

***Doctorate in Professional
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Psychology (DedPsy)***

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**An exploration into the development of
camouflaging behaviours adopted by girls on the
autism spectrum in mainstream secondary
schools: Perspectives of girls and their parents.**

Carolyne Bassett

Institute of Education, University of London

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This research is dedicated to every single girl on the autism spectrum, with a diagnosis or not.



Student Declaration

I hereby declare that the work presented in this thesis is my own, except where explicit attribution is made.

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Abstract

The purpose of this study was to explore how autistic females experience mainstream secondary school particularly relating to masking and camouflaging behaviours. It aimed to explore how they experience their education, their friendships and the differences that may exist in their behaviours at home compared to school as well as the support they specifically receive as an autistic female. This study aims to explore what is contributing to the development of the camouflaging behaviours that are seen more in girls on the autism spectrum during their adolescence when attending mainstream schools. It is widely understood that these behaviours can lead to poorer outcomes such as poorer mental health, exhaustion and burnout and even an increase in suicidality. It is essential therefore that we understand the reasons behind the masking behaviours and how their self-identity is developing as a female on the autism spectrum to tailor the support or create environments that will better support adolescent females on the autism spectrum to feel more at ease and reduce the need to 'camouflage'.

The study used three focus groups, two for autistic girls and one for their parents to explore what their experiences of mainstream secondary school were and whether this has led to masking and camouflaging behaviours developing. There is research that camouflaging behaviours begin to develop in adolescence and this study really wanted to try to explore the reasons behind this. The focus groups were conducted online and moderated to facilitate interaction and discussion between the participants. Data was analysed using thematic analysis and the

following six themes were identified: **1)** Searching for self, the conflicts with their self-identity. **2)** The dismissal and devaluation of Parental concerns. **3)** Meeting social norms in different environments.

4) Impact masking has psychologically and physically. **5)** Taking off the mask - what helps?

And the superordinate theme **6)** Internalising negative perceptions of others.

These themes revealed the challenges the girls experienced in their daily life and the challenges their parents faced in receiving recognition of their daughters needs and eventual diagnosis and consequently this population not receiving appropriate and timely support. Adopting a social theory lens hypothesised that adopting masking behaviours were largely the result of internalising 'stigmatisation', as they did not 'fit' the current conceptualisation of autism nor did they 'fit' into the non-autistic culture and this led to the girls developing strategies to try to conceal and hide their autism and fit within the mainstream school context. The challenges of long-term masking for the girls had significant impacts on the girls' relationships, learning, family life and particularly consequences for their mental health in addition to not receiving adequate support.

Impact statement

In recent years, there has been research looking at autistic women and their experiences of camouflaging and masking. This has highlighted the significant negative costs, including exhaustion, anxiety and depression. The small body of research examining the camouflaging experiences of autistic adolescents reported similar consequences to that in the adult literature. Although some of these do report the autistic girls' experiences from their perspectives their voice is still very under-represented in the research. This study aimed to hear their and parental perspectives to gain a deeper understanding into how they experience mainstream secondary school and what is underpinning the development and maintenance of these masking behaviours. This study has contributed to developing a deeper understanding of masking behaviours and the fact that these have become largely ingrained as the girls face societal pressures and gendered societal pressures to behave in a neuro-typical way. This leads to significant costs for this population, not least with missed opportunities to receive a diagnosis and access to support but most significantly with their social, emotional and mental health needs going unnoticed and unsupported until they reach crisis point when these needs have become firmly entrenched. This paper highlights the importance of working in partnership with parents to ensure early identification and timely and appropriate support is given with some suggested recommendations drawn from the findings and the research. Other novel findings highlight how masking can lead to questioning their own identity and accepting their autism. This has been shown to have

positive effects and so highlights the need to offer support following a diagnosis, particularly when they may not recognise their profile as aligning with the 'autistic' conceptualisation that exists. Developing a more accepting culture within mainstream schools will help this population reduce the need to 'fit in' and mask their identity and this needs to be tackled on several levels, including through increased awareness and training for education professionals, including EPs, school staff and multi-disciplinary colleagues.

Disseminating these findings further will support this objective. Presentations outlining the research and professional implications have been offered to all the participants' schools, with the intention of presenting a virtual summary of the research and key recommendations in the Autumn term 2022. In the author's locality, the research will be presented to the EP service at a research training day in July 2022. There will also be a written summary and key findings e-mailed to all the participants. This paper will also be more widely disseminated to an academic audience via a peer reviewed publication.

Furthermore, in conducting the research it became apparent that this is a group who do not wish to be singled out and gaining their perspectives proved to be challenging. This needs to be borne in mind in future EP work to consider sensitively how to include and capture the young person's voice in their person-centred planning.

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List of Acronyms and Abbreviations

EP	Education Psychologist
EPS	Educational Psychology Service
DfE	Department for Education
EHCP	Education, Health and Care Plan
UK	United Kingdom
EF	Executive Function
SEN	Special Educational Needs
SEND	Special Educational Needs and Disabilities
CAMHS	Children and Adolescent mental health services
SS	Social services
ADD	Attention Deficit Disorder
Afab Amab	Assigned the female gender at birth Assigned the male gender at birth
FG AG	Focus Group Autistic Girl
OG I	Older Girl Interviewee

Chapter 1.0: Introduction

1.0 Chapter Introduction:

This chapter will introduce the research rationale and purpose, including the background to the research from a personal and professional perspective. The chapter will clarify the language and terminology and define the principal concepts of autism, masking and girls on the autism spectrum. The research paradigm will be covered as this impacts the direction the study takes. The historical, social and current contexts of autism will be explored and their relationship to the gender disparity that exists in diagnosis and presentation. It will conclude with a summary of the key discussion points including how camouflaging and masking impact on diagnosis for girls leading to them being underrepresented in the majority of research around autism. This creates a vicious circle, leading to a male-dominated conceptualisation of autism, leaving girls on the autism spectrum being misdiagnosed and, in many cases, missing entirely, resulting in an exacerbation and deterioration in their mental health.

1.1 Terminology and language use in this paper:

This research will be referring principally to the autism spectrum as recommended by the University of Birmingham and the Autism Centre for Research and Education following studies with people on the autism spectrum who object to terms like disorder or condition, (Parsons et al., 2018). Identity-first language will be used interchangeably as recommended by the autistic community themselves and some of the participants within this study, as they do not see themselves as separate from their autism. In attempting to reduce

the power imbalances between the autistic community and existing research, their voices need to be represented. This contrasts with terminology used in the diagnostic manuals but as the critical realist research paradigm aims to involve the marginalised and create a more equal relationship between the researcher and the participants, it is vital that the voices of people on the autism spectrum are identified and represented. As most of the participants of this study were recently diagnosed, their preference for the terminology used was a girl on the autism spectrum. This may have been partly due to not fully embracing their autistic identity yet and feeling that they wanted to keep this separate from their identity - at least initially, while discovering more about what autism is and how this may manifest for themselves. To represent their views and reduce the power imbalance between myself as the researcher and the participants it was vital to incorporate their preference in the language being used in this research. Bottema-Beutel et al., (2020) compiled guidance to help researchers make language choices reducing stigmatisation of autistic people, and these will be adhered to as it is important that the discourse around autism is examined critically and that existing research which holds power (published and having a legacy) is influential in this regard.

1.2 Research paradigm:

To carry out this research, the educational research paradigm needs to be made explicit from the start as this will shape the direction of the approach and methodology. A research paradigm consists of the ontology, epistemology, methodology and the methods to be used (Scotland, 2012). It is impossible to engage in research without first committing to an ontological and

epistemological position, as this will often lead to differing research approaches towards studying the same phenomenon (Grix, 2004, p.64).

The critical realist paradigm adopted here takes the ontological position that reality has been shaped by historical and cultural factors including social, political, economic, ethnic and gender values (Guba and Lincoln, 1994, p.110). Reality is a socially constructed entity but is in a state of change, constantly being influenced. Language has power and can shape reality (Frowe, 2001, p.185) through the interaction between language and other independent aspects meaning certain views and voices are amplified. The critical realist ontological framework leads to an epistemology of contextualism. Contextualism can be described as a type of constructionism (constructionism-lite) in that it doesn't assume a single reality and sees knowledge as emerging from the context and reflecting the researcher's positions. This argues that knowledge or 'truth' is local, situated and always provisional (Madill et al., 2000; Tebes, 2005), knowledge will be true in certain contexts. This 'truth' is influenced by power relationships, for example, what constitutes knowledge is determined by the social and positional power of the advocates of the knowledge (Cohen et al., 2009 p.27). In comparison with social constructivism which believes we are born into a world where meaning has already been made (Crotty, 1998), the critical realist paradigm believes that people are not only within the world but also reality is alterable by human action. In adopting this critical realist paradigm, the historical context of autism must be considered alongside the representation of girls on the spectrum.

This research aims to promote the relations of equality between the researchers and participants. Reflexivity will be considered carefully, in a functional sense

by examining how the research tools used by the researcher will have influenced the research process and by acknowledging the researcher's personal reflexivity and how this subjectivity has influenced the research (Wilkinson, 1988).

1.3 The purpose, rationale and reasons for direction of the study:

The interest in this research developed through my professional role as an educational psychologist, experience as a teacher for children with special educational needs (SEN) and as a parent to two neurodiverse daughters, one of whom is on the autism spectrum. Being female has also influenced my perspective and my passion for inclusion and equality has developed and been shaped through these experiences. As a mother, being aware of how my own biases may impact is essential but it is also important to acknowledge that this is a motivating factor in this research. Having witnessed the difficulties that my daughter has faced linked to her autism, which was undiagnosed until age 11, the lack of recognition by the professionals to offer appropriate and timely support has led me on this research journey. As a Trainee Educational Psychologist and prior to this a specialist teacher for children with SEN for 10 years, I recognised her difficulties from the age of three but even then, professionals and school staff dismissed these concerns and her need for support. This was largely due to her presenting differently between contexts, at school she suppressed her fears and uncertainty, clinging like a life raft to one friend she had known since nursery. On returning to the house after school she would experience an outpouring of dysregulated emotions daily from the ages of four until 13, leaving her exhausted and unable to participate in any activities

outside of school. In my personal experience, even when a diagnosis was in place, due to the internalisation of her difficulties, secondary school were still unable to fully recognise and meet her needs. Without my constant and persistent efforts, she would have remained unsupported. This led me to the following questions: How and why are girls still being missed and unsupported? Are they suppressing and 'masking' to such an extent that this is negatively impacting on their mental and emotional health? How can mainstream secondary schools support this population better including the provision that is made available? And my experiences also left me curious as to how a well-educated, white, middle class, professional mother with expertise within the field of autism, can be so easily dismissed by school and professionals when raising concerns. What are the implications and experiences of other parents?

The purpose of this study is to explore how autistic girls and young people experience mainstream secondary school, particularly relating to why they develop camouflaging and masking behaviours that may mean they are not identified. It aims to explore how they experience education, friendships and the differences that may exist in behaviours at home compared to school as well as the support received as a female on the autism spectrum. It also aims to discover the parental perspective on the challenges involved in receiving the initial diagnosis and subsequent challenges in ensuring their daughters receive support.

In J. Halsall's doctoral thesis (2020) which looked at camouflaging within specialist units attached to mainstream schools, she found that girls on the autism spectrum masked more when attending the mainstream classes. As

most girls with autism will attend mainstream settings is important to explore what contributes to the development of these masking behaviours in school. It is becoming understood from research that these camouflaging behaviours lead to poorer long-term outcomes like poorer mental health, exhaustion and burnout and even an increase in suicidal ideation (Hallett et al., 2013; Mayes et al., 2011). It is essential we understand the reasons behind the development of masking behaviours as well as the costs of masking and how these impact their developing self-identity as a female on the autism spectrum. This increased understanding will help the Educational Psychology (EP) profession and teachers to tailor support or create environments that better support adolescent females on the autism spectrum to feel more at ease and reduce the need to wear a metaphorical mask.

Although there is variability across studies, girls are less likely to receive a diagnosis of autism than boys. Some studies show a gender ratio of four boys to one girl (Fombonne, 2018) for those with an intellectual disability. For girls without a learning disability (with an IQ over 70 - these are girls more likely to be attending mainstream secondary schools), there is a larger ratio of as much as 6:1 (Fombonne 2009; Kirkovski et al., 2013; Loomes et al., 2017; Volkmar et al., 1993) and in some studies this has been found to be as high as 10:1 (Fombonne, 2018). When they do receive a diagnosis, it is at a later age than boys and they receive less targeted support and interventions in school (Begeer et al., 2013).

These later-diagnosed individuals often suffer concurrent mental health issues like anxiety disorders (Hallett et al., 2013) and depression (Mayes et al., 2011)

which are potentially related to long term stress in adaptation to daily life in society (Lai and Baron-Cohen, 2015). Higher rates of anxiety are found in autistic females in the adolescent and pre-adolescent stage (Leikanger et al., 2011) leading to poorer outcomes including academic performance (Nail et al., 2015).

There is minimal research focusing solely on the experiences of females on the autism spectrum in mainstream secondary school, largely due to this under-recognition and representation of them being autistic. Mainstream schools in line with legislation are expected to promote inclusion for all children with SEN, including girls on the autism spectrum. The implications of unidentified needs in girls are serious, as a consequence of neglect of their specific needs, and also as a result of potentially co-occurring conditions like anxiety, increased lifetime suicidality and school absenteeism. Camouflaging strategies are more evident in autistic females without learning difficulties, (Dworzynski et al., 2012; Kreiser & White, 2014) and this explains the relevance of this research with participants within mainstream settings without identified learning difficulties.

Within special educational needs and disabilities (SEND), certain populations of children and young people are more visible than others. Boys on the autism spectrum are more likely to gain the attention of practitioners and teachers earlier and receive support as they present with more externalising features (Dhuey & Lipscomb, 2010). Internalising behaviours are under-reported by teachers (Youngstrom et al., 2000), with the associated social-emotional challenges of females unrecognised by practitioners and parents/carers.

It is likely that the domination of a SEN male landscape with an emphasis on behaviour has contributed to this under-representation of girls in terms of identifying their need and to the forms of support they experience.

It is essential that the voices of girls are researched as a separate entity to boys to redress the dominant male discourse existing within schools regarding SEND provision. To try to address the systemic challenges facing schools with ever-increasing rates of pupils with SEND and Education, Health and Care plans (EHCP's) and limited resources in terms of finances and staffing meaning girls continue to be under-identified or not provided with appropriate and timely support. They continue to be misdiagnosed with mental health needs or difficulties exclusively when they are intrinsically linked with their autism profile, and this also means their needs continue to be inaccurately identified and they do not receive appropriate interventions. Their higher mental health needs consequently continue to go unnoticed and unsupported without this increased understanding, and as Educational Psychologists it is essential we continue to challenge the status quo and represent the needs of all children and young people with SEN.

1.4 Autism definition and historical and current context:

In adopting the critical realist and contextualism paradigm, it is important to understand the social and historical context of autism and the impact this has on our conceptualisation and how this impacts the relationship between autism and gender. Autism is a lifelong, neuro-developmental condition which some studies suggest affects approximately 1.6% of the population in the United Kingdom (Taylor, 2013). As autism is a spectrum condition, meaning a wide

variation in the type and severity of symptoms experienced, so different epidemiological studies using different measures will report different prevalence rates.

In the 1940s, child psychiatrist Leo Kanner (1944) became aware of children whose condition shared three defining characteristics – inability to relate to people or situations, failure to use language to communicate and a desire for sameness, resulting in limited play, characterised by stereotyped, repetitive activities lacking creativity and social interaction. These children were the first to be identified by Kanner as having early infantile autism.

At the same time in Austria, a similar group of individuals was described by Hans Asperger (1943). Domains such as social and communication were identified as deficient with obsessional interests and behaviour. Their dislike of change and dependence on rituals and routines were also identified but they differed from Kanner's group because there were no significant delays in early linguistic or cognitive development. This early work pioneered our understanding of autism although it did not become a clinically recognised condition until the third edition of the Diagnostic and Statistical Manual of Mental Disorders in 1980 (*DSM-III*; American Psychiatric Association, 1980). International classification of what constitutes autism has seen significant changes since the 1980's to the terminology, different labelling of sub-types and how it is diagnosed. Happe & Frith (2019) identified seven major changes in how autism was conceptualised, operationalised and recognised from its first inclusion in the DSM-III in 1980 to our current understanding:

1. The diagnostic criteria are now broader.

2. Autism is more common – (they admit females are under-recognised).
3. Conceptualisation has changed from childhood disorder to lifelong condition.
4. A shift from being something discreet and distinct, to a more dimensional view.
5. Many different types of autism are now recognised.
6. Current conceptualisations view the complexity and co-morbidities of autism as being the ‘norm’, and not viewed as ‘pure’ autism.
7. Recognising a neurodiverse perspective of autism today compared with previous conceptualisation as a developmental disorder.

The current Diagnostic and Statistical Manual of Mental Disorders (5th ed.; *DSM-5*; American Psychiatric Association, 2013) refers to autism as sharing a dyad of impairments - a “persistent impairment in reciprocal social communication and social interaction, and restricted, repetitive patterns of behaviour, interests or activities.” In the DSM-V, Asperger’s syndrome has been absorbed into the term “Autism Spectrum Disorder” (ASD). ICD 11’s (International Classification of Diseases-11) updated diagnostic criteria for autism is more in line with the DSM-V in that Asperger’s syndrome and other developmental disorders are now absorbed into the category of ‘autism’. It includes the same two categories as highlighted in the DSM-V (dyad), pointing to the importance of examining unusual sensory sensitivities.

Since the early identification of autism came from this predominantly male-based research (Hans Asperger's group had no females, Kanner's had three females and 11 males), criticisms levelled at these definitions have claimed they produced a male bias in the conceptualisation, leading to male bias in the diagnostic criteria (Rivet & Matson, 2011). There have also been criticisms levelled at some of the diagnostic tools such as the Autism diagnostic observation schedule (ADOS) having a male bias (Mandy et al., 2012).

This results in fewer girls identified and diagnosed, particularly at the higher functioning end of the spectrum (Dworzynski et al., 2012) and when they do receive a diagnosis it is later than boys (Begeer, 2013). Later diagnosis will have meant they may have already been subject to years of misunderstandings and the negative costs associated with this, potentially leading to increased masking, negatively impacting their social and emotional mental health.

This has direct consequences on the autistic female population. If their presentation is different to the way it has been defined and widely understood, they may not meet the criteria, or may not be put forward for diagnosis in the first place.

This leads to fewer women being recognised and identified, their needs going unsupported and its impact, as well as their continued under-representation in research and in our own knowledge of girls and females on the autism spectrum.

1.5 Gender differences in autism:

There is a hypothesis that it is the gender-external differences in how autism is presented that mean females are being missed or misdiagnosed. It has been shown that girls typically have a different presentation, often showing fewer rigid or repetitive-type behaviours like stimming (Van Wijngaarden-Cremers et al., 2014). Girls' special interests tend to reflect those of their peers, like bands or animals (Sutherland et al., 2017). Their social differences may be less apparent than boys, choosing one or two friends they are very close to, often with exclusivity issues being overly reliant on them, rather than being disinterested in their peers (Kopp & Gillberg, 1992). This aligns with the experience of the author's daughter in primary school. In the playground autistic girls tend to look less isolated than boys and so may be getting missed (Dean et al., 2017). This piece of research also suggests that they are more likely to be playing on the periphery of the action than being actively involved.

Another hypothesis is that girls modify behaviours, as gender expectations are imposed on them from an early age (Wing et al., 2011). Gender differences particularly in relation to 'camouflaging' may be due to societal pressures to conform to gender roles (Kreiser & White, 2014). Girls are more likely to receive a misdiagnosis than boys, and this is usually in relation to developing subsequent mental health and well-being issues (Rubenstein et al., 2015). Studies have highlighted the high risk of co-morbidity with depression and anxiety in adolescents and adults on the autism spectrum with reported prevalence rates for impairing anxiety varying between 11 – 84% across studies and depressive symptoms varying from 10 – 14% (Simonoff et al., 2008). Girls are more likely to internalise presenting characteristics with an increase in anxiety and sadness/depression (Kim, 2001; White, et al., 2009).

Research has pointed to a substantial increase in adolescent mental health problems in the last 30 years (Collishaw et al., 2004). It has been suggested that individuals on the autistic spectrum may be the most vulnerable group in this regard (Ghaziuddin et al., 1998), with up to 30% reported to experience clinically recognisable disorders (Green et al., 2005). The longer-term consequences of such difficulties include an increased risk of leaving school without qualifications (Colman et al., 2009), unemployment (Healey, Knapp and Farrington, 2004), family and relationship problems (Colman et al., 2009), mental health problems in adulthood (Hofstra et al., 2002), and increased financial costs to society (Scott et al., 2001).

One final hypothesis for this later diagnosis of autistic girls could be because of girls concealing difficulties through learned strategies to 'blend' in with their environment by masking behaviours, and this will be further explored following the definition of what is meant when we talk about camouflaging and masking.

1.6 Definition of camouflaging and masking:

In this paper I will principally be referring to masking but will at times talk about camouflaging behaviours. It is important to define both terms.

Hull's definition of Camouflaging (2018) identifies the use of strategies - whether conscious or not - to mask autistic characteristics and compensate for social difficulties associated with autism and has been extensively demonstrated in autistic adults. Hull et al., (2018) identified three key components of camouflaging: compensation (the use of strategies to overcome specific social difficulties associated with autism), masking (the use

of strategies to hide one's autism) and assimilation (the use of strategies to blend in with others in social situations). Descriptions of camouflaging first appeared in clinical and autobiographical writings; usually to describe and explain the presentation of autistic girls and women, as well as the often-under-recognised diagnostic and support needs of this group. Autistic girls and women (and some boys and men) were described as using social strategies to adapt to the demands of their social environment, thereby camouflaging their social difficulties and differences (Attwood, 2007). Initially, these strategies were thought to predominately involve the effortful performance of non-autistic social behaviour, learnt over time through careful observation and imitation (Attwood, 2007; Gould & Ashton-Smith, 2011; Kopp & Gillberg, 1992; Holliday Willey, 1999). However, this often exhausting and stressful camouflaging was seen as masking rather than resolving underlying social difficulties. These clinical and autobiographical writings stimulated qualitative research aimed at conceptualising camouflaging by exploring the lived experiences of autistic girls and women (e.g., Bargiela, Steward, & Mandy, 2016; Cridland, Jones, Caputi, & Magee, 2014; Tierney, Burns, & Kilbey, 2016), but also boys, men, and non-binary people (e.g., Hull et al., 2017; Livingston, Shah, & Happe, 2019). Across this research, autistic people provided rich and detailed accounts of camouflaging, significantly advancing the field. Importantly, findings suggested that many autistic people of all genders use a diverse range of camouflaging behaviours and strategies in navigating the predominately non-autistic world, often at great personal cost. In this paper I will principally be referring to and using the term 'masking' because this is one of the words most often used by autistic people

themselves in their writing. I believe, as also defined by Hull, Sedgewick and Ellis that all these words refer to the same underlying concept and so I use the terms, masking and camouflaging behaviours somewhat interchangeably with a greater emphasis placed on 'masking' to respect the terminology used by autistic people.

'Masking' in this context refers to autistic masking - when autistic people and children use strategies (whether or not they are aware) to hide or conceal their autistic differences from others. This may include the suppression of their more autistic traits and characteristics or adopting behaviours specifically to appear more neurotypical like learning to appear as if they are giving eye contact or adopting a practised social smile which may appear to cover up anxious feelings, or rehearsing social introductions to feel more able to manage within social contexts. Masking is not unique to people with autism, people can mask for a variety of reasons, not least due to stigmatisation so may mask aspects of themselves that they feel will be judged negatively by society like sexuality, mental or physical health difficulties or just aspects of their personality. Although that perspective will be considered through the social stigma theory lens, this research will concern itself solely with autistic masking and how this impacts autistic girls because of the effort it expends and the consequences for this population.

"Camouflaging behaviours", but predominantly "masking" will be the terminology used to describe behaviours they adopt when they need to blend in, not wanting to be recognised for having any difficulties so they try to mask

their academic difficulties, sensory differences and social difficulties, hiding their emotional responses by suppressing them.

Different types of masking have been defined by Hull et al., (2018): instinctive, subconscious, ingrained and conscious masking. Instinctive was likened to a survival instinct or the freeze element of the 'fight, flight, freeze' response. This is the instinct when there is a threat by a predator to fight, flee or to become still (freeze) and to wait until danger has passed. For autistic people this can be an instinctive move to keep their distress hidden when in a position of high stress or risk. Subconscious masking develops over time in response to what they perceive as traumatic events - this could be being reprimanded by a teacher or having a negative reaction to a behaviour which becomes deeply internalised and embedded into their memory, this can act as a trigger for future events, and they learn to suppress their natural reactions, creating a 'mask'. Ingrained masking is similar to instinctive masking but is a learned response, something which once was a conscious response but has now the default response because of social expectations and societal pressures, which may be greater for girls. Finally conscious masking, which refers to actively masking in a situation where they feel they cannot be themselves, strategizing about what and how to mask until they are removed from that situation and can drop the mask.

It should be noted that some existing research uses different terminology and language like "compensation strategies" and "assimilation", and this will be considered within the literature review.

Although research in masking and camouflaging is relatively recent, Lorna Wing first proposed and described the 'camouflage hypothesis' in 1981. This was the idea that autistic girls may appear to have better social skills because they had learned to copy, imitate, practise and rehearse behaviours from people and psychologists and researchers began to take up the idea that this might explain their difficulties in receiving a diagnosis compared to boys and men. This theory may have been overlooked temporarily when the predominance of Baron-Cohen's (2002) 'extreme male brain theory' came to light. This suggested those of both sexes with autism had more masculine-structured brains. It became popularised through mass media but may have negatively impacted and delayed more research into the representation of autistic females who did not present in this way and impacted the development of our understanding of autistic girls. More recently, research interest in camouflaging and masking has increased as researchers began to listen to the autistic community who had been describing this phenomenon for years (Holliday-Willey *Pretending to be normal* 2014).

1.7 Autistic girls, masking and later diagnosis:

In research and accounts written by adult females on the autism spectrum they talk about their ability to 'mask' their autism to fit in (Dean et al., 2017). Camouflaging has been defined as the concept of adaptation to different environments (Lai & Baron-Cohen, 2015). Adolescent girls may feel greater pressure than boys to fit in socially with peers and this may impact adolescent girls on the autism spectrum who may try to adapt their behaviour to 'fit in' (Kreiser & white, 2014). This pressure may be different according to the context

and environment and can lead to differences reported in the outward presentation of girls on the autism spectrum across different settings (Halsall, 2020). This results in differences in perceived social and communication difficulties across contexts, leading to missed or a misdiagnosis of their needs and parents have often spoken about battles with schools to be taken seriously.

Masking has some positives for the students, as the ability to blend into their environment successfully means they do not create negative awareness of their difficulties with peers or staff. It may also mean that their difficulties are not correctly identified, and appropriate support is missed. Autobiographical descriptions and clinician observations suggest this masking comes at a cost: it often requires substantial cognitive effort, can be exhausting and lead to increased stress responses, meltdown due to social overload, anxiety and depression, and even a negative impact on the development of one's identity (Attwood, 2007; Boyd et al., 2011; Lai et al., 2011; Simone, 2010; Willey, 1999; Williams, 1992). This greater internalisation of their behaviours may lead to the higher levels of anxiety and depression that exist in this population.

Due to the current conceptualisation of autism being male-centric, girls' gendered social expectations, and concealing their difficulties, girls with autism are underrepresented. Autistic girls tend to internalise difficulties, leading to greater mental health issues in adolescence and beyond which also leads to other consequences like poorer academic performance, poorer long-term outcomes including employment and relationships. This under-identification may lead to a deterioration of the family/school relationship ensuring that the girls and by extension their families are further isolated and unsupported. As

Educational Psychologists it is crucial that we help to give a voice to all children with SEND. It is written into the legislation (SEND Code of Practice, 2015) and this piece of research will attempt to redress this imbalance and improve our understanding and the support offered.

Chapter 2.0: Literature Review

2.1. Chapter Introduction:

A review of the literature aims to find out what is already known about the topic, how this has been found out and what more there is to know (Gough et al., 2012), leading to the development of the research questions.

The critical realist paradigm takes the position that reality has been shaped by historical, social and cultural factors. It is important to outline the political and social context first and the existing legislation around inclusion for children on the autism spectrum before reviewing the literature exploring camouflaging strategies and anxiety for girls with autism.

This chapter will review the extant literature with autistic girls exploring camouflaging and masking behaviours. Research focusing on female adult populations will also be reviewed due to the paucity of literature in this field. Research as previously discussed, has led to a male-bias in current conceptualisation and understanding because of the predominance of autistic males in studies. The aims of the literature review will be to provide greater understanding of motivations for masking and the strategies involved. Additional research aims will be to consider the costs of camouflaging and

whether this leads this population to experience higher anxiety and mental health issues.

Finally, to develop our understanding of the need for this population to camouflage their behaviours, the different theoretical models that may underpin this development of camouflaging and masking behaviours will be examined and the research will be further explored in light of this.

2.2. Current context in which this research is situated:

What is inclusion and inclusive education?

Inclusive education sees the teaching of children with special educational needs and disabilities (SEND) as existing within an interacting and multi levelled system where children are situated in mainstream classrooms within mainstream school in their local education authority, informed by whole school, local authority regional and central government policies which all interact with one another.

The UK Government's recent Green paper (SEND review, DfE, March 2022) sets out plans for an inclusive system starting with improved mainstream provision offering early and accurate identification of all children and young peoples' needs, high quality teaching and prompt access to targeted support. Autistic girls without additional learning disabilities are mostly being educated within mainstream schools but are missing out on this early and accurate identification of their needs, thus not accessing the targeted support. This creates a vicious cycle of late intervention leading to low confidence from parents and carers that mainstream institutions can meet their needs effectively due to inefficient allocation of support.

Historical and current context of Inclusion:

In the late 18th century, children with SEND were educated separately, with specialist schools set up for those in the middle and upper classes. It wasn't until the 1960s that moves for change gathered, with the notion that people with disabilities should have equal opportunities. By the 1990s, the evolution towards a more inclusive educational practice began (Hodkinson, 2007; 2009). The Disability Discrimination Act (1995) made discrimination against disabled people illegal, and in 2010 this was merged into and then superceded by the equality act (2010). The late 20th and early 21st century saw inclusion become central to mainstream schools, with a Code of Practice first established (DfES, 2001).

In 2014 the Children's and Family Act established a new SEND support system - the revised and updated SEND Code of Practice (2015) - providing statutory guidance for children and young people from birth to the age of 25 with SEND. Two broad levels of support were established, SEND support and Education and Health Care Plans (EHCPs). SEND support is given to children and young people in pre-schools, schools and colleges from the school's notional SEND budget and may include additional help from a teacher. EHCPs are legal documents for people up to the age of 25 needing greater support, outlining the person's needs, support required and the outcomes to achieve. The Code of Practice states where a child has SEND but no EHCP they must be educated in a mainstream setting, except in specific circumstances. All local, authority-maintained mainstream schools and academies in England are expected to admit children and young people with SEND including those on the autism spectrum. Autism is currently the most prevalent primary need for boys (32%)

and girls (17%) with an EHCP (DfE, 2018). Most autistic girls and young people with no identified learning difficulties are being educated within mainstream settings, ensuring that this piece of research is contextually situated for this population.

Teaching standards were introduced by the Department for Education (DfE, 2011) and stated teachers are expected to have a clear understanding of the needs of all pupils including those with SEND. The development of these standards continues, with current teacher training including training around teaching students on the autistic spectrum. The Green Paper reviewing national SEND provision and its quality (March 2022) included data that found 41% of teachers in 2019 reported there was appropriate training in place to support pupils at SEN support level or above, but this was a decrease from 2018 when 59% of teachers agreed.

At the curriculum level, teachers employ an eclectic model of strategies derived from developmental theory and research when educating students with autism (Howlin, 2010; Guldborg, 2010; Greenwood & Abbott, 2001).

Education guidelines and principles have been developed to encourage a more consistent practice within education and social care across UK (Jones, 2019). The DfE identified principles of 'good autism practice', including the need for policy and planning at all levels, developing practitioner understanding of autism and working in partnership with families.

It should be noted that current strategies and policies concerning young people on the autism spectrum do not reference gender at all and there may need to be a review of the evidence taking this into account.

2.3 Literature search methodology:

To carry out the literature review exploring autistic girls and masking, PsychINFO, ERIC and Google scholar databases were selected, as these are well-known and respected in the field of education. Initially several scoping searches were completed to refine search terms and the results from these were scanned for relevance. Articles returned by these searches were used to identify any additional key words to include in the final search. The first searches were carried out between October 2020 and January 2021. During 2021 and 2022 the author kept abreast of current research which may also be referred to within this thesis but also identified a study for the later inclusion into the literature review.

The initial list of search terms is outlined in appendix A.

The database search initially returned 321 results. A filter was applied to limit the search of the documents published in English, in peer reviewed journals and since 2001 when the SEND code of practice was published reflecting new government strategy promoting inclusion to examine this within the current context of inclusion within mainstream provisions. These findings will then be synthesized and utilized to help develop interview schedules for the girls on the autism spectrum and their parents.

