

# We are all different but there's something kind of

fantastic about that: Exploring autistic adolescent

female's constructs of self and identity, a

narrative approach to research using the creative

# arts.

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#### Abstract

This is a narrative study that explores autistic adolescent females' constructs of self. Adolescence is a pivotal time for the development of an individual's self-concept and social identity (Erikson, 1968). Research suggests that 28% of autistic young people received their diagnosis after beginning secondary school. (Hosozawa et al., 2020). Autistic women have frequently been reported to have gone undetected, had incorrect diagnoses, or had delayed diagnoses. Schools are increasingly looking in how best to support autistic girls who have gone under the radar or trying to make sense of their diagnosis. In this research, adopting a critical realist positionality, I have explored how young people construct a positive sense of self. A creative and narrative approach, using collage inquiry was used to talk to eight adolescent females who had a diagnosis or self-identified as autistic. Using the 'Listening Guide,' to analyse each participant's narrative (Woodcock, 2016).

I identified the themes; trusted relationships, peer interactions, the school setting, and their understanding of autism as contributing to the participant's understanding of self. Having a good understanding of their strengths and time to engage in their interests supports the positive self-constructs as the YP can succeed in activities they are confident in and find both enjoyable and relaxing. The research findings highlighted the significant roles mothers play for the YP in their identity formation and advocating for them. A special emphasis was placed on prioritising the voice of the young person.



The University Of Sheffield.

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# A table of abbreviations.

Acronym	Definition
SEN	Special Educational Needs,
LG	Listening Guide.
EP	Educational Psychologist.
ASC	Autism Spectrum Condition.
ASD	Autism Spectrum Disorder.
ADHD	Attention Deficit Hyperactivity Disorder.
ТЕР	Trainee Educational Psychologist.
ҮР	Young Person.
SENCO	Special Educational Needs Coordinator.

#### **Chapter 1: Introduction**

"People are more than just bundles of measurable traits, and each autistic person is first and foremost a human, with a lived experience that is often what we imagine of any human life." (Daniel Wechsler, 2019)

#### Introduction

This chapter will discuss the background of my research to help readers understand the rationale for my thesis. I will detail the research context, reflecting on both my personal and professional reasons for undertaking this research. Secondly, the justification for the language and vocabulary will be discussed.

There has been an increased focus and interest regarding autistic females within academic research and in the media. There is a strong argument that autistic females frequently go undetected, get the wrong or late diagnosis (Gould, 2017). Unfortunately, acquiring a diagnosis tends to come after a mental health crisis, which frequently involves anxiety, depression, or an eating disorder (Lai et al., 2015; Rynkiewicz & Lucka, 2018). Although I believe the usefulness of receiving an autism diagnosis is an important area to reflect on, it is not the focus of this research (Begon & Billington, 2019). Instead, I have taken a holistic approach that seeks to understand autistic females constructs of self and identity through a narrative method.

It is crucial to understand that researchers bring their own personal context to any narrative research with the potential to influence the findings (Riessman, 2008). I shall therefore address my personal and professional reasons for writing this thesis in the interest

of transparency and reflexivity. Historically, I have held a within child understanding of autism aligning with a medical model. As a mother of an autistic child this provided some 'comfort' that her diagnosis was not because of her upbringing. I am aware that historically mothers were seen as the cause with Bettelheim's 'refrigerator mother' influencing how autism was perceived (Douglas, 2014). In the years following my daughter's diagnosis, I have had the privileged position of being able to reflect on my understanding through reading and learning from my daughter as well as the young people I have worked with in my career.

When working as a specialist teacher, I observed social skills interventions that instruct autistic young people on how to behave in a non-autistic manner as the standard procedure. This strategy has troubled me when serving in an advisory role where schools view you as the 'expert.' I questioned the ethics of instructing autistic children to 'pretend' to be what is viewed as 'normal' to integrate into regular classroom settings. I was always worried about the long-term effects of this, especially since autistic individuals were receiving such a damaging message. When my own daughter was diagnosed as autistic at the age of 8, I naturally became her advocate. I wanted to ensure we had open conversations about autism and for me to be honest with her. I initially made the mistake of trying to help her by using her diagnosis to rationalise the things she found challenging. With hindsight I realised that I had created a deficit-focused narrative around autism. I sought to understand how I can help support my daughter in developing a positive sense of self and identity. I attended a talk by Dr. Luke Beardon (senior lecturer at Sheffield Hallam University) who discussed the significance of assisting autistic young people in creating a positive sense of self. As a mother and a professional, this resonated with me and gave me the motivation to explore how we can do this and critically reflect on my understanding of autism.

Throughout the research I sought to maintain objectivity by ensuring my own personal experience of autism did not result in bias. I was able to do this by engaging in reflection and reflexivity as well as conversations with my thesis supervisor, colleagues, and peers. Member checking throughout the process helped to ensure it was the participants voice that was heard within the narratives. I have explored my emotional responses, values, and beliefs to help me think about the potential impact of these preconceptions within the study using a research journal. I have included reflective boxes that are intended to provide an understanding of the process.

# Language within the research

In an attempt to try and understand what autism is, I found that there is an ongoing debate regarding language. How autism is described or referred to can create passionate and strong responses. My intention during this research is to use respectful language and not portray autism as a disorder that needs to be fixed. When various constructions are employed to describe someone, language can be stigmatising (Gernsbacher, 2017). The term 'autism' will be used to refer to what many researchers refer to as Autism Spectrum Disorder (ASD), Autism Spectrum Condition (ASC), that are listed under the diagnostic category Autism Spectrum Disorder in the DSM V (American Psychiatric Association, 2013) or the ICD-11 (World Health Organization, 2018). I have avoided using any functioning labels e.g., high-functioning or low-functioning in the research in my goal to use as little medical or deficit-focused language as possible.

I feel it is important to learn more from those who have first-hand experience of being autistic. I aim to explore and illustrate the variety of experiences while fostering an

appreciation for the various understandings and constructions of autism. Throughout my goal has been to empower participants, to provide them the opportunity to share their narratives. I therefore encourage readers to be open to having their preconceived notions of autistic women challenged when they read this dissertation.

Quotes from participants in my research and other studies have been cited in italics.

#### **Chapter 2: Critical Literature Review**

# Introduction

My aim for this section is to consider current research, critically reflecting on what is currently known about adolescent autistic girls and their understanding of self. I will provide contextual information about autistic girls, their diagnosis as well as reflecting on the implications of 'masking' (Pearson & Rose, 2021) and well-being in relation to identity. Finally, I will critically discuss research on autistic identity. I will argue that there is a need for more research into autistic young people's understanding of self, supporting my rationale for the research question.

# Literature review approach

As I was considering multi-paradigms in my research, I conducted a critical review (Grant & Booth, 2009) of the research using the databases Psycinfo, SCOPUS (Elsevier), Web of Science, Eric (EBSCO) and Google Scholar. In order to ensure a thorough search strategy was used, all pertinent studies were included. The most important themes in the literature were gathered and used to set the stage for the current study. A search using keywords was carried out, these included relevant terminology such as, autism, autistic, Asperger's, self, self-concept, identity, identities and social identity. Research whose titles or abstracts didn't contain enough details to match the inclusion criteria were read in a second screening step to ascertain eligibility. This was done to find any potentially relevant research. A snowball method was then utilised to locate any more literature to incorporate after this point. Studies that referenced the self-concept, identity, or social identity of young autistic people (including Asperger's syndrome or any other DSM V category in the abstract or title) were taken into

consideration if they were written in English, had undergone peer review, used a qualitative methodology, and were primarily geared towards adolescents. This technique was designed to make sure that no material was missed just because of language by restricting the review's scope to the peer-reviewed publications that were most relevant to the current topic of interest. A summary of the key studies that were most relevant is included in appendix 2.

#### An overview of autism

Autism is a vast topic: a recent Google search on 'autism' brought up 21,200,00 results, it has become a lucrative business. There is a plethora of books, magazines, products, journals, events/conferences, consultancy, and schools that are devoted to autism (Runswick-Cole, 2016). In the media there have been several celebrities that have talked about being autistic including Chris Packham and more recently Christine McGuiness. McGuiness talked of her diagnosis in her documentary 'Unmasking my autism' which sought to highlight the experiences of autistic girls. Current prevalence rates within the UK population are said to be 1-2%, that is 1 per 100 children (National Health Service, 2020). Autism was listed as the main need for more than 82,800 (30%) of English students with an Education and Healthcare Plan (EHCP) (Department for Education, 2020). When comparing genders who are diagnosed autistic, there is a 2:1 male to female ratio (Kirkovski, Enticott, & Fitzgerald, 2013), previously this was estimated at 4:1(Mandy et al, 2012).

# **Diagnosing autism**

It was in the 1940s that the biomedical view of autism was first introduced through the work of Leo Kanner (1943) where he wrote about autism as a cognitive disorder. Wing and Gould (1979) proposed that autism can be identified using the 'triad' of symptoms which

included a lack of social interaction, rigidity of thought and disordered communication. This cognitive deficit model of autism has been criticised by some researchers, clinicians, and autism self-advocates (Rose, 2018, Beardon, 2008). It was in 1980 when autism was first formalised as a diagnostic category in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DMS-III) (American Psychiatric Association, 1980). There have been some changes in the way that autism is categorised with the 'triad' now being reduced to two categories, impaired social communication and interaction in addition to restricted behaviour. Although the social interaction difficulties continue to be a requirement in order to receive a diagnosis of autism, there is still a significantly small number of studies that investigate the underlying nature of this social instinct and its absence (Wing, 2011).

The most recent DSM-5 (APA, 2013) published criteria for diagnosis that includes one single category of 'Autism Spectrum Disorder', this means that there are none of the previous subdivisions such as Asperger Syndrome. This removal has been described as an important and somewhat controversial decision (Ghaziuddin, 2010). The argument for the removal of these subcategories is that it is difficult for clinicians to decide on the boundaries between them, therefore a spectrum covers different presentations. A criticism often used against the DSM is the way it pathologizes behaviour through the creation of labels that can create stigmatisation (Charland, 2004). Through the removal of the subcategory of Asperger Syndrome it can be argued that it also has the power to remove identities. Many people who were diagnosed with the label Asperger's syndrome have reacted strongly to the removal of this from the DSM-5 as they identified with this label more than autism (Wing, Gould & Gillberg, 2011).

Furthermore, social constructionism asserts that a person's thought process, including the categories and ideas that give them a context for understanding the world, is determined by the language they use. (Burr, 2003, p.8). The usage of autism constructs in both public and private settings is therefore believed to provide autistic individuals with a frame of reference from which to establish a sense of their own selfhood. All professionals looking to support and enhance outcomes in education and beyond should therefore pay attention to ongoing study and growing knowledge of how autistic people construct self-concept and social identity.

Recent research suggests that the time when the diagnosis is received can have an impact on an individual's self-esteem. Corden, Brewer and Cage (2021) argue that an autistic individual's personal identity changes over time after diagnosis, with more negative characteristics initially approved and a potential for decreasing discontent. The results also suggest that later identification is related to higher dissatisfaction and lower self-esteem. Berkovits et al. (2020) argues that autistic individual's perception of their diagnosis is influenced by their awareness of the stigma associated with being autistic. A wider view is taken by Williams et al (2019), their meta synthesis identified three interconnected dimensions of experience, including challenges related to being autistic, relationships (especially with peers), and the inclusivity of the school environment. These elements interact and play a part in how many autistic students negatively position themselves as "different" from their usual peers.

#### **Constructs of autism**

Historically, there has been a dominance of positivist research which took a more 'scientific' view of autism. This research had a focus on how to 'fix' or 'treat' autism and used ableist language (Bottema-Beutel et al., 2021.) Research that is informed by autistic voices that seeks to deconstruct ableist narratives is much needed (Bagatell, 2007). Happe and Ronald's (2008) research and theory of the 'fractionable autism triad' highlights the complexity of autism. They argue that not all individuals present the same, therefore not one specific cause can be found. It is not simply locked into DNA and so an autistic individual's well-being cannot be screened or 'treated'.

# **Critical perspectives**

There is an emerging field of research that takes a critical look at autism. This research questions whether the diagnosis of autism is critically valid, encouraging reflection on whether the label is useful to those who receive the diagnosis (Runswick-Cole, Mallet & Timimi, 2016). Timimi et al (2010) suggests that autism is a social construction with society only becoming concerned with patterns of behaviour which have always existed, when it has a economic or political impact on the functioning of a society. This perspective is further supported by Oliver (1992) who describes disability as a product of social and economic structures, emphasising that it should not be seen as a tragedy, a view that aligns with my own positionality. This approach suggests labels of disability are determined by public policy which pose a level of professional dissonance (Hahn, 1985).

It can be argued that a diagnosis is needed to enable individuals to access services and resources which they would not be able to receive without this label (Volker & Lopata, 2008).

A further argument for a diagnosis of autism is that the education system requires categories for those children who do not conform or are able to access formal teaching. A label helps teachers to access the right support for the need, to offer what is different from and additional to the teaching within the classroom (Jordan, 2007). I would challenge this view as again it is using the categories to pigeonhole children who do not fit into the 'norm' and learn in the way that we are told they should learn. According to Milton, an autistic academic and researcher, "opening up a respectful discursive space, where autistic development is not framed from the start as "disordered" is necessary. (Milton, 2017, p. 461). It is this position that my research is framed within.

# Labels and identity

From a social constructionist view, the narratives that surround autistic individuals and their families become a way of life. For them, the term autism has tangible effects because language prompts social behaviour (Burr, 2003). The language around subcategories such as high and low functioning further add to the negative discourse. One way to address this was suggested by Beardon (2017) who argues that a blanket Autism Spectrum label without sublevels can ensure that the focus remains on an individual's potential and not judgement of the person. Latif (2016) argues that young people should be able to access services and support without the need for a 'lifelong label'. The implications of being given a label of a 'lifeline' disorder is 'internal stigma', this can be associated with low expectations for a person's long-term outcomes and a lack of hope as a person's responsibilities are shifted from themselves to the diagnosis. This results in people believing that the person is not in control of their behaviour and the blame lies on their autism. As a result, any expectations for them to develop and change as they grow are lowered or taken away. Tomlinson, Bond and Hebron

(2021) found similar results when interviewing autistic girls who reported a change in language used when discussing their futures. The girls reported that once they received the diagnosis, the word 'when' was replaced by 'if' when referring to their long-term outcomes. In contrast Macleod et al (2013) found that the majority of participants accepted and were positive about their autism diagnosis. They acknowledged autism as an essential component of their identities, or what they called an autistic identity, and expressed a desire to learn about or interact with other autistic experiences.

# Autism in females.

In recent years there has been an increased awareness of autism in girls as historically it was considered a predominantly male disorder (Mandy & Lai, 2017). Beeger et al. (2013) and Rutherford et al (2016) suggest from their research that the mean age of diagnosis for females is greater than males. The findings suggest that more girls are unidentified in pre-school and primary school with less numbers being referred to the autism pathway. This over-representation of males may be attributed to the use of gender-biased standardised instruments and clinical expectations (Goldman, 2013). An example of this is the gender bias found in the Repetitive Behaviour Scale -Revised (RBS-R) restricted interests' subscale, this lists 'typically male' interests such as trains, cars and dinosaurs (Wolff et al., 2016; Solomon et al. 2012). Lai et al. (2011) suggests there are behavioural differences and noted that females reported ongoing sensory challenges and fewer socio-communication difficulties than males.

Sociocultural expectations can potentially have an effect on how autism is expressed in females as well as how their behaviours are perceived (Kreiser & White, 2014). Research

suggests that girls are not as easy to identify as they tend to internalise their difficulties presenting with more surface-level social skills (Hebron & Bond, 2019).

There is a limited amount of research that focuses on autistic girl's experiences in education and what would contribute to make one that is positive (Tomlinson et al, 2021). Some researchers have tried to understand the differences between genders, proposing cognitive deficit theories which include the Baron-Cohen's (2002) Brain Differences Model (BDM), the Greater Variability Model (GVM) and the Liability Threshold Model (LTM) both proposed by Wing (1981). It is important to consider that these theories are based within a medical model. More recently Kaat et al (2020) suggested the small sample sizes created limitations in the research, using a larger sample of participants the study found a different pattern with minimal sex differences within the tools. Rivet and Mason (2011) argue that there is a need for more research into autistic females. Gaffney (2020) found that girls used their diagnosis as a way of making sense of historic and current behaviours with varying acceptance.

# Flying under the radar.

There is still no definitive agreement on the concept, metrics, and mechanisms of autistic camouflaging in spite of increasing research (Fombonne, 2021; Williams, 2022). Radulski (2022) argues that there is a need for refining the definitions of masking and camouflaging as there is a tendency for these terms to be used interchangeably within research. Hull et al. (2019) argue that masking is only one component of camouflaging. Masking is the internal process of becoming aware of one's own visible autistic qualities and acting to cover them up, whereas camouflaging is the exterior process of assimilating in order to not be visibly

acknowledged as being autistic. (Lai et al.,2011; Hull et al., 2019; Radulski, 2022). Masking may also be to blame for the propensity for late diagnosis (Begeer et al., 2013), as it is thought that autistic females mask more frequently than autistic males (Lai et al., 2017). This view however is not supported by all research (Pearson & Rose, 2021).

There has been a growing interest and recognition for the need to support girls in education which was documented in the publication 'Girls and autism: Flying under the radar' (NASEN, 2016). When asked about their school experiences as part of their study, autistic girls reported feelings of isolation, being lonely and misunderstood (Honeybourne, 2015). A similar study replicated these findings in addition to highlighting them experiencing anxiety (Goodall & MacKenzie, 2019). The implications of unmet needs in education and the long-term detrimental impact of this, is highlighted in the research by Baldwin and Costley (2016). From their findings, they argue that unmet needs result in higher levels of mental health disorder, social exclusion and isolation which can be experienced into adulthood. Bargiela, Steward and Mandy (2016) supports this suggesting that females who are missed are more likely to experience mental health difficulties e.g., anxiety or an eating disorder. This research suggests that masking their difficulties can be a factor in their long-term mental health needs. Cook et al (2021) describes masking as a strategy to hide a person's autism in response to a strong desire for social connection and acceptance. Schneid and Raz (2020) develop this further, suggesting that camouflaging is part of a 'toolbox' for impression management. The research argues that even if they see being autistic as a positive part of their identity, the social stigma makes it challenging for them to not hide aspects of themselves.

Goffman's (1963) work around impression management describes the role that individuals play, which are driven by a need to be taken seriously by others, wanting other people to believe you are the person you present. Although Goffman's work was not specifically focused on autistic individuals, autism researchers have hypothesised that camouflaging is related to a component of impression management (Schneid & Raz., 2020; Jorgenson et al., 2020). Building on the theory of, Hull et al (2017) proposed that masking is an attempt to present as typical when engaging in conversation, following rules and using tricks such as flipping back a question in order to maintain a reciprocal conversation. Although research has attempted to conceptualise and quantify camouflaging behaviour within the autistic population, it is still very much in its early stages and so the construct of camouflaging or masking is still not clearly demarcated (Fombonne, 2020). It can be explained as a difference between the "neurotypical," externalised behaviours and the atypical, internalised social and cognitive capacities (Lai et al., 2017).

There are many reasons for camouflaging, however there were some common themes found in the literature informed by autistic females' experience. One of the most frequent reasons found was to fit in or avoid negative reactions from others, something that all individual's will do at some point in their life. One of the most concerning findings from the literature review was the link made between high levels of masking and suicide in autistic adults (Beardon, 2017; Pelton et al, 2020; Cassidy et al, 2020). An explanation offered for this is that autistic people who feel the need to mask can feel less authentic and not accepted by other people. This lack of acceptance results in a lack of belonging and loneliness leading to suicidal thoughts (Smith & Jones, 2020).

#### **Adolescence and Identity**

Recent research in the UK shows that, 28% of autistic youngsters received their autism diagnosis after starting secondary school. In 2020, Hosozawa et al. Young people "typically enter a stage of profound psychological transition" during adolescence, a time of intellectual and social transformation as a result of external pressures, according to Blakemore et al. (2010, p. 926). The life stage of adolescence is one of great change and transition, there are body and brain changes, relationship and behavioural changes, sexual development, and the development of identity. According to Sebastian et al. (2008), adolescence is a period of profound change for ideas of the self. O'Connor et al. (2018) found that receiving a diagnosis of a psychological condition during this crucial time, encourages individuals to re-evaluate their identities. It is during adolescence that a young person would seek autonomy from their parents and have a greater drive to make connections with their peers. They may begin to commit to more social aspects of their identity, showing a greater concern in how others perceive them. It is during adolescence that we are faced with the task of self-definition, particularly in Western cultures (Kroger, 1996).

Experiencing uncertainty in their identity is a normal process in adolescence (Erikson, 1968). There is however a lack of empirical studies that explore identity formation, Becht et al (2021) argues that more research would enhance an understanding as to whether identity uncertainty is a normative process of adolescence. It is therefore difficult to establish whether this uncertainty is more prevalent in autistic young people as there is a lack of research to make comparisons. According to Erikson's (1968) theory, identity formation is influenced by how society defines a person, as well as by how they perceive themselves and other people. Some young people's identities change after receiving an autism diagnosis and

become an integral component of their sense of self. (Huws & Jones, 2008; Molloy & Vasil, 2004). While a diagnosis can help people make meaning of their past experiences and challenges, some people report feeling burdened by the weight of a diagnosis. (Gaffney, 2020).

What the research does highlight is that autistic people report being unable to be their 'authentic selves' within social situations and so over time they present themselves as nonautistic, both consciously and unconsciously changing their behaviour (Hull et al, 2017). This is described as a reaction to a social message that a person's autistic identity is not acceptable, highlighting the significant role the environmental context plays. Within the literature there was a distinct lack of research that explores how autistic young people experience a positive sense of self, the role of the environment in this and other contributing factors. I will now consider different psychological theories of identity, the literature which focuses on identity and reflect on its relevance to my research.

# **Psychosocial stages theory**

Historically, identity was defined in a straightforward way by social rank and kinship networks which was predetermined at birth (Baumeister, 1987). The term 'identity' and 'self' for social scientists have held specific meanings. Erikson (1968) wrote about a model that represented the psychosocial development across a lifetime which included the formation of identity. Erikson contends that psychosocial crises at successive developmental stages lead to the emergence of a person's personality. The model consists of eight developmental stages, the fifth of which, which takes place during adolescence (12–19 years), is crucial for identity formation. It is during the identity vs confusion stage that Erikson suggests a favourable

resolution leads to an individual developing a sense-of-self and personal identity. It highlights how crucial adolescence is for identity formation by causing "role confusion" and a lack of identity clarity when it is unresolved. In his work on the psychosocial nature of identity from 1968, Erikson acknowledged the crucial part that the community plays in identifying, encouraging, and assisting in the formation of the teenage ego. Identity development, according to Erikson is a reciprocal relationship between the individual and context. It is a process of recognising and being recognised by significant others. This shows that confusion or a lack of clarity can affect a female's concept of herself if she receives a late diagnosis of autism. If we consider the transition to high school where friendships become more complex, demands increase and the need to 'fit in' becomes even more important. It begins to suggest why there may be difficulties in autistic young people understanding their identity.

# Social identity theory

Self-concept is defined as the belief a person holds about who they are, including characteristics (Baumeister, 1999). It is a collection of characteristics, traits, roles, relations, and group memberships that define who an individual is, making up a succession of identities (Oyserman et al., 2012). The part of one's self-concept that stems from belonging to social groups, along with the emotional significance associated with it, is referred to as social identity (Duszak, 2002; Tajfel, 1981). According to social identity theory (Tajfel & Turner, 1979; Macleod et al., 2013), an individual's social identity is influenced by their affiliations with both in-groups and out-groups. This theory suggest there are three mental processes involved in the formation of a social identity. The first process is social categorisation, this is where an individual will sort people into an in-group depending on similarities with themselves and those that have no similarities into an out group (Hogg & Reid, 2006).

The second mental process known as social identification occurs when an individual adopts the identity of a designated group. The assessment of a person's group membership is what determines how high that person's self-esteem is (Hornsey & Hogg, 2000). It is possible for someone to acquire the collective identity, which might cause depersonalization because it trumps the person's individuality (Stets & Burke, 2000). Finally, the last stage is social comparison, this is where an individual will compare their group to find negative characteristics of the out-group as an attempt to raise their own self-image. This process can lead to a 'us' and 'them' with the potential of stigmatisation (Tajfel & Turner, 1979). It can be argued that social comparison is of particular importance for autistic teenagers who are frequently the targets of bullying at school (Cappadocia et al. 2012), and Sterzing et al. (2012) found that this group is up to four times as likely to experience bullying than non-autistic peers. Due to the frequent peer rejection, autistic adolescents may find it difficult to understand their place in society.

Working through self-identity problems is seen by Parker and Gottman (1989) as the most crucial task in adolescence for their social and emotional development. Through intimacy and self-discovery, teen friendships act as a channel for self-discovery. Forming and maintaining friendships can have implications for autistic girls as the complexity and difficulty of teenage relationships can be challenging (Tierney et al., 2016). Despite possessing the desire for interaction with others (compared with autistic males) (Lai et al., 2015) in addition to the motivation for friendships the challenges influence their constructs of identity and selfesteem (Sedgewick et al., 2016).

#### A sense of self

Symbolic interactionist such as Cooley (1902) and Mead (1934) propose a theory of the "looking glass self". People learn about themselves from the perspectives of others, especially close friends, and family members. They contend that without a sense of the other, there can be no notion of "I," and that one's sense of who they are comes from understanding how they are perceived by others. Over time this view becomes incorporated into the stable view of self. Social comparison theory offers an alternative view, that a person's concept of self is dependent on the views that others hold in that situation. Self-conception is said to be affected by social comparison, that people will compare themselves with others to reach conclusions about themselves (Videbeck, 1960; Festinger, 1954). Bagatell (2004) supports the view that autistic people's identities are not something there to be discovered but are constructed through engagement with their social worlds. The research however was conducted with adults and so it is difficult to know if this is relevant for young people. Pasupathi and Hoyt's research (2009) emphasised the significance of friends in the development of adolescent narrative identity. This has implications for autistic individuals who may find forming and maintaining friendships difficult, particularly if their peers do not understand them or do not have an awareness of autism.

Self-concept and "social identity" can be regarded as dynamically constructed (Oyserman et al., 2012) within a social context because it changes over time and across contexts. According to Burr, "*the language that a person uses provides the very categories and concepts that provide a framework of meaning for them*." (Burr, 2003, p.8). Social constructionism shifts even more away from an essentialist viewpoint on the social identity and selfconstruction processes and in the direction of anti-essentialism. That is, there is no presumption that one can somehow access and quantify something called a self-concept or social identity. Terms like "autism," "self-concept," "social identity," "adolescence," and even "girls" are seen as social constructions when the topic at hand is examined through a social constructionist lens as opposed to as distinct things that exist independently of the language and social processes that define and support them.

Jerome Bruner (2002) describes narrative identity where we create and re-create selfhood through the stories that we talk about ourselves. The stories grow in complexity and detail as we move through childhood, through adolescence into adulthood. It is when a person reaches adolescence that some theorists believe we become motivated to understand and achieve a complete understanding of self (Habermas & Buck, 2000). Beardon (2019) suggests for wellbeing within the autistic community, they need the opportunity to learn about what it means to be themselves, an individual and autistic.

Corden, Brewer and Cage (2021) looked at the impact of receiving an autism diagnosis on an individual's sense of self. A correlation was found between when the diagnosis was received and an individual's self-esteem. The findings imply that an autistic individual's personal identity changes over time after diagnosis, with more negative characteristics initially approved and a potential for decreasing discontent. The results also suggested that later identification related to higher dissatisfaction and lower self-esteem. In their investigation into how teenagers perceive their autism diagnosis, Berkovits et al. (2020) discovered that about half of participants (N=38) discussed the stigma associated with having an autism diagnosis. Williams, Gleesen and Jones (2019) explored how autistic pupils make sense of themselves in the context within mainstream education. They found three interlinking experiences that contributed to their understanding of self and seeing themselves as 'different' to their neurotypical peers. The three factors were difficulties link to autism, interpersonal relationships with peers and the school environment. The research however involved a small sample and so generalisability is problematic. Individual sense making about the self was highlighted as a key area for further research, in addition to intervention that improves selfesteem and well-being. Baines (2012) suggests autistic adolescents are not isolated from the sociocultural process of identity development, arguing it is a conscious strategy used to promote to others a positive perception of themselves. As Baines used a small sample for the research it is not clear if these findings can be generalised.

# Identity and mental health.

When considering autistic mental health difficulties, a key concept to reflect on is identity. Sedgewick, Hull and Ellis (2020) argue that it is difficult to have a positive outlook on life without good self-esteem. O'Connor et al (2018) suggests that self-legitimation, selfenhancement, and self-understanding can be benefits of a diagnosis. They argue that there are risks to one's self-concept with a need to re-evaluate one's identity, impacting on selfesteem. Further benefits included social identification with people who shared the same label, but disadvantages included feelings of stigma from others as a result of the diagnosis.

Cooper et al. (2017) found a positive correlation between having a strong social identity and having fewer mental health concerns, even though autistic participants reported having worse mental health than those without a diagnosis of autism. In the study by Bargiela et al. (2016), it was discovered that females with late-diagnosed autism were able to access a recently acquired sense of "fitting in" with other autistic persons, which boosted their sense of self-worth. Research on the removal of the Asperger's Syndrome diagnosis from DSM 5 (American Psychiatric Association, 2013) has focused on participants' positive identities as a result of their diagnosis of Asperger's and their sense of community with other people who share their views on autism. (Chamberset al., 2019; Smith & Jones, 2020).

Tomlinson, Bond and Hebron (2021) documented autistic girl's experiences as part of their research. One girl shared her reluctance to share her diagnosis with others as she found it hard to accept. Another girl shared her frustration in the adult's responses to her diagnosis; she noticed when talking about her future there was less optimism. The study argued that the results highlighted a need for more research to understand how autistic girls develop their sense of identity, as this can increase the vulnerability in mental health difficulties. Tierney et al (2016) emphasised the link between masking and identity, suggesting that the results of habitual pretending not to be autistic wears away an individual's sense of identity. Furthermore, this area of research would then inform professionals in how best to support girls in mainstream settings. When looking at the research there was very little that had looked at what helps autistic children to understand self or encourage a positive feeling of who one is.

# **Double empathy problem**

Morgan (2023) suggests that autistic girls' social identities were founded on concepts of 'fitting in' and 'sticking out'. This supports Sedgewick, Hull and Ellis' (2022) research which suggests that autistic people feel safer to 'drop the mask' when with other autistic people,
describing the experience as more relaxed or less effortful. This is further supported by Howard and Sedgewick (2021) who suggested that communicating with other autistic people was like 'finding their tribe'. Milton (2012) suggests that the difficulties between autistic and non-autistic people is not totally because of the 'poor' communication and empathy skills. Heasmen and Gillespie (2018) found from their research using online gaming, groups of autistic people created their own norms which may seem odd to outsiders. A level of flexibility was observed which meant that the group were both responsive and supportive to all involved.

Does this mean that to have a positive sense of self, autistic adolescents need to have the opportunity to spend time with other autistic people? As discussed previously, Social Identity Theory assumes that a part of the self-concept is defined through belonging to a certain social group. This belonging can provide meaning and purpose with positive psychological consequences (Haslam et al. 2009). According to Cresswell and Cage's (2019) research, getting together can operate as a buffer against discrimination, which can be a protective factor against the detrimental effects of marginalisation by minority groups (Postmes & Branscombe, 2002). An important consideration is how autistic people incorporate their autism diagnosis into their social identity.

#### Neurodiversity

Siberman (2015) explains how autism has influenced various groups, such as political, social, and tribal activism. He describes the evolution of activism, starting with the first wave, in which parents resisted having the blame previously put on them, and the second wave, which pushed for a cure. The third wave, known as autism activism, advocated for the

diagnosis of autism as a disability that cannot be cured. The neurodivergent movement, in which people self-identify as autistic without receiving an official diagnosis, is the most recent wave. This movement argues that autism is actually a brain difference that occurs naturally and is not a disorder. On balance there is more research to suggest that using an approach that considers autism as a 'difference' in processing or experiencing the world is a more accurate approach, there is much less research that supports the 'deficit' view (Baron-Cohen, 2017).

The social model of disability (Oliver & Sapey, 1983) is where neurodiversity originates because it rejects the idea that autism is just an issue that is within autistic people. It promotes the idea that autistic people are a minority group, hindered by a society that is centred on the 'neurotypical' population. This model argues that society should change rather than the person (Graby, 2015). This paradigm stresses societal barriers that prevent inclusion rather than 'within person' pathology. A poor fit between a person's characteristics and the demands of their social surroundings leads to disability. The neurodiversity discourse views autism as a neurological variety rather than a pathological condition that needs to be treated (Singer, 1998; Barnes & McCabe, 2012). According to the neurodiversity paradigm, autism is an identity rather than a disease (Kapp et al., 2013). Autistic people are not deficient compared to non-autistic or 'neurotypical' people (Brownlow & O'Dell, 2009; Cooper et al., 2021; Kapp et al., 2013), and all neurotypes share a profile of challenges in addition to strengths (Pellicano & Stears, 2011). It gives autistic people access to a critical dialogue through which they can contest the inaccurate and modifying how the general public views autism (Brownlow & O'Dell, 2013). The neurodiversity paradigm provides opportunities for the development of an autistic identity that is strengths-based, fosters pride in oneself, and makes one feel a part of a community, avoiding stigmatising language (Cascio, 2012; Bagatell, 2007; Bumiller, 2008).

#### Identity and imposter syndrome

Tomlinson, Bond and Hebron (2021) documented autistic girl's experiences as part of their research. The study argued a need for more research to understand how autistic girls develop their sense of identity as this can increase the vulnerability in mental health difficulties. Tierney et al (2016) emphasised the link between masking and identity, suggesting that the results of habitual pretending not to be autistic wears away an individual's sense of identity. Imposter syndrome is when an individual worries that they will be exposed as a fraud when doubting their own skills, achievement, or identity. Although not unique to autistic people, research suggests it can be a long-term effect of masking, experiencing imposter syndrome around their autistic identity (David & Henderson, 2010; Smith & Jones, 2020). It is understood that a person's sense of self, distinctiveness, and social group membership all contribute to their "identity" (Ryan & Deci, 2014). Understanding their identity is crucial for understanding their place in the world and how they should behave (Hammack, 2008). A 'disability identity' is a particular type of identification that, according to Mogensen and Mason (2015), can help people feel accepted and bring about belonging. According to Gill (1997), 'integration', or fusing the conflicting elements of a person's identity, is essential for a person to be at ease with their disability identity and to be mentally well. According to Gill (1997), it can be difficult to 'come together', or integrate the various aspects of one's internal self, because others frequently view disability as something that is external to the individual and is unimportant. As a result, the person divides themselves into 'good' and 'bad' parts and never feels completely accepted. This suggests that for autistic women, the long term implications of masking and camouflaging is that it becomes automatic which can create confusion. The suppression of their autistic traits means they may not be seen as 'autistic enough' in order to align themselves with a 'disability identity'. Botha and Frost (2018) suggest that this creates stress around autistic identities as a minority which directly impacts on mental health.

