checklists on pg.10-13), and discussing the contents during consultation. Also, more widely, providing training for school staff in this area could be hugely beneficial (ideally with the input of autistic girls themselves). Furthermore, highlighting themes/red flags identified during this research, and sharing these during consultations when planning with schools could further aid identification and support (see further in the section below, 'Recommendations from the Girls').

With regards to 'Time', the girls ranged in age from 16-25 years and therefore they were able to reflect on different points of their journeys at various stages. Despite the girls' not having an autism diagnosis during their biggest school transition (primary to secondary school), transitions were discussed at length by the girls' and their parents, as being a challenging area. What could be considered seemingly small transitions, such as having a substitute teacher for a day or changing classrooms, had a massive impact on the girls' ability to learn. Therefore, as EPs it is important that we raise this issue to SENCos/school staff, to ensure all transitions are carefully planned, organised and managed.

Lastly, 'Context' involves four sub-sections, 'Microsystem', 'Mesosystem', 'Exosystem' and the 'Macrosystem'. In terms of the 'Microsystem', 'Mesosystem', and 'Exosystem', the parents felt they were mainly providing school with the support and tools to cater to their daughters' needs. Therefore, ensuring school staff have access to training on autism in girls is essential, to better plan and support these girls in their schools, and removing the onus away from parents. It is important to note that this training should ideally be conducted by someone autistic (as the girls in this research discussed). Further, the significance of interacting with an autistic person was identified in Whitlock et al. (2020), who found that school staff with personal experience of autistic individuals were better able to recognise autism, whereas autism training had little effect in this regard. This approach of autistic-led training would also hopefully lead to earlier identification.

Many of the parents reported not feeling heard by the school, and therefore this finding highlights the importance of communication between home and school. As EPs, we can bring together families during joint consultation settings, to facilitate containment, develop relationships between the two settings, and signpost relevant support agencies. Additionally, as discussed above, encouraging collaborative working amongst multi-agencies such as CAMHS or GPs ensures all viewpoints and professional opinions are considered, allowing a richer picture of the girls to be developed.

Lastly, with regards to the 'Macrosystem', the girls reflected on the shock they received from their teachers, school staff, and wider family members surrounding their diagnosis. This reaction was reported very difficult for the girls, and unhelpful. By

increasing wider community awareness of autism in girls, and being offered post-diagnosis support, EPs can help many of these families who noted that they felt 'left to handle the diagnosis alone'.

A final reflection is that, as EPs, we need to be involved at all levels. We currently support girls and their families at the micro and mesosystem, but ultimately we need to consider the macro and exosystem by utilising multi-agency working, conducting research, influencing government policy and teacher training on a wider level. These are important goals for the future.

6.6 Recommendations for school staff working with autistic girls (from the girls themselves)

Many of the girls gave very valuable advice of how things could have been better for them during their school years. Given my commitment to amplifying the voices of autistic girls, Table 2 is presented for school staff to reflect upon. Indeed, as EPs, we could share this table during consultations. Ultimately, the final words in the thesis should be from the girls.

Table 2: Recommendations from the girls

Summary of recommendation		Quote
Classroom environment	Calm and quiet	Definitely calmer. Definitely quiet (Alex)
	Periods of quiet reading during school day (Primary and secondary school)	We used to have like quiet reading time [in Primary].... which I don't understand why.... they stopped that at a young age.... (Alex)
	Sensory adjustments	<p>[My ideal school] would have no smart board, make rooms sensory accessible (dimmed lights, quieter sound coming from smart board) (Adalyn)</p> <p>Turning down the brightness of the lights a bit (Harriet)</p> <p>Having an opportunity to have like sensory stuff... I've got a bracelet, every single day in high school in form, I would get yelled at and told to take it off... And I'd put it in my</p>

		pocket because it wasn't uniform, and then I'd take it back out immediately because I could not manage without fiddling with it because it was my way of staying grounded.... It was very important to me (Harriet)
Classroom layouts	Teacher space	The teacher quarters - around the centre of the room, so it's not an awkward having to go to the front to ask about things... (Harriet)
	Individual / personal desks	Definitely a bit more like personal space, like having personal desks but still being like close, close enough to people that you can talk to them.... (Alex) [My ideal school would have] individual desks (Gemma)
	Seating options	[My ideal school would have] bean bags, floor desks... (Adalyn)

		<p>[My ideal school has] different chairs being available.... I like beanbags... but roller chairs are also good and having just different like types of chairs that you can sit in at every point instead of having just specific desks, that can be easily moved around... (Harriet)</p>
	<p>Student voice matters</p>	<p>Have them [students], have a say in the seating plan. That was a massive thing for me. I quite literally, I ended up leaving a lesson crying before, just in the middle of the lesson, because of a person who was sat next to me kept calling me slurs and the teacher was doing nothing about it.. letting us be able to have input on where we're sitting, if it's too loud, because it was right near the door as well which had to be open, so there was everyone walking through the corridors, and I'm getting insulted constantly. And really, it used to be my favourite lesson English... but</p>

		that ruined the entire experience from, from being in that year in that seating plan.... (Harriet)
Wider school environment		[My ideal school would be] calm and quieter... inclusive... (Adalyn) [My ideal school would be] small, quiet, safe and mainstream (Gemma)
	Inclusivity/accessibility	Making a school environment more accessible for autistic individuals like the girls changing rooms loud, lots of smells, because they've got all perfumes and stuff, and it's all very difficult having a quieter space, where they will instead lock the bathrooms so that we had to get changed there and do just different things like that and making small accommodations... (Harriet)

		<p>Having general things to make everyday life easier for people regardless, maybe even paper towels instead of hand drying... having alternatives in places... and it just makes the entire day experiences more difficult from that one experience of... once you've had that, then it's in your head and then everything else becomes more difficult because you're more susceptible to it..... (Harriet).</p>
	<p>Access to calm spaces</p>	<p>Definitely having places that people can go either on their own or with other people, that are just calm low light, like comfortable places where you can either just sit in silence, do nothing... (Alex)</p> <p>Create a quiet, safe space for girls to go if feeling overwhelmed (Gemma)</p>

		<p>[My ideal school] it would have quiet areas available, just generally around that, you know, those are always there if you need them... having some form of space for regulation, rather than a busy canteen and stuff like that, having options for that (Harriet)</p>
<p>Teachers</p>		<p>‘Do not say talk amongst yourselves, instead give a task to do!’ (Rebecca)</p> <p>I think the most important is to create a feeling of safety in the classroom by establishing set routines and especially by playing to their students interests to create engagement with the subject matter (Sas).</p> <p>This could be accompanied by more lenient deadlines to allow less anxiety surrounding completing homework, and</p>

		<p>more student support throughout their time at school (Sas)</p>
	<p>Knowledge of autism – differences in boys and girls</p>	<p>Understanding the basics of autism anyway.... especially how it presents differently in different people.... and sort of looking out, being more aware of the traits in certain people.. Because I know if I had had someone that knew more about autism, that was able to sort of give me attention, I would have been diagnosed a lot younger, and it would have meant that I would have had a lot less trauma, I guess, from just growing up undiagnosed....And it would have meant that I would have had a lot more help growing up.....(Alex)</p> <p>I think that teachers in schools in general just need to be taught about, you know, seeing the signs of autism,</p>

		<p>because it would have been so beneficial for me to be diagnosed earlier (Alex)</p> <p>[Secondary schools could support girls going through diagnosis by] providing accurate info in their referral letters (know the traits in girls) (Adalyn)</p> <p>Remember students support plans...Train teachers with better knowledge of autism in girls (Gemma)</p>
	<p>Build a relationship and get to know me</p>	<p>I think it's very important that you go and speak to the individual on their own. You've got to build up a rapport with them enough that you feel like you can go and say, so what would you want from me? What can I do to help you make the environment more comfortable for you? (Alice)</p>

		<p>... if you haven't picked it up [autism], you don't know the kid well enough, is what I would say.... if you've got enough of a relationship with the student and enough of an open mind you will be able to tell... (Alice)</p> <p>I think asking people, because like everyone's needs is so different. But like, if you just sat down with me and said – 'What's, what's difficult, what is the barrier to learning?' I can tell you exactly what the problem is and then it can be solved... like a lot of the time, people assume that every autistic person struggles with eye contact, or every autistic person struggles with loud noises. Whereas like, that's not necessarily the case. Like for me, auditory processing is like a really big deal. But for a lot of people that wouldn't even be something that would be an issue. So I think that, you're unlikely to have loads of autistic students in your</p>
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		<p>class. So like, if you if you're aware of, if you're aware that you have autistic students in your class, have that conversation with them, ask what you can do to make things easier...(Kirsty)</p>
<p>Friendship/peer support</p>	<p>Opportunities for autistic girls to interact</p>	<p>Giving autistic girls the opportunity to interact with other autistic girls?... I never really I, I struggled a lot with seeking out new friendships.... and I think that, that having school sort of help in that, in seeking them out and giving opportunities to autistic people to just sort of get to know each other and maybe find a peer that you can relate to because I know for a fact that I never had that.... (Alex)</p> <p>I think having like a club or an acceptance club that could even like help. The school, we had an LGBT society... I think doing something similar to that, but with like autism or other neurodiversity would be useful... (Alex)</p>

Autistic advocates and training		<p>I think that some schools kind of give talks to the teachers on what autism is like, but I think it cannot be done by someone who doesn't have it. And I think that's the key....</p> <p>I'll come and talk to you about it because I feel very passionately about people who don't have the issues, preaching about them... (Alice)</p> <p>Yeah, to have the school speak to actual autistic kids who go to that school on how they could help and they could change it, is always useful... (Alex)</p> <p>There needs to be more support for people like me in this exact position and I can be that support for someone else... (Harriet)</p>
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		<p>What I liked is that they [university] have a special autism programme... they run it throughout the year and... they did one yesterday talking about executive function and adapt transition and just generally what they can offer to support and some techniques that might be helpful.... And all the people who were involved in delivering that programme were autistic and like the staff members, and that was just it was it was the reason why I picked [that university] was because they were so willing to offer support... (Kirsty)</p>
<p>School transitions – what would be helpful?</p>		<p>Going in, to sort of get an idea of what the days will be like, having timetables.... I used to get my timetable on the day that I started, which sort of, meant that I didn't get any time to prepare for like... I'm very, the way that I plan is I visualise in my head.... And if, if my day doesn't go how I</p>

		<p>visualised it in my head, then it sort of makes me panic and freaks me out a bit... (Alex)</p> <p>I think if you can go to the school... just before you start, maybe with some other autistic students and like your parents... (Alex)</p> <p>Going around the school, talking to your Form Tutor or to the teachers that you might be having... where I'd be going to classes, what my day would look like.... Like, specific times as well.... I was never told like what time the lesson starts and when it like ends, and when lunchtime is and when lunchtime ends and when break is... because it's very different to primary school (Alex)</p>
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		<p>The first week was all getting different books and getting the planner and stuff like that, if I had access to them beforehand, and I could get used to the layout, I could understand that... if you'd had them, maybe even just a week in advance, go in, pick them up, then you'd have that ready you'd have it prepared, you'd be able to know what correlates with what lesson and if there's anything extra you need to bring to certain lessons like calculator and protractors to Maths or if geography uses more colour pencils and different things like that... (Harriet)</p> <p>[School staff could support autistic girls transitioning from Primary to Secondary by] organising a visit to the school beforehand, meeting the new teachers, viewing a map of the new school and ensuring the transition is smooth as possible – that all members of staff have the appropriate</p>
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		training as to best cater to the student's needs, focus on specific struggles of the student and put an appropriate plan in place to aid student (Sas)
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References

- Allen, M. L. (2009). Brief Report: Decoding Representations: How Children with Autism Understand Drawings. *Journal of Autism and Developmental Disorders*, 39(3), 539–543. <https://doi.org/10.1007/s10803-008-0650-y>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.) Washington, DC: Author. <https://doi.org/10.1176/appi.books.9780890425596>
- Asperher, H. (1944). Die 'Autistischen psychopathen' im Kindesalter. *Archiv Für Psychiatrie Und Nervenkrankheiten*, 117(1), 76–136.
- Attwood, T. (2006). The pattern of abilities and development of girls with Asperger's Syndrome. In T. Attwood, T. Grandin, & T. Bolick (Eds.), *Aspergers and girls* (pp. 1-8). Arlington, Texas: Future Horizons.
- Autistic Girls Network. (2022). Autism, Girls, & Keeping It All Inside. *Autistic Girls Network*. [Keeping-it-all-inside.pdf \(autisticgirlsnetwork.org\)](https://autisticgirlsnetwork.org/Keeping-it-all-inside.pdf)
- Baldwin, S., & Costley, D. (2016). The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism*, 20(4), 483–495. <https://doi.org/10.1177/1362361315590805>
- Bargiela, S., Steward, R., & Mandy, W. (2016). The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *Journal of Autism and Developmental Disorders*, 46(10), 3281–3294. <https://doi.org/10.1007/s10803-016-2872-8>
- Beaver, R. (1996). *Educational psychology casework: A practical guide*, London: Jessica Kingsley Publications.

- Billington, T. (2006). Working with autistic children and young people: Sense, experience and the challenges for services, policies and practices. *Disability & Society*, 21(1), 1–13. <https://doi.org/10.1080/09687590500373627>
- Blume, H. (1997, July 1). 'Autism & the internet' or 'it's the wiring, stupid'. MIT. Retrieved from <http://web.mit.edu/m-i-t/articles/blume.html>
- Bottema-Beutel, Kristen, Kapp, K., Steven, Lester, N., Jessica, Sasson, J., Noah, & Hand, N., Brittany. (2021). Avoiding Ableist Language: Suggestions for Autism Researchers. *Autism in Adulthood*, 3(1), 18–29. <https://doi.org/10.1089/aut.2020.0014>
- BPS. (2021). Code of Ethics and Conduct. *The British Psychological Society*. [Code of Ethics and Conduct | BPS - British Psychological Society](#)
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.
- Braun, V., & Clarke, V. (2017). *Yashasvi gunatmak sanshodhan: Navshikya vidyarthiyansathi vyavharik margdarshan*. New Delhi: SAGE Publishing India.
- Braun, V., & Clarke, V. (2019). Reflecting on thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 13(2), 1-16
- Braun, V., & Clarke, V. (2022). *Thematic analysis: A practical guide*. SAGE.
- Bronfenbrenner, Uri. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.
- Bronfenbrenner, Uri. (1989). *Ecological systems theory* (Vol. 6). *Annals of Child Development*.

- Bronfenbrenner, Uri. (2005). *Making Human Beings Human: Biological perspectives on human development*. SAGE.
- Bryson, S. E., Rogers, S. J., & Fombonne, E. (2003). Autism Spectrum Disorders: Early Detection, Intervention, Education, and Psychopharmacological Management. *The Canadian Journal of Psychiatry*, 48(8), 506–516. <https://doi.org/10.1177/070674370304800802>
- Burden, R. (1998). Assessing Children's Perceptions of Themselves as Learners and Problem-Solvers: The Construction of the Myself-as-Learner Scale (MALS). *School Psychology International*, 19(4), 291–305. <https://doi.org/10.1177/0143034398194002>
- Cage, E., & Troxell-Whitman, Z. (2019). Understanding the Reasons, Contexts and Costs of Camouflaging for Autistic Adults. *Journal of Autism and Developmental Disorders*, 49(5), 1899–1911. <https://doi.org/10.1007/s10803-018-03878-x>
- Calder, L., Hill, V., & Pellicano, E. (2013). 'Sometimes I want to play by myself': Understanding what friendship means to children with autism in mainstream primary schools. *Autism*, 17(3), 296–316. <https://doi.org/10.1177/1362361312467866>
- Cameron, L., & Murphy, J. (2002). Enabling young people with a learning disability to make choices at a time of transition. *British Journal of Learning Disabilities*, 30(3), 105–112. <https://doi.org/10.1046/j.1468-3156.2002.00165.x>
- Cassidy, S. A., Robertson, A., Townsend, E., O'Conner, R. C., Rodgers, J. (2020). Advancing Our Understanding of Self-harm, Suicidal Thoughts and Behaviours in Autism. *Journal of Autism and Developmental Disorders*, 50(10). <http://dx.doi.org.libproxy.ucl.ac.uk/10.1007/s10803-020-04643-9>

- Cassidy, S., & Rodgers, J. (2017). Understanding and prevention of suicide in autism. *The Lancet Psychiatry*, 4(6), e11. [https://doi.org/10.1016/S2215-0366\(17\)30162-1](https://doi.org/10.1016/S2215-0366(17)30162-1).
- Coffey, A. (2013). Relationships: The key to successful transition from primary to secondary school? *Improving Schools*, 16, 261–271. <https://doi.org/10.1177/1365480213505181>
- Cohen, S. R., Joseph, K., Levinson, S., Blacher, J. & Eisenhower, A. (2022). 'My Autism Is My Own': Autistic Identity and Intersectionality in the School Context. *Autism Adulthood*, 4(4), 315-327. <https://doi.org/10.1089/aut.2021.0087>
- Constantino, J.N., & Gruber, C.P. (2005). *Social Responsiveness Scale (SRS)*. Los Angeles, CA: Western Psychological Services.
- 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*, 33(3), 302–315. <https://doi.org/10.1080/08856257.2017.1312797>
- Cook, J., Crane, L., Hull, L., Bourne, L., & Mandy, W. (2022). Self-reported camouflaging behaviours used by autistic adults during everyday social interactions. *Autism*, 26(2), 406–421. <https://doi.org/10.1177/13623613211026754>
- Cook, J., Hull, L., Crane, L., & Mandy, W. (2021). Camouflaging in autism: A systematic review. *Clinical Psychology Review*, 89, 102080. <https://doi.org/10.1016/j.cpr.2021.102080>
- Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. L. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, 20(2), 153-162. <https://doi.org/10.1177/1362361315573636>

- Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals. *Journal of Autism and Developmental Disorders*, 48(11), 3761–3772. <https://doi.org/10.1007/s10803-018-3639-1>
- 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 Disorders During Adolescence. *Journal of Autism and Developmental Disorders*, 44(6), 1261–1274. <https://doi.org/10.1007/s10803-013-1985-6>
- Cunningham, M. (2020). 'This school is 100% not autistic friendly!' Listening to the voices of primary-aged autistic children to understand what an autistic friendly primary school should be like. *International Journal of Inclusive Education*, 0(0), 1–15. <https://doi.org/10.1080/13603116.2020.1789767>
- Dann, R. (2011). Secondary transition experiences for pupils with Autistic Spectrum Conditions (ASCs). *Educational Psychology in Practice*, 27(3), 293–312. <https://doi.org/10.1080/02667363.2011.603534>
- de Giambattista, C., Ventura, P., Trerotoli, P., Margari, F., & Margari, L. (2021). Sex Differences in Autism Spectrum Disorder: Focus on High Functioning Children and Adolescents. *Frontiers in Psychiatry*, 12, 539835. <https://doi.org/10.3389/fpsy.2021.539835>
- Dean, M., Harwood, R., & Kasari, C. (2017). The art of camouflage: Gender differences in the social behaviors of girls and boys with autism spectrum disorder. *Autism*, 21(6), 678–689. <https://doi.org/10.1177/1362361316671845>
- Dean, M., Kasari, C., Shih, W., Frankel, F., Whitney, R., Landa, R., Lord, C., Orlich, F., King, B., & Harwood, R. (2014). The peer relationships of girls with ASD at school: Comparison to boys and girls with and without ASD. *Journal of Child*

Psychology and Psychiatry, and Allied Disciplines, 55(11), 1218–1225.

<https://doi.org/10.1111/jcpp.12242>

Department for Education. (2014). *The Children and Families Act*. London: DfE.

Department for Education. (2015), *SEND Code of Practice: for 0-25 years- statutory guidance for organisations who work with and support children and young people with SEND*. London: DfE.

Dillon, G. V., & Underwood, J. D. M. (2012). Parental perspectives of students with autism spectrum disorders transitioning from primary to secondary school in the United Kingdom. *Focus on Autism and Other Developmental Disabilities*, 27(2), 111–121. <https://doi.org/10.1177/1088357612441827>

Estrin, G. L., Milner, V., Spain, D., Happé, F. & Colvert, E. (2021) 'Barriers to autism spectrum disorder diagnosis for young women and girls: a systematic review', *Review Journal of Autism and Developmental Disorders*, 8(4), 451– 470.

Evans, B. (2017). *The metamorphosis of autism*. Manchester University Press. https://doi.org/10.26530/OAPEN_625488

Filipek, P. A., Accardo, P. J., Baranek, G. T., Cook, E. H., Dawson, G., Gordon, B., Gravel, J. S., Johnson, C. P., Kallen, R. J., Levy, S. E., Minshew, N. J., Ozonoff, S., Prizant, B. M., Rapin, I., Rogers, S. J., Stone, W. L., Teplin, S., Tuchman, R. F., & Volkmar, F. R. (1999). The screening and diagnosis of autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, 29(6), 439–484. <https://doi.org/10.1023/a:1021943802493>

Fletcher-Watson, Sue, Adams, Jon, Brook, Kabie, Charman, Tony, Crane, Laura, Cusack, James, Leekam, Susan, Milton, Damian, Parr, R., Jeremy, & Pellicano, Elizabeth. (2019). Making the future together: Shaping autism research through

meaningful participation. *Autism*, 23(4), 943–953.
<https://doi.org/10.1177%2F1362361318786721>

Fox, M., Martin, P., & Green, G. (2007). *Doing practitioner research*. Sage.

Gallais, T. L. (2008). Wherever I go there I am: reflections on reflexivity and the research stance. *Reflective Practice: International and Multidisciplinary Perspectives*, 9, 145-155.

Giles, D. C. (2014). 'DSM-V is taking away our identity': The reaction of the online community to the proposed changes in the diagnosis of Asperger's disorder. *Health (London, England: 1997)*, 18(2), 179–195.
<https://doi.org/10.1177/1363459313488006>

Goodall, C. (2015). How do we create ASD-friendly schools? A dilemma of placement. *Support for Learning*, 30(4), 305–326. <https://doi.org/10.1111/1467-9604.12104>

Gould, J., & Ashton-Smith, J. (2011). Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. *GAP*, 12(1), 34-41.

Gould, J. (2017). Towards understanding the under-recognition of girls and women on the autism spectrum. *Autism: The International Journal of Research and Practice*, 21(6), 703–705. <https://doi.org/10.1177/1362361317706174>

Gov UK (2021). Ethnicity facts and figures: Census Data. Retrieved from [Ethnicity facts and figures – GOV.UK \(ethnicity-facts-figures.service.gov.uk\)](https://www.ethnicity-facts-figures.service.gov.uk)

Gray, L. (2018). *Exploring the experiences of school exclusion for pupils on the autism spectrum* [UCL Institute of Education].
<https://discovery.ucl.ac.uk/id/eprint/10056262/1/Exploring%20the%20experiences%20of%20school%20exclusion%20for%20pupils%20on%20the%20autism%20spectrum.pdf>

- Gray, L., Bownas, E., Hicks, L., Hutcheson-Galbraith, E., & Harrison, S. (2021). Towards a better understanding of girls on the Autism spectrum: Educational support and parental perspectives. *Educational Psychology in Practice*, 37(1), 74–93. <https://doi.org/10.1080/02667363.2020.1863188>
- Greathead, S., Yates, R., Hill, V. C., Kenny, L., Croydon, A., & Pellicano, E. (2016). Supporting children with severe to profound learning difficulties and complex communication needs to make their views known: Observation tools and methods. *Topics in Language Disorders*, 36(3), Article 3.
- Grebe, S. C., Mire, S. S., Kim, H., & Keller-Margulis, M. A. (2022). Comparing Fathers' and Mothers' Perspectives About Their Child's Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 52(4), 1841+. <https://dx.doi.org.libproxy.ucl.ac.uk/10.1007/s10803-021-05077-7>
- Halsall, J., Clarke, C., & Crane, L. (2021). “Camouflaging” by adolescent autistic girls who attend both mainstream and specialist resource classes: Perspectives of girls, their mothers and their educators. *Autism*, 25(7), 2074–2086. <https://doi.org/10.1177/13623613211012819>
- Harding, E., & Atkinson, C. (2009). How EPs record the voice of the child. *Educational Psychology in Practice*, 25(2), 125–137. <https://doi.org/10.1080/02667360902905171>
- Harmens, M., Sedgewick, F. & Hobson, H.(2022) ‘The quest for acceptance: a blog-based study of autistic women's experiences and well-being during autism identification and diagnosis’, *Autism in Adulthood*, 4(1), 42– 51
- Harrington, C., Foster, M., Rodger, S., & Ashburner, J. (2014). Engaging young people with Autism Spectrum Disorder in research interviews. *British Journal of Learning Disabilities*, 42(2), 153–161. <https://doi.org/10.1111/bld.12037>

- Hill, V., Croydon, A., Greathead, S., Kenny, L., Yates, R., & Pellicano, E. (2016). Research methods for children with multiple needs: Developing techniques to facilitate all children and young people to have 'a voice'. *Educational and Child Psychology, 33*.
- Hiller, R. M., Young, R. L., & Weber, N. (2014). Sex Differences in Autism Spectrum Disorder based on DSM-5 Criteria: Evidence from Clinician and Teacher Reporting. *Journal of Abnormal Child Psychology, 42*(8), 1381–1393. <https://doi.org/10.1007/s10802-014-9881-x>
- Honeybourne, V. (2015). Girls on the autism spectrum in the classroom: Hidden difficulties and how to help. *Good Autism Practice (GAP), 16*(2), 11–20.
- Hsiao, M.-N., Tseng, W.-L., Huang, H.-Y., & Gau, S. S.-F. (2013). Effects of autistic traits on social and school adjustment in children and adolescents: The moderating roles of age and gender. *Research in Developmental Disabilities, 34*(1), 254–265. <https://doi.org/10.1016/j.ridd.2012.08.001>
- Hull, L., Lai, M.-C., Baron-Cohen, S., Allison, C., Smith, P., Petrides, K., & Mandy, W. (2020). Gender differences in self-reported camouflaging in autistic and non-autistic adults. *Autism, 24*(2), 352–363. <https://doi.org/10.1177/1362361319864804>
- Hull, L., Levy, L., Lai, M.-C., Petrides, K. V., Baron-Cohen, S., Allison, C., Smith, P., & Mandy, W. (2021). Is social camouflaging associated with anxiety and depression in autistic adults? *Molecular Autism, 12*(1), 13. <https://doi.org/10.1186/s13229-021-00421-1>
- Hull, L., Mandy, W., & Petrides, K. (2017). Behavioural and cognitive sex/gender differences in autism spectrum condition and typically developing males and females. *Autism, 21*(6), 706–727. <https://doi.org/10.1177/1362361316669087>

- Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.-C., & Mandy, W. (2017). "Putting on My Best Normal": Social Camouflaging in Adults with Autism Spectrum Conditions. *Journal of Autism and Developmental Disorders*, 47(8), 2519–2534. <https://doi.org/10.1007/s10803-017-3166-5>
- Humphrey, N., & Lewis, S. (2008). 'Make me normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism*, 12(1), 23–46. <https://doi.org/10.1177/1362361307085267>
- Hurlbutt, K., & Chalmers, L. (2002). Adults With Autism Speak Out: Perceptions of Their Life Experiences. *Focus on Autism and Other Developmental Disabilities*, 17(2), 103–111. <https://doi.org/10.1177/10883576020170020501>
- Jarman, B., & Rayner, C. (2015). Asperger's and Girls: What Teachers Need to Know. *Australasian Journal of Special Education*, 39(2), 128–142. <https://doi.org/10.1017/jse.2015.7>
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217–250.
- Kelly, G. A. (1955). *The psychology of personal constructs. Vol 1. A theory of personality. Vol 2. Clinical diagnosis and psychotherapy.* W. W. Norton.
- Kirkovski, M., Enticott, P. G., & Fitzgerald, P. B. (2013). A Review of the Role of Female Gender in Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 43(11), 2584–2603. <https://doi.org/10.1007/s10803-013-1811-1>
- Kopp, S., & Gillberg, C. (1992). Girls with social deficits and learning problems: Autism, atypical Asperger syndrome or a variant of these conditions. *European Child & Adolescent Psychiatry*, 1(2), 89–99. <https://doi.org/10.1007/BF02091791>