Framework for assessing quality and relevance of the included studies:

All the studies included in this literature review were published in peer-reviewed journals since 2001 and had representation of females on the autistic spectrum. For the purposes of this review, the studies were evaluated for their quality and

rigour using Yardley's framework (2000) which outlined four characteristics of good qualitative research.

1. Sensitivity to context.
2. Commitment and rigour.
3. Transparency and coherence.
4. Impact and Importance.

The way in which each piece of research fulfills these criteria will vary and is dependent on the approach used (Secker, Wimbush, Watson & Millburn, 1995) but the framework can provide considerations and ways in which the qualitative research has attempted to address them.

2.4 Children and Adolescents on the Autism Spectrum and masking:

The literature review focused specifically on adolescents and children on the autism spectrum and camouflaging and masking identified seven studies for inclusion. These are included in the table in the Appendix B with a summary of the findings.

Dean et al., study (2016) conducted a mixed methods concurrent study with 96 primary school children. Their study comprised of 24 girls and 24 boys on the autism spectrum and a matched sample of 48 children who were not on the autism spectrum. They used the playground observation schedule of peer engagement, finding the girls adopted compensatory behaviours (remaining close to peers in proximity) compared to boys and they may join in with activities more, but in a peripheral fashion, e.g., swinging a jump rope for the entirety of the play time rather than being allowed a turn to jump rope. Girls are not as easily identifiable as boys in the playground as having social, communication difficulties. Limitations included the size and scope of their study.

Cook et al. (2018)'s research used semi-structured interviews with 11 girls on the autism spectrum and a parent of each. Findings included that parents observed their daughters could effectively hide their characteristics of autism. This 'masking' provided solutions to some social difficulties, but negatives in terms of late diagnosis or missed or misdiagnosis or the development of more severe difficulties as a result such as lower academic performances, or increased anxiety and mental health difficulties. They also found girls preferred to hide differences and were reluctant to be labelled. The tendency to camouflage led to greater internalisation of problems leading to greater stress and anxiety (Bussey et al., 1999; Keenan and Shaw 1997; Kreiser & White 2014). This study also suggested that autistic girls in mainstream settings reported a higher level of school absenteeism and an increased tendency to mask their autism to fit in.

Tierney, Burns & Kilbey's (2016) research with 10 adolescent females on the autism spectrum using semi-structured interviews found that participants were motivated to have friendships and obstacles to this caused them discomfort and distress. Participants used masquerading strategies (peer-imitation and masking) to overcome obstacles to developing and maintaining friendships so there are benefits but costs were in terms of emotional energy and barriers to accessing support. These findings imply that, females on the spectrum may have an innate social drive which motivates them to devise strategies to overcome social and communication difficulties which at different times were both helpful and unhelpful. It concluded that a more gender-sensitive approach is needed to provide adequate assessment and support for girls on the spectrum.

Parish-Morris et al.'s (2017) research with 65 verbal school aged participants on the autism spectrum included 49 boys and 16 girls, and a comparison group of non-autistic children. They examined speech samples from the Autism Diagnostic Observation Schedule (ADOS) (Pauses were marked with 'UM' or 'UR'- research suggests they are pragmatically distinct e.g., 'UM' is used to signal longer pauses and may correlate to greater social communication sophistication compared with 'UR'). Girls on the spectrum and non-autistic girls and boys displayed a higher 'UM' ration compared to boys on the spectrum. Findings suggest 'UH' suppression and a higher 'UM' ratio may be used as 'linguistic camouflage' to normalise the way a girl sounds when compared to same-aged non-autistic peers, allowing them to "blend in" with their peers and boys on the spectrum sounded more atypical with a greater 'UH' ratio.

Rynkiewicz et al., (2016) research was conducted with 33 high functioning diagnosed Polish girls. The Polish version of the Autism Spectrum Quotient child (AQ child) was administered. They found the girls exhibited a tendency to use gestures in a more vivid way than the boys. High functioning girls on the autism spectrum may present better on non-verbal (gestures) mode of communication than boys. This may camouflage other diagnostic features of autism.

Livingston et al., (2019) research with 136 autistic adolescents, 112 males 10-15 years old and 24 females 10-15 years old, found that higher compensators had higher verbal IQ, better executive functioning but greater anxiety.

Halsall's doctoral thesis (2020) looked at camouflaging strategies of adolescent females attending specialist resource provisions attached to mainstream

schools. This found girls use a range of camouflaging strategies to hide aspects of their autism and their learning needs to avoid being identified as struggling academically. It also identified the variation in camouflaging behaviours in different contexts. Girls on the autism spectrum were guided by their parents and educators to adjust aspects of their behaviours when accessing mainstream school. Environmental pressures to camouflage are grounded in the social expectation that autistic people need to adjust their behaviours to be socially accepted (Hull et al., 2017).

Alongside this external pressure, intrinsic motivators to camouflage include supporting connections with peers and developing relationships. The camouflaging attempts were not sophisticated enough to facilitate successful connections with neurotypical female peers, resulting in repeated experiences of rejection and isolation. The most successful friendships were between autistic girls and mainstream pupils identified as having special educational needs, enabling the girls to feel accepted and reduce camouflaging strategies (Cook et al., 2017; Tierney et al., 2016).

A negative cost of camouflaging that Halsall (2020) found was exhaustion and this was the case even when the camouflaging strategy was successful. A further negative cost was high anxiety experienced by the girls on the autism spectrum within the mainstream school and missing out on appropriate and targeted support. Parents highlighted that girls' transition from school to home was characterised by the girls being exhausted, emotional and upset. Longer term consequences identified was the impact on autistic women's identity development, e.g., not fitting in to the stereotypical expectation of autism (based on the typical presentation of boys on the autism spectrum) contributing to a

decline in their mental health. Another long-term consequence was the negative impact on learning, where girls either avoided the learning situation or focused on camouflaging their academic challenges resulting in their underachievement. Mainstream teachers appeared unaware of their struggles as they internalised behaviours and superficially presented with 'on task' behaviours (Bargiela et al., 2016). Halsall's study also identified a delay in appropriate support for girls because of delayed diagnosis (due to professionals not recognising their needs) or mislabelled needs.

Finally, research by Jorgensen et al., (2020) looked at levels of social camouflaging in autistic and neurotypical adolescents to study the differences by sex and diagnosis using the camouflaging autistic traits questionnaire (CAT Q) a self-report measure of camouflaging behaviours in adults (Hull & Mandy 2020). Consistent with previous findings, females reported higher levels of camouflaging than males. This was only true when comparing scores on the CAT-Q without accounting for age, when accounting for age there was no longer significant differences by sex. When comparing participants scores on the three CAT-Q subscales: compensation, masking and assimilation there were variations. There were no significant differences in compensation and masking. Compensation relates to measures such as actively compensating for difficulties in social situations and includes 'learning social cues from television, film or books' or watching others and trying to copy their behaviours. Masking relates to "strategies used to hide autistic characteristics or portray a non-autistic persona" (Hull et al. 2019, p. 825), the items included in this scale are not specific to autism traits. A possible explanation for the higher scores reported on the masking subscale by neurotypical participants is that the items

on the masking scale reflect behaviours that are closely related to social awareness. Adolescence is a time when the social demands increase, and girls become more aware and concerned with how others view them. In the subscale of assimilation, consistent with previous research autistic participants reported higher levels of assimilation than non-autistic participants. Assimilation includes strategies that reflect trying to fit in with others in social situations.

2.5 Adults and Camouflaging:

The main findings from the previous research conducted with adults are summarized in the table in the Appendix B.

Bargiela et al., (2016) undertook research with 14 women aged between 18 and 35 on the autism spectrum. They used semi-structured interviews and framework analysis of the data which was chosen for its transparency and rigour (Ritchie & Spencer, 1994), followed good practice guidelines for qualitative research (Mays & Pope, 2000) and conducted credibility checks as well as adopting a consensus approach (Barker & Pistrang, 2005) to identify themes which highlighted some significant gender issues. Being female led professionals to miss their autism and a diagnosis conflicted with their feminine identity. They identified as 'being a girl in a boy's world', meaning that they felt their autistic identity conflicted with the view that autism predominantly affected males and how this fit with their identity as a female. All the women in the study said they found socializing in large groups challenging. Some said they would "wear a mask" or adopt a certain persona, to appear 'normal' to others. Negative consequences from 'masking' were identified like feeling exhausted,

confusion over their identity and some women acted so 'neurotypical' that people would question their diagnosis.

Hull et al., (2017) research looked at 92 adults on the autism spectrum, 55 of whom were females and used semi-structured interviews to explore the concept of 'camouflaging'. To ensure transparency, rigour and commitment (Yardley, 2000) good practice guidelines for qualitative research were followed (Barker & Pistrang, 2005) as well as the six phases of thematic analysis (Braun & Clarke, 2006) and to ensure the credibility of their interpretations they adopted a consensus approach with all authors involved in refining the themes and a further the use of member validation to increase credibility (where the themes were checked and validated by members of the research study).

Motivations for camouflaging included fitting in with others and increasing social connections. Short and long-term consequences of camouflaging were reported as exhaustion, challenging stereotypes and threats to their self-perception. Camouflaging was identified as rewarding for individuals because it enabled them to achieve what they wanted (e.g., getting through a necessary social situation or connecting socially) but came with costs.

Cage & Whitman's (2018) research used an online cross-sectional survey using the CAT-Q (a questionnaire designed specifically to look at camouflaging behaviours) to identify high and low camouflagers and 'switchers' – who were sometimes high and sometimes low in different contexts. There were 262 autistic adults who took part. Their research found consistently low camouflagers had lower stress and anxiety than both switchers and high camouflagers. Higher camouflagers showed the highest levels of anxiety.

There was a significant impact on mental health for the camouflaging group in general. Two reasons for camouflaging were identified; conventional reasons such as getting by in the workplace or within the education system and relational reasons to get by in their relationships. There was no difference found between the groups in terms of depression. There was a gender difference in that they found autistic females camouflaged more than males. Qualitative reasons included to 'pass' or 'fit' in the neurotypical world and avoid bullying and stigma. This research attempted to gain the participants voice firstly on the relevance of the topic to the autistic community and the survey used was reviewed and adapted in consultation with two autistic people this ensured sensitivity to the context. By using a survey this allowed a large number of people on the autism spectrum to take part, surveys can be criticized when it comes to digging for deeper meaning and the qualitative answers they received may not necessarily allowed for a deeper exploration of why camouflaging happens in certain contexts. The research used a consensus agreement on the qualitative responses to ensure there was an attempt to minimise researcher bias.

Hull & Mandy's (2020) research used an online survey of 778 participants in total using autistic and non-autistic sample, of these 182 were autistic females and 108 were autistic males.

The authors reported that autistic females had higher camouflaging scores than autistic males and there was greater use of specific masking and assimilation strategies by females. No gender differences existed in the compensation subscale. Gender differences in camouflaging exist for individuals with autism only and not in the non-autistic population.

Schuck et al., (2019) research with 17 autistic males and 11 autistic females compared to 34 non-autistic adults found camouflaging to be more common in autistic females. Camouflaging correlated negatively with emotional expressivity in females on the autism spectrum. This led the authors to question whether the toll of masking leads to this dampening of the female's positive affect as they were shown to exhibit fewer positive emotions. There were some limitations including using modest and convenience sampling which makes generalisations difficult, and these findings would need to be replicated on a larger scale.

Lai et al., (2017) used MRI (magnetic resonance imaging) technique to assess neural activation within the right temporo-parietal junction and ventromedial prefrontal cortex during mentalization and self-representation tasks. They operationalised camouflaging in their research as the discrepancy between extrinsic behaviours in social-interpersonal contexts and intrinsic status. Their research was conducted with 29 males and 28 females on the autism spectrum and matched sample groups without autism finding that females on the autism spectrum had higher camouflaging scores compared to males on the autism spectrum. There was an association between greater camouflaging and depressive symptoms in men and an association between greater camouflaging in women and an increase in their Signal Detection Sensitivity (SDT). Signal Detection sensitivity measures the sensitivity of our sensory systems, and this threshold is the least intense amount of stimulation needed for a person to be able to see, hear, feel or detect the stimulus.

A significant negative correlation was found between greater camouflaging in women and a smaller regional volume of grey matter in their brain scans. There

are some criticisms to this study, the age range was broad from 18 years to 45 years and the sample size was considered too modest to make generalisations.

Cassidy et al., (2019) research with 160 undergraduates of whom 86.9% were female found that the camouflaging of autistic traits is associated with an increased risk of experiencing thwarted belongingness and lifetime suicidality. This research highlights the need for this fundamental piece of research and disputes the argument that girls on the autism spectrum do not need a diagnosis (Frith, 2020) or 'qualify' for extra support. Their presentation might be different with a greater internalisation of behaviours, but this can have greater consequences.

Finally, a later inclusion into the literature review by Beck et al., (2020) completed a study with 58 women with autistic traits not all formally diagnosed with autism and they completed questionnaires about camouflaging and mental health. Analysis showed women who reported above average levels of camouflaging was associated with having suicidal thoughts, reduced daily functioning and mental health challenges and this was regardless of whether their traits were mild or severe. Self-reported camouflaging efforts (using the CAT Q) total scores significantly predicted psychological distress while measures of autistic traits did not. Thus, suggesting that it is the camouflaging effort linked to mental health issues rather than the severity of autistic traits although the relationship maybe an increased prevalence of mental health concerns is common with women with autistic traits or is it autistic traits are common among women with mental health concerns?

2.6 Critical additional research that will also be considered with this population, females on the autism spectrum and the development of camouflaging behaviours:

When considering the consequences of camouflaging, one key theme throughout the literature was the increased anxiety and internalisation of symptoms that females experience and so a brief overview of some of the anxiety literature was also reviewed. 40% of children on the autism spectrum meet the criteria for a clinical diagnosis of anxiety disorder compared to 10% in the general population (Hallett et al., 2013). Childhood anxiety is associated with poor outcomes in a range of areas including academic performance (Nail et al., 2015); social skills (Langley et al., 2014); increased risk factor for long term anxiety and depression (Mayes et al., 2011); self-injurious behaviours (Kems et al., 2015); disruptive behaviours and difficulties in relationships (Kim, et al., 2000) and increased rate of negative thoughts (Farrugia & Hudson, 2006).

Higher rates of anxiety have been found in children on the autism spectrum without intellectual disabilities. Increased rates of anxiety have also been found in older autistic children, at least above 10 years of age (van Steensel et al., 2011; van Steensel & Heeman, 2017; White et al., 2009). The pre-adolescent developmental stage may be of particular interest, as an increased female prevalence of anxiety is reported in typically developing adolescents and pre-adolescents (Leikanger et al., 2012).

A limitation to all the studies exploring anxiety and gender differences is they used measures designed for the typically developing population. The assessment of co-occurring anxiety in children on the autism spectrum can be

complex as the symptoms of anxiety can be difficult to distinguish from autism characteristics.

In considering the overview of the anxiety literature and the gender differences, it highlighted the need for more research especially within the school environment. The review of the camouflaging literature found a link between the role of anxiety and higher camouflaging scores and so this will be considered within this research and within discussions.

There has also been a piece of research that has greatly informed this piece of work in developing ideas and understanding of autistic masking; Rose & Pearson's (2021) research examined the concept of autistic masking using social identity theory and the literature on stigma and marginalisation to examine how masking might intersect with different aspects of identity such as gender.

2.7. Theoretical models influencing 'Camouflaging':

The cognitive theories: Theory of Mind, Executive dysfunction and Weak Central Coherence will be considered and defined. I will also critique these three theories through the critical realist and the contextualist position to discuss how these approaches, when applied to those on the autism spectrum, become 'modification or treatment programmes' (Milton 2012) and ways to change the person on the autism spectrum to fit in with the mainstream culture of our society. As this research primarily intends to give voice to those on the autism spectrum and cognitive theories of autism have been largely criticised by the autistic community, the social theories: social identity theory and the

theory of the 'double empathy problem' (Milton 2011) will also be considered with regard to the development of camouflaging behaviours.

Cognitive theories:

Theory of Mind (ToM) was first defined by Baron-Cohen (1985) and refers to the ability to infer what others are thinking and use this to anticipate and understand their behaviour (Happé, 2015). It was hypothesised to explain the persistent difficulties in social communication for autistic individuals, using evidence from false-belief tasks. ToM is one of the two major components of empathy, sometimes known as 'cognitive empathy'. The other major component is known as 'affective empathy', or the drive to respond with an appropriate emotion to someone else's mental states. One argument was this research largely discounted the subjective experiences of those on the autism spectrum themselves as lacking in empathy. Recent research carried out by the Autism centre for Education and Research (2020) has found that it is mainly cognitive empathy that is affected in autistic participants without learning disabilities but that the affective empathy is intact.

The Central Coherence theory by Frith (1989) proposed that autism is characterised by a specific imbalance in the integration of information at different levels, for example, in Frith's words 'central coherence' is the ability to draw together diverse information to construct higher level meaning in context. In having a weaker central coherence so the ability to construct meaning of the whole context has led to strengths for people on the autism spectrum by their ability to see the information in a more 'piecemeal' approach. For instance, the

ability to complete jigsaws by shape or the ability to remember unrelated items as opposed to related items.

In contrast to the central coherence hypothesis, Executive function (EF) theory differs with its main claim being that people on the autism spectrum have executive function deficits causing social and non-social abnormalities. The terminology of 'executive functions' covers a multitude of cognitive abilities like cognitive flexibility, working memory, inhibition and action monitoring and these are key in goal-directed problem solving. There is a growing body of research which examines EF in individuals on the autism spectrum reporting reduced performance in many tasks designed to measure EF (Demetriou et al. 2019; Pellicano, 2010).

In relation to camouflaging, executive dysfunction theory would inhibit camouflaging as the deficit model would imply that people on the autism spectrum had weaker cognitive flexibility and capacities to apply a sophisticated strategy such as camouflaging. Research by Livingston et al. (2019) seems to substantiate this as they found that increased IQ and EF skills were associated with reduced autism symptomology. They hypothesised that higher EF skills and IQ mediated successful compensation for social communication difficulties by facilitating the retrieval of learned social rules and information.

The autism community criticises these cognitive theories for focusing on a purely deficit model and thus other theories will need to be considered too.

Double Empathy problem (Milton, 2012):

Social models of autism align with the wider social model of disability, emphasising the disabling effect of the environment, including other people's

negative attitudes. In the context of autism, one influential theory based on a social model, is the double empathy problem (Milton, 2012). This account makes the point that a successful social interaction requires the participation of two people.

This theory re-frames the deficit cognitive models to consider the differences occurring between people of different dispositional outlooks (people on the autism spectrum versus people not on the autism spectrum) and can be redefined as a question of reciprocity and mutuality within an interaction. The 'double empathy problem' refers to a breach that occurs between people of different perspectives when empathic and communicative attempts are made and misunderstood, the issue doesn't solely relate to the person on the autism spectrum as it is experienced by both parties.

Although this model is not primarily a psychological theory, instead describing autism at the behavioural level, it can be tested experimentally. A number of pieces of evidence have recently emerged that support this model (Sasson et al., 2017) showed neurotypical raters short pieces of information from autistic and non-autistic contributors and found they rated autistic people as more awkward and said they were less likely to become friends with them, despite judging both groups as equally trustworthy and intelligent. These judgements show how disadvantaged autistic people may be, as negative first impressions take hold incredibly quickly. More recently, Sasson & Morrison (2017) published follow-up work revealing that disclosing the diagnostic status of the autistic people, and especially increasing the knowledge of autism in the rater, improves first impressions. This indicates that interventions in the neurotypical

community could play a role in improving the social experiences of autistic people – and that disclosing diagnostic status may be an important part of that. Crompton et al., (2020) investigated the effective information transfer between separate groups of eight (chains) people. The chains comprised one group of eight autistic people, one group of eight non autistic people and two mixed groups of alternating autistic and non-autistic people with the intent to successfully transfer information from one participant to the next. It could be expected that successful information transfer may be particularly deficient among autistic people. However the findings alligned with the double empathy theory proposed by Milton suggesting communication difficulties arise from a mismatch in neurotype. Within the diffusion chain paradigm autistic people recalled information shared by their autistic peers as effectively as non-autistic people, yet information sharing was significantly poorer in chains of mixed neurotypes. These deficits in information transfer between autistic and non-autistic peers were accompanied by significantly poorer self-rated interactional rapport. This provides support towards the double empathy problem with the results challenging traditional assumptions of autistic social impairments. The quality of the transfer of information within autistic chains did not differ from the information transfer in non-autistic chains, including the ability to share information and build rapport with their autistic peers. This is consistent with previous research that autistic people experienced close social bonds and empathy with other autistic people, though they may experience specific difficulties when interacting with non-autistic people (Crompton et al., 2019; Morrison et al., 2019).

These studies highlight that the neurotypical majority play a significant role in the interactive experiences of the autistic minority.

Social identity/ stigma theory: (Goffman, 1963)

The social stigma theory was first described by Goffman in (1963), making the distinction between stigmatized attributes that are “discredited” (i.e., visible and readily apparent to others), versus “discreditable” (i.e., invisible and can be hidden from others). Visible stigmatized attributes include race, sex, and physical disabilities, while invisible stigmatized attributes include gender identity, sexual orientation, and mental illnesses. More recent work has developed this concept of concealable stigmatized identities, referring to identities that are socially devalued and negatively stereotyped but can be concealed (Quinn & Earnshaw, 2013). Living with a concealable stigmatized identity affects psychological wellbeing, with individuals experiencing heightened psychological distress (Quinn et al., 2014; Quinn & Chaudoir, 2009). Autism can be understood to a certain extent as a concealable stigmatized identity, particularly with the participants within this research who had all been diagnosed later (due to the fact their behavioural characteristics were not immediately apparent) and did not have any associated learning difficulties.

Individuals with concealable stigmatised identities have two main coping strategies to either attempt to ‘pass as neurotypical’ by concealing their stigmatised identity or ‘reveal’ their identity, which is to disclose their stigmatised identity.

Botha & Frost (2020) found higher levels of the concealment of autism associated with increased levels of internalised stigma and lower levels of social well-being. Perry et al., (2021) found higher perceived stigma predicted higher levels of self-reported camouflaging supporting the position that camouflaging is a response to stigma. Concealment and camouflaging were seen as potentially helpful to protect from stigma, but exhausting to maintain, not being true to oneself and leaving stigma to go unchallenged. Thompson-Hodgetts et al., (2020) scoping review found autistic people experiences with fears of stigma following disclosure and professionals should be wary about encouraging others to disclose their diagnosis.

Social Identity theory:

“Social identity theory posits that people’s self-esteem is highly influenced by others’ views of their social group” (Tajfel & Turner, 2001).

Social Identity Theory (Tajfel & Turner, 2004) proposes that when a group is stigmatised, group members seek to regain positive identity through individualistic strategies (such as disassociating from one’s in-group e.g., the autistic community and attempting to assimilate with a higher status group such as the non-autistic group) and collective strategies (such as positively re-defining the in-group through joining supportive networks and advocating for their rights).

Research by (Nario-Redmond et al., 2013) found those who strongly endorsed disability or neurodivergent differences as a central aspect of their identity were more likely to support collective strategies aimed at improving the status of the group by reclaiming their status as valuable and advocating for social change.

Stronger disability identification was found to predict higher self-esteem. It is notable that many autistic adults described autism as a positive part of their identity while many autistic adolescents did not. Existing literature suggests there may be some age-related differences in autistic identity development. Cresswell & Cage (2019) found stronger alignment with non-autistic culture linked to more positive self-perceptions among autistic adolescents in comparison to the findings with autistic adults. This highlights the need for and importance of building a positive autistic identity for all from a younger age.

Given this insight as EP's who align with the social model of disability, it may be time to re-consider the cognitive theoretical framework, and instead consider cognitive theories as only one way to attempt to develop our understanding of camouflaging behaviours alongside the double empathy problem, and social identity and stigma theory.

2.8 Integration of theories and research:

It is important to consider how the theories and the research interact to develop our understanding of camouflaging and masking.

In adopting a critical realist and contextualist framework it can be said that camouflaging takes place only within the specific context.

Research which demonstrated the significance of the environmental context (Livingston et al.,2019) found that this could help or hinder camouflaging depending on social expectations and how an individual with autism needs to fit into a particular structure. This aligns with the double empathy problem (Milton 2012) and the social stigma theory (Goffman, 1963) that the girls' experiences of judgement by the wider society, their peers and their school

affect how they behave and adopt or develop camouflaging behaviours to attempt to 'fit in' and how we have a long way to go before acceptance of neurodiversity is universal. Hull et al., (2017) found girls on the autism spectrum were also guided by their parents and educators to adjust aspects of their behaviours when accessing mainstream school. Environmental pressures to camouflage are grounded in the social expectation that autistic people need to adjust behaviours to be socially accepted. This is also demonstrated with the current interventions being offered in mainstream schools which focus on enabling the autistic child/ young person strategies to learn the skills of their non-autistic peers such as social skills training. Qualitative reasons in research by Cage & Whitman (2018) included to 'pass' or 'fit' in the neurotypical world and avoid bullying and stigma, fitting with the social stigma theory proposed by Goffman.

Teachers and educational professionals are asked to establish and maintain effective relationships with families for three reasons, especially with children and young people with SEND. There is considerable evidence that increased parent involvement is associated with more positive student outcomes (Cox, 2005; Desforges & Abouchar, 2003; Fan & Chen, 2001; Fishel & Ramirez, 2005; Guli, 2005; Henderson & Mapp, 2002; Hoard & Shepard, 2005; Jeynes, 2005, 2007; Zellman & Waterman, 1998). Secondly, there is a social justice argument that engaging families is the right thing to do (Auerbach, 2012; Riehl, 2012; Theoharis, 2012). Finally, parent involvement is written into law (SEND code of practice (CoP), 2015). Sections 6.65 of the CoP states that under SEND support, schools should meet parents at least three times a year to review outcomes and provision. Section 6.66 states that it strengthens the impact of

send support by increasing parental engagement and providing information on the impact of send support outside of school. Section 6.67 states that schools should provide opportunities for parents to share concerns and agree aspirations and outcomes for the pupil and 6.69 states schools should allow adequate time to fully explore parental views and plan effectively. Research has found secondary school experiences for children and pupils with SEND are more likely to be positive if parents and teachers work together productively (Rodriguez, Blatz & Elbaum, 2014).

In reality, parental experiences are often undervalued and parent professional relationships can be problematic (Ryan & Runswick-Cole, 2008; Read 2000; Seligman & Darling, 2007). The term “partnership” is often loosely defined suggesting some sort of cooperation and sharing of ideas and influence, but this does not always happen in practise. There is a consensus that positive parent teacher partnerships are critical to inclusive education, but repeated reports highlight how difficult this can be when children have a disability (Phtiaka 2006; Mann et al., 2015; Lalvani, 2015; Runswick-Cole 2018). This parent partnership ‘ideal’ can then be impacted when the parents are disbelieved when they first raise concerns about their child.

In considering the social challenges arising in the research like playing on the periphery of games from a young age (Dean et al., 2017), wanting friends but this causing them distress when there were difficulties (Tierney et al, 2016) and their ‘neurotypical’ friends knew they were different even when teachers didn’t (Bargiela et al.,’s 2017) these can be viewed in light of Milton’s (2012) theory of the ‘double empathy problem’. It could be viewed that as well as the girls having difficulties with their relationships with neurotypical peers, their peers are also

finding it hard to have successful relationships with them; and this would advocate an approach such as peer education of neurodiversity so that both cohorts could understand each other better. This may also help develop a more positive view of autism among their peers and with the girls themselves as the education would be highlighting differences not disability. Cook et al., (2017) found the most successful friendships were between autistic girls and mainstream pupils identified as having special educational needs, enabling the girls to feel more accepted and reduce their camouflaging strategies. Dean et al's., (2016) recommendations for future research and interventions included the use of strength-based approaches to support girls' participation in peer groups (Wilding & Griffey, 2015) and would help foster a sense of belonging and inclusion to their schools.

The overall research states if practitioners continue overlooking subtle social challenges and internalising behaviours, then camouflaging is not protective and will only lead to greater mental health difficulties. This causes an escalation of needs leading to more severe social, emotional and mental health needs and these become entrenched. This will then place a heavier financial burden on schools and society than if early and accurate identification occurs. Beck et al.'s research (2020) found women who reported above average levels of camouflaging were associated with having suicidal thoughts, reduced daily functioning and mental health challenges and this was regardless of whether their traits were mild or severe. Suggesting that it is the camouflaging effort linked to mental health issues rather than the severity of autistic traits. The review of the camouflaging literature found a strong link between the role of

anxiety and higher camouflaging scores, which will be considered within this research and discussions.

2.9 Research questions:

The literature led to the refined research questions with the key themes extrapolated from the research to help construct the interview schedules for both the parents and the girls on the autism spectrum, a copy of which can both be found in the Appendices.

The main research questions developed from the literature review and the findings were:

- Why do girls on the autism spectrum camouflage during their experience of mainstream school?
- What differences exist in the behavioural presentation of girls on the autism spectrum (particularly relating to masking) between mainstream secondary school and their home environment?
- What are the costs and benefits for girls on the autism spectrum attending a mainstream secondary school in adopting 'camouflaging' or 'masking' strategies and does this lead to less support/interventions being offered and made available?
- What are the supportive factors that were identified that have helped support the autistic girls to feel more accepted/ more supported and need to 'mask' less?

2.10 The Authors reflexive stance and position on Autism as a diagnosable category, the pathologisation of autism and perspectives that exist in the research.

A critical realist perspective must consider that if we frame autism purely as a psychiatric invention, pathologising the set of behaviours which are observed and rated by neurotypical researchers such as with Theory of Mind, Executive function and Central coherence theory then this neglects that those behaviours pre-existed and can therefore exist outside it. If we view autism knowledge at this behaviourist, surface level it does not account for what the embodied experience of being autistic might actually be like and only relies on appearances to provide explanatory theories. Therefore, our predominant understanding of autism is a behaviourist and neurotypical interpretation of autistic behaviour. Autistic emancipation is intrinsically tied to the recognition of autistic contributions and to the creation of policy and practice that is informed by such knowledge. This needs to change for a deeper understanding of what autism is. Many autistic people even define their own autistic disposition as conceptualised by the neurotypical majority.

Medicalised approaches using a deficit model do stigmatise autistic people (Grinker, 2015) but the concept of neurodiversity can and does help many to understand themselves better. Neurodiversity proponents tend to adopt a form of the social model of disability, distinguishing between a biological basis but celebrating it as part of natural human variation and challenging negative conceptions of autism and improving accommodations and services (Baker, 2011). The author's position views autism within a biopsychosocial model, this takes account the intersectionality of all these factors contributing towards our current conceptualisation. As referred to in this introduction autism is an evolving target that is not determinable outside of the time, culture and social

norms which prevail which makes the biological element just one fraction of autism (Chapman, 2020; Hacking 2006).

Chapter 3.0: Methodology

3.1 Chapter Introduction:

This chapter provides further information on the researcher's theoretical, ontological and epistemological stance and how this impacts the methodology and analysis. It will provide an overview of the researcher's background and knowledge to improve the reflexivity and transparency. This chapter will include the methodology used to gain insights into the experience of girls on the autism spectrum in mainstream secondary schools and their camouflaging behaviours. It will also detail the methodology used to elicit the parental perspectives.

A description of the process of data collection and analysis using reflexive thematic analysis is given with a step-by-step guide covering the process of how coding decisions were made and justifications for levels of analysis. Yardley's (2000) quality criteria for qualitative research of is referred to: sensitivity to context, commitment and rigour, transparency and coherence and impact. The depth of description and personal reflection included is an attempt to meet the stringent level of reflexivity needed in a quality study using reflexive thematic analysis (Smith, 2011a).

3.2 Approach to Research:

Ontological and Epistemological considerations:

The critical realist paradigm chosen takes the ontological position that reality has been shaped by historical and cultural elements, including social, political, economic, ethnic and gender values (Guba and Lincoln, 1994, p.110). Reality is a socially constructed entity but is in a state of change, always being influenced by several factors. Language also influences reality (Frowe, 2001, p.185) through the interaction between language and aspects of an independent world, but also encompasses power relations which may be used to privilege certain voices. The critical realist ontological framework leads to an epistemology of contextualism. Contextualism can be presented as a type of constructionism (constructionism-lite) because it will not assume a single reality and sees knowledge as coming from the context and reflecting the researcher's point of view. This argues that knowledge or the 'truth' is local, situated and provisional (Madill et al., 2000; Tebes, 2005). In contrast to constructivism, it retains an interest in understanding the 'truth' and so has a realist element. Arguing that while no single method can attain 'truth', knowledge will be true in some situations. This 'truth' is also shaped by societal power dynamics, for example what constitutes knowledge is governed by the social and positional power of the advocates of the knowledge (Cohen et al., 2009 p.27). Compared to social constructivism which believes we are born into a world where meaning already exists (Crotty, 1998), the critical realist paradigm believes that people are not only within the world, but that reality can be changed through their action. In adopting this critical realist concept, the historical context of autism will be considered and how girls on the spectrum are represented.

Critical realist and contextualism methods enable reality to be examined from a cultural, historical, social and political point of view, including the use of open-

ended questions and interviews and focus groups and this mostly results in qualitative data. The analysis of this data will include thematic analysis and will also be considered under this critical realist and contextualism lens for interpretation.

The proposed research paper will also promote an equal relationship between participants and researcher. Reflexivity will be carefully thought through - in a functional sense by examining how the research tools utilised will have influenced the research process and also by recognising the researcher's personal reflexivity and how any subjectivity will have influenced the research (Wilkinson, 1988).