### **Complexities of Positioning**

I will reflect on the complexities of the different positioning with relation to the concepts of: autism; gender and masking. In the next chapter I will consider the relationship between the concepts and how this is relevant when trying to understand adolescents constructs of self. For transparency I will conclude with a reflection on my own positioning.

### Gender

Butler (2005) suggests that gender is the discursive technique by which "sexed nature" or "a natural sex" is generated and established as a "prediscursive" antecedent to culture, a politically neutral surface on which culture acts. The terms "sex" and "gender" are frequently used synonymously. The contrast between sex and gender, despite the fact that they are unique, is significant. Whether a person has a XX or XY chromosome, or both (other combinations are possible and would be classified as Intersex), sex is biological. According to Foucault (1979), systems of power within society create the people they later come to represent. Butler (2005) argues that there is an identity that can be grasped through the category of women.

In general, society identifies just the two biological sexes and the two gender categories—male or female—with very little overlap (Richards & Barker, 2013). There are societal norms and expectations for each of these genders, male and female. These regulations set standards for a variety of items, including attire, activities, and attitudes. They are not set in stone and change with different communities and eras (Brill & Pepper, 2008).

Historically the discourses around women has evolved and changed. In the industrialised world not too long ago, the general public paid little attention to the accepted role of girls because it was so widespread. Folklore from previous generations, such as fairy tales, nursery rhymes, religious tales, and morality tales, came together to propagate the idea that girls are fundamentally different from boys and describe the negative consequences for those who did not follow this expectation. Butler (1990) asserts that one can feel more feminine or masculine by repeatedly completing some ritualistic behaviours. In primary school, this can involve putting on a school summer dress or pair of shorts, playing football or breaking out into a dance routine during playtime, or selecting an animal-themed book from the school library. Butler (1990) contends that this public display then contributes to an individual's internalised gender construction. According to studies, the earliest years of school are when binary gendered views and expectations about what it means to be a boy or a girl truly start to matter (Paechter, 2007; Thorne, 1993; Walkerdine, 1998).

According to Martin and Ruble (2004), children generally discover the significance of their own gender around the age of two. Gender stereotypes that society has constructed frequently influence the toys that young children play with and the activities that they are encouraged to engage in (Francis, 2010). This can lead to diverse experiences for each gender

as well as the development of unique skill sets (Eliot, 2018). These early experiences may have long-term effects, impacting the formation of interests in particular, gendered jobs that may persist into adulthood (Hayes, Bigler, and Weisgram, 2018), and, more crucially, they may limit aspirations (Eccles, 2009; Francis, 2002). Butler (1990) supports Foucault's (1979) theory that normalising power causes us to want to do what we have to do, believing that these are our own ideas, by arguing that our wants are based on social norms rather than our own inherent individualism.

Shehy and Solvason (2023) looked at how teachers portrayed femininities and masculinities to see how their understanding of gender might affect how the students they teach create their gender identities. The data indicates that limiting binary gender stereotypes persist, raising the possibility that teachers may still be limiting their students' opportunities even though one might assume that gender stereotypes are outdated and that modern British society has moved past such discourses. Young people could appear to be struggling to fit into the quickly evolving and more complex adult world without the conventional codes of gender-appropriate behaviour. Boys' and girls' peer cultures develop during the early years, with distinct disparities between the two (Goble et al. 2012). According to Lamb et al. (2009), peers actively "teach" their classmates stereotypes and reject or treat them negatively if they don't fit in. However, they also point out that educator intervention has helped young children detect and reject their peers' sexist remarks.

Fausto Sterling (2000) contends that despite progress, many unintentional presumptions continue to overtly and covertly send gender messages. According to Wenger (1998), schools function as 'community of practise' where people can learn about social norms, particularly

those pertaining to gender, from one another. As they work to establish their own selfunderstandings and identities as girls at a certain time and place in their academic careers, the learning that takes place in girls' informal groups is collaborative, intentional, and mutually engaged (Gill, Esson, and Yuen, 2016)

According to Namaste (2000), those who do not identify as 100% male or 100% female provide a challenge for society because there are no established guidelines or social norms for interacting with them. Kennedy and Hellen (2010) noted that a significant portion of the literature relates to the concept of gender identity "disorder," starting from the premise that there is a problem and a need for therapy (Ansara and Hegarty, 2012). Transrights and the experiences of students and employees who identify as gender nonconforming in the educational setting have been major topics of discussion in recent years in the media (Koyama, 2020; Morgan and Taylor, 2019). During discussions with teachers of gender fluidity and transgender children were virtually non-existent in the data Sheehy and Solvason (2023) collected, despite their prominence in current gender debates. The majority of the observations in their sample were binary in character. This shows that the gender rhetoric in contemporary media and academia is at odds with the realities of the study's group of teachers' daily lives and careers. The government has produced on relationships, sex and health guidance for schools (DfE, 2022) which acknowledges that navigating issues surrounding gender and biological sex can be difficult and delicate. The guidance suggests that by implying that YP may identify as a different gender depending on their personalities, interests, or clothing preferences, for example, you are reinforcing negative stereotypes. The guidance stresses that teachers should always try to treat individuals with sensitivity and support, even while they should not convey to YP that because they do not fit gender stereotypes, either their personality or their physique is flawed and has to be changed. However, Sheehy and Solvason (2023) argue that "the average" teacher can still have a fairly binary understanding of gender, which might unintentionally hurt young children who are unsure about their gender identity. This can leave teachers in a difficult position if they are not aware of the impact of their own understanding. This guidance has created some debate with teaching unions as the lack of clarity in how to support YP can have damaging effects for the YP and make the teaching professionals vulnerable (Fazackerley, 2023).

Paechter (2006) argues that the majority of us are men in male bodies and women in female bodies, however our own understanding of our masculinity and femininity varies at different times and in different situations Being aware of someone's gender identity is very different from understanding how their masculinity or femininity is constructed. Each person trying to conform to the pervasive cultural and societal standards may unintentionally be constrained by gender stereotypes, despite the fact that these are performed in various ways and are viewed differently. This strongly implies that teachers may unintentionally convey sexist ideas to their students.

According to certain theorists, society should view gender as considerably more nuanced (Butler, 2015), or as a continuum along which all people will fall regardless of their biological sex (Genderbread person, 2016). It is thought that younger adolescents may explore identity alternatives more thoroughly than older adolescents (Kroger, Martinussen, Marcia 2011), and more gender diversity may be anticipated among early and middle adolescents than among late adolescents. A different view is that recognising and accepting a different identity than the majority of people may be harder than growing up following social norms. As a result, adolescents may exhibit more gender variant experiences than earlier in childhood because the formation of non-conforming gender identity and becoming aware of it may take more time. There has been a shift in gender being linked to biological sex and being understood more as an individual sense of self and style. Connell (1995) argues that the concept of gender is not viewed as being connected to a binary division between masculine and feminine but rather as a range of alternative ways to be masculine and feminine connecting to time and location as individual choice. In other words, gender is viewed mainly as social construction.

According to Paechte (2007), the family, the peer group, and the school are the three main contexts for children in Western society where the communal creation and learning of masculinities and femininities takes place. As a result, educational psychology has a wide range of possible applications in these three fields. I feel that it is important to consider the integration of multiple points of view so that reality might be comprehended better. As discussed, gender is considerably more nuanced. I am aware of the potential marginalisation they may experience due to their diagnosis but also the social cultural expectations they may experience due to their registered sex on the school system.

## **Autism Positioning**

It is difficult to explore my position on autism as a researcher without reflecting on the journey that the label has been on. As discussed, autism is currently viewed as a developmental syndrome that frequently lasts into adulthood and has genetic and biological correlations. The UK's first "disability-specific" law, the Autism Act, was approved in 2009, underlining the importance of the autism diagnosis in redefining methods to mental health treatment, social welfare, and individual rights.

Rutter (1979) suggested that modifications to how children have been evaluated and treated for developmental problems of various kinds have resulted in an increase in the use of the autism diagnosis. Lorna Wing (1993) has consistently claimed that she did, in fact, broaden the definition of "autism" to encompass more instances. Nadesan (2005), argued that cognitive science has played a significant role in shaping the present paradigm for understanding autism. It has not however taking into account the changes in how we understand children to develop which potentially contributes to reported rises in prevalence of autism which can mean that children are being given a label as they do not fit into an outdated view of 'normal development' (Evans, 2017). Hacking (2009) suggests a category (such as autism) is constantly being remade through discussions among experts in the field, autistic individuals, parents, and professionals. This interplay between social movements, medical organisations, and experts in the field creates and shapes our knowledge, diagnostic classification, and how autistic people are perceived and understood.

Ford, Goodman and Meltzer (2003) argue that there is an increase in demand for diagnosis in later childhood when their behaviours start to cause problems because social demands exceed capacities. Key transitions in education when demands increase can result in changes and behaviours which can lead to parents seeking explanations and support through reasonable adjustments. The largest increases in the recording of new autism diagnoses between 1998 and 2018 were among secondary school-aged children, compared to younger children, older children, and adolescent children (Russell, 2021).

There is a growing argument that autistic identity is beginning to cast doubt on medical term disorder. Some activists argue for autistic individuals to be classified, but in a different, more realistic way that emphasises lived experience and knowledge (Kapp & Ne'eman, 2020). Russell (2020) argues that an individual's perceptions of their identity and health are partially reflections of the society and culture in which they live. If this is the case then an individual's interpretation of autism will reflect the values of society as a whole.

A growing number of individuals with the label of autism have documented their lived experiences such as Temple Grandin. Sinclair (2012) writes in the book 'Don't Mourn for Us' urging parents to embrace autistic children rather than view them as tragic cases; to enter the child's world rather than normalise it and push them towards unwelcome transformation. Sinclair (2013) stated that the diagnosis of autism becomes a significant component of an individual's sense of self.

The term "autistic" was historically stigmatising however the efforts of neurodiversity advocates have tried to change how autism is perceived. This is creating discussion and reflection around the label of autism and how it is viewed. The Autism Education Trust (AET) have worked with schools to encourage understanding autism as a different way of experiencing the world rather than a withdrawal or incapacity to interact with it.

#### Gender, Autism and Masking

As discussed, an influential narrative is that female autistic behaviour and traits differ from those of autistic males and therefore have missed out on an autism diagnosis (Bargiela, Steward & Mandy, 2016). Some argue that there is a "female autism phenotype" (FAP), a set of (biological) features specific to women, but because of social, developmental, and environmental circumstances autism in females manifests itself in different ways as they get older (Holtmann, Bölte, & Poustka, 2007). This concept of FAP is rejected by some autistic advocacy groups arguing that this concept is based on gender stereotypes rather than biological evidence (Wassell, 2022).

Miller, Reese and Pearson (2021) suggests that masking has to do with everyday social behaviours (like identity management), and stigma avoidance is frequently the motivating factor. Different "neurotypes" experience masking in many different ways, which could potentially be influenced by external feelings of stigma and difference. What is referred to as "autistic masking" probably resembles other strategies for eradicating stigma. Some parts of masking (such the suppression of what is referred to as 'stimming') do seem more unique to the autistic neurotype (Miller, Reese & Pearson, 2021).

One argument is that autistic women who can successfully mask their condition have experienced difficulties in receiving a diagnosis. It is believed that women may be better at masking their autism by imitating social interactions (Kalei Kanuha, 1999). It could be argued that the previous discussion regarding cultural expectations of gender can be linked to the concept of masking. Every woman (and every man) takes on a role to fit in with social relationships (Russell, 2021). On reflection from the previous discussion and the work of Butler (2006) who makes the case that the idea of gender is in some ways an improvised act.

The question arises of how can one tell a woman who is neurotypical from an autistic person who is acting socially in everyday life?

The DSM-5 (American Psychiatric Association, 2013) describes masking as a strategy used by women and girls to hide their autism. Therefore, masking is almost the exact opposite of pre-1990 understanding of autism, in which lack of understanding of social norms and the omnipresence of autistic behaviours across settings were indicators. Masking is the ability to read social norms, be adept at fitting in, and not have behaviours that are pervasive across settings. Even though it is not a characteristic of autism, conforming to social norms is seen as an indication and is used to diagnose autism in practice (Hayes, 2020). According to Butler (2006), if gender is performative, then the activities that are supposed to "express" gender are not actually expressing anything other than the illusion of a stable, underlying gender identity. There is a continued debate between what is masking of autistic traits and girls conforming to a gender stereotype. If gender is performative, perhaps other normative social behaviours and identities are also performed. From this position it is difficult to make a diagnosis of a difference based on social behaviour.

It appears that gender and autism have a difficult relationship for women. Autism, lack of social conformity, and sexuality seem to be intertwined issues. Autism and gender certainly interact on a variety of biological, psychological, social, and bio-political levels (Cheslack-Postava & Jordan-Young, 2012). Russell (2021) found that some women experienced pressure to adhere to gendered societal standards. In order to do this, masking is used as a strategy to help them live up to such expectations.

It is important to consider the different positions regarding gender and autism as it frames the decisions I have made regarding the participants and focus on the research. Methods that are essentialist and reductionist may struggle to be able to capture the complexity of autism. Taking a critical realist approach can offer a framework for considering how biology, which is frequently the domain of positivism, interacts with cultural, social, and linguistic phenomena to produce enablement or disablement. I feel I do not have a firm position in my understanding what autism is as it evolves as I reflect and learn from those with a lived experience. I think it is important to hear the voices of those with a lived experience. I am able to reflect and acknowledge on both the complexity and the impact society has on the label which is important when considering the constructs of self for adolescents.

# Conclusion

A lack of female participants in the research was a gap identified in the literature review. Only Gaffney (2020) and Morgan (2023) restricted their study to female subjects; all others either included a majority of men or only men. This lack of attention to the experiences of girls is not new in autism research (Lai et al., 2015), but it may also increase the disproportionate risk that girls will not receive a clinical diagnosis (Loomes et al., 2017). The lack of research into autistic girls constructs of self, considering what can be learnt makes it difficult to know how they can be supported to develop a positive sense of self. In this study, identity is viewed as a dynamic self-concept that is best understood within the social constructionist framework. (Hiles, et al., 2010). Mo, Viljoen, and Sharma (2022) suggested that there is a need to explore autistic individuals constructs, using more than just semistructured interviews. During the search for literature there was little research that used narrative and collage inquiry to explore constructs of self. One thesis by Carver (2020) used narrative inquiry to explore autistic adolescent girls sense making of their autistic identity.

Following a critical review of the literature, the questions I want to explore in the research are:

- What can be learned from autistic adolescent females constructs of self and identity?
- What are the environments and relationships that help autistic adolescents develop a positive sense of self?

#### **Chapter 3: Methodology**

#### **Overview**

In this chapter I will outline my position as a researcher, discussing my philosophical assumptions which relate to both my ontological and epistemological position that inform my methodology (how the knowledge is obtained) decisions. It is suggested that a research paradigm can be understood as the beliefs upon which the research decisions are based upon (Guba & Lincoln, 1994). I will discuss the justifications for the approach I adopted and the implications for my research in addition to outlining the research design, the pilot study, and data analysis.

### **Epistemological and Ontological position**

A philosophy which believes that 'reality' exists and is associated with the natural sciences is positivism. Researchers who align themselves with positivism believe that scientific models can be used to find out the 'real truth' of facts and theories as reality is there to be accessed (Bhaskar, 1998). Previous research of autistic females has tended to focus on the 'autistic female phenotype' looking at the defining characteristics. The research is based upon a positivist epistemology which has informed current understanding of autism. This type of research looks to uncover a single truth and so is reductionist, assuming findings can be generalised (Guba & Lincoln, 1982).

A philosophical approach that is post-positivist is critical realism, offering an alternative that suggests that an objective reality cannot be limited to human understanding or knowledge (Fletcher, 2017). It acknowledges that there is much more to know than what any

existing methodology can access as the world exists independent of the knowledge, we have of it (Bhasker, 1998). I needed to ensure that my philosophical position aligns with both my professional and personal approach to collaborating with autistic females whilst supporting my critical autism perspective, acknowledging, and understanding that there exist multiple versions of autism (Began & Billington, 2019).

Epistemology focuses on how knowledge is acquired through the relationship and interaction between researcher and participant (Stainton-Rogers & Willig, 2008). Whereas an ontological position refers to beliefs of what exists, epistemology focuses on how a researcher studies or comes to know these theories, focusing on methods, scope and validity (Moon & Blackburn, 2014). A critical realist ontology and epistemology served as the foundation for my research, adopting and combining both "constructionist and realist positions." (Sims-Schouten, Riley & Willig, 2007), acknowledging that the real world is influenced by external power influences that as a researcher I may not be aware of (Bhaskar, 1998).

A critical realist position acknowledges that within the social world there are inherent power structures, i.e., gender, race and class which can significantly influence how one perceives and therefore behaves in the world (Smith & Elger, 2014). As I identified in my literature review, power operates in the diagnostic criteria and within the lives of autistic young women, I felt this was something that needed to inform my research approach. As Timimi et al (2010) suggests that the label of autism is socially constructed with society based on patterns of behaviour observed in predominantly males, critical realistic perspective felt appropriate. A critical realism ontology and epistemology served as the foundation for my study, adopting and combining both "constructionist and realist positions" (Sims-Schouten, Riley, & Willig, 2007). I adopted a realist ontology and took a critical realist position arguing in favour of a real reality with causal potentials or powers (Bhaskar, 2013).

I strived to ensure that my positionality informed every choice made throughout the research process in order to guarantee the coherence and credibility of my thesis (Saunders, Lewis & Thornhill, 2009). My drive was to empower the YP involved in my research, this was an important factor when making a decision regarding my methodology. I strived to report my findings in a transparent way that remained aligned with my positionality.

From a critical realist position, class, gender, and race power structures that are inherent in the social world are seen to have a considerable impact on how we perceive the world and, as a result, how we interact within it (Smith & Elger, 2014). For autistic girls and women, this is significant as they may feel pressure to fulfil the social expectations of their gender role therefore causing conflict between this and 'their autistic selves' (Bargiela, Steward & Mandy, 2016, p.3290). By assuming a critical realism position, my research also embraced a constructionist epistemology, which acknowledges that reality is subjective and that each person's particular cultural and historical background has a significant impact on how they see the real world (Burr, 1998; Willig, 2013). According to Oliver (2011, p. 4) our understanding of reality is regarded to be "mediated through the filters of language," which means that cultural discourses prevalent in today's culture can affect how we interpret, comprehend, and react to particular experiences. According to my literature review, established cultural discourses of femininity which emphasise how women are expected to behave may be implicated in their constructs of self. I would argue that this makes my epistemological stance appropriate.

#### Choosing a methodology

Quantitative methods are appropriate for deductive theories and objectivist ontologies (Bryman, 2012). While this type of method concentrates on finding connections or relationships among many people, qualitative studies delve deeply into a specific subject as experienced by a select few people (Yardley, 2000). As my research had 'exploratory' goals and an emphasis on 'subjective experience', I chose to use a qualitative approach. My ontological and epistemological position guided my methodology choices as my aim was to empower participants through giving them the opportunity to have an unrestricted voice. I did not want a reductionist method that could potentially compartmentalise or categorise people. It was important that during the research I used a qualitative method which enabled me to be continuously reflective so that I could increase my awareness of any pre-held thoughts and gain a new insight and understanding (Willig, 2008). As previously discussed, I wanted to provide a space where I could co-construct with. As I was working with a group of young people who could potentially be marginalised for being autistic, I felt a more open approach was suitable. I decided a narrative approach was the most appropriate for this.

#### Using a narrative approach

After reviewing and carefully considering other qualitative methods, I felt that adopting a narrative approach was best suited to my research. Narrative research involves creating a 'story' that has a meaningful structure (Dennett, 1992; Schiff, 2017; Reissman, 2008). People are thought to be storytellers who experience themselves and their lives in narrative terms, with storytelling being seen as a natural method of recounting experience (Burr, 2003). The process of creating this story is sensitive to an individual's context, supporting both psychological well-being and identity development (McAdams & McLean, 2013). A

researcher's own experiences and stories serve as the foundation for their areas of interest in narrative inquiries, which are always highly autobiographical (Clandinin & Connelly, 2000). As previously discussed, the motivation for this research stems from my own story as a mother of an autistic girl. Holloway and Biley (2011) suggests the researcher may be better able to comprehend the language used by participants, their thoughts and emotions, and the meanings they have assigned to particular circumstances if they have personal experience with the topic area being investigated.

The narrative approach's compatibility with the critical realist positionality of my study, which recognises and captures both the individual and the context, is another important justification for using it (Moen, 2006). I was guided by the assumption that embedded within political, cultural and wider social context is individuals meaning making how we make sense of our own experiences is both shaped and limited by society's discourses and narratives (Burr, 2015; Gergen, 2015; Johnstone & Boyle, 2018). I argued in the critical literature review that narratives and constructions of autism are mainly based upon the medical model, using what could be argued as dehumanising terms (Milton, 2014). Research of autism has mainly taken a positivist, scientific view therefore creating a deficit narrative, seeing it as a disorder and creating internal stigma (Latif, 2016; Baron-Cohen, 2000; Chown & Beardon, 1997). Narrative has been described as a growing approach within educational psychology as there is recognition of its humanistic perspective, emphasising voice and being person centred, all of which are central to my research. It suited both the emancipatory and feminist stance of the research as it will 'give a voice' to those that are marginalised or silenced (Toolis & Hammack, 2015; Schiff, 2017).

As I was exploring the constructs of self, I felt I needed an approach that would consider both the individual and the context. Erikson (1968) described the psychosocial nature of identity development and acknowledged the role community played in this. As narrative inquiry considers the individual's experience, social experiences and environments (Dewey, 1938; Clandinin & Connelly, 2000), offering a considerable amount of flexibility I felt this would provide a space for the YP to share the participant's conceptualisations about their self. Narrative methodology considers the co-constructed narratives that are created between the participant and researcher in a holistic approach (Webster & Mertova, 2007). I was optimistic collaboration with YP would be promoted using a narrative approach; that would offer a chance to connect (McAdams & McLean, 2013) and have an element of co-construction through dialogue with the YP (Morgan, 2002).

# **Visual methods**

The use of arts can be used to tap into emotions as it is highly engaging, it has the potential to jar people into both thinking and seeing differently (Yorks & Kasl, 2006). Art has the ability to bring about both the knowledge of self and others (Gerber et al, 2012, p41). An argument for using an arts-based approach the way in which it can be used to access what is usually inaccessible, cultivating new connections and insights. The use of arts-based research methods offers a supportive approach which creates a non-confrontational experience and encourage personal expression regardless of an individual's cognitive ability (Lynch & Chosa, 1996). As I was working with autistic adolescent girls, I needed to consider how they may feel when talking about a topic such as identity. I didn't want them to feel pressured to feel they needed to 'have all the answers.' I felt it was important to create a relaxed atmosphere where they would be comfortable to talk about aspects of their identity that they may not normally

reveal in a school setting. The benefits of using visual methods are the range of inclusive, flexible, and accessible tools (Burke, 2008). I was able to select a method that would address some of the concerns I held. In my role as a TEP, I recognised the potential arts-based approaches had in supporting CYP when talking about their experiences. This approach can help to create a safe space which reduces the pressure that direct questioning can sometimes be created in one-to-one situations.

# **Collage inquiry**

There are three categories which can be described as broad which are considered in the field of creative research: research into, with or through the arts (Bradley & Harvey, 2019). One of the ways that research through visual art can be carried out is through the use of collage.

The term collage means 'to stick' which derives from the French verb 'coller'. It involves the process of sticking bits of different materials to transform it into something new which could be argued to be greater than the sum of its parts, where new ideas may be discovered (Chilton & Scotti, 2013; Scotti & Chilton, 2018). I felt that this method can be a tool that brings diverse elements together in a powerful way to offer alternative constructs to the ones people already hold. One concern I held about using an arts-based research method was that there may be a reluctance to engage for the fear that the participant does not have any artistic ability. Collage however is reported to not raise this kind of concern (Leitch, 2009), as the method uses materials that are readily available it does not require a certain level of skill (Prasad, 2018).

As collage is argued to be a 'safe container' (Kramer, 1975) I felt this was important as I would be working with vulnerable adolescents to create what I hoped would be moving, powerful and emotional stories through a visual representation (Leitch, 2009). Research carried out by Prasad (2018) used collage as a visual resource to facilitate interviews with children who were involved as co-researchers. Prasad's study illustrated how visual methods can be used alongside and to compliment language-based data, to find out about lived experiences of young people who were positioned as 'creative experts'. The researcher's role in this type of research becomes the 'attentive audience' as the collage is used to reflect on and enable conversation as part of an elicitation process (Butler-Kisber, 2010).

As the participant's may have a different style of communication from that of my own it was important that I used a medium which they felt comfortable with, this would potentially provide the autonomy to communicate in their own preferred way (Grover, 2004). Knowles and Cole (2008) argue that the arts offer an accessible tool for the reader, researcher and participant as it is innate to human nature. This child-centred research method gives young people the opportunity to explore their own views, narratives, and opinions (Barker & Weller, 2003). Jennings (2011) suggest this approach empowers the young people as there is no right or wrong, something which is important to my research.

The flexibility of this method helped my research to be accessible and inclusive. When I began the collage session there was some initial apprehension from the participants, but this was around making choices of what to put on their collage and where. I think the preparation sheet in the booklet helped with this. For those young people who had completed it, they had a structure to work from. They were clear what they wanted to include and brought their own pictures to add to the collage. From the pilot I recognise that the potential of too much choice could be overwhelming and so had prepared folders with categories with different pictures cut out in addition to full magazine, comics and printings also available. This reduced some of the reluctance that some of the young people had about engaging in art as they could look through the folders to select pictures. I offered a range of mark making materials which offered flexibility as some of the young people preferred to use art, doodles and graphics to create their collage.

# Participatory approach

Using an arts-based approach such as collage inquiry helps bring the participants into the process as it is participatory in nature (Leavy, 2020). There is a need for collaboration which this approach facilitates as there needs to be a relationship between all involved to both make and interpret images (Banks & Zeitlyn, 2015). The use of a collage gives people the chance to pause and think about their own experiences before sharing them with researchers. (Knowles & Cole, 2008). Minkler (2004) argues that a participatory approach is not just a method as it values the role of collaboration between the researcher and participants. The difficulty I experienced was trying to balance the requirements of the University thesis deadlines and gain ethical approval with the drive to be as collaborative as possible. I used Franks (2011) 'pockets of participation' as a guide. I recognised that there would be both implicit and explicit power differential in the research method, I was a professional in a school where there is an established hierarchy in addition to the research involving interviews where I would be asking the questions. I felt that the use of visual would reduce some of the potential power

differentials as collage materials are accessible and generally people are not intimidated by the prospect of making a collage (Scotti & Chilton, 2018). In addition to this the process used in arts-based research tools such as collage inquiry enables participants and researchers to engage in co-meaning making. I looked to find ways that the participants could develop 'participative ownership' (Franks, 2011, p.4) of certain aspects of the research process, in essence rather they became stakeholders. Participants were invited to read through their transcription to ensure it accurately reflected the discussion and that they were happy for all the information to be included. The participants were presented with a list of '1 statements' which were taken from the analysis of their interviews. Each participant was then invited to read through their poem, highlighting the statements they felt represented them the most or they felt were important to them and needed to be included in the poem. Participants were encouraged to annotate the list of statements with any reflections they had as they worked to create the '1' poem. Full instructions were given to the participants in their booklet which took them through the stages (see appendix 12)

# Summary

Throughout the research my goal was to empower the YP through giving them agency, addressing power imbalances as they become 'active participants'. The participatory nature of the research needed to place the YP at the centre, I needed to make sure that involvement was not tokenistic (Lundy, 2007). As I wanted an approach that would allow me to empower the YP to share their stories in a child-centred, sensitive manner I felt narrative offered this (Fraser, Lewis. Ding, Kellet and Robinson, 2004; Chown et al, 2017). The use of a visual art method such as collage inquiry would provide the YP with the scaffolding to do this. I will

explore in more detail the chosen method and research design in the following chapter before I discuss issues regarding quality of research and ethics.

# **Research design and procedure**

# **Overview of the research process**

In this chapter I aim to outline the design and procedure of my research including the ethical considerations I made. I will detail the narrative approach taken and discuss the implications of my pilot study. Following this I will consider my study in relation to the commonly used principles to assess the quality of qualitative research. The chapter will conclude with a discussion regarding my data collection, transcription and method of analysis.





# **Ethical Considerations**

### **Research Participants**

When using a narrative approach, the required number of participants for a study can vary according to the purpose, chosen method and degree of detail within the created stories (Wells, 2011). The narrative approach tends to produce in-depth stories therefore for the pilot study I recruited one single participant and 7 for the main data collection. I felt that I had enough time to ensure I carried out a detailed and comprehensive analysis of their narratives.

I used the following selection criteria to recruit participants:

- Aged between 11-18.
- In full-time education.
- Classed as female on the school registration system.
- Know they have a diagnosis of autism spectrum disorder (including autism, Asperger's Syndrome, high functioning autism, pervasive developmental disorder) from an appropriate professional, or are on the pathway to a diagnosis or self-identify as autistic.

I wanted my research to reflect the real world of Educational Psychology practice. A characteristic of this world is that young people often have several 'areas of need' within the SEN code of practice, and sometimes have multiple diagnoses therefore I didn't want a criterion that excludes other areas of identified need.

When planning my research, I gave considerable thought to the sampling criteria. After reviewing the literature, I felt that there was a lack of research regarding autistic females' understanding of identity particularly adolescents. A large majority of the research is based within a medical model looking at deficits with little research exploring their constructs of self, particularly research that is participatory. Whilst I acknowledge that autistic males are underrepresented in this area of research, I felt it was important to adopt a feminist stance in my research, historically males have been overrepresented in research, which can be argued to have led to the marginalisation and lack of consideration for autistic females (Tomlinson, Bond & Hebron, 2020). In the past there has been an assumption which wrongly believes male research can be generalised and transferred to women (HesseiBiber et al., 2004), can be argued to have perpetuated in society both the inequality and oppression.

Participants who have an autism diagnosis as well as those who self-identify as autistic were included in my criterion. Research has shown that in comparison to males, females tend to receive a diagnosis at a later age. As I wanted to work with adolescents, I felt the discrepancy in diagnosis ages was important to consider (Lockwood, Milner, Spain, Happe & Colvert, 2020). Increasingly more people are self-identifying, but they are opting not to follow the diagnostic pathway. It was crucial to me as the researcher to refrain from imposing the necessity for a diagnosis in order to give the participants' perspectives a chance to be heard. When deciding on the criteria, I was certain that I should not 'police' participant's identities. Participants should be allowed to participate if they firmly believe they are autistic. Preventing them from participating because they do not have a diagnosis, I could be potentially denying that person their identity. I was concerned that by including participants who have not received a medical diagnosis of autism they could potentially not have the

support networks available should they need them if an emotional response was experienced from the self-reflection. To address this, I discussed with the participating school my concerns who shared that the participants would have key adults available and a quiet place to go if they wished to use it. I also included in their research booklets a sign posting page of support helplines and numbers that they could use (see appendix 12).

I chose to work with adolescent participants as I felt that not only is this underrepresented in the current research but this stage in life is important in identity development (Baumeister & Leary, 1995; Erikson, 1968). As the participants were adolescents, asking them to engage in self-reflection, sharing thoughts and feelings that are personal to them, it could be considered potentially sensitive. When reflecting on this I felt that the unique insights that young people have to offer were important and not giving them the opportunity to share these could potentially have adverse effects (Atkinson et al., 2018). I considered in my research design how the process would be emotionally supportive and sensitively address the topics of discussion which I will discuss further in this chapter.

#### **Recruitment Process**

Throughout the research process, I was guided by the ethics and quality assurance principles that the British Psychological Society (BPS) provide in relation to EP practice and research (BPS. 2014, 2018); the Health and Care Professions Council's (HCPC, 2016) professional guidance in addition to the ethical approval process of the University of Sheffield and their principles. To ensure all the information was accessible both information sheets and a video were provided to outline the research (see appendix 9). The information included

the aims, method, what the process would look like, how the data would be stored and details on the debrief.

To recruit participants, I approached the SENCOs within my placement local authority. I used an introductory email which then followed with a meeting with the SENCOs to explain the research. I felt that it would be more appropriate for the SENCOs to share the research information initially. I didn't want the participants to feel pressured to participate and so we agreed that a poster would be displayed in the learning hub to see if there was an expression of interest from the young people who use the room (See appendix 13). It was agreed that the identified link teacher would then share the information sheets with any of YP who enquire about the research. When discussing the recruitment process with the SENCO and link teacher we agreed that the participants would need to be comfortable working within a group for the two sessions. Advertising in the learning hub meant that those who were interested would be familiar with the other YP who use the space and engage in the social and therapeutic group activities that take place within the room. During the meeting I emphasised the importance of the young people having talked about their diagnosis or selfidentifying as autistic within school and with staff. It was agreed that the potential participants would be made aware of the two group activities and that the need for confidentiality would be emphasised. The link teacher was confident that the YP would be familiar with this as they discuss confidentiality and create boundaries at the beginning of their talking and art therapy sessions. The information sheets, video link and consent forms (see appendix 11) were sent out to parents/carers and participants to gain informed consent. The link teacher talked the participants through the information sheets to ensure they understood what each session would entail. The video was provided as a brief overview to

support the more detailed information sheets (<u>https://youtu.be/oorFC-ooeOO</u>). The right to withdraw and principles of informed consent were included in the information given and reiterated at the introductory session to the participants. Informed consent was a continuous activity within the research process. I reminded participants of their right to withdraw at each meeting emphasising there was no need for a reason.

Participants or parents/carers were given the contact details for myself via the information sheet and were encouraged to contact me or the SENCO if they had any questions or concerns before, during or after the research and data collection process.