- Kopp, S., & Gillberg, C. (2011). The Autism Spectrum Screening Questionnaire (ASSQ)-Revised Extended Version (ASSQ-REV): An instrument for better capturing the autism phenotype in girls? A preliminary study involving 191 clinical cases and community controls. *Research in Developmental Disabilities*, 32(6), 2875–2888. <https://doi.org/10.1016/j.ridd.2011.05.017>
- Kreiser, N. L., & White, S. W. (2014). ASD in females: Are we overstating the gender difference in diagnosis? *Clinical Child and Family Psychology Review*, 17(1), 67–84. <https://doi.org/10.1007/s10567-013-0148-9>
- Lai, M.-C., Baron-Cohen, S., & Buxbaum, J. D. (2015). Understanding autism in the light of sex/gender. *Molecular Autism*, 6(1), 24. <https://doi.org/10.1186/s13229-015-0021-4>
- Lai, M.-C., Lerch, J. P., Floris, D. L., Ruigrok, A. N. V., Pohl, A., Lombardo, M. V., & Baron-Cohen, S. (2017). Imaging sex/gender and autism in the brain: Etiological implications: Imaging Sex/Gender and Autism in the Brain. *Journal of Neuroscience Research*, 95(1–2), 380–397. <https://doi.org/10.1002/jnr.23948>
- Lai, M.-C., Lombardo, M. V., Auyeung, B., Chakrabarti, B., & Baron-Cohen, S. (2015). Sex/Gender Differences and Autism: Setting the Scene for Future Research. *Journal of the American Academy of Child and Adolescent Psychiatry*, 54(1), 11–24. <https://doi.org/10.1016/j.jaac.2014.10.003>
- Lai, M.-C., Lombardo, M. V., Pasco, G., Ruigrok, A. N. V., Wheelwright, S. J., Sadek, S. A., Chakrabarti, B., MRC AIMS Consortium, & Baron-Cohen, S. (2011). A behavioral comparison of male and female adults with high functioning autism spectrum conditions. *PloS One*, 6(6), e20835. <https://doi.org/10.1371/journal.pone.0020835>

- Lai, M.-C., Lombardo, M. V., Ruigrok, A. N., Chakrabarti, B., Auyeung, B., Szatmari, P., Happé, F., & Baron-Cohen, S. (2017). Quantifying and exploring camouflaging in men and women with autism. *Autism*, 21(6), 690–702. <https://doi.org/10.1177/1362361316671012>
- Lai, M.-C., Lombardo, M. V., Ruigrok, A. N. V., Chakrabarti, B., Wheelwright, S. J., Auyeung, B., Allison, C., & Baron-Cohen, S. (2012). Cognition in Males and Females with Autism: Similarities and Differences. *PLoS ONE*, 7(10), e47198. <https://doi.org/10.1371/journal.pone.0047198>
- Lawson, W. B. (2020). Adaptive Morphing and Coping with Social Threat in Autism: An Autistic Perspective. *Journal of Intellectual Disability - Diagnosis and Treatment*, 8(3), Article 3. <https://doi.org/10.6000/2292-2598.2020.08.03.29>
- Leedham, A., Thompson, A. R., Smith, R., & Freeth, M. (2020). 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*, 24(1), 135–146. <https://doi.org/10.1177/1362361319853442>
- Livingston, L. A., & Happé, F. (2017). Conceptualising compensation in neurodevelopmental disorders: Reflections from autism spectrum disorder. *Neuroscience and Biobehavioral Reviews*, 80, 729–742. <https://doi.org/10.1016/j.neubiorev.2017.06.005>
- Livingston, L. A., Shah, P., & Happé, F. (2019). Compensatory strategies below the behavioural surface in autism: A qualitative study. *The Lancet. Psychiatry*, 6(9), 766–777. [https://doi.org/10.1016/S2215-0366\(19\)30224-X](https://doi.org/10.1016/S2215-0366(19)30224-X)
- Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. *Journal*

- of the American Academy of Child and Adolescent Psychiatry*, 56(6), 466–474.
<https://doi.org/10.1016/j.jaac.2017.03.013>
- Mackay, S. J., & Parry, O. (2015). Two world views: Perspectives on autistic behaviours. *Journal of Health Psychology*, 20(11), 1416–1426.
<https://doi.org/10.1177/1359105313512515>
- Makin, C., Hill, V., & Pellicano, E. (2017). The primary-to-secondary school transition for children on the autism spectrum: A multi-informant mixed-methods study. *Autism & Developmental Language Impairments*, 2, 239694151668483.
<https://doi.org/10.1177/2396941516684834>
- Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A., & Skuse, D. (2012). Sex Differences in Autism Spectrum Disorder: Evidence from a Large Sample of Children and Adolescents. *Journal of Autism and Developmental Disorders*, 42(7), 1304–1313. <https://doi.org/10.1007/s10803-011-1356-0>
- Mandy, W., Murin, M., Baykaner, O., Staunton, S., Cobb, R., Hellriegel, J., Anderson, S., & Skuse, D. (2016). Easing the transition to secondary education for children with autism spectrum disorder: An evaluation of the Systemic Transition in Education Programme for Autism Spectrum Disorder (STEP-ASD). *Autism*, 20(5), 580–590. <https://doi.org/10.1177/1362361315598892>
- Mattila, M.-L., Kielinen, M., Linna, S.-L., Jussila, K., Ebeling, H., Bloigu, R., Joseph, R. M., & Moilanen, I. (2011). Autism Spectrum Disorders According to DSM-IV-TR and Comparison With DSM-5 Draft Criteria: An Epidemiological Study. *Journal of the American Academy of Child & Adolescent Psychiatry*, 50(6), 583-592.e11. <https://doi.org/10.1016/j.jaac.2011.04.001>

- Mcallister, K., & Maguire, B. (2012). Design considerations for the autism spectrum disorder-friendly Key Stage 1 classroom. *Support for Learning*, 27(3), 103–112. <https://doi.org/10.1111/j.1467-9604.2012.01525.x>
- McLennan, J. D., Lord, C., & Schopler, E. (1993). Sex differences in higher functioning people with autism. *Journal of Autism and Developmental Disorders*, 23(2), 217–227. <https://doi.org/10.1007/BF01046216>
- McNerney, C., Hill, V., & Pellicano, E. (2015). Choosing a secondary school for young people on the autism spectrum: A multi-informant study. *International Journal of Inclusive Education*, 19(10), 1096–1116. <https://doi.org/10.1080/13603116.2015.1037869>
- Moran, H. (2001) Who Do You Think You Are? Drawing the Ideal Self: A Technique to Explore a Child's Sense of Self. *Clinical Child Psychology and Psychiatry*, 6(4), 599-604. <https://doi.org/10.1177/1359104501006004016>
- Moran, H (2006). A very personal assessment: Using a personal construct psychology technique (Drawing the Ideal Self) with young people with ASD to explore the child's view of the self. *Good Autism Practice (GAP)*, 7(2), 78–86.
- Moseley, R. L., Hitchiner, R., & Kirkby, J. A. (2018). Self-reported sex differences in high-functioning adults with autism: A meta-analysis. *Molecular Autism*, 9(1), 33. <https://doi.org/10.1186/s13229-018-0216-6>
- Moyse, R., & Porter, J. (2015). The experience of the hidden curriculum for autistic girls at mainstream primary schools. *European Journal of Special Needs Education*, 30(2), 187–201. <https://doi.org/10.1080/08856257.2014.986915>
- Moyse, Ruth. (2021). *Missing: The autistic girls absent from mainstream secondary schools*. <https://doi.org/10.48683/1926.00097405>

- Müller, E., Schuler, A., & Yates, G. B. (2008). Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism*, 12(2), 173-190. doi: <https://doi.org/10.1177/1362361307086664>
- National Society for the Prevention of Cruelty to Children, NSPCC, (2008). *All about me: ChildLine teachers' pack for children and young people with special educational needs (Key stage 2/Key stage 3)*. Retrieved February 2 2023 from <http://www.nspcc.org.uk/Inform/resourcesforteachers/classroomresources/>
- Parsloe, S. M. (2015). Discourses of Disability, Narratives of Community: Reclaiming an Autistic Identity Online. *Journal of Applied Communication Research*, 43(3), 336–356. <https://doi.org/10.1080/00909882.2015.1052829>
- Pavlopoulou, G., Wood, R., and Papadopoulos, C., (2020). Impact of Covid-19 on the experiences of parents and family carers of autistic children and young people in the UK. Retrieved 3 January 2021, from https://discovery.ucl.ac.uk/id/eprint/10101297/3/Pavlopoulou_COVID19%20AUTISM%20FINAL%20GP.pdf
- Pearson, A., & Rose, K. (2021). A Conceptual Analysis of Autistic Masking: Understanding the Narrative of Stigma and the Illusion of Choice. *Autism in Adulthood*, 3(1), 52–60. <https://doi.org/10.1089/aut.2020.0043>
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, 18(7), 756–770. <https://doi.org/10.1177/1362361314529627>
- Perry, E., Mandy, W., Hull, L., & Cage, E. (2022). Understanding Camouflaging as a Response to Autism-Related Stigma: A Social Identity Theory Approach.

Journal of Autism and Developmental Disorders, 52(2), 800–810.
<https://doi.org/10.1007/s10803-021-04987-w>

Peters, R., & Brooks, R. (2016). Parental perspectives on the transition to secondary school for students with Asperger syndrome and high-functioning autism: A pilot survey study: Parental perspectives on the transition to secondary school for students with Asperger syndrome and high-functioning autism: a pilot survey study. *British Journal of Special Education*, 43(1), 75–91.
<https://doi.org/10.1111/1467-8578.12125>

Portway, S., & Johnson, B. (2003). Asperger Syndrome and the Children who 'Don't Quite Fit'. *Early Child Development and Care*, 173(4), 435–443.
<https://doi.org/10.1080/0300443032000079113>

Portway, S. M., & Johnson, B. (2005). Do you know I have Asperger's syndrome? Risks of a non-obvious disability. *Health, Risk & Society*, 7(1), 73–83.
<https://doi.org/10.1080/09500830500042086>

Posserud, M.-B., Lundervold, A. J., & Gillberg, C. (2006). Autistic features in a total population of 7-9-year-old children assessed by the ASSQ (Autism Spectrum Screening Questionnaire). *Journal of Child Psychology and Psychiatry*, 47(2), 167–175. <https://doi.org/10.1111/j.1469-7610.2005.01462.x>

Punshon, C., Skirrow, P., & Murphy, G. (2009). The 'not guilty verdict': Psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism*, 13(3), 265–283. <https://doi.org/10.1177/1362361309103795>

Ranson, N. J., & Byrne, M. K. (2014). Promoting Peer Acceptance of Females with Higher-functioning Autism in a Mainstream Education Setting: A Replication and Extension of the Effects of an Autism Anti-Stigma Program. *Journal of*

- Autism and Developmental Disorders*, 44(11), 2778–2796.
<https://doi.org/10.1007/s10803-014-2139-1>
- Ravenette, T. (1999). Personal construct theory in educational psychology: A practitioner's view.
- Rivet, T. T., & Matson, J. L. (2011). Review of gender differences in core symptomatology in autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(3), 957–976. <https://doi.org/10.1016/j.rasd.2010.12.003>
- Roman-Urrestarazu, A., van Kessel, R., Allison, C., Matthews, F. E., Brayne, C., Baron-Cohen, S. (2021). Association of Race/Ethnicity and Social Disadvantage with Autism Prevalence in 7 Million School Children in England. *Jama Paediatrics*, 175(6), <https://doi.org/10.1001/jamapediatrics.2021.0054>
- Ruiz Calzada, L., Pistrang, N., & Mandy, W. P. L. (2012). High-Functioning Autism and Asperger's Disorder: Utility and Meaning for Families. *Journal of Autism and Developmental Disorders*, 42(2), 230–243. <https://doi.org/10.1007/s10803-011-1238-5>
- Russell, G., & Norwich, B. (2012). Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders. *Clinical Child Psychology and Psychiatry*, 17(2), 229–245. <https://doi.org/10.1177/1359104510365203>
- Russell, G., Steer, C., & Golding, J. (2011). Social and demographic factors that influence the diagnosis of autistic spectrum disorders. *Social Psychiatry and Psychiatric Epidemiology*, 46(12), 1283–1293. <https://doi.org/10.1007/s00127-010-0294-z>
- Rynkiewicz, A., Schuller, B., Marchi, E., Piana, S., Camurri, A., Lassalle, A., & Baron-Cohen, S. (2016). An investigation of the 'female camouflage effect' in autism

- using a computerized ADOS-2 and a test of sex/gender differences. *Molecular Autism*, 7(1), 10. <https://doi.org/10.1186/s13229-016-0073-0>
- Salmons, J. (2014). *Qualitative online interviews: Strategies, design and skills*. Thousand Oaks, CA: Sage Publications, Inc.
- Sanders, E. B. N. (2002). From user-centred to participatory design approaches. In Frascara J. (Ed.), *Design and the social sciences: Making connections* (pp. 1-8). Taylor & Francis.
- Sciutto, M., Richwine, S., Mentrikoski, J., & Niedzwiecki, K. (2012). A Qualitative Analysis of the School Experiences of Students With Asperger Syndrome. *Focus on Autism and Other Developmental Disabilities*, 27(3), 177–188. <https://doi.org/10.1177/1088357612450511>
- Sedgewick, F., Hill, V., Yates, R., Pickering, L., & Pellicano, E. (2016). Gender Differences in the Social Motivation and Friendship Experiences of Autistic and Non-autistic Adolescents. *Journal of Autism and Developmental Disorders*, 46(4), 1297–1306. <https://doi.org/10.1007/s10803-015-2669-1>
- Sedgewick, F., & Pellicano, E. (2019). Friendships on the autism spectrum. In Carpenter, B., Happé, F & Egerton, J., *Girls and Autism: Educational, Family and Personal Perspectives* (pg. 126). Routledge.
- Smillie, I., & Newton, M. (2020). Educational psychologists' practice: Obtaining and representing young people's views. *Educational Psychology in Practice*, 36(3), 328–344. <https://doi.org/10.1080/02667363.2020.1787955>
- Sproston, K., Sedgewick, F., & Crane, L. (2017). Autistic girls and school exclusion: Perspectives of students and their parents. *Autism & Developmental Language Impairments*, 2, 239694151770617. <https://doi.org/10.1177/2396941517706172>

St Luke's Family Care, (1997). *Bear Cards*, Bendigo, VIC: St Luke's Innovative Resources.

Stadnick, N. A., Aarons, G. A., Martinez, K., Sklar, M., Coleman, K. J., Gizzo, D. P., Lane, E., Kuerbs, C. L., & Brookman-Frazee, L. (2022). Implementation outcomes from a pilot of 'Access to Tailored Autism Integrated Care' for children with autism and mental health needs. *Autism*, 26(7), 1821-1832. <http://doi-org.libproxy.ucl.ac.uk/10.1177/13623613211065801>

Strang, J. F., van der Miesen, A. I., Caplan, R., Hughes, C., daVanport, S., & Lai, M-C. (2020). Both sex-and gender related factors should be considered in autism research and clinical practice. *Autism*, 24(3), 539-543. doi: <https://doi.org/10.1177/1362361320913192>

Ssucharewa, G.E. (1925). Die schizoiden Psychopathien im Kindesalter. *Monatsschrift für Psychiatrie und Neurologie*, 60(3-4), 235–247.

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*, 23, 73–83. <https://doi.org/10.1016/j.rasd.2015.11.013>

Tomlinson, C., Bond, C., & Hebron, J. (2020). The school experiences of autistic girls and adolescents: A systematic review. *European Journal of Special Needs Education*, 35(2), 203–219. <https://doi.org/10.1080/08856257.2019.1643154>

UNICEF. (1989). The United Nation Conversation on the Rights of the Child.

Van Wijngaarden-Cremers, P. J. M., van Eeten, E., Groen, W. B., Van Deurzen, P. A., Oosterling, I. J., & Van der Gaag, R. J. (2014). Gender and Age Differences in the Core Triad of Impairments in Autism Spectrum Disorders: A Systematic Review and Meta-analysis. *Journal of Autism and Developmental Disorders*, 44(3), 627–635. <https://doi.org/10.1007/s10803-013-1913-9>

- Watkins, E. E., Zimmermann, Z. J., & Poling, A. (2014). The gender of participants in published research involving people with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 8(2), 143–146. <https://doi.org/10.1016/j.rasd.2013.10.010>
- Westwood, H., Mandy, W., & Tchanturia, K. (2017). Clinical evaluation of autistic symptoms in women with anorexia nervosa. *Molecular Autism*, 8(1), 12. <https://doi.org/10.1186/s13229-017-0128-x>
- Whitlock, A., Fulton, K., Lai, M.-C., Pellicano, E., & Mandy, W. (2020). Recognition of Girls on the Autism Spectrum by Primary School Educators: An Experimental Study. *Autism Research*, 13(8), 1358–1372. <https://doi.org/10.1002/aur.2316>
- Williams, J., & Hanke, D. (2007). ‘Do you know what sort of school I want?’: Optimum features of school provision for pupils with autistic spectrum disorder. *Good Autism Practice (GAP)*, 8(2), 51–63.
- Willig, C. (2008). *Introducing qualitative research in psychology: Adventures in theory and method*. McGraw-Hill Open University Press.
- Wing, L. (1981). Asperger’s syndrome: A clinical account. *Psychological Medicine*, 11(1), 115–29. doi:10.1017/S0033291700053332.
- Winstone, N., Huntington, C., Goldsack, L., Kyrou, E., & Millward, L. (2014). Eliciting rich dialogue through the use of activity-oriented interviews: Exploring self-identity in autistic young people. *Childhood*, 21(2), 190–206. <https://doi.org/10.1177/0907568213491771>
- Wong, C., Odom, S. L., Hume, K. A., Cox, A. W., Fettig, A., Kucharczyk, S., Brock, M. E., Plavnick, J. B., Fleury, V. P., & Schultz, T. R. (2015). Evidence-Based Practices for Children, Youth, and Young Adults with Autism Spectrum

- Disorder: A Comprehensive Review. *Journal of Autism and Developmental Disorders*, 45(7), 1951–1966. <https://doi.org/10.1007/s10803-014-2351-z>
- World Health Organisation. (2020). International Classification of Diseases. 11th. Retrieved from <https://icd.wh.int/en/>
- Zakai-Mashiach, M. (2022). "I Was Like a Bird Without Wings": Autistic Women's Retrospective Experiences in General Schools. *Journal of Autism and Developmental Disorders*, <https://doi.org/10.1007/s10803-022-05717-6>
- Zeedyk, M. S., Gallacher, J., Henderson, M., Hope, G., Husband, B., & Lindsay, K. (2003). Negotiating the Transition from Primary to Secondary School: Perceptions of Pupils, Parents and Teachers. *School Psychology International*, 24(1), 67–79. <https://doi.org/10.1177/0143034303024001010>

Appendices

Appendix 1: Study advertisement



ARE YOU AN AUTISTIC GIRL AGED 16-25 YEARS OLD?

I'M A YEAR 2 TRAINEE EDUCATIONAL PSYCHOLOGIST AT IOE (UCL) CONDUCTING RESEARCH TO UNDERSTAND AUTISTIC GIRLS SCHOOL EXPERIENCES, CAN YOU HELP?

Who are we looking for?

Young women aged **16-25**, who received their diagnosis during **Secondary School**. Also, your **parent/carer**.

What happens if I take part?

You will be **sent an information pack**, containing a drawing activity and you can **choose** whether to be asked some questions (*about your school experiences*) by **me, or by your parent/carer**. You could also **write the answers if you wish**.

Why should I take part?

You will be contributing to developing **research highlighting autistic girls' experiences**, raising awareness, and potentially improving autistic girls' future experiences with schools/EPs.



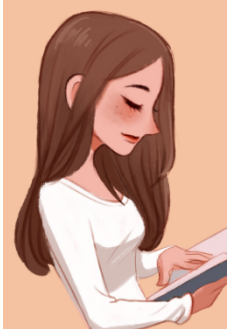
Then, **your parent/carer will be asked some questions** by me about your experiences.

To take part or to find out more:

You can contact me via lucy.wozniak.15@ucl.ac.uk, or via: https://uclioe.eu.qualtrics.com/jfe/form/SV_dgPKJMDfGs6SEdM



If you are a parent/carer: https://uclioe.eu.qualtrics.com/jfe/form/SV_7OoTOcAfhaiPUIE



Appendix 2: Information sheet for the parents/carers



‘School experiences of autistic girls who were diagnosed in adolescence: Views from young people and their parents/carers’

Information sheet for Parents/Carers

My name is Lucy Colat-Parros, and I am training to be an Educational Psychologist at IOE in London. I am also a qualified primary school teacher and previously taught autistic children and young people.

I am inviting you to take part in my research project to understand the *school experiences of autistic girls who were diagnosed during their adolescent years*. The main aims of this research are to *improve outcomes for autistic people, identify areas in which improvements could be made for girls and their families*, and ultimately to help develop ways to *better support autistic girls during their school years*.

I very much hope you would like to take part in this research. This information sheet will try and answer any questions you might have about the project, but please don't hesitate to contact me (EMAIL) if there is anything else you would like to know. Additionally, if you require any further information about this study, please do not hesitate to contact my supervisors, Dr Laura Crane, (EMAIL) and/or Dr. Melernie Meheux, (EMAIL)

Why are we doing this research?

The main aim of this research is to understand autistic girls' and their parents/carers school experiences during their adolescent years, focussing on key transitions, such as the move from Primary to Secondary School, as well as pathways to receiving a diagnosis.

Why am I being invited to take part?

We would like to speak to parents/carers of autistic girls who were diagnosed during their adolescent / Secondary School years. Your daughter should currently be aged between 16-25 years of age.

What will happen if I choose to take part?

If you choose to take part, it would be great to get to speak with you and your daughter, with regards to their experience of education. This will be done via telephone or an internet video call – whichever you prefer. With your permission, I would also like to record this interview (so I can ensure that I record

everything you say accurately). After I've transcribed the interview and take out identifying information, I will delete the recording, and no one apart from myself or my supervisors will view this recording.

Interviews should take no longer than one hour and all information you provide will be held in confidence, unless safeguarding concerns arise. Please also note that participation is voluntary – even if you choose to take part, you still have the option to withdraw from the research up until the point that I finish analysing my data (December 2022).

Are there any benefits to taking part?

Participants in research such as this often find it rewarding to be a part of supporting the wider autism and educational community. It is hoped that this research will be used to help improve the school experience / transition process for girls, and potentially help improve the diagnosis process.

Are there any drawbacks to taking part?

Questions or discussions may evoke emotions or experiences that make you feel uncomfortable, especially if experiences of school have been negative. You will be given full autonomy over whether you or your daughter wish to answer questions, and you can end the interview at any point. All interview questions can be reviewed beforehand to ensure you are conformable to participate.

Can I see the results of the research?

Yes. I will email a copy of the summary to all participants once the project has been completed (by June 2023).

What will happen to the data collected?

All recordings made will be stored securely and deleted once transcription has been completed. The transcripts of the interviews will be anonymised (in that identifiable information such as names will be taken out) and kept according to UCL policy (for a minimum of ten years). The interview transcripts will only be accessed only by myself, Lucy Colat-Parros or my supervisors, Dr. Laura Crane, Dr. Melernie Meheux.

If you wish to do so, you can read and access more about the UCL general research participant privacy notice, which explains how we will store any data you provide in line with General Data Protection Regulations (GDPR): <https://www.ucl.ac.uk/legal-services/privacy/ucl-general-research-participant-privacy-notice>.

The results of the research will be shared in my thesis, that will be made available via the UCL library. We hope to also share the results of the research in an academic journal and via accessible summaries.

You can access this information sheet and the consent form via:
https://uclioe.eu.qualtrics.com/jfe/form/SV_7OoTOcAfhaiPUIE.

Privacy Notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in research studies, click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data is: 'Public task' for personal data, and 'research purposes' will be the lawful basis for processing special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk

If you have any further questions, please contact me on (EMAIL)

Thank you very much,

Lucy Colat-Parros

Trainee Educational Psychologist / Doctoral Student at IOE

Appendix 3 : Information sheet for the girls

'School experiences of autistic girls who were diagnosed in adolescence: views from young people and their parents/carers'



Who Am I?



Hi! My name is Lucy Colat-Parros.

I'm a student at UCL, where I'm training to be an Educational Psychologist (EP).

EPs support children and young people in schools. Before I started my training, I worked as a Primary School teacher (including with autistic children).

What am I doing?

As part of my studies, I am doing a small piece of research about **autistic girls' experiences of school**.

I'm especially interested to know about the school experiences of girls **who didn't get their autism diagnosis until they were in secondary school**.

I'd like to talk to girls, their parents/carers, to find out more about this, and how EPs might be able to help make experiences of school better.

To take part you should:

- Be female
- Be aged 16-25
- Received an autism clinical diagnosis after starting Secondary School
- Have attended a Secondary School in the United Kingdom

What will happen if I take part?

1) You will be sent a package (*via post or email - whichever you prefer*) with the interview questions, information about myself and a drawing activity called 'the ideal school'.

2) You can then decide whether to have myself interview you (*via video or telephone*) or your parent/carer, or you can simply write the responses to the interview questions.

Participation is voluntary – if you take part, you still have the option to withdraw from the research up until the data is anonymised.

Results/data collected

I will email a copy of the summary to all participants once the project has been completed (by next summer 2023).

The data collected will be pseudonymised, and kept according to UCL policy and under the terms of the General Data Protection Regulation (GDPR).

If you'd like to take part...

If you are interested to take part (and your parent/carer agrees), scan the QR code:



Or please contact me on:
lucy.wozniak.15@ucl.ac.uk



Appendix 4: Consent forms for parents/carers

'School experiences of autistic girls who were diagnosed in adolescence: views from young people and their parents/carers'

Parent Consent Form

If you are happy to participate in this study please complete this consent form by ticking each item, as appropriate, and return to the research team via the contact details below:

- 1) I confirm that I have read and understood this information sheet, and have had the opportunity to consider the information, ask questions, and have had these questions adequately answered.
- 2) If my daughter is currently below the age of 18 years of age, I give my consent for my daughter to participate in this study and have had the reasons for the study explained, how my daughter will be involved, and any questions answered to my satisfaction.
- 3) I understand that my participation is voluntary and that I am free to withdraw until the point of write-up, without giving any reason.
- 4) I know that I can refuse to answer any or all of the questions and that I can withdraw from the interview at any point.
- 5) I agree for the interview to be recorded, and that recordings will be kept secure and destroyed at the end of the project.
- 6) I know that all data will be kept under the terms of the General Data Protection Regulation (GDPR).
- 7) I agree that small direct quotes may be used in reports (these will be presented in a way that means you are very unlikely to be personally identified from any quotes used.)
- 8) I understand that in exceptional circumstances anonymity and confidentiality would have to be broken, for example, if it was felt a child or someone else was not safe. This would be reported to my research supervisor in the first instance.

This project has been reviewed and approved by the Department of Psychology and Human Development at UCL IOE.

I would be grateful in advance of the interview you could answer the following questions:

1) Your gender: _____

2) Your ethnicity: _____

3) What was / is currently your daughter's secondary schooling provision:
o Mainstream school o Special Needs

4) Did your daughter attend any other(s) secondary schooling provision? _____

5) What county did you live in when your daughter was at secondary school? _____

Name:.....

Signature:.....Date:

Name of researcher: Lucy Colat-Parros

Signature:

Date: 12th May 2022

Enter text

Appendix 5: Consent forms for the girls

'School experiences of autistic girls who were diagnosed in adolescence: views from young people and their parents/carers'

Young Person Consent Form

If you are happy to participate in this study please complete this consent form by ticking each item, as appropriate, and return to the research team via (EMAIL):

- 1) I confirm that I have read and understood this information sheet, and have had the opportunity to consider the information, ask questions, and have had these questions answered. This means I agree to take part.
- 2) I understand that I can choose whether or not I take part. I know that I am free to withdraw until the point of write-up, without giving any reason. I don't need to give a reason, and the decision will have no negative consequences for me or my family.
- 3) I know that I can refuse to answer any or all of the questions and that I can withdraw from the interview at any point. I understand I have access to consent cards to use during the interview if needed.
- 4) I agree that small direct quotes may be used in reports (we will do our very best to ensure you are very unlikely to be personally identified from any quotes used).
- 5) I understand that everything I say will be recorded and kept confidential, unless there is a safeguarding concern (e.g.. you are at risk of being harmed). This would be reported to my research supervisor in the first instance.
- 6) I understand that I can be interviewed by the researcher, Lucy Colat-Parros, or by my parent.

This project has been reviewed and approved by the Department of Psychology and Human Development at UCL IOE.

I would be grateful in advance of the interview you could answer the following questions:

- 6) Which county did you live in when you were at Secondary School? _____
- 7) What is your age? _____
- 8) Your gender: _____
- 9) Your ethnicity: _____
- 10) What was/is your current secondary schooling provision:
o Mainstream school o Special Needs
- 11) Did you attend any other(s) secondary schooling provision? _____

Name:.....

Signature: Date:

Name of researcher: Lucy Colat-Parros

Signature:

Date: 12th May 2022

Appendix 6: Interview schedule pre-pilot for parents/carers

DEdPsych Thesis (UCL IOE)
Researcher: Lucy Colat-Parros

Title: School experiences of autistic girls who were diagnosed in adolescence: views from young people and their parents/carers'

Interview schedule for Parents/Carers

Interview Number

Part A: Briefing and recheck consent

Thank you very much for offering to take part in my research – I really appreciate it. In this interview, I'd like to talk about your daughter's adolescent school experience (including any key transitions, such as the move from Primary to Secondary School). I would also like to understand further when and how they received their autism diagnosis.

I'm going to ask a few questions to find out a little bit more about you, then we will begin discussing your daughter's school experiences.

Everything we discuss today will be kept confidential, for example, if I use any information obtained today for my study in my final report, your real name or any other identifiable information will not be included. The only time I'd tell anyone about what you say today is if there is a safeguarding concern (something you tell me makes me think you or your daughter could be at risk of any harm).