3.3 The Researcher's position:

The concept of reflexivity is a key factor in the world of qualitative inquiry and is described as "the practitioner acknowledging active subjectivity and opening the practitioner up to the diverse and contingent nature of their own knowledge and truth" (Moore, 2005, p111). Gough (2003) refers to Wilkinson's three distinct forms of reflexivity: personal, functional and disciplinary (Wilkinson, 1988). At the very least quality qualitative research should include a visible acknowledgement of the personal position of the researcher, there should be an attempt to be transparent in the motivations, interests and attitudes that have influenced the researcher's decisions every step of the way. These have been introduced and will continue to be explored.

My perspective and research interests are informed by personal and professional experiences. My youngest daughter with autism rarely drew attention to herself, preferring to struggle on academically and hide difficulties

from her peers and practitioners to ensure she was not singled out or treated differently. This meant she missed out on appropriate support and has under-achieved in most subjects, as well as socially being more excluded from her 'neuro-typical' peers, who from an early age could tell she was different and labelled her as 'weird'. In most discussions with her teachers and other education staff, my concerns were dismissed. At first these concerns were not considered as her presentation in school was that of a model pupil. She listened to her teachers and even when struggling with her work, she would try to hide this by presenting with 'on-task behaviours' such as completing pages of beautifully illustrated work, to conceal her lack of understanding of what had been asked. With peers she would try to present a façade of keeping all her emotions contained until the daily return from school when she finally felt safe to release the emotions and would describe to me how she had been excluded from her friends or called 'weird'. Fortunately, she had one close friend - a boy - who had similar presenting behaviours to her and they enjoyed playing the same games or just enjoyed being in close proximity when having after school play dates, completely absorbed in their respective interests.

Before training as an EP, I worked as a specialist teacher for children with SEND in the Early Years. I supported many children on the autism spectrum and the majority were boys. My interest and passion for the identification, diagnosis and support of girls stems from my personal experience of having an autistic daughter who was not diagnosed until she was 11 years old, despite initial difficulties being highlighted at the age of three with her paediatrician. I became interested in the subtle differences in presentation of autism between the genders and whether these differences were more commonplace than

realised and whether this was leading to girls' under-identification of being on the autism spectrum? This also made me question whether the support they were missing out on has led to exacerbations poorer mental health than their non-autistic peers? Through my work as a trainee Educational Psychologist in one London borough, a SENDCo who had many years of experience and additional qualifications with working with children with SEND within an all-girls school reported to me: "***I don't think we have got it right for girls on the autism spectrum yet***". This quote resonated with me personally and professionally: how are these girls being recognised and supported in mainstream schools and what can be done to make improvements and support this population? Are current strategies and supports aimed more at the 'typically male' representation of autism and will they be appropriate for this population? This led to my decision to carry out this research with this population and to gain the parental perspectives too. In being aware of my own situation, I have utilised the knowledge of my supervisors and a recently graduated psychology student to ensure that the themes identified within the analysis were accurate and based on the data to ensure that my own perspective and biases have not influenced these findings unduly. I kept a reflexive diary to consider each stage of the process and ensure that I was fully aware of my biases, extracts from which can be found in appendix M.

(My position as a reflexive researcher will be considered at all stages throughout this research process).

3.4 Current Context of the COVID-19 Pandemic:

It is necessary to highlight the current context of the pandemic and the differences this may have brought to the research. In March 2020 the COVID-19 pandemic brought about the most significant changes to education in the last 70 years. Schools were closed to all children initially but opened again to critical key-worker children, including children identified as vulnerable, or as having SEND but the decision to attend school was down to parental choice. Over time schools moved towards educating virtually with online lessons and work, key worker children were still able to physically attend school if this was preferred. This virtual education may have had some potential benefits for children on the autism spectrum or with high anxiety but also came with negative costs. This will be explored further within the focus group questions.

In the UK Government's SEND review, a Green paper published in March 2022, it reflected that for children and young people with SEND they had been disproportionately impacted by the pandemic. 68 % of the parents questioned as part of the SEND review reported that their child's needs were 'not met at all' or only 'somewhat met' during the pandemic.

This context has impacted the research by designing the research to be fully accessible virtually, this also enables a wider geographical reach of the participants. Recruitment of girls on the autism spectrum to participate in this study proved very challenging by the very nature of their social and communication difficulties. Requiring them to communicate some of their thoughts and experiences about school to an unfamiliar person albeit in a preferred online format is not a straightforward task. From an initial 12 participants, all of whom met the original criteria for inclusion in the study, four were not eligible to participate by the time the study started as they were no

longer currently in the mainstream environment and a further four no longer wished to take part.

3.5 Research Design:

Due to the nature of the research paradigm being utilised it was deemed appropriate to use a qualitative research design. Choosing a qualitative research design it is essential to adopt the qualitative sensibilities highlighted by (Braun & Clark p.9) these include: an interest in process and meaning, a critical and questioning approach to life and knowledge, the ability to reflect on and step outside the culture to become a cultural commentator, the development of a double-consciousness, (to listen intently but critically reflect on this too), reflexivity and good interactional skills that helps establish 'rapport and trust'.

Another key tenet of qualitative research is that the data is produced in particular contexts by participants who are located within specific contexts. It recognises the subjectivity but does not treat it as bias to be eliminated from research at all costs leaning towards a contextualised analysis to take this into account. Qualitative research can be divided into two camps (Reicher, 2000), experiential and critical. Experiential qualitative research validates the meanings, views and perspectives expressed by the participants. Their interpretations are accepted and prioritised. As such it seeks to make sense of how the world is seen and understood from the participants' perspective. As a key research aim was to 'give voice' to girls on the autism spectrum, who are largely missing from the research in autism thus far, using an experiential qualitative design meets this objective.

In employing a qualitative research design, there were three types of questions that needed to be considered. These three steps are outlined below.

Step one: Establishing the research questions and what is trying to be found out. Initial questions guiding the research led to the review of the literature to find out what was already known in this area and what more was needed to be known. The literature review allowed for further refinement of the research questions. Once the research questions were established, this led to further development of the literature to contextualise what was already known about the topic and what more there was to know considering the established research questions. The research questions are set out below:

- 1) Why do girls on the autism spectrum develop camouflaging behaviours during their experiences of mainstream secondary school?
- 2) What differences exist in the behavioural presentation of girls on the autism spectrum (particularly relating to masking) between mainstream secondary school and their home environment?

Additional Research questions identified:

- 3) What are the costs and benefits for girls on the autism spectrum attending a mainstream secondary school in adopting 'camouflaging' or 'masking' strategies and does this lead to less support and interventions being offered?
- 4) What are the supportive factors identified that have helped autistic girls to feel more accepted/ supported e.g., the quality of friendships/ or acceptance of their diagnosis?

Step two: The next phase was to identify the questions to ask the participants to generate the data. This was developed through studying the extant literature and the research questions to identify key themes when planning the interview questions for the participants to generate their thoughts, views and experiences. In adopting a qualitative sensibility – it is best to refer to their thoughts, views, experiences rather than attempting to quantify this as ‘data’.

Step three: Finally, the questions that needed to be considered when trying to extrapolate the meaning of the data in answering the research questions. This will be covered further in the discussion, how meaning was elicited to answer the research questions from their own words without imposing too much of my own interpretation.

3.6 Recruitment and Participants:

It was hoped that 10-15 girls on the autism spectrum could be recruited, with the ideal number being 12 - all in mainstream secondary school, allowing for subsequent withdrawals and at least one parent focus group as well to gain the parental perspectives. Due to the small number of girls on the autism spectrum attending mainstream secondary schools within my local area, purposive sampling was used to identify participants. Participants were eligible to take part if they met the following inclusion criteria: The girls on the autism spectrum would be 1) aged between 11-21 2) formally diagnosed with autism by an appropriate health care professional and/or multi-disciplinary team 3) able to access and understand written questions and type their responses (schools and parents to disclose reading levels and disclose if they felt they had any

underlying learning difficulties that may impact on their understanding). The parents who took part would all be eligible / invited to take part as a parent of one of the participants, but it was not a requirement that a parent must take part. In total there was six participants in the first focus group with six parents in the corresponding parent group. There were a further three autistic girl participants in the second focus group, four were due to take part but one was absent on the day and subsequently two older girls on the autism spectrum of 17 and 21 years of age were interviewed about their experiences retrospectively. A table has been created to show the demographics of the sample of autistic girls, n=11 and a separate table for the parents n=6. (Appendix C)

Recruitment:

An independent special educational needs training provider was approached and information about the project included in their monthly newsletter. I also attended their online training event aimed specifically at parents of girls on the autism spectrum, where I presented a brief outline of the research. At the end of the SEN parent information evening about Girls and Autism, I was allocated 10 minutes to talk about my research. This is where I took the opportunity to expand a little bit more about the aims of the research and what it was about. I discussed the concept of girls with autism often being overlooked by professionals due in part to the fact they have managed to conceal or camouflage some of their autistic traits and how this can make it much harder for this population to get the support they need and the consequences that this can lead to. This first recruitment drive led to the first focus group of autistic girls and their parents, so that the parents were aware that this covered

camouflaging and masking behaviours and they then talked to their daughters about it. It was discussed that their daughters may or may not be aware of their masking behaviours, but I was interested to explore their views particularly in relation to any differences between their school and home persona and how they found their experiences of secondary school in general.

This attracted several interested parents and informed consent was then considered with 'opt in' sampling for participants. The interested parents were provided with more information about the research and data collection methods and a consent form. Once informed about the purpose of the research and having discussed it with their daughter, a signed consent form was returned. As the parents received their information, a letter about the project designed at a more child and autism friendly level for the identified participants was sent to inform them about the research to ensure they were also happy to participate before giving consent. A 'YouTube' video link was included in the information to allow the young people with identified social and communication difficulties a more accessible, clearer and perhaps preferred (visual) explanation of the project to support their informed consent. Recruitment proved to be challenging. The initial interest from the SEN training provider generated 12 interested parent-daughter dyads, but only four of these elected to take part. Further recruitment of two additional autistic girls and their parents took place by the author contacting two SENCo's that were well known to the author. Due to this unanticipated reduction in recruitment, only six girls took part in the first focus group alongside six parents in the concurrently run parents focus group. In practice the research had been designed so that it could all be accessed virtually with any restrictions in place. This may have made the recruitment

more difficult, as the researcher would have been introduced to the girls and parents without these restrictions and I felt this may have negatively impacted on their capacity and commitment to the research as it depersonalised myself as a researcher. A further impact of COVID-19 was the timing of the research which may have heightened feelings of screen fatigue with many choosing to opt out of another virtual meeting/ focus group.

With the co-operation of a local mainstream secondary school with a specialist hub for children with autism, the SENCo and the researcher collaborated on a new recruitment drive. In setting up the second autistic girls focus group I worked closely with the SENCo clarifying that the autistic girls who were recruited had to be accessing the mainstream classes. This research was explained fully to the SENCo who then invited me into the school to meet the group of identified autistic girls who had agreed to participate. The SENCo had personally spoken to some of the autistic girls in their mainstream setting and their parents so that the consent could be obtained and the participants identified. Initially five girls were interested but one withdrew before the focus group started. Another withdrew on the day the focus group started due to illness, but it was decided to go ahead with three participants due to the current high rates of Covid-19-related absence during this phase of the data collection. During my school visit to introduce myself, I expanded again on the subject matter, that their voices were being sought about their experiences of secondary school in general, any differences that they displayed between home and school and whether they were aware of anything that they did to hide their 'autism', display behaviours that they might have felt were not their genuine or authentic feelings in order to fit in or to conceal their differences. It also allowed

them the opportunity to ask me any questions and in both cases I was as transparent as possible, disclosing both my status as a researcher but also as a parent to an autistic daughter.

At the time the local authority where the researcher worked was advising that any work that could happen remotely, should. Through conversations with the SENCo, it was decided that we would maintain contact while the girls logged in while at school onto the platform that had been used previously - Piazza. As this site was being used in a remote way, the researcher was able to offer virtual support and moderation while the autistic girls were online. At the end of the focus groups due to the nature of their social and communication difficulties, some of the responses were quite limited and even with heavy moderation some of the participants did not elaborate on their answers. As a result of this, interviews with two girls on the autism spectrum who had since left school were also conducted (one of 17 years of age and one 21 years of age) and they were able to respond retrospectively. See appendix G and H for a copy of the interview questions. In addition to this there was a separate focus group for six of the parents to gain their perspectives.

I excluded self-diagnosed autistic people at this stage of their development, between the ages of 11 and 18, because not many teenage/pre-teenage girls were identifying themselves as autistic due to possibly a lack of their own awareness and perceptions of what autism is (at this age) and how it may present differently in girls. This may change in the future and in my own practice as an EP looking to increase neurodiversity acceptance where young people may become more aware of their differences and self-identify as neurodiverse prior to seeking any formal diagnosis. Ethically, it was easier to select

participants who had been given a formal diagnosis of autism although this was something I considered very carefully prior to my thesis.

Barriers to the recruitment process and reasons for including the two interviews with the two older autistic females who had recently left mainstream education:

As described above, the participants recruited through the independent SEN training provider forming the first focus group, were largely parents within the same county and subsequently their daughters. This is because the SEN training provider worked as a specialist teacher for children with autism and was quite well known and established within the county. Although the training was virtual and could therefore be accessed from a much wider geographical spread, the participants that stated they were interested and still interested after speaking with their daughters, were all drawn from the same county.

The second focus group proved more challenging to recruit. Several organisations were approached by the author but reaching out in this way and lacking a more personal touch (being unable to meet them due to COVID-19) did not harness anymore interested participants. A final recruitment drive by the author within the county's schools where I worked as a trainee EP, resulted in one very enthusiastic SENCO keen to have a focus group at her school. The school in question already had a specialist resource provision for children on the autism spectrum and this attracted parents with children with SEND so that they had a higher proportion of children on the autism spectrum in attendance. In discussion with the SENCo, the exclusion and inclusion criteria were clearly outlined so that the autistic girls identified to be in the focus groups were in attendance full time within the mainstream secondary school so that their

experiences were comparable to the first focus group. The SENCo was originally able to recruit five girls and obtain their consent. One of the girls chose to opt out before the focus group took place and one of the group tested positive for COVID and was absent from school.

Once the consent was obtained the SENCo and I met with the group of girls to introduce myself to them but to elaborate on the research aims and to discuss the concept of camouflaging and masking. The girls had the opportunity to ask questions about the research, have any questions answered that they may want to know over and above the information and consent form that they all had access to, and they all talked a little bit about their experiences and their autism. It was decided in order to replicate the first focus group's conditions as closely as possible, when the focus group was running, I would be moderating online - the other reason for this was the girls' preference that I would be an online presence instead of in person as it would make them feel less restricted as to what they could type or disclose. Their SENCO would be on hand to help them if needed especially with anything more technical and the SENCo and I had each other's phone numbers in case this was needed.

After the three focus groups had taken place, two with the autistic girls and one with the parents, it was discussed with my research supervisors that although there were some great responses from the autistic girls, there were also limitations to some of their communications, particularly elaborating on their answers even when prompted by myself. It was discussed by the author that two older autistic girls who were 17 and 20 at the time respectively may agree to be interviewed about their experiences at mainstream secondary school (which they had recently left) and may add more depth to the data already

generated. The author knew one of the girls through her eldest daughter and knew the other girl through a work colleague but had never personally met her. It was agreed that this could prove beneficial if they were willing, to add more depth and richness to the voices of the autistic girls. Ethically as I knew one of the older girls, I ensured that she did not feel under any obligation to participate and reassured her that every answer she gave would be treated with the strictest of confidence and her well-being was my primary concern. Both girls agreed readily as they felt it was a very important piece of research and wanted to help in any way they could. The research aims and content was clearly outlined and the concept of camouflaging and masking made transparent. Their interview questions were designed from the focus group questions but from a retrospective perspective. However, it also was designed to be a bit more fluid and adaptable to their answers to enable them to follow their own thoughts and explore these in more depth.

3.7 Ethical approval and consent:

Ethics approval was obtained via the Department of Psychology and Human Development at UCL Institute of Education, University College London (see Appendix D for details). All materials were piloted and reviewed with a small group of neuro-diverse children personally known to the researcher who did not participate in the research project. In accordance with the pupils' preferences for sharing their views, the online focus groups were concluded to be their preferred format, (although it was designed for virtual administration, the second focus group were asked if they'd prefer to be in person as COVID-19 restrictions had eased) However, they stated that they would prefer to type their responses and have time to read the questions in advance before reflecting on

their responses. Throughout the data collection process, I used my professional expertise as a trainee EP to monitor the girls' involvement and where necessary I would check in with the parent if they were not engaging and review whether they were still happy to be involved. An important aspect of ethical research is ensuring informed consent. This poses additional challenges for vulnerable groups, such as individuals who have social communication difficulties. All standard ethical expectations for psychological research (e.g., right to withdraw, anonymity) were followed (British Psychological Society, 2014). Pupil information and parent information and consent forms can be found in Appendix E and F.

3.8 Sensitivity of topic:

Social interaction can be challenging for individuals with autism, and many experience co-existing anxiety. This research focused on potentially sensitive issues (e.g., friendships, coping skills and identity) and there was a possibility that the girls could have become anxious when discussing this. Throughout the research, the girls' wellbeing remained the primary focus. Following any comments that were related to issues that could have been a safeguarding and wellbeing concern such as disclosing previous attempts to self-harm, the girls were offered an individual telephone call from the researcher and an email signposting them to the recognised resources, these are highlighted in the consent forms. This was also discussed with the research supervisors. The fact they were disclosing historical acts of self-harm, it was felt that this approach was appropriate, but this would have been escalated further if they had reported current acts. The girls were all given the option to have a de-brief at the end of the focus groups. They all chose not to take up this option. Further details of

the ethical considerations that arose from the study, including confidentiality and data protection, and the factors implemented to address these, are described in Appendix D.

3.9 Methods and Procedure:

Due to the nature of the research aims and the context of the COVID-19 pandemic, virtual focus groups were used with the participants. Focus group interviews are an appropriate method to employ when conducting exploratory studies (Willig, 2001). Focus groups typically consist of between six and 10 participants, but this can range from as few as three/four (Kitzinger, 1995) and as many as twelve (Goss and Leinbach, 1996) depending on the research purposes. Smaller groups are more appropriate when exploring complex and emotive topics or to encourage more detailed accounts. Focus group research is useful in revealing beliefs, attitudes, experiences and feelings of participants through interaction, in comparison to other methods, such as individual interviews, observation or questionnaires (Gibbs, 1997). They can also be good to access the views of underrepresented or marginalised social groups (Wilkinson, 1999), as speaking with others 'like you' may be less intimidating than speaking just to a researcher (Liamputtong, 2007).

In this research, focus groups were chosen over interviews as the author wanted to obtain participants' shared understandings to elicit the specific culture of this group within mainstream schools. It was hoped that it could empower the participants - with the sharing of views meaning they would realise they are not as isolated in their experience or perspective and can lead to some kind of individual change and could help shape a more positive identity. This is

particularly pertinent in the case of girls on the autism spectrum who are under-represented and underdiagnosed and may not have met other autistic girls.

The virtual platform that was used for these online focus groups was 'Piazza'. This is a very secure site designed to encourage interactions and allows moderating the groups as they are happening. In light of the participants social and communication difficulties, the online focus group had the key questions already written down for them and a two-week window to answer the questions to allow them to feel less anxious than in an interview situation where they are expected to answer the questions there and then. This affords them a more reflective stance where they may answer in their own time. Online focus groups can also be seen as giving less confident participants opportunities to contribute more to the discussion than they would in person, particularly in relation to sensitive topics. Their answers were typed and there was no facility to have their cameras on or to speak. Research by Gillespie-Lynch, Kapp, Shane-Simpson, Smith & Hutman (2014) found autistic participants perceived benefits of using computer mediated communication in terms of increased comprehension and control over the communication and the opportunity to express themselves.

(Morgan, 1988; Morgan and Krueger, 1993; Powell and Single, 1996; Gibbs 1997) summarised the main appropriate uses of focus group methodology as being: discovering new information and consolidating old knowledge; obtaining multiple and different perspectives from participants in their own words; gaining information on participants views, attitudes, beliefs, responses and perceptions on a topic, therefore, why people feel the way they do; examining participants shared understandings and exploring the culture of particular groups;

brainstorming and generating ideas; gaining insights into the ways individuals are influenced by others in a group situation (group dynamics); and finally exploring complex, controversial or sensitive topics.

The focus group questions were identified from the review of the literature which highlighted three key themes, their friendships, their sense of belonging and their sense of identity as well as a question relating to the current context of being educated during the COVID-19 pandemic and its possible impact. In adopting a responsive structure to the focus groups with online moderation this allowed a degree of structure to support the interviews' relevance to the research aims, also providing enough flexibility to allow for ideas and themes to emerge which had not previously been anticipated (Mertens, 2005; Robson, 2002). In utilising semi-structured style interview questions this responds to the very individual experiences of all participants involved in this study. The focus groups were conducted virtually by the researcher, but this still allowed the researcher to clarify any questions and encourage active participation and involvement, whilst enabling the affective responses of the interviewee to be monitored throughout the process, so sensitive debriefing could be used if necessary. Ethically, it is important for this research to consider ways to reduce the autistic girls' anxiety in situations that they feel are potentially intimidating. Two semi-structured focus group interview schedules were developed; one for the autistic girls and young people and one for the parents (Appendix G and H). The interview schedule for the autistic girls were reviewed and co-constructed with two older girls on the autism spectrum. The themes identified for the focus group for the girls on the autism spectrum were exploring their feelings about their friendships, and the school experiences as well as differences that exist in

their behaviours between home and school and their sense of self identity as a young girl/person on the autism spectrum. The focus groups were first piloted with a small group (4) of girls/ young people with neurodiverse needs between 15-21, this helped to develop and construct some key ground rules which I have included in Appendix I. The interview schedule for the parents was also piloted with one parent of an autistic girl. This pilot of the focus group enabled me to reflect on that the need for more moderation than initially thought, as the autistic girls/ young people did not have many interactions between participants. The first of the focus groups ran concurrently with the parents' group who did not need such high levels of moderation. The second of the girls focus group ran four weeks later following further recruitment, obtaining their consent and allowing for the school holidays.

3.10 Data analysis:

Thematic analysis was conducted following the focus groups with a reflexive thematic analysis approach used (Braun and Clarke (2006, 2013, 2019). A critical realist framework was used to make sense of the data. This means that the accounts of the participants are taken as both being true to them but also influenced and mediated by the wider social context in which they are situated (Houston, 2001; Willig, 2013).

The data analysis process involved the six steps highlighted below by Braun and Clarke (2006,2013,2019) involving moving through data familiarisation and re-familiarisation, coding, theme development and review.

1. Once the data had been collated and transcribed, the initial data familiarisation began. In addition to reading and re-reading the

data it was important to look deeper and actively explore the data for meaning. This involved asking questions such as how the participant is making sense of their experiences, what assumptions they are making and what kind of world is revealed through their accounts. The data was analysed at a semantic level but also at a latent level, to explore what was underneath what was said or what is being implied.

2. Coding then began. In this research complete coding of the data set took place. This means that the entire data set was coded with the aim of identifying anything and everything of interest in answering the research questions. Initially the coding was completed at a semantic level, mirroring the participants language and concepts. This meant the data was driving the codes and the process was largely inductive. It is not a binary process though and the data was also analysed and coded for its latent meanings which do invoke the researchers conceptual and theoretical frameworks. Although analysis primarily followed an inductive approach, it's acknowledged that there is no such thing as a truly inductive approach as the researcher's position, previous knowledge and understanding and biases will undoubtedly play a part in the process and both semantic and latent meaning in the data was explored. (An example of coding and an extract is included in appendix K).

3. The codes were collated and once the process had identified the codes to be included, these were printed out so that the researcher could manually develop the themes.
4. Identifying patterns and themes across the data set involved printing out the collated codes from the girls' data set including the two older girls interview data as essentially, they were all answering the same questions just from either a retrospective or current position. This manual development of the themes was preferred by the author as a more immersive process than using software. (Photos of the initial theme developments and the process involved can be seen in the Appendix L).
5. This process (step 4) was repeated separately using the parents' data until the themes were developed from both sets of data.
6. These themes were then reviewed, initially with a recent psychology graduate in person who looked at the coded data, blind to the researchers position and then they reviewed the themes together. The themes were refined following discussion with the research supervisors. Once the themes were clarified there were five themes from the autistic girls' data and four themes from the parents' data (a copy of which can be found in the Appendix J). In looking at the themes developed overall, three themes aligned very closely between the girls' data and the parents' data. It was then decided that these three themes would become shared themes and be reported together in the results section. This would avoid unnecessary repetition but would be

made clear and viewed from the two different perspectives. These amalgamated themes involved only a few minor changes of moving one of the parents' sub-themes into a different theme to align more closely with the girls' data and thus giving the theme an even stronger basis for its development. There were then two additional themes from the girls' data, and one stand-alone theme from the parental perspective.

Analysis was led by the researcher, but following a collaborative approach with the research supervisors, DD and CC as well as with a psychology graduate and the participants with regular input and discussion about themes and theme development (appendix J).

In adopting a critical realist approach which incorporates an emancipatory approach, the voice of the participants was sought at every stage, checking back with the participants on my theme development, the questions that were asked and inviting all the participants in receiving feedback after the study has concluded. Following thematic analysis, the results and themes were further interpreted and discussed through the critical realist and contextualism lens considering the previous literature and theory to answer the research questions.

3.11 Reflexivity through the data collection stage:

To address the power imbalances existing between the researcher and the research participants, it was important that the author's presence as the researcher was considered carefully. One of the benefits to focus groups over interviews is that they reduce the researcher's power and control. The intention of moderation was to elicit further meaning and deeper insights, whilst being

mindful to how the researcher's presence may alter the dynamics and the findings.

Reflexive journaling was also used as a tool to increase self-awareness during the process of data collection. (Excerpt in Appendix M). Reflexive notes were made before and after each focus group and referred to. The use of reflexive journaling throughout the process and using a critical realism perspective made clear that this research is borne out of a specific context. Elements of insider-outsider status, power, and privilege, all played a role in the construction of the results, and their interpretation. As has been mentioned, the lead researcher for this project also has an autistic daughter, meaning a shared identity with parental participants (referred to as insider status (Perry, Thurston, and Green 2004)). On one hand, this intimate knowledge of the experience of being a parent allowed for a more intimate understanding of what it means, which has been described as missing in autism research (Chapman 2019). It also means that perhaps another researcher would have interpreted the data differently. This was disclosed to all the participants. Reflexive journaling also allowed for me to be conscious of the power bestowed in describing the data and led to reviewing themes with one of the participants from each of the focus groups (as interpretation of data is an action which with consequences (Teo 2010)). It has already been highlighted in the introduction that the power has traditionally resided with researchers in autism research, and how there has been a long-standing tradition of the autistic person being the 'subject', which can lead to further marginalisation and stigmatisation of the participants. To minimise the power imbalance at every stage, their opinions were sought and included. Following the initial development of the focus group questions, these were then

further developed and co-constructed with an older girl on the autism spectrum, who did not take part in the research.

The data generated from the online focus groups aimed to add depth and give meaning to the girls' experiences, providing some tentative explanations with their responses. This data was thematically analysed by me and a co-researcher who helped to identify and check themes together ensuring they were consistent. It was also important to be aware of and attempt to reduce my own biases as much as possible. For example, the development of themes may have been influenced if a particular comment resonated deeply and this might influence my thematic analysis by giving this more prominence than it might merit. This awareness and use of reflexive journaling was a constant source of clarification as well as checking between me and the co-researcher. Themes were also reviewed with a participant from each perspective, an older autistic girl and a parent.

Chapter 4.0 Results:

4.1 Chapter Introduction:

This chapter presents the qualitative findings from both participant groups, the autistic girls and the parents. In the analysis of the data there were themes represented by the girls which aligned very closely to a theme from the parents'

data (Appendix J). To avoid repetition or duplication these themes will be discussed together but from the two perspectives. A repositioning of some of the sub-themes helped to create a more cohesive framework to allow for this analysis without detracting from any of the themes or sub-themes that the data generated. This process is outlined in more detail in the Appendix J with the original five themes highlighted in the girls' data and four themes from the parental perspective and then the flow chart describes how these were amalgamated and where a sub-theme may have been re-positioned.

A key objective of this research is to ensure that the autistic girls' voices and perspectives are heard and included in all research involving them. Following the results from the shared themes, the girls' perspectives' will be discussed first, this chapter will then present the independent themes from the autistic girls followed by the stand-alone parental theme. In this section, each theme will be introduced, with the associated sub-themes described, using some quotes from the participants from both data sets as the introduction to the sub-themes to bring them to life and to clarify where the themes have been drawn from and the two perspectives. This aims to reduce the power of the researcher using quotes from the participants, as this is their research, and it can be best explored in their own words.

4.2. Thematic map and overall theme development

The thematic analysis within this section will report on six themes in total: (Table 1.0) three shared themes, two independent girls' themes and one stand-alone parental theme.

TABLE 1.0 Themes that developed from both sets of data:

Shared Themes from both the girls and parents' data	Independent themes from the girls' data	Independent themes from the parents' data
<p style="color: #0070C0;">Internalising perceptions of others – Girls' theme</p> <p>Negative self-perception- parents theme</p>	<p style="color: #0070C0;">Searching for self, the conflicts with their self-identity</p>	<p>The dismissal and devaluation of Parental concerns</p>
<p style="color: #0070C0;">Meeting social norms in different environments-Girls' theme</p> <p>Difficulties adjusting to differing expectations- Parents theme</p>	<p style="color: #0070C0;">Taking off the mask what helps?</p>	
<p style="color: #0070C0;">Impact masking has psychologically and physically-Girls' data</p> <p>Physical and Psychological impact on girls well-being-Parents theme</p>		

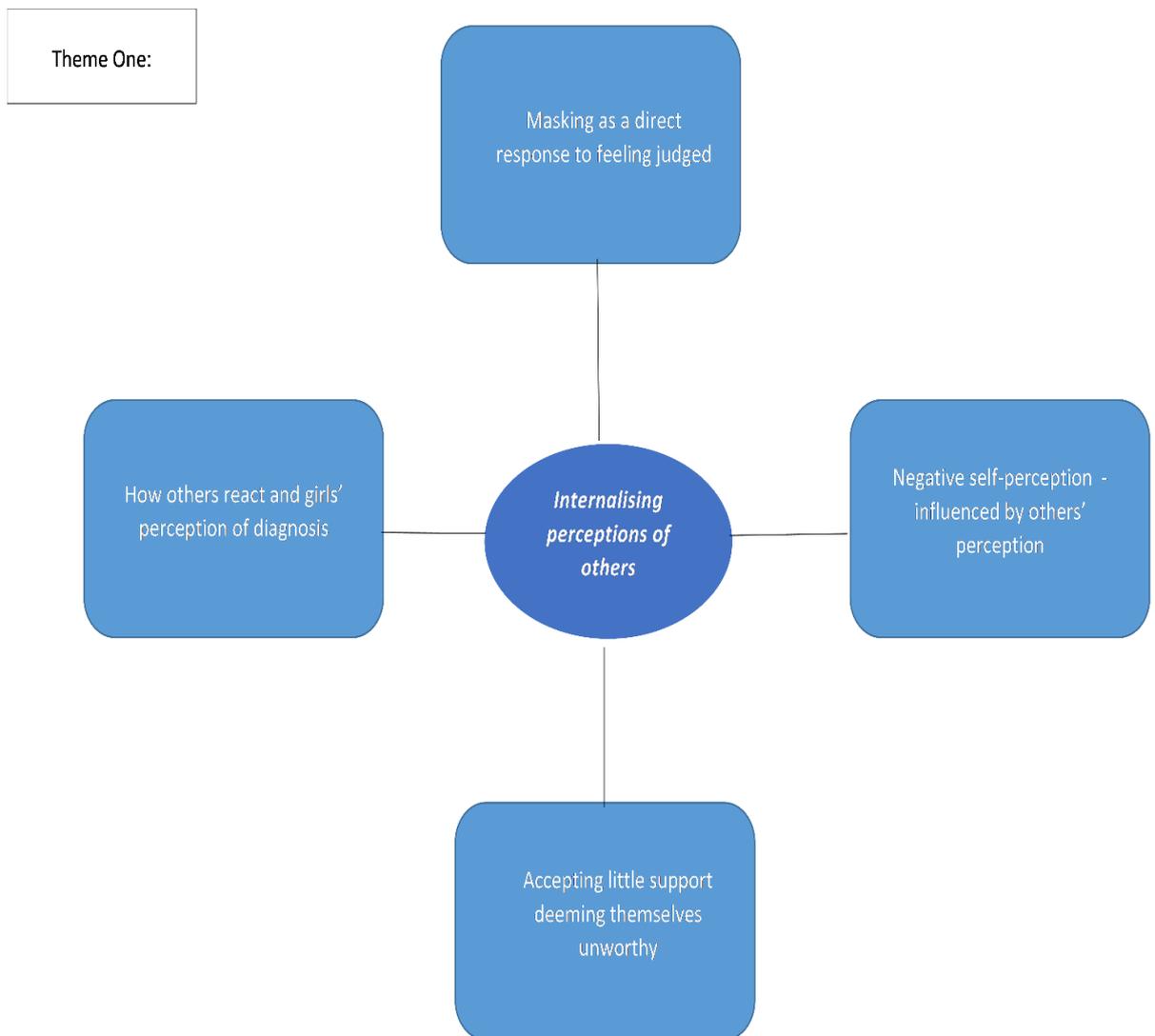
Key: Blue - the girls' themes. Grey - the parents' themes. Orange - the shared themes

4.3 Thematic Concept Map:



4.4 Theme one:

1) Internalising perceptions of others



4.5 Theme introduction:

This examines how masking and camouflaging behaviours develop from others' reactions towards autism and more specifically how they may perceive other people's perceptions of what autism is, others' reactions to their diagnosis and how others may intentionally and unintentionally judge the autistic girls for not behaving in 'neurotypical' ways. The development of the camouflaging behaviours may incorporate them suppressing their natural 'autistic behaviours'

such as reducing repetitive behaviours when they have been made aware of the negative effect these may have on others. This may reduce the volume that they talk at or alter conversation topics so that they are not annoying others with their special interests. This may start to occur at a young age as they become aware of how others perceive them. This theme is considered to be the superordinate theme as the impact of the girls' perceptions of others affects their masking behaviours in different contexts as masking can be viewed as a reactive process towards how they are perceived. This will impact on every other theme but is bi-directional in nature as the themes will also impact on their own perceptions.