#### Reducing risk of distress

I was aware of the potential for the participants to experience anxiety through participation as often autistic young people experience anxiety at school (Lopata & Thomeer, 2014). They may feel pressured to share sensitive information or talk about feelings that make them feel uncomfortable or become upset during the interview. To address this, I used an introductory session to build rapport with participants and the collage-creating session further built on this. These sessions gave both me as the researcher and the young people an opportunity to get to know each other more so that the interviews would feel a little more relaxed and enable conversation to feel less formal.

# Confidentiality

The participants all understood that they would be involved in two group activities. It was important that we created some boundaries to ensure that all of the YP were protected throughout the process. The link teacher talked the participants through the information

sheet, emphasising that they would be part of a group for two sessions which would require them consent to a group agreement like the ones they use in school. It was agreed that I would use a familiar format to discuss boundaries and expectations in the information session. The link teacher provided me with the list of agreements which we read and discussed if we were happy to use them or add any further lines (see appendix 14).

### Use of language.

There is the potential for participants to feel offended about the language I use about being autistic or regarding their identity e.g., gender as they may not identify as female. The criteria asked for participants who are registered as female on the school register, but it was important that I acknowledged each participant's preference for how they identify. I checked with participants what language they would like me to use such as 'autistic person', ASD/Aspergers, etc. From my previous discussion regarding autism as an identity I felt it was important to use the language that the participants were more comfortable with. Literature suggests that there is a growing preference identity-first language by autistic adults rather than person-first language (Taboas, Doepke & Zimmerman, 2022). Person-first is where you name the person, followed by their disability e.g., person with autism. Identity-first language is where the disability is seen as part of a person's identity with equal importance to gender, race, etc... and so would refer to a person as an autistic person. To maintain anonymity, I asked participants choose their own pseudonyms from a list offered to them. I created the list with the participant of the pilot study who advised me that there should be some names that could be perceived as gender neutral. The use of pseudonyms was important due to the ideographic nature of the research as there was the potential for them to be identifiable.

# **Pilot study**

I felt a pilot study was important given that I would be working with potentially vulnerable young people. I wanted to create a safe environment where there was elements of both collaboration and trust amongst myself as the researcher and the YP. I had limited experience of using both collage inquiry and narrative interviews and so felt the pilot study would help to develop my skills in these methods. The pilot study is an important part of the research process as it enables the researcher to identify potential difficulties and address them to reduce the risk of collecting unreliable data (Harding, 2013).

The pilot study participant was identified by a SENCO within a high school as having met the criteria and recruited the same way as the other participants. The participant selected the name Charlotte from a list I had created of pseudonyms. She reflected on the list and how this could be improved which I addressed and included her suggestions for the other participants. Reflections about these sessions were used to inform subsequent sessions with other participants.

### **Data Collection**

#### Introductory session

The introductory session was carried out as a group with all the YP meeting together along with one of the learning resource teachers who has a positive relationship with all of the YP. The aim of the session was to talk about the research and provide an opportunity for the YP to ask any questions or clarify anything they were unsure of. I was aware that this could be a potentially overwhelming session with a lot of information to take in and so I created an information booklet for each participant. The booklet was used during the session where I talked through each page and sign posting them to key information. The YP were then asked to complete a page of prompts in preparation for the collage session where they would bring pictures with them to create the artwork with.

When discussing the research arrangements with the school we decided that the introductory session would take place on a non-uniform day. The teacher felt the YP would feel more comfortable in their own clothes as would enable me to get to know them a little more by what they wore. Initially the session felt a little formal, but the non-uniform helped as I was able to engage in conversation about certain aspects e.g., the football shirt that one girl was wearing opened a discussion about who they support. Once I felt the YP were comfortable I talked about the research and took them through the information booklet. The use of memes and Bitmoji pictures seemed to engage the YP with the booklet as they laughed and pointed out what they liked about the information sheets as we discussed it.

## Collage making session

The collage making session was conducted as a group with the support of the same teacher. A range of materials were provided including magazines, comics, stickers, mark making materials, glue, and scissors. The teacher provided support by printing any specific pictures that the YP required but had not brought with them. The YP arranged the room to how they wanted it, working around one table with the materials in the centre. At the request of the YP, music was played during the session whilst they worked.

#### Semi-structured interviews

Within social science research, semi-structured interviews are the most common method (Willig, 2008). The use of the method aligns with my aims to be as participatory as possible in my research process. It is not seeking to extract theory driven information, instead I wanted to have the flexibility to explore what the YP share using an inquiry led approach. Semi-structured interviews are reflexive, enabling me as the researcher to reflect upon what each participant shares in addition to the experience of being with the participant (Willig, 2008). This type of interview involves the acknowledgement of the impact of the researcher's presence in the process and reflecting on this (Burman, 1994). As previously discussed, I felt this was important as I was conscious that my presence as the researcher would need to be part of the reflective process. I was also aware that I would be coming into the research process as a mother of an autistic girl and so therefore would need to challenge my own pre-existing biases. Having an awareness of this subjectivity was important for the research to be authentic (Burman, 1994; Willig, 2008).

The semi-structured interview gave a space for an authentic conversation to explore the participant's understanding and view of who they are. It enabled me to be both reflective and reflexive about what was being discussed whilst considering my impact as the researcher. The interview needed to feel like a conversation, the collage helped act as a supportive tool which they used as a reference for talking. The collage opened up the conversation and by showing a curiousness for the different elements the discussion flowed naturally as the participants relaxed into the interview. Using the collage to look at and support discussion reduced any pressure that the participants felt in holding eye-contact.

The interview gave the participants an opportunity to feel understood and listened to through the reciprocal exchange (Reissman, 2007). When making the decision about the design of the interview I felt I needed to maintain a balance where the questions were open in order to allow for exploration of the research question. I also felt that it would be important for the participants to have some structure and opportunity to see the questions prior to the interview for the participants to feel prepared in order to reduce any potential anxieties. Initially I didn't include questions about autism as I believed it was important that as the researcher, I did not influence them in any way, maintaining an open way that they could share their own accounts and experiences (Clandinin & Connelly, 2000). Following on from the pilot study I reflected on this and realised that it became the 'elephant in the room' if I did not ask about their autism as this featured strongly in how they see themselves and also is part of the research question and information sheets (See appendix 12). The questions were open ended, exploring interests, strengths, relationships, and environments that the YP felt were important. I felt these questions explored the areas identified in the literature review as factors that contributed to self-construction.

As I was working with young people who could potentially be disadvantaged, empowering them in the process was critical so that I could validate and represent their views (Mishler, 1986). Through the use of semi-structured interviews Salmon (2007) argues that participants feelengaged, understood, and empowered, avoiding feelings of the research being 'done to' them. I critically reflected on this as I wondered if I had empowered the YP by using a semistructured interview rather than a discussion where the YP would be free to talk about themselves in any way they wanted. I felt it was important to be sensitive to the needs of the YP by offering some structure with questions that were shared prior to the interview. I used
a flexible approach however which meant each interview followed its own direction based on the YP's collage and what the YP shared. Using the interviews and working with the YP in the analysis stages meant that the YP were involved and therefore I was 'speaking with' rather than 'speaking for' the YP which can lead to the contribution of marginalisation and disenfranchisement of minority groups (Alcoff, 1992).

Visual cards were used to support participants to indicate whether they wanted to continue, pause or stop the interviews. They were reminded of their right to withdraw and the cards were explained verbally and an information sheet was included in their booklets (see appendix 9). All participants were made aware that the interviews were recorded and that this was stored in line with data protection regulations.

Using this interview method has the least number of negative effects on participants but offers high levels of social justice (Salmon, 2007). It is important to acknowledge the question of reliability and authenticity which I will discuss in detail later in the chapter. Interviews have been criticised as they create the need for the participant to present a desirable self to the interviewer and for the impact of what can be described as a 'fleeting' relationship between the participant and the researcher (Denzin, 1970). A further criticism of this method by Denzin is that a person's internal world cannot be penetrated through language alone. Denzin (1970) suggests that people do not fully know the extent of their feelings, memories and knowledge and distortions of these are possible therefore what participants say cannot be fully trusted. As part of the research design, I included sessions where the participants spent time with me prior to the interviews taking place. Using the collage making gave the participants time to explore their own understanding of who they are which was a conscious decision in order to

address the discussed concerns with this method choice. I would also argue that the assumption held by Denzin (1970) regarding people's knowledge of views and thoughts is in itself oppressive, suggesting an individual has no autonomy or awareness of their own thoughts.

I think it is important to not discount my own abilities to be a reflective listener and apply psychological theories as a reflexive practitioner within this process.

# Data analysis: The listening guide

Practitioners of narrative theory hold that people use the stories they tell to make sense of their experiences. This comes naturally to us; when we recount an experience, we combine characters and circumstances to form a story. A dominant storyline that creates meaning develops as the events or episodes are linked and ordered into a whole during the telling of a story (Polkinghorne, 1988). As a result, narrative redirects our focus from "what happened" to how each individual interprets the events (Reissman, 2008). As opposed to other kinds of qualitative research, narrative techniques use data that is presented as a story. Our narratives can provide a window into the human condition (Reissman, 2008). I assumed that hearing participant experiences would offer a useful and organic manner to discover the answers to my first and second research questions and that it would provide a distinctive approach to this field of study.

There is no set method for analysis in narrative research, and a wide variety of methods have been created to analyse story data. I found this to be intriguing since it meant I could look for an analytical strategy that honoured the unique experiences of the participants; I wouldn't

have to blend the stories of several people and could pay attention to their originality. When deciding on an approach to my analysis it was important that voice remained central to my research. The analysis needed to align with my positionality and so I didn't want to try and fit the participants into pre-existing categories. I wanted an approach that was less reductionist which offered an alternative that was less reliant on coding schemes. I considered a range of different methods of analysis before selecting to use the 'Listening Guide' (LG) (Brown & Gillian, 1993; Gilligan & Eddy, 2017). As this method was originally designed to explore how both women and young girls were affected by the power of men (Brown & Gillian, 1993) and is described as a feminist, voice centred methodology (Woodcock, 2016) it seemed compatible with my own feminist stance of my research.

The LG is different to other methods of analysis as it identifies "the mind's ability to dissociate or push knowledge and experience out of conscious awareness" (Gilligan & Eddy, 2017, p.79). It is through the creation of 'I poems' as part of the analysis process that Gillian and Eddy describe the multiple ways in which a person speaks about themselves which brings into light the ways the mind works, connecting deeply to emotions. As discussed in theories such as social identity theory (Tajfel & Turner, 2004) I felt a method of analysis that considered an individual's social and cultural environments was well-suited to my research which LG does when engaged in the 3<sup>rd</sup> and 4<sup>th</sup> listening of the analysis. During these listening's it was important to attend to the ways the YP talk about their relationships and how they experience them, the impact of cultural norms and values, political resistance and any self-silencing that features in the narrative (Brown & Gilligan, 1993). This was achieved through mapping out the different voices (see appendix), listening for the relationships between them. Whilst I listened, I underlines the corresponding text and made reflexive notes. Once completed I

considered what were the most frequently occurring and identified the similarities, differences, and contradictions within the voices. I was aware that Brown and Gilligan's (1993) approach has been criticised for viewing social class, culture, and gender as descriptors of individuals. I felt it was important when engaged in these listening's I considered these factors as the girls' ways of thinking about their sense of self (Lykes, 1994).

A requirement of using LG is for the researcher to listen to each participant's narrative "at least four separate times, each time listening in a different way" (Brown, 1988, p.33). Initially I was concerned that this method was too prescriptive, however further reading suggests LG is a frame which the researcher actively engages with during the process of analysis (Gilligan, Spencer, Weinberg & Bertsch, 2006, p.268). This gave me the flexibility to decide how I would implement each step within my research.

#### Stage one: Listening for the plot.

The initial stage of the analysis was to listen to the stories that each participant shared, looking to increase comprehension of each narrative's events to make them clearer (Brown & Gilligan, 1993; Woodcock, 2016). Whilst listening to the recording I highlighted in blue any words or phrases which I felt were important e.g., repeated words or phrases that created an emotional response (Brown & Gilligan, 1993). As part of the process, I recorded notes in blue including my own emotions and thoughts as the researcher, recognising my privileged position and thinking about how my responses influence how I interpret the stories that are being told (Brown & Gilligan, 1993; Gilligan et al., 2006). To assist in the recording of this I used a table to record the identified words in one column and my responses or interpretations

in another column. Finally, I wrote a concluding summary of each participant's narrative, identifying the key themes that emerged from the first listening (Woodcock, 2010).

# Stage two: listening for the 'l'

The second stage of analysis involved listening to the narrative whilst paying particular attention to the *"first-person voice*" of the participant (Woodcock, 2016, p.4). Initially I wanted to complete this section with the YP but felt that there needed to be an element of analysis prior to working with the young people. Time constraints meant that I needed to prepare the 'I poems' prior to sharing them with the YP rather than actively completing the highlighting together. On balance I thought the discussion and member checking was more important than the actual process of highlighting and editing. Each participant was given a copy of the whole transcript with the highlighted parts in addition to the poem created from the statements which I had lifted from this to ensure there was nothing missed.

As part of the process, I highlighted in green each 'I phrase' that was contained within their narrative (Gilligan & Eddy, 2017). Following this I then placed each of the 'I phrases' onto a separate line, including a section break which helped with detecting any change in content in the poem (Gilligan & Eddy, 2017). As part of the analysis at this stage I was sensitive to the 'you' statements and their meanings which could be illustrating what the participant either unconsciously or consciously distances themselves from (Woodcock, 2016). The 'I poems' were then shared with the young people as part of a member check of the analysis carried out to ensure they felt it was representative of what they believed.

#### Stage three: listening for contrapuntal voices.

The third stage of analysis involved listening for the different voices which are present within each narrative. It was important at this stage that particular attention was paid to different voices and the tensions, dissonances, and harmonies between them (Gilligan, 2015). This stage is an important part of LG as it recognises the different voices that are woven throughout, rejecting that there is just one, transparent voice (Sorsoli & Tolman, 2008). Each detected voice was highlighted in pink (Gilligan et al., 2006).

## Stage four: analysis

Once the three stages of LG were completed, the final stage involved creating an analysis of the evidence gained through the listening (Gilligan & Eddy, 2017). There is a lack of specific guidance in how to do this (Petrovic, Lordly, Brigham & Delaney, 2015). I was concerned that this would create challenge when carrying this stage out, however the process of the three stages prior to this helped me as the researcher to fully immerse myself in each participant's narrative. It made sense therefore to use the stages as a structure to write up my findings to discuss the different voices. (For examples of the stages of analysis see appendices 4-8).

Third and fourth listening's, referred to as contrapuntal listening's by Gilligan et al. (2006), are a more thorough manner for a researcher to go over previous study topics and examine the ways in which themes either interact melodically or are in conflict with one another. Contrapuntal third and fourth listening's are a useful tool for delving further into themes and their connections. This fourth phase, though, requires a lot of work. It entails examining all of the data produced in each stage, including all interpretations and reflexive notes, and assimilating, synthesising, and considering them all (Gilligan et al., 2003; Sorsoli &

Tolman, 2008). The LG, after all, concentrates the evaluation of the data's content as well as how participant's convey it (Sorsoli & Tolman, 2008). What distinguishes the LG from other qualitative approaches is that it "codes specific portions of narratives but still examines them holistically (i.e., in context)" (Sorsoli & Tolman, 2008, p. 499). Within this phase data was hightlighted and categorised together with an examination of contrapuntal sounds (Sorsoli & Tolman, 2008). Thematic and pattern analysis, was one of the components that allowed me to record the main themes and ideas raised by participants, even though it was not the LG's primary goal (Sorsoli & Tolman, 2008). Then, in the fourth phase, I combined the identified themes with the information from Steps 2 and 3, listening for contrapuntal voices. This was done by identifying the different people, environments and experiences that were spoken about when describing who they are. These voices were intertwined with the I statements but were described as influences in how they saw themselves. It was these patterns that I was able to pick out and create themes that helped answer question 2 of my research (see Appendix 6, 7 and 13).

The ability of paradigmatic thinking, according to Polkinghorne (1995, 10), "*is to bring order to experience by seeing individual things as belonging to a category*." A paradigmatic analysis's ultimate goal is to create themes (or categories) and give those themes definitions or bounds. My approach to phase 4 follows Creswell's (1998) suggested of immersing yourself into the data and identifying themes from the data which build a comprehensive story. I felt this was in line with the listening guide's steps and would give an appropriate structure to answer the research questions while incorporating the YP's voice to create a story based on their collage and interview.

The conclusion of a narrative analysis is a story, according to Polkinghorne (1995, 15). In this kind of analysis, it was my role to arrange the data components into a narrative that connects and provides the data context. It is crucial for narrative researchers to be aware of the conclusion as their research is commencing (Connelly, 1990). I was aware that my questions set out to explore what can be learnt and sought to identify what environments and relationships can support positive constructs of self and wanted to present the narratives with the themes that emerging from the in depth listening. I combined related themes that were discovered to be in areas of each participant's narrative in order to start developing categories. To do this, each theme from the participant's reflections on their collage and interview questions, was given an appropriate label, and included in that section of text. Then, I created broader categories. Ongoing, reflexive writing, especially during the data analysis stage, is one of the LG's pillars (Gilligan et al., 2003). I took notes during the four listening's and wrote down my observations, ideas and interpretations. The aim and application of the LG were clarified for me by published recommendations in the literature, but it was essential that I navigate the implementation process on my own. I was able to come up with my own strategy after realising that there was no "cookie cutter" approach to its application and allowing myself to fully immerse myself in the listenings. I wanted to make sure that the data condensation procedure didn't result in the loss of any important details.

When deciding how to approach this I considered the work of Polkinghorne (1995). The term "narrative" in the context of narrative inquiry refers to a discourse form in which events and happenings are arranged into a temporal unity using a plot (Polkinghorne, 1995). Inductive and deductive methods are both used in the paradigmatic analysis of narratives to find recurring and contrasting themes. Depending on the objectives of the research, these

analysis techniques may be utilised singly or in combination (Sharp, Bye & Cusick, 2018). Like Watt (2007), who discussed the advantages of reflexivity in qualitative research, journaling helped me access and release ideas that I might not have been able to explicitly express. I started to see connections as I thought about the data more and more. Attending to the interactions between themes offered support to recognise where themes react with one another and where tensions between themes exist. This allows a richer understanding of participant stories (an example of my exploration of relationships between themes can be seen in appendix 7 & 15). This stage of the LG enables researchers to be sensitive to the complex and interrelated nature of themes within an individual's story.

In the writing up of my analysis, I interchangeably employ voice poems and complete quotations. Where I think the full context will help the reader comprehend or where there is less emphasis on multiple perspectives, quotations are left in their entirety. Voice poems are included when they help the reader understand how the voices interact in the themes (the relational aspects of the themes) or when they help one voice stand out. There are aspects of the study that take into account the 'they' voice to address my second research question: What environments and relationships contribute to a positive sense of self. My initial study question, "What can be learnt from autistic adolescent girls sense of self?" is addressed in the remaining portions of the analysis. A video was created using the participant's I Poems and art work which can be viewed alongside the findings (https://youtu.be/llXq5PlhahU).



# Reflection

The different phases helped me to get to know each participant. I found the multiple listenings' of the interview whilst recording my emotional reactions and thoughts helped support my reflections when considering the findings. Working through the other phases, highlighting the different voices, picking out the 'I' statements and organising the singular pronoun, first person, second person and second person plural began to build a bigger picture. I also found through mapping out the voices into a theme mind map, I had developed an understanding of the relationships and environments which contributed to The different phases helped me to get to know each participant. I found the multiple listenings' of the interview whilst recording my emotional reactions and thoughts helped support my reflections when considering the findings. As these related to the collage I found it helpful to develop the analysis further, selecting quotes that related to each element of the collage. Once all these stages were completed, I felt I had a good understanding each participant and the different elements that they talked about when talking about who they are.

# **Quality of research**

Well-established criteria can be used to assess the quality of quantitative studies; however, it is not appropriate for research that is qualitative (Yardley, 2000). As a qualitative method, narrative values subjective experience it therefore means that the principles of positivism including objectivity, generalisability and reliability cannot be used to evaluate this research. As discussed previously, the data in this research consists of participants' feelings, thoughts, and experiences, it assumes that the knowledge is both contextual and subjective (Willig, 2013). Criteria including reader evaluation and internal coherence can be used to evaluate qualitative research (Willig, 2013).

#### Worthy topic

There are a number of different principles that have been proposed to assess the quality of qualitative studies. It was Tracy (2010) that suggested that research which is good quality can be considered to be both relevant and timely. Tracey argues that it should be significant, evocative, and interesting. As research around autism in girls is still developing but still relatively new (Hagan, Bond & Hebron, 2022; Honeybourne, 2015; Jarman & Rayner, 2015), I would argue my research is timely and supports the development of educational professionals' knowledge base. As a TEP I have had an increased number of autistic adolescent girls as part of my casework. Schools are asking for support to understand how best to support them or the young people sharing frustrations that they do not feel understood or believed.

## Trustworthiness and credibility.

The qualitative research process enabled me to collect a rich source of data. I was able to collect over a series of sessions due to the commitment of myself as the researcher and the participants attendance and participation of each session. There is a propensity to place emphasis on the validity of research, which can be described as the degree to which inferences can be derived from the precise descriptions the research generates (Jupp, 2006). Yardley's (2017) criteria to assess the quality and validity of this qualitative research includes

both commitment and rigour. Investing the time to transcribe and analyse the data required commitment to ensure as the researcher I was fully immersed in the data. Using member checks was a key part of the data analysis and reflecting on this as part of an ongoing process. Spending time with the participants to build both a rapport and some trust ensured each participant felt comfortable to share their stories in an open and honest way (Lincoln & Guba, 1985). I disclosed my position as a mother of an autistic teenage girl as I felt it was important to be transparent and open about my own positionality to support the rapport building (Chavez, 2008).

I was not looking for one objective truth or reality, instead I wanted to present the subjective and unique stories of each young person involved. Mathison (2009) argues that all collected data is susceptible to some form of manipulation or distortion, I recognised as the researcher there was potential that I could influence the findings. To address this, I included direct quotes within the discussion of the findings (Reissman, 2008).

I made a choice to focus on dependability and confirmability when reflecting on my research findings. Including detailed descriptions of the research process and being fully transparent as the researcher to address both dependability and confirmability (Lincoln & Guba, 1989). Tracy (2010) suggests that self-reflexivity, honesty, transparency, and vulnerability can bring about sincerity in research. I considered any decisions I made in the research design and process. As there are participatory elements within my research, I considered the four types of reflection as described by Bergold and Thomas (2012) including my own personal attitudes, the group relationships, the research process itself and lastly the wider social field. Engaging with a research diary I was able to include reflections which

discussed my responses, feelings and thoughts during the process. The participants were also provided with materials to record their reflections and encouraged to share should they wish. I have stated my positionality within the research to ensure that it is not a *"figment of the evaluator's imagination"* (Guba & Lincoln, 1989, p.243).

# Transferability

As my research used a narrative approach involving a small number of participants, I felt that its purpose was to provide an account of their stories rather than a source of generalisability (Emerson & Frosh, 2009). I decided to focus on the transferability of my research rather than the generalisability, I considered whether the findings of my research could be transferred to other situations and contexts. My design included a detailed description that provided a rich source of information of the methodological design and procedure was provided to support other researchers in comparing and judging the applicability of my findings to their own. My aim was to provide detailed narratives of each participant within the findings to encourage readers to examine how the participants' experiences relate to their own circumstances or professional practice. (Guba & Lincoln, 1989).

#### Chapter 4: Research Findings

## **Overview**

This chapter presents my findings and interpretation of each participant's narratives, following analysis. Whilst completing this chapter, I have been mindful to present each young person's narrative using their own words, interspersed with sections of each participant's I poem in the blue boxes. I aim to reveal the patterns I found within their stories. I hope this provides a holistic understanding of each of the girls who took part. I strongly urge readers to use the appendices and references so that each participant's story can be heard within the analysis.

A diagram has been used to represent the themes and subthemes identified. Reflection boxes are included to help support the reader in gaining a picture of the participant and any reflections I had through the process. Any research or literature will be discussed alongside the narrative within the discussion section.

## Alex's story

#### Pen portrait

Alex is 14 years old, she lives at home with her parents and dog. Alex is a "positive girl who's got a lot of potential, I am really sporty, athletic, artistic." Alex likes to spend time with her dog and listen to pop music especially the band Years and Years. Alex likes to draw and is looking forward to her graphics lessons now that she has taken her options. Outside of school Alex likes to play on her PlayStation, watch YouTube and go swimming. Alex likes to visit her relatives caravan where she enjoys the peaceful surroundings. Football is important to Alex as her family have both played and been dedicated followers of her team. "I mean, obviously like and my whole Dad's family played for Football team." She is a committed supporter of her local football team where she attends every week with her season ticket. Alex's family are important to her as she comes from a loving, supportive family. "I'm really lucky to have a mum and dad and I love the fact that they're like are there for me always." Being kind to others is important to Alex who is sensitive to her family and friend's needs. "A kind person to be around with, always ask people if they need me. Always there for like people like that I'm positive." Alex describes herself as having a short fuse which she feels has caused some trouble with her peers and resulted in her being bullied. Alex has a clear sense of right and wrong and is protective of her friends. "If someone says something about friends I would be like you hurt them you hurt me it's like just leave us alone." Alex has a diagnosis of autism and takes medication for ADHD. Alex describes herself as a nice pupil and tries her best in her work. She aspires "to be a fitness instructor or something to do with the law. Because in the past I've learned a lot about the law."



# **Theme 1- Connections**

# Mother, family and her dog.

Alex loves her family and her dog; they are pivotal in her recognition of her own strengths and feeling secure and valued. The relationship that Alex has with her mum helps her to feel understood. "*We have like a right strong mum and daughter relationship*." (347) Family offers a sense of safety as Alex recognises that she is loved unconditionally. "*I'm really lucky to have a mum and dad and I love the fact that they are there for me always*." (347) The importance of connection and trust is highlighted in Alex's ability to accept feedback on her own need for development. *"The only thing that they would really change about me is my attitude a tiny bit. Because I can be a bit of a pain in the bum*." (434) Alex feels pride because she is part of a respectable family with a work ethic. *"I don't want to come from a family that has done nothing."*(724) Alex is protective of her family and emphasises her loyalty to them, not wanting to let them down. Alex feels she is in a fortunate position to have the parents that she has. Alex shared how important her dog is to her and included a drawing of her in her collage. "My dog means everything to me" (20).

I live with my mom my whole life. I have really strong connections with my parents. I'm really lucky to have a mum and dad. I love the fact that they're there for me always. I am lucky for that. I've got a really nice mum and dad. I love my mum and dad.

# Friends and others.

Alex has adopted an identity position of being a caring protector. "If someone says something about friends, I would be like you hurt them you hurt me." (188) Her empathic nature means Alex feels deeply when others are upset, creating a need to help them feel better. "If someone's upset, I get upset." (556) Alex believes she is fun to be around. "Crazy, they would describe me as crazy." (445)

Alex is a devoted football supporter of her local team, a love she shares with her family and friend. *"It's just me and my best friend. It's like because obviously when we sit like two feet away from each other" (258).* Alex refers to her interest in football as predetermined by her family, *"I have been born in a 'Football team' shirt"* (734). Football is central to her family's culture as there are members who have played for her team which she is proud of. It gives Alex a sense of belonging with the football shirt as a symbol of this.

#### **Theme 2- Interests**

Alex uses interests as a form of escapism. *"I watch football and that just like takes my mind off of anything else". (242)* Alex sees herself as needing to be calmer, she uses music, Youtube or gaming to help her. *"It takes my brain away from everything else." (245)*. Alex enjoys watching crime dramas and murder documentaries. She likes to think about how people behave and why as she has a clear sense of right and wrong." *It was really interesting though to learn about the law and like what consequences you can have when you murder someone like. But not (just) when you murder someone, when you do anything really. I mean, like, you can have so much bad consequences coming your way."* Alex describes herself as *"artistic"* (402) explaining that she enjoys drawing.

# Theme 3- Justice/Empowerment

# Bullying and protection.

Alex is open about her struggles that she has experienced since transitioning to high school due to bullying. These experiences have challenged how she sees herself. *"I would describe myself as a really nice calm person to be around but sometimes I'm not." (402)* Alex feels that she needs to protect herself from others. *"Anybody who gets in the way in my life I just want to kapow them away."* (67) There is tension in Alex seeing herself as caring protector and the struggle with how her peers have made her feel. *"One side of me makes me feel like, wow, how pity do these look and how stupid they are. One side of me feels like, I'm really upset with, like the way that people try to treat, but it's more 50/50 between them both." (153)* There is confusion in how friends have been unkind or rejected her. *"I don't get why they just do it to me."* (147) Alex finds some solace in her favourite musician having similar experiences of

marginalisation and stigma due to his sexuality. *"He represents the struggles, what I'm going through sometimes."* (115)

#### Misunderstood.

Alex sees herself as having a "short fuse" (122), she has internalised the emotional responses to the bullying. Alex battles with making sense of the strong feelings she has experienced. "I just get annoyed over, nothing really sometimes. I just like proper switch inside." (643) Alex feels the consequences of her reacting can be unjust. "I react in a certain way, that will lead me into trouble." (220) "I got in more trouble because my parents are more harder on me." (234)

As a learner Alex describes varying levels of understanding from the teachers. "*Depends* on what the teacher is." (680) She tries to avoid getting into trouble by not fidgeting, something she finds challenging. "*I fidget sometimes it's like I can't help it. It's a bit hard sometimes. I can put up with it for a bit.*" (504)

> I feel like I'm gonna have like a breakdown. I felt like I was going to scream my head off. I felt like grabbing. I was that mad.

#### Theme 4-Expectations.

To help resist the self-othering narrative as a result of her interaction with her peers, Alex has a good understanding of her strengths. *"A positive girl who's got like a lot of potential really sporty, athletic, artistic." (400).* Alex feels empowered by having high expectations and a strong moral compass which she shares with her parents. *"I've come from a really nice, respected family"* (722). Her values are reflected when she talks about liking having money *"I do like money, but I don't like the fact that like I do" (310).* Alex accepts her diagnosis of autism and ADHD as part of her identity, using it to help understand some of the differences she identifies between herself and her peers. *"I see things differently than other people. I have some ways of coping with it" (630).* Alex has an expectation that people share the same values as her. When her friends let her down, she can be frustrated. *"I was really upset my best mate didn't even say anything" (574).* 

# **Theme 5- Future hopes**

# Education.

Alex describes her school experiences as rocky but believes she is a "*nice pupil*" (459). She is optimistic that initial challenges she faced in her education are now improving. *"I've turned the page and I've restarted, and everything is good so far" (474).* 

## Career.

Alex has aspirations for her future career. "I want to be a fitness instructor or something to do with the law. Because in the past I've learned a lot about the law" (689).

# Self-esteem

Alex compares herself to other girls in her school. *"I wish I looked like them, I wish I liked myself" (536).* Although Alex expresses a desire to look like her friends there is an optimism. *"A positive girl who's got like a lot of potential really sporty, athletic, artistic" (400* 



# Reflection

Alex's narrative was one of resilience. She presented as having a positive outlook and determination even though she had experienced adversity. She was enthusiastic throughout the sessions. Alex was very sociable with the other girls in the group, and she engaged in conversation with the girls. There was an openness about her that seemed to help in the research group as she promoted conversation with the others and put them at ease with her humour.

# **Billie's story**

# Pen Portrait

Billie is 14 years old, she lives with her mum and sibling. She has a strong affinity with animals. Billie spends a lot of time at the stables where she owns and rides two horses. She has looked to understand horses in order to help train them. *"I like horse psychology. I love looking into it. I like doing it more natural horsemanship way."* Billie takes her responsibility to the horses seriously and works hard to ensure their needs are met. She finds her time with them calming, they have given her a purpose and helped her mental health. *"He's the reason I'm still here."* Billie has owned a number of pets but especially loves her reptiles including a snake. Billie has a natural talent for instruments. *"I play a lot of different stuff. My current sort of main focus is piano. I love the piano. But I also play violin, I can play a teeny, weeny little bit of guitar, I can play the flute."* Billie is in the top sets for her subjects and particularly enjoys learning languages. *"I love Spanish. I just really liked languages. I'd love to learn Russian."* Billie likes to watch Stranger Things and Buffy the Vampire Slayer. She enjoys listening to 80's music. She has a group of friends who she spends time with but prefers to remain unnoticed by her peers.

Billie has a positive view of being autistic and sees it as part of her identity. *"If you take away the autism part of my brain, there's not very much left. Because it shapes your personality.* And there's nothing wrong with that." She wishes people could be more accepting of difference in race, sexuality, and disability. Billie aspires to travel to France. She wants to learn to play the guitar and trumpet. Billie would like to work with animals and has a desire to be a vet but the length it takes to train concerns her.





# **Theme 1- Animal Lover**

Billie loves animals and has owned a range of pets. "I prefer to keep my companions cold blooded" (203). She talks of her affinity with cold blooded animals especially snakes. "They're not too hectic. They just do what they would naturally do, instead of fitting themselves for other people" (212). Billie describes how she likes the natural behaviours that cold blooded animals display. She can become frustrated when these behaviours are affected by others, something she later connects to her own life experience. "I see way too much in even like animals they're not expressing their natural behaviours, because they're scared" (208).

Billie describes her emotional well-being prior to owning her horse. *"I was really struggling with self-harm, suicidal thoughts when I bought him" (323)*. Billie describes the positive impact that caring for her horse has had. *"He's the reason I'm still here" (330)*. She is interested in understanding what his behaviour communicates. *"I like horse psychology. I love looking into it"* (56).

## Theme 2- Protection.

# Of herself

Billie relates her frustrations of animals masking to her own challenges of navigating social expectations. *"I can't display natural behaviours that I would do because people think it's weird" (233)*. Billie describes the need to play a role, *"I have to be somebody I'm not a lot of the time"* (231). Billie hides aspects of herself which affects her wellbeing. *"I have to behave the way that I don't want so that people don't hate me. And it's tiring. And I don't like it" (244)*. Billie prefers to go unseen or be left alone. *"When you're watching a film, and then they have the big focus and there's a blurry bit in the background, I want to be the blurry bit in the background" (296)*.

# Of her horse

Billie is protective of her horse who she feels at times is misunderstood by others. She has invested time in building his trust and visiting the stables which provides a form of escapism. *"I'll just sit on the floor and he'll stand over me" (313).* This seems to mirror her own experiences of relationships with her peers who she feels do not understand her and she does not understand them. Billie shares her frustration that people cannot take the time to understand her, something she has been determined to do for her horse. Billie uses selfdeprecating humour; I wondered if this was a way of protecting herself from criticism. *"I'm a very, very boring person" (145).* 

## **Theme 3- Relational Self**

# Family

Billie has a strong relationship with her mum who she feels understands her as she is also autistic. Billie talks of difficulties with her mental health, some of which she attributes to her relationship with her father who she no longer sees. *"I hate myself so much because of him"* (594).