Also, if you can't or don't want to answer any of the questions, that is fine, we can move onto the next one. Also, you can stop the interview at any time if you need to by telling me or using one of the cards included in the pack.

I will be recording the session and also using a Dictaphone as I won't have time to write down everything we say. It will only be watched / listened to by me, and it will be deleted once I've transcribed our interview.

I also would like to remind you that you are free to withdraw from this interview at any time.

Is there anything you'd like to clarify before we begin, are you feeling comfortable to start the interview?

Part B: Demographics

The first thing I'd like to do today is to take some information from you about you and your child:

- 12) Which county did you live in when your daughter was at Secondary School?

- 13) Your gender: _____
- 14) Your ethnicity: _____
- 15) What was / is currently your daughter's secondary schooling provision:
o Mainstream school o Special Needs
- 16) Did your daughter attend any other(s) secondary schooling provision?

Part C: Schooling experience

Now, I'd like to ask you some questions about your daughter's school experiences.

- 1) Can you describe your daughter's experience at Primary School, what was positive and what was negative?
- 2) How was your daughter's secondary school chosen?
- 3) When your daughter was in Year 6, what (if any) support was put into place prior to transition from Primary to Secondary School?
- 4) How do you feel teachers/school staff could better support autistic girls transitioning from Primary to Secondary?
- 5) What positive experiences has your child gained from secondary school?
- 6) What negative experiences (if any) have occurred for your child during secondary school?
- 7) Looking now to the future, how do you feel teachers could better support girls with autism in Secondary School?

Part D: Autism Diagnosis

I'd like to ask you some questions about the route to diagnosis for your daughter, if you do not feel comfortable answering any of these, we can move on to the next section or stop at any time.

- 1) What were the initial areas of concern that lead your daughter on the pathway to diagnosis?
- 2) How old was your daughter when the diagnosis process first begin?
- 3) Who was the first professional you met regarding autism?
 - i) Which professional gave your daughter her diagnosis?
- 4) Do you feel the school could've been more/less involved during this time?
- 5) What support (at school) was put in place once your daughter received her diagnosis?
 - i) If none, what do you feel could have supported her during this time?
- 6) Overall reflecting on your experience as a family, how do you feel Secondary schools could better support girls with autism during diagnosis?

- 7) How do you feel an educational psychologist could better support girls/their families during this process?

Part E: Ending

Do you have any further questions or anything you'd like to add before we close the interview?

Thank you very much for your participation, it is greatly appreciated. I will listen to the recordings and delete them once I've transcribed them. All names or personal information will be anonymised and pseudonymised. My supervisor will be the only person to have access to the data collected, and it will be stored on her encrypted laptop and deleted after 10 years as per UCL GDPR policy.

Once my study is completed and finalised, I will email participants a copy to read if they wish to do so.

Appendix 7 Interview schedule pre-pilot for the girls

DEdPsych Thesis (UCL IOE)
Researcher: Lucy Colat-Parros

Title: 'School experiences of autistic girls who were diagnosed in adolescence: views from young people and their parents/carers'

Interview schedule for Girls

Interview Number

Part A: Briefing and recheck consent

Thank you very much for offering to take part in this research – I really appreciate it. In this interview, I'd like to talk about your school experiences. I would also like to understand further when and how you received your autism diagnosis.

I'm going to ask a few questions to find out a little bit more about you, then we will begin discussing your school experiences.

Everything we discuss today will be kept private, for example, if I use any information obtained today for my study in my final report, your real name or any other identifiable information will not be included. The only time I'd tell anyone about what you say today is if there is a safeguarding concern (something you tell me makes me think you could be at risk of any harm).

Also, if you can't or don't want to answer any of the questions, that is fine, we can move onto the next one. Also, you can stop the interview at any time if you need to. I have attached a set of 'traffic light cards' to this pack, which you can use if you like to show if you are comfortable / not sure / uncomfortable.

I will be recording the session using a Dictaphone I won't have time to write down everything we say. It will only be listened to by me, and it will be deleted once I've transcribed our interview.

I also would like to remind you that you are free to withdraw from this interview at any time.

Is there anything you'd like to clarify before we begin, are you feeling comfortable to start the interview?

Part B: Demographics

The first thing I'd like to do today is to take some information about you:

- 17) Which county did you live in when you were at Secondary School? _____
- 18) What is your age? _____
- 19) Your gender: _____
- 20) Your ethnicity: _____
- 21) What was/is your secondary schooling provision:

o Mainstream school o Special Needs

Part C: Schooling experiences

Now, I'd like to discuss the ideal school drawing that you completed and then ask you some further questions about your school experiences.

- 1) With regards to the drawing you have completed, firstly we are going to talk about drawing 1: your non-ideal school, can you tell me three things about this school. What kind of school is this?
- 2) Can you describe some of the things you drew in the classroom?
- 3) What are the children doing in your classroom? Can you tell me three things about these children?
- 4) What are the adults doing in your classroom? Tell me three things about these adults.
- 5) With regards to your feelings, tell me three things about the way you feel at this school?
- 6) With regards to the second drawing you have completed, drawing 2: your ideal school, can you tell me three things about this school. What kind of school is this?
- 7) Can you describe some of the things you drew in the classroom?
- 8) What are the children doing in your classroom? Can you tell me three things about these children?
- 9) What are the adults doing in your classroom? Tell me three things about these adults.
- 10) With regards to your feelings, tell me three things about the way you feel at this school?
- 11) Is there anything else you'd like to talk about with regards to these drawings?

Now we are going to talk about your school experiences in more detail:

- 8) What did you enjoy most about your Primary School years?
- 9) What (if anything) did you find difficult?
- 10) What did you enjoy most about Secondary School?
- 11) What (if anything) did you find difficult about Secondary School?
- 12) When you moved from Primary to Secondary School, was there any type of support, for example, were there any professionals involved?
 - i. If you had indeed received support with this transition, what was positive / negative about this?
 - ii. If you hadn't received support, how do you feel teachers/school staff could support autistic girls transitioning from Primary to Secondary?
- 13) What (if any) type of support was put into place after the transition (in terms of settling into the new school)?
- 14) Looking now to the future, how do you feel teachers could create better learning environments for girls with autism in Secondary School?

Part D: Autism Diagnosis

I'd like to ask you some questions about the route to diagnosis, if you do not feel comfortable answering any of these, we can move on to the next section or stop at any time.

- 8) When did you first hear about the word autism relating to yourself?
- 9) How old were you when the diagnosis process first began?
- 10) Who was the first professional you met when this process began?
 - i) Which professional gave you your diagnosis?
- 11) Do you feel your school could've been more/less involved during this time?
- 12) What support (at school) was put in place once you had your diagnosis?
 - i) If none, what do you feel could have been put in place?
- 13) Overall, how do you feel Secondary Schools could better support girls with autism going through the diagnosis process?
- 14) How do you feel an educational psychologist (such as myself) could support you during this process?

Part E: Ending

- 1) Do you have any further questions or anything you'd like to add before we close the interview?

Thank you very much for your participation, it is greatly appreciated. I will listen to the recordings and delete them once I've transcribed them. All names or personal information will be anonymised and pseudonymised. My supervisor will be the only person to have access to the data collected, and it will be stored on her encrypted laptop and deleted after 10 years as per UCL GDPR policy.

Once my study is completed and finalised, I will email participants a copy to read if they wish to do so.

Appendix 8: Interview schedule post-pilot for parents/carers

Title: School experiences of autistic girls who were diagnosed in adolescence: views from young people and their parents/carers'

Interview schedule for Parents/Carers

Interview Number

Part A: Briefing and recheck consent

Thank you very much for offering to take part in my research – I really appreciate it. In this interview, I'd like to talk about your daughter's adolescent school experience (including any key transitions, such as the move from Primary to Secondary School). I would also like to understand further when and how they received their autism diagnosis.

I'm going to ask a few questions to find out a little bit more about you, then we will begin discussing your daughter's school experiences.

Everything we discuss today will be kept confidential, for example, if I use any information obtained today for my study in my final report, your real name or any other identifiable information will not be included. The only time I'd tell anyone about what you say today is if there is a safeguarding concern (something you tell me makes me think you or your daughter could be at risk of any harm).

Also, if you can't or don't want to answer any of the questions, that is fine, we can move onto the next one. Also, you can stop the interview at any time if you need to by telling me or using one of the cards included in the pack.

I will be recording the session and also using a Dictaphone as I won't have time to write down everything we say. It will only be watched / listened to by me, and it will be deleted once I've transcribed our interview.

I also would like to remind you that you are free to withdraw from this interview at any time.

Is there anything you'd like to clarify before we begin, are you feeling comfortable to start the interview?

Part B: Background/Rapport Building

Could you tell me a little bit about your daughter, her name, current age and how she found the process of the interview/ideal school activity?

Part C: Schooling experience

It would be really good to get a sense of your daughter's journey, if you could map it out on paper, starting with her birth year....

Next, please could you plot any schools she attended along the timeline, with the approximate dates. Ok, now I'd like to ask you some questions about her schooling experiences as we talk through these dates:

- 15) Can you describe your daughter's experience at Primary School? What was positive and what was negative? What could have been better?
- 16) How was your daughter's secondary school chosen?
- 17) When your daughter was in Year 6, what (if any) support was put into place prior to transition from Primary to Secondary School? How effective was this? What could have been better?
- 18) Can you describe your daughter's experience at Secondary School? What was positive and what was negative? What could have been better?
- 19) Throughout your daughter's whole school experience, what is the one thing you would have wished for, to make her experience better?

Part D Timeline: Autism Diagnosis

Finally, please could you plot her diagnosis period on the timeline, with the approximate dates, and I'd like to ask you some questions related to this time:

- 15) What led your daughter on the pathway to diagnosis? Were the school involved at all?
- 16) Were the school involved in the diagnostic process at all – if so, in what way?
- 17) What support (at school) was put in place (a) before your daughter received her diagnosis and (b) after your daughter received her diagnosis?
 - ii) If none, what do you feel could have supported her during this time?
 - iii) If some, how effective did you find this? Is there anything that could have been done better?
- 18) Overall reflecting on your experience as a family, how do you feel Secondary schools could better support autistic girls during diagnosis?

Part E: Ending

Do you have any further questions or anything you'd like to add before we close the interview?

Thank you very much for your participation, it is greatly appreciated. Once my study is completed and finalised, I will email a copy to read if you wish to do so.

Appendix 9: Interview schedule post-pilot for the girls

DEdPsych Thesis (UCL IOE)
Researcher: Lucy Colat-Parros

Title: 'School experiences of autistic girls who were diagnosed in adolescence: views from young people and their parents/carers'

Interview schedule for Girls

Interview Number

Part A: Briefing and recheck consent

Thank you very much for offering to take part in this research – I really appreciate it. I'd like to talk about your school experiences which are really valuable as there is no way of making things better for autistic girls than hearing from you yourselves.

I'm going to ask a few questions to find out a little bit more about you, then we will begin discussing your school experiences. I would also like to understand about how you received your autism diagnosis.

Everything we discuss today will be kept private, for example, if I use any information you tell me today in my final report, your real name or any other information that could identify you will not be included. *The only time I'd tell anyone about what you say today is if something you tell me makes me think you could be at risk of any harm.*

Also, if you can't or don't want to answer any of the questions, that is fine, we can move onto the next one. Also, you can stop the interview at any time if you need to. I have attached a set of 'traffic light cards' to this pack, which you can use if you'd like to show if you are comfortable / not sure / uncomfortable.

I will be recording the session using a Dictaphone I won't have time to write down everything we say. It will only be listened to by me, and it will be deleted once I've transcribed our interview.

I also want to remind you that you are free to stop the interview at any time, for any reasons.

Is there anything you'd like to check before we begin, are you feeling ok to start the interview?

Part B: Background/Rapport Building

Could you tell me a little bit about yourself....

- 1) How old are you?
- 2) Can you tell me about your current/last Secondary school, was it mainstream, alternative provision or specialist schooling?
- 3) How did you find the process of the interview/ideal school activity?

Part C: Schooling experiences

Now, I'd like to talk about the ideal school drawing that you did and then ask you some further questions about your school experiences.

- 12) About the drawing you have done, firstly we are going to talk about drawing 1: your non-ideal school, can you tell me three things about this school. What kind of school is this?
- 13) Can you describe some of the things you drew in the classroom?
- 14) What are the children doing in your classroom? Can you tell me three things about these children?
- 15) What are the adults doing in your classroom? Tell me three things about these adults.
- 16) About your feelings, tell me three things about the way you felt at this school?
- 17) With regards to the second drawing you have completed, drawing 2: your ideal school, can you tell me three things about this school. What kind of school is this?
- 18) Can you describe some of the things you drew in the classroom?
- 19) What are the children doing in your classroom? Can you tell me three things about these children?
- 20) What are the adults doing in your classroom? Tell me three things about these adults.
- 21) About your feelings, tell me three things about the way you feel at this school?
- 22) Is there anything else you'd like to talk about with these drawings?

Part C Timeline: Schooling experience

It would be really good to get a sense of your schooling journey, perhaps you'd like to map it out on paper in a timeline format while we are talking, starting with your birth date and ending now....

First, please could you plot any schools you attended along the timeline, with the approximate dates.

Ok, now I'd like to ask you some questions about your schooling experiences as we talk through these dates:

- 20)What did you enjoy (if anything) about your Primary School years?
 21)What (if anything) did you find difficult?
 22)What did you enjoy (if anything) about Secondary School?
 23)What (if anything) did you find difficult about Secondary School?
 24)When you moved from Primary to Secondary School, was there any type of support, for example, were there any teachers involved or did you get to visit the school beforehand?
 iii. If you had received support, what was positive / negative about this?
 iv. If you hadn't received any support, how do you feel school staff could support autistic girls transitioning from Primary to Secondary?
See below for some examples:

Visiting the new school beforehand	
Meeting the new teachers	
Viewing a map of the new school	
Other:	

- 25)What (if any) type of support was put into place after the transition (in terms of settling into the new school, or during the first few years?)
 26)Looking now to the future, how do you feel teachers could create better learning environments for autistic girls in Secondary School?

Part D Timeline: Autism Diagnosis

Finally, please could you plot your diagnosis on the timeline, with the approximate dates, and I'd like to ask you some questions related to this time:

- 19)When did you first hear about the word autism relating to yourself?
 20)Were the school involved in the diagnostic process at all – if so, in what way?
 21)What support (at school) was put in place (a) before you received your diagnosis and (b) after you received her diagnosis?
 iv) If support was put in place, how effective did you find this? Is there anything that could have been done better?
 v) If none, what do you feel could have supported you during this time?
 22)Reflecting on your timeline, how long did it take you to get your diagnosis?
 23)Overall, how do you feel Secondary Schools could better support autistic girls going through the diagnosis process?

Part E: Ending

Do you have any further questions or anything you'd like to add before we close the interview?

Would you like me to use a pseudonym in the report, instead of Participant 1 for example?

Thank you very much for your participation, it is greatly appreciated. Once my study is completed and finalised, I will email you a copy to read if you wish to do so.

Appendix 10: Written interview schedule post-pilot for the girls

Title: 'School experiences of autistic girls who were diagnosed in adolescence: views from young people and their parents/carers'

Interview schedule for Girls

Part A: Briefing and recheck consent

Thank you very much for offering to take part in this research – I really appreciate it. I'd like to [hear about your school experiences which are really valuable as there is no way of making things better for autistic girls than hearing from you yourselves.](#)

There are a few questions to find out a little bit more about you, then there are questions about your school experiences. I would also like to understand about how you received your autism diagnosis.

Everything we discuss today will be kept private, for example, if I use any information you tell me today in my final report, your real name or any other information that could identify you will not be included. *The only time I'd tell anyone about what you say today is if something you tell me makes me think you could be at risk of any harm.*

Perhaps you would like to chose a name which I could use in reference to you, this could be a name you really like? If so, please write it here: _____

Also, if you can't or don't want to answer any of the questions, that is fine, just move onto the next one.

Part B: Background/Rapport Building

Could you tell me a little bit about yourself....

4) How old are you? _____

5) Can you tell me about your current/last Secondary school, was it mainstream, alternative provision or specialist schooling? _____

6) How did you find the process of the ideal school activity?

Part C: Schooling experiences

Now, I'd like to ask you about the ideal school drawing that you did and then ask you some further questions about your school experiences.

23) About the drawing you have done, firstly we are going to talk about drawing 1: your non-ideal school, can you tell me three things about this school. What kind of school is this?

24) Can you describe some of the things you drew in the classroom?

25) What are the children doing in your classroom? Can you tell me three things about these children?

26) What are the adults doing in your classroom? Tell me three things about these adults.

27) About your feelings, tell me three things about the way you felt at this school?

28) With regards to the second drawing you have completed, drawing 2: your ideal school, can you tell me three things about this school. What kind of school is this?

29) Can you describe some of the things you drew in the classroom?

30) What are the children doing in your classroom? Can you tell me three things about these children?

31) What are the adults doing in your classroom? Tell me three things about these adults.

32) About your feelings, tell me three things about the way you feel at this school?

33) Is there anything else you'd like to talk about with these drawings?

Part D Timeline: Schooling experience

It would be really good to get a sense of your schooling journey, perhaps you'd like to map it out on paper in a timeline format while you are thinking about the questions, starting with your birth date and ending now....

First, it may be helpful to plot any schools you attended along the timeline, with the approximate dates.

Ok, now I'd like to ask you some questions about your schooling experiences as we talk through these dates:

27)What did you enjoy (if anything) about your Primary School years?

28)What (if anything) did you find difficult?

29)What did you enjoy (if anything) about Secondary School?

30)What (if anything) did you find difficult about Secondary School?

31)When you moved from Primary to Secondary School, was there any type of support, for example, were there any teachers involved or did you get to visit the school beforehand?

v. If you had received support, what was positive / negative about this?

- vi. If you hadn't received any support, how do you feel school staff could support autistic girls transitioning from Primary to Secondary?

See below for some examples (please tick if these are options you think would help or write your own):

Visiting the new school beforehand	
Meeting the new teachers	
Viewing a map of the new school	
Other:	

- 32) What (if any) type of support was put into place after the transition (in terms of settling into the new school, or during the first few years?)

- 33) Looking now to the future, how do you feel teachers could create better learning environments for autistic girls in Secondary School?

Part E Timeline: Autism Diagnosis

Finally, please could you plot your diagnosis on the timeline, with the approximate dates, and I'd like to ask you some questions related to this time:

- 24) When did you first hear about the word autism relating to yourself?

- 25) Were the school involved in the diagnostic process at all – if so, in what way?

26)What support (at school) was put in place (a) before you received your diagnosis and (b) after you received her diagnosis?

vi) If support was put in place, how effective did you find this? Is there anything that could have been done better?

vii) If none, what do you feel could have supported you during this time?

27)Reflecting on your timeline, how long did it take you to get your diagnosis?

28)Overall, how do you feel Secondary Schools could better support autistic girls going through the autism diagnosis process?

Part F: Ending

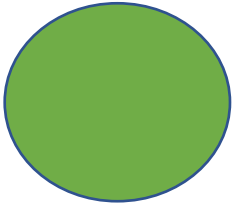
Do you anything you'd like to add before we close the interview?

Thank you very much for your participation, it is greatly appreciated.

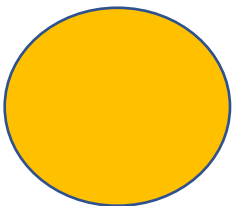
Once my study is completed and finalised, I will email you a copy to read if you wish to do so.

Appendix 11: Traffic light cards for consent

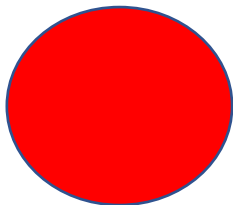
Consent Card guidelines:



The green card is for you to use when you are **happy to start the interview or continue.**



The yellow card is for you to use **if you start to feel uncomfortable,** and I will move on and ask you another question.



If you want to stop the **interview immediately,** you can show the red card. You do not need to explain unless you want too.



If you don't understand a question, you can show this card and I will ask it in a different way.



This card can be used if you need to have a break. When you are ready to continue, you can use the green card again, or the red card if you wish to stop completely and try again at another time.


Appendix 12: One page profile sent to girls as part of their pack


Lucy

What we might do together...

Talk about your experiences....

Talk about your drawings...






What is important to me...

My Family


Being a positive role model for my son

Animal welfare 

Yoga

What I would like to get better at...

Exercise


Getting more rest 

Eating well

Spending more time with my family

People describe me as...

Kind

Emphatic 

Good listener

Caring


Helpful

My Job

I work with children and young people (like you!) to find out what they enjoy and what they sometimes find difficult.

I also work with schools and families to try to make changes to support children and young people.

I am training to be an 'Educational Psychologist' but please feel free to call me Lucy!




What happens if you do not want to work with me?

If you do not want to meet with me or do any work together, you do not have to! We will only meet or do as much as you would like to.

If you have any questions, you can write them down or ask someone to write them down for you and I will try my best to answer them when we meet.

I look forward to meeting you!



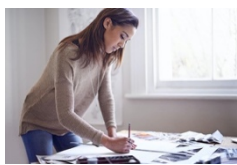
Appendix 13: Guidelines for drawing the 'ideal and non-ideal school' technique

Guidelines for the drawing the 'Ideal and Non-Ideal School'

Dear Parent,

Drawing the Ideal School technique has been adapted from an approach by Heather Moran (2001), who was a teacher and EP. The technique enables children and young people to become actively involved in understanding themselves and expressing their views.

Here are some guidelines to support you whilst completing this activity with your child. *Please don't hesitate to contact me for any support.*



You will need:

1. **Equipment:** a black pen and two sheets of A4 paper (included in the pack).
2. **How long will it take?** Allow about an hour, perhaps with a short break if necessary.
3. You can **write for your child** to take the pressure off them while they draw.
4. The idea is to make **quick drawings/sketches**. Reassure your child that **it doesn't matter if an error is made**.
5. It is important to record **exactly** what your child says using their own words
6. If they are **overly anxious about drawing, either model stick people drawings first or just record their verbal responses**.
7. Allow time for them to process the requests – **repeat/reword/simplify the questions if not understood**.
8. Provide **reassurance that there are no right or wrong answers/responses**.
9. Be **sensitive about sharing the drawings with others**, ask the child's permission and ensure that other adults understand that the child has trusted you in revealing such views, which must be respected. :



*Drawing 1: You are going to draw the kind of school **you would not like to go to.***

- 1) Step One: Think About the kind of school you would NOT like to go to. This is not a real school. Make a quick drawing of this in the middle of the paper.
- 2) Step Two: 'The classroom': think about the sort of classroom you would NOT like to be in. Make a quick drawing of the classroom in the school. Draw some of the things in this classroom.
- 3) Step Three: 'The children': think about some of the children at the school you would NOT like to go to. Make a quick drawing of some of these children.
- 4) Step Four: 'The adults': think about some of the adults at the school you would NOT like to go to. Make a quick drawing of some of these adults.
- 5) Step Five: 'You': Think about the kind of school you would NOT like to go to. Make a quick drawing of what you would be doing at this school.

Feel free to use the space below and the next page(s) for your drawings.

*Drawing 1: Drawing the kind of school **you would not like** (continued)*

*Drawing 2: Drawing the kind of school **you would like***

- 1) Step One: Think About the kind of school you would like to go to. This is not a real school. Make a quick drawing of this in the middle of the paper.
- 2) Step Two: 'The classroom': think about the sort of classroom you would like to be in. Make a quick drawing of the classroom in the school. Draw some of the things in this classroom.
- 3) Step Three: 'The children': think about some of the children at the school you would like to go to. Make a quick drawing of some of these children.
- 4) Step Four: 'The adults': think about some of the adults at the school you would like to go to. Make a quick drawing of some of these adults.
- 5) Step Five: 'You': Think about the kind of school you would like to go to. Make a quick drawing of what you would be doing at this school.

Feel free to use the space below and the next page(s) for your drawings.

*Drawing 2: Drawing the kind of school **you would like** (continued)*

Appendix 14: Ideal School / Non-Ideal School Feedback from participants

- P3: It was fairly easy but it did bring up some strong emotions.
- P4: Difficult to think back, especially to high school which wasn't a pleasant experience for me overall
- P5: I've actually, already did that in March, because I'm a young ambassador with the National Autistic Society, so everything you were saying before about hearing the voices of autistic people, I was like 'Yep, absolutely' (laughs), so I did that with a group of people but it was nice to sit down and do it by myself... And I noticed a lot of themes with... just consistency really....
- P5: ...It's easier for me to write but one of the people there was literally studying architecture, so they drew it when I did it in March.... We were able to do like the design of the rooms and the layout and things....
- P6: I can't draw (laughs) I don't like drawing so basically, I didn't draw, I just answered the questions, I mean like the limit of the drawing was I've got a little house shape in the middle....
- P7: Very difficult to draw what I wanted to represent. It wasn't pleasant to think about my past experience at school.
- P8: I chose to write, even though I usually enjoy drawing, as I was self-conscious about my drawings and felt I could express myself better by writing about it. The activity highlighted to me that it was quite difficult to remember my time at school as anything more than simply 'terrible', which means it is possible that my answers aren't very helpful.
- P11: Umm, the only thing she said was, she was a bit kind of thrown by having to draw things... I think it probably felt like it was too. I think probably felt childlike too... Yeah, I think that's what it was. And she just felt she was just like, I don't know what to begin with that. I don't think I could do it in that way. It feels too young.... An approach to me....
- P12: She said it was good. She probably said she's interested in psychology and she's about to go to university and study psychology. So I think she was just interested from that side of things anyway, but she is a real autism advocate and she's really passionate about it, so anything like this she really likes....
- P13: I probably think because of her age, and maybe also because of her autism, she would have rather just written an answer, she really struggled to draw them, in fact she came to me to ask for help with some of the drawings and in the end I just said write it.... Because I think you put the drawings to try and make it easier... But for her, the way her brains wired, she was like oh, this is really difficult to draw, but I can just explain it in words, so I said right just put it into words...

Appendix 15: Proposal for Piloting for Head of Autistic Girls Network

Title: 'School experiences of autistic girls who were diagnosed in adolescence: Views of young people and their parents/carers'

Project Aim

The main aim of this research is to understand the school experiences (broadly and during key transition points) of a group of autistic girls who were diagnosed in adolescence, from their perspectives and that of their parents/carers. It will further examine these girls' pathways to diagnosis and how this experience interacts with support.

It is hoped that this research will improve outcomes for autistic children and young people (CYP) and develop the Educational Psychology knowledge base in order to better support autistic girls during their school years. This project is unique as there is currently, to our knowledge, no research specifically examining this topic.

Research Questions

From the perspective of the girls and their parents:

- 3) What was their overall experience of school and school support like: what worked well and what improvements could be made, and did this change over time?
- 4) What was the girls' experiences during key transition points, such as the move from Primary to Secondary school: what worked well and where could improvements be made?
- 5) To examine the girls' pathway to autism diagnosis during their adolescent years, and how this interacted with experiences of school support, what worked well and where could improvements be made?

Data Collection

For this study, data will be collected in two ways: using semi-structured interviews and a psychological tool ('the ideal school'). This was chosen for gathering the autistic girls voice, to aim to ensure they can express their thoughts, feelings and experiences as comfortably as possible.

The interviews with the girls will involve reflection on 'the ideal school' task (see attached) which will have been completed beforehand with their parent/carer. Then the interview will be 'lead by the girls', encompassing them drawing a timeline of their school milestones including diagnosis point, which will allow for a more informal shared discussion. The parents interview will be similar, taking a timeline approach and allowing for reflection on the experience of the 'ideal school' task with the girls.

Participants

The aim of the research is to recruit 10-12 autistic girls and their parents/carers. Girls who are autistic can be difficult to recruit due to them being under-recognised (Gould

& Ashton-Smith, 2011) and it is hoped the sample will be achieved through pursuing various avenues for recruitment, including, advertisements via the Autism Girls Network (who currently have over 12,000 followers via Twitter), via the Ambitious about Autism Youth Network and through the schools' network in my current local authority in which I am on placement.

Autistic Girls Participants

The ideal sample age of the girls would be 16-25 years of age, due to their ability to reflect on their schooling across the entirety of secondary school. Importantly, this age range would also exclude individuals who have had entirely disrupted secondary schooling due to the COVID-19 pandemic. Participants will be chosen through purposeful and convenient sampling methods, on the basis that they have received an autism diagnosis in adolescence, are aged between 16-25 years of age, are female and reside in the United Kingdom.

Parent participants

The parents/carers will be chosen based on the understanding that they will also participate in the research and have a daughter who was diagnosed as autistic during their adolescent years who is currently aged between 16-25 years of age. They will be required to provide consent for their daughter's participation if their daughter is currently 18 years of age or younger.

Recruitment

With regards to the recruitment process, initially an advert will be circulated among the networks discussed (*see attached*) and this will feature a link to Qualtrics (*see links on advert*). The links take you to the information sheets, consent form and some demographic questions.

If individuals were interested in participating, dialogue will be established, and a pack will be posted out to the girls and their parents/carers.