In the author's reflexive journal, it was noted that her daughter had developed her own perception of herself as 'weird' following her friends' comments, when she was in year 4 of primary school. Excerpt from author's own reflexive journey (appendix M):

There are four sub themes identified within this main theme which will be considered in turn, but further reflection will take place on the themes within the discussion section.

Table 2.0. Shared theme and sub-themes

Overarching theme: Internalising perceptions of others	
Girls sub themes	Parental sub themes
How others react to the diagnosis	Girls' perceptions of the diagnosis.
Masking as a direct response to the feeling of being judged by others.	

Negative self-perceptions- how the girls view themselves as influenced by others' perceptions.	
Accepting little support as deeming themselves unworthy or undeserving of support.	Lack of support but feeling they will do anything rather than ask for support.

Autistic girls' sub-theme one: How others react to the diagnosis.

FGAG 1 **"It explains to people why I act the way I do"**

FGAG 2 ***"it shouldn't be seen as something laughable"***

OGI 1 ***"for a while after my diagnosis I pretended I didn't have it.... but now I feel more at ease with my diagnoses."***

FGAG 2 **"She (my friend) knows about my autism and is so understanding and loves me regardless".**

This sub-theme was drawn from comments made about how others perceived their autism diagnosis and their reaction to it from the autistic girls' point of view. The codes were mostly derived from feelings of negativity that they had encountered from others towards people with an autism diagnosis.

Several girls also felt that these negative perceptions existed but knew that this should be challenged. Quotes such as "It shouldn't be seen as something laughable", tells the girl's experiences of having a diagnosis or label and knowing that this should not be laughed at but at the same time fearing this might happen. Implicit in the underlying message of her narrative is that she knows some people may find it laughable. A more helpful reaction to their diagnosis was one girl's response that this might bring more understanding

from others towards her and help to explain that they might find certain things difficult. One of the older girls who was interviewed and did not receive her diagnosis until the age of 20, felt this helped her to make sense and “contextualise her life” with this new-found knowledge. Most autistic girls had more than one diagnosis and leading some of them at least to question the validity and accuracy of the autism diagnosis. This may have been impacted from the perceptions of others about the way that they presented as girls on the autism spectrum. One of the focus group older girls talked about her denial about the diagnosis as she only knew of two boys with autism at the time of her diagnosis who presented with very severe needs and learning disabilities. This did not fit with her presentation making her question the validity.

Subtheme from the parents: **The girls’ perceptions of their diagnosis.**

The parental perspective highlighted the girls initial lack of acceptance of their label and the diagnosis.

FG P1 “...***doesn’t fully accept it, she feels like being autistic is a bad thing and it makes her ‘weird’.***”

FG P5 “**reluctant to accept her diagnosis/label.**”

FG P4 “***helped her understand why she is who she is, but she is incredibly guarded about who she tells.***”

The parental perspective demonstrated that the girls were - at least initially - reluctant to accept their diagnosis and hesitant to disclose it to anyone. This mutually occurring sub-theme in both data sets highlighted that only two girls from the participants were given any information or support when they received their diagnosis about autism - and one was due to their parent being proactive

and providing this support themselves. The other received some support from her primary school. Receiving any diagnosis at a later age, it would be natural that there will be questions about what it means for them and how this will affect them or make a difference to their lives. Most of the autistic girls (8 out of 11) talked about the diagnosis itself as being perceived negatively by others but two of the girls also talked about the positives when they received some information and support immediately following their diagnosis. Their daughter's reluctance to disclose their diagnosis to anyone could have had a positive impact on how they were supported and even understood by others. In thinking about the wider context of society, their diagnosis as girls on the spectrum would have still been considered somewhat of an anomaly with very few examples of famous women and role models on the autism spectrum.

Subtheme two: Masking as a direct response to the feeling of being judged by others.

FGAG 5 *"I mask to look more 'normal' and less 'weird'".*

OG 12 *"I really can pinpoint a time when I started masking. I really like consciously started doing it in probably year eight/ year 9. And that was when I think people started to comment on me being like annoying and stuff. And I was like, oh okay, I can't just act how I want to anymore. I actually need to think before I do all these things and I think that definitely lead to like really high masking with what just seems kind of like very high anxiety behind it."*

FGAG 1 *"I am anxious that I will do or say something wrong and I will embarrass myself"*

FGAG 3 *"I feel pressure to be the same as others"*

This sub-theme reported by the autistic girls' data commented how they masked as a direct response to the feeling of being negatively judged by others. FGAG 2 "I mask to make myself look 'somewhat normal'" highlights the implicit message by masking to try to pass as a neurotypical, they are disguising their true self feeling they will be judged negatively by others. It wasn't possible to obtain from the data when this first began to happen but being labelled as 'weird' from primary school onwards, would highlight that the negative messages that they receive start at a young age.

Subtheme three: Negative self-perception- how the girls view themselves was influenced by others' perceptions of themselves.

OG 12 "I don't think I ever experienced feeling the same as others. I think it was always commented on that I was very weird. You know from start to finish."

OG 11 "The thing with the thing with kind of what happened is I think a lot of people actually kind of told me how I was being annoying and in very specific ways. So it was almost like in my brain. I've been given a list of these things you don't do and then. I just would you know, it was things like.

I think definitely like controlling my own volume.

In the first year, couple years of high school I was very like.

Uhm, boisterous, perhaps UM. I, I'm sure you're very aware for me like I like to do some singing and I know that this singing definitely annoyed people a lot. yeah, so that that those kind of things. I mean, I think,

especially with things like the singing like people were saying, how annoying that was. And to me it was just like such a 'Oh my God, this is my favourite thing to do' and I mean really. So I definitely felt like the masking was me very much like suppressing myself I, I definitely got very very quiet and would always think before I said things, just I was always, always so scared of like doing the wrong thing or annoying people."

This sub-theme highlights that the negative words and actions of others become deeply internalised. They begin to perceive themselves as others view them as weird and annoying and start to suppress some traits that have been negatively commented upon. This could be likened more to an accumulation of others' negativity impacting on their own perceptions about themselves and the effect this judgement has on their internal sense of self.

Sub-theme four: Accepting little support as deeming themselves unworthy or undeserving of support.

FGAG 2 "I'm scared to ask in case they think it is not an acceptable reason to leave class."

FGAG 3 "I used to have a 1:1 Support lady at my school but not so much anymore which is slightly annoying as I struggle in a lot of topics."

FG AG 5 "i used to get support in school but that stopped about 3 months ago. a lot of my friends have "exit passes" to go to the pastoral offices if they get overwhelmed but I don't have one for some reason"

FG AG 6 " : "Not really, i usually just handle things by myself or occasionally with a friend who knows my difficulties. I probably have

only been talked to about 4 times by a learning manager in my whole time at secondary school. There's not many places or times i can go to calm down, I've been at school for a while and still don't know where the room is to calm down. I know the teachers do help though, as my friend who has adhd goes to sen meetings and she also goes the 'chill' room, where students can calm down if stressed etc. But i, personally, haven't been told anything about the meetings or where the chill room is so i don't really want to just turn up. Im also scared to ask in case they think its not an acceptable reason to leave class”

The autistic girls' comments highlighted that they didn't feel comfortable to ask for support and were accepting when support was reduced or taken away completely. None of the girls in the study felt they did not need support particularly with their social, emotional and mental health needs. One girl commented that they had their support person taken away which annoyed them as they were still struggling, but beyond reporting feeling annoyed, she did not challenge this decision. Other girls mentioned they knew of others within their school with SEND who received support but didn't think it would be an option for them.

Parental subtheme: Lack of support but also feeling the girls will do anything to not ask for support

Parents quotes:

FG P4 ***“when they hit an obstacle they are almost certainly not going to ask for help.”***

FG P6 ***“School don't seem to be proactive.”***

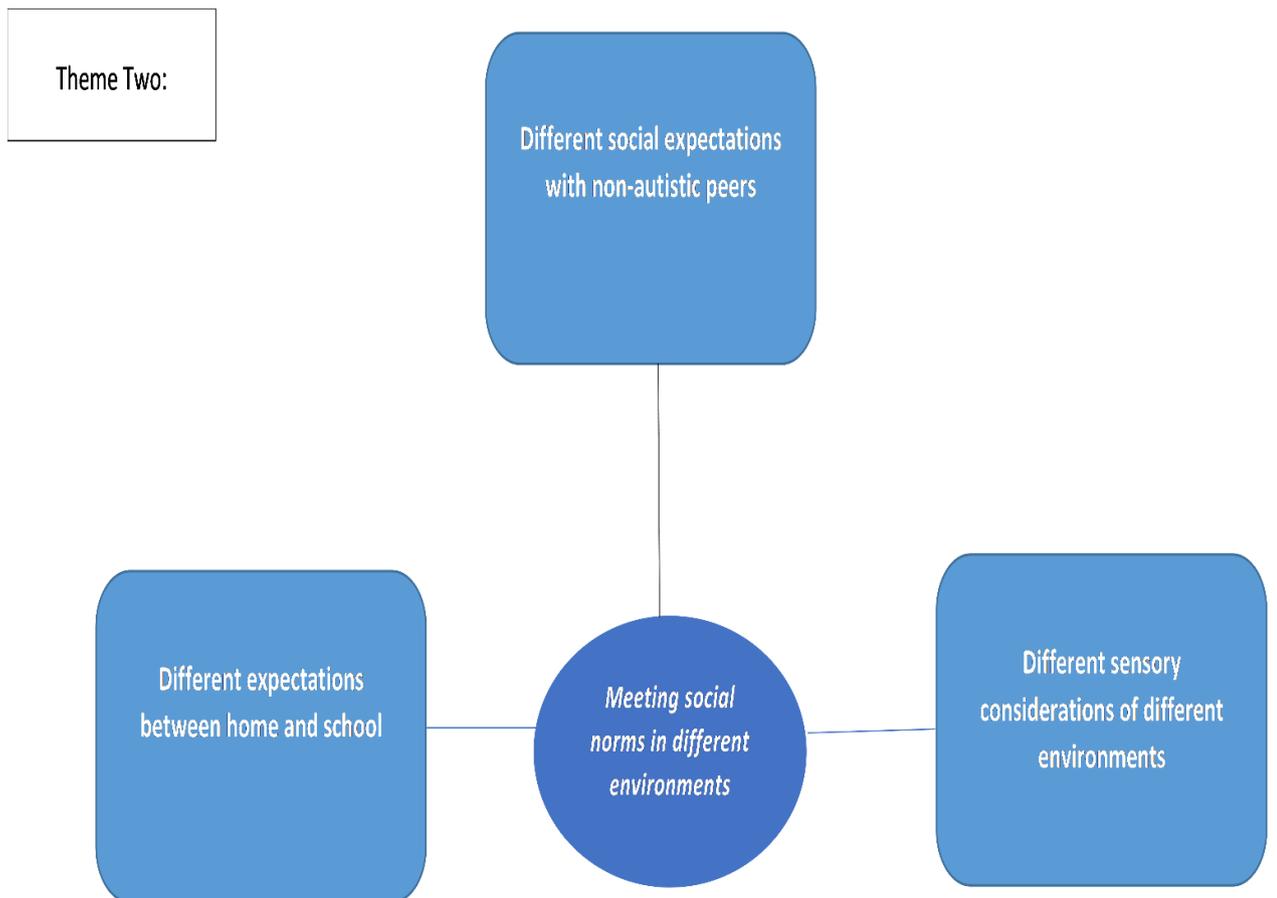
FG P3 ***“Not even on the SEN register!”***

This sub-theme was identified within both the parents' and the girls' data. This sub-theme identifies how little support they get as a group, with parents commenting on the 'battle' with schools to give their daughters more support. It also identified how little help they ask for or deem themselves worthy of (latent underlying context to the subtheme from the girls' responses). This parental perspective highlights that as well as not feeling deserving of support they also do not want to draw attention to their difficulties by asking or accepting support. This sub-theme emphasises a lack of understanding from educational staff about the importance of support, what support may be helpful, and the dismissal of support needs by their schools. This is in conjunction with the girls actively avoiding asking for help. This will be discussed further within the socio-economic and political context and the financial implications of providing those supports within a strained financial context of SEND funding provision where the resources may already be being diverted elsewhere.

SENCo's will take the girls' voice into account when looking at their overall support needs and if a student is not asking or even actively choosing **not** to have the support then it is a difficult balance to get right. This needs to be properly examined. They may be outwardly resisting support but underlying this, there could be a myriad of reasons. Future research would be beneficial to understand what is driving the resistance and this would help inform future provisions and support for this population. From these findings, the need for sensitivity and discretion with the support offered is important.

4.6 Theme two:

Figure 3. Shared theme two and sub-themes:



Shared theme two: ***Meeting social norms in different environments.***

Parental theme: ***Difficulties adjusting to different expectations in different environments.***

4.7. Theme introduction:

This shared theme looks at the different expectations and social norms placed on the autistic girls in different contexts and how to meet the expectations they will suppress their more autistic behaviour or present in a different way so as not to be singled out. It also discusses difficulties the autistic girls have in their daily life switching between contexts and how during COVID-19 this caused further difficulties with a whole new set of expectations and delivery of lessons.

Table 3.0. Shared theme two and sub-themes:

Theme two: Meeting social norms in different environments	
Girls sub themes	Parental sub themes
Different expectations between home and school during COVID-19	Home/school learning expectations differing during COVID-19
Different social expectations with their non-autistic peers	Navigating the social minefield of mainstream and feeling grateful to have made friends
Different sensory considerations of each environment and the impact this has	Sensory considerations and reasonable adjustments they need to accommodate their sensory differences

Autistic Girls Subtheme one: **Different expectations between home and school and home/school learning expectations during COVID-19.**

Autistic girls' quotes:

FG AG 5 ***"At school I have learnt to mask my 'autistic traits' because of society. I am more calm at school and not as energetic as I am at home, and definitely not as confident. I think I am still myself most of the time maybe, just a calmer, quieter version. I'm still definitely not seen as a 'quiet' or 'shy' person, I'm still talkative but just more scared to talk. At home i will say whatever comes to mind. With my closest friend, who knows i am autistic, i am definitely how i am at home. I think i have taught myself to not show or make it obvious i am autistic in public places/places where a lot of people are - I am afraid of being judged so i unintentionally, sometimes, change some of my most noticeable traits, especially with people who i feel may judge me."***

FG AG 6 ***"at school I'm quite a different person than at home. I like to "mask" my disability, in other words, make myself look somewhat normal whereas when at home I sort of let go and be the true version of myself"***

FG AG 2“i prefer home school because i can move on at my own pace and take my time and there isnt people trying to annoy me or shouting in the class it s just me and its nice and also they put so much pressure on you to all be the same and do this do that and move on so fast and call you out to read things which is stressful because if you say something wrong you have a whole class laughing at you.”

These quotes highlight the impact that different expectations both academically and with their peers can have on them and the development of masking or suppressing of their true characteristics to be more ‘acceptable.’

In this sub-theme the girls voiced the way they felt they were expected to be in the school context impacted on how genuine and authentic they could be, talking about their true and authentic selves coming out more when at home.

The autistic girls commented almost universally that they present a more subdued version of themselves at school. Becoming quieter, more passive and more conformist to try not to draw any additional attention to themselves.

Much of the discourse by the autistic girls included safety and trust and feeling more vulnerable in the school environment, leading them to conceal

difficulties because they did not feel safe to express them. This would suggest

the benefit of having a supportive and trusted key-person within their school environment that they could go to when necessary. The impact that COVID-

19 had on their learning cannot be underestimated although it is too early for official statistics. Their comments relating to the unusual context of the

COVID-19 pandemic also referenced how difficult they found home learning.

The Green paper (2021) refers to the fact that the most vulnerable,

disadvantaged and those with SEND made the least progress. The focus

group participants all commented that they found it hard not to be able to ask questions of the teacher during 'live' lessons and struggled to work in their home context as they find it hard to view it as a learning environment.

Parental Subtheme one: ***Home/school learning expectations differing during Covid-19.***

Parents' quotes:

FG P1 ***"Too anxious to return to school after Covid-19."***

FG P5 ***"Found school to be an easier learning environment."***

FG P2 ***"She has not returned to school after covid despite the school trying to reintegrate her, her mental health has deteriorated and she spends a lot of time alone in her room."***

FG P3: ***"She enjoyed not having to go to school during the lockdown but getting her to do any kind of work at home was almost impossible. But this wasn't a huge surprise as she has always struggled to do homework outside of school."***

From the parental perspective, these quotes highlight the impact that different expectations both academically and of being judged by peers can lead to the further development of 'masking behaviours'. This sub-theme looked at the difficulties that managing different expectations between home and school impacted on them. The comments included during home learning they had no-one to ask about the lesson or the expectations. They were aware that they *could* ask a question by putting on their microphone, but this would have shone a spotlight onto them and their academic difficulties, which most of the girls were trying to avoid/hide. In school they would have had peers sitting close by that they could ask to help if needed. In light of the sudden expectations completely changing to encompass home learning, they had great difficulty with

completing work within their home environment. This was commented universally by the parents that their daughters struggled to work at home, although there were some positives from the experience such as reduced sensory distractions. Most of the autistic girls and their parents commented that the girls found the school environment to be the easier environment from a learning perspective, the physical environment and structure of schools made it easier for the girls to complete academic work. However, the home environment was preferred by some for the change of pace and the reduced sensory distractions. The abrupt change to the routines by COVID-19 left many of the students feeling additionally challenged with anxiety and reporting further sleep disturbances.

Autistic Girls Subtheme two: Different social expectations with their non-autistic peers

Autistic girls' quotes:

OG I1 ***"I often tried to fit in with people by copying their mannerisms and words that they say a lot. When I only had one close friend, in year 7 and for a short amount of time in year 11, I would basically use all the words they said and make similar jokes that they would make to me, back to them. I still do practice conversations in my head because I struggle with social anxiety and probably will never not struggle with it, but I am a lot more confident now that I'm no longer in secondary school."***

OG I2 ***"I was always so paranoid about around all of them, but I still. By that point, I've gotten good enough at masking that it wasn't a stress too much. I could just kind of mask. I know it was. It was very easy to output a palatable version of myself to these people and I didn't have to worry too much I think."***

If I think about that time, though, that's kind of when I started having my like. My seizure's, my meltdowns. I think I was getting very stressed and ways that I did not understand at all because I was around this group that I didn't feel comfortable around. That was masking and very like high stress and just leading to these kind of um, kind of tipping points."

This sub-theme looks at how different understandings between the minority group (autistic girls) and the majority group (their non-autistic peers) can impact on their development of camouflaging and masking behaviours. They want to be accepted by their peers and so use different strategies such as mimicking their non-autistic peers' interactive style, even copying their mannerisms and their jokes to appear more like them.

Subtheme two -parental perspective: **Navigating their social difficulties in mainstream and feeling grateful to have made friends.**

Parents' quotes:

FG P6 ***"She knows she struggles socially with her friends this impacts on her self-esteem."***

FG P4 ***"she has really struggled with friendships and navigating the social side of school."***

FG P5 ***"Up until recently she had a close group of 4 friends, however since she has been school avoiding she only really has one close friend who she mostly talks to online and will see once every two weeks."***

Although this conscious or unconscious masking may lead to more acceptance and inclusion, it does not seem to resolve their overall social difficulties as reported by the parents who have witnessed many of their daughters 'friendships breaking down and the impact this then has on their mental health over time.

Autistic Girls Subtheme three: **Different sensory considerations of each environment and the impact this has.**

Girls' quotes:

OG I2 ***"It was just the halls would be absolutely packed, so noisy and it was just like sensory hell for three minutes that you're trying to get to your next lesson. The lights in the new build gave me all sorts of headaches and stuff."***

OG I1 ***"My school is quite big, a lot of people from other places travel to go there which means trains were always very crowded, which made me hate my journey to and from school. When I was in lower school, most teachers were quite strict and didn't feel friendly but by year 10 and 11, pretty much all of my teachers were very helpful and much more chill."***

FG AG 2 ***"The things that I find stressful in school are the amount of children in the class and how loud that makes it. I don't like having to talk to the teachers and answering questions in class because everyone is looking at me and I feel very self conscience"***

The different sensory environments were a big factor in the self-reporting of the girls' anxious feelings. Avoiding certain areas of the school and becoming distressed at times by aspects of the school day they found overwhelming such as the noisy and busy halls or their journey to and from school and how this could then impact on to how they are feeling for the rest of the day. The specific stressors of the school environment were the crowds, lighting, big classes, moving between classes and the noisy environment in general. One of the autistic girls commented that they would prefer smaller class sizes to learn in.

Sub-theme three-parental perspective: **Sensory considerations and reasonable adjustments that need to be made to accommodate their sensory differences.**

Parents' quotes:

FG P1 "***Wearing certain clothes can make her uncomfortable.***"

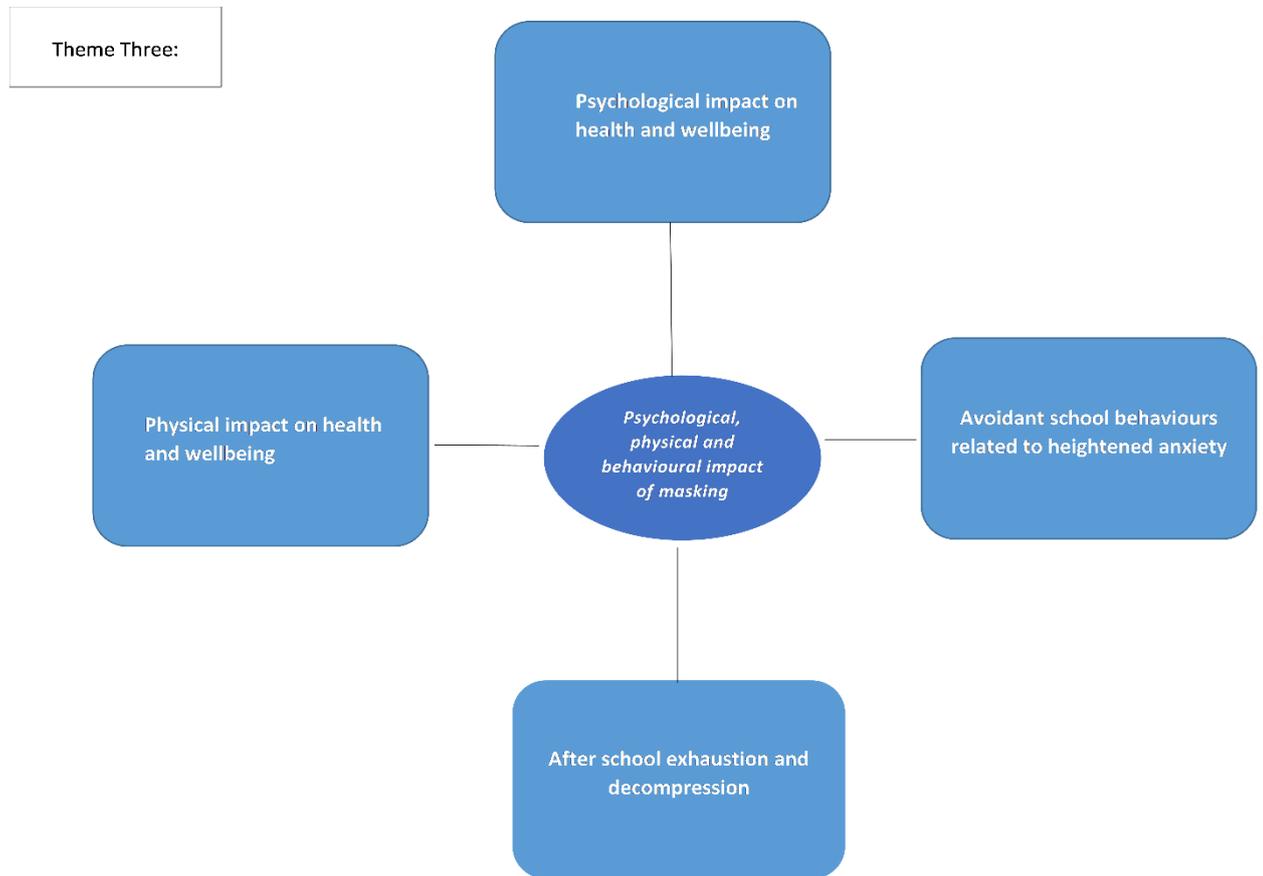
FG P2 "***Loop earplugs has helped.***"

There were some positive comments from the parents who reported on school making small reasonable adjustments for their daughter's needs such as the use of earplugs and adapting some expectations such as the uniform requirements. Some felt this did not go far enough as most of the girls had expressed difficulties with not having access to a quiet space when needed and their parents reflected on this. Some girls also commented on further adjustments that could have helped such as using music to help them to calm down when needed.

Figure 4:

4.8 Theme Three:

Shared Theme Three:



Shared Theme Three: The Psychological, physical and Behavioural Impact of masking

4.9 Theme introduction:

This shared theme examines the costs and consequences on their physical, psychological health and behaviour from masking over time. This theme also examines how these difficulties impact and interact with each other. For example, difficulties with sleep behaviours will affect how they react to the school, their peers and challenges that the mainstream environment may bring.

Parents also reported an independent sub-theme which was the need for decompression on their return from school.

Table 4. Shared Theme three and sub-themes

Theme two: The psychological, physical and behavioural impact of masking:	
Girls sub-themes	Parental sub-themes
Physical health and well-being, sleep and periods.	Heavier periods and period pains felt more intensely than their neurotypical peers. Sleep disturbances and poor sleep patterns.
Psychological impact on health and well-being	Unexpressed emotions and worries leading to an increase in anxiety and mental health issues.
School avoidant or EBSA type behaviours where the girls are leaving the classroom or non- attendance at school.	School avoidant and reluctant behaviours- school avoidant tactics by girls trying to reduce or manage their school stress.
	After school exhaustion and decompression on return from school.

Sub-theme one: Physical health and well-being, sleep and periods

Girls' quotes:

FG AG 2 ***"I have insomnia and my sleep is very strangely patterned. I sleep in 2–3-hour intervals and normally between 11pm-12am and wake up at 6:50am on a school day and 8am on a weekend"***

FG AG 4 ***"No matter what time i attempt to sleep, i usually always wake up at around 7am. It is hard for me to get to sleep as i get anxious at night and i usually don't get a good enough night sleep, but i probably get an average of 6 or sometimes 7 hours"***.

FG AG 6 ***"i used to always think alot before i slept like about what happened in the day or what could happen the next day and would barely get any sleep and be really tired but recently have found it better"***

to sleep with music so no other noises wake me and i go to bed at around 9:30 but start to sleep at 10-10:30 and get up at 7 so 9-8 hours sometimes less”.

FG AG 8 “i get to sleep about 1.30 and wakeup about 6.00. I dont like sleep. i play on my phone in bed or watch tv”.

Five out of 11 autistic girls commented on poor sleep but some chose not to answer this question so this may not be truly representative. Of the five comments, they felt this had a direct impact on the way they managed to cope at school the following day with some feeling so exhausted that they admitted to falling asleep during lessons. One of the girls discussed their sleep difficulties were affected by how much she ruminated on the day at school when trying to go to sleep and that this would keep her awake most nights for a few hours. A different girl also reported on feelings of high anxiety at night-time.

Sub-theme one-parental perspective: **Heavier periods and period pains felt more intensely than their neurotypical peers.** This subtheme was also amalgamated with the parental Sub-theme two: **Sleep disturbances and poor sleep patterns.**

Parents quotes:

FG P2 “she does suffer badly with period pains.”

FG P3 “I was aware that certain studies have suggested neuro-diverse girls seem to suffer heavier periods with more pain....

It could be due to the brain’s interpretation of the stimuli-they are over responsive to the period pains and cramping.”

FG P1 "***her sleep is poor...***"

FG P2 "***her sleep is often disturbed, and she has sleep anxieties and will think about everything that has worried her during the day***"

The parents talked about their children's poor and inconsistent sleep patterns as well as having painful and heavier periods which were reported almost universally by parents. This was elaborated on by one parent who suggested there may be a link between more painful periods and the way their brain processes pain. This is associated with interoception, the body's internal senses that regulate how the brain responds to the internal signals, such as satiety signals, continence urges, responses to pain and temperature changes and may be linked to our bodies responses to recognising our emotions, emotional regulation and control. There is some emerging literature looking at the experiences of menstruation on autistic girls and this will be discussed further. The link between anxiety and physical symptomatology cannot be discounted here with the girls. Especially in the event of being too unwell to attend school with psychosomatic symptoms such as feeling ill or being sick before going to school. The impact of sleep on their presenting anxiety and how they manage within the school environment needs to be considered carefully too with this population.

Autistic girls Subtheme two: Psychological impact on health and well-being

AG FG 2: "***I mask to hide my feelings and emotions, which leaves me feeling exhausted and anxious***".

AG FG 4: "***Self-harm is always a consideration to help me to cope with my emotions***."

OG I2 “*The same person who diagnosed me with autism also diagnosed me with PTSD.*”

This shared sub-theme was the most frequently coded and the prevalent sub-theme from the entirety of the girls’ data set. With 100% of the autistic girls reporting on their psychological well-being needs and how this needed addressing but in almost all cases they were not receiving any support in this area. A couple did disclose they had received counselling but with varying success. One reported that she felt it ‘had done more harm than good’ in her specific case, whereas another girl had found counselling to be helpful. A couple of the girls disclosed thoughts of, or actual attempts of self-harm and one parent reported her daughter had taken an attempt on her own life at seven years of age. The majority of the girls said that it was their inability to know how to cope with their emotions and manage these and eventually learn to self-regulate that caused them the most challenges. The sensory theory of interoception could be a factor here in their ability to recognise their emotions and in particular, it is their reduced ability to recognise the emotions at earlier stages, so they are only managing to respond when they reach crisis point, rather than recognising the escalation in their anxiety. This reflects a need for supporting their emotional development and helping them develop better emotional awareness, knowledge, vocabulary and self-management strategies from a younger age.

One of the girls also discussed the impact of her anxiety on her family and reporting that her parents were scared as they really didn’t feel they had the skills to help her cope. The impact of COVID-19 has seen a rise in the SEMH

needs of all students and this means parents are bearing more emotional costs as resources and provision are stretched further to meet the needs.

As an impact of COVID-19, after the initial interruption, school became virtual for a period in 2020 and girls with autism who may have received some level of support with emotional and mental health needs from school, would not have received ongoing support. Autistic girls and their parents wouldn't necessarily think about home as their place to get their emotional well-being needs met and so the last two years would have had a further impact on their health and mental health.

Sub-theme two-parental perspective: **Unexpressed emotions and worries**

leading to an increase in anxiety and mental health issues.

FG P2 ***"her bottled up emotions often come out at home as very challenging behaviours."***

FG P3 ***"now and particularly with the onset of puberty she has become more withdrawn and secretive, she worries about everything."***

FG P4 ***When she is worried she will often start stimming, clicking her fingers or moving them in a certain way. She will often get overwhelmed and cry. She will not talk to me about her worries she will only really talk to her sister but her sister is very rarely here at the moment"***

FG P5 ***"It is clear she has a lot of worries as she is very often anxious. She's not one to talk about it and if I try and discuss it she usually says she doesn't know why (presumably alexithymia?)"***

The overwhelming feeling and underlying meaning behind the parents' words about their daughters' mental health challenges were a growing sense of

helplessness at improving the situation. As their daughters had entered adolescence, they became more reluctant to confide in their parents at a time when their mental health deteriorated. Feeling very concerned by their daughters' behaviours and the withdrawal from them as parents, impacted further on familial relationships. A couple of the parents reported that their older children were a source of some comfort to their daughters as they might occasionally reach out to them when they were struggling.

Sub-theme three: Avoidant school behaviours and the impact of heightened anxiety on the flight, fight and freeze response.