# **Friends**

"I have a few friends who have other learning disabilities and stuff. So, it's nice to not feel completely like an outsider" (289). Billie's friends have commonalities which help her to feel a sense of belonging. "They make sure that I'm not feeling pressured to behave, how they behave, so that I can be the way I need to be and I don't, feel embarrassed about it or anything" (287). Billie sees herself at fault for not maintaining friendships. "I have like, one or two friends that I like, cling to with my entire life. And that's how I end with no friends. As it's just been a constant struggle. I ended up just hating me and I can't do anything about it" (464). Billie has contradicting narratives describing herself as independent but in need of protection.

#### **Teachers**

Billie's relationships with her teachers are` important, she enjoys subjects more if she has a positive relationship with them. Her engagement in a subject can depend on the teacher's pedagogy. "*My English teacher is just all over the place and it's overwhelming" (746)*. Billie continues to make progress despite her difficulties with teachers, but it takes more energy for her to remain engaged.

## **Others**

Billie describes consciously making choices of what she shares about herself. *"I feel like I can't talk about stuff that I'm interested in" (232).* Billie finds it difficult to understand her peers at times. *"Everybody has to make everything a big drama. And everybody has to be included in everything, everyone, except my friends who get it" (241).* 

Billie admires a celebrity who she feels is like her and therefore can relate to her. *"I sort of felt like she was a basic replica of me. And I was so excited because I loved it"* (820). Billie felt positive affirmation that people liked the celebrity that she shared traits with. Billie was pleased about the actress's portrayal of LGBTQ+ characters.

## **Theme 4-Strengths**

# Languages and music

Billie enjoys languages, music, PE and English. *"I think I just picked that sort of stuff up really easily"* (439). She particularly has a talent for playing a range of instruments which she has done from an early age. *"I've been playing music since I was five."* (424).

# Horsemanship

Billie describe the work that she has done with her horse who was very nervous when she first got him. She has used her research to understand what his behaviour is communicating to know how best to help him. *"I like horse psychology. I love looking into it. I like doing it more natural horsemanship way."* (56)

# **Theme 5-Powerless**

# Forgetful

There is a feeling of being powerless in trying to remember what she needs for school. Billie made the link between her mental health and the overwhelming feeling she gets from school. Billie talks about a vicious cycle of trying to remember but then the more tired she becomes, the less she remembers. *"I get very, very, very tired and I get overwhelmed. And then my schoolwork suffers" (763).* 

> I never managed to do my homework on time. I just forget. I get told off. I'm not being lazy. I just forget everything all the time. I get tired to remember everything. I get tired. I forget more stuff. It doesn't work very good. I'll remember it on the day. I'll just get told off.

## Misunderstood.

Billie wants to express herself through her choice of clothing, however this creates anxiety as she can be a target for negative attention. *"I got called an emo fag for the way I dress"* (559).

# Stigma

Billie is aware that there is a lack of understanding around autism which creates a negative response from others. "most people don't take the time to which I think is really stupid because people are so scared of the unknown for no reason." (676) Billie recognises that there is a need for an understanding and acceptance of all identities. Billie is pleased there is more diversity within popular culture but feels there is still a way to go for people to be more accepting. "Like there's none of that. Oh my god, YOU'RE GAY. Or you're black and it's just everyone's chill with each other. And its sort of just like, that could be the future if people would stop dicking about and get a move on." (931).

#### **Theme 6- Autistic**

# Deficit

Billie overall has a positive view of being autistic, mainly referring to it as part of her identity. The label of autism has helped her to understand why she finds social relationships difficult. "*Different parts of your brain. It's like the friendship bit is like cracked" (473).* Billie saw her diagnosis as inevitable as her mum and sister are autistic. Billie described the five years wait for medical confirmation of something she already knew as unpleasant.

# Identity

"If you take away the autism part of my brain, there's not very much left. Because it shapes your personality. And there's nothing wrong with that" (658). Billie sees being autistic as part of her identity and describes how she thinks it is "cool" (656). *"I also got diagnosed with a tic disorder and social anxiety. But we also think I have ADHD"* (611). Billie uses several labels to describe who she is. Billie shared a frustration in how people do not share her interest or understanding of autism and she finds it *"fascinating"* (679).

#### Sensory

Billie describes some sensory behaviours with a preference for quiet, calm areas like the aquarium. She does not like to be touched and explained her frustration when people hug her without warning. Billie shared some of the sensory experiences which she finds pleasurable such as running in circles and sitting on cold floors. *"I like really cold floors but like the nice smooth ones."* (529).

I'm not a freak. I do not understand social cues. I'm very, very all over the place. I'll just completely shut off. I don't really care. I have autism. Who am I?

## **Theme 7- Future hopes**

"I think you're always discovering who you are, basically, until you die" (670). Billie sees herself constantly evolving. She has goals for the future for travel and learning new skills. "I can leave school and I can do what I want with my life" (240). Billie talks about having autonomy once she leaves school and how her choice of career is limited as she feels she could not remain in education for the time needed to qualify as a vet.

# Reflection

Billie was insightful and at times I found her narrative mature and wise. Billie's story was of resistance. She has clear views of what she feels is right and how people should be treated. Billie is aware that there is a lack of understanding of autistic girls and so is selective in what she reveals to people to protect herself. Her love of animals provides escapism and enjoyment.

Initially Billie was very quiet when I met her, and my first impression was that she may find the research process challenging. I discussed this with the link teacher and realised this was an assumption I had made of Billie. She was much more confident during the interview in sharing her experiences and views once she had become more familiar with me.

## Mia's story

# Pen Portrait

Mia is 12 years old and enjoys listening to music. Mia likes to make play lists of her favourite artists from a variety of genres. "Some of them are like, slower, more calm, but some of them are like they're different." Mia notices the beauty in the natural world and likes to capture this in the photographs she takes. She likes sunsets and refers to this as "the golden hour". Mia notices the colours that it creates and captures it in the pictures she takes. Mia likes to go on walks where she can look at the different details. Mia describes it as "calming". She enjoys walking in the rain when she doesn't have to worry about her school uniform or her hair. Having the freedom to just experience in the rain is described as "*peaceful*". She appreciates when it is winter and it has snowed so that she can get cosy and warm inside. "I'm good at drawing sometimes I like doing digital art do you know like on procreate." Mia loves her dogs. "They are really cute. I love them and they help me a lot." Mia likes to spend time with her mum and will helps in her shop or tidying the house for her. Mia likes to be with the people she feels close to. "People who are really close to you know because when you are close to someone, like you can be really yourself." Mia describes herself as quiet in school and feels she is smart in some of her subjects. She found the transition to high school challenging which affected her mental health. "It started in primary school, and then it got worse progressively worse in high school." Mia self-identifies as autistic but can feel conflicted as she did not receive an official diagnosis when on the pathway. Mia can be frustrated at the support she receives as she feels she is not understood. "I've had, many people, come and talk to me and things like that. And I just feel like nothing's actually helped." This experience has created an interest in psychology which she would like to pursue as a career.

Figure 4: An overview of Mia's themes and subthemes.



## **Theme 1- Connections**

## With nature

Mia has an eye for detail and notices the beauty in the natural world. She finds peace and calmness by taking walks, observing the beauty of sun sets. *"I like it when I can see this, it's like, golden hour"* (46). Mia enjoys photography and she uses this interest during her walks. Mia likes to experience the weather by walking in the rain and getting wet. *"I don't know, it is just nice, peaceful"* (65).

# Family

"I can be myself some of the time, but I can only truly be myself when I'm with my mum" (470). Mia talked of how her mum understands her the most. She describes hiding aspects of herself when she is not at home and with her mum. *"Sometimes I'm not fully my real self. Not how I am, no one will ever see how I am"* (516). Mia enjoys spending time with her mum as this is when she feels relaxed and not having to play a role.

#### **Friends**

Mia has a small number of friends who she describes as close. She enjoys spending time with them and feels safe with them. Mia feels her closest friend is able to 'tune in' to her and how she is feeling. "She can tell when like she will ask me if I'm okay and then like she'll know if I'm not. We know a lot about each other" (395).

# **Theme 2- Creative**

Mia likes to engage in creative activities. *"I'm good at drawing sometimes. I like doing digital art" (358).* She enjoys listening to a range of music which she creates playlists for.

I like listening to music. I like watching films. I like spending time with my dogs. I like spending time with my mum. I like watching Tik Tok.

# **Theme 3- Misunderstood**

Mia has an interest in psychology and has experienced difficulties with her own mental health. *"I come from a perspective of where I understand a lot of struggles" (100).* She described a frustration in not being understood from people who haven't experienced

difficulties themselves. There was a sense of helplessness as she felt nothing had helped her. *"They make comments of almost like, you don't look depressed, you can't look depressed"* (113).

Mia has a desire to be with people who have had similar experiences as her, where she can talk safely and be understood. "To talk to people who struggle with the same things as me. Like they don't have to have a diagnosis of anything. But just go through the things that I've gone through. I'd love to go to a group where, like, people understood, that I understood them and they understood me. We all understand each other" (640).

Mia shared her frustration as teachers can struggle to understand her. "Some would say smart, some would say quiet, gets on with my work. Others would say rude, talks back" (408). She receives sanctions when they think she is "talking back" (410) at them. "I've talked to my mum about it, people will think that I'm being rude. And I'm like, saying something rude. But I'm not trying to be rude. It's just me" (420). Mia describes a position of being powerless as even after the explanation, teachers will tell her she needs to do something about it or learn to talk in a different way. "I don't try to be anything; it's just how I am" (445). Despite this Mia still has some positive self-belief as a learner.

Mia has experienced being on the autism pathway but has no official diagnosis which has left her feeling frustrated and confused. *"Sometimes I feel like I do have it but then sometimes I feel like I don't" (598).* She shared how her mum is the person closest to her and believes Mia is autistic. She talked of other people sharing mixed opinions about her being autistic which conflicted her own understanding. She feels the official diagnosis is not important as she recognises aspects of herself which she feel relates to being autistic but believes she needs to figure out how to help herself.

#### Masking

Mia expressed a fear of showing aspects of who she is to her peers. *"I feel like people would just call me weird"* (484). As discussed previously she feels she can only be herself around her mum.

#### Theme 4- In need of support.

Mia feels her own experiences would enable her to help others. Mia expressed regret for the strategies that she has used to cope which has impacted on how she feels about herself. *"I've done some things I wish I never did but now I feel differently and bad about myself" (537).* Mia described the transition to high school as difficult and the catalyst for her emotional difficulties. *"It got progressively worse in high school. I'm trying, trying to get there" (542).* 

"It's really hard for me to like someone and keep liking them" (691). Mia at times receives support from a teaching assistant in school. It is important to Mia that she likes the adult, that they understand her and have a trusting relationship. She describes how this can be challenging as she can find sustaining relationships with adults in the school difficult.

Mia expressed some confusion over needing to accept help but not trusting the professional's abilities. She talked of needing to help herself but there is some uncertainty in how.

I kind of acknowledged that. I really want to stop doing it. I need to accept the help.

# **Theme 5- Executive Functioning.**

## Attention and Forgetful

Mia describes herself as quiet and smart She feels that at times she can be annoying as she needs to be on the move or has a small attention span which her friends struggle to understand. *"I'm bored all the time. Have to be doing something. I can't just sit still" (367).* Mia likes when she works at home as she can listen to music which she feels helps her concentration. Mia forgets to complete homework and will remember when it is too late.

# **Organisation and Motivation**

Mia recognises her strengths in photography and drawing. She likes things to be tidy but feels her organisational skills can make it difficult to know where to start a task. *"I just find it really hard and I don't know why" (225)*. Mia can find it difficult to motivate herself to do something. *"I find it hard to like get the motivation sometimes"* (226). She uses the strategy of setting herself a small goal and taking it one step at a time.


# Reflection

Mia's story was of uncertainty as she looks for answers to why she experiences differences in her social relationships, well-being, and education. Mia grew in confidence in the process within the group. Initially she was very quiet and considered in her responses. During the last session she commented on how much she had changed since the interview and how her responses would be different as a result. She enjoyed interacting with the other participants.

# Molly's story

# Pen Portrait

Molly is 13 years old. She loves her pet dogs and cats. She describes herself as "*creative, kind and loyal*". Molly has her own TikTok and YouTube channel. "I animate songs with my characters and I'm working on a series about my dogs". Molly enjoys playing online games such as Minecraft and Roblox. She uses her creativity skills to create rooms in her game based on her interests. "I've made my dog a bedroom because I was bored. So, I like playing with my dog in her in her room." Molly enjoys school and has a group of friends who she spends time with reading in the library. "Modern Languages is quite fun. I like art. I like English and I only like math sometimes. I'm not a big fan. I don't like PE I'm not a big fan of PE." Molly describes herself as quiet in school and likes to keep to herself. Molly feels this helps her to avoid negative attention from potential "bullies."

Molly is positive in her approach to lessons that she finds difficult. Molly has decided she will choose options for her GCSE's based on the subjects she enjoys the most. Molly has online friends who she works collaboratively and are based across the world. Molly





# **Theme 1- Creative Interests**

# Animator, gaming and drawing

Molly enjoys spending her time playing games such as Minecraft and Roblox. Molly uses her strength in drawing to create cartoon characters in her animations. *"I make animations on my iPad and post them to YouTube" (20).* She uses her love of her pet cats and dogs as inspiration for the animations she creates. *"I animate songs with my characters. I'm working* on a series about my dogs" (43). She has people following her channels, watching her videos.

# **Theme 2- Connections**

# Online Community, Friends and Family.

Molly's relational self has different contrasts. She interacts with people online whom she refers to as friends. *"I chat to people. I am working on a collab with some people" (160).* Molly will negotiate roles and work collaboratively with these people to produce animations. *"They're just like friends. I haven't met them in real life. They live in different countries" (200).* Molly has friends in her school who she spends time in the library with. Molly shares how her parents support her and help her to understand what being autistic means. *"My parents do, they try and get me to understand it and stuff" (469).* 

# **Theme 3- Autonomy**

# Misunderstood.

Molly enjoys art and English. She is clear that her dislike of PE is not down to her being lazy, she just does not like to run around. Molly sees herself as a well-behaved learner who is quiet.

l don't really talk. I'm quiet. I'm quite well behaved. I'm forgetful. Molly describes herself as forgetful, finding it hard to remember homework or equipment. She tries to use strategies to help. "*I do write lots of stuff in my planner. The pages are full of I've got literally no room to write my homework anymore*" (290). Molly wants to do the right thing but if time passes, she knows she will not remember. "*I leave it for a couple of days then it will be forgotten*" (307). Molly describes the feeling of being scared when she realises that she has forgotten her homework. "*I still get in trouble for it because it's homework*" (318). Molly is resigned to the fact that she can't remember and so therefore it is inevitable that she will get into trouble.

# **Options**

Molly is looking forward to some autonomy through the options that she takes. She plans to choose subjects that she enjoys as she does not think there are any which will fit in with her aspiration. *"I don't think there'll be many classes that would work with that" (52).* 

#### Theme 4- Injustice and Empowerment.

#### **Bullying**

Molly witnessing bullying and so avoids it by staying under the radar. "They don't really do it to me. They do it to my friends. They're just always really mean and commenting. My friend's like quite small and they comment on the size. It's not nice. I don't like listening to it" (427). Molly recognises how unfair the situation is and describes being powerless as she is vulnerable to being targeted if she spoke against the 'bullies'. I would just stay quiet. I don't like getting involved. I don't like watching it either. It's a horrible thing to watch.

Molly knows that she is different with those peers who she feels are bullies. *"They're really annoying people. I don't like them. They're just, they're just bullies" (421).* Molly uses this strategy but is clear that she would stick up for herself if she was treated poorly by them. *"If someone's mean to me. I'm just gonna be mean back" (410).* 

# **Autistic**

*"I'm not actually fully sure I know what it actually is"* (456). Molly sees being autistic as a difference in processing. *"I know it is where you see the world differently to others" (455).* Molly is aware of how others understand autism which causes a frustration as it is not accurate. *"It just makes me feel mad" (510). "I don't think it's a bad thing"* (485). There is an acceptance of her diagnosis which Molly sees as a positive aspect of herself. *"I think it means you are just special" (490).* Molly doesn't see the diagnosis as having an impact on her life. *"I think it doesn't really change anything"* (492).

# Stigma

Molly described the stigma that she has experienced regarding autism. "I heard someone say that there was like missing pieces in the table" (521). "This girl said autistic people chewed on them and I know it's not true because they don't do stuff like that" (526). Hearing her peers talk about autistic people like this makes Molly angry. "They obviously don't understand because they don't have it but it's not true" (534).

# **Theme 5- Animal Lover**

Molly talked about her pet cats and dogs, sharing anecdotes about them and their characteristics. It is the love for her pets that inspires her drawings and animations. "*I'm working on a series about my dogs.*" (44).

# **Theme 6- Future Hopes and Aspirations**

Molly is unsure about what she wants to do in the future but has small goals around her own skills. *"I'll probably try to be an animator. It's just I don't know what else to do" (579).* She is clear about what she needs to do to help her get her goals.

# Reflection

Molly's story was that of belonging and connections. She has settled into school with a group of friends within school who share similar qualities and interests. She is able to avoid attention through being quiet in class and not addressing peers who treat people unfairly. I reflected on my own understanding of friendship and how this is something I need to aware of. Molly described what is similar for other YP who interact with others using online platforms, a different kind of friendship.

#### **Rissa's story**

# Pen Portrait

Rissa is 13 years old who moved to the schools after struggling to attend her previous one. She lives at home with her parents and dogs. She enjoys listening to emo and rock music. She likes to express her music taste through the clothes that she wears. "My clothes have a certain style, and represents me and makes me feel comfortable." She finds listening to music as calming. Rissa is at her happiest when she is playing Dungeons and Dragons where she can take risks and make decisions about her character. She aspires to become a dungeon master and lead her own campaign. Rissa likes to attend Comic Cons where she participates in cosplay. Rissa recognises that her interests could be considered as alternative. "I'm not what people would normally think is fun, like, things that I find fun, the thing that I enjoy the thing that people don't usually enjoy." Rissa enjoys playing Roblox, watching Stranger Things and talking to her online friends. Rissa is creative and likes to relax when she draws. Rissa is most confident when she is with her friends and has a desire to be more independent. She avoids situations where she may be noticed by her peers. "Stay away from people that purposely draw attention to me stay away." She describes her autism label as a superpower and feels frustrated when teachers do not understand her. Rissa describes the positive relationship that she has with her mum and the encouragement she gives her. Rissa has a diagnosis of autism which she refers to as her 'superpower'.





# **Theme 1- Creative interests**

# Cosplay and Role play games.

Rissa enjoys spending time engaged in her interests. She is aware that this may make her seem unusual to her peers. *"I'm not what people would normally think is fun" (32)*. She attends Cosplay conventions and a weekly Dungeons and Dragons group where she feels a sense of belonging. Rissa enjoys the role-playing aspect and the form of escapism that the game provides. *"I have lots of fun and I make friends. And I am also very free with it because I can make decisions. Like I can choose to do whatever I want" (158)*.

# Music, Drawing and Gaming

Rissa enjoys listening to her music and finds it helps her to relax. "*I would listen to my music and calm down* "(182). When talking through her collage she shared how she enjoys drawing and playing on Roblox.

# **Theme 2- Connections**

There is frustration that Rissa's interests make her subject to judgement. Rissa sees this as her peers being unable to open their minds to other things. *"I enjoy the things that people don't usually enjoy. So, they think it's weird, because they can't see outside of their bubble and what they like. They can't reach, branch out into other things and can't see what I like" (34).* For Rissa there is a real 'us and them' narrative, where she places herself and the people who she feels most comfortable with on the margins as they are not accepted by the majority.

I'm not what people would normally think is fun.

I enjoy the things that people don't usually enjoy.

I do what I like.

I am around people that like the same things as me.

I know they will not judge me.

# Friends and online communities

Rissa describes the support her friends give which enables her to engage in activities she would not be able to do on her own. *"They're very supportive. We're all like friends, none of us argue. We are all quite close" (169).* Rissa gains confidence from being with her friends. *"It* 

*feels like nobody else is watching me" (129).* She has built a network of friends online with whom she enjoys spending time with. *"I like playing games with my online friends." (25).* 

#### Family

"My mum, she makes me feel it's not bad, it's good. So, she makes you feel good about who you are" (211). The unconditional positive regard that Rissa's mum provides helps her in developing a positive self-image. She describes a similar relationship with her dungeon master who encourages her to take risks. "If I want to make a decision in my game, she will like support me on that" (221).

#### **Theme 3- Autonomy**

#### Fashion and hobbies

Rissa likes to wear clothes that are described as emo or gothic. "*My shoes and my clothes have a certain style and represents me and makes me feel comfortable*" (12). She feels the clothes represent her but is conflicted as they make her vulnerable to attention and teasing. "I don't like to draw attention to myself, because I don't like when people stare at me, because it puts me in pressure and it puts me in situations that I don't like" (98). When Rissa is with her role-playing community, she feels she has a sense of control over what she does as she is empowered to make decisions. "I am also very free with it because I can make decisions." (159)

#### Masking

There is a frustration as Rissa wants to be an individual but tries to avoid engaging in behaviours such as stimming which could draw attention to her. *"I stay away from people that purposely draw attention to me, I stay away from doing something like a twitch or* 

something that might make people look. If I keep things in that might happen, I can't control them, but they might be loud" (108).

I am quite well behaved. I don't like to draw attention to myself. I don't like when people stare at me. I keep things in that might happen. I can't control them.

# Misunderstood.

"It's important to me that the teachers especially see that this superpower is serious" (264). Rissa feels that there is a lack of understanding of autism as in her previous school she was not believed. "It feels like I'm not good enough for the same help as everyone else" (265).

# Theme 4- Injustice/Empowerment

Rissa rationalises being an outsider as a choice as she does not conform to peer pressure. There are conflicting narratives as she perceives popular people as having a problem free life but believes they conform. Rissa wants to be unique and not conform but feels this is challenging. *"If you're like a popular person with no, like problems or anything, you might just enjoy going on your phone and talking. And like going out shopping, and like try on clothes and stuff. Stuff that makes you look (the same) instead of doing things that you like" (43).* 

# Autistic, Inequality and Being Believed

Rissa recognises that there is a stereotypical view of autism which is biased towards males, making it challenging for girls. "Autistic boys in that school (Rissa's old school) are very much treated differently to autistic girls. They mask a lot more; they don't show their emotions a lot. So, I've noticed that we get a lot less help" (264). Rissa sees herself as different to what people expect autistic people to be like. "Girls don't express their autism as much as boys" (275). Rissa is frustrated with the ignorance of some teachers. "They can't do the research and they just can't see behind that masking. They can't do research on it and educate themselves to be able to help these children" (286).

#### **Theme 5-Personal goals**

Rissa has aspirations to be able to do things independently without needing the support of her peers. She has a good understanding of herself and can identify steps to work towards this. *"I'm not sure like maybe just going to little quieter places and then building up" (198).* 

# •**•**••

#### Reflection

Rissa's story was of connection and belonging. She has interests that she feels a sense of unity with but also allow her to escape from a world that is less accepting of difference whether that is through role play, cosplay or part of her music identity and clothing e.g. emo. Rissa probably surprised me the most as she was quiet and appeared nervous yet when she spoke, she talked with conviction and determination. She recognises the need for people to be more accepting and sees being autistic as an identity which brings with it different strengths. In the last session Rissa reflected how her story would be very different since moving to a school that understands and cares about her.

#### Sadie's story

# Pen Portrait

Sadie is 15 years old and enjoys shopping in Primark. She likes to look nice and is interested in fashion. She likes spending time with herfriends and the local shopping centre. Sadie talks about making "new friends" when they go to the shops who she will keep in touch with via social media. Sadie enjoys being spontaneous and talks about having fun with her cousin when they go for drives. Sadie likes "hearing about gossip" when it is not about her. She has one close friend who she will talk to. Sadie likes to laugh and be "crazy" and believes her friends thinks she is the "funniest". Sadie has not disclosed her autism diagnosis for fear of rejection from her friendship group. Sadie likes listening to music and going to concerts. "I always have my headphones on when. I listen to them on the bus on the way home. I got an Alexa because I really like music. And it makes me like get dressed guicker and stuff. Like when I'm taking forever so I like music a lot." Sadie likes to draw and watch crime documentaries. Sadie describes being at home as "boring" as her mum works nights. Sadie expressed a desire to spend more time with her mum as she makes her laugh. Sadie described her dad as "weird" and how he makes her laugh. She has recently experienced her parents separating and the loss of her grandmother. Sadie felt this impacted on her engagement in school and needed the teachers to understand. Sadie describes herself as quiet in school. "I actually really like my teachers this year. And I've got better classes and lessons." Since taking her options Sadie has preferred her school timetable but does not particularly enjoy school. "Going home is the best bit of school".Sadie is conflicted about being autistic but feels it is the reason she struggles with her learning. She does not want to be treated differently. "I don't want people to know." Sadie had aspirations to be a police officer but was uncertain if she would do this. She was told she would have an increased opportunity due to being autistic.





#### **Theme 1- Interests**

# Netflix, Fashion and Music

Sadie enjoys listening to music and going to see bands play. *"I always have my headphones on" (308)*. Music helps her during bus journeys and motivates her during routines. "*It makes me like get dressed quicker and stuff" (312)*. Some of Sadie's interests centre around relationships, she included a football team in her collage that she supported when her stepdad was in her life." *I used to watch them, or he took me to a game and stuff, so I don't really watch it since" (33)*. Although Sadie shared her enjoyment of activities, there was some self-criticism as she didn't see these as a hobby or something that made her interesting. *"I'm not a very busy person"* (341). Sadie struggles to sustain activities. *"I don't really stick to* 

*hobbies*" (346). Sadie relies on peers to engage in hobbies, once they no longer attend Sadie feels she is unable to do it alone. "*I did drama for two years and then after that I quit because I had no one to do it with anymore cuz three of my friends quit" (349).* 

# **Theme 2- Connections**

# **Friends and Others**

"I like hearing about gossip when it's not from me" (8). Sadie has friends that she likes to spend time on the weekend doing activities such as shopping, gossiping, and having a laugh. "I feel more comfortable when I'm with my friends" (127). Sadie feels supported by her friends and doesn't feel she will be judged. "I don't have type of friends like that" (271). Sadie is aware that she has to be careful about what she says and prefers the company of one friend who she feels she can trust. "We don't like stirring drama. So, every time we say something we just say to each other" (276).

"I don't really speak that much when I'm not around them" (685). Sadie describes the confidence she has when she is with her friends as she knows they will support her. "I know that if someone judges me then my friends will stick up for me" (689). Sadie knows her friends find her reliable. "My friends like if they want to do summat then they always ask me or something but not with other people" (377). Sadie refers to people that she has recently met as friends. "Usually, I get like a lot of new friends this week and I've only been friends for like three weeks or summat" (702).

# Family

Sadie likes to spend time with her cousin who she feels she has the most in common with. "She's into all things I am because basically we are the same" (79). Sadie's cousin is on the autism pathway, and she describes how they have similar traits. Sadie talks of enjoying her time with her mum. "My mum is a bit weird too, like really weird" (201). Sadie's describes her mum as being spontaneous and making people laugh. She recognises that her mum knows her the most and is able to be herself with her. "I think your mum is like one of the easiest persons to annoy because you're literally like spend every day with her. So, I'm always annoying my mum and nagging her and stuff" (413).

#### **Theme 3- Autonomy**

#### **Options**

"I actually really like my teachers this year and I've got better classes and lessons" (501). Sadie liked the autonomy that choosing her options gave her. "You actually get to do things you like" (515).

# Forgetful

Sadie struggles to remember her homework which creates difficulties for her in school. "In year seven I had 10 behaviour points for homework. And then year eight I had 20 summat for behaviour and homework" (610).

#### Misunderstood

"Some teachers say that I don't put effort into work, but some teachers understand that I don't like putting my hand up because I feel like a bit stupid, (standing) out (from) the rest of *the class and (looking) slow*" (473). Teachers who are sensitive to Sadie's needs help reduce feelings of anxiousness. "*She will always come to me without having to put my hand up*" (478). Sadie felt that teachers didn't understand her in the earlier years of high school. "*They were just saying that you don't have enough effort and like telling me off*" (558).

# Masking

Sadie refers to herself as weird but only shows this to certain people. "I can be like really crazy like in front of people like I am really comfortable with" (55). "In a room full of normal people everyone is still different. So just because you're autistic doesn't really mean that you're different. Because you're still different, like everyone else" (1054). Sadie described a relief of learning how autistic girls are different because they mask and so therefore, she can hide it easily. She expressed an enjoyment of working with the other autistic girls as part of the research as there was less risk of judgement and more understanding. Sadie describes the difficulties she has with hiding her attention difficulties as her peers cannot understand why she cannot concentrate. Sadie felt in the research group this was accepted. There was less pressure to conform therefore she would be able to attend or be supported to get on with her work without having to hide her difficulties. "They might get put on track easier than other people" (1077).

I usually forget some of it. I was supposed to do homework. I didn't do it. I was supposed to do it. I didn't do it.

# **Theme 3- Injustice/Empowerment**

# In need of support

*"I'm really far behind compared to everyone else" (869).* Sadie doesn't have a positive view of herself as a learner. She feels she didn't get the right support early on in her education which has now created a helpless situation. *"I just gave up a bit, I think the reason why I'm more like bit stupid now" (876).* 

## **Autistic**

Sadie attributes some of her difficulties to not receiving a timely diagnosis of autism when it was initially identified in primary school. "*My teachers always used to say to my mum in primary school that they think I'm autistic, but my mum didn't really like get anything for it at the time" (879).* Sadie feels that the right understanding and support within school can make a difference for her. "*It feels a bit better when teachers actually understand*" (963).

> I were really bothered about it. I do think about it everyday. I do something wrong. I think. I am autistic.

*"When I first got diagnosed with it. I am not going to lie I did cry" (779).* Sadie is conflicted in her understanding of what it means to be autistic. She refers to functioning labels to rationalise that she is ok as she is low on a scale of severity. *"The marks like 1,2,3 and 4. I'm only a one so I'm not that bad" (857).* Sadie attributes her diagnosis as the reason why she finds learning hard and is in lower sets. She refers to non-autistic people as normal which adds to the self-othering tone of her narrative.

Sadie shared how her biggest fear when she was diagnosed was the reaction of others. *"I thought that everyone is going to treat me different, but I wanted to be treated like everyone else" (780).* To remain accepted Sadie doesn't share her diagnosis. *"My friends, they don't know at all" (1028).* Sadie describes the need to keep her diagnosis hidden until she leaves high school where she can then disclose it to people, she would not have to see on a daily basis.

#### **Sanctions**

*"It's pretty stupid really because I can't really help it"* (990). Sadie can 'zone out' when overwhelmed in her lessons which she has received sanctions for. *"She put three counters on the table. She said I'm gonna take one out every time you zone out but, I usually zone out when I don't know what I am doing"* (968). Sadie described how she felt powerless in this situation. *"I don't do it on purpose. Like, sometimes I'll just be sitting doing work. I'll get stuck or something and I'll stop there and stare in space and I'll get carried away"* (979).

#### **Theme 4- Aspirations**

"I did want to be a police officer but someone came in school to speak to me about it because I apparently, I've kind of more of a chance of doing it because I'm autistic. But I don't know if it is something I want to do anymore." Sadie is unsure about what she wants to do in the future. She talks of more opportunities to be herself once she leaves high school and doesn't have to worry about what other think about her if they know she is autistic.



I felt Sadie's story was of a need to connect. Sadie described a home life where she was at times longing for connections or time with her family. There was an unpredictability in when she would have time with them or what her parents would do, describing them both as weird. Sadie likes to with her peers and meeting new 'friends'. I have to admit I was slightly nervous in how she described how she makes friends with people when out at the shopping centre. After one meeting she refers to these people as friends. I wondered if there was a vulnerability here around relationships particularly as this is a concern around autistic girls. I wondered if it felt quite isolating for Sadie as she has not told any of her friends that she is autistic. Perhaps this is related to the deficit view she has around the label.

# Sarah's story.

#### Pen Portrait

Sarah is 13 years old. She lives at home with her mum and dog. Sarah loves her dog and enjoys spending time with him. She likes to "cuddle and kiss him." Sarah has an interest in psychology and understanding how people's mind work. She has a particular interest in the psychology around criminals. Sarah likes to relax in her bed and watch crime documentaries and films with her mum. Sarah was particularly interested in murder documentaries and try to understand why people do what they do. "I love finding out about how people's minds work." She likes to cook especially vegetarian dishes. Sarah has struggled with an eating disorder and so likes to make meals where she knows what ingredients have been used. Sarah enjoys the subjects English and drawing. "I was able to take the option of graphics." She likes to express herself through the drawings she creates. "I get to express how I'm feeling without hurting anyone else."

Sarah has experienced life changing illness where she spent a significant amount of time in hospital. Her health difficulties have impacted her appearance, cognition and well-being which she is coming to terms with. *"It has definitely made me think about myself a bit more."* Sarah experiences short term memory difficulties and has a diagnosis of autism and ADHD. Sarah is quiet in school and tends to keep to herself. She is very private and doesn't share much about herself. As she has had a number of moves to different areas and schools, she has not built many friendships. Sarah has a desire to make friends but finds it difficult to do this. She likes the *"security"* that accessing the learning support hub offers her as she feek it is a safe space. Sarah wants to be able to visit America in the future and would like to go to New York.

Figure 8: An overview of Sarah's themes and subthemes.



# **Theme 1-Survivor/Fighter**

Sarah had an illness which caused two strokes which affected her memory. Sarah is conflicted in her body image as the illness affected her appearance and appetite. *"I do get very annoyed at myself that I eat loads. And I get really upset about it" (162).* The experience has made Sarah at times feel isolated. *"Sometimes it feels like I'm the only one" (167).* Sarah described how she would control what she ate by limiting meals and increasing her walking. *"I struggled with an eating disorder for around a year" (18).* Sarah saw herself as 'skinny' during this time. *"It wasn't my greatest time, and everyone was scared for me" (587).* 

I also had a tumor. I suffered from two strokes. I was stuck in hospital for nearly four months. I struggle with my memory. My struggle. My leg gets very tired. My right leg gets very tired. I get very weak.