The pack consists of:

- 'one page profile' about myself (for the girls to familiarise themselves with me)
- the interview questions
- the 'ideal school drawing activity'
- a set of traffic light consent cards – these for the interview, to show they are ready/ok to proceed/wish to move onto another question/wish to stop the interview, to provide the autistic girls with a further tool to express their wishes/consent

The girls can then decide if they wish to participate in the interview with myself via internet video calling or have their parent/carer interview them and record this (depending on which method they are more comfortable with). Following this, a convenient time will be arranged for the parents/carers to have their interview with myself. It was important to try to complete the parent/carer interview after the girls' interview, as it may have allowed for necessary reflection for the parents/carers.

(See interview schedules attached).

Appendix 16: Example of girls transcript (from video interview)

Interview 1: Girl 'Participant 1'

Interviewer: Hello....

Participant 1: Hi there...

I: Hello... Thank you so much for agreeing to meet me. I know it's a bit strange when you're sort of having an interview with somebody you've never met before.

P1: Oh no it's fine, don't worry about it!

I: Have you... Have you participated in other research before?

P1: I have, yeah. About eight months ago I did a project. I did some interviewing for someone's psychology degree.

I: Oh okay... Thank you very much for offering to take part. I really appreciate it. And I'd like to talk to you about your school experiences, which are really valuable as there's no other way of making things better than hearing from you yourself. And that's what's really important is that we're trying to gain parents and carers input. But the girl's input is obviously the most important because a lot of the research that's out there doesn't actually have the voice of the girls. And you're the ones who went through the experiences.

P1: Hmm-mmm

I: So.... I'm going to just ask you just a few questions to check, I know you did the consent form, but I'll just double check that what I've got written down is correct from there. And then we'll talk about your experiences and your diagnosis experiences. Everything we discuss today will be kept completely private. For example, if I use, what would tend to happen is there would be sort of quotes used and I would put participant one or two or three, but if you wish, some girls wish to have a pseudo-name that they choose to use. So it's up to you if you'd rather me put participant number or you'd rather choose a name....

P1: Hmm-mmm okay

I: So you can have a think about that if you.. if you wish to.. let me know later if you if you prefer that. And yeah, the only time I have to tell anyone about what we say today is if there was a safeguarding concern - if I felt that you were at risk of any harm.

P1: Ok..

I: If you don't want to answer any questions today that is completely fine. I hope that you were able to sort of look through them before so you could feel comfortable if there was anything you didn't want to answer. I'll be recording this session using a Dictaphone because I will have to transcribe it later. And again, please feel free to stop the interview at any time. Are you feeling okay to start?

P1: Yeah, yeah... fine yeah...

I: Okay. So, just to confirm you're 18 right now..

P1: Yeah...

I: ... and you were in mainstream schooling?

P1: Yes.

I: Okay, and that was in (County).

P1: Yes, it was.

I: Okay. Perfect. Thank you. And did you manage to complete the ideal school or do you prefer to do it together?

P1: I completed it, I didn't draw it. I wrote it down. And so because my drawing skills are shocking (laughs)

I: Would you feel comfortable in sharing it with me, obviously with your name not showing and whatever method is easier, you can just take some photos on your phone or via email later on.... As long as your name's not showing and you feel comfortable sharing that, is that okay?

P1: Yes that's fine, okay.

I: Did you find it quite straightforward to do? I've done it with quite a lot of groups of school... young people in secondary schools. How did you find it?

P1: Yeah, very straightforward. Yeah.

I: Okay. Okay, good. So, okay, so I guess, because you chose to write I'm just wondering whether.... Do you want to sort of talk me through, so your non-ideal school, so the first one, the one that you really wouldn't want to be in...

P1: Hm-mm...

I: Could you tell me three things about somewhere you really wouldn't wanted to have gone to school?

P1: Yeah, a lot of it's kind of based off of classes, that I really hated especially when... when I was in secondary school. Umm so very kind of unorganised and the teachers don't have much control over the classroom. I find that very, very stressful.

I: Hmm-mmm..

P1:Errr... so people without my kind of, without my sort of level of work ethic. I've always found it hard to know how people respond when I say that I really like 'setted groups', as opposed to kind of a mixed ability class, purely because I've always been in the kind of the top sets and you know, I'm quite a very diligent student... So I've always preferred to be in a sort of environment where everyone else is sort of feeling the same way about the work and you don't feel like you've got to fight to be able to do it and not got to contend with so many people who are trying to cause distraction....

I: Hmm-mmm...

P1:And then very cramped classrooms is another thing. I hate. The couple of classrooms where we're sort of all shoulder to shoulder... could barely you know... not got enough room to properly write and it's been like everyone's looking over your work all the time... not a fan of that... very stressful for me....

I: Mmm.... So you would prefer... it's really interesting... You would prefer as you were saying, when you are in sets and when you're sort of around peers who are at your level and you're able to.... did you feel that you always had work that was too easy for you... a lot of the work....

P1: Ummm... in primary school that was definitely a kind of an issue that I was sort of, because it is probably you know, it's the most general point about education like that's where everyone is kind of doing exactly the same thing and I did find it quite difficult in primary school. I did have a couple of very good teachers who kind of could see that and would make a concerted effort to give me extra work.

I: Hmmm...

P1: I have that a little bit in the first couple of years of high school as well. When I think it was English and Science they hadn't, they didn't set them until year nine. So I had a couple of teachers who would give me a bit of extra work to do. Umm but yeah, sometimes I did kind of feel like I was being held back a little bit because of everyone else.....

I: That's really frustrating...

P1: Definitely, really frustrating....

I: That's yeah, that's really frustrating. That's interesting... thank you for sharing. And so you sort of describe the children I guess in the, in the classroom context, so I guess what you would feel in a non-ideal context... would be the noise. So being very loud and disruptive. Is there anything else that sort of peers would be doing that would be really wouldn't want to be around?

P1: Ummm the sorts of people who are constantly being the cause, they cause conflict with the teacher all the time, when there's absolutely nothing.... Those sorts of people I've never been able to... well my problem as well is I can't understand why they do it. I just... I kind of go, 'Why can't you... Why can't you just do the work you've been given it to do? You've been told that you have to do it, so just do it. Like, what's the problem?'... If you've got an issue with it, speak to a teacher quietly about it. So that's always been I found that really, really hard. I don't like it when.... I don't like shouting. I don't like conflict in general. So to be in a classroom where there's like that one, you know, there's that one kid that always wants to have an argument with that teacher. Not fun.....

I: I completely get that.... Yeah.... And the adults in your classroom so teachers that, you know, I guess reflecting on sort of the negative teachers that you also discuss ones you'd had that weren't supportive, what types of things would teachers be doing that you really wouldn't want in a classroom?

P1: Umm... people who teach us who can't they can't control the class they can't you know, if people are kind of, you know, not obeying the rules or, or talking back, they can't kind of squash it or anything.... it just gets worse and worse because they haven't got, you know, respect from the class... and also, the sort of teachers that kind of humour the kids who have bad behaviour and they sort of, I hate, I hate when teachers, they try and be your 'matey' with the kids that weren't.... they want the bad kids to like them more than the good kids.....

I: Hmmm...

P1: It hurts me so much because I am like I'm the one that's sat here doing the work. I would love to talk to you about this subject, because I really like the subject, we can have a really nice conversation, but you just want to talk to them, because they're so loud....

I: Hmmmmm.....

P1: That always, really, really frustrated me.

I: Yeah, I really, I really understand that because you're wanting to get the most you can out of the lesson..... And you're wanting to learn and you're there to learn... Yeah, I get that that's really frustrating.... And that, like you said was more of a secondary school thing.....definitely for you...

P1: Yeah.... Definitely, yeah that was always, that was something that in sort of like, when I did my GCSEs and have the options classes because they can't be setted.... I found that my, my History class in particular, was quite broad... and there were a couple of kids who would just take the Mick constantly, and it was just so distracting the whole time.

I: Hmm... that's really frustrating. So I guess like thinking about you and how you'd feel if you were in that school and that was your school... umm yeah...what would your sort of feelings be if that was that, cramped classroom, with the loud noise, stressful, lots of conflict going on, noisy shouting.... As we talked about - frustration, is there anything else that you feel... that you would sort of describe as your feelings there?....

P1: Ummm I think probably, there's probably something up.. I think I'd also feel kind of, like I've been done a disservice by the environment I've been put in because I know sort of what I'm able to achieve and what I can do in the classroom setting and then to have an environment where I just can't cope and I can't focus. I'd feel just like... as if I'd been kind of let down a little bit by that...

I: Definitely, indeed..... Thank you because onto the.. the opposite of the positive, ideal school.....So could you tell me three things about... so I know you wrote it down. So three things about your ideal school... that you would see as your ideal school...

P1: Ummm So like ummm definitely not a kind of... sort of work in silence kind of situation because I don't like that either.... But like, you know, a quiet level of chat. That's not too disruptive. And people sort of get the work done and then chat, that kind of thing.... Umm a little bit of kind of banter with the teacher, but not too much..... But just not, it's not, you know, it doesn't feel like a super, super strict environment....

I: Yes...

P1: An environment where kind of everyone, all the kids want to do the work and people aren't trying to be distracting.... you don't have to love the work..... They just want to get it done.

I: Yes...

Because because they know that once they get it done, then you can chat because the work is done. That sort of environment and yeah, where the teacher has control over the room and the kids...

Hmm..

Not in a super strict way - just that they the kids respect them. If they say 'Come on, let's get this finished'.... And then we can you know, do something else and then the kids go 'Yeah, I can do that'....

I: Yes, yeah, just that that structure... there is that structure there. So I guess Yeah, with the teacher side, it would be like you said, having that control not too much but obviously enough.

Would you sort of say, ummm I don't know if this is something you ever, but.... you talked before about the listening aspects, so I guess and.... building those relationships, would that be something so, building those sort of personal relationships with everybody..

P1: Yeah...

I: Yeah having that that relationship.... and you're, the children in the classroom.... The young people, I'm sorry, I was a primary school teacher. So I still always gravitate to saying children.... the young people in that school. Is there anything else you want to sort of add to that? I guess, you talked about getting the work done. Is there anything else you like to add to that...?

P1: I don't think so.... Just kind of people... kind of on my wavelength with it you know.. because I've had the experience a couple of times where you're sort of the odd one out for doing the work..... I don't lie you know... and you know people go 'Are you really doing the work?'.... and you know, a classroom where everyone will just do it because they should be doing it.....

I: Yeah, yeah.... You definitely don't want to feel that and I guess even with the setting.... Did you feel that you were sort of around like minded peers when you were in the sets?

P1: Yeah, definitely more so.... I mean, there was some, some kids that were sort of, you know, they were smart enough to be there, but they didn't really want to do the work. But on the whole, yeah, it was definitely more ummm yeah, an environment where people were a lot more like me (laughs)

I: (Laughs) ... Okay, thank you. Just anything else want to add in about the ideal school or I can review it when you send it across.....

P1: Umm no... I think that's everything, yeah...

I: Okay. And again, this is sort of completely up to you if you prefer just to talk through or it's just, you sort of want to doodle this while you speak... if you want to draw it out - not for me to see but just for you to think things through.... because we're going to talk about your schooling journey, so if you want to, you can sort of draw out a timeline and sort of map things along but again, completely up to you... So, okay, so what did you enjoy, if anything about primary school?...

P1: I, on the whole had quite a good primary school experience. There were times where I had a really difficult time, but it wasn't to do with the school if you know what I mean....

I: Hmm- mmm

P1: My struggles were very much separate from the school and I'm quite lucky in the sense that generally a lot of my struggles have been quite separate from school but in primary. I went to a very small primary school we only had I think it was 200 ish kids in the whole school.... Umm yeah, so not very big at all...

I: Hm-mm..

P1: It was a majority feminine staff.... I don't think I ever had a male teacher in primary school. So I think definitely when I was younger, that was more suited to me from a kind of... because I've always been very attached to my mum having quite a maternal sort of, teaching experience was quite beneficial when I was younger...

Appendix 17: Example of girls written transcript (sent to me)

Title: 'School experiences of autistic girls who were diagnosed in adolescence: views from young people and their parents/carers'

Interview schedule for Girls

Part A: Briefing and recheck consent

Thank you very much for offering to take part in this research – I really appreciate it. I'd like to hear about your school experiences which are really valuable as there is no way of making things better for autistic girls than hearing from you yourselves.

There are a few questions to find out a little bit more about you, then there are questions about your school experiences. I would also like to understand about how you received your autism diagnosis.

Everything we discuss today will be kept private, for example, if I use any information you tell me today in my final report, your real name or any other information that could identify you will not be included. *The only time I'd tell anyone about what you say today is if something you tell me makes me think you could be at risk of any harm.*

Perhaps you would like to chose a name which I could use in reference to you, this could be a name you really like? If so, please write it here:
_____Adalyn_____

Also, if you can't or don't want to answer any of the questions, that is fine, just move onto the next one.

Part B: Background/Rapport Building

Could you tell me a little bit about yourself....

- 7) How old are you? **16**
- 8) Can you tell me about your current/last Secondary school, was it mainstream, alternative provision or specialist schooling? **Mainstream**
- 9) How did you find the process of the ideal school activity?

It was fairly easy but it did bring up some strong emotions.

Part C: Schooling experiences

Now, I'd like to ask you about the ideal school drawing that you did and then ask you some further questions about your school experiences.

34) About the drawing you have done, firstly we are going to talk about drawing 1: your non-ideal school, can you tell me three things about this school. What kind of school is this?

Crowded, Loud and Alienating

35) Can you describe some of the things you drew in the classroom?

Bright smart board, bright lights and tightly packed chairs and tables.

36) What are the children doing in your classroom? Can you tell me three things about these children?

Throwing things, shouting mean things and running around.

37) What are the adults doing in your classroom? Tell me three things about these adults.

Raising their voices, telling me off, not listening to me and my explanations.

38) About your feelings, tell me three things about the way you felt at this school?

Isolated, upset and angry.

39) With regards to the second drawing you have completed, drawing 2: your ideal school, can you tell me three things about this school. What kind of school is this?

Calm, quieter, inclusive.

40) Can you describe some of the things you drew in the classroom?

Bean bags, floor desks, smaller room, no smart board, less people per class.

41) What are the children doing in your classroom? Can you tell me three things about these children?

Talking calmly, sitting down, friends with me

42) What are the adults doing in your classroom? Tell me three things about these adults.

Calm, reassuring, understanding

43) About your feelings, tell me three things about the way you feel at this school?

Relaxed, able to socialise, happy

44) Is there anything else you'd like to talk about with these drawings?

N

Appendix 18: Example of parents transcript

Interview 9

Participants 9 and 10

I: Thank you very much for offering to take part in this research. In this interview, I'd like to talk about your daughter's adolescent school experience, including those key transitions. So the primary to secondary move and also understand further when and how they received their autism diagnosis. So, I'll just check in to see that I have all the right details about your daughter...and everything we discuss today will be kept completely confidential. So for example, if I use any information in my final reports that could be sort of like a quote, then it will be under participant, it will just say participant and a number. And so no real name or any identifiable information will be included. The only time I would say to have to tell my supervisor and report things from today would be if there was a safeguarding concern, that would make me think your daughter was at any risk. If you don't want to answer any questions, that's fine. We can move on to the next one. And you can stop the interview at any time if you need to. So yeah, and as I said, I'm recording the session as I won't have time to write everything down. And it will be deleted once I've transcribed and I'd like to remind you, you're free to withdraw at any time. Is there anything you'd like to clarify before we begin?

P9 and 10: No we're fine

I: Okay, thank you. And so just to confirm, because just to make sure that when (NAME) sends me her... (NAME) that is your daughter..

P9 and 10: Yes

I: ... and she is 16?

P10: Just 16

P9: Just turned 16

P10: she's gonna send that today to you she's told me...

I: Oh, bless her. Please tell her like to take her time and maybe after the interview if after you know if there's anything that you sort of think about and you want to share. Yeah, yeah, that's great. And if she can scan or send a photo umm anyway, that's this easiest for her.... So, okay, so it's really up to you, the first part we're going to talk about the schooling, her schooling experience, if you wanted to, you could sort of write out on a piece of paper dates, if you don't need to, if you sort of know it..

P9: I've got the DISCO element of assessment because we did all of this then so I thought it's just easier to go from that...

I: perfect Okay, thank you... Thank you. So um, so firstly, can you describe (NAME)'s primary school experience, so what was positive in your eyes? What was what was negative and what could have been better?

P9: We initially chose to send her to a small Catholic school around the corner from us on reflection now, I think it's, it's umm interesting that we obviously chose that small setting

because we felt that, that would suit her. And when... when other people were going to the local, the other local primary school to the bigger two class intake... we really strongly keen to just go with the smaller Catholic school setting and we fought quite hard to get her into there. So obviously, we didn't know anything about her. You know, she's meeting all the developmental milestones at that point. We didn't have any worries about her at all... socially she was able to maintain eye contact, and it's all due every... all the age appropriate milestones were met, but there was obviously something in that decision we were making at that point that we reflect on about....

P10: Yeah...

P9: But when she first started in that primary school, she had a really positive experience because it was such a homely environment. And there were umm there was a teacher and a teaching assistant and the teacher was this very big, umm homely kind of character who took all the children under her wing, she used to make them fresh toast every day. So (NAME) would very much cling to adults.

P10: Yes..

P9: and she did it all through pre-school as well....

P10: Yeah, I was gonna say even in preschool, she had a she didn't really have really good relationships necessarily with her peers but she picked out one adult, a key worker and we're still friends with her now today. She can build really strong attachments to adults...

P9: and there was a joke in preschool. She had a post-it note, which was their mechanism of telling you if your child's fallen over or bumped their head, they'll give you a post-it note and (NAME) had aliment of the day.... because she would always invent something wrong with her so that she could spend time with this chosen adult....

I: ...she just felt safe...?

P9: And that carried on into primary school and she did find that positive...

I: it's like a safety perhaps that she felt with the, with an adult as a opposed to sort of peers her age and that sort of sense of safety maybe....?

P10: Yeah

P9: I think she because they're employed... their... They're going to like you because they can't show you they don't like you because they're a member of staff. So there was... there's.... you're not vulnerable in that situation.... You are always going to be listened to.....humoured you know, smiled at, comforted... whereas your peers, that might be a bit more risky. You may be rejected at times, but with a member of staff they are paid to not reject you (laughs) so it's a very safe place.

I: Yes, yes.

P9: Yeah. But we really felt the alarm bells started ringing in Year Two she had a really lovely Canadian teacher.

P10: Yeah, young lady...

P9: Young, pretty, early, newly qualified, and she left and went back to Canada. And (NAME) had an over the top reaction for that, it was like Grief...

P10: it was bordering on grief....

P9: Yeah. And it lasted for a good year to get to the point... we named our guinea pig after her...

P10: well, Maple, we named it Maple...

P9: Because she was Canadian (laughs).. you can't call the guinea pig (NAME), so we had to call it something else (both laugh)

P10: (Laughs) that would be too weird

I: So was the school sort of, you know, because this is sort of where the first port of call... but of course, isn't it where you expect like the school to sort of be going...

P9: Well, I think they did that classic thing of don't tell the children until right at the end of term when she's leaving, whereas now it's quite well known isn't it, that you give children half a term's notice or terms notice that a teacher is leaving..

P10: It was literally 2 weeks..

P9: And they just kind of went, 'Oh, she's off and everything's fine, this is going to be your new teacher!' But nowadays, you wouldn't do that you'd prepare them and just give everyone time to say their goodbyes.

I: Yes. Yes...

P9: So, So yeah, it's just a shift in thinking I think since those times... but it was in year three, then she a very no nonsense kind of teacher who she really, really disliked very actively. And at that point, we were going in and out for school. I was getting phone calls saying (NAME)'s tummy ache, she's coming in and out of assembly saying she had tummy ache....She couldn't ... she was finding assemblies very hard. She's having to put headphones on or sit near a favoured music teacher. ..

P10: Close to the exit....

P9: ... And I would go and collect her from school. She'd be sat down with a bowl and it's like I can see as her mother.... She's not got tummy ache, there's something going on that, you know, it's obviously a child's way of expressing that she was anxious.

I: Yes. Yeah.

P9: And that's, that was where we kind of like okay, she can't cope with assembly, she can't cope with loud noises. And on one occasion, this teacher that (NAME) didn't like, would say things like, 'oh, tomorrow we're going to do a science experiment, it's going to be really exciting! It's going to be a really big explosion!' And for (NAME) she felt that the roof was going to

blow off the school... she was very worried and didn't want to take part in anything that was going to be a surprise or different. And that's where we started to get a little bit....

P10: Yeah, but I mean, we didn't... we weren't thinking autism at the time..

P9: No

P10: And the school weren't at all...

P9: No, it was anxiety...

P10: anxiety yeah..

P9: and phobias..

P10: it would move from one thing to another...

P9: and that's when we started to call it whack a mole, because you'd fix one thing, Fix You know, I am someone, I am, I will fix it....

P10: You are a fixer!

P9: I am fixer.. I'm trying to fix one thing or there's something else... I'd go into school to talk to the teacher trying to smooth things over duh duh duh, and then you know, and then something else would happen. So she did start, they put her on the register to receive Elsa.

I: Okay.

P9: But it was very sporadic. I think umm there was a lot of transition at the time the head teacher was leaving, they had many, many different head teachers. The school was on special measures. And so the school itself umm was kind of falling apart at that point. And it was reflected in the fact that this Elsa just never really happens when it, they said it was going to... I'd pick her up on a Tuesday and say did you see Miss.. how was it? And she'd say 'Oh no, she never came for me today'

I: What a shame..

P9: And that was really difficult for her because she was losing trust in the adults around her and that's what she really valued in the school. So we moved her. We went to one of these parent meetings where they talked about the OFSTED... Special measures and the budget was shot to pieces and teachers... everyone's leaving. And we so we just made the move to jump to the school I told you earlier where everyone was taking their kids (laughs)....

I: So that was around Year Four?

P9: That was year three, Easter of Year Three..

I: Okay. And then what shame that all... that was completely understandable, but then with all that sort of change going on around them to have that consistency because Elsa can be brilliant intervention. But obviously if it's not being run, and that's one of the things it has to be run

consistently. Otherwise the intervention just doesn't you know, provide what it should be, you know, the outcome of it should be...

P9: Yeah

I: So, okay, so then she moved across to the new school...

P9: She moved across and that was a really easy transition..

P10: because well, you were, you were working there..

P9: I was working School, which is our primary reason for sending her back because that made life just a lot easier. And so I knew all the staff she knew a lot of the students... she'd been there before because I worked there... and also all of her friends from preschool were there... and they were all like, oh, (NAME)'s here.... So she was a bit like a celebrity when she arrived. So she was really happy and then she was going into assembly and almost immediately she took a part in the play and did a speaking role. And we were like, What in God's name has just happened to us.... (laughs) Now I see what's she's doing, she was reinventing herself because that's what you can do when you go to a new place. She does it frequently now as autistic young person where she goes this is what I'm going to be today to these people, put this face on. And so she's, she was fine there for, for a good few years but they did an assembly... this is (NAME)'s stories that they did an assembly on autism for all the children and typically (NAME) this is very typical of her she goes in it she's like me, she goes and introduces herself to people. So she walked out of assembly and knocked on the door of the SENCO and said oh hi you probably don't know me I'm new to the school, My name is (NAME) and I think I'm autistic....

I: Wow...

P10: yeah..

I: Do you think she sort of understood at that age or you know...

P10: yeah, yeah

P9: Yeah, she watched the video, you probably know it, the one where the kids poor all the bubble bath and there's bubbles all the way up to the ceiling and the kids are enjoying the sensory experience of it and the girls talking about... Do you remember that video?

I: Yeah, but that's so powerful and that was in year four?

P9: That that was yeah, yeah...

I: Wow. So perhaps it was sort of that comfort of being in a much more nurturing or sort of comfortable environment and she sort of felt that she could feel free to... so interesting. So very...

P9: It was a very inclusive school, high level of send, high level of Pupil Premium. Yeah. So there were people there that you you literally wouldn't bat your eyelid if you saw all the differences under the sun with her and no one minded... none of the children and the teachers were really, really good at handling it. Everything was differentiated... yeah so in that way it

was a good school for her, but she did continue there with some ELSA. And they... because of the nature of the school they all just knew her and they knew her quirks and what she was like....

P10: But they... she, she had a lot of adult relationships and that was a lot of you as well, because she'd stay after school and talk to your teachers and stuff.

P9: Yeah...

I: Yes, yes.....So when that moment sort of happened, did you then sort of say, Okay, we need to, you know, did the school sort of say, was there any sort of talk around we need to sort of see an EP or like or seek...

P9: No, they had her on like a Tier-One intervention at that point and the SENCo would say to me, Oh, we've got her at tier one, and so that just means we're just gonna do some basic intervention with her. She'll see an Elsa she'll, you know, because it was still very much anxiety that we were focused on and phobias.... So, we were really, and then they, at one point, the SENCO came to see me and I remember her doing it in the classroom and there were other members of staff around and I'm was kind of pissed off that, you know, she's doing in front of other people... because I'm parent but a member of staff so, it's a really blurry line....

I: Yes, yes... Definitely

P9: And she was like, I think we're gonna move... move her to a tier two intervention, because actually, she's starting to show bigger signs of stress. And, you know, maybe there's some, some kind of au, au... she did mention the word that maybe there's some autistic traits that because obviously, she can't diagnose her, can she or say that... and I remember coming home to (HUSBAND) and because there was so many high need children there we were just a bit like, they just say that to everyone... (laughs)

P10: Everyone... They just want to label her...

P9: They want to label her.. (laughs) And we just thought it was anxiety...

P10: I think the trouble is... she shows more... her... her autism is, shown more at school.. whereas at home, we weren't seeing any struggles really... at all... So she's, she's much safer, she feel's safer at home, and you know, she's better at home, you don't see it...

P9: And because we didn't know about the way autism presents in girls, we didn't know anything about masking... So you think of your children in terms of not being able to maintain eye contact or not having great verbal skills...

P10: And she can do all that...

P9: She was playing piano, she was in top set for everything. We just.... I sound really apologetic, but I feel like I feel kind of embarrassed that we just didn't know.. we just didn't know..

P10: We just didn't pick up on it.. we really didn't ...

Appendix 19: Example of coding transcript (Phase 2 TA)

Transcript 1: Codes Interview 1, Participant 1

<u>Transcript</u>	<u>Code label</u>	<u>Code</u>
<p>I: Could you tell me three things about somewhere you really wouldn't wanted to have gone to school?</p> <p>P1: Yeah, a lot of it's kind of based off of classes, that I really hated especially when... when I was in secondary school. Umm so very kind of unorganised and the teachers don't have much control over the classroom. I find that very, very stressful.</p> <p>I: Hmm-mmm..</p> <p>P1:Errr... so people without my kind of, without my sort of level of work ethic. I've always found it hard to know how people respond when I say that I really like 'setted groups', as opposed to kind of a mixed ability class, purely because I've always been in the kind of the top sets and you know, I'm quite a very diligent student... So I've always preferred to be in a sort of environment where everyone else is sort of feeling the same way about the work and you don't feel like you've got to fight to be able to do it and not got to contend with so many people who are trying to cause distraction....</p> <p>I: Hmm-mmm...</p>	<p>School experiences</p> <p><i>Classroom environment: negatives</i></p> <p><i>Peers: negatives</i></p> <p><i>Classroom environment: negatives</i></p>	<p>Unorganised classroom</p> <p>Teachers have lack of control over students</p> <p>Peers of different ability mixed together</p> <p>Prefers ability sets</p> <p>Struggles with peer distractions</p> <p>Cramped classrooms and space</p>

P1:And then very cramped classrooms is another thing. I hate. The couple of classrooms where we're sort of all shoulder to shoulder... could barely you know... not got enough room to properly write and it's been like everyone's looking over your work all the time... not a fan of that... very stressful for me....

I: Mmm.... So you would prefer... it's really interesting... You would prefer as you were saying, when you are in sets and when you're sort of around peers who are at your level and you're able to.... did you feel that you always had work that was too easy for you... a lot of the work....

P1: Ummm... in primary school that was definitely a kind of an issue that I was sort of, because it is probably you know, it's the most general point about education like that's where everyone is kind of doing exactly the same thing and I did find it quite difficult in primary school. I did have a couple of very good teachers who kind of could see that and would make a concerted effort to give me extra work.

I: Hmmm...