OG I1 ***"I did want to move schools at some points and most mornings I would feel extreme anxiety before going."***

School, as described by the autistic girls themselves, can feel overwhelming and their only way to manage at times is to avoid a class, the corridors or school altogether using a variety of strategies; accessing the toilets, medical room or a time out card to leave the class/room or avoiding school altogether whenever it has become too much. This has been likened to being in an elevated level of stress and anxiety when the 'fight, flight or freeze' response may lead to the girls trying to avoid the stressful environment. This can lead to an immediate reduction of the stress hormone cortisol which will reinforce this response as a coping strategy but lead to greater anxiety when next facing the same stressor. One of the autistic girls explained that she 'hides out when at school' to cope with her emotions.

Parental Sub-theme three: School avoidant and reluctant behaviours-school avoidant tactics by girls due to trying to minimise/ reduce or manage their school stress.

FG P6 ***“she used her time out card only once when she became so distressed in class when she was wrongly accused of being late.... however, most times she would not want to use it as it would draw attention to herself.”***

FG P6 ***“she has always been a reluctant school attender and has used all sorts of reasons and symptoms to stay home but I have tried to educate her on anxiety and how this will make it worse in the long term.”***

One girl in the study attending a mainstream secondary school, has not been able to return since the disruption brought about by COVID-19. The parents discussed how it was often a battle to get their children to school, with many displaying physical symptoms such as being sick or shaky before school.

Independent parental Sub-theme four: **After school exhaustion and decompression**

FG P3 ***“she often storms in and goes straight to her room to decompress”***

FG P4 ***“she will go to the toilet urgently and then go straight to her room where she will unwind until dinnertime – sometimes falling asleep.”***

FG P2 ***“I always leave her to her own devices for at least 30 mins. I know she will come to me if she needs anything but I've learnt it's best to leave her to decompress. Depending on how her day has gone, she can sometimes be stressed. At the very least she's usually mentally tired from masking all day.”***

This independent parental sub-theme encapsulates the feeling of overwhelm that the girls on the autism spectrum feel after a day of school which was reported by every parent. This need by the autistic girls to come straight in and decompress in their own space before being able to take part in any aspect of family life. This exhaustion being so extreme in some cases that some girls

would fall asleep or appear almost catatonic to their parents, until they had had sufficient time alone to re-engage with family life.

Figure 5

4.10 Theme four:

Independent Girls Theme four: Searching for self- the conflicts with self-identity

Theme Four:



4.11 Autistic Girls' Theme Introduction:

This theme covered the issue of identity and was developed from the autistic girls' data. Identity is a key concept when exploring mental health issues in relation to autistic masking. It can be difficult for any young girl entering adolescence finding their identity and it is an important factor in developing a healthy self-esteem, ego and outlook on life. Some autistic people face further challenges to their identity as they often report not feeling 'autistic enough' or do not fit the stereotypes that they and society are used to. This is often the case for young autistic women and non-binary people, as the stereotype is deeply ingrained as a 'male' condition. This can be further complicated if they are masking in most of their interactions, other people may be more likely to

judge them as not 'really' autistic or 'less' autistic than others. The lack of visible role models may also impact the development of a positive self-identity as a young autistic female.

Subtheme one: What it means to be a girl/teenager on the autism spectrum?

Girls' quotes:

FG AG 1: *"I have a diagnosis of asd, but also believe I might have bpd as well after doing research. sometimes I think of autism as a negative thing"*

FG AG 4: *"I have a diagnosis of autism and anxiety and am currently trying to get diagnosed for inattentive ADD"*

FG AG 7 *"i got diagnosed with ASD and depression in the summer and I have traits of ADHD. sometimes I think other people in society see it as a negative and debilitating thing but I don't think it's all that bad because it really explains to people why I act the way I do"*

A quote from one of the autistic young people discussed the difference in autism if you were assigned the female gender at birth (afab) compared to being assigned a male gender at birth (amab).

FG AG 8 *"I don't really care what autism is, unless someone spreads misinformation about it then I have a couple of things to say. One thing I hate about stereotypical autism is that afab and amab have the same. It frustrates me a lot because it simply isn't, and autism in afab people are significantly different and need a greater level of understanding before you can even suggest something about it than amab."*

The high level of masking that exists exacerbated the conflict with self-identity - one girl talked about taking on other people's characteristics to the point where she was unsure who she even was.

The interviews with the older girls provided a richer development of some of these questions with their ability to reflect on this stage of their development.

OG 12 *"I have masked to the point where I didn't need to try. I copied mannerisms from the people I spent the most of my time with, so how I act fluctuated with who I was with the most, I now have a better sense of who I am and don't need to wear the mask as much."*

This quote highlighted the lack of self-identity consistency and cohesion that existed during her adolescence but how her sense of self-identity continued to develop beyond this time.

Subtheme two: **Lack of clear gender identity. Fluidity with sexuality as well**

FG AG 8 *"Autism is different for everyone, but only in specific parts. Did you know, it's more common to find non-binary autistic people because they find gender constructs and the social life of being described as a male or female is stupid and confusing. Just be who you want to be, you don't need to follow rules and fit in if there's no real reason for it being in place."*

FG AG1 *"I often find that my sexuality and gender identity fluctuate so sometimes I'll be a straight girl, other days I'll feel like a straight boy"*.

FG AG 5 *"I don't really know what my sexuality or pronouns are. Because of my autism I engage in other people's behaviours so tbh I am still confused."*

OG 12 *"I have masked to the point where I didn't need to try. I copied mannerisms from the people I spent the most of my time with, so how I act fluctuates with who I am with the most."*

FG AG 8“Autism is different for everyone, but only in specific parts. Did you know, it's more common to find non-binary autistic people because they find gender constructs and the social life of being described as a male or female is stupid and confusing. Just be who you want to be, you don't need to follow rules and fit in if there's no real reason for it being in place.”

The current autism profile is male dominant, but we are now seeing an emergent broader ‘female phenotype’ presentation being proposed although we have no non-binary autism profile. This re-classification is not helpful to have binary male and female presentations as many autistic people will not conform to this or the ‘typical’ gendered presentation.

Many autistic people struggle with gender identity and sexual identity can be more fluid, as well as a diminished sense of self brought about by their need to mask. Most girls by the age of 11, have developed gender identity, e.g., a girl knows that she is a girl and relates to girls differently than to boys (Gurian, 2002). This type of relating to other females may be delayed or different for autistic females. Gender stereotypes can be limiting - girls and women have traditionally been expected to be polite, kind, nurturing, empathetic and docile. A more straightforward, direct and honest approach that an autistic female may exhibit is not seen in the same way as if a male had these same characteristics where it might be considered a strength. Many girls and young women on the autism spectrum may identify less with their own gender, which can separate them from bonding with other females (Zaks, 2006). This conflict with gender identity can have a negative impact on their developing self-esteem (Lonsdale, 1997). Young women on the autism spectrum may not conform to the unspoken social rules (which are increasingly complex for adolescent girls) and if they feel

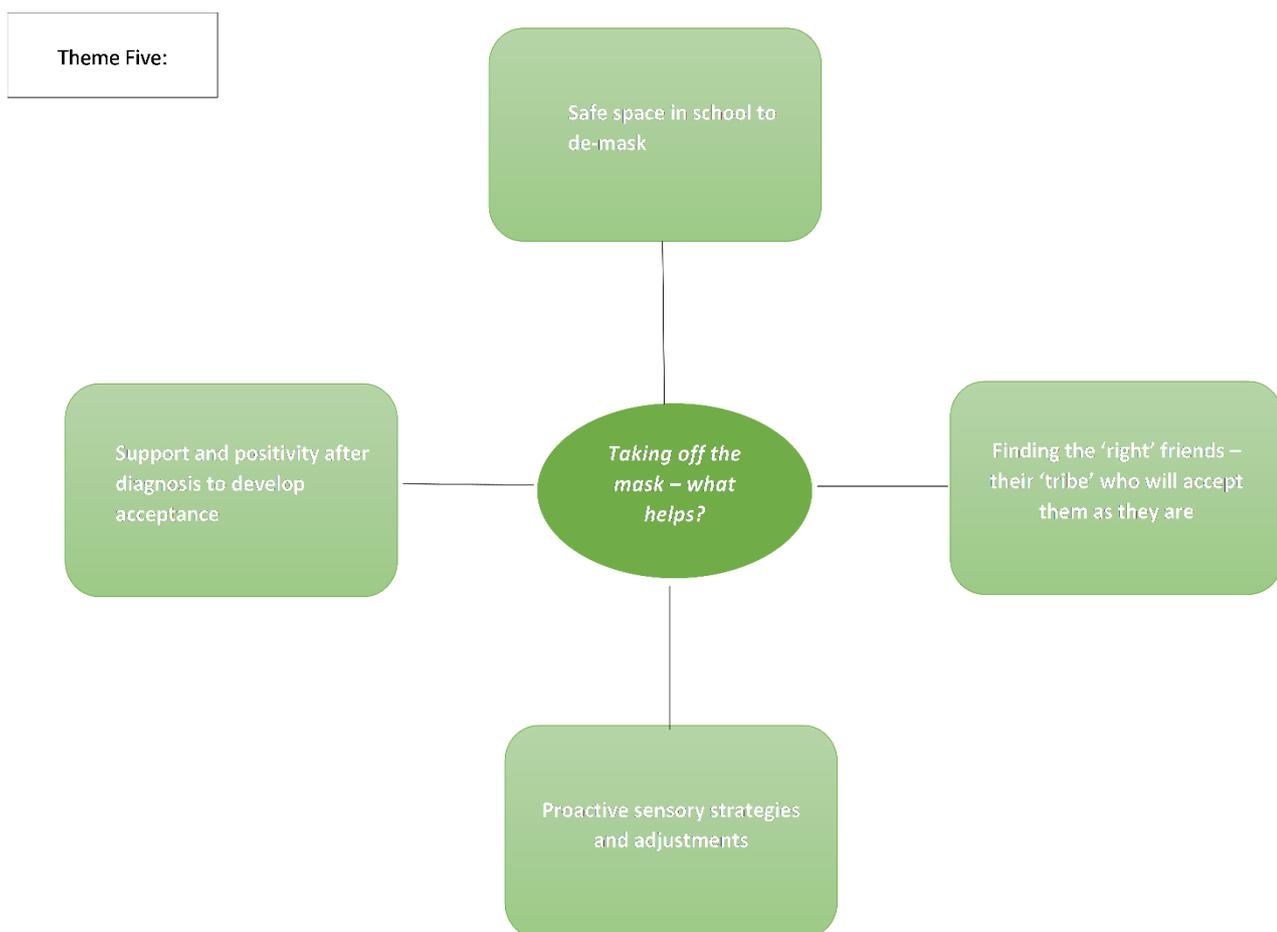
they are not fulfilling their female role, they may begin to question their gender identity, or their fears may be internalised resulting in higher rates of depression and anxiety and lower self-esteem (Zaks, 2006).

This highlights the need for future research both to ensure no groups are excluded from the narrative but also to explore any gender identity dysphoria in depth with each individual with autism. They may have a genuine desire to be considered the opposite gender than they were assigned at birth, but in some cases, it may be that the gender constructs that society have created do not make sense to them and they would prefer to be known as gender non-binary with gender non-specific pronouns such as they/them and theirs. Each case would need to be considered individually but the young person should always have access to some counselling with someone with expertise with children and young people on the autism spectrum.

Figure 6.

4.12 Theme five:

Independent Girls Theme five: **what helps us to take off the mask:**



4.13 Theme Introduction:

This theme reported by the autistic girls and young people looked at the positive factors that helped them to feel comfortable and reduce the need to mask. This was influenced by a comment from a SENCo about schools not getting their provision right for this population, so we should be asking the girls what they think would help to make a difference and involve them from the outset. The sub-themes developed this further by looking at four areas that made a difference in their lives at school and beyond.

Sub-theme one: **Support and positivity after diagnosis which helped them to develop acceptance**

FG AG 2 “My dad made me a powerpoint about myself to tell me. My whole family sat down to go through it. The powerpoint took me through the things i needed to know about autism, and stories of me as a child where my dad suspected i had autism. It reassured me on things and was a calming way to tell me. It told me all about autism and interesting facts about it, including famous people who have it. It was a really nice, emotional but interesting way to tell me, and it let the news down gently so i didn't begin overthinking things.”

FG AG 6 “i have only really found out a lot of things in the last like 3 years and i feel i have had a lot of support with my mom making anything she can to go in place to help me and i have really talked about how it made me feel”

This sub-theme was reported by only two of the younger autistic girls, but this had made a positive difference when the same two girls talked about their acceptance of the diagnosis and seemed important to highlight that by giving support after receiving the diagnosis - and framing that support in a realistic but positive way - could help the girls' acceptance and identity. This sub-theme was also reported in an interview with one of the older girls, who said that following diagnosis at the age of 20, she found support online which helped frame her autism positively and she 'felt proud to be autistic'. The other two children said how it really helped them to understand themselves and they were also proud of their diagnosis. Further comments from the autistic girls said that it helped others to understand them more following their diagnosis and another couple of the autistic girls who may not have received formal support following their diagnosis advocated the use of researching autism themselves. It is worth bearing in mind that when developing the sub-theme of theme three, looking at the impact psychologically of masking, there were several comments that

stated the reverse of this, that because they had not talked about their diagnosis with anyone this left them with unexplored feelings and ambivalence.

According to Hall, Kleinert & Kearns (2000) students with self-determination skills have more positive and successful post-school outcomes. Self-advocacy is part of the process towards self-determination, this involves educating and empowering children and young people with SEND to advocate for their own needs and determine their destiny. To begin this journey, they must receive accurate and timely knowledge of what autism means following their diagnosis, communicating both the positive aspects of their diagnosis and considering their individual strengths as well as discussing the areas of difficulties for. This education should also incorporate discussions around disclosure, bearing in mind that this can result in negative outcomes for the young person and needs to be carefully considered.

This support should draw on positive theories of psychology, rather than using the medical model of autism with its deficit model of autism but viewing their strengths as key and highlighting these as well as their specific areas of support.

Sub-theme two: Safe space in school to de-mask.

FG AG 3 ***“at my school there is a send hub witch makes it easier to focus on my breathing and i dont usesally talk to anyone there i just sit there till im ready or i would hold it in because i think ill be fine”.***

FG AG 4 ***“i sometimes feel different to a majority of my class mates but every Wednesday from 12:30-1:00pm, on our lunch break, we have a small group of neurodiverse girls that all meet together and talk about our time at school. It’s a student run club by students in the 6th form.”***

FG AG 3“*Yes in the send hub I can sit in a room and think and gather myself so when I’m feeling stressed I go there and just be myself!*”

This sub-theme was described in some way by all the autistic girls’ experiences. They needed a safe space within school where they could de-mask and ideally the school would provide that in the form of a wellbeing room or the SENCo room but if the autistic girls did not have access to a safe space, they would explore other options. The girls’ toilets were considered one such ‘safe space’ where they felt able to release some of their withheld emotions. There are consequences to this; the toilets are not an exclusive or private safe space and will be needed by the other pupils. The hygiene within a secondary school with up to 800 students is often a source of concern and it is not a space where anyone would voluntarily want to spend their time. This need for a space is not a luxury but a necessity to help them in times of distress to manage their emotional regulation. Space is often at a premium in schools, as is the availability of adults to ensure they are being safe-guarded and this is a consideration that needs to be considered. Creating a space that can be used by all students at times of distress would benefit the school population as a whole. It would also need to be discussed and agreed at a systemic level as school staff may feel like this is a non-inclusive policy to allow them a space to be alone - this may be comparable to ‘isolation’ and viewed by some as a punitive measure. In its design and implementation, the purpose of the space would need to be established - to allow a student with high anxiety to self-regulate their emotions when they choose and not enforced by a teacher. The space could be designed with this population helping to choose colours for the

wall, what could be in there and how big or small this may be. If the space is large enough there could be a few wellbeing spaces cleverly designed so they feel like they are in there alone.

Sub-theme three: Finding the right friends, their tribe who will accept them as they are.

OG 12 “I almost immediately kind of ditched that group and found another group. Who were the weird kids? Very much so and looking back, probably most of them were autistic as well and I think I kind of went to this new group as just wanting. The total opposite wanting to really not feel like I could be annoying to these people and they totally did not judge me.”

FG AG 3 “I have a small circle of close friends, maybe 3 or 4, and they're the ones that I trust with everything. outside of that is mutual friends and there's a lot of those but I don't talk to them as much as I do my close friends”

FG AG 7 “But there was another girl who i am still best friends with from my primary that doesn't go to my secondary school and i am so so thankful for her as i can just be myself around her. Our parents are best friends thanks to us now too so we go everywhere together including holidays, she is pretty much my sister at this point.”

The importance of their friendship group cannot be under-estimated in terms of feeling accepted. The latent message was that they felt grateful to have friends who would accept them as they are. One of the older girls on the spectrum discussed how she immediately felt a huge sense of relief when she found her ‘tribe’, people she could truly be herself with. She also quantified this as mostly they were neuro-divergent too. This aligns with findings in the literature review

that suggested that children and young people on the autism spectrum felt more accepted by others with SEND. This may lend itself towards more group work and activities together within schools to help them find their 'tribe', realise they are not alone and increase their sense of belonging to their school. This could also be explored further with extra-curricular clubs listening to this population and what they would like.

Sub-theme four: Proactive sensory strategies and adjustments.

FG AG 2 *"I have an autism support worker who meets me when I come in and takes me to my lessons and I have the option to go into the learning development room whenever I'm struggling."*

FG AG 1 *"The things that help me when I'm in school are a time out card, a toilet pass and being able to leave lessons to go into the learning support room"*

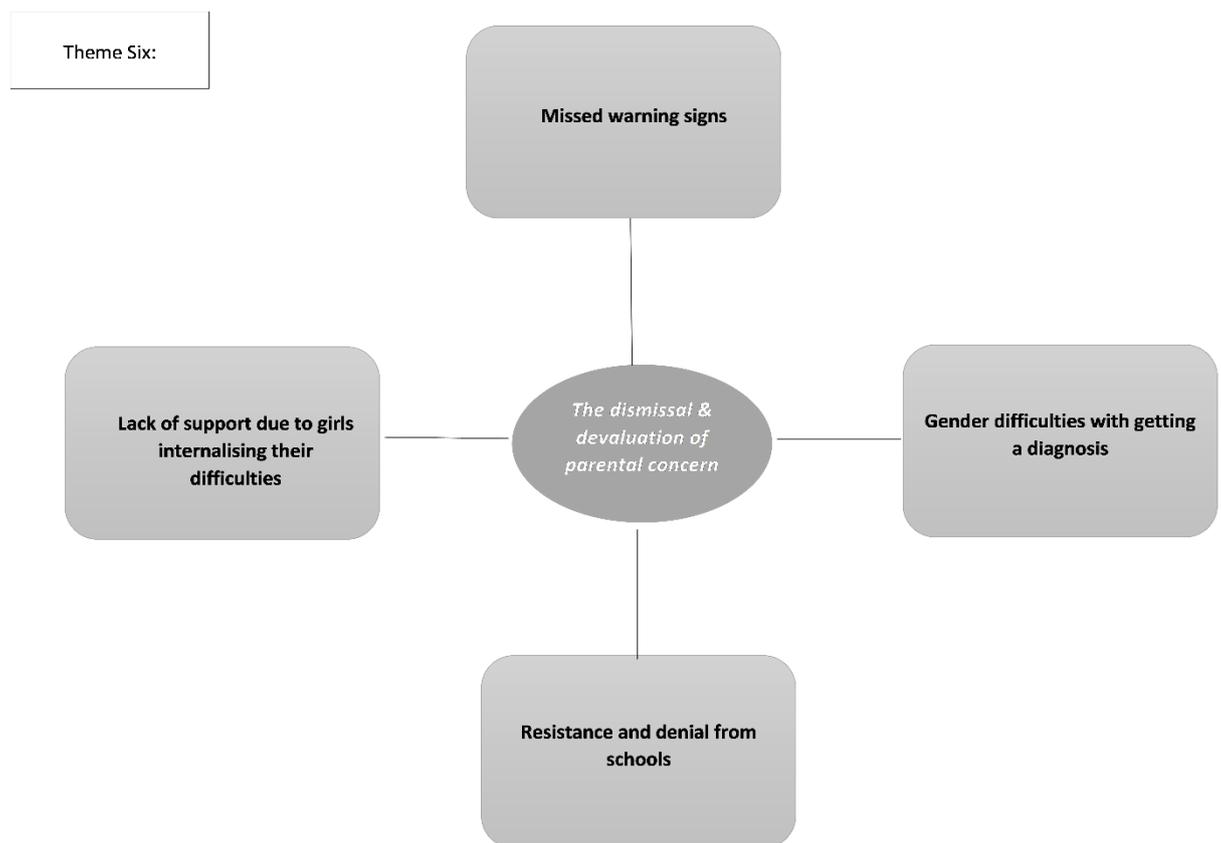
FG AG 7 *"The things I find stressful in school are the amount of children in the class and how loud that makes it. Having ear buds to pop in would really help."*

The autistic girls described how overwhelming the mainstream school environment felt, with all commenting on some aspects of the sensory environment they found difficult to manage. The noise, lights, crowds and smells were commonly cited by the girls. This is likely to be due to sensory over-responsiveness. Ben Sasson et al., (2010) characterised sensory over-responsiveness in autism by heightened and unusual reactivity to sensations. This over-responsiveness is manifested by extreme or unusual negative reactions to sensory stimuli such as noisy or visually stimulating environments (Dunn, 1997). These sensitivities can occur in every sensory domain; visual, auditory, olfactory, degustation and the tactile sense as well as in the 'internal'

senses such as interoception, proprioception, vestibular (or kinaesthetic) (Schauder et al., 2015). The same person may experience both hyper (over) and hypo (under) responsiveness to different senses. For example, they may be hyper-responsive to noise and hate any noises they perceive as too loud but be hypo-responsive to the sense of smell and seek out different smells, often the stronger the smell the better. This mix of sensory responses can also change with the context and across the lifespan.

Figure 7.

4.14 Theme six:



Independent Parental Theme: **The devaluation and dismissal of parental voice and their concerns**

4.15 Theme Introduction:

The final theme was an independent theme from the parents' perspective looking at their experiences as parents and the dismissal and devaluation of their parental voice from professionals. Research has identified the large gap that exists between the age at which parents first raised concerns and mean age at which diagnosis occurred (Fletcher-Watson et al., 2017). In some cases, parents may struggle to have their child's needs recognised by clinical services, especially if the child is cognitively able and/or skilled at masking. Likewise, autistic people who receive a diagnosis in later life often regret the time it took to identify their autism (Sedgewick, 2019).

Sub-theme one: Missed warning signs- early warning signs and initial concerns from parents were dismissed by professionals and not taken seriously.

FG P4 "She has an older brother with ASD. I had suspicions that she had ASD from age 4- separation anxiety, special interests, need for routine etc which I recognised from her brother- but no behaviour issues at that time."

FG P3 "I saw early signs at pre-school, but it was by years 3-5 and increasing meltdowns that we linked everything together.... school scoffed at our concerns"

FG P5 "we started seeing signs from as early as pre-school in terms of touch and sound sensitivity, inappropriate ways of dealing with anger, embarrassment etc plus a myriad of routines which had to be kept..."

The parents talked about their early concerns and how they were dismissed initially by professionals and teachers. Interestingly, two separate parents used the term 'scoffed at'. This devaluation of the parental voice contrasts with the SEND code of practice (2015) which highlights the need to work collaboratively with parents, children and young people in developing their support needs. The future development of the CAT Q for children may help the educational profession to properly assess a child in every context to get a broader perspective of what is going on.

Sub-theme two: Gender difficulties with getting a diagnosis – in presenting in a less stereotypical way they found it harder to get their diagnosis and were diagnosed later missing early support and interventions.

FG P4 *"If we had 30 of your daughter in our class, we'd be delighted.....this made us doubt ourselves for a while."*

FG P5 *"School made us feel that we were looking for something that wasn't there."*

FG P6 *"She was seen by a multi-disciplinary team at the time re some ASC concerns but was initially discharged as she 'seemed' to play quite well, although this was all learnt from home."*

This sub-theme while still emphasising the dismissal they felt as parents, also explored the fact that the girls were presenting differently to the teachers' perceptions of what autism looked like. They did not recognise their needs and could not identify this different presentation as autism. In particular, their exemplary behaviour in class was mentioned as was the fact they had at least one friend in school, even if this friendship was thwarted with difficulties or extreme 'closeness', and exclusivity. Difficulties reported by the parents in their after-school presentation either shocked their teachers, or the parents felt that

they were judged as bad parents and this was why their child behaved badly for them. This resulted in the parents feeling increasing isolation from the school.

Sub-theme three: Resistance and denial from schools in accepting parental concerns.

FG P2 ***“She had her diagnosis at 6 years of age, but school denied it.”***

FG P2 ***“School denied it until she had an extended period of anxiety and an attempt to take her own life at the age of 7”***

FG P4 ***“Certainly with respect to getting our concerns initially taken seriously by the primary school. Before we got the diagnosis there was no support, even actually scoffing at our concerns.”***

FG P5 ***“Yes I certainly found resistance from primary school. Lots of ‘well we don’t see anything like that at school’ as if it were just a problem at home or with parenting.”***

This sub-theme explores the denial of parental concerns and in particular the power imbalance that allows this. The parents in this research were not from ethnic minority, lower socio-economic or lower educational backgrounds. If they experience this level of dismissal, then this may be exacerbated if the child is from a minority ethnic group or from a lower socio-economic class.

Sub-theme four: Lack of support due to male dominated SEND landscape-comparing to boys who are externalising their behaviour and their limited budget to provide support for all children with SEND equitably.

FGP6 ***“my daughter will have an emotional collapse every day after school, but school don’t see this.....the toll it takes is traumatic and horrible.”***

FG P5 “***Before the diagnosis no support was given by the school.***”

FG P3 “***In primary school they felt she was doing fine in every way and would not have agreed with a diagnosis, even though she was overwhelmed and exhausted every day with a constant daily battle to get her to school and to eat anything at all...***”

The final sub-theme looked at the parents’ attempts to get support for their daughters, but this was lacking in most cases and universally before a diagnosis. This sub-theme needs to consider the current social and political landscape dominating SEND provision and the fact that externalising behaviours are much more likely to be a ‘red flag’ for support while the internalising and emotional support needed for autistic girls is being missed and unsupported. In the parents’ perspective, this is letting this population down.

Chapter 5.0: Discussion

5.1. Chapter Introduction:

This thesis explored whether autistic girls and young people educated within mainstream secondary schools used masking strategies and what underpinned the development and maintenance of these. It explored how these masking behaviours presented in different contexts, what the underlying motivations were for doing so and the consequences of using this as a coping strategy. Autistic girls have long been under-recognised, misdiagnosed and misrepresented by existing theories and strategies, leading to significant consequences. This aims to ‘give voice’ to their lived experiences and attempt to uncover a deeper understanding of masking behaviours.

In this chapter the research questions will be examined individually with reference to the results and themes that emerged from the data, existing theories underpinning camouflaging behaviours and the wider literature, as well as the current social and political context.

5.2 Research Question 1:

Why do girls on the autism spectrum camouflage during their experience of mainstream school?

To answer the first of the research questions, this study intended to find out why camouflaging behaviours develop or continue as the girls travel through mainstream secondary school. As this research intended to be aware of power imbalances and it was important to ensure no deception took place, the aims of the research were clearly stated from the outset. This ensured that the participants knew this research was relating to masking behaviours specifically and all consented to take part. Their consent implied that they had thoughts about masking and possibly used this strategy. It was also essential to refer to the parental perspectives as much of their masking behaviour may have been an unconscious response that parents have seen developing gradually over time.

Contrary to the belief that autistic people struggle to perceive other's thoughts and actions, research has found that autistic individuals are acutely aware of how they are being stigmatised and perceived by others (Rose & Pearson, 2020). This then impacts on how they then internalise this stigma and apply negative stereotypes to themselves, leading to a harmed sense of self-worth and deteriorating mental health. Some autistic individuals choose to protect

themselves from stigma by concealing and camouflaging their autistic traits, leading to tensions between concealment of their autism and disclosure, societal perceptions versus their self-perceptions and positive and negative aspects of diagnosis, suggesting support is needed in all these areas.

The first of the six themes identified in this research – **internalizing negative perceptions of others** identified how masking (in this case the suppression and concealment of aspects of their autism) developed and arose from the reactions of others towards autism in general and more specifically how they internalise others' perceptions of what autism is and reactions to their diagnosis. This also developed because of how others intentionally and unintentionally judge the autistic girls for not behaving in conventionally neurotypical ways. These findings also discuss how the autistic girls internalise reactions of others leading to negative self-perceptions about what it means to be autistic. Another key finding was their acceptance of receiving little or in some cases, no support - even while their own lived experience is that they are in desperate need.

These findings highlight how stigma theory has influenced these behaviours. Building on the social stigma theory by Goffman, (1963), more recent work has developed the concept of concealable stigmatized identities, which refer to identities that are socially devalued and negatively stereotyped but can be concealed (Quinn & Earnshaw, 2013). Living with a concealable stigmatized identity affects psychological wellbeing, (Quinn et al., 2014; Quinn & Chaudoir, 2009). Autism can be understood as a concealable stigmatized identity, particularly with the participants within this research who had all (apart from one who received her diagnosis at six years of age) been diagnosed later and they

did not have any associated learning difficulties. Individuals with concealable stigmatised identity's have two main coping strategies available to them to attempt to 'pass as neurotypical' - concealing their stigmatised identity or to 'reveal' and disclose their stigmatised identity. As the participants with one noted exception did not receive their diagnosis until later, they could not reveal and accept their autistic identity and would have had only one coping strategy available to them: try to fit in by concealing and masking their differences. This means that their masking behaviours may have started as soon as they received negative messages about their behaviours and is very likely that most had constructed some forms of 'masking' prior to beginning secondary education.

Research in this area has found that atypical verbal and non-verbal communication behaviours displayed by autistic individuals are associated with poorer first impressions and reduced intention to pursue social interactions on part of typically developing individuals across all age groups (Sasson et al., 2017). Other research has found negative societal stereotypes which are attached to the diagnostic label of autism spectrum (Dickter & Bruk,2021; Russel & Norwich,2012). Hurtful stigma towards autistic people could be elicited by both the label of autism and the behaviours of autistic people that deviate from social norms (Butler & Gillis, 2011; Gillespie-Lynch et al., 2020). Botha & Frost (2020) found higher levels of the concealment of autism associated with increased levels of internalised stigma and lower levels of social wellbeing. Finally, Perry et al., (2021) found higher perceived stigma predicted higher levels of self-reported camouflaging supporting this position that camouflaging is a response to stigma.

Many autistic girls are diagnosed later as they do not have an immediately apparent 'diagnosis' profile, so concealing their 'autistic' identity is likely to promote and protect their self-esteem, at least initially. Although concealment and camouflaging were seen as potentially helpful to protect from stigma, it has been found to be exhausting to maintain, conflicts with their self-identity by not being true to oneself and leaves stigma to go unchallenged (Beck, Lundwall, Gabrielsen, Cox, & South, 2020; Cage & Troxell-Whitman, 2019; Cassidy et al., 2019; Hull et al., 2021; Lai et al., 2017; Livingston, Colvert, Social Relationships Study Team Bolton, & Happé, 2019)

Research on self-stigma interventions from the field of mental health discuss possible interventions such as empowering autistic people to challenge negative stereotypes, constructing a positive autistic identity, developing self-advocacy skills and evaluating the pros and cons of disclosure (Yanos et al., 2015). This should be achieved in collaboration with the autistic community to redress the power imbalances that underpins stigma production. Support and positive messages that autistic girls may receive particularly post diagnosis will affect their acceptance of their autism and help develop their own self-advocacy and self-determination leading to more successful outcomes in later life. The discourses that autistic people are exposed to during, and post-diagnosis have been found to affect how they integrate autism into their own identity (Bagatelle, 2007; Leedham et al., 2020).

To achieve this, interventions targeting the non-autistic population are equally crucial. Awareness of autism may have improved globally with studies in Australia (Jones, Akram, et al., 2021), Denmark (Jensen et al., 2016), France (Durand-Zaleski et al., 2012), Korea (Park et al., 2018), United Kingdom (Cage

et al., 2019), United States and Canada (Mitchell & Locke, 2015). These show that although the general population has an increased basic knowledge of autism, the results also reflected misunderstandings and reluctance to interact with autistic people (Jensen et al., 2016; Park et al., 2018). Jones, Akram, et al. (2021) highlighted gaps between people's awareness of autism and the lived experience of autistic people, suggesting that public knowledge may be superficial and that there is a need now to move from 'awareness' to a deeper understanding and acceptance. This move towards acceptance of neurodiversity will help to remove the stigma and marginalisation that is underpinning the development of the masking behaviours.

The parental perspective also identified a theme unique to them, **the devaluation and dismissal of parental concerns** by professionals. Research has identified the gap between the age at which parents first raised concerns and age at which diagnosis occurred (Fletcher-Watson et al., 2017). The crux of missing these earlier opportunities will have resulted in these girls missing out on early intervention and support and would have continued to use the only coping strategy available to them – masking their difficulties and differences at great personal cost to their well-being.