# **Theme 2-Changes**

Sarah has been through changes in her health, appearance, and home at an important time for her development of her identity time. Sarah has had to adjust to the changes and what it means for her. Sarah's illness caused body changes which were out of her control.

## In need of support

Sarah relies on support within the school and has built trusting relationships with the adults within the learning hub where she has a sense of belonging.

# Body image

"It has definitely made me think about myself a bit more because before I didn't really used to be bothered about my weight and stuff. But now I'm very cautious." (156) Sarah has struggled with her body image following her eating disorder and illness.

## **Theme 3-Autonomy**

*"I do really like being veggie because I think about the animals and stuff" (338).* Sarah describes herself as a part time vegetarian, choosing to eat mainly vegetarian food but having some meat as part of her diet. Sarah makes the link of her reluctance to eat meat with her eating disorder. *"I always used to think that eating meat was really fattening for you" (343).* 

# **Options**

Sarah enjoys lessons where she is able to engage in her interests which she chose to do through her options. "There was a choice for me between art and graphics, they said that I'd be more into graphics because it is more drawing" (373). "Art is mainly like painting and like, you know really intricate boring stuff, so I chose graphics" (377).

# Memory

Sarah relies on adults to help her find her way around school and organise her belongings. *"I struggle with my memory." (21).* 

#### Masking

Sarah hides how she feels at school and will release her emotions once she is home. *"I feel sad, that's why I draw it because I think I'm quite a sad person. Like if anyone is mean to me, I get quite sad. In school, because I'm quite you know, I'm quite tough in school, except for when I come home. I cry my eyes out"* (254).

# Misunderstood

"I don't really tell much people about my diagnosis, only the teachers know" (765). Sarah has a diagnosis of autism and ADHD; she accesses the school's learning support. Sarah is concerned about how her peers would see her if they knew of her diagnosis. *"I think people will start treating me differently if I told them that, and I don't want to be treated any differently"* (768).

# **Theme 4-Connection**

# Family

"I love hanging out with my mum. She's like my top person in my whole life, I love her" (33). Sarah likes to spend time with her mum who has been a source of support through some challenging times. "She's like, my little safe, like, my guard" (542). Sarah's mum gives her encouragement and reassurance. "I think my mum helps me be myself. She always talks to me and says, oh, you look great or you're absolutely fine. Don't worry, don't panic" (540). Sarah's parents have separated. "Me and my dad had a very tricky relationship" (292). She describes a frustration of not being understood by her dad. "I just get annoyed because I think why is my dad like this. You know, my mum isn't" (519). Sarah loves to spend time at home cuddling her dog. "I have a dog he's really cute" (6). I don't have any friends. I'm trying to find friends. I used to be very outgoing. I used to go up to people. I can hang out with them. I don't really do that anymore. I wait for them to come to me. I don't have any friends.

# Desire for friends

Sarah describes a frustration of not being able to make friends. She tries to reason that her change in appearance should not make a difference in her ability to form friendships. "*I don't think I'm fat, but I think I may have a bit of weight on me. It's just I see people and they've got loads of friends and they're a bit big. But I am like, well that shouldn't, like the way you look shouldn't be based on your friends or anything" (195). As Sarah has moved schools, she doesn't have any long-standing friendships. Sarah struggles with the complexity of adolescent relationships, how to initiate interactions or sustain it. "<i>I felt a bit like, I'm just rushing around after them. But that may just be how it is when you first become friends*" (124). In class Sarah finds it a little easier when there is structure and people sat next to her. "*It's just outside of school and then play, like, playground time, where I can't find anyone to hang out with*" (869).

#### **Theme 5- Interests**

Sarah enjoys some of her subjects particularly English as she likes to make up stories. She enjoys graphics and likes to spend her time drawing. *"I can only draw if I'm looking at a picture. I can't draw from a memory" (37).* Sarah describes how she likes to draw pictures of contrasts, good vs evil or sad images as a form of escapism. She makes the link between the images she draws and her own hiding of emotions. *"I get to express how I'm feeling without* 133

*hurting anyone else" (459).* Sarah loves her dog and enjoys cuddles with him. Sarah has an interest in criminology, she enjoys watching dramas about serial killers. Sarah wants to learn about the how and why criminals commit offences. *"I find it really interesting to, you know, uncover the deep things about them" (31).* 

I came here. I was autistic. I have ADHD. I've been in learning support. I feel good.

# Theme 7-Aspirations

*"I want to become a psychologist because I love finding out about how people's minds work"* (26). Sarah aspires to use her interest in psychology as a career. Sarah wants to travel to New York in the future. *"I wanted to go to America ever since I was little"* (40).



# Reflection

It was hard hearing Sarah's story without reflecting on the emotional responses it creates. Her story was one of survival but there was a sadness and loneliness which made me want to help her. At times I gave some reassuring comments when she shared how sad she was about her appearance and memory. I felt this was important for her to feel safe and contained whilst we engaged in the interview.

Sarah compares herself to what she was like in primary school seeing this as confirmation that there is something 'wrong' with her. I wondered if she had not moved schools or had time off would she feel this way as she may have lasting friendships from those she made at primary school. Having a wider view of the environment and circumstances may help Sarah feel less like there is something wrong with her.

# Scarlett's story

Scarlett is 12 years old and lives at home with her mum. *"I'm really funny."* She likes anything that she thinks is cute especially puppies. Scarlett would love to have a dog of her own and particularly loves Labradors. She loves to collect soft toys which she names. *"As soon as I get home I give them a big squeeze and I feel happy."* Scarlett loves Peter Rabbit as he reminds her of family holidays and has a teddy which she takes everywhere with her. Scarlett loves Halloween and everything that is associated with it. She likes to dress up and go trick or treating. Scarlett has a good imagination and looks forward to her magical elf on the shelf that visits her each year. *"They lose their magic. If you touch them you have to put cinnamon and salt around."* 

Scarlett will explore what is popular with her peers to share what they are interested in. As a result, she now enjoys playing Roblox and watching videos on TikTok. She likes to go swimming and shopping with her friends. Scarlett sweet foods such as chocolate and strawberries. She believes that everybody should be unique and different and this should be celebrated. Scarlett has a diagnosis of autism and struggles with sensory experiences particularly in managing her own hygiene. Scarlett has a close relationship with her mum who she feels understands her. She has a clear sense of right and wrong and does not like bad manners. She doesn't enjoy school and gets frustrated by inconsistencies in her teacher's expectations and support.

"I would like to work at Roblox when I am older. I am very good at computers and I have played Roblox for a while so I will have a bit of experience."



# Figure 9: An overview of Scarlett's themes and subthemes.

#### **Theme 1-Creative**

#### Imagination

Scarlett has a good imagination; she looks forward to the 'elf on the shelf' visiting her. She describes the rules for looking after them to ensure they remain magic. "*I'm not touching it. That's how it loses its magic*" (226). Scarlett believes they get up to mischief and will offer examples to support this. "*I think he accidentally like slammed the door because his hands are small*" (249).

# Social Media, Costumes and Being Creative.

Scarlett enjoys using social media where she will create videos of her transition when dressing up for Halloween. *"I did like a really good transition on Tik Tok. Like so it was just me normally with my bucket, throw it up in the air. And I caught it and I was in my costume"* (307).

Scarlett has a favourite celebration which she recognises may not be popular. *"I like Halloween more than Christmas. I just don't know what it is that I like about it. Some people think I'm weird for it"* (36). Scarlett's vision of Halloween could be described as romanticised. *"On Halloween you can go out into like forests and (there are) scary fogs. Do pumpkin picking (and) go to pumpkin patches"* (281).

## **Theme 2- Connections**

# Family

Scarlett describes her relationship with her mum as close. "She's the only one I have got" (806). She finds it difficult when they have a disagreement. "I just wanted a hug and everything, but that is not how it works" (796). Scarlett enjoys spending time with her mum in the Lake District and going swimming. Scarlett knows her mum understands what is important to her and describes the lengths she goes to in order to get her the teddies she collects. Scarlett's mum helps her to navigate what is currently popular to help her fit in. "I got it because people were just like saying stuff like why don't you have Tik Tok?" (43).

#### Friends

Scarlett has a small number of close friends that she will meet up with. *"We do shopping* or go to the park or get something to drink like a Café Nero" (467). Her friends share similar interests which can make her subject to teasing by other peers. *"People were going around* saying 'do you play Roblox?' and we were like 'no that's weird', because obviously we didn't want people to know because, they were just being rude" (136).

# **Theme 3- Unique**

# Interests

"We are all different but there's something kind of fantastic about that" (31). Scarlett likes that people are all unique. "We are all different. We can't just be the same because if we were all the same, we would be boring." She talks confidently about what she likes and doesn't conform to what other people think she should like. "I'd rather have everyone be different than just be like one person" (185). Scarlett loves collecting teddies, she likes to carry them around and hug them. "As soon as I get home, I give them a big squeeze and I feel happy" (818). Scarlett finds her teddies comforting, they helped her cope in primary school. Scarlett found a change of teacher who didn't understand the importance of the teddies difficult. "He was like put that back now you're not having that in my class put it back now" (1003).

#### Strengths

"You need a bit of confidence from time to time, because (there) might be something, I don't know scary, that you're gonna have to do. You might have to go out and perform and everything and then really you would like some confidence" (441). I thought it was interesting that there were conflicting narratives in how Scarlett talked about herself. Scarlett describes having to 'perform' when she is out which can be scary but sees herself as confident. Scarlett talked about having confidence to stand out from the crowd and tackle challenges. "I have loads of confidence" (415). Scarlett believes she is funny as she laughs with her friends.

> l'm really funny. l'm a pro at Roblox. l am a good pet collector. l am playing Roblox.

#### **Theme 4-Autistic**

"I'm not going to die, am I?" (996) Scarlett describes the confusion of receiving her diagnosis of autism and she was unsure what this meant. "I was like I can't give it to you can I. She was like no it is not an infection you are just born with it" (996). On the day she received the diagnosis Scarlett described the journey home with her mum. "She was just like started crying and obviously we were like happy" (989). Scarlett feels she does not understand what it means to be autistic. "My mum thinks she's autistic. That was my first question. Who did I get it from?" (1074). Scarlett explained that she only knew one other autistic person who was a boy. "He wasn't really on my level" (1085).

"My mum says that I mask in school" (824). Scarlett expressed a confusion as she doesn't understand what masking means. Scarlett shared what happens when she gets home from school. "I just start letting everything out" (825). She describes how her emotional reactions cause her mum concern. "She goes stop it because you are scaring me or rather stop it because someone's gonna call the police" (545).

#### **Theme 5- Injustice**

#### Misunderstood

Scarlett describes her confusion of school expectations and the sanctions she receives. "I don't really understand really, (am I) shout(ing) out or asking question)s)? I have to be completely honest" (580). Scarlett receives breaktime detentions which her mum is informed of through an app. Scarlett describes the worry this causes. Without an explanation of what it is that she did wrong, Scarlett feels powerless as she is unable to do things differently. "I don't understand if I got it because I was doing something wrong, or if I wasn't" (597).

# Peer pressure

Scarlett recognises that sometimes she will engage in activities such as Roblox and TikTok initially because they are deemed popular. She has a clear sense of right and wrong however and will not engage in activities that her peers do if she feels they are wrong. Scarlett shares her frustration with friends who are bad mannered. She distances herself from people who use inappropriate language or make poor choices. "*Apparently, he vapes. So, I don't really want to be near him if he vapes" (109).* 

# **Theme 6- Sensory**

Scarlett finds self-care routines difficult which creates tension with her mum. "My mum has like massive arguments and I've just been absolutely in tears" (736). Any potential judgment of her for her personal hygiene is not enough to convince her to have a shower or brush her teeth.



# **Theme 7- Aspirations**

Pet

Scarlett loves dogs and would love to have a Labrador of her own. "I love puppies, and (pointing to the collage) there is a little chubby happy dog" (6).

#### Career

Scarlett's description of herself as a learner depends on the subject and teacher. "*Maths teachers would probably think I am annoying*" (574). She enjoys computers and describes herself as hardworking in this subject. Scarlett aspires for the future based on her interests. "I would like to work at Roblox when I am older. I am very good at computers" (665).



Scarlett's response to her diagnosis and the description of the concerns she had made me wonder if there is enough support for the YP through the diagnosis pathway. It must have been a frightening experience to be given a diagnosis within a medical setting and try and make sense of this. I can understand why Scarlett would worry that she could infect people or die. I wonder if there is a better setting for YP to go through the pathway and receive their diagnosis which isn't in a medical setting or appear clinical. Scarlett's mum has supported her in her understanding of autism which she felt was part of what made her unique.

I reflected on Scarlett's mum within her narrative as it resonated with me. The battle regarding Scarlett's personal hygiene and managing her sensory needs seemed to create tension. Scarlett was not concerned about this but acknowledged it caused her mum some stress. I wonder if this is due to the pressure that I have experienced myself as a parent. Trying to balance the pressure from what society expects and responding to your child's needs can create tension. Her mum's comments about people calling the police or noticing her smell indicate she is aware of the judgements potentially being made about her. I understand how stressful this dilemma feels.

#### Discussion

"Disability is not an object—a woman with a cane—but a social process that intimately involves everyone." Davis. L., (p.2, 1995)

# **Overview**

In this thesis, I looked to explore autistic adolescent females constructs of self. My aim was to reflect on how the relationships and environments contribute to a positive self by listening to their stories and giving priority to their voices. In this chapter of my thesis, I will independently address each of my research questions while establishing connections to pertinent and current literature. After some reflection following the analysis of the participants' stories, I considered the themes that were present in all eight of the narratives. I felt I was more able to discover potential implications for professional practise by recognising patterns among their stories, while still appreciating their uniqueness and subjective nature. I did not intend on generalising these themes to all autistic young women; rather, I wanted to point out some potential ways that experts might one day be able to change the lives of some of these girls. In keeping with the critical realism positionality of my thesis, I also acknowledge my part in developing these themes and the possibility that other researchers might have found different similarities in the same study.

I will reflect on the research questions as well as the implications for academics and the field of educational psychology. Finally, I'll discuss any limitations and offer suggestions for future research.

#### **Research Question 1**

What can be learned from autistic adolescent female's constructs of self and identity? I will discuss the themes that I identified from the analysis of the different narratives.

# Self as inhibited.

Common to all of the eight YP was the view that they were forgetful, sharing frustrations of not remembering to do their homework. Mia described the difficulties she experiences in knowing how to start a task or what order to do it in. Sadie shared her need to be active and on the move. Billie described her struggle to maintain her concentration and attention levels. These experiences can all be described under the umbrella of executive functioning (EF) (Dawson & Guare, 2018). Differences in EF are argued to be a critical predictor of outcomes for autistic YP in academic functioning (St. John, Dawson & Estes, 2018). This view of having a poor memory contradicts research by Nowell et al (2020) who argues that autistic individuals are more adept than non-autistic individuals at maintaining hyperfocus, paying attention to details, remembering things, and being creative. Each of the YP viewed these traits as problematic, and all took place within the educational context. Bodner et al (2019) argues that EF performance can be impacted upon as a person's cognitive load increases. Autistic children are described as having a 'spiky' profile of cognitive ability which include patterns of difference in functional vocabulary, social comprehension, visual processing speed and working memory (Oliveras-Rentas et al., 2012). Within a day in a secondary school a YP will experience a number of transitions, different instructions, different teaching styles and types of information. This can create anxious responses which can include avoidance, acting out or withdrawing into their own world (Eaton, 2019). Sadie described her feelings of helplessness when she appears to daydream in lessons and her teacher introduced a

behaviour management system to address this. As the YP continue to receive negative feedback for struggling to organise themselves or forgetting their homework, they begin to internalise this as something that is wrong with them (Honkasilta et al., 2016).

Some of the difficulties the YP described can be linked to the theory of autism inertia. Research has found that autistic YP reported having trouble beginning, pausing, and switching between tasks that were out of their conscious control (Murray, 2017). Just like Mia, the participants had frequent planning challenges, some experienced difficulties starting even routine actions. Billie described feelings of exhaustion from the daily routine and demands school life created. The research suggests that daily activities and wellbeing of the individuals can be significantly impacted by inertia. (Buckle et al., 2021). Research suggests that students can develop abilities that are important for self-determination, by learning how to manage their time (Hampshire et al, 2014). For many YP, teaching them to self-manage is a valuable strategy in achieving independence (Pendergast & Watkins, 2009). Hampshire et al. (2014) suggests working in collaboration with parents, providing a homework plan that utilises check lists can support YP in self-management of homework. There are a number of online platforms that schools use to record homework that has been set which both parents and the YP can access to support this. Making explicit the purpose and value of the homework task can maintain motivation (Xu, 2010).

#### Sensory

Autistic individuals have been observed to have both hyper and hypo sensitivity to sensory stimuli, as well as a delayed pace of sensory information integration. (Tomchek & Dunn, 2007; Robertson & Baron-Cohen, 2017). Research suggests that sensory sensitivities can have a

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significant impact on the lives of autistic individuals (Grandin, 2015). Billie, Alex, Molly and Scarlett all described sensory needs and behaviours. It's critical to assist autistic girls in being conscious of their sensory difficulties and of their own emotions. By supporting the YP to do this will increase their self-awareness, which will improve their ability to understand others (Smith, 2019). This increased self-awareness I feel should not lie solely with autistic YP. The double empathy problem (Milton, 2012) suggests there also needs to be an increased awareness from other non-autistic people to understand sensory experiences of their own and others to understand each other's behaviours. Schools tend to be created with the sensory needs of neurotypical people in mind (Ashburner et al., 2008). Due to the high sensory demands of school, autistic people may feel "out of place' in mainstream spaces" (Davidson, 2010, p. 306; Donnellan et al., 2013).

# Self as unique

Within Erikson's (1968) theory of psychosocial development, it is during adolescence that a YP makes choices which will form a stable internalisation of self. The YP narratives described differences, qualities that made them unique. Scarlett argued that everyone is unique with the variety preventing boredom as we should all have different likes. Sadie tended to use the word 'weird' when talking about difference but at times she would caveat that this weirdness was a good thing. Rissa and Billie's narratives both described a desire to be a unique individual but shared frustration that others wanted to conform. As discussed in the literature review, adolescents are faced with the task of self-definition (Kroger, 1996). The YP's narratives described the need for autonomy to dress how they like or pursue their interests but were conflicted with their desire for approval. Deci and Ryan's (2000) Self Determination Theory (SDT) argue that when autonomy is not met, maladjustment and psychopathology have been linked in both adolescents and adults.

#### **Autistic Self**

From listening to the narratives of the YP I reflected on their constructs of being autistic, this was one aspect of their story and not the defining or only one. Initially I had deliberated over whether to include questions regarding autism as I didn't want to lead the participants. Following the pilot study, I felt there was a desire to talk about the diagnosis, perhaps they expected it to be discussed following the recruitment procedures and information sheets that were shared. On reflection I wondered if some of the YP would have talked about being autistic had I not asked the guestions. When asked about what it means to be autistic, for some of the YP their constructs of who they are varied. I wondered if this was due to their understanding of autism and the discourses significant others held. For some of the YP their constructs of autism was that it is a core part of their self, referring to it as part of their identity. These findings are similar to other research which has involved autistic adolescents (Humphrey & Lewis, 2008; King et al, 2019; Cresswell & Cage, 2019). Currently to be given the label of autistic you have to go through a process which leads to a medical diagnosis, this runs the risk of a person being reduced down to a label (Hodge et al., 2019). Billie describes how her autism cannot be separated from who she is and Rissa refers to her "personalities of autism." There is a growing push for autism to be seen as an identity, much like other communities e.g., LGBTQ+.

I would argue that it is important to critically reflect on the value and function of a label. Some of the YP were facing the challenge of making sense of their diagnosis of autism and

navigating their own identity (Huws & Jones, 2008). Sadie described crying and thinking about her diagnosis on a daily basis. Mia was conflicted in accepting or rejecting the label. Scarlett's reaction to being given the diagnosis of autism at the hospital, fearing she may die or infect others, illustrates that the communication of the label is an important consideration as well as the understanding of it.

There is a danger that when a YP has a label like autism, teachers attribute a lack of academic progress to this. UNESCO (2001) stated that labels can undermine the goal of inclusion by framing the issue of learning as one that exists "inside the child" and therefore avoiding scrutiny of pedagogy. Scarlett described her frustration in the support that she receives. Adults tend to complete work for her rather than teach her the necessary skills to work independently. Scarlett recognised that this approach would not equip her with the necessary skills to make progress independently.

Current thinking is that autism should be viewed as part of a social identity approach (Dirth & Branscombe, 2018). There was some tension between the YP's own views of autism and society's which meant that regardless of any positive identity they held, there is still a degree of internalisation of the stigma they experience. Molly described her peers talking about autistic people biting chunks out of the school tables. For some the label of autism helped to make sense of the differences they have experienced in social relationships and sensory experiences. Rissa refers to her diagnosis as her superpower but feels frustrated that it doesn't automatically guarantee acceptance or support. Evidence suggests that there is a positive correlation between having a stronger autistic social identity and better mental health and well-being (Cooper et al., 2022). This suggests that having a good understanding

of one's autistic identity can help to reduce social anxiety, something which is common in autistic adolescents. For others like Billie and Molly the diagnosis of autism was value neutral, it is simply a category. For both girls they had a clear understanding of their strengths and talents. They described their autism as a difference which was part of them, it didn't define them.

## Strengths and interests.

The collages aided in understanding each YP's perceptions about their areas of expertise and passion. All eight of the young people discussed their talents, which provided insight into their positive self-concepts. Alex saw herself as sporty, kind and good at drawing. Sarah felt her strengths were in English, drawing as well as cooking. Rissa sees herself as funny and good at drawing. Billie recognises she has a talent for playing instruments and learning languages. Sadie describes herself funny and also can play an instrument. Scarlett sees herself as confident and good at computers. Molly feels she is good at drawing and creating videos. Mia has an eye for detail within the natural environment and is good at taking photographs.

Each YP listed the qualities they believed to be positive in themselves, such as kindness, the ability to make others laugh, and a strong moral compass. Being distinctive and having the courage to be different were also cited by Rissa, Billie, and Scarlett as favourable qualities. These qualities were found as contributing to higher levels of life satisfaction (Nocon, Roestorf & Mendez, 2022). Monotropism theory (Murray, 1992), describes the difference in learning styles as autistic minds preferring depth and non-autistic minds being more responsive to breadth. It was interesting to note that after completing their options, resulting in more time in the school day for their preferred subjects, the Year 10 YP showed greater satisfaction with

their school experience. Sadie described positive feelings when she now looks at her timetable as she has lessons she enjoys. Sarah spoke positively of her academic achievement following her options as she excelled in graphics. Choosing subjects has capitalised on strengths and increased motivation (Lanou, Hough & Powell, 2012).

The YP all described types of creativity when talking about themselves. According to Baron-Cohen et al. (2009), three skills common to autistic individuals are sensory hypersensitivity, attention to detail, and a propensity for marked systematisation of the world. The central hypothesis is that autistic individuals can gain exceptional attention to detail due to their sensory hypersensitivity. All eight YP talked about their enjoyment of and interest in music, how they used it to help them relax or motivate them. Music can have a positive impact on reducing psychological stress (Knight & Rickard, 2001; Thoma, 2013). The YP all talked about how they prefer to work whilst listening to music to aid concentration (Kranowitz, 2016). Music features in the YP's constructions of self and is part of their identity. Billie and Rissa both choose emo fashion which can be described as representing their choice of music genre. Alex followed a musician which she felt she could relate to their life experiences. (Butler, 1990; Werner, 2009). Scarlett talked about liking music that trended on TikTok which meant she had similar interests to her peer group (Petersen, 2007).

### Social self

All eight narratives shared the common theme of connections which are crucial to their sense of self and identity (Brown et al, 1998). The majority of participants portrayed themselves as different from their neurotypical peer groups, expressing a sense of not fitting in. With the establishment of social roles, adolescents start to build a sense of self and an

identity (Erikson, 1968). This develops within a changing social environment, determining who and what is acceptable and whether they will have a sense of belonging or alienation (Allen, 2020). An individual's concept of self is formed from both the social and environmental circumstances (Allen et al, 2021). The results supported similar research suggesting that the YP's perceptions of themselves, changes depending on the situation and the people they are with (Burke & Stets, 2009). Within the YP's interviews there was a self-othering narrative that emerged. Although talk did not directly refer to what it means to be 'normal,' there was a focus on what it means to be not 'normal'. Billie used the term 'freak' whereas Rissa and Sadie used 'weird' to express this.

### Friendships

Friendships are an essential component of a YP's growth and can contribute to a happier and more fulfilling existence (Antonucci and Akiyama, 1987). There was a clear yearning for, and value placed on friends throughout all eight narratives. According to the social identity theory (Tajfel & Turner, 1979), people seek out social groups by navigating their social identities. Inside a group, a person will identify with its members and assess how valuable they are as a result of membership (Rubin & Hewstone, 1998). Rissa, Sadie, Billie, Lily and Mia described the confidence they had when with their friends. Rissa's view of herself in Dungeons and Dragons is that she is confident and able to take risks. This is in contrast to the quiet person she described herself to be in school, where she feels she needs support. Friendship-building and confidence-building are all benefits of cosplay and role-playing games which some of the YP like to engage in (Petrovic, 2019). Molly described how she has a community of friends who are animators and Scarlett's friendships share an interest in Roblox and gaming. Reflecting on the literature, I wondered if this is because autistic YP may feel

powerless and seek out like-minded minority groups to identify with. Emo culture, Cosplay and gaming fandom offers a more approachable and accepting group for those who feel cut off from mainstream culture (Jenkins, 2006). The YP may find a space on digital platforms to communicate and express themselves in ways they may not have had before. Rissa, Billie and Scarlett felt at ease with peers that they felt were like-minded. Having the opportunity to be with others who had similar perspectives and lived experiences was seen as beneficial for these YP (Slavich & Cole, 2013).

Recent research indicates a link between mental health needs and social contact (Schitz et al., 2021). Research has suggested that there is a possible overlap with autism traits and social anxiety which can cause negative self-belief, high expectations and catastrophizing of potential failure (Clarke & Wells, 1995). Rissa described the need to be with her friends in order for her to feel confident to go to a park or a shop, without them she is unable to do these things. There is an increased risk of peer victimisation for autistic YP which can increase their vulnerability to social anxiety (Weiss & Fardella, 2018). Interventions for social anxiety tend to focus on a person's negative self-belief. Sarah expressed feelings of loneliness and sadness since moving to her new school where she has found it difficult to make friends. Some of the reasons for this she had internalised, rationalising that other overweight people had friends so she should be able to.

## Masking and stigma.

The YP shared experiences of school that at times challenged how they see themselves, in comparison to who they are at home or within other contexts where they have positive social relationships. Alex described her experiences of being bullied because of her emotional responses towards negative interactions with her peers. Autistic people can experience discrimination (Botha & Frost, 2020) which can challenge self-esteem and emotional wellbeing of autistic YP and increase the risk of mental health difficulties (Lai et al, 2019). Rissa describes the stereotypical view that her teachers had about autism which meant she wasn't believed. Scarlett described the cruel treatment her autistic friend received for being different by his peers. According to Goffman (1990), Western cultures require a great amount of physical control, loss of control is therefore stigmatising, and dealing with it requires particular abilities such as masking. As YP cannot leave this social identity as autism is a lifelong neurodevelopmental difference, autistic YP try to hide their traits so that they can be seen as non-autistic (Pearson & Rose, 2021).

Billie described a need to remain in the background whilst also expressing a positivity about being autistic and a desire to be herself. Research has found similar inconsistencies between promoting the autistic identity of the girls and the desire to blend in. (Halsall, Clarke & Crane, 2021). Rissa described how she perceives the 'popular' peers as having an easier time with no stress, as they like what everybody else does and therefore fit in. Research suggests that some autistic girls look to the classmate who appears to be doing everything right and having no stress, in order to survive they copy the peer as an attempt to fit in (Gould & Ashton-Smith, 2011). However, not all participants shared that they masked. Despite her mum telling her that she did, Scarlett felt she does not feel the pressure to fit in with society's expectations of her. There were some inconsistencies in this narrative however as she described the need to be confident in 'playing a role'. Although it has been a prominent trait in the conversation about autistic women, it cannot be assumed that all autistic women will conceal (Hull et al., 2020; Milner et al., 2019).

Billie, Rissa, and Molly have an understanding of autism and the difference in presentation of females (Bargiela et al., 2016; Cook et al., 2018; Mandy et al., 2012; Moyse & Porter, 2015). Rissa described how she is seen as *"quiet"*, as opposed to the boys who "*act out*," therefore the school does not take her seriously or offer support. Sadie's teacher believed that she was not trying in class therefore she did not get the help she needed.

## Body image and appearance

For some of the YP, comparisons were made of their appearance against their peers. Similar to other research some of the YP expressed dissatisfaction about their own bodies further othering themselves (Krumm, Ferraro & Ingvalson, 2017). Alex expressed a desire to look like the girls she classed as pretty. Both Billie and Rissa's choice of clothing was described as different and provoked negative attention from their peers. Sarah described her battle with an eating disorder and her body image. Research has highlighted the higher prevalence of eating disorders and obesity in autistic adolescents in comparison to their PNT peers (Walters et al, 2010; Fonville et al, 2013). The development of eating disorders has been attributed to the absence of a sense of self, feeling different, and not fitting in (Brede et al., 2020).

## **Mental health**

Out of the eight participants, six discussed their own struggles with mental health issues. According to Zener (2019), adolescent autistic girls appear to be particularly susceptible to mental health issues. The experiences of the current participants corroborate this. Billie spoke about her anxiety and suicide ideation. Rissa talked about her desire to not be anxious when having to do independent tasks. Mia described her difficulties with anxiety, self-harm and a frustration in not receiving the right help. Alex and Sarah talked about their difficulties with sad phases. It is important to note that autism is not a mental health condition, however there is evidence that people with autism frequently experience anxiety and the challenges that go along with it. Furthermore, as Mia mentioned, overwhelming anxiety and self-harm can develop into a personal identity. However, it can be more challenging to investigate this if an alternative explanation for the behaviour becomes available, such as autism (Molloy & Vasil, 2004).

Feeling different from peers and having people misunderstand featured in all eight narratives. As all participants stated at various points in their narratives, feeling different and misunderstood can cause isolation, which might limit possibilities for identity exploration or lower motivation and confidence to do so (Mogensen & Mason, 2015). This is demonstrated by Sarah's experience in secondary school as previously discussed.

### **Self-actualisation**

Within the narratives the YP discussed their aspirations and goals for the future. For some YP (Mia, Billie, Molly, Scarlett, Sarah and Alex) had aspirations of a future career which centred around an interest or their own experiences. Mia shared her aspirations to work within mental health as she felt she could offer support based on her own experiences. For Rissa her goals were more around a desire to be independent and less reliant on her friends. Similar research has suggested that the stages of developing a vocational self-identity, beginning with 'who they are and who they like to become,' are strongly linked to the employment aspirations and alternatives of young people with disabilities. This is accomplished by providing support to assimilate a wide range of experiences and possibilities for self-discovery to a developing sense of self (Lindstrom et al, 2012).

### **Research Question 2**

Are there environments and relationships that help autistic adolescents develop a positive sense of self?

Luke Beardon (2020) argues for the consideration of the equation.

# Autism + Environment = Outcome.

When talking about environment Beardon includes relationships, language, and a positive sense of self. Within the narratives the YP described different relationships and environments that contributed to their sense of self which I will reflect on in this section.

## **Mothers**

The mothers of the participants played a beneficial role in their identity formation and their well-being (Marcia, 1966). Alex, Mia, and Sarah all reported to be their happiest and most like their 'true selves' when they were with their mothers, suggesting that the home environment has a substantial impact on the girls (Bronfenbrenner & Morris, 2006). Sadie talked about her mum being pivotal in advocating for her with her teachers. Mothers strive to build and maintain positive identities for their children through their mediation, which involves interpreting and reinterpreting their children's behaviour to alter how outsiders see them and respond (Rocque, 2010). It is not that mothers of autistic young people (YP) behave as proxies for themselves; rather, they recognise that because the public does not fully understand autism, it is difficult for them to grasp how their children might express themselves. Rissa, Scarlett and Lily all shared how their parents, particularly their mothers, empower them through positive neurodiverse messages which support findings from other research (Cascio, 2012).

# Friendships

Participants spoke of influential friendships outside the family, which is consistent with previous research. (Feist, 2013; Gaffney, 2017; Logsden, 2010). Rissa described the confidence her dungeons group gave her. Sadie described the happiness she experiences when she is with her friends. In order for the person to form a healthy self-concept and identity, it is crucial for both family and friends to be encouraging and accepting of them. One unexpected finding from the research was how much the YP responded to and enjoyed working as part of a group. Sadie reflected on this, sharing how she felt she had a shared understanding with the group and was not at risk of being judged. Within the population, there is a growing sense of belonging for autistic individual, and the concept of an autistic "tribe" is being discussed more frequently (Beardon, 2022). Although not all YP will desire or need to feel like they belong to a tribe, it is something that might be encouraged to provide the YP the sense of belonging they might otherwise lack. To feel like one belongs in a meaningful way can be a pleasant component of childhood and beyond (Ryan & Deci, 2000).

Double empathy describes the attempts made to communicate meaning between people with different dispositional outlooks and personal conceptual understandings (Garfinkel 1967). Milton (2012) coined this phrase to express how it might be challenging for autistic and non-autistic people to grasp each other's communication or viewpoints. The YP's experience of the research, supports the evidence that shows autistic young people feel more connected when they interact with other autistic young people (Crompton et al., 2020; Milton & Sims, 2016).

### **Teachers**

When talking about their experiences of school, the YP shared the varying descriptions their teachers would use about them. The YP was more positive about the teacher's opinion of them if they liked the teacher's pedagogy or the subject. Some of the girls (Billie, Sadie, Mia, Scarlett) talked about the teacher's presentation style or that the adult was attuned to their needs. Sadie described how one teacher understood that she needed subtlety and would check in with her discreetly to prevent attention being drawn to her. Jarman and Rayner's (2015) findings, that teachers should take a personal approach, be flexible, and make their students feel liked, was supported by Sadie and Billie's descriptions of their teachers. However, there were situations within the girl's narratives when staff members lack the expertise or awareness necessary to adequately support autistic girls (Jarman & Rayner, 2015). There was some frustration about not being believed due to a lack of understanding of how autism may present in girls, this is similar to other research (Gaffney, 2017; Jarman & Rayner, 2015).