P1: I have that a little bit in the first couple of years of high school as well. When I think it was English and Science they hadn't, they didn't set them until year nine. So I had a couple of teachers who would give me a bit of extra work to do. Umm but yeah, sometimes I did kind of feel like I was being held back a little bit

Primary vs secondary

Struggled when work wasn't differentiated

Needed more challenging work

<p>because of everyone else....</p> <p>I: That's really frustrating...</p> <p>P1: Definitely, really frustrating....</p> <p>I: That's yeah, that's really frustrating. That's interesting... thank you for sharing. And so you sort of describe the children I guess in the, in the classroom context, so I guess what you would feel in a non-ideal context.... would be the noise. So being very loud and disruptive. Is there anything else that sort of peers would be doing that would be really wouldn't want to be around?</p> <p>P1: Ummm the sorts of people who are constantly being the cause, they cause conflict with the teacher all the time, when there's absolutely nothing.... Those sorts of people I've never been able to... well my problem as well is I can't understand why they do it. I just... I kind of go, 'Why can't you... Why can't you just do the work you've been given it to do? You've been told that you have to do it, so just do it. Like, what's the problem?'... If you've got an issue with it, speak to a teacher quietly about it. So that's always been I found that really, really hard. I don't like it when.... I don't like shouting. I don't like conflict in general. So to be in a classroom where there's like that one, you know, there's that one kid that always wants to have an argument with that teacher. Not fun.....</p>	<p><i>Peers: negatives</i></p>	<p>Difficulties with peers who cause conflict with teachers and disrupt the classroom</p> <p>Difficulties with peers who cause conflict</p>
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<p>I: I completely get that.... Yeah.... And the adults in your classroom so teachers that, you know, I guess reflecting on sort of the negative teachers that you also discuss ones you'd had that weren't supportive, what types of things would teachers be doing that you really wouldn't want in a classroom?</p> <p>P1: Umm... people who teach us who can't they can't control the class they can't you know, if people are kind of, you know, not obeying the rules or, or talking back, they can't kind of squash it or anything.... it just gets worse and worse because they haven't got, you know, respect from the class... and also, the sort of teachers that kind of humour the kids who have bad behaviour and they sort of, I hate, I hate when teachers, they try and be your 'matey' with the kids that weren't.... they want the bad kids to like them more than the good kids.....</p> <p>I: Hmmmm...</p> <p>P1: It hurts me so much because I am like I'm the one that's sat here doing the work. I would love to talk to you about this subject, because I really like the subject, we can have a really nice conversation, but you just want to talk to them, because they're so loud....</p> <p>I: Hmmmmm.....</p> <p>P1: That always, really, really frustrated me.</p> <p>I: Yeah, I really, I really understand that because you're wanting to get the</p>	<p><i>Teachers: negatives</i></p>	<p>Teachers who lack control</p> <p>Teachers who befriend pupils</p> <p>Wanting to be recognised for working hard</p>
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<p>been kind of let down a little bit by that...</p> <p>I: Definitely, indeed..... Thank you because onto the.. the opposite.. the positive, ideal school.....So could you tell me three things about... so I know you wrote it down. So three things about your ideal school... that you would see as your ideal school...</p> <p>P1: Ummm So like ummm definitely not a kind of... sort of work in silence kind of situation because I don't like that either.... But like, you know, a quiet level of chat. That's not too disruptive. And people sort of get the work done and then chat, that kind of thing.... Umm a little bit of kind of banter with the teacher, but not too much..... But just not, it's not, you know, it doesn't feel like a super, super strict environment....</p> <p>I: Yes...</p> <p>P1: An environment where kind of everyone, all the kids want to do the work and people aren't trying to be distracting.... you don't have to love the work..... They just want to get it done.</p> <p>I: Yes...</p> <p>P1: Because because they know that once they get it done, then you can chat because the work is done. That sort of environment and yeah, where the teacher has control over the room and the kids...</p> <p>Hmm..</p>	<p><i>Teachers: positives</i></p>	<p>Peers are motivated to work</p> <p>Positive, balanced relationships with teacher</p> <p>Not a punitive environment</p> <p>Teacher has control over the classroom and environment</p>
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P1: Not in a super strict way - just that they **the kids respect them**. If they say 'Come on, let's get this finished'.... And then we can you know, do something else and then the kids go 'Yeah, I can do that'....

I: Yes, yeah, just that that structure... there is that structure there. So I guess Yeah, with the teacher side, it would be like you said, having that control not too much but obviously enough. Would you sort of say, ummm I don't know if this is something you ever, but.... you talked before about the listening aspects, so I guess and.... building those relationships, would that be something so, building those sort of personal relationships with everybody..

P1: Yeah...

I: Yeah having that that relationship.... and you're, the children in the classroom.... The young people, I'm sorry, I was a primary school teacher. So I still always gravitate to saying children.... the young people in that school. Is there anything else you want to sort of add to that? I guess, you talked about getting the work done. Is there anything else you like to add to that...?

P1: I don't think so.... Just kind of people... kind of on my wavelength with it you know.. because I've had the experience a couple of times where you're sort of the odd one out for doing the work..... I don't like you know... and you know people go 'Are you really

<p>doing the work?'.... and you know, a classroom where everyone will just do it because they should be doing it.....</p> <p>I: Yeah, yeah.... You definitely don't want to feel that and I guess even with the setting.... Did you feel that you were sort of around like minded peers when you were in the sets?</p> <p>P1: Yeah, definitely more so.... I mean, there was some, some kids that were sort of, you know, they were smart enough to be there, but they didn't really want to do the work. But on the whole, yeah, it was definitely more ummm yeah, an environment where people were a lot more like me (laughs)</p> <p>I: (Laughs) ... Okay, thank you. Just anything else want to add in about the ideal school or I can review it when you send it across.....</p> <p>P1: Umm no... I think that's everything, yeah...</p> <p>I: Okay. And again, this is sort of completely up to you if you prefer just to talk through or it's just, you sort of want to doodle this while you speak... if you want to draw it out - not for me to see but just for you to think things through.... because we're going to talk about your schooling journey, so if you want to, you can sort of draw out a timeline and sort of map things along but again, completely up to you... So, okay, so what did you enjoy, if anything about primary school?...</p>	<p><i>Primary School experiences</i></p>	<p>Positive PS experience</p> <p>Small PS</p>
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<p>P1: ... it was like they would just kind of think go along with the differences for the most part.... Yeah, generally I had a good, a good primary school experience. And I had a lovely head teacher, who, as well as I had counselling for anxiety a couple of times when I was in primary school, she would often take me to her office to do some like worksheets and things like that, which was lovely...</p> <p>I: Oh that's nice.....</p> <p>P1: Yes and I had a really bad fear of fire. So umm when they were going to test the fire alarm and do a fire drill. She'd take me out of the class and I could go and do the fire alarm, so that I knew that it was just... just a drill and I was panicking... I had a really good experience to be fair...</p> <p>I: ... It sounds like they were really understanding and just nurturing and supportive what you would want in your schooling...</p> <p>P1: Yes...</p> <p>I: that's really positive. And especially like that fire example is really key because they really thought about you as an individual....</p> <p>P1: Hmm yeah...</p> <p>I: Yeah.... and so did you... Did you find... well I guess the next question was about anything difficult, but like you were saying, I guess, like they were meeting sort of your needs...</p> <p>P1: Hmm-mmm..</p>	<p><i>Transitions: Primary to Secondary</i></p>	<p>Positive PS experience</p> <p>Transitioned to closest school, with peers, 'natural' progression</p>
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I:and if you had any difficulties they would support that. So I guess memories were quite positive....

P1: Definitely. Yeah, it was a very lovely time, on the whole.

I: And then okay, I was going to ask about secondary school, but I think firstly, sort of the move from primary to secondary..... So cause we're talking about primary school, was there any sort of support, did you sort of know, you know... were you a part of which decision of which school you were going to... or did you know, sort of in advance this is the school or was it sort of just natural and happened and this is the school I'm going to....

P1: Yeah it was quite natural because the sort of the high school that I went to is like 10 minute walk from my house, and a five minute walk from the primary school I went to, so it was very, very natural that I would go there or my friends are going to go there....

I: yes...

P1: ... The primary school I went to did all that kind of transition stuff with that specific high school to go anywhere else just seems a bit silly really, yes..... Yeah, it wasn't.... It wasn't a difficult decision to make at all....

I: Yes.... And the transition that you talked about, was that something you were, did they involve you as sort of pupils in it?... Umm I mean,

Transition days for pupils and parents

<p>or was it sort of very parent and teacher-led...</p> <p>P1: No, they did kind of a good kind of equal split. So I think we did a couple of days when I was in towards the end of Year six... Err we went up to visit the high school, we did a couple of... we did the fun stuff. So we did like a food tech lesson and things like that. And we had a look around the school I think we had umm... we went to the canteen we tried, we had the fingerprint things to pay.... So we did that for a couple of days... And then they had a couple of evenings that were just for parents to go and look at a couple of PowerPoints or examples of work and things like that... So they were quite. It wasn't just like... to the parents. There was a lot of... they were quite involved with the kids as well...</p> <p>I: That sounds good. That sounds... yeah, that sounds brilliant, because it really can sort of differ...</p> <p>P1: Hmm-mmm..</p> <p>I: ... and sort of different people's experiences. So I guess on the whole you found it quite positive and you are sort of ready to go and it's yeah....</p> <p>P1: Hmm yeah yeah...</p> <p>I:obviously nervous, but I guess optimistic about the experience....</p> <p>P1: Hmm yeah...</p> <p>I: And, and so talking about secondary school, what were the things that you</p>	<p><i>School experiences: Secondary School</i></p>	<p>Mixed experience in SS</p> <p>Academics were positive</p>
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<p>enjoyed about secondary school?.... Would you say....</p> <p>P1: it's interesting looking back on it.... because it's such a mixed bag for me secondary school... when I think of it.... I loved, I must sound like such a geek, but I loved the lessons I really, I really enjoyed ummm especially in like year seven and eight trying the new subjects that I'd never done before... Ummm you know, really going in depth into like sciences because we got to use Bunsen burners and things like that....</p> <p>I: Hmmm...</p> <p>P1: And then, you know, learning different languages and I suppose... kind of like when I reached at year 10, getting to really go in-depth with the subjects that I loved.... I really, really enjoyed that.... And I got... I've had some fantastic teachers that I just love and I'm so sad that I'm now leaving them..... I absolutely love them... Umm so I think that was probably the thing for me about secondary school that was the most, ummm the best part was the kind of... the actual learning part, the teacher part....</p> <p>I: Yes.... That's really lovely.... really lovely. Sort of, I guess, summary of like, yeah, and I understand that, you've just left haven't you...?</p> <p>P1: Yes, yes I've just finished so I go to uni in September.... I'm going to (Uni) funny enough...</p>	<p><i>School environments</i></p> <p><i>Peers and friendships</i></p>	<p>Social aspects of SS were the hardest part</p>
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<p>I: Wow.... That's amazing.. have you visited and everything then?</p> <p>P1: yeah, I've done quite a lot... I had just a couple of weeks ago... I had the Disability department gave me like a tour of... I'm doing history.... So they gave me a tour of the history faculty.....</p> <p>I: ... What an exciting next stage of your life.... Okay, so that's really interesting about the transition.... And in terms of like the negative side of things. I know we're going to talk a little bit about when your diagnosis happened... Does that sort of feed in, with I mean, do you want to talk sort of a little bit about.... let's talk first about negative sort of things of secondary school that would probably be easier.... We talked a lot about sort of the classroom environment with the ideal school, would you say sort of what you discussed then, was that similar to the negative side of things that you encountered....?</p> <p>P1: Yeah, it was to some extent, I think, yeah, it was... no class is perfect. I had a couple of classes that as much as the subject was maybe all right, I just didn't like the environment at all.... Ummm I think for me, a lot of the time, my issue stemmed more from the social aspect of school....</p> <p>I: Yes.</p> <p>P1: ... So sort of going from quite a small Primary School to quite a decent size high school. And suddenly the things that were like... different about me, weren't</p>	<p style="text-align: center;"><i>Diagnosis</i></p>	<p>Felt different in SS versus PS</p> <p>Bullied in SS and started masking</p> <p>Felt they 'had to mask' in SS</p> <p>Diagnosed at 15</p>
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alright anymore. And I like...
I was bullied quite a lot in
year seven, because I hadn't
yet caught... I hadn't, I
basically... I hadn't caught
up to the masking point yet,
because I hadn't really had
too....

I: yes...

P1: In Primary school all that
much.... And I was, I was all
of a sudden sort of put in an
environment where I did
have to... And obviously I
didn't realise at that point
because I wasn't, I wasn't
diagnosed until I was 15. So
I didn't realise that that's
what I was doing at that point
{masking}. But I kind of
learned that what's I had to
do... once I'd reached high
school. Umm... so yeah,
from a social point of view, it
was.... I always had
friends....

I: Hmmm...

P1:but I always had a lot
of people that still picked on
me at the same time, so it
was sort of... it was a bit
mixed. I was never
completely on my own but
ummm yeah, I was. I was
picked on quite a bit....
Umm....

I: Were they your friends
from primary school.... And
then did it sort of change
then do you think with the
setting that when you got to
secondary, did the friends
change towards you?

P1: Umm.... No, I don't think
so. Ummm I had two friends,
well three friends that I really
stuck with and I'm still friends
with all three of them now.
Umm they, they followed on

School experiences

Social aspect was the
most difficult part of
SS

from primary school, but umm I sort of, I think in year seven, it was more that I kind of stuck with them and then by year eight I had a bigger group of people for... just from high school so I've never been the sort of person that's found making friends quite difficult.... And I think partly that's just because I'll just talk to anyone. I'm just quite open and I just I'll say whatever to people but ummm so I found it kind of alright to make friends once I kind of learned the Social Code....

I: Mmmmm...

P1: ... But it was learning that realising the things that I could and couldn't say, that was probably the most difficult part of high school because it was so you know what girls like? It's just so nuanced. And it was all these things that I'd be like, why are we doing that? Why are you saying that? Can I not just.... Can I not just say this or do it? And it's no, you can't you can't do that.... (Laughs)
But um yeah that's probably the worst part of Secondary School... (Laughs)

I: Yeah.... and you know, it's interesting because when you read a lot of autistic girls experiences in the literature, sort of it is that social side, that is when things sort of really change and the friendships and er sort of exactly, exactly what you sort of said obviously every experience is very personal and how that manifests is unique but I think did the school sort of when you were talking about the bullying, were they supportive? Did

Peers: bullying

Overall felt supported by the school with bullying

<p>they sort of know what was going on? Did they support you in any way?....</p> <p>P1: Ummm yeah, I had a, I had a good form tutor in year seven. And she was, she's actually my mum is an ex teacher and she.... my mum had trained her. So yeah, it was a bit of a kind of a link. So she was she was good. She, when I went and I told her about what was going on, and she did go and deal with it straightaway.....</p> <p>I: Good...</p> <p>P1: It didn't... It didn't finish straightaway, because that's not really how it works, but it did....it did definitely umm kind of put the fear of God in them a little bit because they knew they had a teacher on their back....</p> <p>I: Yes...yes....</p> <p>P1: ... And she was a little bit of a point of contact for quite a few years afterwards as well, ummm so yeah, they were... it was never the sort of school where you know, something like that would happen and they would be like 'Oh, go go and deal with it on your own, we can't really do anything about it'. They did everything that they could to try and resolve the issue...</p> <p>I: Yes, yes, that's, that's good. That's really important. And I think having that person that then supports you later on, as well. And it's important those relationships in secondary school because Secondary School is just so different in terms of relationships, you've got so</p>	<p><i>School experiences: what can be done to make things better?</i></p> <p><i>Teachers</i></p>	<p>Build relationships with autistic pupils and find out what they need</p> <p>An autistic person should give guidance/training</p>
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many different teachers, to so many sort of transitions throughout the day.... Yeah, so that's that sounds really positive. Ummm and how do you feel that teachers could create better learning environments and sort of school environments for autistic girls in Secondary School... What types of things do you think... what do you think they need to know if they've got a girl with... an autistic girl in their class or in their lesson? I know everyone's unique but or sort of things to look out for....

Diagnosis

Teachers didn't pick up autism and were not aware enough

P1: Yeah hmmm, I think, I think I would probably say that as a starting point, I would say I... what I'm going to tell you it's not a blanket rule. I think it's very important that you go and speak to the individual on their own. You've got to build up a rapport with them enough that you feel like you can go and say, so what would you want from me? What can I do to help you make the environment more comfortable for you? Ummm I think as well having... I don't know I'm not 100% sure.... I don't know if this happens already.... But I think I think that some schools kind of give talks to the teachers on what autism is like, but I think it cannot be done by someone who doesn't have it. And I think that's the key.... I would be, and I've said this to people before, it... (laughs) literally just give me a call (laughs)... I'll come and talk to you about it because I feel very passionately about people who don't have the issues, preaching about them....

School experiences: Teachers

Teachers need awareness of autism presentation in girls

<p>I: Hmmmm...</p> <p>P1: ... Because, because how do you know you can, you can say that, you know, but you read it from a textbook or you've seen it in somebody else. And that's not the same thing at all..... Umm and I think that if you get the right autistic person to do the talking, you know, people are going to know so much better because that was.... My the issue for me, was that it was such a shock to all my teachers when I got diagnosed, you know, they had absolutely no idea.... and I think that's part of the problem is that somebody like me, who, like, you know, my family looks back and I look back and I go, how did we not know? Umm but my teachers didn't think that, whereas I think if you're clued up enough on how different it is and all these, all these things that can present and how it can look, especially in girls who are forced to conform, otherwise, they're completely... completely ostracised. I think you'll just... it makes for such a healthier person really.... I think that's probably the.... that's the key, is to just teach them everything that they can know about it.....</p> <p>I: Yeah... yeah... You've summed it up so beautifully...</p> <p>P1: Hehe (laughs)...</p> <p>I: ... That's exactly and that is why sort of autism research now is taken over the last few years... is trying to and you know, the sort of</p>	<p><i>Diagnosis</i></p>	<p>Mental health declined which lead to diagnosis</p> <p>CAMHS first point of call on diagnosis journey</p>
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science model of the professional sort of, you know, feeding in and doing the research and that's why it's got to take a participatory approach to make the impact because you need the voices of the people who've lived that experience and someone like you, like you said, being able to go into schools and talking with people...

P1: Hm-mm..

I: I think it's, it's amazing that you're doing this research firstly, so thank you... So just I'm conscious of the time and taking up your time.... So to do with the diagnosis you were talking... we talked a little bit about that. When you talked about you know, going into secondary school, you were 15 when you got diagnosed... When did you first hear that word Autism relating to yourself or sort of what was sort of the moment when, how did sort of the process begin of your journey to diagnosis?

P1: Well, ummm the summer after, so the summer, going into year 11... Umm I'd started to kind of struggle with my mental health in a way that I hadn't previously.... It's sort of more like, I experienced a lot of anxiety and I had kind of generalised anxiety disorder and separation anxiety.... But when I was kind of, when I was 15, it turned to sort of like depression symptoms.... Umm so I had been speaking to a school counsellor at the beginning of Year 11...

I: Okay...

Diagnosed privately due to long waitlists

<p>P1: and they had referred me to CAMHS.... So in my initial CAMHS assessment, so that's you know two hours, I'd been chatting to this nurse. Umm and I was kind of, I was not expecting it at all... But at the end, my mum came in and I was sat talking to him and he just went 'You need to look at an autism assessment'. And I was like, 'Rrrright, okay...', because I just didn't think that that would be the thing at all. So that was when I first heard it and the sort of person that I am, being autistic. I straightaway went home and I researched it, until I find anymore on it.... And I went, 'Oh, shit. Yeah, that's it.... Yeah, that's exactly what it is'... (laughs) Umm so I think like a month after I went for a private assessment because the CAMHS nurse, he said himself, he said 'You wouldn't get diagnosed on the NHS because of the diagnostic criteria, the way they did the assessments, you just wouldn't and the waiting list is too long anyway...' so fortunately, we were able to go privately...</p> <p>I: yes...</p> <p>P1: So within a month, I had my diagnosis....</p> <p>I: That sounds really, that's good that you got it at that time...</p> <p>P1: Definitely...</p> <p>I: ...So you were in year 11... so were the school involved or did, were the school involved at all... or sort of did you have to go in and sort of feed things back, the report?....</p>	<p><i>Diagnosis</i></p> <p><i>Teacher understanding/awareness of autism</i></p>	<p>School staff surprised at diagnosis</p>
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P1: I think, yeah, my mum definitely sent she sent the full report in and I was dealing with the same... because I confided quite a lot in the same teacher that had supported me in the bullying, with the bullying in Year seven....

I: Yeah..

P1: So my mum's kind of, she thought, well, we'll just start with her. So she explained she sent... she sent the report in, that teacher was just like, 'really...?', she was honestly.. and this is somebody who has known me since Year 7 but was was completely shocked. So yeah, she sent that in and then it got forwarded on to SENCO. And then like safeguarding and stuff like that, so they were all aware..... And then they I don't think the schools in any way involved in my diagnosis.... Umm but they did receive everything afterwards and then I was kind of on the SENCO radar after that....

I: And did they provide any support after this diagnosis... was there any difference at school....?

P1: Well, by that point, I'd already sort of had like.... I had a timeout card that I could just show and then leave my lessons and I could go to the Student Support Office and go and sit in the library or, you know, do whatever I needed to do...

I: Yes..

P1: So I already sort of had that...

I: Okay...

P1: ... Then sort of like a formal reason for having that as opposed to just I can't cope in lessons, but I've got, now I've got an actual reason. And then so the Senco leader, she, we had a meeting with her, and she sort of you know, just she talked to me, she kind of introduced herself to me. And then I had... umm it wasn't actually until year 12 because I went to the sixth form attached to my high school....

I: yes..

P1: It wasn't unti Year 12 I sort of had, like a designated person within the Senco that I could go to...

I: Okay....

P1: ... But I think that was partly because COVID hit umm when I was like halfway through year 11 so it sort of made all that sort of stuff quite difficult.... Mmmm....

I: You mentioned about the timeout card and the sort of having the space, was that something that were you involved in that, sort of advocating, 'this is what I need' or did the school sort of say, 'Here you go, these are these tools'....

P1: (laughs) it's ... well in my school because I know it's it's kind of a little bit funny how many people I know that have those exact timeout cards for various reasons, but it's sort of in my school is

a little bit like.... you go to them and you say that you've got this problem and it's quite, you know, consistent you have this quite a bit and it means that you know, you're struggling with something and that kind of knee jerk reaction is to go well, 'we'll give you this timeout card as a starting point and then you know, we can maybe do something else', (laughs) But yeah, so I know a lot of people with the timeout card... they've had it in the past.. I do think it was it helpful. Definitely....

I: Yes...

P1: But looking back, I say I 100% abused it and I... because I... I was in such a dark place. You know, I just... I did my A-Levels, no my GCSE Maths exams in the November, ummm and I didn't umm I forgot I had them, because I had no memory like my brain was like, like, part of it had broken at this point.... I had no memory, I had no motivation. I was just like, yeah none completely...

I: Hmm...

P1:... and um I just, the fact I had this card, I kind of like... well I just can't today so I just won't....

I: Hmm..

P1:... so then I kind of got into a bit of a habit.... So I sort of feel like they did what they could...

I: yes...

P1: ... I don't blame them for giving me the card. But now

I look back on it and I know that I shouldn't have used it the way I did because I just used it whenever....

I: Yeah, I guess though like you said, it helped and I think what's really important now and you touched on it exactly.... We go into schools, it's sort of we try to also ask the young person what is it that you would need, because too often it's sort of 'Here are the tools'... so I guess in hindsight like you said, it was good it was there but it also could have been a little bit more suited...

P1: I think sometimes I sort of, sometimes I needed a bit of a you know... I needed after... After I've been down to student support, you know, three or four times that week coming out of a lesson.... I sort of, I would have, I kind of needed someone to go, 'Okay, well, you've been out three or four times this week.... Is the lesson really that bad? You can, you can afford to go to it....' I just, I think I kind of, I think occasionally I did sort of need a bit of a kick up the bum to sort of say, go to this lesson because you can...'

I: yes, yes...

P1: .. That was definitely not the case all the time, sometimes I did genuinely need the break and I needed to go and sit somewhere else to do the work...

I: Yes.

P1: But I did maybe need checked a little bit more....Maybe someone

keeping tabs on how often I was using it.

I: Yes.

P1: Because it did reach a point where I wasn't, I basically didn't go to any of my chemistry lessons anymore because I've missed one and then I missed another one. And then I went oh my god I missed loads, so I can't go to them anymore, because I'm so behind.... I think umm it's just lucky for COVID that I didn't have to take the exam because I don't think I would have done anywhere near as well if I actually had to sit it... (Laughs).... Yeah but...

I: So I think like that sort of key person would have been helpful in terms of like, just monitoring things a bit more for you...

P1: yeah..

I: ...like in terms of that person that could sort of see like you said... hmm, that's really, that's really helpful... And I think in a secondary school context again, it's sort of tricky, isn't it.... Where...

P1: Hmm..

I: .. Where depending on the school, whether they've got the staff for that or but it sounded like you had some quite important figures, the counsellor, the Year 7 form teacher... Umm but I think that yes, somebody sort of monitoring, that would have been, would have that sort of more, I guess, an in-depth relationship.... Yeah...

*Diagnosis
Awareness of autism in girls*

P1: Yeah and I think a lot of people were... because of where I was at... were kind of afraid to say no to me and just afraid to force me to do anything.... Yeah and I can only say in hindsight that you know, that was the best thing to do.... But I do. I do completely understand that, you know, teachers have so much on and you know, where I was at, they didn't want to have to push me because they didn't know how I would react to it...Yeah. So yeah, yes....

I: And again, as teachers and school staff better understand, then this will help, won't it like in the bigger picture, they can better understand things.... So, yeah, you talked about how long it took you to get the diagnosis which luckily was quite fast, so that's a relief. So the final question is... sort of, I guess, reflecting on everything we've talked about, which has been a lot, how do you feel secondary schools could better support autistic girls going through... I was going to ask going through the diagnostic process, and I know yours was quite short....

P1: Hmm..

I: But do you think there are things that the teachers should be sort of looking out for and that it would have allowed you to have the diagnosis earlier.....

P1: Hmm yeah, I think ummm, I think so... it is a stereotype unfortunately, but the sort of kids that like to get their head down and don't,

Lack of understanding of autism in girls by people / school staff

don't do well in unsetting kind of environments, because that was always for me.... I always felt, and that was part of a struggle for me with people in terms of not liking me, because I always seemed, I guess I always seemed a bit stuck up in terms of academia because I would be in a mixed set class, I'd be frustrated with all the people around me who didn't want to do the work, or couldn't do it like I could do it....

I: Hmm..

P1:..I think, I think it's important that to support these kids, take them out of that environment, and put them in an environment with people like them and they'll, they'll, they'll work better.....But I think yeah, noticing that and sort of going... Hmmm, that on its own maybe isn't, put up with some other things, definitely....

I: hmm..

P1: I think also just be completely open minded about what autism could look like. And I definitely don't ever rule anything out. I think it put me off and it's still, it's still kind of upsets me sometimes if I'm speaking to somebody and they go 'Oh I never would've known' or 'You really don't seem like it' and I'm like well, that what are you doing by telling me that... apart from saying that you know, I'm not I'm not as autistic as the rest or whatever,... you know... I'm not minor? Ummm.. I don't... when my teacher, as much as I really liked that teacher,

Diagnosis: experiences and feelings around process

Diagnosis: awareness of autism in girls

Mixed emotions about diagnosis when going through process

Improving understanding autism in girls (teachers)

when she shared how surprised she was – that i'd been diagnosed. That wasn't helpful at all.....

I: No..

P1: ... And I think just never, just never being surprised if you come across a kid who is diagnosed with it, no matter what you thought autism did look like or you thought that they didn't have any traits of it..... You don't know the kid and if you can't, clearly, if you haven't picked it up, you don't know the kid well enough, is what I would say....

I: Yeah

P1: I think if you, if you've got, if you've got enough of a relationship with the student and enough of an open mind you will be able to tell... you know what I mean?

I: Definitely, that's really helpful. And that's, yeah, that, that surprise and that sort of, I guess when it's Yeah, I think the word autism is thrown around a lot in a causal manner in the media and by people..

P1: yeah..

I: ..and like you said, it all comes down to understanding... and of not judging and being curious and open minded and not... umm yeah, putting your pre judgments and biases onto, onto what you think autism is like.... I don't know exactly what your diagnosis tools were like but...

P1: ... I was quite, I was quite lucky.... Well I

definitely would not have had the same experience with, had I gone through the NHS but when I went privately, it was... I loved the day I got my diagnosis. I had a great day.... Umm my assessment was fantastic because at first I was like, as much as I'd kind of, from my research has sort of gone, 'Yeah I could see that definitely'..... At first I was kind of like, 'is this right for me to be here?'...

I: yeah..

P1: But then the more I got talking, the more I was like, 'yeah, no, I do that. Oh, my God!' and nobody had talked to me in this way before... so it was, it was great. But yeah, just I think, Yeah, another thing, the thing that can definitely work with a lot of teachers would be to kind put that NHS criteria out of their minds and what they're taught, when they're taught about what autism looks like.... Yeah, a little bit of the NHS stuff.... But a lot of the stuff that would be on a private assessment would be great to be taught, because yes, that is what it actually looks like more often than not....

I: ...yeah, that's that makes so much sense.... It sounds like a very holistic assessment that you had... I don't want to take up lots of your time.... So do you have any further questions or anything you'd like to add in....? Before I know... yeah, I know we've talked about lots of different areas, but is there anything else you'd like to add?...

P1: Ummm I don't think so.
No, I think that's, I think I've
pretty much covered
everything (Laughs)...

I: Thank you so much for
sharing your own
experience...

P1: Oh your very welcome.