It is important to note that the parents in this study were all well-educated, white and not from lower socio-economic status groups and yet they all experienced some level of dismissal from professionals. If this is the case here, further research and studies will need to research the issue of intersectionality to explore what level of dismissal may occur with parents from black and minority ethnic groups, lower socio-economic status and/or less well-educated and examine the impact that this may have on diagnosis and support. It is known

that prevalence figures for autism show a disparity exists between people from black and minority ethnic populations with much lower diagnosis rates. The majority of work examining this racial disparity has been carried out in the United States but has found that non-white autistic children face delays in diagnosis and are less likely to be diagnosed as autistic overall (Mandell et al., 2009). Beyond this potential bias in the diagnostic process, it has also been found to be more common that non-white autistic people are more likely to be misdiagnosed with other conditions. For example, black American boys are more likely to have a prior diagnosis of behavioural and conduct disorders or anger management problems. This disparity is present for individuals from racially and ethnically minoritized groups and has both health and educational implications (Gourdine et al., 2011; Mandell et al., 2009) black children are typically diagnosed much later (Maenner, 2020; Mandell et al., 2002) regardless of access to primary care (Emerson et al., 2016); are more likely to receive a misdiagnosis (Mandell et al., 2007; Travers et al., 2011); are seen by more specialty service providers before obtaining an accurate ASD diagnosis (Mandell et al., 2002); and begin treatment later than Caucasian children (Yingling & Bell, 2019)

To ensure attempts were made to redress the power imbalance that exists between participants and researchers, feedback on the thematic development was sought from both participant groups. The following quote from a focus group parent described her agreement with the themes:

FG AP 4 “I do also agree there is a big problem with professionals, especially in schools and especially with autistic girls as they do present differently to autistic boys.

I think they often forget that although we aren't trained professionals, we are experts in our own children and I know for a fact I have spent months upon months constantly researching neurodiversity and I truly believe that makes me an expert of my own child (and my own newly discovered neurodiversity). It's disheartening at best to be dismissed when we've spent so long connecting the dots.

I also believe there needs to be much more training for all school staff. I really don't feel they understand our children sadly."

Bottema-Beutel et al., (2020) compiled guidance to help researchers make language choices that reduced stigmatisation of autistic people and the fact the research may be published will increase its power and legacy. Dismissive language was directed towards the parents when concerns were being expressed to their daughters' schools with two separate parents both commenting that the schools 'scoffed' at their initial concerns. In this piece of research, following diagnosis, information and supportive messages were sadly lacking in almost all the all the participants' experiences. Professionals should learn to support autistic individuals when receiving their diagnosis in exploring positive aspects of their diagnosis, as well as giving them information about autism and building on their strengths in addition to addressing their challenges (Brown et al., 2021) and help increase their self-advocacy and self-esteem.

Halsall's (2020) doctoral thesis aligns with this research that societal pressures and pressure to camouflage are grounded in the social expectation that autistic people need to adjust behaviours to be accepted (Hull et al., 2017) and the autistic girls were found to be guided by their parents and educators to adjust aspects of their behaviours when accessing mainstream. This finding corroborates that the approaches and interventions used primarily to support children and young people on the autistic spectrum are tailored to make the autistic children adapt to the mainstream environment and not that the

environment and context needs to be more accommodating. The research (Cook et al., 2017; Tierney et al., 2016) also highlighted that the most successful friendships were between autistic girls and children in mainstream identified as having special educational needs (other neurodiverse pupils) enabling the girls to feel more accepted and reduced their camouflaging strategies. This was also highlighted in this study where autistic girls felt more relaxed and comfortable with likeminded peers. Milton's (2012) study identifying the 'double empathy problem' advocated that the autistic girls and their non autistic peers would all benefit from a peer education programme of neurodiversity so both populations can begin to understand each other better.

Research has suggested that autistic women and girls may have a different set of challenges regarding their social experiences but that these variations are probably driven by the social environment and gendered socialisation rather than diagnosis. Autistic women and girls don't experience different autism, they experience different conditioning. It is essential that we recognise the role that gender expectations and other intersectional aspects play in the development of one's sense of identity alongside the development of the mask. Previous research related to the intersection of autistic and gender identities have focused on one gender (e.g., Taylor, 2019). Taylor's (2019) research on female identity and autism argued that stereotypical depictions of autism and normative femininity presented "identity threats" to autistic women and girls, who experienced incongruence with such representations, resulting in identity confusion and negative self-esteem: clearly, this has a clinical relevance. However, focusing too narrowly on one gender identity risks reproducing essentialist accounts of gender, foreclosing opportunities to trace the workings

of gender as a construct. There is also research that looks at minority stress theory, which states that people with minority identities experience more stress than those who fit with the cultural majority (Meyer, 1995). Those who fit into multiple minority groups (such as female and autistic) experience more stress and this takes its toll mentally and physically (Cyrus, 2017; Hayes et al., 2011).

5.3 Research Question 2:

What differences exist in the behavioural presentation of girls on the autism spectrum (particularly relating to masking) between mainstream secondary school and their home environment?

This question sought to investigate differences that existed between school and home environments, how they presented themselves and what was driving and motivating behaviours. As a fundamental aim of this research was to gain perspectives of the autistic girls, it was important to also seek the parental views as some of these masking behaviours may be too ingrained to be at the conscious level.

The findings from the data sets looked at the different expectations and social norms placed on the autistic girls in different contexts and how in meeting the expectations they will suppress more autistic behaviour or present in a different way so not to be singled out. It also discusses difficulties the autistic girls have in their daily life switching between contexts and how during COVID-19 this caused further challenges with the delivery of the curriculum in a completely virtual way. The parental perspective also highlighted the need for decompression after a day spent in school adopting these masking behaviours.

The girls talked about the fact they stayed quieter at school than at home and generally presented a more subdued version of themselves, having learnt to mask their 'autistic traits'. They all talked about not wanting to be singled out and presenting a much quieter version of themselves at school largely borne through fear of being judged or stigmatised by their peers and others. This resonates with a piece of feminist literature about women who have learnt to take up less space than men and this coupled with their autism diagnosis (that is still struggling to be recognised) drives this need to take up even less space as a young autistic female / young person (Butler, 1990).

The findings that explored the different understandings between the minority group (autistic girls) and the majority group (non-autistic) can impact on their development of camouflaging and masking behaviours. They want to be accepted and so use different strategies such as mimicking their non-autistic peers' interactive style, even copying their mannerisms and jokes to appear more like them.

"Social identity theory posits that people's self-esteem is highly influenced by others' views of their social group" (Tajfel & Turner, 2001).

Tajfel & Turner's work on social identity theory illustrates the need particularly at this important phase of their development to 'fit in' to a social group and to find their own tribe. As so few girls are diagnosed comparatively to boys and they may never have met another girl on the autism spectrum, they base this desire to 'fit in' with their non-autistic peers who research has identified (Halsall, 2021) instinctively recognise their subtle differences even when masking, which

can lead to subtle victimisation and bullying, for example being excluded from the group or jokes made at their expense.

(Nario-Redmond et al., 2013) research found those who embraced disability or neurodivergent differences as a key aspect of their identity were more likely to demonstrate and predict higher self-esteem. It is notable that many autistic adults described autism as a positive part of their identity while many autistic adolescents did not. The current literature suggests there may be some age-related differences in autistic identity development. Cresswell & Cage (2019) found stronger alignment with non-autistic culture linked to more positive self-perceptions among autistic adolescents in comparison to the findings with autistic adults. This highlights the need for and importance of building a positive autistic identity as early as possible, embracing the positives of receiving a diagnosis, identifying similar pupils that could support one another and ideally this needs to be established by secondary school.

The double empathy problem can be one way to think about the key issues at the social level in secondary school and Milton's theory (2011) is based on the misunderstandings from social interactions and communications between the autistic population and the non-autistic population. It is a 'double problem' because both people experience it, and it is not located with only one person or group. This can lead to further stigmatisation and 'othering' of the autistic population. If there is a breakdown in interaction, or a failure to communicate meaning, a person who sees their interactions as 'normal' can denigrate those who act or perceive things differently (Tajfel & Turner, 1979). This also locates the problem with the other person and absolves the non-autistic person of

responsibility and the autistic person as being further marginalised or 'othered' (Said, 1978).

Viewing the social difficulties through the lens of the double empathy framework highlights the importance of social interventions targeting the non-autistic population as well and promoting a broader neuro divergent acceptance by all secondary school students. As previously discussed, this needs to consider broader societal acceptance of neuro diversity as well.

The findings also highlighted key sensory processing difficulties for this population. Sensory over-responsiveness (Sasson et al., 2010) can be present from early on in their development, but many (especially undiagnosed) autistic people are told they can't possibly be experiencing what they claim by a non-autistic population who have never heard the sound of electricity running through the walls or been triggered by the flicker of the fluorescent lighting. Autistic people can develop anxiety around what each new room or environment will look and feel like to them. This can become another obstacle to daily life for many autistic people, they may avoid any aversive sensory input which can impact on their ability to leave their homes and enter different sensory environments. This illustrates how difficult switching between environmental contexts can have on the autistic population and how the ingrained masking may appear from a very young age, creating more internal cognitive dissonance about what they are experiencing and what they are told they should be experiencing.

Different sensory environments were a significant factor in the self-reporting of the girls' feelings of anxiety. Avoiding certain areas of the school and becoming

distressed at times by aspects of the school day, such as the noisy and busy halls or the journey to and from school could impact how they feel for the rest of the day. This underlying feeling of sensory overwhelm could be one of many factors contributing to the girls' elevated anxieties and distress which they then suppress. Proactive sensory regulation could be one way of helping the girls achieve a better equilibrium with well-being rooms, sensory breaks, calming activities and quieter spaces for them to access. In light of the increased financial stress of SEND budgets, this could be allocated as a provision directly from the SEND budget to benefit this group of students - but also every student in the school may need to access this space at different times in their school career. Both parents and students acknowledged that where their school had made small, reasonable adjustments such as letting them wear earphones or slight adjustments made to the uniform expectations, this made a big difference to being more able to manage the sensory environment.

5.4 Research Question 3:

What are the costs and benefits for girls on the autism spectrum attending a mainstream secondary school in adopting 'camouflaging' or 'masking' strategies and does this lead to less support/interventions being offered and made available?

This can be best considered and answered with some of the responses from the shared theme from both the parental and girls' data, '***The Psychological, Physical and behavioural impact on health and well-being***'. This theme looked at the consequences on their physical and mental health but also the impact it had on behaviour - from the perspective of developing school-avoidant

behaviours and from the parental perspective of their need for decompression immediately following their return from school.

To examine this further the impact masking has on their anxiety and mental health issues will be considered. This area had the most overall codes derived from all the participants (parents and the autistic girls) highlighting that their significant emotional needs were largely going unmet. 100% of the participants reported on their psychological well-being and how this needed addressing, but in almost all cases they were not receiving any support in this area. A couple of the girls disclosed thoughts of, or actual attempts of self-harm and one parent reported her daughter had attempted to take her own life. These girls need support from the earliest stage with their mental health needs, when concerns first arise regardless of a diagnosis.

The research that exists in this area aligns closely to the findings from this study. Cassidy et al., (2019) research with 160 undergraduates, most of whom were female 86.9% found camouflaging of autistic traits is associated with thwarted belongingness and increased lifetime suicidality. Dean et al's., (2016) research summarised that if practitioners continue overlooking subtle social challenges and internalising behaviours then camouflaging is not a protective factor and will lead to increased anxiety, greater mental health difficulties as well as lower academic performance and a higher level of school absenteeism.

Most of the emerging literature in this area suggests that masking is associated with mental health problems, and that the more someone masks, the more likely they are to experience mental health problems. Research is beginning to find potential long-term consequences to masking including identity issues,

imposter syndrome, eating disorders, anxiety, depression, cognitive dissonance and self-harm as well as increased suicidal ideation. The associations that have been found are correlational at this early stage rather than causal and must be treated cautiously. This highlights the need for more research in this area such as with this study.

The findings also identified difficulties that the autistic girls were having with sleep and menstruation. Adequate sleep has been associated with good health (Chen et al., 2006). Autistic adolescents are particularly vulnerable to lifelong sleep problems irrespective of their IQ (Richdale & Schreck, 2009 pp403-411), most commonly sleep onset delay, frequent nocturnal waking and shorter overall sleep duration (Malow et al., 2006; Miano et al., 2007). Several research studies report that sleep disturbances impact on daily functioning including low mood and elevated stress levels (Taylor et al., 2012). There is limited research on successful interventions and education to help autistic adolescents sleep better. Increased recognition of what helps autistic adolescents sleep better would have benefits for reducing depression (Lovato & Gradisar, 2014 pp521-529) and anxiety disorders (Willis & Gregory, 2015 pp125-131). Sleep has also been identified as a strong predictor of quality of life (Pavlopoulou & Dimitriou, 2019a p296) so identifying ways to improve autistic people sleep must be prioritised. The autistic girls and parents discussed issues that the autistic girls had with sleeping, reporting heightened anxiety about sleep where they would begin to ruminate on the day, others reported early waking, awakening during the night and being unable to get back to sleep. This poor quality of sleep tends to be the norm rather than the exception with this population and will

undoubtedly and as research shows play an interactive role in how well they can cope at school the next day.

Heavy and painful periods were also reported here - mainly from the parents who all commented on how their daughters suffered. This is an area that is greatly under-researched, however, there are some studies that have researched developmentally disabled women and compared them to non-disabled women (Ditchfield & Burns, 2004; Rodgers & Lipscombe 2005), and found frequent reports of painful periods (dysmenorrhoea), heavy periods (menorrhagia), menstrual hygiene issues and cyclical mood and behavioural changes akin to pre-menstrual syndrome (Burke et al., 2010). Little is known about the menstrual experiences of women and girls specifically on the autistic spectrum. The few existing studies report marked changes linked to menstruation in autistic girls and women including cyclical self-injurious behaviours (Lee, 2004), mood symptoms and emotional dysregulation (Burke et al., 2010) and an amplification of autistic symptoms and repetitive behaviours (Hamilton et al., 2011). A more recent study (Steward, Crane, Roy & Pellicano, 2018) suggests that in line with this existing research, autistic people's menstrual experiences are distinct from non-autistic people placing additional extra strain on what is already a more challenging life. The participants in Steward et al's (2018) research reported overwhelmingly negative experiences, heightened sensory sensitivities, greater executive dysfunction and worse emotion regulation problems including shutdown, withdrawal and heightened anxiety. It is critical that future research is done in this area to understand the prevalence of these menstrual symptoms and their causes. One study (Obaydi & Puri, 2008) found it may be related to higher levels of hormonal fluctuations

and their impact, but this needs further investigation. One important step to help support autistic girls with dealing with menstruation is to increase their knowledge of menstrual related issues and equip them with strategies to deal with pain and mood changes. This is especially important for autistic young people as they are less likely to gather information about this topic from their peers (Steward et al., 2018).

In the earlier discussion, the different types of masking described by Sedgwick et al., were explored - one of these is instinctive masking. This is when a fear response deep in the brain sets off a survival instinct, similar to people who have experienced trauma and who can be hyper-vigilant to possible threats. Some people compare this to the 'fight, flight or freeze' response, which is the deep-rooted survival instinct to either fight off a predator, flee a predator or become still if we saw a predator and not to draw attention to ourselves. In developing avoidant school behaviours, the autistic girls have entered the 'flight' part of this response. They want to avoid the situation causing them heightened anxiety by fleeing or avoiding it. There were several behaviours identified by the autistic girls and their parents that could be described as an avoidant strategy, not just school reluctance and attendance issues but also using the toilets or the SENCo or pastoral room as a safe space to escape. One of the girls in the study attending a mainstream secondary school has not returned to school since COVID-19. There is currently a lot of discourse and anecdotal evidence among the EP profession that since COVID-19, there are increasing numbers of girls with very heightened anxiety unable to return to school. There is no official research or existing statistics to examine if this is impacting more on girls with a diagnosis of autism or who would meet the diagnostic criteria.

Department for Education (DfE) statistics pay little attention to gender and other pupil characteristics regarding exclusion. Growing evidence suggests that girls are more likely to self-exclude or experience informal exclusion (Osler et al, 2002), girls are also more at risk of early exits and school moves than boys (Social Finance, 2020). The highest rates of exclusion for pupils are for those with Social Emotional and Mental Health (SEMH) needs, which as demonstrated reflect this population's needs (Graham et al., 2019).

A mainstream secondary school SENCo who was working in the London Borough of Islington in 2019 reported: "***we just haven't got it right yet for girls with autism***".

Mainstream schools are in most cases aware that they are "not quite getting it right" for this population and attempting to rectify this, but there needs to be more research to ensure that this population receive the correct support, as well as more education for teaching staff about differences in autistic presentation. It is important that autistic girls do not continue this trajectory which leads to more emotional based school avoidance, self-exclusion, poorer academic outcomes, poorer life outcomes including being in sustained employment as well as the increase in their social and emotional health needs being under recognised and unsupported. There needs to be increased understanding from educational professionals into the way this population may present, this is where earlier recognition and earlier intervention and support are crucial. The doctoral thesis by Halsall (2019) explored how autistic girls attending a specialist resource base attached to a mainstream school masked more within the mainstream school environment and discussed that some of the support afforded to them by attending the specialist resource base could be replicated

in a more accepting mainstream culture. A positive aspect of a specialist school may be to get more of the support they need, but at the risk of being excluded from their local community. In mainstream education they are not yet fully accepted, understood and supported. There is also a shortage of specialist places available and within the broader context of inclusion and since most of the girls do not have an EHCP, this will also have an impact on their ability to access these provisions. It is therefore essential to improve the provision in mainstream.

Psycho-education with this population to teach them how to recognise their emotions, their anxiety and their 'fight, flight and freeze' response could go some way towards supporting this group. Teaching in small groups vertically across year groups so they gain different perspectives about cognitive behaviour strategies, emotional regulation strategies and how they can help to recognise their anxiety and their fight, flight and freeze response and learn to manage it for themselves may help them be better equipped to meet their own needs throughout their life span. This could also include the proactive sensory regulation strategies and mindfulness to help them recognise and respond to their own sensory signals when they need a time out break.

Another finding identified by the parents' data this talked about the ***After-school exhaustion and decompression*** that the girls needed after their return from school to their home environment.

This encapsulates the feeling of overwhelm and overload that the girls on the autism spectrum feel after a day of school and the impact of their ingrained, instinctive, and conscious masking, and was reported by every parent. It also

encapsulates how all the factors outlined in this discussion interact and impact on each other leading to greater levels of anxiety and stress. This has become colloquially known as the 'four o'clock time bomb' which informally describes the circumstances that all the parents reported following a day of school. Effectively the rapid removal of the mask that they have held in place all day to cope can be released as soon as they are at home and in a safe place. It is important to think about the impact that this has not just on the autistic girls but on their whole family. Parents who witness this daily and who are then disbelieved by the educational professionals, can feel at best disheartened, but at worst it can impact on the entire family's mental health and well-being. Statistics show there is a higher likelihood of relationship breakdown when there is a child with autism (Hartley et al., 2010) and siblings may lack the attention they need at times too.

In thinking about some of the consequences to masking I have included the explorations about searching for self. This encapsulates their self-identity as a young autistic female. Identity is a key concept when exploring mental health issues in relation to autistic masking. It can be very difficult to have a healthy self-esteem and outlook on life if you are struggling to know who you are and what your true or authentic personality is. 'Imposter syndrome' has been termed the recurring fear of being discovered or exposed to be a liar or fraud and can be a side effect of long-term masking. If someone is engaging in conscious masking, they may feel like they are lying to other people and be scared that they will be found out. Some autistic people have described how they have had to 'come out' as autistic (Davidson & Henderson, 2010; Smith & Jones, 2020) after concealing their identity. Participants also described feeling disconnected

from the label of autism and searching for other explanations and co-existing conditions as they felt they did not feel autistic enough. This being more common among women and girls on the autism spectrum and non-binary people as they do not fit the stereotypical presentation. Instead of using knowledge of atypical presentation of autism to acknowledge that autistic people are likely to present in several different ways, we risk simply shifting the goal posts to a different set of limiting criteria by calling it a 'female presentation'. This could potentially lead to further difficulties in recognising men/ nonbinary people and who present a profile more in line with the 'female' autism or excluding women/nonbinary people who do not fit the 'female autism' profile. The creation of subtypes can lead to additional stigma manifesting.

There is a dearth of research in the area of non-binary people and autism and gender dysphoria, although one systematic review of the literature by Thrower et al., (2019) has been conducted finding some evidence suggesting that autism and ADHD are more prevalent in the transgender community. Further rigorously designed research is needed to examine the prevalence of autism amongst people with gender dysphoria and add to the paucity of research. People with neurodevelopmental conditions and gender dysphoria should be supported in the strengths of neurodiversity and gender diversity and reassured that these conditions do not preclude any forms of affirmative clinical care (Turban and van Schalkwyk 2018). One argument presented here by one of the participants was that typical gender constructs do not make sense to the child or young person with autism which may lead to them questioning their own gender identity.

5.5 Research Question 4:

What are the supportive factors that were identified that have helped support the autistic girls to feel more accepted/ more supported and need to 'mask' less?

The final research question attempted to find out what supportive factors were identified, and whether this knowledge could be used to start drawing some of the research together and provide recommendations for mainstream schools.

Some of the positives the participants discussed included being given information about their diagnosis which helped a couple of the participants to feel they could view this in a more positive way and accept their neurodiversity more quickly. These views, although only expressed by two of the participants, helped to highlight the difference this could make to the population. Most of the parents commented on the fact their daughters were reluctant to disclose their diagnosis and had trouble initially accepting it. This was not the case for the two who had received some support and information. Within the context of schools' funding this only needs to be a relatively short piece of work, but the benefits could be far reaching.

Having a safe space in school to take off their mask and relax was very important to the participants, when this area was not identified or available, they would try to create their own by using the girls' toilets as a safe space. This is not ideal within a busy school and highlights the fact that a space like this should be more commonplace. Ideally somewhere they can feel free to de-mask with a key adult they trust and have built a good relationship with. One of the

participants disclosed the importance of being with a group of fellow neurodiverse girls once a week where she felt she could be herself. Halsall's doctoral research also highlighted that the girls with autism found it easier to be themselves and make friends with other children within the school identified as having SEND needs. This kind of shared space could become invaluable in not only increasing the girls' sense of belonging but in forming some more positive friendships.

Autistic girls described the relief and gratitude they felt once they had found their tribe of friends, who accepted them as they were and how this made the biggest difference to them. Again, this finding highlights the importance of meeting other neurodiverse children within the school to help build a sense of community and belonging with children and young people with whom they feel they have something in common. Relating this back to social identity theory by Tajfel and Turner, identifying with their autistic peers, (minority group) as opposed to their non-autistic peers (the majority group) could bring benefits to them as a group and on an individual level.

There was also a consensus here from the children and their parents on the need for making sensory adjustments and this was viewed in a more positive way with schools identifying and making reasonable adjustments that made a difference to the children and young people. However, there was still more that could be done. Identified areas that were more difficult for these children included the crowded corridors during the race to get to the next lesson, the dinner hall with the noise of the students and the sensory onslaught of the smells and noises.

Chapter 6.0: Conclusion

6.1. Chapter Introduction:

In this chapter, the findings will be summarised with novel insights that this research has elicited, including a discussion of an internalising vs an externalising presentation and model of autism.

The strengths and limitations of the research will be covered before drawing this to a conclusion with the implications for the EP profession. This will utilise the Bronfenbrenner framework (2005) to discuss the EP implications at all levels. This chapter and thesis will conclude with suggested recommendations drawn from this research and the existing literature, thus giving 'voice' and agency to the autistic girls before considering the possible barriers.

6.2 Research summary and conclusion:

The findings presented some novel understanding and insights into the way autistic girls and young people begin to mask before even being consciously aware of it, in response to societal, gendered expectations and unconscious prejudice and stigmatisation. This continues into their secondary experiences bringing new challenges and the recognition finally that they are on the autism spectrum. This diagnosis is not always met with the support they need to help them to navigate mainstream secondary successfully. In part, this will be considered within the discussion of a more internalised presentation in the current context of inclusion and SEND funding - with schools being transparent about the fact their staff and resources are being deployed elsewhere, usually

with a focus on externalised behaviours. This male-dominated SEND landscape means that girls' needs are continuing to go unmet. They are internalising difficulties to the point that they are self-harming, unable to participate in family life on return from school, having thoughts of suicidality and being unable to know how to manage their emotions on a daily basis, which are all being exacerbated by difficulties associated with their autism profile. Sensory, social, academic, sleep and menstruation issues are all interacting and impacting on their social and emotional and mental health. The green paper highlights the costs of not recognising and accurately identifying and supporting SEND needs which will have greater long-term costs and implications for society. As a woman and a mother to a girl on the autism spectrum, this has clearly driven this research but in doing so I have given a voice to this hard-to-reach population to explain in their words what is needed. In failing them, we are failing all autistic girls and some boys too by minimising their need for support just because their difficulties are being aimed inwards at themselves rather than externalised.

An internalising presentation vs an externalising presentation.

In conclusion, the dominant model of autism was based on the 'typical' male presentation, both in the historical context through which the original conceptualisation of autism was developed and later through the over representation of males through the diagnostic process being based on this model of understanding. This in turn has led to their dominance in existing research and this informs the targeted interventions and supports on which they are based. This may fit some individuals on the autism spectrum of both

genders and non-binary people but should not be the only classification in our understanding of autism.

It would be dangerous to conclude this is the definitive 'male' or even 'typical' presentation for males, not all males will fit into this presentation style and many males may also present with a more 'internalised' presentation, with masking and camouflaging being present in this population too.

A re-classification of autism should be seen in light of an 'internalised' and 'externalised' presentation with subsequently newer diagnostic tools to meet both representations equally. The Cat Q (developed for adults) is currently being redeveloped and trialled to develop an additional measure for children by Dr Sedgewick and Dr Hull. This could be further developed to identify a more internalised presentation of autism that will help earlier identification of this population who have been under-diagnosed, later diagnosed than compared to an externalised presentation or missing completely from the diagnostic pathway and research and supports that exist. This all needs to be carefully considered in light of intersectionality and the under-representation of certain minority and ethnic groups from the existing diagnostic data. As the 'internalised' presentation carries a significant cost to the mental health of this population, it is essential that more research is done with full participation of this group. Under representation has led to them not receiving adequate or timely support or receiving support that is not fit for purpose for a group who do not wish to draw any attention to themselves. Supports need to be designed across all age groups to truly celebrate neurodivergences and differences, with better help from all professionals at the time of diagnosis, allowing them to celebrate and accept their autism and challenge the negative stereotypes that exist. The

cultural shift must be addressed with all schools and all pupils to address the 'double empathy problem' that exists in society. Autism awareness has increased but autism acceptance is still in its infancy. The 10 key recommendations (Table 5.0) which should be considered are drawn from this research and the other literature but as autism research with this population is still in its relative infancy these may need to be altered and amended as new research comes to light.

6.3 Strengths and Limitations of this Research:

Strengths:

As one of the principle aims of this research was to empower autistic girls, this was considered carefully **at every stage** and designed so that the girls' findings were reported first in the results section. My ontological approach and position ensured I considered the power dynamics very carefully and this is referred to throughout this paper. Considering the difficulties that this population have in expressing their views to an 'outsider/researcher' a further strength to this study was gaining the parental perspective to elaborate on how their daughters experience both mainstream schools and to gain their perspectives too.

A further strength was having two older girls' perspectives by interviewing them with their retrospective experiences of attending a mainstream secondary school and this elicited in both reports a lot of additional detail and data which could have been further developed with a few more interviews of this age group. Potentially the parents could also have been approached for interviews after they disclosed their own autism diagnosis. Finally, although recruitment to the study proved difficult, the result is that this thesis will start to redress the lack of

autistic girls in the research that does exist, and this will help to promote better identification, education and support in the future.

Limitations:

One of the limitations to this study was the difficulty recruiting a large enough number of girls on the autism spectrum and parents to take part in the study. This makes it difficult to generalise the findings although the research does align with other studies in this area increasing the confidence and importance of the findings. However, the views cannot be considered representative of all autistic girls in mainstream as only those that could access the virtual focus groups and did not have any difficulties that through their ICT competence and literacy skills could participate. The fact that the second focus group took part in school may also have impacted their findings as their anxiety may have been high and they may not have felt they could express their true thoughts and feelings while being supervised by the SENCo.

The site Piazza, while secure with on-site technical support, was not designed necessarily with modern teenagers in mind. In hindsight a more teenage friendly tool like 'WhatsApp' may have seen better participation and engagement with their answers and interactions with other's posts.

A further limitation to this study involved the fact I did not fully explore parental views in light of when they had their own diagnosis, and this could have added more depth to the data. There were also challenges inherent to successfully eliciting the autistic girls' perspectives. (Beresford et al., 2004) outlined limitations of using semi structured interviews with children and young people

with social communication difficulties and significant levels of social anxiety, I tried to control for this by using an online focus group with the questions already presented to them (and in discussions this being a preferred format) but this did not facilitate much interaction between them. With hindsight and without the impact of COVID-19, it would have been beneficial to meet the girls personally and devise some activities that would have developed some group belonging and bonding before asking them to interact (albeit virtually) with each other.

A further limitation through difficulties with recruitment meant that no additional measures were used, such as assessing their executive function skills using the BRIEF 2 to explore any relationship between EF skills and masking.

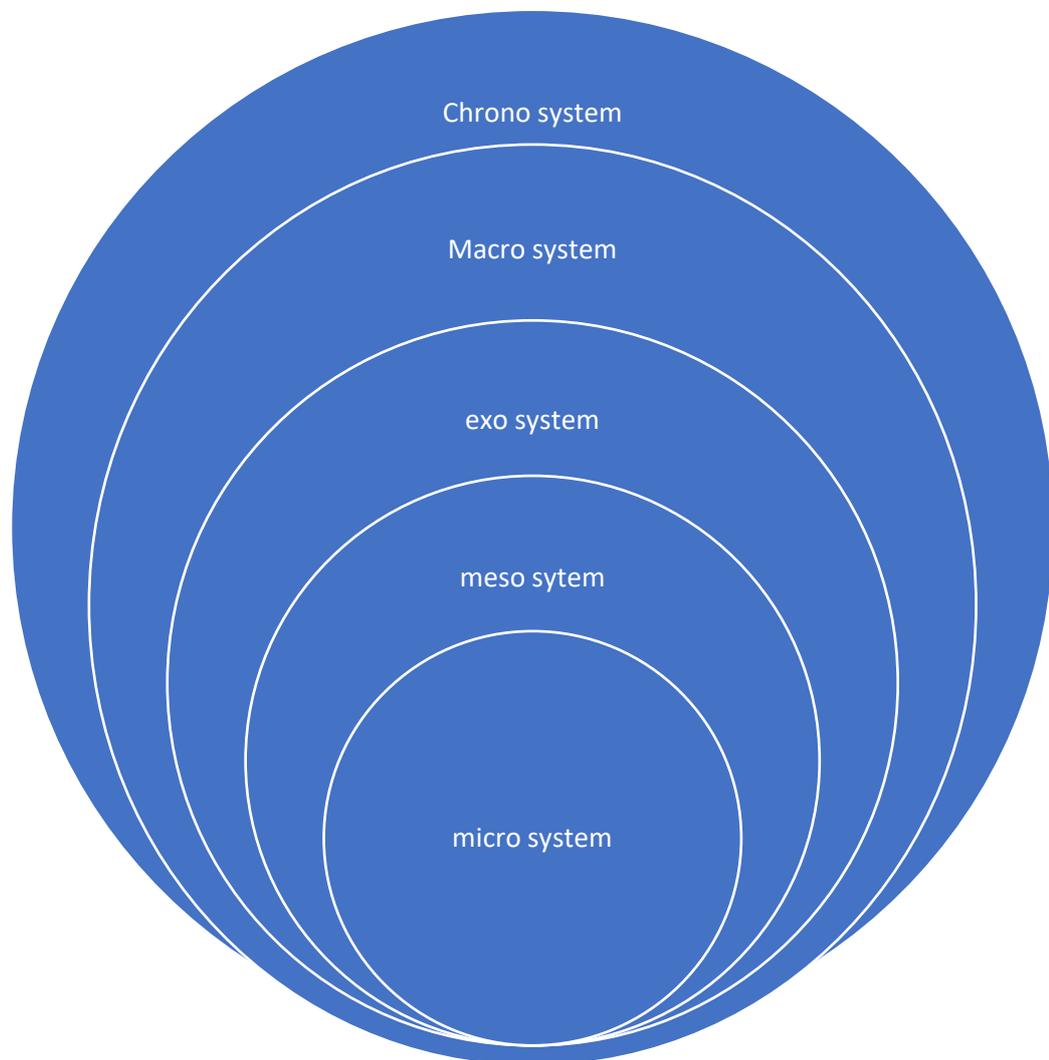
6.4 Future research directions:

Research in the areas of gender dysphoria and autism spectrum is one key area for future research. There is currently a paucity of research in this area. Further research into the area of intersectionality should also be conducted, this study has found how girls on the autism spectrum feel marginalised and may suffer further stress as a result, but this leads to further questioning about the impact of belonging to multiple minority groups such as being female and autistic and black and gay. It is critical future research is done in this area to understand the issues that intersectionality may have on this population. It was also identified through these findings the prevalence of menstrual pain and associated symptoms within this population and further research in this area would be beneficial. It will also be essential that further research is conducted to look at masking behaviours from even younger ages. Finally, research is also needed to examine the resistance from autistic girls towards accepting support.