### Animals

Several YP stories emphasised the value of the animals in their lives. This theme lends credence to a growing body of research that lists a number of advantages to interacting with animals. Alex and Sarah talked about how their dogs help them unwind. According to research, pets can help people feel less anxious (Wright et al., 2015). Animals can also provide further support through sensory stimulation and calming effects (Grandin, 2011). Mia found the sensory experience of stroking her dog helped when she was talking about difficult emotions. There is a strong argument for the therapeutic effect of horses for persons battling with mental health challenges (Grandin, 2011; Folse et al., 1996). Billie talks about her horse

and how it helps her with her mental health, giving her a purpose. Zenenga et al. (2023) discovered that connecting with animals improved autistic YP's motivation, empathy, and overall well-being. Animals as a source of motivation featured in some of the YP's narratives. Billie talked about how she dedicates her own time to working at the stables. She engages in research to help her understand how best to help her horse. Molly's animation and interests were also inspired by her own pets.

#### Language

Once a young person is given the label of autism, their story becomes one of being 'broken' or disordered (Nadesan, 2005,141; Frank, 2010. Within the YP narratives there was a combination of language used. Billie and Rissa tended to use identity-first language including phrases such as 'superpower'. Sadie, Sarah and Mia used person-first language. Sadie used functioning labels, rationalising that she was ok as she only scored a 1 in the diagnosis process. During our group work, Rissa described a letter she had received from the hospital that referred to her as 'suffering from autism'. Billington (2006) encourages professionals to consider how they speak of and write of YP. I believe we underestimate the unconscious effects that language can have on an individual. The most recent Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; American Psychiatric Association, 2013) conceptualization of autism as an illness, emphasises that symptoms cause functional impairment and have an impact on a person's quality of life; as a result, symptoms should be eradicated to improve quality of life (Baker, 2011; Kapp et al., 2013). Using terms such as condition and disorder implies something needs fixing or that there is an illness that requires treatment. All of the YP within the research had a sense of who they are and what they like, each of their narratives was fascinating and they were willing to share this. When reflecting

on the YP's narratives, there was little sense in the YP's accounts of disordered selfhood. This supports the argument that language used to describe autism should not rely on functioning labels or descriptions of severity. By accepting autism as an identity, it does not mean you disregard the challenges that the YP face. A consistent identity first language can support the YP in creating a positive construct of self and having a sense of satisfaction and pride. I would argue that some of the challenges the YP face can be addressed through the environment and the people within it, rather than explaining it as a deficit where the problem is solely routed within the individual.

### In summary

The literature review identified that future research, according to Corden, Brewer, and Cage (2021), concentrate on figuring out how to help autistic people establish a positive sense of self. It is important to recognise the discrepancies between subject and identity positions through time and between situations, as well as the difficulties in integrating them. McLean (2008) highlights the discomfort from challenges to a YP constructs of self, such as those experienced by the YP in this study (Besley, 2001). Yet, if YP are helped to absorb abstract ideas, reflect on their experiences, and make sense of obstacles, challenges to identity positioning can give possibilities for growth (McAdams & McLean, 2013). The ideas of "power" and "threat" intertwine with each of the subjects covered above. Through societal discourses of "normality" that prioritise and value certain physical attributes, behavioural traits, and abilities or skills over all others, the participants' interpersonal relationships and the environments in which they were situated appear to have reinforced the subliminal operation of power. These results corroborate other studies that contend that an autistic adolescent's sense of self is influenced by their diagnosis, trusted relationships, peer interactions, and the

educational environment. (Williams, Gleesen, and Jones, 2019; Habermas & Bluck, 2000). Furthermore, the research highlighted the important roles families have in developing positive constructs of self (Mikami et al.,2019). Having a good understanding of their strengths and time to engage in their interests supports the positive self-constructs as the YP can succeed in activities they are confident in and find both enjoyable and relaxing. Historically, professionals have constructed mothers as either not able to cope, difficult or deluded about their child's needs (Darling, 1979; Taylor, Bogdan & Lutifiyya, 1995). The role of the activist mother is usually underappreciated, yet mothers can fight to influence change on behalf of their children (Ryan & Runswick-Cole, 2007). The research findings highlighted the significant roles mothers play for the YP in their identity formation and advocating for them.

# Implications

In this part of the discussion, I will consider the implications for schools, EP practice and potential applications of collage inquiry.

# Implications for Educational Psychologists and schools.

The narratives of the YP emphasised the need for schools to encourage peers to understand and accept autistic peers (Bond & Hebron, 2019; Humphrey & Symes, 2010; Morewood et al., 2019). Their stories highlight a need for promoting an inclusive culture within the school that values diversity (Farrell, 2004). EPs and school can work together to encourage this inclusive culture based on the context of the school. Tomlinson, Bond and Hebron's (2022) research findings made clear the significance of an inclusive school culture, staff awareness, and individualised planning; these elements have been emphasised in literature on general autism education and in respect to autistic girls in particular. To further synthesise the research findings to consider how best to support autistic adolescent girls, I reflected on Bronfenbrenner's bio-ecological system model, adapted by Allen et al (2016) to consider how schools can create an inclusive culture and support their development of a positive sense of self.



# Figure 11: Bio-ecological system model and a sense of belonging at school (Allen, 2016).

I believed that this approach was a suitable fit for this research in considering ways in which to support YP and educational experiences of autistic adolescent girls based on the stories the YP had told. Each of the four levels will be considered in relation to my findings.

## Individual

At this level Bronfenbrenner considers the personal characteristics that become a stimulus to another person e.g., age, gender, skin colour which can influence interactions due to expectations people hold. As discussed previously sociocultural expectations can affect how girls are expected to behave (Kreiser & White, 2014). As Scarlett said, "we are all different but there's something kind of fantastic about that." The term 'autism' does not provide conclusive information about the person, without knowing the individual's unique abilities and requirements. The EP role could be to encourage those working with YP to consider how each person will have a different perspective and experience of the world, and autism may indicate a difference in how they think and perceive it (McCann, 2019; Eaton, 2019). EPs can challenge any potential low expectations others may hold of autistic YP due to the label (Gillman et al, 2000). As was already stated, it is critical to start with the individual in order to provide the best assistance for YP. This seems to be especially crucial when working with autistic adolescent girls who frequently get missed or a misunderstood due to the stereotypical view of autism. The participant's stories in this study illustrate the uniqueness of their individual experiences and point out the significance of engaging with YP first to get their perspectives.

# Use of Language.

We might begin by revisiting the performative function of language as discussed previously to determine how Educational Psychologists (EPs) might strive to use some of the insights offered by the research findings (Burr, 2003). As employees of Local Authorities, EPs are occasionally suggested to be involved in the "regulation and control" of various segments of education as a result of the statutory duties (Billington et al., 2000, p.60). EPs can consider the language they use and challenge the deficit constructs, encouraging the recognition of strengths and celebrating differences. There is a risk that excluding "problem talk" from discussions of autistic YP could potentially lead to a situation in which EHCNA panels fail to recognise the support requirements that autistic young people have, preventing them from receiving necessary services. Training on how language shapes YP's identities and how this affects their practice should be provided to both LA employees and school staff.

Individually, the YP wanted support in order to start exploring and comprehending their experiences. The YP all admitted to forgetting things or having weak memories, questioning their own cognition and abilities. As experts in education, EPs could potentially be in an advantageous position to support YP in supporting them to understand their own metacognitive abilities and to direct them to reliable resources and services that can provide assistance and advice in managing their homework, organising themselves and recording information.

Participants' conversations on their own mental health and the value of being understood, believed, and supported are suggested. This idea is consistent with government policy and literature, such as the "Future in Mind" report (Department of Health, 2015), the Mental Health Green Paper (DfE, 2017) and the guidance Promoting and supporting mental health and wellbeing in schools and colleges (DfE, 2021) which suggested placing mental health specialists in each school and introduced discussions about mental health into the classroom. As discussed, systems are complex and multi-layered and whilst this is a positive step it is not the only solution. Mia, Sarah and Billie all mentioned seeking support from professionals with varied degrees of success. The girls described a feeling of not being heard or understood however when it worked well within school it was with the adults that had built a positive relationship, listened and responded in the way the girls wanted to be helped. From my own experience as a TEP I have spoken to SENCOs who explain that resources are limited within school but recognise the importance of relationships. Although the Future in Mind report

offers a strategy, what an ecological approach reinforces that inclusion requires a multilayered approach. This does not mean that for some people who are struggling with mental health difficulties it isn't crucial that they have access to people who are qualified to support their emotional well-being and mental health. I would argue though that this is not the only solution but needs to be part of a systemic approach.

### Microsystem

## **Relationships**

Each participant reflected on relationships in a variety of ways. Relationships with family, friends, peers, and teachers were noted as being particularly supportive as well as challenging for each participant in different ways. Everyone has a need to belong and feel connected to others, and when this need is not met, it may have an impact on a YP's constructs of self and emotional well-being (Ryan and Deci, 2000),

The promotion of positive relationships consequently is helpful for YP in fostering a positive sense of self. This seems to be the case for the participants who each mentioned different people they had a good relationship with, including their mothers, Rissa's dungeon master, Sadie's cousin, and Sarah's teacher. It appears acceptable to propose that educational professionals working with autistic YP, if not all CYP, should make fostering positive interactions a priority. According to Goodall and MacKenzie (2019), trusting relationships are forged with those adults who know the requirements of the girls and that positive interactions with staff were intrinsically related to individual teacher understanding. In their research the school placed a strong emphasis on a student-led approach that aimed to help students

improve their problem-solving abilities. My findings show that each of the three girls came up with their own answers to issues, and the literature (such as Wild 2019) makes obvious the advantages of this self-advocacy strategy. These difficulties underscore the necessity for continued staff education. Hillier, Young, and Weber (2014), emphasise staff education needs to include how autism manifests in females, as well as the modifications that can be done, especially in challenging secondary school settings. I would argue that there may not be a need for specific training if the school takes a person centred and inclusive approach to education.

## Create a Sense of Belonging.

All eight of the YP's narratives made clear how crucial it is to give adolescent autistic girls a sense of belonging. According to research, friendships that are mutually beneficial offer a sense of safety and support, inclusion and encouragement from peers and setting. Uphold ing social norms can all help autistic females feel like they belong (Myles et al., 2019). To have a beneficial effect on their psychological health and identity development, their sense of belonging should be fostered. For the YP in the research this belonging centred around shared interests e.g., sport, art or hobbies.

Many of the YP talked about specific teachers or adults in school who understood them and were supportive. Adults in schools can work with YP to create an empowering story about themselves through exploring subject positions, gaining agency, and finding coherence and meaning in adversity through the development of trusted relationships (Mc Adams & Mc Lean, 2013). Where the YP felt supported, the adult's had taken a personal flexible approach which made pupils feel valued and believed (Jarman and Rayner, 2015). Many schools have buddy schemes in place that might be helpful for autistic students (Laghi et al., 2018). This could be developed further as a mentoring role with autistic peers supporting each other. However, the person must first be recognised as needing support, which might be difficult if the person masks their difficulties. From the YP narratives there was an awareness of people being singled out for being different. Morewood, Humphrey & Symes (2011) focused their research on schools creating an inclusive culture where YP felt included, accepted, and understood through the development of the 'saturation model'. The term "saturation" refers to the core idea that for inclusive concepts and practises to be effective, they must penetrate every part of school life. As a result, for a school to be considered 'autism friendly,' there must be a high level of knowledge and understanding of autism throughout the institution. The concept is thus a whole school ongoing strategy that involves assisting, instructing, and increasing everyone's comprehension within the school community. I wonder if such a model as this would pre-empt the need for masking for these girls.

## Challenge Assumptions.

All working EPs should be reflective practitioners (Quicke, 2000), being aware of the effects of their own presumptions and preconceptions. Careful consideration to their own beliefs and presumptions regarding autistic girls should be given. This study has brought to light how crucial it is for professionals to remain reflective. Using narrative strategies can assist people to express their constructs of self and collage inquiry can offer insightful information.

Effective professional consultation is a suitable method for applying psychology with a variety of consultees and clients in diverse contexts. Kennedy, Cameron & Monsen (2009) argue that EPs can make a distinctive and essential contribution to improving outcomes for

children, young people, and their families (a contribution that is firmly grounded in psychological theory, research, and applied practise). According to Sladeczek et al (2006), the conjoint behavioural consultation method entails working in collaboration with both teachers and parents/carers to address the academic, behavioural, or social challenges of a YP across home and school settings. EP's can encourage education professionals to be curious about how YP present and look to explore this with their parents who have a good understanding of their child

## **Exosystem- Community**

According to students and parents, an inclusive mindset at the school level that encourages full inclusion for students with ASD and is welcoming has been regarded as a crucial component (Tobias 2009; Starr and Foy 2012). An inclusive culture at the school level that promotes full inclusion for all students including those with the label of autism and is welcoming has been recognised as an important component, according to students and parents (Tobias 2009; Starr and Foy 2012). According to Morewood, Humphrey, and Symes (2011), this is supported by positive teaching attitudes, a dedication to inclusion, supportive leadership, and staff training. This supports the findings of this research where the girls shared the positive experiences fo teachers who understood and who adapted their teaching approach to support them (Sadie, Sarah and Molly) and their frustration at the teachers who seemed to lack an understanding or supportive approach (Mia, Sadie, Rissa and Scarlett). Falkmer et al. (2015) study stressed the value of relationship- and trust-building with parents. Sadie and Mia described how her mum had advocated for them in school to help understand what support they needed. Sincere communication serves as a foundation for trust, and many parents value being involved in the decision-making process (Lindsay et al. 2016). As

highlighted within the findings all of the girl's mothers played significant roles in encouraging a positive sense of self.

Since adolescents spend most of their time in school, the school community is still a crucial place to go for support. Since the presence of trustworthy adults in the classroom has been linked to positive outcomes and increased self-esteem for YP, it is crucial that educational professionals develop their own understanding of identity development to ensure they are well-positioned to offer support (Dessel, Kulick, Wernick & Sullivan, 2017; Leonard, 2019). Tomlinson, Bond, & Hebron (2022) found that inclusive school ethos, staff awareness and personalised planning were all facilitators for a positive school experience of three autistic girls. Despite the well-established facts that autistic children struggle socially, emotionally, and behaviorally, it is claimed that these crucial areas are not adequately addressed in support plans (McDonald et al. 2019). In order to acquire social skills, recognise potential friends, start friendships, and keep them going, all three girls expressed a desire for friendship and connection with their classmates (Jamison & Schuttler, 2017; Sedgewick et al, 2015). Additionally, more attention needs to be put on whole-school initiatives to combat stigma, promote equity for neurodiversity, and reduce discrimination (Botha, Dibb & Frost, 2020).

The school's sensory environment may have an effect on participants' experiences. All of the participants mentioned having trouble with their senses. uniforms for students, school toilets, open-plan classrooms, dining areas, etc. Therefore, it is crucial to consider how challenging it would be for autistic YP to feel like they belong in a setting without any autonomy or consideration for their needs.

### Macrosystem

Political ideas like inclusion influence the experiences of parents and pupils at the macrosystem level. Some parents dispute the advantages of mainstream inclusion for children with ASD, despite legislation efforts in many nations to do so (Tissot 2011). It is common to hear discussions about inclusive education as involving attitudes and teaching methods that accommodate the diversity of educational culture, practise, and policy (Ainscow and Booth, 2002). Additionally, according to Humpfrey and Symes (2014), inclusive education necessitates that all members of the staff have a clear and shared understanding of what inclusion entails, together with shared expectations of inclusion that must be supported by the school leadership (Horrocksetal., 2008). The phrase "inclusive education" frequently focuses on children with disabilities.

In their analysis of the behaviours and choices made by educational leaders regarding autistic children, Dotger and Coughlin (2018) identified a pervasive culture and structure that frequently excludes individuals with needs when situations in the classroom become challenging.

According to some studies (Cambron McCabe, 2006; Marshall and Oliva, 2006), developing leaders that support social justice and inclusion is one strategy to enhance inclusive education in schools. Diversity awareness is a related issue at the macrosystem level. Disability legislation has underlined the value of making adjustments to satisfy individual needs in the UK and other nations. This might not, however, be implemented uniformly in all mainstream schools.

Whilst schools continue to operate inside a market economy pressure from the government to perform well in national league tables there will pressure for YP to perform in the curriculum that is set in all subjects at secondary level. To try to address the achievement and performance issues, there has been an increase in medicalising behaviours that deviate from the ever-narrowing norm (Timimi, 2005). The stigma that can them be experienced due to a lack of understanding of the medical labels and prevent a sense of belonging in the school community or create a school ethos of acceptance and tolerance (Bond and Hebron, 2016). For the YP in the research there was an aware ness of the stigma that was attached to the label of autism (Sadie, Molly, Mia). The need to belong also featured in the YP's narratives, there was a recognition that their interests or fashion sense were not deemed to be 'popular' or what their peers would be interested in. This need to conform could be argued as similar to the research previously discussed around the gender expectations a YP may experience in school from their peers and teachers (Butler, 1990, Shehy &Solvason, 2023)

There were many positive experiences described in the YP's narratives. High levels of pastoral care, peaceful safe spaces, animal interaction, interest groups, music and oneon-one therapeutic sessions were all identified as beneficial to the girls. Although the situation is complex and cannot be addressed merely through resources they are all important elements that an EP can help a school explore. I am aware however that this requires additional funds and staffing to give the YP the flexible and tailored approach they require. Increasingly in the UK context in which this research took place, a label is increasingly the only way to get support and better financial resources in the existing system of educational supply (Hodge, 2006).

### **Collaborative Working and Creating Agency.**

As a profession, we are in an excellent position to first hear what YP have to say and to encourage them to express their concerns and strengths in a variety of ways. As stated in Burden (1996), referenced in Harding & Atkinson (2009), p. 126, EPs "*commonly do things to children and for children, yet too infrequently do things with children.*" Our familiarity with a range of consultation and assessment methods enables us to choose the most effective way to encourage young people to participate in our work. In order to hear the child's voice, EPs reportedly use discussion-based techniques, task-related procedures, therapeutic-based approaches, and indirect ways, according to Harding and Atkinson (2009). Incorporating the voice of the young person in planning is emphasised with the SEND Code of Practice (DfE/DoH, 2014). Verhoeven, Poorthuis, and Volman's (2018) review found that studies relating to identity were dispersed across different research fields, making it difficult to put theory into practise, and that strategies and practises used by teachers unintentionally affected adolescents' identity development. These findings have implications for the role of EPs in training schools to support adolescents' identity development.

My research focused on innovative strategies that can also be applied during evaluation to enable YP to express themselves freely. Using collage to focus on strengths and interests helps YP explore who they are which can help to gain a sense of how they see themselves in a non-threatening and accessible way (Leitch, 2009). Sharing this tool with both EP services and schools may help YP get constructive, intentional help to encourage good identity positioning. In order to increase YP's agency regarding how they choose to position themselves within their narrative accounts, EPs can work with schools, parents, and professionals. They can also support YPs in developing preferred narratives through their engagement and interaction in socio-cultural contexts (Freeman, 2014), and they can negotiate power through microlevel discourses to resist dominant stories (Besley, 2001). Honkasilta et al. (2016) suggest inclusive discourse involving YP after an autism diagnosis, promoting YPs' individuality, actively challenging unfairly imposed social norms and expectations, and giving priority to YPs' experiences rather than the diagnostic category. There is a role for EPs and/or schools to investigate the accounts of YP who have received an autism diagnosis. Prosser (2008) encourages building a bank of narrative tools, such as the collage, that can be used to develop and maintain one's own narratives in place of imposed deficit identities.

Narrative approaches can help YP explore their identity and through this process recognise, value, and highlight their strengths, interests, values, joys, and accomplishments. They may also give them a space to make sense of the diagnosis they have been given; choosing which aspects to incorporate/accommodate into their identity and which to reject; and navigating the restrictions of the educational system and the system's resulting tendency to promote an intrapersonal perspective. Given the trend identified by Prentice (2000), according to which YP are more likely to have a negative self-image when surrounded by individuals who have a deficient view of their diagnosis, this is especially noteworthy and valuable.

EPs can through systemic work and consultation encourage schools to work flexibly creating systems that reflect an understanding of the needs of each YP and emphasising that all children should be treated with compassion and inclusion (McDonald and Lopes, 2014). Despite the fact that the girls in this study shared certain common experiences, it is crucial to

remember that they are all unique individuals with unique needs and talents. Morewood et al (2011) describe a whole school saturation approach for effective inclusion of students, schools that have effectively integrated autistic young people underline the necessity for adaptable provision to meet individual needs. O'Hagan et al (2022) further support this arguing that to meet needs and maximise academic ability an individualised curricula was valued. With schools under increasing pressure to perform and cover the statutory curriculum this can be difficult to find a way to achieve.

## **Person-Centered Planning (PCP)**

A method to life planning utilised in education, health, and social services is called personcentered planning (PCP) (Robertson et al.,2007). PCP techniques are based on humanistic and positive psychology theoretical frameworks (White & Rae, 2016). Humanistic psychology emphasises the quality of a person's existence as well as their personal growth and development (Schneider, Pierson & Bugental,2014), while positive psychology emphasises a person's strengths that help them succeed (Seligman & Csikszentmihalyi, 2014). In light of this, PCP seeks to empower people by prioritising their desires and goals during the decisionmaking process. The emphasis in PCP is on the voice of the individual rather than the professional because it is thought that these people's needs and wishes may be overlooked by the system (Holburn,1997). The involvement and utilisation of the individual's families, who play a crucial supportive role by attending and actively participating in PCP meetings, is another characteristic feature of PCP (Mansell & Beadle-Brown,2004).

Considering how we work with YP to gather their views and incorporate this into the work we do is an implication of this research. If they have greater agency, autistic adolescents may potentially be more likely to view their diagnosis as a strength (Mogensen & Mason, 2015). Since viewing diagnoses as a benefit is protective of psychological wellbeing and identity development (Carrington & Graham, 2001; Cooper et al., 2017; Feist, 2013), promoting autistic girls' agency may eventually support the development of their psychological wellbeing and sense of self. Perhaps the EP's role is to encourage YP to explore their identities in ways that honour their unique assets and de-stigmatize their features through enabling discourses which challenges deficit constructs or binary narratives regarding gender . During the statutory process the EP can use the opportunity when gathering the YP's views to highlight their strengths and skills. Using approaches such as Planning Alternative Tomorrows with Hope (PATH, Pearpoint, O'Brien, & Forest, 1993) are person-centred, solution focused tools that can inform outcomes involving the YP in a positive way. Approaches such as this allow for some resistance to medicalised deficit-orientated and reductive assumptions.

This study makes the argument that there is a risk of 'othering' autistic people when they are compared to their non-autistic peers through the formulations EPs make. The label of autism can lead to assumptions regarding social relationships, masking, or the potential for a deficit view of that YP. The YP narratives within the research highlight the importance of relationships and the need to understand autism as a difference rather than a deficit. It highlighted that stigma and other people's perceptions of autism can impact on how they behave and the YP well-being. Instead of focusing on targeting behaviours that are different to the 'norm', EPs might help schools and parents to rethink their expectations and explore why they are focused on certain improvements as the intervention's aim. Any goals for change should be developed collaboratively with autistic YP and should not be limited to the adult's concerns and agenda that about the YP.

The SEND and Disability Code of Practise (Department for Education [DfE], DoH, 2014), which offers statutory guidance for organisations working with YP with SEND, places a significant emphasis on PCP. It reads, for instance, "*Children and young people and their parents or carers will be fully involved in decisions about their support and what they want to achieve*" (DfE, DoH, 2014, p. 11). Assessment and planning are based on the strengths and capabilities of children and young people, according to the 2014 Code of Practise (White & Rae, 2016). PATH entails the construction of a bright future through solution-focused questioning to create a colourful visual depiction of future hopes and visions—or a "graphic"—of those dreams and visions (Bristow, 2013). Six steps make up the conventional PATH method, which works backwards from the young person's future goals towards the present. Then, the YP, family and professionals jointly decide on actions and goals that could assist the YP in achieving their objectives. (Wood et al, 2019) found that YP benefited from increased self-assurance and motivation, improved school support, and a sense of purpose when involved in a PATH.

When reflecting on the recommendations for EPs and what inclusive practice looks like I would argue that the approaches which relies on professionals and leader's skills do not require a specific label. Some teachers argue that labels are a necessary element giving them an understanding of needs and the appropriate strategies (Hodge, 2006). Goodley and Runswick-Cole (2012) argue that labels can be used or refused when they potentially restrict an individual's life opportunities. Teachers can 'file away' a child's label unless it is needed for empowering purposes, this way the only label that is needed is an individual's name. In this way inclusive education would be where education professionals get to know their students

and respond to their own individual ways of learning, socialising, processing emotions and responding to the environment.

# Training

The participants within the research all shared a frustration of not being believed or understood. For the YP in the research who felt that autism was part of their identity they felt it was important that the professionals understand what the label of autism means to them. The white paper titled 'Autism, Girls and Keeping it all inside' (Autistic Girls Network, 2022) is a document which aims to help professionals have an understanding.

I would argue that EP's are well placed to support education professionals to critically reflect on function of the label of autism. Can these girls qualities be regarded as part of the ordinary spectrum of individual difference rather than pathologising what is considered to be different from the "norm"? (Schrag & Divoky, 1981). I would argue there are a number of important factors that EP's can offer training in or support schools in creating an inclusive environment to support the girls in the research as well as all other YP. The National Autistic Society Moonshot Vision (2022) principles for a future reality can be used to help schools meet the needs for all students. The principles include:

- value individuals.
- maximise strengths.
- Guarantee support.
- Reject stereotype and stigma to create a space free from discrimination.

• Design spaces and services that are inclusive with flexible adjustments.

Some of the girls (Mia, Molly, Alex, Sadie and Billie) shared their frustration for receiving sanctions for forgetting homework which left them feeling powerless or being misunderstood in their communication style which led to them receiving a punishment (Mia, Sadie and Scarlett). EPs can encourage the transition from conventional approaches to behaviour management, which heavily emphasise rewards and consequences tied to behaviour, to a more humanist, relational, and universal approach, which is inclusive of all and can be beneficial to the entire school community. This can be done through training on relationship-based policy and practice (Preece and Howley, <u>2018</u>). One approach to this is based on the model of INCLUSIVE, Learning Together (Education Endowment Foundation, May 2023). Training can include whole school restorative practice and resources that uses socioemotional skills curriculum materials. EPs can then facilitate action group meetings each term with a small group of staff and students to discuss action plans for enhancing the school environment and inclusion practises, guided by the findings of needs assessments that students complete.

Many teachers try to be reflective practitioners who can examine their own work, identify issues that arise, relate them to prior knowledge and experience, and work to tailor their actions to the requirements of the students while considering the context's unique characteristics (Schön, 1987). The time and space for teachers to do this has become extremely limited and EPs can help education professional to understand the change process (Collinson & Cook, 2001). According to Verhoeven et al. (2018), schools need to be mindful of their unintentional impact on young people's identity development. As discussed previously EPs can support school through training in developing an individual and whole

school approach to promoting good mental health (Tomlinson, Bond, and Hebron, 2019). Clarke et al (2021) found that systematic Social Emotional Literacy approaches for promoting wellbeing as a whole school approach rather than stand alone interventions.

Training that ensures all education professionals understand the SEN Code of Practice (DfE, 2015), emphasising that all teachers are teacher of SEND and encouraging a flexible approach. Sadie and Sarah both expressed an improvement in their school experiences following their options. Rissa had shared how school have built in rest breaks through the day which helped her feel happier at school. Individualised timetables with provision for academic potential as well as SEN was found to have positive impact on well-being (Kidd and Kaczmarek, 2010). All the girls had interests which they shared made them feel happy, confident or relaxed. Having opportunities to build this into their timetable may reduce the need to take time off school and improve their well-being which can support a positive sense of self as a learner.

## **Positive Narratives**

As discussed, for the YP their diagnosis is part of their constructs of self but does not determine how they see themselves. Each YP recognised their strengths and the relationships that supported a positive sense of self. The dominant narratives around their constructs of self and identity are influenced by the stigma around the label of autism In narrative therapy, a person is supported in examining and revising the stories they tell themselves about the outside world (Epston & White, 1995). With the aim of encouraging social adaptability while addressing particular living issues. Cashin et al (2013) found improved outcomes on a variety of psychological and biological tests following the intervention of narrative therapy in autistic young people.

We often underestimate the extent to which social norms, constructions, and discourses create issues, and as a result, our experiences with mental health. Courtney's (2021) narrative work on 'normality' has helped to shift constructs so that autistic individuals can adapt and internalise positive and empowering narratives about themselves. If the wider community challenged stigma and there was an increased understanding through education and training then could less reductive narratives of autism be fostered.

## **Collaborative Working**

As discussed within the narratives the YP's family is a key support system This is particularly true of their mothers who are key in advocating and supporting their daughters. Historically, parents have been challenged by teachers about their own understanding of their autistic child (Lindsey et al. 2016). I believe the research illustrates how mothers must be given more power and be heard to influence society for autistic girls through their advocacy and parenting experiences. Charities such as the Autistic Girls Network are doing this, empowering the mothers that are involved to advocate for their daughters. Collaborative working with parents and schools. particularly around the differences between home and school is important to provide the right support.

All of the participants made clear the value of receiving the appropriate, personalised support through their narratives. Using person-centred planning, emphasises strengths and interests as well as considering areas of need (O'Brien, 2002; Sanderson, 2000; Bond & Hebron, 2019; Honeybourne, 2016). Other factors that need to be considered include, environmental (Morewood et al., 2019), sensory sensitivities, negative emotions, social

interaction, and educational support. All of these factors featured in the girl's narratives as areas in which they needed support in different ways which were appropriate to them.

This study emphasises the critical function of EPs and school staff. Professionals such as EPs and teachers, provide autistic YP with opportunities to apply and demonstrate their strengths in social contexts where they can be acknowledged, reframed, and positively reinforced. These opportunities can assist YP in developing a position of identity that is valued by the school's cultural system (Crossley, 2000). It appeared crucial for the YP to be able to investigate alternative interests and identity roles. Additionally, as described as essential by Molloy and Vasil (2004), exploring interests and identity roles aids in the development of a sense of self that can build upon abilities outside of their autism diagnosis. This is evident in the YP constructs; Alex as sporty, Billie and Sadie as musically talented, Lily and Scarlett are proficient in computers, Sarah and Rissa as creative and Mia a good photographer.

#### Strengths and Limitations of the Research

### **Participatory Approach**

I am conscious that historically autism research has tended to exclude autistic individuals or dehumanise them (Cowen, 2009). According to Minkler (2004), participatory research should not be considered a research methodology but rather a strategy that exemplifies the researcher's desire to participate in the research process in a collaborative manner. (Minkler & Wallerstein, 2003; Minkler, 2004). I used a methodology that is participatory in nature (Leavy, 2020) as I didn't want my research to be 'done to' the YP but with them. Using the collage visuals helped to lessen some of the potential power imbalances. (Scotti & Chilton,
2018). It is argued that in order for research to be completely participatory, participants have to be involved in the analysis (Freire, 1996). I felt this was a limitation of my research as due to the time constraints, if I had analysed the YP narratives collaboratively with them, I would have given certain voices the attention they deserved. I would have liked to teach the YP how to complete the analysis or complete more member checking at each stage of my analysis. I shared the I poems with the YP in an attempt to gather their views, encourage reflection and ensure it is an accurate reflection of the YP. Each YP highlighted the poem to say which parts they felt were most relevant and what they would like to be removed. During the session we engaged in a discussion about what they had taken from the research and their responses to how the I poem represented them. In the session they designed their graphics for the animation that would be included along with their 'I poems'. I hope that my research has provided a platform for the YP's stories and enabled them through pockets of participation.

#### **Visual Methodologies and Collage**

The collage method had benefits in that it produced enough data, promoted verbal dialogue, prompted memories, emotions, and ideas. The collage inquiry was an effective tool for participants to share their narratives and encouraged them to think carefully about their experiences. There were some limitations as some of the YP did not come prepared with pictures as requested. I had prepared folders with clippings however it meant they had to use what was available rather than images they may have chosen themselves. If the research was to be repeated, I would allocate more time for the collage making session where the YP can plan and work on their pieces for longer.

## Reflexivity

According to Gadamer (1989, cited in Boréus & Bergström, 2017), every reader approaches a work with their own prejudice. It is crucial to acknowledge how, as a researcher. I have brought a variety of life experiences, personal constructions, attitudes, and social circumstances to this research as the researcher. I am unable to make the kind of objective claim that an empiricist would expect to make; rather, in understanding what the YP in my research have said, I have drawn on my own subjective experience and prejudices.

As a mother of an autistic adolescent girl, it is not a realistic position to think that by researching this topic, I could somehow separate myself from the experience of being a mother. Katherine Runswick-Cole (2016) describes the difficult decisions I have experienced as a TEP and researcher, in deciding how much I disclose about being a mother of an autistic YP. This "mother-researcher" dilemma (P.20, Runswick-Cole et al., 2016) explains the concerns that work will be "dismissed as biased and partisan" because it won't be "taken seriously in (typically male-dominated) academia or even in the context of qualitative research that pays attention to the 'positionality' of the researcher."

I approached the task of presenting my findings with a similar trepidation as a mother researcher. I am aware that this work does not reach objectivity. I would also contend that this does not render my conclusions and suggestions invalid. Instead, the reader should be aware of an additional layer brought by the involved hermeneutics. Being the mother of an autistic YP, I believed it was crucial to assume a level of reflexivity, which has been supported by a social constructionist perspective. I may be able to relate to some of the themes found in my research as a mother-researcher (Runswick-Cole et al., 2016). I may have employed them myself or observed them in my child's self-constructs. Yet, I'm not acting alone in this

effort. As a reflective practitioner, I have seen first-hand how language is used to "do something" other than simply communicate ideas.

The idea of generalisability is another potential limitation in my thesis. In keeping with my critical realism positionality, I tried to emphasise the uniqueness of the participants' experiences while acknowledging the ways in which each person's particular social and cultural background shaped and influenced them. Although it would be inappropriate to generalise the conclusions beyond the extremely narrow scope of my study, I tried to give readers enough information to allow them to assess whether any findings were applicable to or relevant to their own lives.

# **Recommendations for future research.**

The YP within my research were all white British and from middle class backgrounds. I am acutely aware that other ethnic minorities are excluded out of the mainstream cultural and scientific discourse around autism (Lovelace et al, 2021; Diemer et al., 2022). Future studies, in my opinion, should try to build on my findings by widening the participant criteria e.g., ethnic minorities, lower socioeconomic backgrounds. Research suggests that gender dysphoria is more prevalent in autistic people than in non-autistic people (Glidden et al., 2016). I would recommend exploring how gender and constructs of self-interact in future research.