Appendix 20: Extract from journaling during coding

20/02/2023

Reflections

Today was the first attempt at coding. I found myself reflecting on being in classrooms and thinking about the environment and how an autistic person would feel, trying to 'set into their shoes'.

I thought about the research questions, interestingly during supervision with my Research supervisor, we discussed key areas from the first transcript.

Reflecting on 'diagnosis', I thought about the girls' journeys and how many of their access had been through parent advocacy, CAMHS referrals or counselling.

I also noticed an interesting code, which I discussed with my supervisor, around 'attachment bonds – early childhood – separation anxiety'. I remember this coming up during another interview. Is this linked to other girls' experiences or a small pattern. Something to consider when coding and thinking of key areas. I am also being mindful of my position and role as a mother to a young toddler, this area is something constantly on my mind.

22/02/2023

Reflections

Having re-read all of the girls interviews and coded them, I've also drawn a spider diagram to organise my codes and thoughts.

Reflecting on the 8 girls, not one received any support from school towards diagnosis. I found this eye-opening, as SENCOs, EPs were not involved. Thinking about masking, awareness of presentation in girls.... All of these factors the girls recognise and discuss. Parents advocating – but what about those who don't have this? Or the means to do this?

Appendix 21: Example of the codes and code labels (Phase 2 Analysis)

Girls:

Code labels with extracts/quotes

Participant 1

Participant 2

Participant 3

Participant 4

Participant 5

Participant 6

Participant 7

Participant 8

Code label	Code	Extract/Quote
<i>The school environment plays a huge role in how I can learn</i>	Space is important	<p>P1: very cramped classrooms is another thing. I hate. The couple of classrooms where we're sort of all shoulder to shoulder... could barely you know... not got enough room to properly write and it's been like everyone's looking over your work all the time... not a fan of that... very stressful for me....</p> <p>P2: the classrooms, very like crowded very, umm not a lot of personal space. In my schools, it was like two people to each desk and all the desks were pushed in the middle and there was not enough room for all of those. And I hated being that close to people...</p> <p>P3: {Non-ideal school would be} crowded with tightly packed chairs and tables.</p> <p>P4: {Non-ideal school would be} overcrowded</p> <p>P4: {Non-ideal school would have} large shared desks</p> <p>P5: For the non-ideal school, school just very loud, bright and busy. Just the kind of place it's very filled with people, very fast paced. And different... difficult to orientate yourself in.</p> <p>P5: [In my ideal school] I also put an outdoor space in the centre of the school... because then it's accessible from different points and you're not walking out into a big crowded amount of people - there's different ways that you can get to that outdoor space...</p> <p>P5: [I enjoyed at Primary School] the outdoor space, it was that there was so much of it that you could go to a corner and... be away from everyone... it was all quite spaced</p>

		<p>out, so you'd have your own environment of choice for that day...</p> <p>P6: [My non-ideal school would have] lots of students.... And I guess, like those schools which are really not designed to be schools and that have like tiny classrooms, and tiny corridors and then like, everyone ends up in the corridors and then it's like, between lessons and that was like super overwhelming...</p> <p>P6: [In my ideal school there would be] not too many people in each class</p>
	<p>Sensitivities to sound – <i>potentially merge the two into sensory ?</i></p>	<p>P2: I definitely struggled with even just like moving around the school because the corridors quite like narrow but there was a lot of people and it was always really noisy and it made me really anxious</p> <p>P3: {Non-ideal school would be} loud</p> <p>P4: {Non-ideal school would be} noisy and students would be making lots of noise in the classroom</p> <p>P5: ...when there's so much happening, you lack the energy to eat, and the cafeterias can be such loud busy environments...</p> <p>P5: [I found teachers] Interactions with kids [at Primary School] Quite difficult, quite loud. Not ideal. But just generally the way of interacting with primary school kids with the yelling to make silence and stuff like that.</p> <p>P7: [Non-ideal school classroom would have] an open door with loud noise outside.</p> <p>P8: I would like a classroom that provides a quiet, familiar, easy going, non-stressful learning environment... and the sound didn't echo around.</p>
	<p>Sensitivities to light</p>	<p>P3: {Non-ideal school would have} bright smart board and bright lights</p> <p>P5: For the non-ideal school, school just... very bright</p> <p>P5: I actually got these glasses, these are just normal glasses prescription tinted, because I kept having seizures from getting overstimulated, from the bright lights in the classrooms.... [the school] they let me wear sunglasses sometimes, but they had to have lights on for people, they wouldn't get more accessible lights, dimmer lights or put on less of the lights.... So it was directly above me, UV bright light....</p>

		<p>P6: I think I really struggle when there's like... schools err tend to have like fluorescent lighting and things like that, which I find really not ideal and like those started having like, whiteboards which are like basically TV screens kind of thing like rather than being like a projector, but a projector is always like, quite like nice in your eyes, it's like not very, it's not really bright. Whereas in primary school, as we like, they like one summer they like took away all the old projectors and put in like these like, basically like TV screens and they were so bright, and it was just, it's, it was a real barrier for me.... Cause I was like, well, do we want to look at this because it's like - physically hurting my eyes!</p> <p>P6: [My ideal school would have] lights which are like not ridiculously bright and like they try and use daylight rather than, like, umm fluorescent lights.</p>
	<p>Transitions and change are hard</p>	<p>P2: if I would turn up at school and walk to where I had to line up, and if it was a different teacher than my usual teacher like a supply teacher or whatever, I used to like sob because I couldn't deal with the unexpected change....</p> <p>P5: Ummm would have had separate areas for departments so that the school made more logical sense of going, 'ah I have English that will be in an English block, that will be near languages', and stuff like that.... So it just makes general sense... it used to really stress me out, so we had in my high school... we had a lot of science teachers who just kept leaving constantly.... so we ended up having a science lesson in maths or in history, and it would just really throw me off because it's an entirely different environment, the science buildings, they have high stools, they have stuff for science experiments.... and then if you suddenly put that in a new environment with little warning with teachers absences as well, of not knowing until you're meant to already be there...</p>
	<p>Lack of behaviour management</p>	<p>P1: ...people who teach us who can't they can't control the class they can't you know, if people are kind of, you know, not obeying the rules or, or talking back, they can't kind of squash it or anything....</p> <p>P1: very kind of unorganised and the teachers don't have much control over the classroom. I find that very, very stressful.</p> <p>P2: very loud, very busy. Umm and having sort of adults that aren't particularly patient with some people ummm I struggled a lot. I'm like very like noise sensitive.</p>

		<p>P2: I struggled a lot with like people shouting out and people would like throw things around the classroom.</p> <p>P4: [Non-ideal school would have students who] make lots of noise and disrupt the lesson</p> <p>P4: {Non-ideal school would have teachers who] can't take control of the class</p> <p>P7: [In my ideal school] teachers would control the class and be approachable and understanding</p>
	<p>Teachers can have unpredictable personalities</p>	<p>P1 also, the sort of teachers that kind of humour the kids who have bad behaviour and they sort of, I hate, I hate when teachers, they try and be your 'matey' with the kids that weren't.... they want the bad kids to like them more than the good kids.....</p> <p>P2: and if they were quite unpredictable, like one minute they were angry at you or one minute they were like trying to be happy and playful with the students.... I really didn't like that because I didn't know where I stood with them.....</p> <p>P5: the thing of being loud and I've had a lot of experiences in the past of teachers prone to start shouting at the class and get silence and that can be quite without warning... so unpredictable.... quite prone to yelling and not giving precise information about tasks and things, being quite brief in what's happening in the classroom, because then you want to ask questions, and then if you're prone to yelling, sometimes you'll get yelled at for asking the questions and it just makes the entire experience more difficult....</p> <p>P8: [My teacher] would often promise me an extension the day before, then decided to shout at me for not having it finished in front of the entire class. He did this multiple times to the point where I gave up trying to complete things. I promptly stopped showing up and dropped his class instead of taking four a levels. This was a shame because I genuinely enjoyed the subject and I think I would have studied it at university if it weren't for his behaviour.</p>
	<p>Lack of differentiation - I want to work</p>	<p>P1: I did find it quite difficult in primary school. I did have a couple of very good teachers who kind of could see that and would make a concerted effort to give me extra work.</p>

		<p>P1: sometimes I did kind of feel like I was being held back a little bit because of everyone else.....</p> <p>P2: adults sort of being patient and understanding and clear with what we're talking about.... I had a lot of teachers that would say something and I have quite an issue with auditory processing. So I always needed someone to say it and write it down so that I have those two things so I could get it into the brain properly.... And a lot of teachers didn't do that. Even though I asked some of them they still didn't do it...</p> <p>P5: Being able to do the tasks with very clear like numbered instruction... so if you forget them, you're not going this has been too fast, you're able to process it at your own speed.... and you can do your best you can ask for help with the teacher in the centre of a room, if you need a break - you can take it... just being able to work with your own time management....</p> <p>P6: And I guess a big barrier for me is like, when people, I really struggle with auditory processing. So people who are really, you know, who get really like frustrated about repeating things or aren't really, yeah, and just like – ‘Oh, it doesn't matter then’ like if you miss something...</p>
	<p>Teachers should be direct and give clear instructions</p>	<p>P2: And very direct as well. Because a lot of teachers, a lot of the teachers that I had would want you to do something but not tell you directly and then shout at you for not doing the thing, but they never told you directly to do it, they just expected you to know that you have to do (laughs) and which obviously I didn't.... Like yes, so shouting at me and it made it a lot more stressful....</p> <p>P5: [In my ideal school] the tasks umm they'd have very clear instructions for them.</p> <p>P5: [In my ideal school] for the teachers, I specifically put direct with instructions because when things are brief, it's difficult to organise what's going on with that... and patient and well-tempered as well...</p> <p>P7: [In my ideal school] adults would break things down and explain tasks clearly</p>
	<p>Feeling unnoticed because I want to work</p>	<p>P1: It hurts me so much because I am like I'm the one that's sat here doing the work. I would love to talk to you about this subject, because I really like the subject, we can have a really nice conversation, but you just want to talk to them, because they're so loud....</p>

	<p>The classroom environment matters – I can't learn if the environment isn't conducive to learning</p>	<p>P1: I think I'd also feel kind of, like I've been done a disservice by the environment I've been put in because I know sort of what I'm able to achieve and what I can do in the classroom setting and then to have an environment where I just can't cope and I can't focus. I'd feel just like... as if I'd been kind of let down a little bit by that...</p> <p>P1: An environment where kind of everyone, all the kids want to do the work and people aren't trying to be distracting.... you don't have to love the work..... They just want to get it done.</p> <p>P2: I never particularly found schoolwork that hard but because of my surroundings and because of the people, it made it that much more stressful to do work and to like, feel as though I could actually have a decent education because of the surroundings, because it was just, it was really, it was very anxiety filled for me so....</p> <p>P4: [My ideal school would have children who are] behaving and getting on with their work</p> <p>P5: about the children... just them being more understanding... accommodating basically of... it's going to be loud they are kids but understanding when it's too loud and when you need a bit of quiet....</p> <p>P5: [In my ideal school drawing] I've got headphones on and I'm smiling, a little stick figure (laughs).. I feel like my well-being would be supportive....I'd be thriving...I'd be able to access my strategies. I'd be content because I really enjoy education and learning things, but it's just the environment in which that's happening can be very difficult.... it drains all the energy you would have to learn - by existing in the environment to learn....</p> <p>P5: Have them [students], have a a say in the seating plan. That was a massive thing for me. I quite literally, I ended up leaving a lesson crying before, just in the middle of the lesson, because of a person who was sat next to me kept calling me slurs and the teacher was doing nothing about it... she kept me there for months... and there was no adaptations, there was no change for that, even though she could see that it was causing me emotional distress being there, and her reasoning was she was playing Cupid.... Yeah, so main thing is letting us be able to have input on where we're sitting, if it's too loud, because it was right near the door as well which had to be open, so there was everyone walking through the corridors, and I'm getting insulted constantly. And really, it used to be my favourite lesson English because I got, I got nines in my English GCSE because I'm so much of a fan of writing, but that</p>
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		<p>ruined the entire experience from, from being in that year in that seating plan....</p> <p>P5: There was a quote in a book that I read about autistic girls and it said, 'Everyday life can be a trauma - referring to the light and the experiences of noise and the social interactions' and that specifically stuck with me,</p>
	<p>Access to calm spaces at school</p>	<p>P2: Definitely having places that people can go either on their own or with other people, that are just calm low light, like comfortable places where you can either just sit in silence, do nothing, you know, or do something a calming, sort of... I used to, I used to go to the library every lunchtime and sit in the corner on my own and read a book because that was the only sort of solace I had in the whole day... (Laughs)Everywhere else was so stressful</p> <p>P2: if there is rooms or places to go that are slightly calmer, allowing students to use their phones for music or even just, not even just your phone, just being able to listen to music in general.... I do think that that's quite beneficial because, music was a massive thing for me....</p> <p>P4: Make private quiet places for students to use if feeling overwhelmed.</p> <p>P5: [My ideal school] it would have quiet areas available, just generally around that, you know, those are always there if you need them....</p> <p>P5: [The thing I enjoyed most about Secondary School was] the library that is it! ... It was just a quiet space. You had to be quiet in it. There were access to different worlds, in all of the different books available. There were different seating options. Like when I said about the classrooms like there were bean bags or normal seats. Or you could just sit on the floor and no-one would bat an eye because you were reading.... Umm just really liked libraries.</p>
	<p>Autistic people need to be giving teachers training on autism</p>	<p>P1:... some schools kind of give talks to the teachers on what autism is like, but I think it cannot be done by someone who doesn't have it. And I think that's the key.... I would be, and I've said this to people before, it... (laughs) literally just give me a call (laughs)... I'll come and talk to you about it because I feel very passionately about people who don't have the issues, preaching about them....</p>

	<p>Understand me and then you can truly support me, and I can learn</p> <p>My voice matters</p> <p>Relationships with staff matter</p>	<p>P1: I think it's very important that you go and speak to the individual on their own. You've got to build up a rapport with them enough that you feel like you can go and say, so what would you want from me? What can I do to help you make the environment more comfortable for you?</p> <p>P2: I had quite a difficult time with getting teachers to understand me</p> <p>P2: I guess just like, lack of understanding when it comes to like, helping people. Umm it, it's like it seems that it's very based on people having diagnosis and like not actually searching for people that are struggling, that might need help.... And they concentrate on those that have gotten a confirmation from a doctor or something like that. There's a lot of people that get lost like, I got very lost in the system. Because I was quiet. And I struggled very internally with all of my issues...No one sort of paid attention enough to really realise that there was something that I needed help with that...there was like, an issue there, I guess....</p> <p>P2: I have support at college. I know that I feel a lot better about going in.... even if I end up having a meltdown and I get overstimulated, because I have people I can go to and I have the understanding from teachers that you know, it's not because I don't want to be in the school or it's not because I don't want to learn it's just because it's kind of hard for me to do that right now.... And that as soon as I am calmed down and I'm better, I will be back and ready to learn because I do, I do enjoy learning about new things.... It's like one of my favourite things to do - is learning different things.....</p> <p>P2: And I think that that's just, that's the most important thing is knowing that a teacher actually cares what they're doing and what how they're impacting children....</p> <p>P3: [My ideal teachers would be] calm, reassuring, understanding</p> <p>P3: [The best part of Secondary School was] a relationship with 1 particular staff member</p> <p>P5: [The thing I found most difficult about Primary School]... the teachers mostly, I was undiagnosed for quite a long time. And they didn't get it.... of it was just, the general interactions of assuming everyone was on the same wavelength and stuff.... I actually got pranked by teachers several times</p> <p>P5: I had to do so much of my own advocating and when that isn't reciprocated, when that isn't understood and</p>
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		<p>valued that, that's the main issue with, with the teachers in that learning environment.... Consider people's viewpoints when they're having challenges and difficulties that they've gone directly to you because it is your responsibility - hear it out!</p> <p>P6: [My ideal school would be] small enough for you to be an individual rather than just like a number....</p> <p>P6: I guess, part of it comes from the teachers as well because there's like, an emphasis on like, understanding that like different is good and like understanding different people's needs and respecting that and like if bullying happens, like other people standing up for you, rather than like, not saying anything or joining in.... I guess they consider everyone's needs and like see everyone as an individual, and know what, know, like know when to recognise when someone's feeling uncomfortable when something's not right, and know what they can do to support everyone individually... [I'd feel] much more like ready to learn, I guess. More supported, and I think, yeah, I'd be much more able to engage in lessons and like, yeah, learn stuff. Yeah....</p> <p>P6: I think asking people, because like everyone's needs is so different. But like, if you just sat down with me and said – ‘What's, what's difficult, what is the barrier to learning?’ I can tell you exactly what the problem is and then it can be solved... like a lot of the time, people assume that every autistic person struggles with eye contact, or every autistic person struggles with loud noises. Whereas like, that's not necessarily the case. Like for me, auditory processing is like a really big deal. But for a lot of people that wouldn't even be something that would be an issue. So I think that, you're unlikely to have loads of autistic students in your class. So like, if you if you're aware of, if you're aware that you have autistic students in your class, have that conversation with them, ask what you can do to make things easier....</p>
	P vs S school	<p>P1: I, on the whole had quite a good primary school experience.</p> <p>P1: going from quite a small Primary School to quite a decent size high school. And suddenly the things that were like... different about me, weren't alright anymore.</p> <p>P2: I had a lot of problems, all right up into you into like, year five, year six.... Year six was the only year that I ever got support and that was because I had a different teacher</p>

		<p>P2: [In Secondary School] I enjoyed some of the subjects it was more like the work that I enjoyed and I think I enjoyed the feeling of being a bit more grown-up.</p> <p>P3: [Primary school was difficult due to] Friendship, communicating with teachers, assemblies, special days, change in routine.</p> <p>P3: [Secondary school was difficult due to] Everything from socialising / classrooms and assemblies to uniform, teachers and noise.</p> <p>P4: My friends and pupils at the [primary] school were really nice. I enjoyed learning and given extra tasks. [I found it difficult] misbehaving pupils disrupted the class.</p> <p>P4: [What difficulties were there in Secondary School] essentially everything – overcrowded school, struggled to make friends, was bullied, very alone and isolated.</p> <p>P5: [The thing I found most difficult about Secondary School was] ... probably the inconsistency.. of... that was a lot more routine that was predictable in primary school, whereas when you get all young teenagers in a big building together, there's going to be a lot more unpredictability. It might be a productive classroom might be people throwing glue sticks on the ceiling, it might be quiet getting your work done, it might be chaotic, loud, people are fighting. You never know what's going to happen with the day to day and I found that very stressful and very difficult to navigate because it was just quite sudden I was like, 'Oh, I don't...I'm not used to this'. And I don't think I ever got used to it.... Umm the sixth form that I went to just before this - because I'm obviously an adult now, was so much better at consistency or there was never anything like that of - if I know how that class is going to be - it will be that way throughout - because it's the people that want to be in those classes that are there - because they've chosen them as options.</p> <p>P6: I enjoyed secondary school a lot more. I enjoyed the academic side of things. But I also had like more friends in secondary school. My secondary school was like, really good.... in supporting me. So I got a lot more out of it.</p>
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	<p>SEMH Anxiety</p>	<p>P1: I had counselling for anxiety a couple of times when I was in primary school,</p> <p>P2: I was, like, always anxious at school and it definitely would be in this sort of situation.... Ummm just stressed out..</p> <p>P3: I felt Isolated, upset and angry [at school]</p> <p>P4: I felt Alone, anxious, depressed [at school]</p> <p>P8: [In my non-ideal classroom] I am the only person the teacher can call on despite not having my hand up. It makes sense as I had a lot of social anxiety about talking in class and getting answers wrong.</p> <p>P8: Remembering to complete homework, or to bring in items needed for class, it was a big source of anxiety for me [in Primary School], that I would get into trouble because I didn't mean to do this.</p>
	<p>Secondary School enjoying the academic side</p>	<p>P1: it's such a mixed bag for me secondary school... I loved the lessons... trying the new subjects that I'd never done before.... really going in depth into like sciences</p> <p>P1: getting to really go in-depth with the subjects that I loved.... I really, really enjoyed that.... I've had some fantastic teachers that I just love and I'm so sad that I'm now leaving them..... I think that was probably the thing for me about secondary school that was the most, ummm the best part was the kind of.... the actual learning part, the teacher part....</p> <p>P4: {the thing I enjoyed most about Secondary School] Final years - finally being challenged in my learning.</p>
	<p>Challenges of social side/friendships of Secondary school</p>	<p>P1: I just didn't like the environment at all.... Ummm I think for me, a lot of the time, my issue stemmed more from the social aspect of school....</p> <p>P2: I had a lot of issues with people that just didn't get why I was the way I was.... I had a lot of issues that people just didn't like, like difference. I think if you sort of, if you start from a young age of teaching them that differences are okay, and that indifference.... indifference can be like embraced. They tend to grow up into adults who are a lot more kind and respectful and understanding.</p> <p>P2: I hated it. I hated drama. I hated all of the petty like, teenage girl stuff that went on.... And I couldn't, I couldn't understand why it was such a big deal to them.... It wasn't</p>

		<p>to me... which it made it quite hard to stick with friends because they expected me to act like them and think like them when I really didn't....</p> <p>P2: throughout the whole of secondary school it was like that.... I used to get made fun of, for just talking about things that I was interested in, because I would get so passionate about it, because it would be something that, you know, it was my special interest or that I was like, fixated on at that point... And people would just be like, Why are you so obsessed with it? And I didn't understand. Neurotypical people don't tend to get fixated on things as neuro divergent people do.... And I if I like something that became my whole life, it became what I thought of the time, it became like what helped me get through the day sometimes.... and having people around me that wouldn't let me talk about it, and would ridicule me for talking about it, was really, was really hard....</p> <p>P2: ... And I got a lot of, like people were just like, very mean to me... about certain things that I did, that looking back on now.... Everything, all... everything they made fun of me for were my autistic traits and were the things that I did because I was, I don't know, I was struggling or I was trying to cope....</p> <p>P6: I think there was definitely like, definitely an expectation for everyone to be the same or like the idea that like different is bad.</p> <p>P6:[In Primary School] I remember I was like, very engaged with like, Maths and English like, I was very like, engaged in the like, the actual learning side of it. I know I struggled socially. Yeah, I think when, when I was given a task and could complete it and was given clear instructions, then I was fine. But when it was sort of, yeah, I struggled with making friends... I have one friend. I would never have like a group of friends or anything...</p> <p>P7: [In Secondary School one of the most difficult things was] being excluded from friendship groups</p> <p>P7: In Year 7, [I was] bullied by another child, being told I had numerous disabilities, including autism</p> <p>P8: At one point I didn't eat anything for lunch or just ate things I could take from the edge of the lunch hall easily, such as bread rolls and fruit, because it was too embarrassing and scary to sit at lunch alone.</p>
	Navigating friendships	P1: I found it kind of alright to make friends once I kind of learned the Social Code....

		<p>P1: ... But it was learning that realising the things that I could and couldn't say, that was probably the most difficult part of high school because it was so you know what girls like.. It's just so nuanced. And it was all these things that I'd be like, why are we doing that? Why are you saying that? Can I not just.... Can I not just say this or do it? And it's no, you can't you can't do that.... (Laughs) But um yeah that's probably the worst part of Secondary School... (Laughs)</p> <p>P7: [Things I enjoyed about Primary School] good friends up to Year 3</p> <p>P8: In an ideal world the children would be kind and friendly... I would wish that they would be more understanding and amenable to 'strange' children like myself, without seeing it as pity or a duty. I would like if they invited me to hang out outside of school or to go to parties together.</p>
Transitions	Smooth transition and simple decisions	<p>P1: so it was very, very natural that I would go there or my friends are going to go there....</p> <p>P1: The primary school I went to did all that kind of transition stuff with that specific high school to go anywhere else just seems a bit silly really, yes..... Yeah, it wasn't.... It wasn't a difficult decision to make at all....</p> <p>P2: It was kind of a given that I was going to go where both my brother and my sister was, had gone.... Yeah, that's just, we'd all gone to the same school.... so it was just kind of what happens, I guess (laughs)</p> <p>P6: So my primary and secondary were linked, so it was basically the same school but they were like different buildings... it was like, a really, really good transition, because like in my autism assessment, there was a lot of questions around like, did you find that transition hard because a lot of people do... but because it was like, because it was going from one side of the school to essentially the other side of same school.... So it was actually like a really easy transition. I think we had like 10 whole weeks there in year six, and it was like, they'd thought about it so well, and it was like a really smooth transition....</p>
	Support for transitions	<p>P1: we had a look around the school ... And then they had a couple of evenings that were just for parents to go</p>

	<p>and look at a couple of PowerPoints or examples of work....</p> <p>P2: going in, to sort of get an idea of what the days will be like, having timetables.... I used to get my timetable on the day that I started, which sort of, meant that I didn't get any time to prepare for like... I'm very, the way that I plan is I visualise in my head.... And if, if my day doesn't go how I visualised it in my head, then it sort of makes me panic and freaks me out a bit....</p> <p>P2: I think if you can go to the school... just before you start, maybe with some other autistic students and like your parents and stuff, I know that I wouldn't have felt comfortable going the first time without my parents.....</p> <p>P2: going around the school, talking to your Form Tutor or to the teachers that you might be having... Umm sort of, where you'll be... where I'd be going to classes, what my day would look like.... like, specific times as well.... I never knew, like (laughs) specific times because we were just, sort of assumed, like people just assumed that everyone sort of knew that.... But I was never told like what time the lesson starts and when it like ends, and when lunchtime is and when lunchtime ends and when break is... because it's very different to primary school. It's a very different structure. And I think that I know that I would have benefited a lot by just sort of getting to know that structure before I was actually just thrown into, into the deep end and like had to actually do it whilst also being at school with all the people and having to learn....</p> <p>P3: I had 2 extra transition days in a small group. I did not meet any subject teacher but at least I got to see the school.</p> <p>P4: I went for 3 visits and support was arranged with teachers... It was helpful to know support was in place, though often was difficult to use because of social peer pressure or teachers would forget.</p> <p>P5: The first week was all getting different books and getting the planner and stuff like that, if I had access to them beforehand, and I could get used to the layout, I could understand that... the planner did include a map of the school at the back, and I ended up duplicating that printing it off and putting it in my top pocket, so I could constantly refer to it when trying to find my classes... but if you've had them, maybe even just a week in advance, go in, pick them up, then you'd have that ready you'd have it prepared, you'd be able to know what correlates with what lesson and if there's anything extra you need to bring to certain lessons like calculator and protractors to Maths</p>
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		<p>or if geography uses more colour pencils and different things like that...</p> <p>P5: I think the main thing was the uniform, awful change - primary school uniforms soft, quite comfortable... and then suddenly everything is scratchy and boxy and there is a tie involved and it just did not work well for me... there's no flexibility...</p> <p>P6: Because I'm going to uni next week... it's like the next big transition.. so the kinds of things I've asked for are... I've asked for my timetable in advance</p> <p>P7: Visited the school for a day before hand, [and post-transition] had a buddy from Year 10 who met once a week to talk about things and regular meetings with Deputy Head of House.</p> <p>P8: [School staff could support autistic girls transitioning from Primary to Secondary by] organising a visit to the school beforehand, meeting the new teachers, viewing a map of the new school and ensuring the transition is smooth as possible - that all members of staff have the appropriate training as to best cater to the student's needs, focus on specific struggles of the student and put an appropriate plan in place to aid student.</p>
Diagnosis	Obtaining a diagnosis	<p>P1: But at the end, my mum came in and I was sat talking to him and he just went 'You need to look at an autism assessment'. And I was like, 'Rrrright, okay...', because I just didn't think that that would be the thing at all. So that was when I first heard it and the sort of person that I am, being autistic. I straightaway went home and I researched it, until I find anymore on it.... And I went, 'Oh, shit. Yeah, that's it.... Yeah, that's exactly what it is'... (laughs) Umm so I think like a month after I went for a private assessment because the CAMHS nurse, he said himself, he said 'You wouldn't get diagnosed on the NHS because of the diagnostic criteria, the way they did the assessments, you just wouldn't and the waiting list is too long anyway...' so fortunately, we were able to go privately... So within a month, I had my diagnosis....</p> <p>P2: I'd been on CAMHS, I'd got first referred to CAMHS umm in year nine. And then they said that school had to deal with it, because they didn't really listen to me and said that it was only friendship issues.... when I didn't say that. I did say that I had friendship issues, but there were a lot of other issues... the guy that was assessing me just really didn't listen to me... then my mum was like we're not giving up because there's something going on like</p>