6.5 EP Implications:

This study highlights the missed opportunities for early identification and support for autistic girls, due to camouflaging of their autism needs, a less stereotypical presentation of autism based on the male conceptualisation and the dismissal of early concerns voiced by their parents. As an EP it will be fundamental that we consider the findings on several levels; at a systemic and societal level as well as at a family level and at an individual level of providing appropriate interventions and support. This will be considered within the bio-ecological model and framework provided by Bronfenbrenner (2005) to explore the different systems that need to be considered when influencing a person's development and behaviour. These relationships are bi-directional.

Figure 8. Bronfenbrenner's Bio-ecological model



In utilising Bronfenbrenner's model, each system will be discussed from the outside in, beginning with the chronosystem which is the impact of time on development and understanding. The macrosystem incorporates factors at the broader cultural and societal level. The exo system includes more distantly related contexts that may not interact directly with the child/young person such as CAMHS and SS. The meso system explores the relationships that exist at

the micro level and the microlevel is the most immediate context for the child or young person including their family, home, peers and school context.

The chronosystem

As EP's it is paramount that research informs practice. A key implication for EP's is to ensure that as more research emerges over time and as more knowledge emerges from the research that we disseminate this knowledge by providing training for other EPs and professionals, aiming to develop professional and in turn societal awareness and knowledge of camouflaging and its consequences. This should be supported by EPs' commitment to developing the knowledge base regarding autism and its impacts on all aspects of school, including social interaction, learning and their mental health and well-being.

The Macrosystem

At the macrosystem level the broader social and political system in which the autistic girls are situated has been discussed in depth, exploring factors such as the political framework of inclusion and the lack of specialist provision to meet the needs of all pupils with SEND. This is also informed by the prevalent discourse that exists, where autism is defined using the medical model of disability using a deficit model of impairments. It is therefore the EP's role to help change the perception of autism using 'The Social Model of Disability', (Oliver, 1986). This perspective recognises that increased acceptance of neuro divergence and difference is fundamental to reducing individuals desire to camouflage. It is therefore essential that EPs work on a systemic level to

promote wider levels of change, supporting both the inclusion of autistic girls and developing a culture within schools that truly celebrates diversity and explicitly promotes acceptance of difference. This will reduce the need to camouflage and reduce the negative consequences associated with camouflaging.

The Exosystem

The negative consequences of camouflaging have been explored and include the autistic girls increased vulnerability to experiencing mental health difficulties. This research study has found that the girls are camouflaging these difficulties so that their schools remain unaware, and this limits their ability to offer support and provision to this vulnerable population. EPs through their unique positioning within the system, positioned between education and mental health services can explore this further using assessment tools designed to recognise early signs of mental health concerns, enabling them to offer evidence-informed interventions promoting their mental health at an earlier stage. At a broader level EPs have a key role increasing awareness and promoting inclusion at a systemic level throughout the school and wider communities.

The mesosystem

At the meso system level, as an EP it will be necessary to consider the impact of the autistic girls camouflaging behaviours on the family unit. Due to the child's ingrained and instinctive masking at school and the dismissal of parental concerns which have been cited in this research, this leads to their under-recognition by school and their lack of support and provision. The impact that

this has on the family will inevitably lead to them feeling more isolated and segregated from the school and from support and erroneously thinking their parenting may be to blame. A key strength of the EP role is the positioning within the child's mesosystem; using consultation models to work collaboratively with the child, key school staff, and families to gather information, hypothesise and agree outcomes (Beaver, 2011). This means that EP's can explore and bring the individual components of the system together using a consultation framework to consider the different behaviours in different contexts and what this might be communicating about the environments where these behaviours occur most. In time, the EP may utilise a tool such as the CAT-Q for children which would be able to assess their levels of camouflaging in more detail in the different environments.

The microsystem

At an individual level, EPs need to consider the intervention package and support that is recommended to schools when supporting autistic girls, how they would prefer to access support and involving them in their planning by using person centred planning. To fully represent the young person's views within the person-centred planning that the EP and school may implement, including the voices of autistic girls is fundamental. From this research it is clear that they may not feel comfortable in putting their views forward within a multidisciplinary or professionals meeting with the subsequent power implications and their desire to 'fit in' to their society. This will mean careful consideration will need to be given by the EP to the methods of collecting the views of the autistic girls first so that these can be represented within a meeting. The young person would benefit from having time to process the questions and

reflect on them before meeting with the EP separately who can then share their views with all stakeholders.

Current interventions and support have been designed with a more stereotypical presentation of autism in mind based on the conceptualisation of autism that currently exists. This includes interventions that focus on the deficit model of autism and looks at ways to help the child with autism 'fit in' to the mainstream culture and this will only exacerbate their need to camouflage as the implicit message that they are being given with these interventions. Social skills training, social narratives, cognitive behavioural instructional strategies, functional behavioural analysis and video modelling are some examples of evidence informed strategies and interventions for children on the autism spectrum, but these will need to be tailored to each individual's needs. Some of these strategies could be said to be teaching autistic students how to fit into a neuro-typical world, which may lead to the inherent prejudices they already face.

Extracurricular clubs in schools designed to help promote social interactions have again been largely designed with the male conceptualisation of autism in mind, with Lego clubs and gaming clubs as examples of this. To fully promote the inclusion of all children and young people on the autism spectrum, there needs to be a greater diversity of clubs so that all children are considered and clubs designed specifically for this population would help increase their sense of belonging.

6.6 Suggested Recommendations:

From the findings and the identified literature, it is possible to draw some of this together to make some suggestions and recommendations to schools about what could have a positive impact on this population.

Table 5.0 Key recommendations drawn from the research and this study:

10 Key recommendations from the research and this study:	
	What is the recommendation? How can it be implemented?
1	<p>Proactive sensory regulation strategies:</p> <ul style="list-style-type: none"> • Well-being rooms • Regular calming sensory breaks • Access to quiet spaces • Reasonable sensory adjustments • Seating arrangements • Uniform adjustments
2	<p>Support immediately following diagnosis with a structured positive programme designed with autistic people to help autistic adolescents to accept their diagnosis.</p>
3	<p>Increased training for all school staff on the different presentations of autism and the recognition of 'masking', including the importance of listening to parents concerns and not dismissing these so that pupils receive earlier diagnosis, support and interventions.</p>
4	<p>Support and information with menstruation and puberty.</p>

	<ul style="list-style-type: none"> • What is normal? Puberty? Body changes? Terminology? Flow and duration of periods? Do they have the vocabulary to express this? Someone to ask? • How to manage hygiene during periods. • How to cope with mood changes and pain? • How to cope with sensory sensitivities being heightened?
5	Offering neuro diverse acceptance and celebration clubs throughout the school to promote acceptance, promote a sense of greater belonging, encourage self-advocacy and more positive awareness throughout the school community as well as the students finding and making social connections. (Children and teenagers can belong to the group if they self-identify as neuro-diverse or as a neuro diverse supporter).
6	Psychoeducation using Cognitive Behavioural approaches used in small groups, possibly vertical groups throughout school to teach people with autism about the 'fight, flight or freeze' response to anxiety, how to recognise their own anxiety and how to manage this.
7	Every neurodiverse pupil having access to a key person in school that they can talk to when things are getting overwhelming for them, like a form tutor or pastoral lead. This could be in the form of having an identified adult (who should have completed additional training in working with pupils with additional needs) working with a small group that meets once a week to do something fun together where the activity is the focus. However, the time is protected for this member of staff so that once the activity is over, there is time to talk if needed by anyone in the group.

	(Ideally this should engage them in fun activities where they feel safe to de-mask).
8	Having an on-site homework club so that they have the option to complete their work at school, with adults at hand where they can ask to help them if they don't understand the expectations. (Home school learning during COVID-19 was especially tricky for them as they want to keep home and school very separate).
9	Developing key emotional regulations strategies with all pupils, how to recognise and express these safely. Whole-school strategy, embedding it within the curriculum.
10	Developing a whole school peer awareness programme to neuro diversity. This could be incorporated within a more specific diversity curriculum. To help both populations, those on the spectrum and those who are not to develop a much better understanding of each other.

6.7. Barriers to implementation for EPs to consider:

The idea that disability is understood differently across cultural groups is well documented (Coles & Scior, 2012; Ravindran & Myers, 2012; Skinner & Weisner, 2007) and has been coined 'the social construction of disability' (Skinner & Weisner, 2007). Ravindran and Myers (2012) outlined in their conceptual paper that cultural beliefs influence the perception, experience and management of disability and conclude that it is important to gain an understanding of disability within cultural contexts. In our EP practice this means understanding the local context and cultural understanding of the local population and being able to discuss and inform the local schools what this may

mean. Within disability literature, autism itself has been identified as a label that is 'complex' (Ravindran & Myers, 2012), there remains a lack of knowledge and understanding of how the concept itself is constructed differently across cultures. Few studies report a breakdown by culture when they discuss autism and it is well documented that there is a need to diversify the knowledge base of autism to consider the needs of families from minority cultural groups (Desai et al., 2012; Edwardraj et al., 2010; Jegatheeson et al., 2010; Russell & Norwich, 2012). Ravindran and Myers (2012) reported that UK-based autism research has been overly dominated by a white British perspective and, therefore, does not fully represent the needs of non-white groups. Research by Theara & Abbott (2015), (an EP based within the same local authority as the researcher) looked at the experiences of South Asian families and their construction of autism, which was documented as being viewed through the medical model perspective, meaning they are often seeking 'cures' for their child's autism. Their cultural norms also view disability as something which often becomes 'invisible' due to the nature of not seeking support outside the family, this ensures that the condition is not visible to others and inclusion is still in its infancy. The research also looked at the way South Asian families tend to view external support critically as the same level of support does not exist in their home countries and they have been taught to rely only on themselves. A more positive, less disablist construction of autism and difference would mean a major cultural shift - and this might be hard at the local level. As an EP, influencing higher authorities in this culture and more joined up work with health and consultant paediatricians may see a small shift in their move towards a more biopsychosocial model of disability, influenced by the neurodiversity

movement and positive psychology models viewing their strengths and building on these.

The neurodiversity movement is primarily a social-justice movement aiming to end what proponents see as the default pathologization of neurodivergence (i.e., divergence from normal mental functioning) and to instead promote the acceptance and accommodation of human neurodiversity (Armstrong, 2015; Blume, 1998; Chapman, 2019b; Singer, 1999). Instead of being conceived as medical pathologies, a range of disabilities - including autism, have been reconceptualized as manifestations of humanity's "natural variation" (Jaarsma & Welin, 2012). A critical realist approach must take into account this narrative to challenge the dominant cognitive deficit discourse espoused by the medical model and introduce the biopsychosocial perspective, recognising the strengths and contributions a neurodiverse society can bring. This viewpoint takes at least a significant amount of neurodivergent disablement and distress to be primarily caused by social barriers and ableist norms more centrally than by the cognitive traits associated with autism (Chapman, 2019b). Chapman discusses how the neurodiversity movement seeks to bring about a "paradigm shift" (Chapman, 2019b; Walker, 2014) in how we conceive of psychological disability. Drawing further on the example of autism as well as research on the benefits of cognitive diversity in groups, bringing in a biopsychosocial perspective has greater implications for both research and practice. This will ensure that research is not 'done to this population' but research is conducted in collaboration with this population so that meaning and representation is given to the autistic community—thus establishing the basis for a paradigm shift in the sciences of psychological ability and disability. Autistic emancipation is

intrinsically linked to the recognition of autistic contributions and to the creation of policy and practice that is informed by such knowledge.

A further consideration for the EP is how to successfully implement the recognised good policy and practice and to do so we must also consider research from the field of implementation science. Implementation science has been defined as the scientific study of methods to promote the systemic uptake of research findings and evidence-based practices into professional practice & policy (Eccles & Mittman, 2006). Other definitions stress the importance of understanding the behaviour of professionals and key stakeholders as key variables in implementation. Taking into account how to adapt to the local context for example, cultural factors, population demographics and how autism is diagnosed and supported at the local level and how to address the culture and climate of the school and its' community. (Rabin & Brownson, 2012). Schools provide a unique systems context. (Sarason, 1971) Understanding the school's unique positioning within the current wider system such as the political agenda, financial constraints and key legislation that exists and then understanding their local context will be essential for the EP to tailor the support effectively. Klein & Sorra (1996) offered a two-factor model of implementation; firstly, the organisation's climate for the implementation of an innovation, this refers to staff members perceptions of the extent to which the innovation is rewarded, supported and expected; Secondly the organisational members perceptions of the fit of the innovation to their values and beliefs.

Finally extensive research has highlighted the positive impact on student outcomes when teachers engage with parents in the work of schools and children with send (De Fur, 2012). When a child has SEND, parental expertise

can be invaluable to teachers (Schultz et al., 2016). As previously stated, parental experiences are often undervalued and parent/ professional relationships can be problematic (Read, 200; Cole 2004; Seligman & Darling, 2007). From this research it highlighted the importance for schools to work at re-building parental trust and confidence following the parents' experiences of the dismissal of their early concerns, thus offering a restorative approach to the parent/professional partnership from the outset.

A final concern in the implementation of these findings, is how to create safe spaces for children to be alone and decompress without isolating children further from their peers and with consideration to safeguarding measures that schools will need to put in place when considering allocating an appropriate provision.

Finally, in 2022 the country is facing increasing financial hardship and financial constraints are tightening schools' budgets ever further. The evidence base for intervention and support will need to be increasingly well established for schools to consider allocating their finite resources. The need for further research with this often-overlooked population is more fundamental than ever.

The autistic girls within this research did not wish to be singled out. The majority of this provision could be accessed through well thought out and sensitive delivery in small groups and education and training that would also benefit this population by increasing their sense of belonging and by increasing the overall culture and ethos of school to a more accepting place for neuro diverse students like these.

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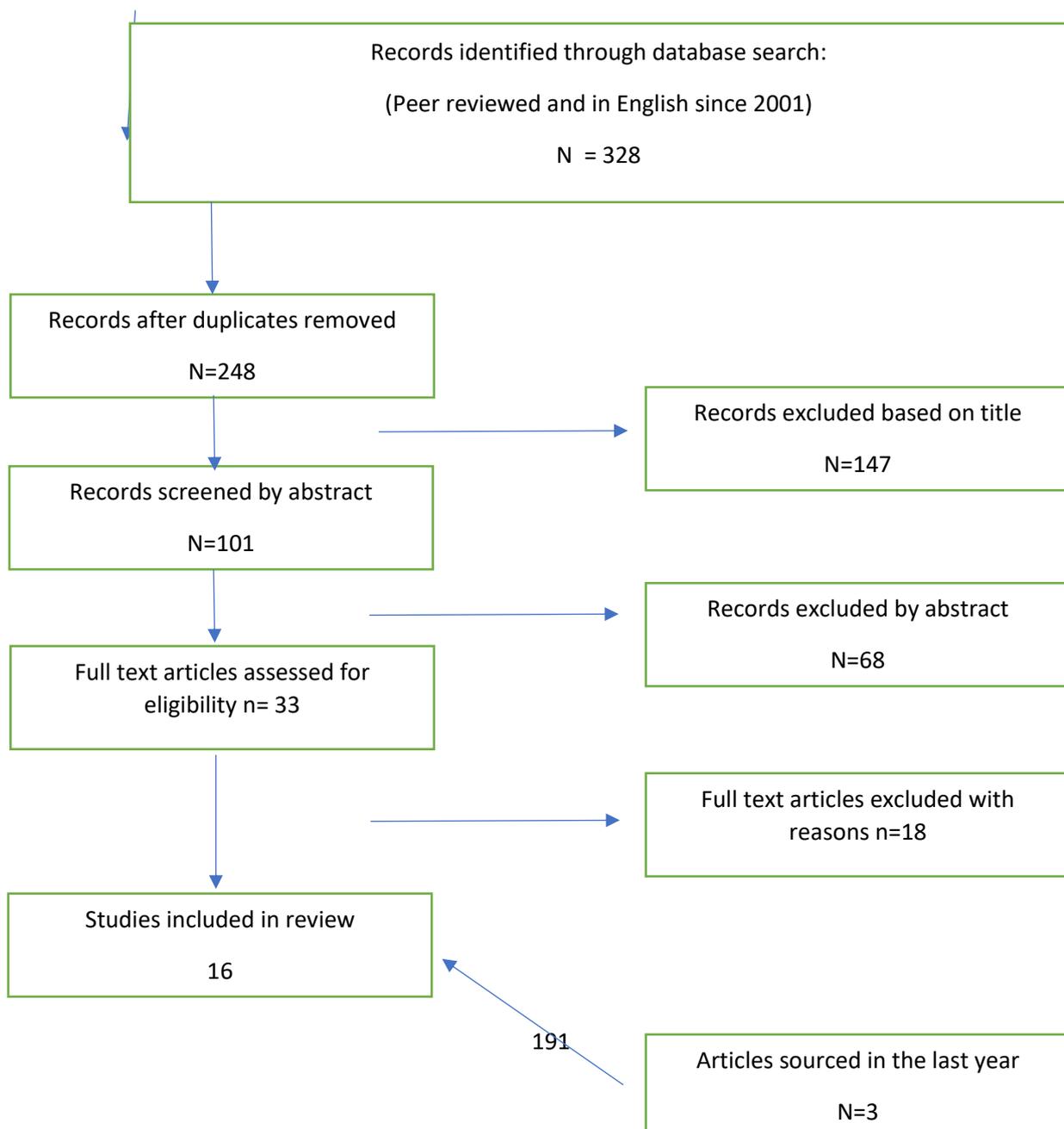
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APPENDICES:

Appendix A. Literature Search

A comprehensive search for peer reviewed studies was conducted in Jan 2021 using three databases: PsychINFO, EBSCO Psychology and Behavioural Science Collection and UCL Explore. Search terms were initially identified from preliminary exploratory research and developed following examination of associated key words on relevant research. Search terms included a combination of 'Autis*' Aspergers, 'ASC', 'ASD', 'Camouflaging', 'Masking', 'Coping Strategies', 'Compensation', 'Females', 'Girls', 'Mainstream secondary school', 'Adolescence' and 'Anxiety'. Abstracts of each article were reviewed to decide whether they met inclusion criteria: participants must include at least one female, who had either received an autism diagnosis or been identified to show traits of autism. Studies including adult populations were included, due to a paucity of research focusing on the experiences of girls under 18 years. 3 articles were included that have been published since the initial review in Jan 2021



Appendix B. Table of Articles from the literature review.

Adults with ASD and Camouflaging/masking

Authors	Sample	Methodology	Primary Outcome variables
Bargiela et al. (2016)	14 women with ASD	Qualitative study-framework analysis	Semi-structured interviews- in depth accounts of “pretending to be normal”.
Main Findings: Their gender led professionals to miss their ASD and their gender conflicted with their ASD diagnosis and their feminine identity. ‘Being a girl in a boy’s world’. Teachers had not identified their difficulties in school but other ch were very aware of the differences from early on. All women said they found socializing in large groups challenging. Some said they would “wear a mask” or adopt a certain persona, copying characteristics from characters in tv, youtube and in literature. Masking would also occur to hide autistic traits to appear ‘normal’ to others. Negative consequences from ‘masking’ were identified such as feeling exhausted afterwards, feelings of confusion over their identity and some women acted so ‘neurotypical’ that people would question their diagnosis.			
Hull, Petrides et al. (2017)	92 adults with ASD. Females with ASD =55 Males with ASD=30 Other=7	Qualitative study-thematic analysis of the data	Semi-structured interviews
Main Findings: Motivations for camouflaging included fitting in with others and increasing social connections. Short- and long-term consequences reported exhaustion, challenging stereotypes and threats to their self-perception. Camouflaging is rewarding for individuals because it enabled them to achieve what they wanted (e.g., getting through a necessary social situation or connecting socially)			
Lai et al. (2017)	30 adult females with ASD. 30 adult males with ASD.	Behavioural and Cognitive measures. Neuroimaging. (Quantitative study)	Camouflaging was operationalized using standardized measures. WASI. ADI-R. Module 4 of the ADOS. Autism Quotient. RMET
Main findings: Females with ASD had higher camouflaging scores compared to males with ASD. There was an association between greater camouflaging and depressive symptoms in men and an association between greater camouflaging in women and an increase in their signal detection sensitivity (SDT). A significant negative correlation was found between greater camouflaging in women and a smaller regional volume of grey matter in their brain scans.			
Cage & Whitman (2018)	262 people with autism. 135 females with ASD. 111 males with ASD and 12 identified as ‘other’, 4 chose not to disclose gender.	Online survey using Qualtrics platform.	Cross sectional survey design. CAT Q questionnaire was also used to identify low camouflagers, high camouflagers and ‘switchers’- (sometimes high camouflagers and sometimes low in different contexts)

Main findings: Consistently low camouflagers had lower stress than both switchers and high camouflagers. Low camouflagers had lower anxiety. Higher camouflagers showed the highest levels of anxiety. Significant main effect of camouflaging group on mental health. Two reasons for camouflaging identified; conventional reasons such as getting by in the workplace or within the education system and relational reasons to get by in their relationships with others. There was no difference found between the groups in terms of depression. Qualitative reasons included to ‘pass’ in the neurotypical world and avoid bullying and stigma.			
Hull, Lai, Baron Cohen, Allison, Smith, Petrides & Mandy (2020)	306 autistic adults 472 non- autistic adults	Online survey using Qualtrics	CAT Q questionnaire Broad Autism Phenotype Questionnaire (BAPQ)
Main Findings: Autistic females had higher camouflaging scores than autistic males, greater use of specific masking and assimilation strategies by females-but no gender differences in the compensation subscale. Gender differences in camouflaging exist for individuals with autism only and not in the non- autistic population.			
Schuck, Flores & Fung (2019)	17 males with ASD 11 females with ASD 34 non- autistic adults.		Autism Quotient to measure ASD symptom severity Social Responsiveness Scale Ritvo Autism-Asperger Diagnostic Scale- Revised Berkely Expressivity Questionnaire (BEQ) Social Phobia & Anxiety Inventory (SPAI)
Main Findings: Camouflaging is more common in females with ASD and not associated with social phobia. Camouflaging correlated negatively with emotional expressivity in females with ASD. Is the toll of masking dampening the females positive affect as they exhibit fewer positive emotions.			
Cassidy, Gould, Townsend, Pelton, Robertson & Rodgers (2019)	160 undergraduate students 18-23 years 86.9% female.	Online survey using Qualtrics- cross-sectional	Autism Quotient- Short (AQ-S) CAT-Q
Main Findings: Camouflaging autistic traits is associated with an increased risk of experiencing thwarted belongingness and lifetime suicidality.			
Beck, Lundwall, Gabrielseon, Cox and South (2020)	58 women with autistic traits	Online survey about camouflaging and mental health. Quantitative	CAT-Q
Main Findings: self-reported camouflaging efforts total scores significantly predicted psychological distress while measures of autistic traits did not. Suggesting it is the camouflaging efforts linked to mental health rather than the severity of the autistic traits.			

Adolescents/children with ASD and Camouflaging/masking

Authors	Sample	Methodology	Primary Measures
Dean, Harwood and Kasari (2016)	96 elementary school children. 24 girls with ASD 24 boys with ASD 24 non-autistic girls 24 non-autistic boys	Concurrent mixed methods	The Playground Observation of Peer Engagement (POPE)
Main Findings: Girls with ASD adopted compensatory behaviours (remaining close to peers in proximity) masking their ASD compared to boys with ASD and may join in with activities more but in a peripheral fashion, e.g., swinging a jump rope for the entirety of the play time rather than being allowed a turn to jump rope. So, girls may not be as identifiable as boys in the playground as having ASD difficulties.			
Critique: Ref Yardley:			
Cook et al. (2018)	11 girls with ASD and a parent for each child	Qualitative study, using thematic analysis of the data	Semi-structured interviews
Main Findings: Parents observed their daughters could effectively hide their ASD characteristics. 'Masking' provided solutions to some of their social difficulties, but negatives in terms of late diagnosis or missed or misdiagnosis or the development of more severe difficulties as a result e.g., lower academic performances, or increased anxiety and mental health difficulties. They also found girls preferred to hide their differences and were reluctant to be given a label.			
Tierney, Burns & Kilbey (2016)	10 adolescent females	Qualitative study- IPA analysis of the data	Semi-structured interviews
Main Findings: Participants were motivated to have friendships and obstacles to this caused them discomfort and distress. Participants used masquerading strategies (peer-imitation and masking). Participants used masquerading strategies to overcome obstacles to developing and maintaining friendships so there are benefits but costs to masquerading were in terms of emotional energy and barrier to accessing support they may need.			
Parish-Morris et al. (2017)	65 verbal school aged participants with ASD 49 boys with ASD 16 girls with ASD Comparison group of 8 non-autistic boys and 9 non-autistic girls	Quantitative study	Speech samples from the Autism Diagnostic Observation Schedule (ADOS) (Pauses were marked with UM or UR- research suggests they are pragmatically distinct e.g., UM is used to signal longer pauses and may correlate to greater social communication sophistication compared with UR) Social Communication Questionnaire Vineland Adaptive Behaviour Scales
Main findings: Girls with ASD and non-autistic girls and boys displayed a higher UM ration compared to boys with ASD. Girls and boys with ASD had equivalent social communication skills and similar levels of severity of ASD symptomatology. Findings suggest UH suppression and a higher UM			

ratio may potentially be used as ‘linguistic camouflage’ in order to normalize the way a girl with ASD sounds when compared to her same aged non-autistic peers, allowing them to “blend in” more easily with their peers and boys with ASD sounding more atypical with a greater UH ratio.			
Rynkiewicz et al. (2016)	33 high functioning polish girls with a formal diagnosis of autism/AS Girls =16 Boys=17	Quantitative	Module 3 of the ADOS 2 Eyes and Faces test Social Communication Questionnaire, Current and lifetime. Polish version of the Autism Spectrum Quotient child (AQ child)
Main findings: During ADOOS 2 demonstrations, girls with ASD exhibited a tendency to use gestures in a more vivid way than boys with ASD. High functioning girls with ASD may present better on non-verbal (gestures) mode of communication than boys with ASD. This may camouflage other diagnostic features of ASD in females. Girls with ASD exhibited impairments on the Eyes and Faces test.			
Livingston, Colvert, Bolton & Happe (2019)	136 autistic adolescents. 112 males 10-15 years old 24 females 10-15 years old	Quantitative	ADOS Self-report anxiety questionnaire WASI Frith Happe animations EF tasks
Main Findings: They found that higher compensators had higher verbal IQ, better executive functioning but greater anxiety.			
Halsall (2020) (Doctoral thesis)	8 autistic adolescent females in a specialist resource base attached to a mainstream school, their parents and an educator	Qualitative	Interviews Observations
Main findings: Negative costs associated with camouflaging included exhaustion, emotional dysregulation, impact on women’s identity, negative impact on learning, camouflaging was superficial, their non-autistic peers were still excluding them. Also misdiagnosis and missed opportunities for diagnosis			
Jorgensen (2020)	Compared autistic and non-autistic	Quantitative	CAT Q

	adolescents to study for differences using the CAT Q for sex and age.		
<p>Main findings: Females reported higher levels of camouflaging than males. However, this was not significant when matched for age. Autistic adolescents only showed significant differences to their non-autistic peers in one of the subscales on the CAT Q, that of assimilation, that of trying to fit in with others in social situations.</p>			

Appendix C. Participant Demographics

Autistic girls Participants information:

	Pseudonym	Age	Age at diagnosis of child/ young person	Any additional co-existing diagnosis	Any additional learning needs	Which mainstream secondary school	Name of senco	SEN Support/ EHC plan?	Anything else that may be relevant-include ethnicity
Child/ young person	Saffron	13	12	no	no	[REDACTED]	[REDACTED]	SEN support	White
Child/young person	Roxanne	12	10	Anxiety, hypermobility	no	[REDACTED]	[REDACTED]	SEN support/one plan	White
Child/young person	Sienna	13	12	Coeliacs disease	No	[REDACTED]		SEN support	White
Child/young person	Ace rola	14		Anxiety	No	[REDACTED]		SEN support	White They/them/theirs
Child/young person	lois	13		Depression ADHD query	No	[REDACTED]	[REDACTED]	None	white
Child/young person	leanne	15		Dyslexia ADHD Irlen Meares syndrome	Yes - dyslexia	[REDACTED]		EHC P	white
Child/young person	Nora	14	6	Anxiety Sleep disorders	no	[REDACTED]		SEN support	white
Child/young person	rosie	12		no	no	[REDACTED]			white
Child/young person	Cassie	21	20	PTSD	no	[REDACTED]		DSA	White
Child/young person	Allaia	17	15	Anxiety	no	[REDACTED]		SEN support	White
Child/young person	Louise	15	11	ADHD	no	[REDACTED]		SEN support	White

Parents info	Pseudonym	Age bracket	Ethnicity	Gender	Level of education	Diagnosis of asd?	Does your child qualify for FSM?	Household income - approx	Anything else?
Mother	Kasey	30-34	White British	Female	Degree	Yes	No	50k +	
Father	Martin	45-50	White British	Male	Degree	No but suspect ASD	No	50k+	
Mother	Roxanne	30-34	White British	Female	A-levels	No official diagnosis	No	Up to 20k	



Father	Vince	40-44	White British	Male	Degree	No	No	50k+	
Mother	Nancy	40-44	White British	Female	Post graduate	Not disclosed	yes	Up to 30k	
Mother	Pauline	35-40	White British	Female	A-levels	yes	no	20-30	

Appendix D Ethical Approval form (signatures deleted)

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: [Pupil and parents voices on the experiences of female pupils on the autism spectrum in mainstream schools](#)
- b. Student name and ID number (e.g., ABC12345678): [Caroline Bassett](#) [REDACTED]
- c. ***UCL Data Protection Registration Number:** [Z636406/2021/05/139](#)
 - a. Date Issued: [21/05/2021](#)
- d. Supervisor/Personal Tutor: [Dr Chris Clarke](#) and [Dr Dagmara Dimitriou](#)
- e. Department: [Psychology and Human Development \(PHD\)](#)
- f. Course category (Tick one):
 - PhD
 - EdD
 - DEdPsy
- g. **If applicable**, state who the funder is and if funding has been confirmed. N/A
- h. Intended research start date: [01/04/2020](#) (or as soon as ethics agreed)
- i. Intended research end date: [31/08/2022](#)
- j. Country fieldwork will be conducted in: [UK](#)
- 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.*

Information about this Research

The purpose of this study is to explore how adolescent females on the autism spectrum experience mainstream secondary school particularly relating to camouflaging. It aims to explore how they experience their education, their friendships and the differences that they may exist in their behaviours at home compared to school as well as the support they receive as a female on the autism spectrum.

In line with legislation and the SEND code of practice (2015) it is essential to gain the voices of all children with SEND. In the literature that exists, the voice of females on the autism spectrum is largely missing. Research by Pellicano et al. (2014) identified the need to focus on improving everyday life outcomes for individuals with ASC, especially females, as being a priority. As such, this is an important area of research. The main research questions are:

RQ1: What are girls on the autism spectrum experiences of mainstream school?

RQ2: What differences exist in the behavioural presentation of girls on the autism spectrum (particularly relating to masking) between mainstream secondary school and their home environment? Where there are high levels of 'masking' their difficulties while at school, how does this impact on their home environment – paying attention to their familial relationships, activity levels, diet, sleep and general well-being?

RQ3: What are the costs and benefits for girls on the autism spectrum attending a mainstream secondary school in adopting 'camouflaging' or 'masking' strategies?

RQ4: Will the quality of friendships (as rated by the FSQ) for girls on the autism spectrum be a supportive factor with their experiences of mainstream schooling reportedly being more positive (focus group interviews and parent focus group interviews)?

RQ5: When 'masking' occurs, does this lead to less support/interventions being offered by school?

This will be a largely qualitative study design. Purposive sampling will be used to identify female participants who have a diagnosis of ASC, are aged between 11-18 years and have experience of mainstream schooling in the UK. One of their parents will also be asked to share their views. A total of 12 parent-daughter dyads will be interviewed in online focus groups divided into 2 groups of 6 children and 2 groups of

6 parents, across mainstream schools. Participants will be recruited via two methods, the first will involve an e-mail attached to a newsletter of parents who have recently attended online training from an independent SEN training company ACE-SEN. The training they attended was on Autism and girls. The second will involve approaching schools within my local authority to gain further interested participants and to widen the diversity of the sample population.

I will arrange an online meeting to introduce myself to each parent/daughter dyad before starting the focus groups, to answer any questions and administer the characterisation methods such as the Ravens Progressive Matrices assessment, a Social Responsiveness Questionnaire and a social communication checklist. I will use semi-structured interview questions within the focus groups to elicit the young person and the parent views. The focus groups will be conducted online on a secure site called Piazza. Interview schedules will be developed after consulting current literature (see attached interview schedules) and include questionnaire measures. This will be used to supplement the qualitative data gathered on their friendships, their experiences of mainstream school, their behaviour and their concept of self-identity as a young female on the autism spectrum. The qualitative data gathered from the focus group interviews will be analysed using thematic analysis informed by Braun and Clarke's (2006) method. All data will be pseudo-anonymised. Due to the exploratory nature of this research, themes will be primarily drawn from inductive methods, while utilising deductive approaches drawn from wider theory that consider the skills used by females on the autism spectrum when navigating secondary school, adolescence and their social relationships. This research will be compiled as a thesis and research briefing, which will be disseminated to course tutors and placement Educational Psychology Service. It will also be offered as an online briefing to all participants, parents and the participants schools. It is hoped that this research will be formatted and submitted to a peer reviewed journal for wider dissemination.

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

A parent per child is also going to be part of a separate focus group.