During the last meeting when reviewing the I Poems, the YP commented how much they had changed from when the interviews took place five months earlier. This was not the aim of the research activity but I felt it was interesting that the YP perceived their own

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constructs to have evolved over the short period of time that the research had taken place. A future research recommendation would be to work with the same YP over a school year to explore how their constructs evolve. In order to further empower those who participate, I further suggest that researchers adopt participatory methodologies.

## Dissemination

The research will be disseminated using a number of platforms. The participating schools have expressed an interest in having a whole staff presentation of the research. I will be presenting my research at the regional EP conference in December. It is my aim to actively look for other opportunities to share this research.

## **Concluding Thoughts**

No generalisations regarding the self-constructs of all autistic adolescent girls are made in this study. Themes didn't just appear; rather, they were built over the course of the research and personal journey, based on what eight autistic adolescent females shared in their collages and interviews. However, the research has made it possible to explore how autistic adolescent females can employ particular narratives to construct their social identities and sense of who they are, as well as to consider some potential negative effects of such constructs. Meeting the girls as part of the research fuelled my drive for a social justice approach which understands disabilities as both relationally and socially created. I hope that this discussion will help to challenge the deficit focus of autism which sees people as disordered. Meeting the participants and hearing each of these girl's stories reinforced the need to rewrite the narrative of what it means to be autistic and how this looks within inclusive education practice. Some of the implications for EPs that result from the research, as well as potential future research, have been considered. Professionals interested in working with and supporting autistic persons are intended to obtain a better understanding of the constructs of self and social identity (Burr, 2003). An emphasis on this, along with reflexive and caring practice, may increase the likelihood that autistic persons may feel safe to express themselves in an authentic way.

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https://autisticgirlsnetwork.org/

## **Appendices**

## **Appendix 1: Personal Reflection**

This research could be described as a labour of love as it came from a drive to make a difference based on my own personal connection to autism. I could say this journey began from the day my daughter received her diagnosis however I do feel I have gone through a journey of self-discovery when I started the doctorate. As a parent I have felt for a long time that I have been fighting for my daughter; fighting the medical professionals, the education system, the local authority and fighting those who do not understand. I have been referred to as the 'warrior mother' which was something that I took personally as I was just trying to make sure my daughter had the same chances as everybody else. One of the biggest battles has been for her diagnosis, being on the pathway from the age of 4 and receiving the diagnosis at 8. I felt quite protective of this label as after it all it meant that I was believed that my daughter was believed and what I naively thought meant that she will get the help and understanding that she needs. I also thought it would help my daughter to understand why she experienced difficulties compared to her peers. As I have progressed through the doctorate and completed the research, I feel it has made me evaluate some of these views.

When reflecting on my recommendations, I have reflected on what inclusion is. I think the most important point would be that practice, adjustments etc... has to be meaningful for the person so that they can have the best quality of life. Does this mean that the person needs to be labelled autistic to do this? Although as described I have been previously protective of this label, I am now not sure it does. For the YP I worked with in this research the main things was they needed to be understood or believed. If they find a corridor too

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busy, a smell too strong or need time to process information before they are required to offer an answer surely this requires someone to be empathic and understanding and not a diagnosis? Each person talked about the value of trusted adults who 'got them' and made adjustments that were small in nature but made a significant impact. When the girls do not perform as well with the expectations such as homework, they internalise this as something wrong with them. If a flexible, child centred approach was taken does this then mean we look at that individual and not just the label.

Each of the girls could identify their strengths and talked about interests that they gained pleasure from engaging in. As a parent I have spent a lot of time exploring different clubs and activities with my daughter to help her find 'her tribe' or something she both enjoys and does well in. Once she found this, I was able to observe a relaxed, happy and confident girl for three hours a week. I hope that this can be the 'norm' in the future where she feels happy and relaxed.

If there was a better understanding of autism, sensory needs and how best to communicate with or interpret the young people's communication then would the y internalise these difficulties as much? I have thought about this when I complete a statutory advice as I find myself battling with this question constantly. It has created some debate about who am I writing the advice for and for what purpose. I consider what the young person wants and needs to survive in the current education system. I also question some of the outcomes that school suggest in who does it benefit? I wonder if there were more opportunities for autistic individuals to be heard within research and policy making can this change. I would like to think so.

I think I was expecting in the findings to discover that autism would dominate the constructs of the participants identity, a bias I am now aware of and have since reflected on. For the young people their interests, pets, family and relationships were all important. School experiences varied depending on pedagogy and how they viewed the teacher and subject. For those who had a good understanding of autism, their family reinforced the message that it is a difference and not something wrong with them, there was an acceptance of the label. I wonder how much time is given to help these young people understand what autism is and how much this relies on parents having the understanding themselves? I was fortunate that I had a level of education and access to professionals in my job that facilitated me in understanding, this privileged position is not the same for everybody. Within my consultations with schools, I have encouraged schools to consider what it is they are wanting for the young person and why? I have encouraged them to engage the young people in consultations so that they can have a say and decide what they feel they need help with. I challenge the use of social skills interventions that teach what can be described a neurotypical skills e.g., holding eye contact when someone talks to them.

Lastly, I have reflected on the role of mothers as I think this is a finding I underestimated. Perhaps this is because of my own bias as you underestimate what you do as a mum at times or it just becomes expected as a mum's role. For the young people I worked with in the research, they all describe how comfortable and safe they felt with their mothers. Their mothers were their advocates who helped them navigate the social world and gave them unconditional positive regard. I hope that from my research I can emphasise the valuable role they play and how important it is for schools to work collaboratively with family to

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better understand the young person. In the future it would be interesting to replicate this research but include mothers to understand their constructs of self or using collage to understand how they see their daughter.

I hope that there can be an increased understanding of autism which is informed by autistic people that challenges stigma and discrimination. If this results in the young people feeling safe and accepted then there is reduced chance of them internalising some of the difficulties which are actually down to environment. If we can empower these young people to understand this then they can have a positive sense of self.

## Appendix 2: Literature Overview

Journal Title	Method	Participants	Critical Reflections
Macleod, A., Lewis, A., & Robertson, C. (2013). "Why	Interpretative	six higher	The results of this small-
should I be like bloody Rain Man?!" Navigating the	Phenomenological	education	scale qualitative study,
autistic identity. British Journal of Special Education,	Analysis (IPA)	students	which examined the
40(1), 41–49. https://doi.org/10.1111/1467-			perspectives of a self-
8578.12015	Flexible, in-depth		selected sample, cannot be
	individual		generalised. Students at a
	interviews		higher education institution
			in the UK made up the
			study's participants. It's
			possible that some or all of
			them came from privileged
			upbringings.
Corden, K., Brewer, R., & Cage, E. (2021). Personal	mixed method	Participants	The correlational nature of
identity after an autism diagnosis: Relationships with	research	were aged	the quantitative data limits
self-esteem, mental wellbeing and diagnostic		between 18-65	the capacity to understand
timing.	"Qualtrics", an	years	other factors such as
	online survey		environment and
	platform		relationships. I would
			question the
			generalisability of the

Williams, E., Gleson, K., & Jones, B.E. (2019). How pupils on the autism spectrum make sense of themselves in the context of their seperiences in a mainstream school setting: A qualitative attism, 23, 8–28metasynthesis of qualitative researchCompared to what is attainable from a single qualitative investigation, the metasynthesis makes claims to knowledge that are more trustworthy and potentially transferable. The findings, however, cannot be applied to different demographics, cultures, and educational contexts, emphasising gaps in the knowledge, as they are based on publications that mostly represent			research as the participant
Williams, E., Gleeson, K., & Jones, B.E. (2019). How pupils on the autism spectrum make sense of themselves in the context of Autism, 23, 8–28metasynthesis of qualitative researchCompared to what is attainable from a single qualitative investigation, the metasynthesis makes claims to knowledge that are more trustworthy and potentially transferable.The findings, however, cannot be applied to different demographics, cultures, and educational contexts, emphasising gaps in the knowledge, as they are based on publications that mostly represent			sample only represented a
Williams, E., Glesson, K., & Jones, B.E. (2019). How pupils on the autism spectrum make sense of themselves in the context of her experiences in a mainstream school setting: A qualitative netasynthesis. Autism, 23, 8–28metasynthesis of qualitative researchCompared to what is attainable from a single qualitative investigation, the metasynthesis makes claims to knowledge that are more trustworthy and potentially transferable. The findings, however, cannot be applied to different demographics, cultures, and educational contexts, emphasising gaps in the knowledge, as they are based on publications that mostly represent			subset of the autistic
Williams, E., Gleeson, K., & Jones, B.E. (2019). How pupils on the autism spectrum make sense of their experiences in a mainstream school setting: A qualitative metasynthesis. Autism, 23, 8–28metasynthesis of qualitative researchCompared to what is attainable from a single qualitative investigation, the metasynthesis makes claims to knowledge that are more trustworthy and potentially transferable. The findings, however, cannot be applied to different demographics, cultures, and educational contexts, emphasising gaps in the knowledge, as they are based on publications that mostly represent			community as they were all
Williams, E., Gleeson, K., & Jones, B.E. (2019). How pupils on the autism spectrum make sense of themselves in the context of their experiences in a mainstream school setting: A qualitative metasynthesis. Autism, 23, 8–28metasynthesis of qualitative researchCompared to what is attainable from a single qualitative investigation, the metasynthesis makes claims to knowledge that are more trustworthy and potentially transferable.Autism, 23, 8–28Image: Compared to what is autiantive metasynthesis claims to knowledge that are more trustworthy and potentially transferable.Autism, 23, 8–28Image: Compared to what is are more trustworthy and potentially transferable.Autism, 23, 8–28Image: Compared to what is are more trustworthy and potentially transferable.Autism, 23, 8–28Image: Compared to what is are more trustworthy and potentially transferable.Image: Compared to what is are more trustworthy and potentially transferable.Image: Compared to what is are based on publications that mostly represent			mostly educated to degree
Williams, E., Gleeson, K., & Jones, B.E. (2019). How pupils on the autism spectrum make sense of themselves in the context of their experiences in a mainstream school setting: A qualitative metasynthesis. Autism, 23, 8–28metasynthesis of researchCompared to what is attainable from a single qualitative investigation, the metasynthesis makes claims to knowledge that are more trustworthy and potentially transferable. The findings, however, cannot be applied to different demographics, cultures, and educational contexts, emphasising gaps in the knowledge, as they are based on publications that mostly represent			level, white British and in
Jones, B.E. (2019). How pupils on the autism spectrum make sense of themselves in the context of their experiences in a mainstream school setting: A qualitative metasynthesis. Autism, 23, 8–28			employment
pupils on the autism spectrum make sense of themselves in the context of their experiences in a mainstream school setting: A qualitative metasynthesis. Autism, 23, 8–28		metasynthesis of	Compared to what is
their experiences in a mainstream school setting: A qualitative metasynthesis. Autism, 23, 8–28 Laims to knowledge that are more trustworthy and potentially transferable. The findings, however, cannot be applied to different demographics, cultures, and educational contexts, emphasising gaps in the knowledge, as they are based on publications that mostly represent	pupils on the autism	qualitative	attainable from a single
qualitative metasynthesis.       Internetasynthesis makes         Autism, 23, 8–28       claims to knowledge that         are more trustworthy and       potentially transferable.         The findings, however,       cannot be applied to         different demographics,       cultures, and educational         contexts, emphasising gaps       in the knowledge, as they         are based on publications       that mostly represent		research	qualitative investigation,
are more trustworthy and potentially transferable. The findings, however, cannot be applied to different demographics, cultures, and educational contexts, emphasising gaps in the knowledge, as they are based on publications that mostly represent	qualitative metasynthesis.		the metasynthesis makes
potentially transferable. The findings, however, cannot be applied to different demographics, cultures, and educational contexts, emphasising gaps in the knowledge, as they are based on publications that mostly represent	Autism, 23, 8–28		claims to knowledge that
The findings, however,cannot be applied todifferent demographics,cultures, and educationalcontexts, emphasising gapsin the knowledge, as theyare based on publicationsthat mostly represent			are more trustworthy and
cannot be applied to different demographics, cultures, and educational contexts, emphasising gaps in the knowledge, as they are based on publications that mostly represent			potentially transferable.
different demographics, cultures, and educational contexts, emphasising gaps in the knowledge, as they are based on publications that mostly represent			The findings, however,
cultures, and educational contexts, emphasising gaps in the knowledge, as they are based on publications that mostly represent			cannot be applied to
contexts, emphasising gaps in the knowledge, as they are based on publications that mostly represent			different demographics,
in the knowledge, as they are based on publications that mostly represent			cultures, and educational
are based on publications that mostly represent			contexts, emphasising gaps
that mostly represent			in the knowledge, as they
			are based on publications
Western cultures,			that mostly represent
			Western cultures,

			secondary mainstream
			settings, and verbally and
			cognitively able male pupils
			with ASD
King, M. C., Williams, E. I., &	photo-elicitation	five adolescent	A common theme was the
Gleeson, K. (2019). Using photographs to explore self-	and semi-	autistic boys	tendency to build one's
understanding in adolescent boys with an autism	structured		identity around hobbies
spectrum condition. Journal	interviews		and pastimes, whether one
of Intellectual and			pursued them on their own
Developmental Disability, 44(2), 232–243.	IPA		or with others, such as
			through joint activities with
			a parent or acquaintance.
Morgan, R. (2023). How do	Foucauldian	ten adolescent	The research participants
adolescent autistic girls construct self-concept and social identity? A discourse	Discourse Analysis	girls'	were made up of girls from
analysis. <i>Educational</i> <i>Psychology in Practice</i> , 1-			the United Kingdom,
23.			United States and Canada.
			A critical reflection could
			be that the research could
			have considered the
			environment and impact of
			gender on the discourses.

Alex Ir	nterview Trans	script	
1	Interviewe	So what I do with Alex is I've recorded these, just so	
2	r 0:09	that I can then transcribe our our chat. And then we	
3		use it to make the poem and then I'll delete the	
4		recordings. Okay. So first of all, what we'll do is we'll	
5		talk about your collage, then we'll go through these	
6		questions here. Yeah. So if you want to talk me	
7		through your collage, and what's on that, so I'm	
8		really interesting to find out about it, what you've	
9		chosen to put on and why you got it now. It's all	
10		going. Ignore right now.	
11	Alex 0:44	So (erm) l've chosen <mark>family and friends</mark> because (.) <mark>I</mark>	Music is a calming
12		like how, like you love your family and like your	strategy which Alex
13		friends and that <mark>they mean t</mark> he world. Mostly (.) I've	recognises helps her.
14		chosen my favorite singer, because that's the thing,	
15		because <mark>I use music to calm</mark> me down some time	Family- belonging to a
16		when I'm getting mad (.) And (erm) especially my	family and needing to
17		favorite singer calms me down a lot. I've chosen my	protect them.
18		I've chosen a very, very good drawing of my whippet,	
19			Needing to calm

20		because I love her to pieces and that my dog means	
21		everything to me.	Pets
22	Interviewe	Yeah. What is your whippet called?	
23			
24	r 1:15		
25	Alex 1:17	Bridget	
26	Interviewe	That's cute.	
27	r 1:18		
28	Alex 1:19	Yeah. And they've also chosen the Burnley badge	Follow a football club
29			
30		because they're my favourite football team in the	
31		whole world (2) And I've also chosen the music and	Kapow- fight against
32		songs like, like, because I like drawing them. And I've	the factors that annoy
33		chosen the kapow, because that's what you do when	her.
34		you're like, <mark>you try to kapow everything away when</mark>	
35		everyone's annoying. Yeah, I've chosen YouTube	Calming strategies-
36		because <mark>I used to watch it to calm me down</mark>	music, YouTube.
37		sometimes. And (erm) <mark>I've chosen the ps4 controller</mark>	
38		<mark>or Xbox</mark> , whatever it is. Just <mark>calm</mark> me because that's	Methods for
39		what I used to communicate with my friends	communication when
		<mark>s</mark> ometime when I am at my dad's. And I've chosen	with friends when at
40		the dollar sign because <mark>I love money</mark> . And (erm)	her dads.

41		Yeah, so and as I don't just like my collage a lot	
42		because it (.) represents me it represents who I am	There is some conflict
43		as a person. So yeah.	in knowing what calms
44			Alex but feeling
45			annoyed by people.
46	Interviewe	That is really lovely, I like this what you put on here	
47	r 2:11		
48			
49	Alex 2:14	Keep calm and love everyone is that what basically	Thinking in absolutes
50		<mark>everyone one should should do in the world</mark> it's not	
51		nice to like fall out with people or to (.) <mark>bully people</mark>	Bullying
52		in a way because it's like they (2) <mark>they don't have</mark>	
53		<mark>anything better to do than just like bully people</mark> in a	Naivety and
54		way that in the but, but they should listen to what	innocence- Alex sees
55		I've put on that because that's what matters in the	the world in an ideal
56		world is that (erm) <mark>you love people</mark> and that <mark>you like</mark>	way. There is a caring
57		<mark>try and like build upon them a</mark> nd like build like	element to what Alex
58		friendships and families and stuff like that. And <mark>no</mark>	says she wants people
59		<mark>one wants to fall out.</mark> So yeah, yeah.	to get on and sees the
60			need to build people
61			up. I wonder if this is
62			from the values her
			family holds.
	l		

63	Interviewe	So the kapow bit did you say the kapow is what you	
64	r 2:51	do?	
65	Alex 2:56	Yes, it's like you're it's like <mark>you karate</mark> kick it away. It's	Battle with thinking
66		like It's like <mark>you go just go away</mark> like everything but	processes or
67		we're not like physically, but like but like in your	protecting herself
68		brain <mark>you just go kapow</mark> and go away and stuff like	mentally.
69		that right?	
70	Interviewe	Okay, yeah, so who who would you kapow who	
71	r 3:09	would you want to go away?	
72			
73	Alex 3:14	Just like <mark>anybody who gets in the way</mark> in <mark>my life</mark> and	People- peers?
74		stuff like that, but but not but don't just think of it in	Trying to protect
75		my head and just go (.) Yeah, stuff like that because	herself from negative
76		it's not nice to like, argue with people. And then	thoughts
77		you're thinking in your head I just want to kapow	
78		them away and stuff like that.	
79	Interviewe	And does that work for you?	
80	r 3:29		
81			
82	Alex 3:30	Yeah, (-)(you did that? ) Yeah, it does. (-)(That's	
83		good. )Yeah.	
84	Interviewe	And you said you love your dog?	
85	r 3:35		

86	Alex 3:36	My dog means the world to me and my dog means	Pet dog is important to
		<mark>the world to me</mark> because (erm) she's like (.) if some	her.
		happened to her <mark>I would be devastated</mark> and and if	
		and she means well to me I'm going to do after	
		school, which is good because I really miss her every	
		single day.	
	Interviewe	So did you not get to see her every day?	
	r 3:53		
	Alex 37:47	Yeah it is yeah, like wow they are good.	

Billie I	Billie Interview Transcript					
1	I	what is it about the kind of the fish in the sea life that you like?				
2 3 4 5	Billie	(erm) They're just very peaceful. They're quite like, calm. And I used to have fish as well just add to the collection of random stuff I've had in my life. But fish is probably one of the most (2) I think (.) the dog and the cat and the rabbit and I had a hamster and I have	The fish are calming.			
6		gerbils at one point. And the fish are the most common ones. The y	Calmess			

7		can get into frogs, and snakes and geckos, and everything else. Like	
8		myself. (erm)I'm getting off topic now (laughs)	
9	1	So you've got so yeah, you've had lots of animals, pets, and that do	
10		you? Like? What is it that you like about the different things that	
11		you've had as the pets?	
12			
13	Billie	Well, I prefer to (erm) keep my (erm) companions cold blooded (.)	l wondered
14		If I can, because there's just <mark>they're so like, calm</mark> , you know, they	when Billie
15		just, they just do what they would naturally do, instead of fitting	was talking
16		themselves for other people, which I see WAY too much in even	about the
17		like animals, <mark>as</mark> well. Now I've noticed as well, the yard, <mark>they're not</mark>	naturalistic
18		expressing their natural behaviors, because they're scared to,	behaviour if
19		which I thought was really, really sad. (erm) (.) But I think, yeah,	this si
20		with like reptiles and amphibians and fish, and that <mark>they're all so</mark>	something she
21		quiet and calm, and they don't really <mark>they're</mark> not too (.) hectic. And	can relate to. I
22		<mark>I love snakes,</mark> especially I love snakes SO much. Because you can	was aware fo
23		just set them around your shoulders, and you can just carry on with	my
24		your day. And for a while because obviously once they can't get too	understanding
25		cold, so you want to be careful with it. But especially if you're like a	of 'masking'
26		warm room, I can just have it round my neck for hours, and they'll	and the
27		just chill. And that's just the presence is there and it's calming (erm)	implications so
28		And it's just really nice. And then dogs are dogs and cats are cats	could be
		and Reg is Reg (laughs). He's (.) he's known for being (.) horrible at	potentially

38and quiet39nature seem40important to41billie42Masking43iwondered if44billie felt that45iway about	29	the yard. People like give him a really wide berth because he will	biased in my
321Describes33Imasking in the animals as34Imasking in the animals as35Imasking in the animals as36Imasking in the animals as37Imasking in the animals as38Imasking in the and quiet39Imasking in the and quiet39Imasking in the and quiet39Imasking in the and quiet40Imasking in the animals as41Imasking in the Billie42Imasking in the Billie43Imasking in the animals as44Imasking in the billie45Imasking in the animals as46Imasking in the animals as47Imasking in the animals as48Imasking in the animals as49Imasking in the animals as50Imasking in the animals as51Imasking in the animals as52Imasking in the animals as53Imasking in the animals as54Imasking in the animals as55Imasking in the animals as56Imasking in the animals as57Imasking in the animals as58Imasking in the animals as59Imasking in the animals as54Imasking in the animals as55Imasking in the animals as56Imasking in the animals as57Imasking in the animals as58Imasking in the animals as	30	kick people who will walk past	view.
33       masking in the         34       animals as         35       disappointing         36       masking in the         37       disappointing         36       masking         37       fleir calmess         38       and quiet         39       and quiet         40       nature seem         41       Billie         42       Masking         43       I wondered if         44       Billie feit that         45       this way about         46       her peers. She         47       discusses later         48       on this which         49       confirms my         50       thoughts. She	31		
34animals as animals as disappointing35Image: State of the sta	32		<mark>Describes</mark>
35disappointing36I37Their calmess38and quiet39nature seem40important to41Billie42Masking43I wondered if44Billie felt that45this way about46her peers. She47on this which49on this which50i	33		<mark>masking in the</mark>
36Image: second sec	34		<mark>animals as</mark>
37Image: Sector of the sector of	35		disappointing
38and quiet39nature seen40important to41Billie42Masking43I wondered if44Billie felt that45Billie felt that46her peers. She47discusses later48on this which49I50I	36		
39nature seem40important to41Billie42Masking43Iwondered if44Billie felt that45Billie felt that46her peers. She47discusses later48on this which49Important to thoughts. She	37		<mark>Their calmness</mark>
40Important to41Important to41Dillie42Masking43Important to44Important to45Important to46Important to47Important to48Important to49Important to50Important to	38		<mark>and quiet</mark>
41Here42Masking43Iwondered if44Iwondered if44Billie felt that45Billie felt that46Image: Shere47Image: Shere48Image: Shere49Image: Shere50Image: Shere41Image: Shere42Image: Shere43Image: Shere44Image: Shere45Image: Shere46Image: Shere47Image: Shere48Image: Shere49Image: Shere50Image: Shere51Image: Shere52Image: Shere53Image: Shere54Image: Shere55Image: Shere <td>39</td> <td></td> <td><mark>nature seem</mark></td>	39		<mark>nature seem</mark>
42Masking43I wondered if44I wondered if44Billie felt that45I billie felt that46I billie felt that47I billie felt that48I billie felt that49I billie felt that50I billie felt that	40		<mark>important to</mark>
43I wondered if44Billie felt that45this way about46her peers. She47discusses later48on this which49confirms my50houghts. She	41		Billie
44A4Billie felt that45this way about46her peers. She47discusses later48on this which49confirms my50io	42		Masking
451this way about461her peers. She471discusses later481on this which491confirms my501thoughts. She	43		I wondered if
46her peers. She47discusses later48on this which49confirms my50houghts. She	44		Billie felt that
4748discusses later48on this which49confirms my501	45		this way about
48on this which49confirms my50thoughts. She	46		her peers. She
49     confirms my       50     thoughts. She	47		discusses later
50 thoughts. She	48		on this which
	49		confirms my
51 like stinks that	50		thoughts. She
	51		like stinks that

r	1		1
52			are calm,
53			peaceful and
54			not
55			hecticpredict
56			able?
57			Calmness
58			The reaction to
59			<mark>her horse from</mark>
60			<mark>others.</mark>
61	1	He puts them in their place and tells them	
62			
63	Billie	Even when minding their own business. He usually only does it to	There are
64		people who don't listen, though, like they'll be like, just be careful,	similarities in
65		because <mark>he doesn't really like people being very close to him</mark> . And	how Billie
66		there's ONE person who constantly does it <mark>because we don't get</mark>	describes
67		on. I knew them when I was younger, and we got on then but for	herself and
68		some reason they don't like me anymore, even though we've had	what she
69		like two conversations, both of them being why he should STAY	identifies as
70		FAR AWAY from my horse or he'll end up in the hospital <mark>.</mark> And <mark>he</mark>	qualities/need
71		<mark>does it every single time</mark> and <mark>I'm kind of hoping I will stop saying it</mark>	s in her horse.
72		now and wait till it gets kicked in (laughs) I learn from it. So	Difficulties
73			with a
			<mark>relationship</mark>

74			<mark>impacts on her</mark>
75			<mark>horse.</mark>
76			Difficulties
77			<mark>create</mark>
78			<mark>confusion.</mark>
79			Understanding
80			others
81	1	I'm interested what you said about the reptiles and how they've	
82		just very natural, but they don't have to behave to fit in, is that	
83		something that you relate to yourself?	
84			
85	Billie	(erm) (3) I think <mark>I have to be <mark>somebody</mark> I'm not a lot of time.</mark> (erm) <mark>I</mark>	Playing a role
86		<mark>feel like I can't talk</mark> about stuff that I'm interested in. <mark>And I can't (.)</mark>	Masking
87		<mark>display natural behaviors</mark> that I would do because <mark>people</mark> think it's	<mark>Aware of what</mark>
88		weird. And <mark>I get called names</mark> . And you know, <mark>I don't get bullied</mark>	<mark>others think</mark>
89		anymore. But <mark>I used to</mark> when I was little. But now I just kind of like <mark>I</mark>	<mark>and influences</mark>
90		<mark>don't understand h</mark> ow <mark>everybody wants to be seen.</mark> And (err) And	<mark>how Billie what</mark>
91		like in the <mark>spotlight,</mark> because <mark>I just want to be left alone.</mark> Like, just	<mark>she does.</mark>
92		to be able to just get on and have a few friends, muck about with	Self
93		them, and then get on with stuff. And then I can leave school and I	preservation
94		<mark>can do what I want with my life.</mark> But <mark>everybody has to make</mark>	<mark>People</mark>
95		everything a big <mark>drama.</mark> And <mark>everybody has to be included in</mark>	wanting to be
		EVERYTHING, even if you don't want to be and it really, really gets	<mark>seen is the</mark>

97		
	want so that <mark>people don't hate me.</mark> And it's <mark>tiring.</mark> And <mark>I don't like</mark>	<mark>Billie.</mark>
98	it.	Avoiding
99		attention
100		Left alone by
101		who?I
102		wondered if
103		this was just
104		certain people.
105		This related
106		back to my
107		thoughts about
108		wanting the
109		calm and
110		peace. Billie
111		sees her peers
112		as creating
113		drama and
114		wanting to be
115		seen.
116		Physical
117		reaction- out
		of Billie's

118			control2
110			control?
119			Powerless
120			<mark>Billie describes</mark>
121			<mark>her peers</mark>
122			<mark>differently to</mark>
123			<mark>how she</mark>
124			<mark>describes her</mark>
125			<mark>animals which</mark>
126			<mark>creates</mark>
127			<mark>confusion,</mark>
128			<mark>maybe</mark>
129			frustration?
130			Billie doesnt
131			want to be
132			included in the
133			behaviour her
134			peers
135			demonstrate
136			but feels a
137			pressure to be
138			liked.
139	1	and when you say people is that other peers is that teachers,	
140			
		adults,	

141	Billie	everyone, except my friends who GET IT a bit. Some people don't.	Made me
142		But <mark>I really, really, really, really struggle</mark> with being touched so so	wonder if Billie
143		much. I don't mind it. If it's not (.) constant. Like if someone wants	needs ot be
144		to give me a hug, and <mark>they give me a warning.</mark> But even if it was like	around people
145		a wide arms, I'll be like, Yeah, okay, hugs. But if someone goes up,	who are similar
146		<mark>hug me</mark> , it's just like, Oh, <mark>my God get off.</mark> And even just like	to be
147		brushing arms with somebody as they walk next to me is enough to	understood-
148		just like <mark>, send me over the edge.</mark> And there's ONE person that I'm	Double
149		friends with, that does it ALL the time, and I can't errr	empathy
150			theory?
151			<mark>Feels</mark>
152			<mark>understood by</mark>
153			<mark>her friends</mark>
154			Understanding
155			Similar to her
156			horse.
157			Frustrations
158			about people
159			not being in
160			tune with Billie
161			and
162			understanding
163			boundaries.

164	Inter	And if you told them (-)	
165	view		
166	er		
167	Billie	<mark>I don't know if they forget,</mark> or <mark>they are just too arrogant to stop</mark> or	Frustrations
168		what. But it really, really gets on my nerves.	with friends
169			who do not
170			understand
171			her.
172			Lack of respect
173			
174	I	So for those people that get it, so your friends that get it and erm	
175		what's different about those relationships?	
176	Billie	Erm they like, <mark>they make sure that I'm not feeling</mark> pressured to	Peer pressure
177		behave, how they behave, so that <mark>I can BE the way I need to be</mark> and	Fear of being
178		<mark>I dont, feel embarrassed about it</mark> or anything. And then, obviously, <mark>I</mark>	judged.
179		<mark>have few </mark> friends who have other learning disabilities and stuff. So	Want to be
180		it's <mark>nice</mark> to (.)not feel completely like an <mark>outsider,</mark> but <mark>I don't feel</mark>	herself
181		<mark>like an insider</mark> either. <mark>I just feel like</mark> I'm just being (2) I'm just	Masking
182		<mark>existing,</mark> and <mark>I like it that way.</mark> You know, like, the best way to	<mark>Peers who</mark>
183		describe it is you know <mark>, when you're watching a film,</mark> and then <mark>they</mark>	understand
184		have the big focus and there's a blurry bits in the background, I	<mark>Similar</mark>
185		want to be the blurry bit in the background. don't actually care	<mark>traits/shared</mark>
186		<mark>a</mark> bout <mark> I like it that way.</mark> (laughs)	<mark>experiences</mark>

187	Is this about
188	existing or
189	belonging? I
190	wondered if it
191	was about
192	being with
193	people who
194	she can feel at
195	ease with and
196	not under
197	pressure but
198	understood.
199	Being
200	noticed <mark>/seen</mark>
201	Not being
202	noticed.

Rissa Interview			
1		Okay. Can you tell me about your collage?	
2	Rissa	It's stuff that I like (.) that makes me <mark>happy</mark> (.) And how I	Happy- the collage includes
3		<mark>identify</mark>	items that makes Rissa

4		Okay, some a little bit more about the different elements	happy, this seems to be
5		of it.	important to her.
6	Rissa	Yeah. So these two, these things up here (.) are the apps	
7		that I like to use to make me happy. Have activities that	<mark>ldentify-</mark> Rissa uses her
8		make me happy. Things that I collect that make me happy,	clothing to express who she
9		and things that I wear to identify me (2)	<mark>is. It also seems to be</mark>
10		Can you tell me a bit more about the things that you	important to be
11		wear?	comfortable- is this sensory
12	Rissa	Like (.) my shoes (.) and my clothes have a certain style,	or about confidence?
13		and represents me and makes me feel comfortable?	
14		That's good. How?	<mark>Clothing</mark>
15		How would? How would you? I'm really interested about	
16		how you have a certain style, how would you describe	
17		that?	
18	Rissa	Don't know	Play- Rissa finds enjoyment
19		Okay, I'm going to ask you some questions. Okay. So how	<mark>in games.</mark>
20		do you like to spend most of your free time currently?	
21		What do you most enjoy? And are you most interested in	<mark>Online friends</mark>
22		right now. And you can use your collage to help you to	
23		remind your things.	<mark>Weird</mark> - Rissa talks about
24	Rissa	I like playing games with my online friends. And I also like	herself as being weird but
25		watching (.) programs. And I like playing outside of like	this seems to be in a

26		play like (2) I like playing online games, and out online	positive way but she
27		games.	acknowledges that other
28		How would you describe yourself?	people does not get the
29	Rissa	(2) Weird (.) but in a good way.	weird.
30		I'm really interested in how you use it. Can you tell me a	Is this about <mark>understanding</mark>
31		little bit more about that?	and <mark>acceptance</mark> ? Double
32	Rissa	Like (2) I'm not (.) <mark>I'm not what people would normally</mark>	empathy? <mark>O</mark> ther people's
33		think is fun, like, things that I find fun, the thing that I	expectations and views of
34		enjoy the thing that people don't usually enjoy. So they	'normal' influence how
35		<mark>think it's <b>weird</b>,</mark> b <mark>ecause t</mark> hey can't see outside of their	Rissa judges herself. People
36		bubble and what they like can't reach, wrap branch out	conform and do not think
37		into other things and can't see what I like.	outside the block-
38		So when you say that, that's not what they expect, what	neurdiversity/embracing
39		would they expect? What is it they would expect things	difference?
40		like?	Fitting in with what is
41	Rissa	I don't know, it just depends on like (2) for example (.) if	expected and not what
42		you're like a popular person with no, like problems or	makes someone happy-
43		anything, you might just enjoy going on your phone and	Rissa's view as this wouldn't
44		talking. And like going out shopping, and like try on	make he rhappy but who si
45		clothes and stuff. (2) <mark>Stuff that makes you look instead of</mark>	to say that for others it
46		doing things that you like doing things <mark>, other people</mark>	does?
47		happy sort of making you happy (2)	

48		Okay. So do you feel that you do do that? Do what other	<mark>Interests</mark>
49		people like it's good.	
50			Fitting in- for Rissa it seems
51	Rissa	No <mark>I do what I like</mark>	important to do what
52		So what do you think your strengths are? Drawing?	makes you happy and not
53	Rissa	(erm) <mark>Drawing</mark> (2) I'm not sure	what makes you fit in.
54		Do you think it's a strength that you do what you like and	
55		not what the people w2nt?	Belonging
56	Rissa	Yes (4)	Acceptance
57		Is that easy to do?	Judgement
58	Rissa	No (2) It depends really	
59		When is it easy?	S <mark>hared interests</mark> of people
60	Rissa	(erm) When I am <mark>around people that like the same things</mark>	she feels she belongs with-
61		<mark>as me and I know t</mark> hey will not judge me (.) or like if <mark>I am</mark>	dungeons and dragons.
62		around a community that comforts me and supports me.	Nor being judged by others
63			is important to Rissa.
64		when is it most difficult?	
65	Rissa	(erm) around people that like <b>can't</b> really see anything	Funny
66		outside. They don't think outside the box. They can't see	Compliant
67		<mark>other people views the very like</mark> the depends like (4)	<mark>Good behaviour</mark>
68		when you say they can't see outside their views, what do	
69		you mean by their views?	