		<p>you're having panic attacks all the time, you can't cope with school.... So I got re-referred in Year 10 I think yes.... And then I don't think any anything came of that either....But then we went privately to do some CBT... then I got re-referred again in year 11... it took up until October of 2020 um to actually be seen by CAMHS and I got referred in 2019 so ummm and then I got a CAMHS worker.... I had to do 10 weeks of CBT on CAMHS even though I'd told them that it didn't work for me.... The 10 weeks kept getting pushed back as well.... and then I had a meeting with my CAMHS worker and I said, 'Look, I don't think that this is just anxiety, I do have anxiety, but I don't think that, that's the cause of all of the other stuff that's happening that I'm dealing with, and I was like something's going on'... And then she was like, yeah, and she talked to my mum as well. And I think she was the one who actually first brought it up to my mum.... Have you ever thought that she might be autistic?.... And my mum was like, I hadn't because like my son's autistic and he's like, very different.... And umm whatever and then she brought it up to me as well. And I said, I think it's ADHD, okay, well, we'll do the autism thing... because I was adamant that it wasn't autism because the way that I saw autism in other people, I was like, that's not me....And then I got referred for, to be put on the waiting list for the assessment... and then I got my assessment in August of 2021 and got diagnosed the same day....</p> <p>P3: [I first heard about autism relating to me] when I was in year 10 talking to my mum (my therapist had told her about it).</p> <p>P5: It was kind of me and my family pushing for it most. My autism diagnosis came around because I was spending a lot of time in hospital, I got diagnosed with chronic illness, and they thought that masking was effecting and making it worse... they got the teachers all to write a bit about me and what they thought of me as an individual and stuff like that, but it was massively driven by me and my family rather than the school.</p> <p>P6: I didn't get my diagnosis until I was 18... school weren't involved, there was talk of them being involved and then they ended up not being involved. I've been under CAMHS since I was like 12... And so we had the conversation with CAMHS, but this conversation happened when I was 18... I think the adult waiting list was I think three years long at the moment. So then they were like, well, that's not gonna work.... So, but I couldn't get it through CAMHS. So I ended up going privately, and I got the diagnosis probably like two or three months after we first had the conversations....</p>
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		<p>P7: Aged 12-13 CAMHS mentioned autism</p> <p>P8: [I first heard the word autism relating to myself] in 2016, when I got my diagnosis. I knew I was a bit different but no one had said anything to me before this. [The school] had to fill in a form sent by the psychiatrist to provide more information on me but that was it.</p>
	<p>Positive to get diagnosis</p>	<p>P1: I loved the day I got my diagnosis. I had a great day.... Umm my assessment was fantastic because at first I was like, as much as I'd kind of, from my research has sort of gone, 'Yeah I could see that definitely'.....</p> <p>P1: ... At first I was kind of like, 'is this right for me to be here?'... But then the more I got talking, the more I was like, 'yeah, no, I do that. Oh, my God!' and nobody had talked to me in this way before... so it was, it was great.</p> <p>P2: I thought that it was me as a person being a problem. And then when I got diagnosed, it was like, 'Oh oh, so it's not me. It's just how my brain works'</p> <p>P2: , I was like, 'okay, yeah, this is good, like this is... I'm happy that this has happened because I understand myself more'.....</p>
	<p>Don't be shocked by my diagnosis, try to understand me</p>	<p>P1: the issue for me, was that it was such a shock to all my teachers when I got diagnosed, you know, they had absolutely no idea....</p> <p>P1: she (mother) sent the report in, that teacher was just like, 'really...?', she was honestly.. and this is somebody who has known me since Year 7 but was, was completely shocked</p> <p>P1: I think also just be completely open minded about what autism could look like. And I definitely don't ever rule anything out. I think it put me off and it's still, it's still kind of upsets me sometimes if I'm speaking to somebody and they go 'Oh I never would've known' or 'You really don't seem like it' and I'm like well, that what are you doing by telling me that... apart from saying that you know, I'm not I'm not as autistic as the rest or whatever... when my teacher, as much as I really liked that teacher, when she shared how surprised she was – that i'd been diagnosed. That wasn't helpful at all.....</p> <p>P1: ... And I think just never, just never being surprised if you come across a kid who is diagnosed with it, no matter what you thought autism did look like or you thought that they didn't have any traits of it.....</p>

		<p>P6: schools sort of initial response was, ‘but you don’t seem autistic?!’.... And then it was ‘But would the diagnosis actually help anything? Like what’s that going to help? Like what’s that going to do?’... And then, and then I was sort of like... and then they listened to me for a bit and then they’re like, ‘Oh, okay, now we actually understand why’.... I think they were just really uneducated as to why a diagnosis is really helpful.</p>
	<p>Understand autism (e.g. girls vs boys)</p>	<p>P1: I think if you're clued up enough on how different it is and all these, all these things that can present and how it can look, especially in girls who are forced to conform, otherwise, they're completely... completely ostracised. I think you'll just... it makes for such a healthier person really.... I think that's probably the.... that's the key, is to just teach them everything that they can know about it.....</p> <p>P2: I mean, 17 years of my life, I was not diagnosed and I was struggling so much but now that I look back on things, I did present as autistic from a very young age, umm and there's certain things that my mum says to me that I did even as a baby, and I was like, Why did no one think that that was abnormal, that maybe like something that needed to be looked into like...</p> <p>P3: [Secondary schools could support girls going through diagnosis by] providing accurate info in their referral letters (know the traits in girls).</p> <p>P5: Before my diagnosis I ended up doing this even of, my dad had a comment of saying, ‘well, everyone’s a little bit autistic’ and I was going ‘no because that’s, that’s massively degrading the experiences of actual autistic people... Everyone has traits maybe but not everyone is - a bit autistic. There are people who are autistic on the spectrum and there are neurotypical people who won’t understand the same struggles...</p> <p>P5: [Secondary School] they didn't even know I was autistic! They didn't know what it was for when they were even asked to write about if they thought I had autistic traits. One of them just put that they thought I was good at physics! I was constantly stimming in lessons, I'd get overwhelmed and go mute in lessons and they just never considered for a second – ah, maybe she's autistic - because I wasn't the model of autistic teenage boy that they've seen in all the textbooks and been educated about.</p> <p>P5: I absolutely agree that it's about knowledge and awareness, but one thing that I'm constantly preaching is</p>

		<p>- that to make things more accessible for autistic people in schools is to make things more accessible, full stop in schools... Of, younger children - I used to refer to small children as 'ahh he's a little autist' - because it's the same things as getting overwhelmed with bright lights, loud can be too much because they're new to the world - they're still sensitive with those things... ... and it's traits that I can spot in myself with my autism...</p> <p>P6: Exactly, it's like well 'What do you know'? Like, everyone suddenly becomes an autism specialist when you say, 'Oh, oh I'm looking to find, to get diagnosis or I think this might be what's going on'... It's, 'oh, but that's, just you know, that's just little boys who have tantrums'</p>
	Advocacy	<p>P2: I like talking about autism, I think that it's an important thing to talk about, um especially in girls, because we're not really known about it...</p> <p>P2: I don't want people to go through what I did, and I know a lot of other people did, because it really does knock your self-esteem when you grow up.... Not knowing that you, just all that's wrong with you, like not even what's wrong with you, is that you just have a different brain and that's why people treat you differently, it's not because you're a bad person or you're like making people's lives worse or like that you're doing it on purpose, it's just because your brain thinks differently..... I know that a lot of a lot of arguments in my house, a lot of like, issues that I had with friends would have been solved so much more quickly if I had known this about myself earlier.... But so yeah, I want to do stuff like this to sort of help hopefully, people in the future not have to deal with that like I do... so...</p> <p>P5: The more people that can push with this kind of thing [advocacy], the better so I'm really glad that you're excited about this because it means we've got new generations coming taking over jobs that actually want to get excited about these things...</p> <p>P5: [I'm part of a project for the] county council's autism Information Hub... there's also a young ambassador that I've managed to loop into this to help with this, because they wanted as many young voices as they could because before that it was all coming from parents and carers...</p>
	Education around autism and diagnosis	<p>P1: the thing that can definitely work with a lot of teachers would be to kind put that NHS criteria out of their minds and what they're taught, when they're taught about what</p>

		<p>autism looks like... But a lot of the stuff that would be on a private assessment would be great to be taught, because yes, that is what it actually looks like more often than not....</p> <p>P1: it is a stereotype unfortunately, but the sort of kids that like to get their head down and don't, don't do well in unsettled kind of environments, because that was always for me.... I always felt, and that was part of a struggle for me with people in terms of not liking me, because I always seemed, I guess I always seemed a bit stuck up in terms of academia because I would be in a mixed set class, I'd be frustrated with all the people around me who didn't want to do the work, or couldn't do it like I could do it.... I think it's important that to support these kids, take them out of that environment, and put them in an environment with people like them and they'll, they'll, they'll work better.....But I think yeah, noticing that and sort of going... Hmm, that on it's own maybe isn't [autism], put up with some other things, definitely....</p> <p>P2: ... And I think people need a lot more awareness... that like, the things that are typical things that teenagers tend to bully other teenagers, are autistic traits....</p> <p>P5: [The thing I found most difficult about Primary School]... the teachers mostly, I was undiagnosed for quite a long time. And they didn't get it.... of it was just, the general interactions of assuming everyone was on the same wavelength and stuff.... I actually got pranked by teachers several times</p> <p>P8: I get the sense that in some schools there is a way to help diagnose girls through the school, rather than having to seek help privately. So perhaps to finetune this in-house process to better pick up on autistic symptoms in girls, and to account for masking when trying to diagnose pupils.</p>
	<p>How my autism unravelled...</p>	<p>P1: Umm I'd started to kind of struggle with my mental health in a way that I hadn't previously.... It's sort of more like, I experienced a lot of anxiety and I had kind of generalised anxiety disorder and separation anxiety.... But when I was kind of, when I was 15, it turned to sort of like depression symptoms.... Umm so I had been speaking to a school counsellor at the beginning of Year 11... and they had referred me to CAMHS....</p> <p>P2: my brother presented so differently to me. I was like, 'There's no way that I'm autistic because I have friends and I socialise and I am able to talk to people, and I'm empathetic and like I feel things so much more than my brother does'...I didn't really think that autism could be something that was applied to me until I was 16, maybe,</p>

		<p>like, or like just literally about six months before I was diagnosed.... And that was because I was trying to get an ADHD diagnosis, because I thought that those traits sort of fit with me.... But then when I started looking into autism and girls, I realised that fit better with me, then the ADHD did... and it fit better with how, I experienced socialisation and like being with other people and because I'd always found it difficult, but I'd sort of like just made myself push through it because I felt like I had to, I guess? And I had to be seen as, that I was doing something... about six months before I was diagnosed was when I first sort of thought, actually, maybe it could be autism....</p> <p>P3: [Length it took to get diagnosed] about 6 months from when 1st interested (we went to a private practice).</p> <p>P4: I had my diagnosis confirmed when I was 17. My guidance teacher was involved in the assessment.</p> <p>P5: It was not with the school, it was entirely driven by us... I had a whole team with a Paediatrician and it was them who were driving the diagnosis and then I had like a two hour meeting in a hospital in (NAME), where they evaluated me and there was really no involvement from the school at all at that point...</p> <p>P6: my mum was like, because CAMHS, there were questions around EEPD or BPD.... And then it was like, this is not.... that in itself is like, I dunno questionable.... and yeah.... And then it was sort of like okay, well my mum was like, 'Well, could it be autism?' and then CAMHS were like, 'Oh, oh actually we hadn't thought of that!' (Laughs).... Umm and they were like Oh, okay.... this really fits, but we can't assess you....! it's ridiculous how it's like the non-professional - my mum who's just like on Facebook trying to work out how best to support me.... Like, essentially found the answer and then brought it to CAMHS and they are like, 'oh, okay, yeah, that's what's going on!' ... and your like, I don't really know how it has to.... It's ridiculous.... It has to take a parent to like, put that idea in their in their heads.... I</p> <p>P8: For me it was instantaneous practically as my mum booked the appointment privately and as previously stated I wasn't really aware of autism beforehand in relation to myself.</p>
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	<p>Post-diagnosis support</p>	<p>P1: Well, by that point, I'd already sort of had like.... I had a timeout card that I could just show and then leave my lessons and I could go to the Student Support Office and go and sit in the library or, you know, do whatever I needed to do... Then sort of like a formal reason for having that as opposed to just I can't cope in lessons, but I've got, now I've got an actual reason.</p> <p>P1: It wasn't until Year 12 I sort of had, like a designated person within the Senco that I could go to...</p> <p>P3: I had a student passport before hand and after I sought out resources like a time-out pass and communication cards. Nothing was given or suggested.</p> <p>P5: [Did the school put in Post-diagnosis support?] They did not... but when I changed into sixth form umm there was a massive change in support entirely, that wasn't entirely because of my autism, it was because I was in a wheelchair as well and I got an EHCP plan and so I had someone with me all the time taking notes for my classes, so kind of everything changed at that point... when I asked for autistic related assistance and support, I didn't really get it because it wasn't a priority at the time with the pandemic.</p> <p>P5: but there still wasn't the, the, the support I wanted for my autism for, of, I'd said – ‘are there any quiet rooms I can go to?’ - No, we're coming back from a pandemic, we do not have any quiet rooms available – they are all busy... ugh!</p> <p>P6: Yeah, also, like, providing support to people without a diagnosis as well because there's a lot of ‘Oh, but you're not diagnosed yet so you can't get support’, which is really frustrating. But also like, so I... we had the conversation with school, but because I was like, in the middle of sitting my A levels and I was also in a mental health crisis.</p> <p>P8: I got my extra time back, which was the original purpose of the diagnostic appointment. I don't think I received any further official support from the school. Some teachers ensured that I could have lunch sessions if I didn't understand something, some gave me paper with the homework assignments on it with additional instructions explaining, and some were more lenient with deadlines.</p>
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		<p>P8: I'm sure far more could have been done by the school, as evidenced by the fact that I was friends with another autistic girl who went to the same school, who was diagnosed far younger than I was and she had a lot more support in place.</p>
	Early Years / Attachment	<p>P1: I've always been very attached to my mum having quite a maternal sort of, teaching experience was quite beneficial when I was younger...</p> <p>P2: I was always a very anxious child. When I like... when I first started I struggled with, like leaving my mom. I used to cry every single morning going into school. And I used to have meltdowns quite easily.... I found it very difficult to like transition into school and actually get there...</p>
	Masking	<p>P1: I was bullied quite a lot in year seven, because I hadn't yet caught... I hadn't, I basically... I hadn't caught up to the masking point yet, because I hadn't really had too....</p> <p>P5: the chronic illness that I'm diagnosed with is functional neurological disorder that generally is triggered by a trauma or an illness. And there wasn't anything specific. It was from my masking. The trauma was built up from 17 years masking without a diagnosis. And that's how I ended up having paralysis and seizures and things because it went so long unrecognised....</p>

What can Secondary Schools do to support Autistic girls?

Classroom environments:

- P2: Definitely calmer. Definitely quiet. And I'm not saying silent because I do like to talk to people and I like having discussions.... But when it gets when there's so many overlapping conversations and so many different noises and like the bells even in secondary school, like the sound of the bell I just hated it....
- P2: Definitely a bit more like personal space, like having personal desks but still being like close, close enough to people that you can talk to them....
- P2: we used to have like quiet reading time [in Primary].... which I don't understand why.... they stopped that at a young age.... Because I think that's quite beneficial for older ages to partake in as well, I know that I would have loved that.... Because it was just, it was just an opportunity to sort of sit on your own for a little bit, reset your mind...
- P3: [My ideal school would be] calm and quieter

- P3: [My ideal school would have] bean bags, floor desks, no smart board
- P3: Make rooms sensory accessible (dimmed lights, quieter sound coming from smart board).
- P4: [My ideal school would have] individual desks
- P5: [My ideal school has] different chairs being available.... Umm I like a beanbags... but roller chairs are also good and having just different like types of chairs that you can sit in at every point instead of having just specific desks, that can be easily moved around...
- P5: I also put the teacher like quarters - their location around the centre of the room, so it's not an awkward having to go to the front to ask about things... It's, everyone has like equal opportunity to discuss.. Yeah, it's the anxiety around that as well, a teacher is there to teach, but if you're so worried about being seen and having to go to the front, and being observed in that situation, it will make it a lot more stressful and difficult to actually allow the teacher to do to do what they do, to do their job...
- P5: I've put a little storage boxes (laughs) with headphones and snacks just to make it easier when going through tasks... I did the box that has headphones and snacks in - because if everything's too loud - people can absolutely be loud - because sometimes they need that to regulate.... and if you're not managing with that on that day, or if it's too much, and you could add headphones or if you're really hungry - you can't concentrate on a task as well, therefore the snacks...
- P5: Have them [students], have a a say in the seating plan. That was a massive thing for me. I quite literally, I ended up leaving a lesson crying before, just in the middle of the lesson, because of a person who was sat next to me kept calling me slurs and the teacher was doing nothing about it... she kept me there for months... and there was no adaptations, there was no change for that, even though she could see that it was causing me emotional distress being there, and her reasoning was she was playing Cupid.... Yeah, so main thing is letting us be able to have input on where we're sitting, if it's too loud, because it was right near the door as well which had to be open, so there was everyone walking through the corridors, and I'm getting insulted constantly. And really, it used to be my favourite lesson English because I got, I got nines in my English GCSE because I'm so much of a fan of writing, but that ruined the entire experience from, from being in that year in that seating plan....
- P7: [How do you feel teachers could create better learning environments for autistic girls in Secondary School] do not say talk amongst yourselves, instead give a task to do
- P8: There's so much that could be done, but I think the most important is to create a feeling of safety in the classroom by establishing set routines and especially by playing to their students interests to create engagement with the subject matter. This could be accompanied by more lenient deadlines to allow less anxiety surrounding completing homework, and more student support throughout their time at school.
-

School environment:

- P4: Create a quiet, safe space for girls to go if feeling overwhelmed.
- P4: [My ideal school would be] small, quiet, safe and mainstream
- P5: having some form of space for regulation, rather than a busy canteen and stuff like that, having options for that, but also having space where there's maybe outdoor access just, just availability to regulate..

- P5: ..but having an opportunity to have like sensory stuff. Right now I've got a bracelet, I only ever have bracelets with 24 beads. And every single day in high school in form, I would get yelled at and told to take it off.... And I'd put it in my pocket because it wasn't uniform, and then I'd take it back out immediately because I could not manage without fiddling with it because it was my way of staying grounded.... It was umm very important to me. And that I've been literal... several years that happened... almost every day the uniform checks, take that bracelet off, leaving the room - putting it back on because it's not manageable without it.... having just sensory toys, almost, available.
- P5: making a school environment more accessible for autistic individuals like the girls changing rooms loud, lots of smells, because they've got all perfumes and stuff, and it's all very difficult having a quieter space, where they will instead lock the bathrooms so that we had to get changed there and do just different things like that and making small accommodations...
- P5: maybe turning down the brightness of the lights a bit
- P5: having some designated quiet spaces just jotted around,
- P5: having general things to make everyday life easier for people regardless, maybe even paper towels instead of hand drying because I'm not the only person, er I've talked to other people since getting my diagnosis, who've gone 'Oh yeah, it is the worst part of a public bathrooms even though it is a public bathroom, it's going to be filled with germs and stuff, but it's just the noise of the hand dryer...'... would be having alternatives in places... **and it just makes the entire day experiences more difficult from that one experience of... once you've had that, then it's in your head and then everything else becomes more difficult because you're more susceptible to it.....**
-

Knowledge of autism

- P2: I guess understanding the basics of autism anyway.... especially how it presents differently in different people.... and sort of looking out.. umm and sort of being more aware of the traits in certain people.. Because I know if I had had someone that knew more about autism, that was able to sort of give me attention, I would have been diagnosed a lot younger, and it would have meant that I would have had a lot less trauma, I guess, from just growing up undiagnosed....And it would have meant that I would have had a lot more help growing up.....So I think that's quite important.
- P2: I think that teachers in schools in general just need to be taught about, you know, seeing the signs of autism, because it would have been so beneficial for me to be diagnosed earlier.
- P3: [My ideal school would be] inclusive
- P4: Remember students support plans, and keep info confidential.
- P4: Train teachers with better knowledge of autism in girls.

Build a relationship and get to know me

- P1: I think it's very important that you go and speak to the individual on their own. You've got to build up a rapport with them enough that you feel like you can go and say, so what would you want from me? What can I do to help you make the environment more comfortable for you?
- P1: if you haven't picked it up [autism], you don't know the kid well enough, is what I would say.... if you've got enough of a relationship with the student and enough of an open mind you will be able to tell...

- P6: I think asking people, because like everyone's needs is so different. But like, if you just sat down with me and said – ‘What's, what's difficult, what is the barrier to learning?’ I can tell you exactly what the problem is and then it can be solved... like a lot of the time, people assume that every autistic person struggles with eye contact, or every autistic person struggles with loud noises. Whereas like, that's not necessarily the case. Like for me, auditory processing is like a really big deal. But for a lot of people that wouldn't even be something that would be an issue. So I think that, you're unlikely to have loads of autistic students in your class. So like, if you if you're aware of, if you're aware that you have autistic students in your class, have that conversation with them, ask what you can do to make things easier....

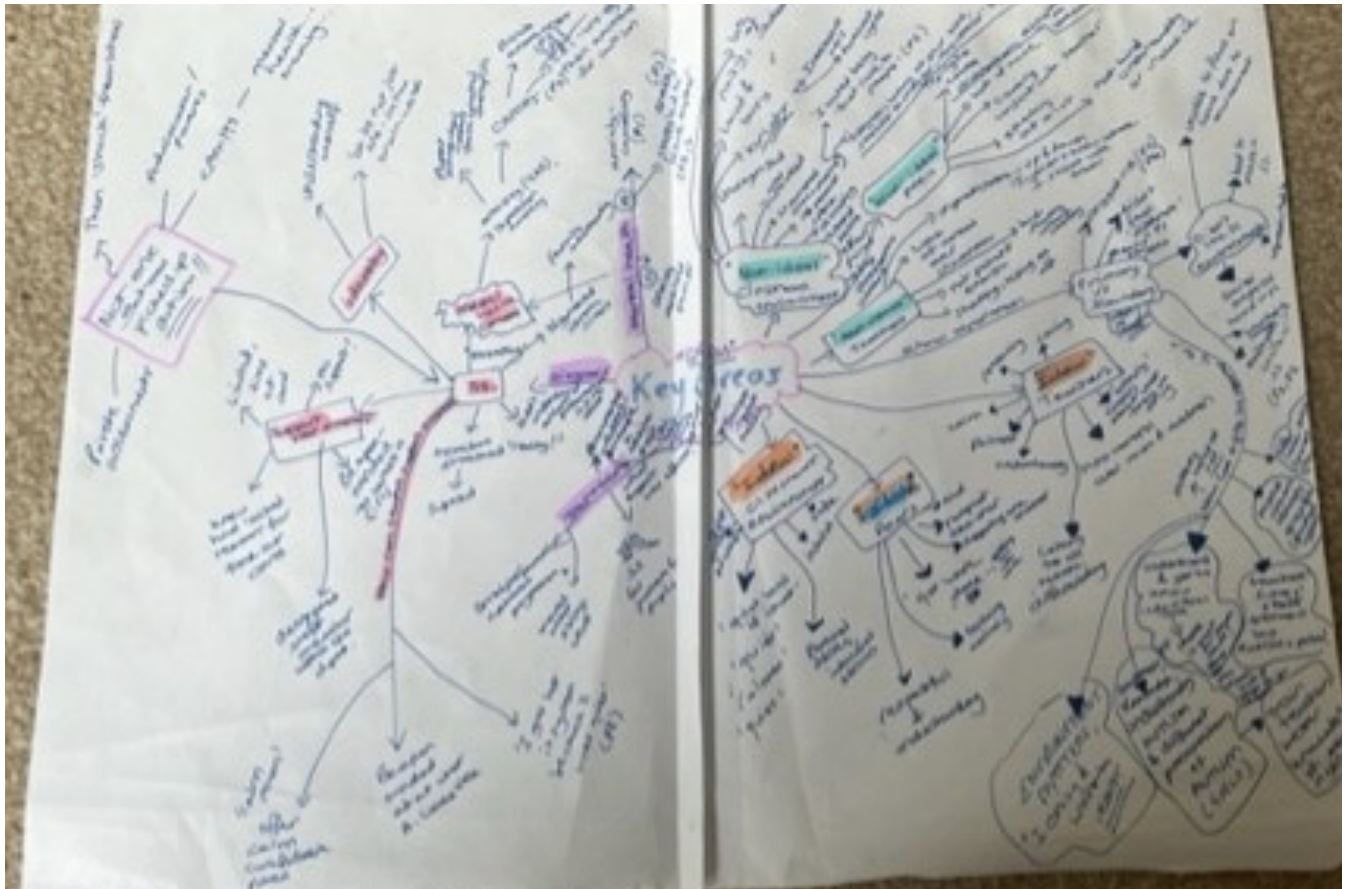
Friendship/peer support

- P2: giving autistic girls the opportunity to interact with other autistic girls?... I never really I, I struggled a lot with seeking out new friendships.... and I think that, that having school sort of help in that, in seeking them out and giving opportunities to autistic people to just sort of get to know each other and maybe find a peer that you can relate to because I know for a fact that I never had that.... Although I knew of other autistic people in the school, obviously I didn't know I was autistic at the time, but ummm they were all very different to me, and I think people tend to think that autism is not common, when in reality in school environments, especially, there are a lot more autistic people there than people would think... And being able to seek out the people that would benefit from talking to people that have similar issues, or interests...
- P2: ...And I think having like a club or an acceptance club that could even like help. The school, we had an LGBT society... I think doing something similar to that, but with like autism or other neurodiversities would be useful....
-

Autistic advocates who gives talks/training:

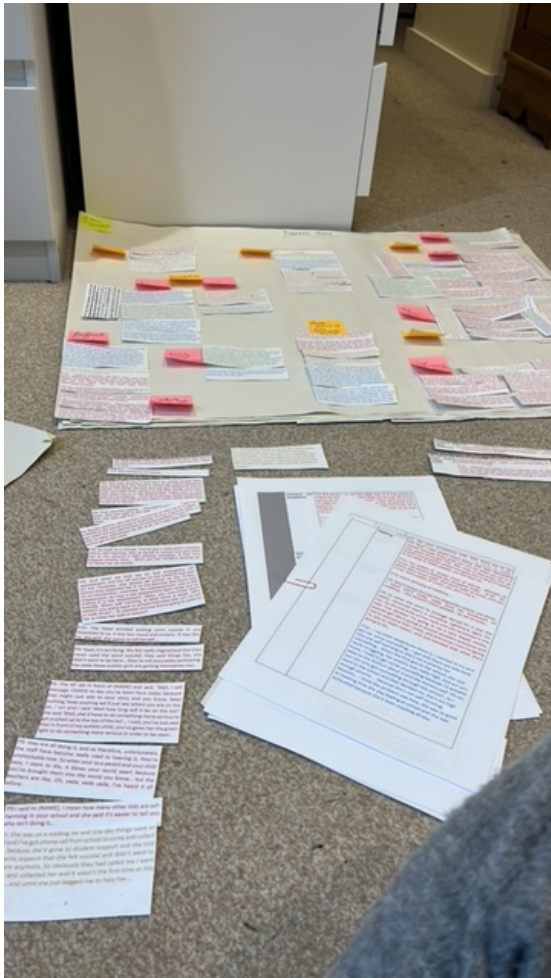
- P1: I think that some schools kind of give talks to the teachers on what autism is like, but I think it cannot be done by someone who doesn't have it. And I think that's the key.... I'll come and talk to you about it because I feel very passionately about people who don't have the issues, preaching about them....
- P2: Yeah, to have the school speak to actual autistic kids who go to that school on how they could help and they could change it, is always useful.....
- P5: there needs to be more support for people like me in this exact position and I can be that support for someone else... I can be in that place. I can be making those leading steps and I can be helping because I'm fascinated with all of it.
- P6: What I liked is that they [university] have a special autism programme... they run it throughout the year and... they did one yesterday talking about executive function and adapt transition and just generally what they can offer to support and some techniques that might be helpful.... And all the people who were involved in delivering that programme were autistic and like the staff members, and that was just it was it was the reason why I picked [that university] was because they were so willing to offer support...
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Appendix 22: Initial drawing of codes, reflexive analysis (Phase 2)



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Appendix 23: The process of generating initial themes (Phase 3)



Appendix 24: Girls: Generating initial themes (Phase 3)