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: Enter text
- b. Owner of dataset/s: Enter text
- 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?
Female pupils on the autism spectrum between the ages of 11-18 and an identified parent/carer for each participant.
- b. What data will be collected? Please provide details of the type of personal data to be collected
Focus group data will be recorded and transcribed. All data will be pseudo-anonymised. FSQ scales and Ravens Matrices questionnaire answers will be stored in a folder securely on an encrypted USB stick to the NHS standard of encryption and locked away.
- 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?
Pseudo-anonymised results will be disclosed to research supervisors and university and professional placements, as well as prepared for publishing in a peer reviewed journal.
Disclosure – Will personal data be disclosed as part of your project?
No personal data will be disclosed.
- 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 be securely stored electronically on my personal laptop which is password protected and not used by anyone else. All files will be password protected. Any paper based consent forms will be securely locked away in my home office. An encrypted USB with advanced encryption may be used and will also be locked away.

*** 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?

The anonymous data from the transcripts will be stored in a folder called transcript data, this will all be anonymised and password protected. If the research is published after completion the results will be saved until 2030. The results of the baseline assessments will also be stored in this way.

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)

No

Will data be archived for use by other researchers? (If yes, please provide details.)

No

- 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’.

Pseudonymisation will be used.

** 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
- Sampling
- Recruitment
- Gatekeepers
- Informed consent
- Potentially vulnerable participants

- Safeguarding/child protection
- Sensitive topics
- International research
- Risks to participants and/or researchers
- Confidentiality/Anonymity
- Disclosures/limits to confidentiality
- Data storage and security both during and after the research (including transfer, sharing, encryption, protection)
- Reporting
- Dissemination and use of findings

Sampling and recruitment:

I intend to collect data from female pupils (between 11-18 years) who have a diagnosis of ASC and attend mainstream schooling, alongside one of their parent/carers. The research will use an opt-in approach, which means that if any party does not opt-in then data will not be collected for that person. Initial contact will be made through a newsletter to parents/carers who have recently attended training on the subject of autism and girls for an independent training company. As this training was delivered online, the parents and their daughters come from different geographical areas and attend different schools. As all my research will also be online this will enable everyone to fully participate despite their geographical location. In order to widen my sample, I will also recruit through the schools in my LA in order to try to increase the diversity of the girls and families participating. An information sheet will be sent out to the families who have indicated their interest who will then be asked if they and their daughter wish to opt-in? A separate simplified consent form will be included for the female pupils on the autism spectrum to ensure their consent is informed as well as a link to a short you tube clip. No data will be collected from the interested parties who opt-out. In addition, once the consent form has been received, I will make contact with each parent/daughter dyad to introduce myself, the research and the online platform that will be used Piazza. This will allow any questions that they may have to be answered.

Informed consent:

All participants will give their written informed consent prior to any data collection and consent will also be confirmed verbally in my initial telephone call to introduce myself, the project and see if they have any further questions before proceeding. For the female pupils with an ASC ensuring informed consent is more challenging. As I am specifically recruiting from mainstream schools this may minimise their possible learning difficulties at least the more severe learning difficulties. I will carry out characterisation methods using the Ravens Progressive Matrices online (chosen due to its non-verbal measures and reliability and validity with this population), and a social responsiveness scale in the initial telephone call to help get a baseline of the participants for my research. Informed consent will be assisted by using simple and clear consent forms and you tube video explaining the project (the link to this is attached within the girls information sheet). Consent and information sheets will

also be sought from the identified parent/carer who will also be present during the initial phone call. All standard ethical expectations for psychological research, such as the right to withdraw and anonymity will be clearly explained.

Safeguarding/child protection:

The researcher has extensive training in safeguarding through her professional role as a trainee educational psychologist and in previous roles as a teacher. During the initial telephone call with the parent/daughter dyad. I will ask for the parent to remain present throughout for safeguarding reasons. I will also make each of the participants school aware that they are taking place in this research and will make it clear if there are any specific safeguarding concerns that I will bring these concerns to their school. I will also arrange a check in with all the participants after the first one or two days after the focus groups have started.

Sensitive topics and risks to participants and researcher:

Parents could experience some discomfort when asked about sensitive issues around their daughter's behaviours at home and at school and general well-being and links have been identified and included within the focus groups so that if any parent needs additional and follow up support it will be signposted to them. Any distinctive identifying information will be removed, emotional responses monitored throughout by myself and a de-brief will be offered to all participants should they wish to have one.

The female pupils will be asked their views on schooling, their friendships and their self-identity as a female on the autism spectrum and this may present them with some emotional challenges due to the nature and sensitivity of these topics. Participants' well-being will always be the researchers priority and if participants share any distress online then support will be offered to them either from a de-brief with myself, signposting to any relevant agencies and support obtained from the parent or school if necessary.

The focus groups may present some emotionally challenging topics and distress for the researcher and if this is the case then support will be accessed through supervision.

Confidentiality, anonymity and limits to this:

Confidentiality, including anonymity will be explained to all participants prior to informed consent and data collection. Data will be kept confidential unless there is a risk to a participant or to someone else. If information is given that needs to be shared, safeguarding procedures will be followed and my supervisors will be informed.

Data storage and security:

Prior to writing the ethics form, the researcher carried out the online GDPR training accessed through the university. There are risks to data storage and security during the research, as the data will be stored on the laptop. However, all data will be pseudo-anonymised and strong password protections and encryptions will be used. Any paper consent forms will be locked away within my personal office but there shouldn't be a need

for paper forms. Password protected transcript data will be securely shared with my supervisor.

Reporting/Dissemination of findings:

All findings will be pseudo-anonymised and quotes that identify any of the participants (in part due to naming identifying circumstances) will be excluded. The overall findings will be shared with participants, their parents and online sharing of the research offered to all the participants schools. There will also be a research briefing accessible to all.

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

Parent information sheet and consent form

Pupil information sheet and consent form and YouTube link to short video clip about the project

Interview schedules for the focus groups for pupils and parents

Piazza information sheet (1 general one for parents, 1 for children)

- 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 [Carolyne Bassett](#)

Date [28.05.2021](#)

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: Dagmara Dimitriou

Do you foresee any ethical difficulties with this research?

no

Supervisor/first reviewer signature:

Date: 12/06/21

Reviewer 2

Second reviewer name: Christopher Clarke

Do you foresee any ethical difficulties with this research?

Carolyn has reflected on all the ethical considerations necessary for this research project and implemented necessary steps to mitigate against any risk.

Second reviewer signature:

Date: 11.06.2021

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.

Appendix E. Information sheet and consent forms for the Autistic girls

Institute of Education



Girls information and consent form

Carolyne

What we will do together:

Talk about what is important to you.

Do some questionnaires.

Talk about your experiences in school and at home and with your friends using an online platform called Piazza.

My job is a Trainee Educational Psychologist. What do I do?

I work with children and young people to find out what they are good at and what is more difficult for them. I often work with school staff, parents/carers and other people who know the child and young person to use the information to try to help make sure that school, life and learning is the best that it can be for them.

My job title is 'Trainee Educational Psychologist'. This is because I am training and studying to become an Educational Psychologist. It is ok to just call me Carolyne if you like.



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

If you do not want to work with me that is ok. I would like you to be a part of this project to see what you think about things, but it is your choice.

You can choose to stop at any point and just need to let myself know or your parent/carer who will let me know.

If you think of any questions you want to ask before we meet, please write them down or ask someone to write them down and I will do my best to answer them when we meet.

What is the project? The project is all about getting your parent's and your voice heard as a female pupil on the autism spectrum about your experiences in mainstream schools. This will cover some issues relating to your interests, your friendships and how you feel about your school and how you behave at school and at home. This will help me and others understand what the experience is like for you as well as help us to consider what could make this better for you and others.



<https://youtu.be/CCH1sMFL68A> please watch a short video about the project.

What will happen if I help with the project?



If you would like to take part, then you will be asked to join an online focus group where there will be a set of questions for you to answer.

You will not have to answer straight away. You can read the questions and then come back online when you are ready to answer them. I will be online to help you if you want any help.

Hello Again!



I hope you liked reading a bit about me. I look forward to getting to know more about you. The second and third time we meet online I will ask you to tell me a bit more about school, your friends and yourself.



Everything you say will be private. I will not use your name or school name in my project. Before we meet, if you agree, I would like you to choose a name to call yourself for the project, so you and I will know who you are but no one else will. The information I collect will be stored so only my supervisors (Dr Dagmara Dimitrieo and Dr Chris Clarke) and I can see them.

What happens to the results of the research?

After I speak to you and some other girls helping with the project as well as a parent or carer, I will write a report about what I have learnt.

What should I do next?

Please talk to your parents and teachers about this project. If you would like to take part, there is a form to fill in on the next page. There are some sentences for you to tick 'Yes' or 'No'. You can change your mind at any time. If you no longer want to take part, then you can tell me or your parent and we will stop straight away.

Any questions? If you have any questions, please contact me on the contact details provided. [REDACTED] Telephone [REDACTED]

This study has been approved by the Research Ethics Committee at UCL Institute of Education. Data Protection Privacy Notice: Notice: The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at dataprotection@ucl.ac.uk. UCL's Data Protection Officer can also be contacted at data-protection@ucl.ac.uk. 186 Further information on how UCL uses participant information can be found here: <https://www.ucl.ac.uk/legal-services/privacy/ucl-general-researchparticipant-privacy-notice> The legal basis that would be used to process your personal data will be [performance of a task in the public interest.] The legal basis used to process special category personal data will be for scientific and historical research or statistical purposes/explicit consent. 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



Consent form for interviews

Please read the sentences and tick 'yes' or 'no':

I have read the information about this project and I would like to take part.



I understand I can stop at any time. I just need to let my parent or Carolyn Bassett know.



I understand that everything I say in this project will be private and my name will not be used.



I agree that any data collected will be processed and stored in line with General Data Protection Regulations (this means it will be kept safely).



I understand that if at any time I have questions about this project I can contact Carolyn Bassett.



I would like to read about this project when it is finished.

I agree to having online discussions with Carolyn Bassett:



Name:

Signature:



Date:

Appendix F. Parents information and Consent forms.

Institute of Education



Parent information and consent form

Title of project: Parent and pupils voices on the experiences of female pupils on the autism spectrum in mainstream schools.

You and your daughter are invited to take part in a study that aims to explore the experiences girls with an autism diagnosis have within mainstream schools. It also aims to explore their friendships, any differences that may exist between their behaviours at home and at school and lastly their self-identity as a female on the autism spectrum. This study is being completed as part of Carolyn Bassett's Educational Psychology doctorate, supervised by Dr Dagmara Dimitriou and Dr Chris Clarke. It is important for you to have a clear understanding of why this research is being done and what it will involve before you decide whether you would like to take part. Your daughter will also receive some information to explain the study, please could you discuss this with them. Please ask the researcher if you have any questions.

What is the purpose of this study? This study aims to explore the experiences that girls with autism have within their mainstream schools and at home and in their relationships, to manage everyday life. We are interested in your experiences of the different skills your daughter uses to manage the expectations of school and home. The information gathered in this study will help develop understanding of how educational psychologists and school staff can best support girls on the autism spectrum and their families.

What would happen if I take part? If you take part then I will arrange a convenient time for us to have an informal discussion, either by telephone, or online first, depending on which you prefer. During this informal discussion I will be available if you have any questions to ask about the project and I will also ask for you and your daughter to agree on a pseudonym that you will both be known by in your parent/daughter dyad so that your confidentiality will be respected throughout. I will also ensure you are aware of how to access the online platform Piazza that will be used for the online focus groups. As a parent there will be some questions around your daughter's experiences at school and home as well as identifying when she was first diagnosed, but there will also be lots of opportunity for you to talk about the things that seem most important to you. The focus group discussion will take around 30-40 minutes. Piazza is a secure online platform where the interview questions will be posted and there is a separate information sheet provided with instructions on how to access this. The interview questions will remain on this platform during a two week window where you can post your responses and interact with others by follow up responses to their posts. At any stage during, or after the discussion you can

choose to pause or withdraw from the study. You do not need to give a reason for withdrawing and there will be no repercussions for withdrawing at any stage.

Other aspects of the study: Alongside our initial discussion, there are three further parts to this study. Two separate focus groups for your daughter to participate with and 1 focus group discussion for your participation. These will all take place online on the platform Piazza, you will have a separate instruction sheet on how to access and participate with Piazza.

Do I have to take part?

Taking part in this study is entirely voluntary and you do not need to give a reason for not taking part. Would my taking part in the study be kept confidential? All information collected as part of this research will be anonymised. All information provided will remain confidential and will be securely stored on password protected computers. When the study finishes in September 2022, we will keep your data in an anonymous format, unless you ask us to delete it. The findings of this research may be published in academic journals and presented at conferences. Responses will be published in a group format and no individual responses will be reported.

Data will be stored following the General Data Protection Regulations. Data Protection Privacy Notice: The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at: data-protection@ucl.ac.uk UCL's Data Protection Officer can also be contacted at data-protection@ucl.ac.uk 194 Further information on how UCL uses participant information can be found here: www.ucl.ac.uk/legal-services/privacy/participants-health-and-careresearch-privacy-notice. The legal basis that would be used to process your personal data will be performance of a task in the public interest. The legal basis used to process special category personal data will be for scientific and historical research or statistical purposes/explicit consent. 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

What should I do next? On the next page there is a set of statements for you to consider if you decide to take part. Anyone who completes the consent form is still free to withdraw at any time and without giving a reason.

Who is organising the research? I am a trainee in Educational Psychology at UCL Institute of Education. Please contact me if you would like any further information, at any time during the project. This research will be jointly supervised by Dr Dagmara Dimitriou and Dr Chris Clarke. They can be contacted at:

This study has been approved by the Research Ethics Committee at the UCL Institute of Education, University College London.

Consent form

Before we start the online focus groups, I would like to speak with you both so that I know you are happy for both you and your daughter to take part in my study. The initial discussion will be around 20-30 minutes long.

Please indicate whether you agree with the following statements or not and tick the boxes to confirm: Yes or No

	YES	NO
I confirm that I have read the information sheet about this project and I am happy to participate.		
I confirm that I have read the information sheet about this project and I am happy for my daughter to participate		
I understand that both my and my daughter's participation is voluntary and we are both free to stop at any time and without giving any reason.		
I understand that all information will be confidential and that my name and personal details and my daughter's name and personal details will not be included in reports or publications.		
I agree that any data collected will be processed and stored in line with General Data Protection Regulations.		
I understand that if at any time I have questions about this project I can contact Carolyne Bassett.		
I would like to receive the results of the research once it has been completed.		
I have read all the information about Piazza and am happy to participate on this platform.		
I agree to participating in an online focus group with Carolyne Bassett on the platform Piazza		

Print Name:

Signed:

Date:



Appendix G. Interview schedules for the Girls:

FQS scales.

FOCUS GROUP TOPIC 1 Questions on rapport, self-identity and friendships:

1. What are your interests and hobbies?



Prompts:

What is your favourite tv show/film?

What music do you like to listen to?

What are you good at?

How would you describe yourself?

2. Do you have a diagnosis of anything? If yes, what?

Prompts:

What does autism mean to you?

Are you happy to talk to your friends about your diagnosis if you have one?

Are you happy to talk to teachers about your diagnosis if you have one?

Would you rather not mention the diagnosis (if you have one) to anybody?

3. Do you feel different or the same as the other children?**Prompts:**

Do you feel different or the same as the other girls at school?

Do you feel accepted by the other children at school?

4. Is there anything else that you want to tell me about yourself that is important to your identity?**5. Tell me about your friends?****Prompts:**

How many friends do you have?

Would you like to make new friends?

What do you like to do with your friends?

Do you prefer talking to them on the computer/ phone or in person?

Do you and your friends enjoy the same things? What?

6. Do you do things with your friends that you don't like to make them happy or try to 'fit in'?

Prompts: Do you ever feel like you have to pretend to be like other girls to help you fit in?

Have you ever tried to copy someone else- the way they act and talk for example- even if it is someone from the telly or internet to try to act a certain way with your friends/new people?

Do you ever practise what you might say in conversations before meeting people?

Do you ever practise facial expressions in the mirror?

Have you ever been bullied?

Do you ever laugh at a joke when you didn't really get it?

Have you ever felt embarrassed by misunderstanding what was going on?

7. Is there anything else you'd like to tell me about you and your friends and your friendships?

FOCUS GROUP QUESTIONS TOPIC 2: School and differences in home/school behaviours



8. Can you tell me about your school, what is it like?

Prompts:

What are the best things about your school?

What are the worst things about your school?

What are your teachers like?

9. Are there things you try to do at school to 'fit in' or become less noticeable?

Prompts:

Do you like being chosen to answer a question in class or asked to speak out?

If online teaching, do you prefer to have your camera on or off?

What do you do at school if you don't understand something?

10. Do you have any support at school? If yes, can you describe it?

Prompts: If you have no support at school, would you like some support?

And if so for what?

11. Do you act the same at school and at home?**Prompts:**

If no, can you tell me more about how you act at school and at home?

What is the first thing you do when you come home from school?

How do you feel when you come in from school?

How do you feel when you are getting ready to go to school?

Do you ever feel like you are two different people at home and at school?

12. What would help you at school to feel more able to be yourself?**13. Do you prefer home schooling or school? Try to explain why you prefer the one you do?****14. At school how do you manage your emotions?****Prompts:**

Do you ever feel worried at school? If yes how often? Always (at least daily)
Sometimes (1-2 times a week) Rarely (1-2 times a month) Never?

Do you ever get upset at school? If yes Always (at least daily) Sometimes (1-
2 times a week) Rarely (1-2 times a month) Never?

Do you ever get angry at school? If yes Always (every day) sometimes (1-
2 times a week) Rarely (1-2 times a month) Never?

What do you do at school that helps you to relax?

What help do you have at school to help you manage these feelings?

15. At home how do you manage your emotions?

Prompts: Do you ever feel worried at home? If yes how often? Always (at least
daily) Sometimes (1-2 times a week) Rarely (1-2 times a month) Never?

Do you ever get upset at home? If yes Always (every day) sometimes (1-2
times a week) Rarely (1-2 times a term) Never?

Do you ever get angry at home? If yes Always (every day) sometimes (1-2
times a week) Rarely (1-2 times a term) Never?

What do you do at home that helps you to relax?

What helps you when you are feeling angry?

What helps you when you are worried?

16. Do you sleep well? Over 8 hours 6-8 hours 4-6 hours or less than 4 hours sleep a night

17. Is there anything else you'd like to tell me about how you behave at home and at school?

Appendix H. Interview schedule for the parents:

Please read the following information prior to reading the questions: Please do not use your child's real name, please use the agreed pseudonym that your daughter has decided on so that we can keep the answers as confidential as possible. Please don't share the pseudonym with others so that we can treat your daughters' answers with the utmost respect and confidentiality and your answers as well. There are links and signposts to helpful organisations at the end should you wish to access any additional support.

1. Can you tell me when your daughter was diagnosed with autism?

Please consider in your answer the following:

Prompts: When did you first have concerns? If it took a long time between your first concerns and your daughter's diagnosis, can you tell me a little but more about why you think that was or try to explain why a diagnosis took a long time?

2. Is your daughter aware of her diagnosis?

Please consider in your answer the following:

Prompts Does she understand what autism is? Is she accepting of her diagnosis? If no, can you tell me more about this?

3. How does your daughter find her mainstream secondary school?

Prompts Was your child happy in her primary school in comparison? Does she ever resist going to school? How does she find friendships? And relationships with staff? What does she like about school? What does she dislike?

4. What was your child's state of mind upon returning from school after COVID and the lockdowns?

Prompts Was she anxious about returning? Happy to return? Did she prefer home schooling? How did she find home schooling? Did she dislike home schooling? Or find it hard to separate home and school and do schoolwork at home?

5. What support, if any, does she have at school?

Prompts What support do you think would be helpful, if any? Do you think your daughter would like support?

6. Does your daughter's behaviour change between home and school?

Prompts In what way, please describe it in both contexts? What has been the positive impact of this? What has been the negative impact of this?

7. Can you tell me about your daughter's friendships?

Prompts Does your daughter try to 'fit in' with others? How does she do this? Does she practice/rehearse ways to communicate before meeting/socializing? Does she try to hide social anxiety? Is there anything she has done to try to 'learn' how to socially interact? E.g., watching a soap opera/tv show aimed at teens repeatedly? Does she prefer to socialize in person or online?

8. Can you describe your daughter's general health?

Prompts Does your daughter sleep well? Does your daughter eat well? Does she have any bowel or urinary issues? Does she have any other health issues? Can she manage her periods independently? Does she suffer excessive period pains?

9. What does she like to do when she first comes home from school?

Prompts Does she appear tired? Happy? Upset?

10. How do you know if she is worried about something?

Prompts Is she happy to talk to you about it? Will she talk to somebody else? Does she bottle up her feelings? Does she express it in her behaviour -please describe? Does she have some coping strategies for when she is worried about something?

11. What does your daughter like to do at home?

Prompts Are these activities she is happy to share at school? Is there anything she does at home that she would want to 'hide' from school?

12. What do you think are her greatest challenges?

13. What do you think are her greatest strengths?

14. Is there anything else that you'd like to tell me about your daughter with regard to 'hiding' or masking her autism from others?

THANK YOU VERY MUCH FOR PARTICIPATING WITH THIS ONLINE FOCUS GROUP/ QUESTIONNAIRE. YOUR INVOLVEMENT IS VERY MUCH APPRECIATED.

If you need further advice on any of the issues that this may have raised for you or your young person, please access the following links:

Error! Hyperlink reference not valid.



[Urgent Support for Mental Health | Every Mind Matters | One You \(www.nhs.uk\)](#)

[Anxiety | Every Mind Matters | One You \(www.nhs.uk\)](#)

[Guidance for parents and carers on supporting children and young people's mental health and wellbeing during the coronavirus \(COVID-19\) pandemic - GOV.UK \(www.gov.uk\)](#)

[Eating disorders - Eating disorders: advice for parents - NHS \(www.nhs.uk\)](#)

Appendix I. Ground rules

Following piloting the focus group with four neuro-diverse children and young people. They had a couple of comments about ground rules for the future.

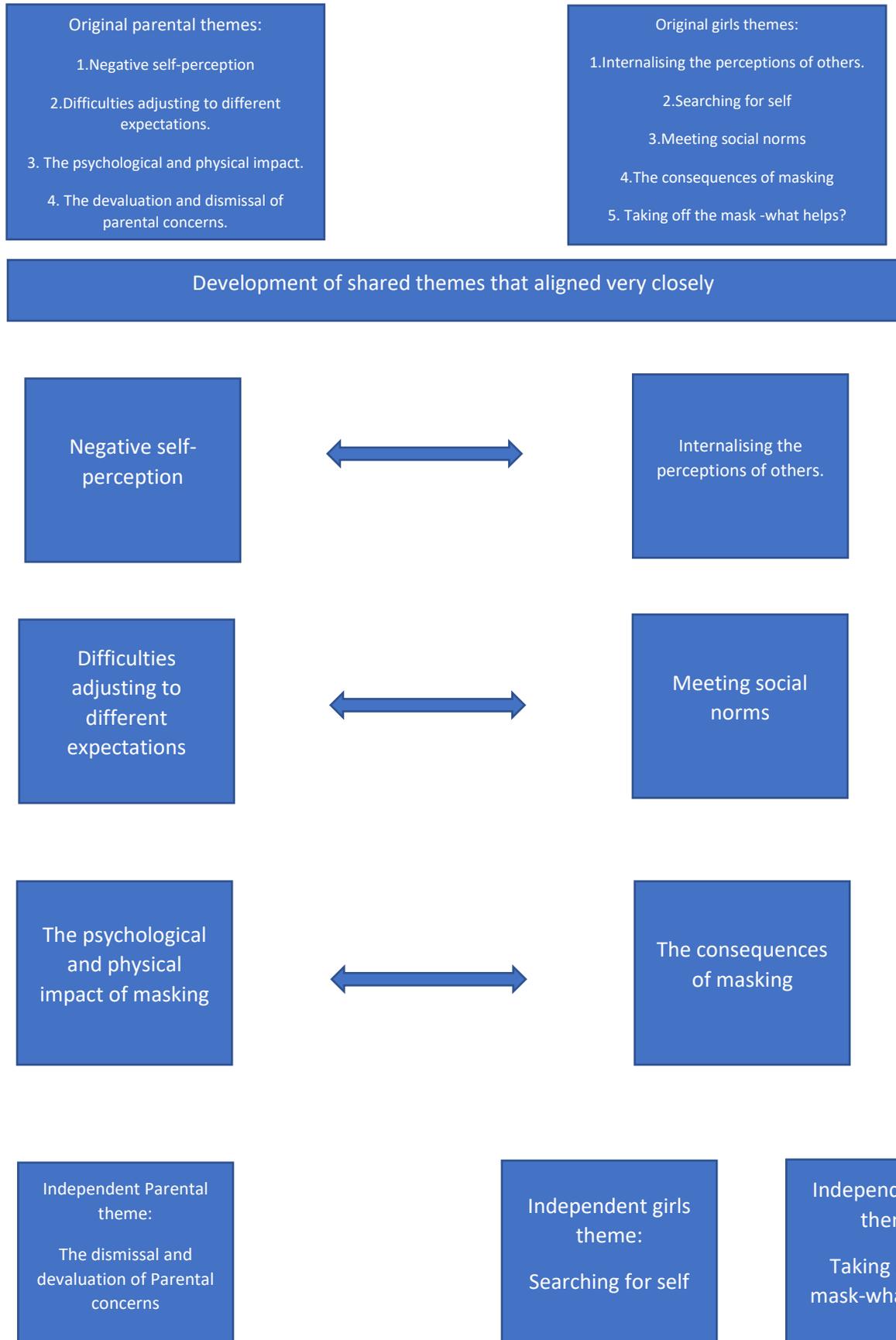
The most important ground rule that they felt would be needed was that it was a safe space to express their views and that if someone disagreed they would be polite about stating their own views but not rude towards someone with an opposing view.

Their lack of interaction in an online focus group highlighted to the researcher that a high level of moderation would be needed to encourage any further questions.

In the piloting of the questions open ended questions were not encouraged or liked by the autistic participants and so they became more closed with more written prompts to try to help them think about ways they could expand on what they had said.

Confidentiality was agreed to be the most important thing but it was also necessary to highlight that in cases if it was felt that there was a safeguarding concern that this would have to be prioritised.

Appendix J. Original themes to shared themes flow chart process



Appendix K

Coding sample of older girl being interviewed using a pseudonym.

1) What does being autistic mean to you? Is there anything else about your identity that is important to you?

Mostly, I haven't felt as though it has had much importance in my life. For a while after my diagnosis, I pretended I didn't have it and even managed to forget that I was diagnosed. But now I feel more at ease with my diagnoses, although I would still say it doesn't really affect much for me.

Brown, Cassie
I mean, it's it's. I feel like it's really good having the diagnosis. I'm glad I've got it. I think for me it's like context really. It just contextualizes my whole life and all of my experience that I had when I wasn't diagnosed. And it's definitely been like very helpful to kind of.

00:04:10.730 --> 00:04:30.820
Brown, Cassie
Especially cause like the same person who diagnosed me with autism also diagnosed me with PTSD. And really as those conversations are going on, they really came hand in hand for me and so having the actual autism diagnosis it definitely helped. Like unpack a lot of stuff that happened when I had no idea that I was autistic, so.

00:04:31.280 --> 00:04:31.680
Carolyn Bassett - Trainee Educational Psychologist
Yeah.

00:04:31.470 --> 00:04:38.410
Brown, Cassie
I definitely like associate well with the label autism, I don't feel any negativity towards here, you know I.

00:04:39.960 --> 00:04:40.220
Brown, Cassie
Yeah.

00:04:41.830 --> 00:04:42.610
Carolyn Bassett - Trainee Educational Psychologist
Thank you.

- BC Bassett, Carolyn
4 -denial of autism initially.
- BC Bassett, Carolyn
5 positive experience of diagnosis- at last this makes sense.
- BC Bassett, Carolyn
6. co-morbid diagnosis related to autism diagnosis
- BC Bassett, Carolyn
7 PTSD due to events that happened due to autism
- BC Bassett, Carolyn
8. proud, no negativity.

00:04:43.610 --> 00:04:51.360
Carolyn Bassett - Trainee Educational Psychologist
When you say you don't feel any negativity towards it, I'm just quite interested in.

00:04:52.420 --> 00:04:54.460
Carolyn Bassett - Trainee Educational Psychologist
Why you made that comment?

208

Carolyn Bassett Student number 19183682 word count: 35860

00:04:55.140 --> 00:04:56.110
Brown, Cassie
Oh I think.

00:04:55.240 --> 00:04:55.560
Carolyn Bassett - Trainee Educational Psychologist
Well.

00:04:56.200 --> 00:05:13.300
Brown, Cassie
Uhm, I think a lot of people really resist a diagnosis or a label. And personally I would have I. I would do anything to to make it so that I could have been diagnosed earlier in my life. I feel like I could have avoided a lot of unnecessary stress, but.

00:05:13.730 --> 00:05:32.880
Brown, Cassie
Uhm, I think that comes from a lot of people do have this idea of like being diagnosable autism. It's

- BC Bassett, Carolyn
9. reluctant to have the label 'autistic' perception of others
- BC Bassett, Carolyn
10 autism diagnosis may give negative feelings

00:05:15.730 --> 00:05:32.680
 Brown, Cassie
 Uhm, I think that comes from a lot of people do have this idea of like being diagnosable autism. It's going to give someone like negative feelings about themselves or something like that, but I I just anyone who I know that has been diagnosed like it can be a difficult process. Kind of rethinking your whole life in that way, but it.

00:05:33.500 --> 00:05:36.390
 Brown, Cassie
 I feel like it normally ends up going quite well because.

00:05:37.460 --> 00:05:37.950
 Brown, Cassie
 You know it is.

00:05:39.090 --> 00:05:46.050
 Brown, Cassie
 It is who you are and um the label or not like you're experiencing the same thing, so you may as well have some way to understand it.

2) Did you attend a mainstream secondary school? How long were you there for? Did you have any other schooling experiences to compare it to? Which if any suited you best? (Why?)
 I attended mainstream secondary school from age 11-16, and never enjoyed it. I went to the same school throughout, but I did want to move schools at some points, and most mornings I would feel extreme anxiety before going. I now attend college and feel much better suited to the environment.

Brown, Cassie
 I did, but it was a grammar obviously.
 00:07:27.680 --> 00:07:28.040
 Carolyn Bassett - Trainee Educational Psychologist
 Yeah.

BC Bassett, Carolyn
 10 autism diagnosis may give negative feelings

BC Bassett, Carolyn
 11. re thinking your whole life- new identity

BC Bassett, Carolyn
 12. label can help with understanding yourself.

BC Bassett, Carolyn
 13 did not enjoy ms secondary school

BC Bassett, Carolyn
 14. school reluctance common

Q8: fitting in at school

fitting in at school

1. Are there things you try to do at school to 'fit in' or become less noticeable?

I try to stay quite in my classes to not draw much attention to myself.

BC Bassett, Carolyn
 Being judged by others

BC Bassett, Carolyn
 Poor self esteem

BC Bassett, Carolyn
 Shame/embarrassment

BC Bassett, Carolyn
 Sensing the worst outcome/ getting it wrong

BC Bassett, Carolyn
 NEED TO HELP THEIR SELF CONFIDENCE

BC Bassett, Carolyn
 More confident in a subject more likely to answer/contribute.

Evian Winters
 I don't answer questions as i am anxious i will embarrass myself. I don't say i want to do things even if i really want to do it in case nobody thinks i should do it/nobody wants me to do it. I am scared to go for form captain, sports leader etc in case i get no votes and embarrass myself. I pick up on other peoples behaviours and use them to 'fit in' more, but i don't do that on purpose. If i desperately need to ask the teacher something i will go up to them so i don't draw attention to myself.

Wonder Woman
 i also dont put my hand up to answer things because i know ill get it wrong and friends wise i have some close ones but dont really want a big crowd of people jus me and my group but in class i dont talk anymore i just sit write and go

CB: This is interesting that three of you have all said how much you try to avoid being noticed.....does anyone feel differently or do all of you try to avoid attention?

Ember Jaymes
 I like to not draw attention to myself so much although if I enjoy the topic I answer a lot of questions, mostly in History and Chemistry

Appendix M. Excerpts from the author's reflexive journal.

As I work through the codes ^{again} with more of a latent level - more of the meaning is beginning to reveal itself to me. Despite obviously my own knowledge & preconceptions influencing what I pick up but a lot of the latent codes I am picking up on are the feelings of being judged, being apologetic for ~~the~~ who they are, too scared to draw attention to themselves, ^{for fear of being judged} or even feel ^{feeling embarrassed} deserving of being offered support - this needs to change but also has brought about feelings of sadness ^{in my own aspiration} towards this population & my overwhelming drive is to try to offer them the 'right' support at the 'right' time to help them develop a better sense of themselves as a person. 'Poor self identity' leads to masking to 'fit in' but we need to find them ways to accept &

17/11/21
 I think there are difficulties with the platform. The children aren't logging on - emails may not be being checked. I have contacted their school and their parents separately to try & encourage them as individuals. I possibly can't thank them for what they've done so far.

I think in order to get enough data from them I may find the questions they haven't answered & have to contact them all separately for their responses as some seem to be forthcoming.

7.30 tomorrow
 I will be live online.