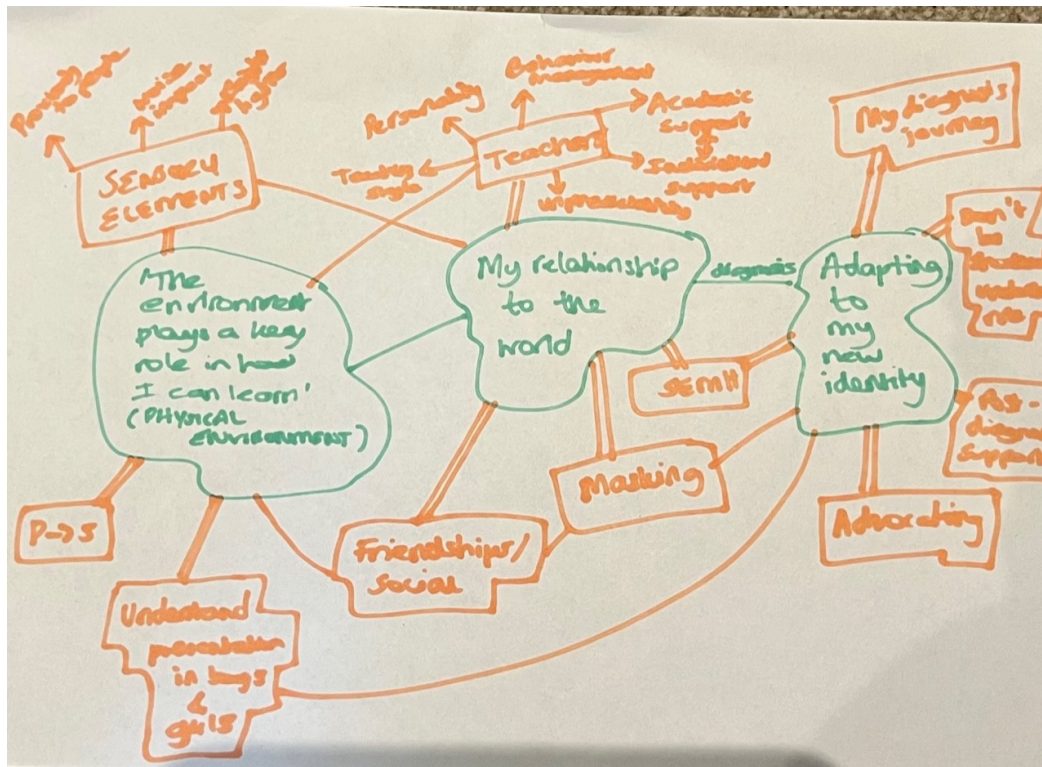
Appendix 25: Parents: Generating initial themes (Phase 3)



Appendix 26: First attempt at devising themes

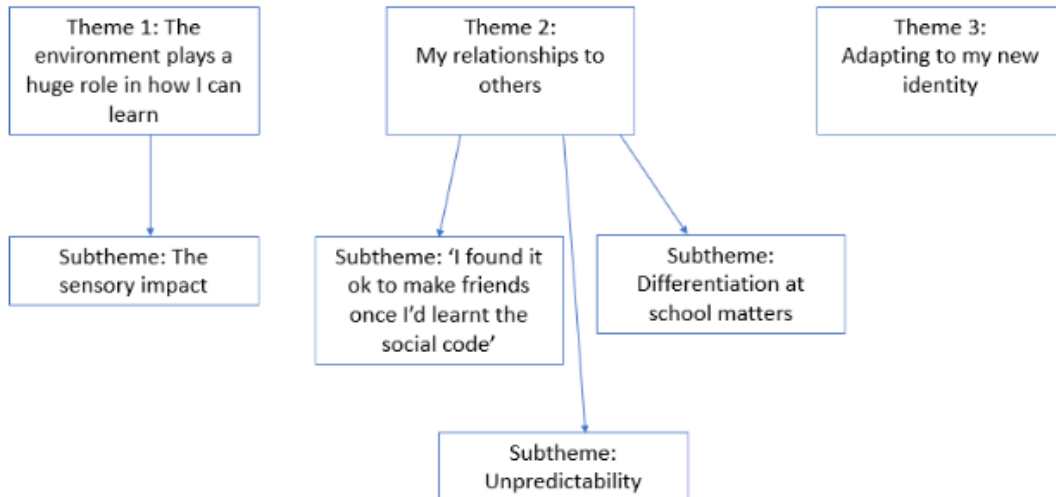
School experiences 'I really enjoy education and learning, but it's just the environment in which it is happening can be very difficult'	Sensory aspects	Proximity to people (n=7) Bright lights (n=3) Noise impact (n=6)
	Friendships / social	
	Teachers matter	Change is hard (n=3) Behaviour management (n=4) Teacher personality (n=2) Unpredictability (n=2) Understanding relationship / individualisation (n=5) I like to be academically challenged (n=4) Instructions – differentiation matters (n=4)
Transitions	Primary to secondary school	N = 3
	Reflections on support	N = 5
Diagnosis	My journey to diagnosis – didn't come from school!	N = 8
	My diagnosis helped me understand myself	N = 2
	Masking	N = 2
	Post diagnosis support in schools	N = 5
	I want to advocate to help others	N = 3
	Length to diagnosis	N = 4
	SEMH before diagnosis	N = 5
	Don't be shocked by my diagnosis, try to understand me	N = 2

Appendix 27: First hand drawn thematic Map – Girls (Phase 3)

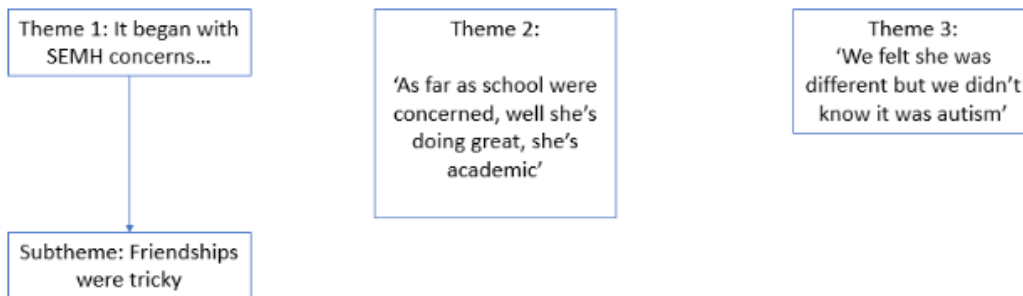


Appendix 28: First refined Thematic Map – Individual Girls and Parents

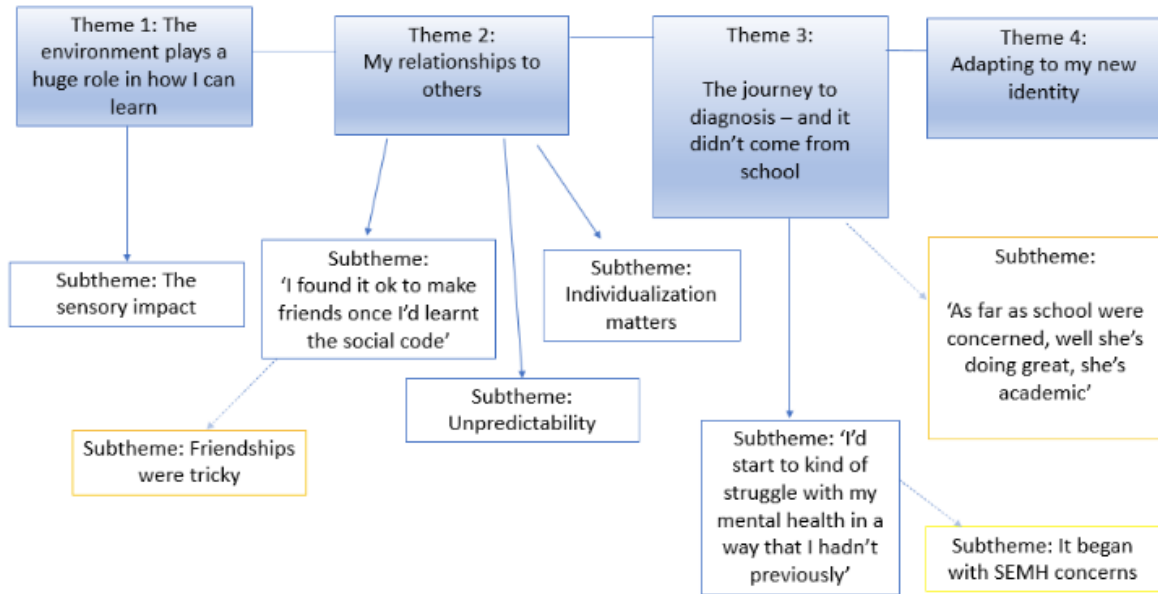
Girls:



Parents:



Appendix 29: Revised Thematic Map, post supervisor discussion: Girls and Parents merged



Appendix 30: Summary of the ‘Ten core assumptions of reflexive TA’

(From Braun and Clarke, p.8, 2022)

1.	It's key to consider ‘researcher subjectivity’ and ‘researcher bias’
2.	Analysis and understanding of data is not considered ‘accurate’ but can be strong or weak
3.	Coding can be individual or collaborative
4.	‘Good quality’ codes and themes are produced through revisiting the data on an ongoing basis
5.	Themes are not summaries, they are patterns
6.	Themes are formed from codes and cannot be detected in advance
7.	Themes don't arise from data but are formed by the researcher during their rigorous engagement with the data
8.	Data analysis is always reinforced by theoretical assumptions
9.	Reflexivity is fundamental to high quality analysis
10.	Data analysis centres creativity within a framework of rigour

Appendix 31: Ethics Forms

Doctoral Student Ethics Application Form

Anyone conducting research under the auspices of the Institute of Education (staff, students or visitors) where the research involves human participants or the use of data collected from human participants, is required to gain ethical approval before starting. This includes preliminary and pilot studies. Please answer all relevant questions in simple terms that can be understood by a lay person and note that your form may be returned if incomplete.

Registering your study with the UCL Data Protection Officer as part of the UCL Research Ethics Review Process

If you are proposing to collect personal data i.e. data from which a living individual can be identified **you must be registered with the UCL Data Protection Office before you submit your ethics application for review**. To do this, email the complete ethics form to the [UCL Data Protection Office](#). Once your registration number is received, add it to the form* and submit it to your supervisor for approval. If the Data Protection Office advises you to make changes to the way in which you propose to collect and store the data this should be reflected in your ethics application form.

Please note that the completion of the [UCL GDPR online training](#) is mandatory for all PhD students.

Section 1 – Project details

- a. Project title: 'School experiences of autistic girls who were diagnosed in adolescence: views from young people and their parents/carers'
- b. Student name and ID number (e.g. ABC12345678):
- c. ***UCL Data Protection Registration Number:**
 - a. Date Issued: 21st June 2022
- d. Supervisor/Personal Tutor: [Dr. Laura Crane \(Research Supervisor\)](#) and [Dr. Melernie Meheux \(Educational Psychology Tutor\)](#)
- e. Department: [Psychology and Human Development](#)
- f. Course category (Tick one):

PhD	<input type="checkbox"/>
EdD	<input type="checkbox"/>
DEdPsy	<input checked="" type="checkbox"/>
- g. **If applicable**, state who the funder is and if funding has been confirmed.
- h. Intended research start date: [June 2022](#)
- i. Intended research end date: [May 2023](#)
- j. Country fieldwork will be conducted in: [England](#)
- k. If research to be conducted abroad please check the [Foreign and Commonwealth Office \(FCO\)](#) and submit a completed travel risk assessment form (see guidelines). If

the FCO advice is against travel this will be required before ethical approval can be granted: [UCL travel advice webpage](#)

- I. Has this project been considered by another (external) Research Ethics Committee?

Yes

External Committee Name:

Date of Approval:

No **go to Section 2**

If yes:

- Submit a copy of the approval letter with this application.
- Proceed to Section 10 Attachments.

Note: Ensure that you check the guidelines carefully as research with some participants will require ethical approval from a different ethics committee such as the [National Research Ethics Service](#) (NRES) or [Social Care Research Ethics Committee](#) (SCREC). In addition, if your research is based in another institution then you may be required to apply to their research ethics committee.

Section 2 - Research methods summary (tick all that apply)

- Interviews
- Focus Groups
- Questionnaires
- Action Research
- Observation
- Literature Review
- Controlled trial/other intervention study
- Use of personal records
- Systematic review – **if only method used go to Section 5**
- Secondary data analysis – **if secondary analysis used go to Section 6**
- Advisory/consultation/collaborative groups
- Other, give details:

Please provide an overview of the project, focusing on your methodology. This should include some or all of the following: purpose of the research, aims, main research questions, research design, participants, sampling, data collection (including justifications for methods chosen and description of topics/questions to be asked), reporting and dissemination. Please focus on your methodology; the theory, policy, or literary background of your work can be provided in an attached document (i.e. a full research proposal or case for support document). *Minimum 150 words required.*

Study Purpose

The idea for this study came primarily from my personal interest of continuing research to support the autism community and my professional experience as an educator for autistic children and young people, prior to undertaking training on the DEdPsy programme. This study will hopefully benefit the autism community and Educational Psychology practice to support autistic children/young people and their families.

Study aims:

This project aims to gain perspectives and experiences from autistic girls and parents/carers, about their adolescent school experience, including navigating the primary to secondary school transition (without an autism diagnosis), and furthermore, how they obtained an autism diagnosis during their adolescent years.

This project is unique as there is currently, to our knowledge, no research looking at autistic girls' experiences with school, including the transitions from Primary to Secondary, at a time when they were yet to receive an autism diagnosis.

The main aim of this research is to understand autistic girls' and their parents/carers experiences throughout their adolescent schooling years, and the impact of a diagnosis on this.

Main research questions:

Research Questions:

From the perspective of the girls and their parents/carers:

- 6) What was the girls' experiences during the Primary to Secondary school transition?
- 7) What was the girls' overall schooling experience and support like?
- 8) Explore the girls' pathway to autism diagnosis during their adolescent years?

Throughout, I will focus on what worked well and where improvements could be made, with particular relevance to EP practice.

Research Design and Data Collection:

A key part of this research is to understand the girls' perspectives and views, and by speaking their parents/carers as well, it will provide further context to understand their experiences (upon reflection of Bronfenbrenner's eco-systemic model, which examines all systems around the child/young person). Due to the nature of the research, which involves investigating an ongoing 'real-world' situation, and not experimental, controlled situations, an interview seemed most appropriate.

Therefore, data will be gathered using a non-experimental design encompassing semi-structured interviews, in order to gain qualitative data. The process will involve two steps:

- 1) Firstly, the girls will have the choice whether they wish to participate in an interview or complete a workbook with questions or draw their replies (which will be sent in advance). Alternatively, if they do wish to participate in an interview they can do so with myself (virtually) or their parent/carer (this will be filmed for myself to watch at a later date and transcribe). As part of the girls' interview, they will have been sent a package in advance with my profile (to familiarise themselves with me) and as well as the questions/drawing, a 'personal construct psychology' activity, with details of how to draw out their ideal and non ideal school.
- 2) The second stage will involve interviewing the parents/carers virtually, allowing for the reflection space after the girls' interview.

The booklet (pack contents) and interview schedules have been attached to this ethics form. They have been designed to encourage discussion about the girls' school experiences including school transition from Primary to Secondary, the diagnostic process and overall experiences of the girls during this time. The interviews feature open and closed questions to acquire a wide range of information from participants, and opportunities for the girls to draw instead of writing an answer. A one-hour slot for each participant will be allocated due to discussion/explanation time. The consent forms and information sheets are also attached.

Recruitment and Participants:

The girls/their parents will be recruited through an advertisement which will be circulated through networks such as Girls Autism Network, the Ambitious about Autism Youth Network, the charity Autistica, and also through SENCo's/EPs in my current LA on placement. The advertisement will feature a link to Qualtrics, which will have the information sheet and consent form, and participants will be able to electronically sign if interested to participate.

The aim is to gain the perspectives of girls and their parents/carers and triangulate these. Initially we discussed gaining teachers/school staff perspectives, but due to the ongoing repercussions as a result of the COVID-19 pandemic, such as absentee rates in schools and extra pressure on school staff, this felt unreasonable. Furthermore, it is highly likely to be difficult to identify one teacher to report in relation each participant given that the young person would have left Primary school a while ago and with regards to Secondary School, there is often a range of teachers.

The aim will be to recruit 10-12 parents/carers and girls. The ideal sample age of the girls would be 16-25, due to their ability to reflect on their transition experience and this would also exclude individuals who have recently had disruptive schooling due to the COVID-19 pandemic.

Girls who are autistic can be difficult to recruit due to diagnosis challenges (Gould & Ashton-Smith, 2011), yet as this project is focussing on girls who are in the age range of Secondary School and older, and due to the large membership data base of females in the Autism Network (one of the key routes of recruitment), it is hoped that the sample size is achievable.

Reporting and Dissemination:

The data will be analysed using reflexive thematic analysis and data will be pseudonymised.

Section 3 – research Participants (tick all that apply)

- Early years/pre-school
- Ages 5-11
- Ages 12-16

- Young people aged 17-18
- Adults please specify below
- Unknown – specify below
- No participants

The sample of parents/carers will consist of parents/carers and their autistic children. The sample of autistic girls will likely consist of those in the age range of 16-25 as detailed above.

Note: Ensure that you check the guidelines carefully as research with some participants will require ethical approval from a different ethics committee such as the National Research Ethics Service (NRES) or Social Care Research Ethics Committee (SCREC).

Section 4 - Security-sensitive material (only complete if applicable)

Security sensitive research includes: commissioned by the military; commissioned under an EU security call; involves the acquisition of security clearances; concerns terrorist or extreme groups.

- a. Will your project consider or encounter security-sensitive material?
Yes* No
- b. Will you be visiting websites associated with extreme or terrorist organisations?
Yes* No
- c. Will you be storing or transmitting any materials that could be interpreted as promoting or endorsing terrorist acts?
Yes* No

** Give further details in **Section 8 Ethical Issues***

Section 5 – Systematic reviews of research (only complete if applicable)

- a. Will you be collecting any new data from participants?
Yes* No
- b. Will you be analysing any secondary data?
Yes* No

** Give further details in **Section 8 Ethical Issues***

*If your methods do not involve engagement with participants (e.g. systematic review, literature review) **and** if you have answered **No** to both questions, please go to **Section 8 Attachments**.*

Section 6 - Secondary data analysis (only complete if applicable)

- a. Name of dataset/s:
- b. Owner of dataset/s:
- c. Are the data in the public domain?
Yes No

If no, do you have the owner's permission/license?

Yes No*

- d. Are the data special category personal data (i.e. personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation)?

Yes* No

- e. Will you be conducting analysis within the remit it was originally collected for?

Yes No*

- f. **If no**, was consent gained from participants for subsequent/future analysis?

Yes No*

- g. **If no**, was data collected prior to ethics approval process?

Yes No*

* Give further details in **Section 8 Ethical Issues**

*If secondary analysis is only method used **and** no answers with asterisks are ticked, go to **Section 9 Attachments**.*

Section 7 – Data Storage and Security

Please ensure that you include all hard and electronic data when completing this section.

- a. Data subjects - Who will the data be collected from?

Parents/carers and 16-25 year old autistic young people

- b. What data will be collected? Please provide details of the type of personal data to be collected

- Name on the consent form for parents/young people
- County residing in (to describe any geographic similarities that may occur)
- Age (of girls)
- Gender
- Ethnicity
- Diagnosis information: when they received it, how they received it e.g. from which professional, what the diagnosis is labelled as, and any comorbidities or other diagnosis
- Depending on diagnosis, a measure of autistic symptomatology (SRS, Social Responsiveness Scale) may be used to characterise the sample
- Ethnicity (to determine the diversity of the sample)

Is the data anonymised? Yes No*

Do you plan to anonymise the data? Yes* No

Do you plan to use individual level data? Yes* No

Do you plan to pseudonymise the data? Yes* No

* Give further details in **Section 8 Ethical Issues**

- c. **Disclosure** – Who will the results of your project be disclosed to?
Only myself and my supervisors will have access to the raw data. The data will be obtained under full and informed consent. If sending between email with my supervisor, EGRESS will be used (records will be encoded when entered onto a computer).
At the end of the project, the results will be written in a thesis, and potentially shared in academic contexts (e.g., journal articles, conferences). The participants will also receive a copy of the results, and results will be shared with EPs.

Disclosure – Will personal data be disclosed as part of your project?

No

- d. **Data storage** – Please provide details on how and where the data will be stored i.e. UCL network, encrypted USB stick**, encrypted laptop** etc. Data will initially be stored on my encrypted laptop. At the end of the project, once the participants have been debriefed, I will delete identifiable personal data. The research data will be sent to my supervisor who will store it for a minimum of ten years, as per UCL policy.

*** Advanced Encryption Standard 256 bit encryption which has been made a security standard within the NHS*

- e. **Data Safe Haven (Identifiable Data Handling Solution)** – Will the personal identifiable data collected and processed as part of this research be stored in the UCL Data Safe Haven (mainly used by SLMS divisions, institutes and departments)?
Yes No

- f. How long will the data and records be kept for and in what format?
Data will initially be stored on my encrypted laptop. At the end of the project, once the participants have been debriefed, I will delete identifiable personal data. The research data will be sent to my supervisor who will store it for a minimum of ten years on UCL systems (e.g., Research Data Storage Service), as per UCL policy.

Will personal data be processed or be sent outside the European Economic Area? (If yes, please confirm that there are adequate levels of protections in compliance with GDPR and state what these arrangements are)

N/A

Will data be archived for use by other researchers? (If yes, please provide details.)

N/A

- g. If personal data is used as part of your project, describe what measures you have in place to ensure that the data is only used for the research purpose e.g. pseudonymisation and short retention period of data’.

Personal data (such as name, email address) will only be kept until participants are debriefed. Pseudonymisation will be used throughout all transcripts. Potentially, the girls could be asked to give a name they'd like to identify with.

** Give further details in Section 8 Ethical Issues*

Section 8 – Ethical Issues

Please state clearly the ethical issues which may arise in the course of this research and how will they be addressed.

All issues that may apply should be addressed. Some examples are given below, further information can be found in the guidelines. *Minimum 150 words required.*

- **Methods/Data collection:** The data collection will occur virtually, via a video or telephone call, whichever participants prefer. This method will be based on my Year 1 Project methodology in which parents met me virtually to discuss home-schooling their autistic child. Participants will receive a 1-page profile about me in advance to familiarise themselves beforehand and ensure a level of comfort.
- **Sampling:** The sample will be approached/recruited via an advertisement. If girls/parents/carers are interested, they review Qualtrics (which will have the information sheet/consent forms) before any data collection will occur.
- **Recruitment:** The head of the 'autistic girls network' has agreed to collaborate with myself and my supervisor for this project and is advising on the study. She will also support recruitment through the network. Additionally, the study will be circulated among charities (e.g., Ambitious about Autism Youth Network, Autistica) and throughout my LA in which I am on placement.
- **Gatekeepers:** As above, Cathy Wassell, Head of the autistic girls network will be collaborating and supporting the project. When other organisations are approached to share information about the research, gatekeepers will be asked for permission too.
- **Informed consent:** All participants will be provided with an information sheet, and my supervisors' contact details if further information is required, and will only participate if informed consent is provided. Permissions will be gained from the participants (parents/carers, young people) in advance via a form and they will be reminded they are free to withdraw from the study at anytime during the interview. Furthermore, consent cards will be included in the pack sent to the girls in advance, which will include a traffic light system of cards to show they are ready/ok to proceed / wish to move onto another question / wish to stop the interview (see pack attached).
- **Potentially vulnerable participants:** The group of young people could be potentially vulnerable. I am a qualified primary school teacher, I have DBS approval and have worked extensively with children and young people for the past 12 years. I will be checking all tools in collaboration with Cathy (head of autistic girls network) and using this as a pilot to ensure the materials are suitable. I will be ensuring all tools are designed in line with best practice for the participation of autistic people in research.
- **Safeguarding/child protection:** If a safeguarding or child protection concern is raised during the interview process or arises, my EP supervisor will be informed immediately.

- **Sensitive topics:** Due to the potential sensitivity that some questions may trigger e.g. sharing experiences of transitions between schools and pathways to diagnosis, participants will be reminded of the confidentiality of their data and their ability to withdraw from the study during the interview (a set of traffic light cards will be provided for the girls to utilise during interviews if they do not feel comfortable to answer or wish to continue – see pack attached). The participants will not have to answer any questions that they do not feel comfortable answering, and this will be made clear in the consent form and again at the start of the interview. The information sheet provided in advance will give an outline of the types of questions to be asked during the interview.
- **Confidentiality/Anonymity:** All interviews will remain completely confidential and all names pseudonymised. Confidentiality will only be breached if there is a safeguarding concern as below. All collected data will be anonymised as much as possible using the phrases ‘parent/carer 1, 2, 3 or girl 1,2,3 etc.’ in reporting and considerable efforts will be made to ensure that no-one will be identifiable in the final report or any subsequent publications. This information will be included in the consent form and participants will be reminded of this at the beginning of their interview. They will further be informed that data will be kept within the university for 10 years in compliance with UCL data protocol.
- **Disclosures/limits to confidentiality:** Participants will be informed that confidentiality will only be breached if there is a safeguarding concern or child protection risk.
- **Data storage and security both during and after the research** (including transfer, sharing, encryption, protection): Data will be gathered by using a Dictaphone recording device whilst conducting the interview via Telephone or via video. Alternatively, If the girls chose to pre-record the interview with their parent/carer, the file will be shared via EGRESS.
- I will transcribe the data anonymously for subsequent analysis and then the original recordings will be deleted.. Transcribed files will be stored on an encrypted laptop until the project is complete. At the end of the project, all of the data is handed over/sent through encryption to my supervisor and it is stored for 10 years as per UCL GDPR policy.
- **Dissemination and use of findings:** The results of the study will contribute to my Doctorate in Educational Psychology. In the report and in subsequent reports (for example, academic publications) extensive efforts will be made to ensure that participants are not identifiable and that no personal data are shared.

Please confirm that the processing of the data is not likely to cause substantial damage or distress to an individual

Yes

Section 9 – Attachments.

Please attach your information sheets and consent forms to your ethics application before requesting a Data Protection number from the UCL Data Protection office. Note that they

will be unable to issue you the Data Protection number until all such documentation is received

- a. Information sheets, consent forms and other materials to be used to inform potential participants about the research (List attachments below)

Yes No

- **Information sheets for parents/carers**
- **Information sheets for young people**
- **Interview schedule for parents to be administered by me**
- **Pack for young person including a one-page profile about me, an Interview schedule for myself or parents for the girls interview, a coloured card set for girls to utilise to stop/answer questions to show comfort levels, and the ideal school activity attached for young people to complete**
- **Consent forms for parents/carers**
- **Consent forms for young people**

- b. Approval letter from external Research Ethics Committee Yes

- c. The proposal ('case for support') for the project Yes

- d. Full risk assessment Yes

Section 10 – Declaration

I confirm that to the best of my knowledge the information in this form is correct and that this is a full description of the ethical issues that may arise in the course of this project.

I have discussed the ethical issues relating to my research with my supervisor.

Yes No

I have attended the appropriate ethics training provided by my course.

Yes No

I confirm that to the best of my knowledge:

The above information is correct and that this is a full description of the ethics issues that may arise in the course of this project.

Name [Lucy Colat-Parros](#)

Date [27th February 2022](#)

Please submit your completed ethics forms to your supervisor for review.

Notes and references

Professional code of ethics

You should read and understand relevant ethics guidelines, for example:

[British Psychological Society](#) (2018) *Code of Ethics and Conduct*

Or

[British Educational Research Association](#) (2018) *Ethical Guidelines*

Or

[British Sociological Association](#) (2017) *Statement of Ethical Practice*

Please see the respective websites for these or later versions; direct links to the latest versions are available on the [Institute of Education Research Ethics website](#).

Disclosure and Barring Service checks

If you are planning to carry out research in regulated Education environments such as Schools, or if your research will bring you into contact with children and young people (under the age of 18), you will need to have a Disclosure and Barring Service (DBS) CHECK, before you start. The DBS was previously known as the Criminal Records Bureau (CRB). If you do not already hold a current DBS check, and have not registered with the DBS update service, you will need to obtain one through at IOE.

Ensure that you apply for the DBS check in plenty of time as will take around 4 weeks, though can take longer depending on the circumstances.

Further references

Robson, Colin (2011). *Real world research: a resource for social scientists and practitioner researchers* (3rd edition). Oxford: Blackwell.

This text has a helpful section on ethical considerations.

Alderson, P. and Morrow, V. (2011) *The Ethics of Research with Children and Young People: A Practical Handbook*. London: Sage.

This text has useful suggestions if you are conducting research with children and young people.

Wiles, R. (2013) *What are Qualitative Research Ethics?* Bloomsbury.

A useful and short text covering areas including informed consent, approaches to research ethics including examples of ethical dilemmas.

Departmental Use

If a project raises particularly challenging ethics issues, or a more detailed review would be appropriate, the supervisor must refer the application to the Research Development Administrator via email so that it can be submitted to the IOE Research Ethics Committee for consideration. A departmental research ethics coordinator or representative can advise you, either to support your review process, or help decide whether an application should be referred to the REC. If unsure please refer to the guidelines explaining when to refer the ethics application to the IOE Research Ethics Committee, posted on the committee's website.

Student name:

Student department:

Course:

Project Title:

Reviewer 1

Supervisor/first reviewer name: Laura Crane

Do you foresee any ethical difficulties with this research?

Lucy has very carefully considered potential ethical issues associated with the research.

Supervisor/first reviewer signature: *Laura Crane*

Date: 27 May 2022

Reviewer 2

Second reviewer name: Melernie Meheux

Do you foresee any ethical difficulties with this research?

No

Second reviewer signature:

Date: 30.05.22

Decision on behalf of reviewers

Approved

Approved subject to the following additional measures

Not approved for the reasons given below

Referred to the REC for review

Points to be noted by other reviewers and in report to REC:

Comments from reviewers for the applicant:

Once it is approved by both reviewers, students should submit their ethics application form to the Centre for Doctoral Education team: IOE.CDE@ucl.ac.uk.