70	Rissa	Because like, they like stuff (2) Like (.) they think that stuff	Not being understood or
71		<mark>is fun</mark> . Or t <mark>hey think that stuff is right</mark> and t <mark>hey think this</mark>	having <mark>different</mark> interests to
72		stuff is wrong. Like they will think that stuff is fun and	the majority.
73		some things are boring. They can't see the other people	
74		might find them fun.	
75		How do you think your family would describe you	<mark>Shared</mark>
76	Rissa	(Erm) (2) <mark>funny (3)</mark>	<mark>interests/community<mark>- feel</mark></mark>
77		Anything else?	at ease- is finding the right
78	Rissa	No, I can't think	tribe important?
79		how do you think your friends describe you?	
80	Rissa	(2) I'm not sure (3)	Othering? Need to be
81		what would you teach you say if I asked them to tell me	understood and accepted.
82		about you?	
83	Rissa	That I am quite well behaved (3)	Invisible
84		How do you feel when you are doing things you enjoy	
85		happy?	<mark>Open minded</mark>
86	Rissa	Happy (.) very happy (.) Feel comfortable (2)	Difference
87		is ready Can you try not to do? Are there any things that	Acceptance.
88		you're trying to do?	
89		Okay. Tell me a bit more about that.	
90	Rissa	Yeah (2) I <mark>don't like to draw attention</mark> to myself,	<mark>Family see her</mark> funny
91		because(erm) (2) <mark>I don't like (.) when people stare at me,</mark>	

92		because it <mark>puts me in pressure.</mark> And it puts me in	Stay away from people-
93		situations that I don't like.	hiding aspects of her autism
94		So what things would you avoid? Doing stop that from	for fear of being teased
95		happening?Like making? Like, what is it? What what kind	Powerless
96		of things would you do to avoid that from happening?	Teachers describe as well
97	Rissa	Like (.) probably just like, t <mark>ry and stay away from certain</mark>	behaved- is this what Rissa
98		areas, like busy areas. Stay away from people that	feels is important?
99		purposely draw attention to me stay away (erm) (2) from	Conflict- wants to be
100		like, doing something like a twitch or something that	herself/think outside the
101		might people look like if I keep things in that might	box but doesn't want to
102		happen, like, <mark>I can't control them, but they might be loud.</mark>	draw attention. Is this down
103			to understanding?
104			Fear of being judged. Out of
105			control- sensory?
106		So what helps you to be yourself	
107	Rissa	being around people that like, for example, my friends (.)	Being with friends gives her
108		<mark>because <b>I am</b> having fun with them,</mark> it feels like nobody	<mark>confidence</mark> - i <mark>snt worried</mark>
109		else (2) Like it wouldn't matter because I'm with a friend	about other people looking.
110		when <mark>I am when I am with a friend</mark> , it's like (.) it was not	F <mark>riends take the pressure</mark>
111		what anyone thinks (.) because we're having a good time.	off to conform and feel
112		And <mark>it feels like nobody else is watching me</mark> . Right but like	more confident- less
113		my friend (2)	awareness of others when
114			with friends.

115		When does that happen? When would you say that	
116		happens the most,	
117	Rissa	probably when we go on days out. So like (2) for example,	Fears appearing weird even
118		usually, I wouldn't like go into the park (.) Because <mark>I don't</mark>	though she sees being
119		know make me look weird going on stuff on myself. But if I	'weird' <mark>different</mark> a good
120		am with a friend, I wouldn't care if like people at the park	thing.
121		looked at me, because I would be with them. We'd be	
122		having fun, it wouldn't matter. Because we would look	
123		cool (laughs) not Cool (.) but like (2)	
124		just looking at collage again. What would you say on	
125		there helps you to feel most like yourself.	
126	Rissa	this	
127		What's that?	
128	Rissa	Dungeons and dragons game	
129		Tell me a bit more about that.	
130	Rissa	It's a it's a game (.) where (erm) I don't know how to	
131		describe it. (It's a game) to game but it's not online. It's in	
132		real life.	
133		So when do you play that?	
134	Rissa	Every Friday (.) (at h9ome) No at a cllub every Friday, <mark>I</mark>	
135		would like to host a game at my house. I don't think any of	
136		my friends will be interested.	

137		Well. So what is it about that, that helps you to feel like	
138		yourself?	
139	Rissa	Because I have lots of fun (2) And (.) I make friends. And I	Has fun with her <mark>friends at</mark>
140		am also very free with it because I can make decisions.	<mark>Dungeons.</mark>
141		Like <mark>I can choose to do whatever I want.</mark> I could like for	Has some <mark>autonomy </mark> in how
142		example (.) I could hide I could go and explore so I can	the game is played.
143		make decisions for myself. I could either benefit from	
144		them or not benefit but it's okay.	
145		Is that making decisions in the game? (yeah) Okay. And	
146		what are the people like there?	
147	Rissa	v <mark>ery accepting</mark> them (.) They're v <mark>ery supportive. We're all</mark>	Accepted and shared
148		like friends, none of us argue. We are all quite close.	<mark>interests.</mark>
149			Collaborative games and
150			shared interests feel
151			supportive and a closeness.
152		Is there any? Is there anything else in your collage that	
153		you would say helps you to be yourself?	
154	Rissa	Yes (3) (points)	
155		What's that?	
156	Rissa	Ear phones	
157		Okay, how do they help you	
158	Rissa	<mark>l listen to my music</mark> ? It makes me f <mark>eel very relaxed.</mark> So ifl	Music is calming- recognises
159		would just <mark>listen to my music</mark> (.) <mark>Calm</mark> down.	she needs help to relax.

160		Okay. Can you tell me when you f I was in a stressful	
161		situation, eel happy?	
162	Rissa	Yeah (.) when <mark>I am doing stuff that I enjoy</mark> (2) or <mark>when I'm</mark>	Happiness relates to
163		with my friends.	<mark>interests and friends.</mark>
164		And what's about when you feel relaxed? So when do you	
165		feel relaxed	
166	Rissa	When I am listening to my music or watching TV.	
167		Okay, so anything you'd like to get better at?	
168	Rissa	Going out in public (2) Like being able to go into a shop (.)	Wants to be <mark>independent.</mark>
169		a busy shop or being able to go do stuff like go to a park or	Barriers
170		go to funfairl without having to have a friend come with	
171		<mark>me.</mark>	
172		how do you think you could do that?	
173	Rissa	(3) I'm not sure(.) like maybe just going to little quieter	
174		places and then building up.	
175		Okay, yeah. Thinking back back. Is there any specific	
176		experiences that you've had that have influenced how you	
177		feel about yourself?	
178	Rissa	I don't know (4)	
179		Okay, is there any specific people that have influenced	
180		how you feel about yourself?	
181	Rissa	My <mark>mum</mark>	Family
182		In what way she makes?	

183	Rissa	She makes me like (.) feel (.) It's n <mark>ot bad, it's good.</mark> So you	Mum helps Rissa to feel
184		m <mark>akes you feel good (.) About who you are.</mark>	good about herself.
185			F <mark>amily validate and</mark>
186			<mark>reassure</mark> Rissa - support
187			positive sense of self.
188		Is there anybody else has influenced how you feel about	
189		yourself? And it could be in any way?	
190	Rissa	Probably, my DM. (Dungeon Master)	
191		Okay. In what way? Tell me a bit about that.	
192	Rissa	Like (.) she (.) like (.) if I want to make a decision in my	Dungeon master
194		game (.) s <mark>he will like (.) like (.) support me on that (2)</mark> Like	encourages to t <mark>ake risks</mark>
195		(.) for example, if I wanted to do something (2) everyone's	and offers reassurance.
196		like, no, don't do that (2) She's like, Yeah, go do it sure (2)	Listens and supports.
197		And also, like, if I don't feel great, or if I'm like, going into	
198		fields that you might want to talk, talk outside.	
199		How does that make you feel?	
200	Rissa	Нарру	
201		So thinking about the people, are there any events or	
202		things that have happened, that have influenced how you	
203		feel about yourself?	
204	Rissa	Don't' know	
205		can I ask you about being autistic? Yeah, it's, what's it like	
206		being autistic for you?	
207	Rissa	It's kind of a superpower (.) But it's also can you tell me a	Dissonance between her
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208		bit more about that superpower as in (.) for example (.)	view of autism and that of
209		<mark>am really clever with <mark>maths</mark>. So <mark>I have a <mark>special interest</mark> (.)</mark></mark>	others.
210		And I'll know a lot about that (.)or I have a lot of	Rissa recognises she has
211		knowledge. I can stay concentrated on one thing that	strengths and talents but
212		really like into it. But another thing is that people know	there is a value placed on
213		that I'm autistic. So sometimes I'd rather teach or my	others recognising this.
214		lessons, p <mark>eople will look at me for that. They will think I'm</mark>	People knowing that she is
215		weird for that. They won't see me as the same.	autisitc is important to Rissa
216			but this seems to be
217			conflicted with the reason
218			behind it which is to explain
219			why she is weird. Her view
220			of autism has negative
221			connotations.
222		What does that make you feel about you?	
223	Rissa	It makes me feel like I'm good (.) We're not good enough.	
224		And I'm really interested in that. So although see it as a	
225		superpower, you feel that other people would see you as	
226		not good enough. And is that important to you?	
227	Rissa	It's important to me that the teachers especially see that I	Seeing autism as an
228		this superpower is serious. And because sometimes it	identity- part of her
229		feels like <mark>I'm not good enough for the same help as</mark>	personality.

230		everyone else (.) For example (2) autistic boys in that	
231		school are very much treated differently to autistic girls (.)	Mask
232		Okay, that's a <mark>mask</mark> a lot more. T <mark>hey don't show their</mark>	
233		<mark>emotions a lot more.</mark> So <mark>I've noticed that we get a lot less</mark>	<mark>Gender differences</mark> - due to
234		help. Like (2) if an autistic boy in our school wanted to	expectations of each
235		come down (.) And <mark>everyone can see the boy not</mark>	gender?
236		wanting to come down and would let him not go to the	
237		lessons for the rest of the day (.) They'd be okay with that	personalities
238		<b>(</b> 2) Or like <mark>they would try and support that</mark> as best as we	Stimming
239		can. If a girl came down (.) that they would like to try	
240		going by Do you think that is? Because <mark>girls don't express</mark>	Rissa is aware of differences
241		their autism as much as boys they do mask so is it that	and shared frustrations on
242		they don't. (.) They don't think it is about that (.) They	being believed or that there
243		<mark>don't</mark> like <mark>stimming</mark> they <mark>don't like showing the</mark>	are different expectations
244		personalities of autism. They don't like they just don't they	which impact on how their
245		just want to hide to try and fit in. But with boys, they don't	autism is accepted ro
246		really, really matter the stim. T <mark>hey're not afraid to like</mark>	percieved based on gender
247		hide their disability, whereas girls they do a lot more.	stereotypes.
248		So how do you think that makes you feel that the adults	
249		are not	
250	Rissa	Annoyed because they they can't do the research and	Need for more awareness,
251		they just can't see behind that masking. So they can't	acceptance and
252		because they can't see behind it. <mark>T</mark> hey can't do research	

253		on it <mark>and</mark> they educate themselves to be able to help these	understanding- staff
254		<mark>children popular.</mark>	training?
255		Do you think there's anything else that we feel is	
256		important to share about you?	
257	Rissa	Νο	
258		Okay, well thank you for your time	
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#### **Appendix 4: First Listening Reflection**

There were some contradictions in Sadie's discussion. She talked of being with her Dad and not having time with her mum but then later said she doesn't get to see her dad much. Sadie also talked about having a group of friends who do not judge her. She feels more confident with them but then shared she has one friend that she is comfortable with, can talk to and doesn't start drama.

She talked of following football which was linked to her stepdad and the time she spent with him. Sadie talks of doing random things and laughing with her cousin who is autistic, spending time in the car with her and doing "random" things.

Sadie talked about feeling like she can be herself when she is with her friends. Sadie recognised that friendships are complex, stating that she finds the company of one friend easier who she feels most comfortable with. Sadie refers to people as 'creating drama' and talked about in Year 9 how people needed to calm. There seems to be a frustration about people not being predictable or dramatic.

Friends seem to have an influence in how Sadie feels, what she does and how she sees herself. Sadie described hobbies that she no longer pursues as her friends no longer do it e.g., drama. When asked to describe herself Sadie talked of how her friends would describe her including funniest, up for anything and have a laugh. This made me wonder if Sadie is potentially vulnerable as she is described as 'up for anything', is this to please them? She gave up hobbies when her friends no longer wanted to engage in them. Sadie talks of enjoying being with her friends and spending time with them but also talks of drama, how they talk about each other and finding the company of one single friend easier. Sadie also talks fondly of her cousin, making comparisons of how they are both autistic. Refers to her friends as weird/crazy. Sadie likes the time she spends with her cousin when they go driving.

Quality time seems important to Sadie, she talked about the time she spends with her dad, friends and there was a desire to spend more time with her mum. There were contradictions as Sadie talked about not spending time with her dad. She included supporting a football team on her collage but this was more about the time she spent with her stepdad rather than the football team itself.

Sadie's interests include music and fashion. She struggled to list any other likes apart from music initially which seems to be a significant interest and features in a lot of what she likes. Sadie will listen to it to help her do things especially routines such as dressing. Sadie likes fashion Primark. Talks of a smiley face bucket hat that she bought from Manchester when she went for her birthday. Sadie enjoys spending time doing spontaneous things which she refers to as random Sadie likes to laugh and enjoys doing things that make her laugh. Sadie refers to herself as weird. She also talks about her dad and mum being weird. Sadie talks fondly of her mum doing strange things for her birthday which everybody found funny.

Sadie has a negative view of herself as a learner, describing herself as not smart. She recognised that there was not the right support for her in Primary school and expressed some frustration that she may not be behind from her peers has she had the right support. Sadie recognised that she wasn't lazy and felt frustrated that teachers perceive this as a lack of effort. Sadie talked about being forgetful as she forgets her homework. She has experienced punishment for this which has not helped the situation. Sadie has cards that she can record the homework on but relies on prompts from the teachers. Sadie has an understanding of what she finds difficult with not wanting to engage in class discussion or 'zoning out' when she doesn't understand what is being taught. Sadie found her art les son difficult as her teacher is difficult to read. I felt frustrated by this as I felt that Sadie had a negative view of herself as a learner but also felt helpless. Where it worked well Sadie described teachers that 'got her' and responded to her needs sensitively. I felt a strong emotional response to this as I felt Sadie has potentially been failed as she is not understood.

Sadie talked about how her mum helps her to understand her autism. When asked about her diagnosis Sadie described how this was something that was done to her. She had not say in the process and didn't realise that she was being tested for it. Sadie is conflicted with her diagnosis, it seems to provide some relief as an explanation for why she finds things difficult or feels different however there is a real fear about others knowing or judging her. Sadie described how she is only 1 on the scale and so she is not that bad.

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Sadie recognises that if her peers knew she would be vulnerable to being teased or seen as different which makes me feel sad for Sadie and wonder if this is due to a stigma of the label and how it is perceived. Sadie talked about how she would be happier once she leaves school for people to know she is autistic.

#### **Appendix 5: Reflective Diary Entry**

## Reflection

When I was completing the first listening, I reflected on a few points. Sadie enjoys the spending time with her friends where they visit the shops or meet new people. I have to admit as a parent this provoked a reaction as I was concerned that she was referring to new people that she had met whilst hanging out at the shops as friends.

Sadie's likes and interests tend to relate to time spent with important people in their life. Sadie shared her desire to spend more time with her mum and how she sees her at the weekend. She describes both her mum and dad as weird, some of the things she described made me aware of my own feelings as a parent and I was conscious of this so as not to make judgements as there was an inconsistency of how Sadie described her time with her parents. Was this typical of adolescents who prefer to be with their friends?

I thought about my own identity and how belonging to a family is quite a strong part of how I see myself. I am a mother, wife, sister, daughter and cousin all of which I feel makes me who I

am. Sadie seems to want to spend time with her family and talks of it being boring at home as she spend times alone in her room. I wonder if this is about finding where Sadie belongs. She likes the time with her cousin and hanging out with her friends.

I reflected on how Sadie used the word weird, random and crazy and how she would pause before using this. I felt this was because she was struggling to find the right words in her vocabulary and is this about difference? I also wondered if Sadie had a better understanding of autism and what this means for her as a learner would this give her better coping mechanisms or the ability to advocate for herself.

If teachers and the education system had a better understanding of girls on the spectrum would they be able to respond to them sensitively and help make their education a positive experience. I also wonder if the curriculum was flexible and able to respond to their strengths and needs would she have a better understanding of herself as a learner. Sadie has enjoyed school more since she took her options as she has had more autonomy in her subjects she chose but also has more time in the subjects she enjoys.

Sadie's view of her autism diagnosis created an emotional response in myself that I felt was important to recognise. I wondered if this medical model of scaling and placing people on a scale in the spectrum was actually helpful? Is this where the neurodivergent movement would help an individual in developing a positive sense of self? I wondered if there is a role for schools in supporting a view of autism that is less stereotypical or stigmatised. Sadie shared how she has enjoyed her time in the group as part of the research as she feel they have an understanding of each other. I was pleased to hear this and had hoped how this could be a safe space for the young people to be themselves.

## Appendix 6: Second Listening Analysis

Billie's Singular pronouns	1st person	2nd person	2nd person plural
(I, me, my & myself)	voice	(they, them, their)	(you, your)
	(we, us,		
	our)		
I ramble		They're still there.	
l talk			
l get nervous.		They lose connection.	
I'm a very, very boring			
person.			
I love sealife.		They're very peaceful.	
		Mum was not impressed	
		She understood why I did it.	
I prefer my companions cold		They do what they naturally	
blooded.		do.	

I have to be somebody I'm	
not.	
I feel like I can't talk	
I can't display natural behaviors	People think its weird.
I don't understand	Everybody wants to be seen.
I just want to be left alone.	
I can do what I want with my life.	Everybody has to make everything a big drama
	Everybody has to be included in everything
I have to behave the way that I don't want	People don't hate me.
l don't like it.	
I really, really, really, really struggle	They give me a warning.
my friends who GET IT	someone goes up, hug me
my God get off.	they walk next to me

send me over the edge.		
I can't		
I don't know if they forget,	they are just too arrogant to	
	stop	
really gets on my nerves.		
I can BE the way I need to		
be		
I dont feel embarrassed		
		when you're
		watching a film
	they have the big focus	
I want to be the blurry bit in		
the background		
l like it that way.		

# Appendix 7: Contrapuntal Voices Analysis

Voice	Image	Quotes	Contrapuntal Voices
Animal lover	PUPPy Contraction	sticker with puppy love, because I love puppies, and there is a little	Scarlett loves dogs and knows the

-			
		chubby happy dog. She's really cute.	power they have.
		The reason I love Labradors is	She had a sad
		because my auntie and uncle had	experience when she
		one and every time I like stopped	found a dog that she
		over there, when I was little, he	cared for when he
		always used to just take my Teddy's	died. She
		out and just start running around the	understands that it is
		house and everything, but then he	not practical to have
		died. I found him	one as she attends
			school and her mum
		I dont know they are just so fluffy	works.
		and cute. They just come in different	
		shapes and sizes chubby (.) small.	
		it won't work out because my mum	
		works a lot (2) And I'm at school so it	
		wouldn't work	
Gamer	RABLOX	Roblox is well people just started	Scarlett enjoys
		talking about it at school and I was	playing Roblox and
	0 ×	like, Can I have Roblox and other	believe she is good
		stuff I'd seen on YouTube stuff like	at it. She
		that. So let me see it. age rating in	understands the
		she was reading everything it had	restrictions around it

	bad reviews and everything I'm on	and has an open and
	Yeah, nothing bads really happened	trusting relationship
	to me. You can't swear on it usually	with her mum who
	because it just talks out in his voice	ensured it was safe
	chat we have to be 13 plus and	to play before she
	everything and then if because that's	were able to play.
	what if I knew because when you	
	used to die you said OOF but now	Scarlett talks about
	they've changed it to GAH it's really	the changes in the
	stupid right just tricked us. I don't	game which she
	know what made it like my (.)	doesn't like.
	playing it. Yeah, and they were	She shares the
	talking about it (.) one of my good	interest of Roblox
	friends (.) I am going up to the cafe	with her friends.
	with him because I haven't seen him	Scarlett is aware that
	for ages. He goes to XXX now erm (2)	the game was at one
	he was the one (.) who started	point not acceptable
	playing Roblox people were like err	within her peer
	You're weird (.) Roblox is bad. And	group and those that
	then me and XXX got it and we like	played it were
	really really liked it. Then people	perceived as
	were going around saying do you	unpopular or teased.
	play Roblox and we were like no (.)	She was aware that

<b>T</b>		
	that's weird because obviously we	people were seen as
	didn't want people to know because	weird at one point
	they were just being rude to XXX and	for playing the game
	everything because he said he	where as now it has
	played Roblox. He can't just go and	become popular it is
	be like, Oh, I was joking now because	now more
	he's already said yeah.	acceptable. There is
		a frustration that the
	I really loved it (2) And one of the	majority judge are
	people I was saying about it HE HAD	those that can
	Roblox himself (2) Exactly (2) So it's	determine what is
	like no point	acceptable and
		those who have their
		own tastes taht are
		not mainstream are
		judged. Scarlett talks
		of the need to deny
		what she is
		interested in to
		avoid being seen as
		weird. There is an
		element of guilt that
		her friend had to be

			a target on her own
			_
			as he had already
			admitted to liking
			the game. There is a
			hypocrisy that
			Scarlett doesnt like.
Teddy		I don't know what just like made it	Scarlett likes the
collector	P, E, T, E, R R, A, B, B, I, T,	my favorite. It's just like my mum	character of Peter
		just taught me one that one day (2)	Rabbit as she has a
		Ah I know why because Peter Rabbit	teddy of him. She
		(.) I like rabbit Peter Rabbit because	relates the character
		it was made in the Lake District but	to where he was
		like different parts. And then owls (.)	created in the lake
		owls scare me it's just up put it to go	district which is
		the district.	where she has been
			on holiday with her
		I used to watch it when I was little	mum and has fond
		and everything (2) so (.) like that's	memories of there.
		what's got me into it	
		I have got a little teddy of him. I have	
		got seven Teddy's	

		I saw Peter Rabbit and I just picked it	
		up and I was like carrying it around	
		the shop behind her and she was like	
		(3) go put that back please. Im like	
		(2) but I want and she was like no	
		you have enough Teddy's (.) but mini	
		Peter rabbit can have Daddy Peter	
		Rabbit and she was no please put it	
		back so I just had to put it back (.) I	
		really wanted it though. So yeah, I	
		didn't get it though (2) I'm still happy	
		with my small one.	
Different	diffevent but	We are all different. But there's	Scarlett sees the
/	fantastic	something kind of fantastic about	positive in everyone
Unique	isut there? "	that. Isn't that I just really like it	being different. She
			feels being the same
		we ARE all different (.) we can't just	would be boring and
		be the same because if we were all	that everybody has
		the same we would be boring	different likes and
		because say (.) because if I said I like	interests which
		Peter Rabbit and then you went I like	should be accepted.
		Peter rabbit and then I said I like	She talks about

	Halloween more than Christmas and	being othered for
	you said I like Halloween on	being different and
	Christmas (.)It's just (.) it's just not (.)	how people will
	just like you know, everything would	treat those that
	everybody would just be the same	present differently in
	and everything. So yeah (.) I'd rather	a rude way. She feel
	have everyone be different than just	this makes it difficult
	be like one person	to disclose being
		autistic for fear of
	I don't know (2) (sneezes) No,	being seen as weird.
	because sometimes when you're	Scarlett is aware that
	different and everything people just	she is judged for
	like (.) really rude to you and	having interest
	everything like (2) you know if you	which are not judged
	have autism, you don't want to tell	as acceptable with
	anyone like obviously like (.) its non	ehr peers. She has
	of your business really isn't it? And	been on the
	then you're just like (2) WEIRD is	receiving end of
	what that's what they think (.) And	questions being
	then they're just like (2) what what	asked what is wrong
	you doing (.) what's wrong with you?	with her because she
	Why Why have you got Teddy with	likes teddies,
	you? You don't need that can you	something that is
	then you're just like (2) WEIRD is what that's what they think (.) And then they're just like (2) what what you doing (.) what's wrong with you? Why Why have you got Teddy with	receiving end of questions being asked what is wror with her because s likes teddies,

		put it back and stuff like that? Then	related to young
		everything because I remember once	children.
		we were in	
Likes	HIT MEEN	Halloween (.) I like Halloween more	Scarlett likes
Hallowee		than Christmas. I just don't know	Halloween and is
n		what it is that I like about it. Some	aware that some
		people think I'm weird for it, but I	popel will not
		don't really care what they think	understand why she
			like sit more than
		I really don't know. I just don't I	Christmas. She
		don't know why like because if	describes imagery
		Christmas it's easy for me to like	that is related to
		describe what I like with Halloween.	Halloween rather
		I just don't really like (.) know how to	then actual
		describe it and everything. It just got	experiences. She
		into it at one point. Probably like	enjoys the social
		because when it's Halloween you	aspect of going trick
		can go out into like forests and	or treating together.
		you're scary like fogs. Do pumpkin	
		picking pumpkin go to pumpkin	
		patches.	

	I	
	Yeah, got trick or treating (3)	
	everything like that. I just love going	
	Halloween shopping	
	Random ones, just there was	
	Coraline which I actually really love. I	
	love her. If you go on Amazon and	
	try and search for them. There's just	
	(2) there's adult ones (.) And then if	
	there is any costumes for kids, you	
	have to buy (.) more separately like	
	buy the raincoat and the boots and	
	hair (.) all separately and like	
	normally like 30 pound all of them.	
	I'm like (2) no thanks	
	Just put a Primark sheet of my head	
Likes	Aurora I just love her voice and	Scarlett likes Auror,
Aurora	everything and so does my mum,	an interest she
	because I you know the erm (2) what	shares with her
	was it you know, Frozen where that	mum. Scarlett tends
	voice was called in.	to liek music which
		she finds on TikTok

I don't know. I just heard her one	which ould give her
day. And like (2) there was just one	the cultural capital
song that I really like (.) here for me.	with her peers.
And it's just like really good. There is	
like a dance but you have to do it	
with your knees (.) my friend can do	
it but I really do not know how to do	
it	
I just like it it is just really catchy	

## Diagram showing reoccurring themes within the participant's narratives.



## **Question 1**

Theme	Participant and line number for reference.
Self as Inhibited	Alex 643, 504
	Billie 763, 473.
	Mia 367, 225, 226
	Molly 290, 307, 318
	Sadie 346, 610, 990, 869, 879

	Sarah 869
Sensory	Alex <i>302</i> Billie 519, 528.
	Mia 367
	Sadie 308, 968
	Scarlett 818, 742, 752, 769, 777
Self as Unique	Alex 630.
	Billie 670
	Mia 445
	Molly 490, 492
	Rissa 32, 34, 12
	Sarah 167
	Scarlett 36, 31, 185, 441
Autistic Self	Billie 658.
	Mia <i>598.</i>
	Molly 456, 510, 485
	Rissa 264, 265, 275
	Sadie 779, 857, 1077
	Sarah 765
	Scarlett 996, 989, 1074
Strengths & Interests	Alex 400

	Billie 378, 439
	Mia 358, 46
	Molly 20, 43
	Rissa 158, 182, 34
	Sadie 308, 312
	Sarah 338, 373, 377, 459, 31
	Scarlett 226, 249, 307, 281, 818, 6,
Social Self	Alex 188, 556
	Billie 235
	Mia 484
	Molly 160, 427, 410
	Rissa 34, 129, 12, 43
	Sadie 312, 780, 124, 869
	Sarah 768
	Scarlett 43, 467, 136, 1085
Friendships	Alex 258
	Billie 289
	Mia 395
	Molly 200
	Rissa 129, 221, 169
	Sadie 349, 8, 127, 271, 276, 685, 689, 1028
Masking & Stigma	Alex 153

	Billie 233, 244, 676
	Mia 516, 484.
	Molly 427, 410, 526, 534
	Rissa 34, 12, 108, 43, 286
	Sarah 254, 765, 768
	Scarlett 824
Body Image &	Alex 536,
Appearance	Billie 559.
	Rissa 12
	Sarah 162, 18
Mental Health	Alex <i>643</i>
	Billie 323, 763.
	Mia . 537, 100, 113
	Rissa 182
	Sarah 167, 18, 587, 343, 195, 254
	Scarlett 415
Self Actualisation	Alex 689.
	Billie 240, 454
	Molly 579
	Rissa 198
	Sarah 26, 40
	1

Scarlett 665
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## Question 2

Theme	Link to Participants
Mothers	Alex 347
	<i>Mia</i> 470
	Molly 469
	Rissa 211
	Sadie 413
	Sarah 33, 542, 540
	Scarlett 806, 796, 989, 1074, 545. 736
Friendships	Alex 188, <i>258</i>
	Billie 287
	Rissa 221, 129, 169
	Sadie 377, 702, 79
Teachers	Alex . 680
	Billie <i>746.</i>
	Mia 408, 691.
	Molly 318
	Rissa 264, 265, 286
	Sadie 501, 515, 473, 478, 558, 968, 963

	Sarah 765 Scarlett 1003, 580, 597, 574
Animals	Alex 20
	Billie. 203, 330, 194
	Mia
	Molly
	Sarah 6
Language	Alex 603
	Billie . 931, 611.
	Mia 113.
	Molly 521, 526, 534
	Rissa 264

## **Appendix 9: Participant Information Sheet**

What you need to know.

## Information sheet.



What it means to be you?

Exploring autistic adolescent female's constructs of self and identity, a participatory approach to research using the creative arts.

You are being invited to take part in a research study. Before you agree, it is important that you understand what this would involve. By showing an interest in reading this information or asking questions you are not obliged to take part, it is only if you want or choose to be involved. Please take time to read the following information carefully.

Who am I?



My name is Nicole McMurdo and I am a student at the University of Sheffield. I am studying for a Doctorate in Educational Psychology. As part of my studies, I am carrying out some research which I would like to invite you to be involved in. This research project has been approved by the School of Psychology Research Ethics Committee. What this means is that my research follows the standard of research ethics set by the British Psychological Society. Before you agree, it is important that you understand what this would involve. Please take time to read the following information carefully.

#### What am I doing?

I would like to work with those who identify as female, have a diagnosis of autism, or \*selfidentify as autistic and attend mainstream secondary school. The aim of the research is to understand how you make sense of who you are and what influences this understanding. This project has been approved by the School of Psychology Research Ethics Committee. This means that my research follows the standard of research ethics set by the British Psychological Society.

\*self-identify means someone who recognises themselves as being autistic but have not had any formal diagnosis.

#### Why have you been asked to take part?

As you expressed an interest in response to the flyer shared by your educational setting, you have been invited to take part in the research to talk freely about who you are. I want my research to give you the opportunity to have your voice heard. You will not be judged in any way and you will be treated with respect. You are free to decide whether or not to take part, and you should not feel forced.

#### What will being a participant involve?

If you consent to being involved as a participant in this study your involvement could last from now until Autumn, 2022. Being a participant in participatory research is where you

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can help make decisions during the research. I will do my best to make sure taking part is a positive experience which you will enjoy by offering choices about how we communicate and work together. As part of your role you will be able to ensure your voice is heard accurately.

The first session will be an informal group session where you will have the opportunity to get to know each other and find out a little more about the research process. You can collect any pictures from magazines, books, printed off the internet and photos that you can bring to the next session.

During the second group session I will meet with the group again and ask you to complete a visual collage to tell me about you and what makes you who you are, this can include feelings, skills, talents, strengths, likes and dislikes. You might include how others may see you at home, in school or with your friends. You can use drawings, words or images from what you have collected. I will bring different materials, magazines etc... that can also be used. I will give you some questions to help you think about your work before we meet again.



At the third session we will talk about the collages and what they mean to you. I will ask you some questions and hopefully we will have an enjoyable conversation. The sessions will be audio recorded so that I can listen to what has been said. The questions will cover topics such as your strengths and likes, what you enjoy doing, how people may describe you, experiences that have influenced how you feel about yourself. I hope this session will be a positive experience and you will be able to make decisions such as how the chairs are arranged, whether you want background music, refreshments or a trusted person with you.



During the last session I will share some ideas with you about your collage and what I think it tells me. I will ask you what you think about this, your views will be valued. I will then share some 'I statements' from the typed record, so that we can create an 'I Poem' which helps represent who you are. I will support you in doing this and your input will be valuable.

## What happens next?

I will ask you if you would like to share your stories and if you would like to think of and discuss how your ideas can be shared with other people and how it can help other autistic females. I would like to create an animation of the collages and the I Poems. I will ask if you are happy for your work to be shared in an animation and whether you would like to take part in this. This will be your choice and there will be no pressure for you to do this if you do

not want to.



## What are the potential benefits or risks of taking part?

## Benefits

• There are no direct benefits from your involvement to you but I hope that it will be an enjoyable experience for you where we will talk about what interests you and your experiences. Where possible I will try to hold our meetings in a place that is familiar, comfortable and quiet.

 Information gained from you and other participants could potentially help to improve how school staff work with young people.

#### Risks

 During the interview you might think about things that could make you feel upset. To support you, there will be follow-up support from a familiar adult if necessary. I have attached an information sheet about the cards that you can use during the interview to indicate when you want it to stop or if you need a break. The interviews can be rearranged for another day if at any time you feel you need to stop.

#### Safeguarding

Any personal details that are shared or discussed during the interview will be anonymised and will remain confidential. The only time this would change is if you told me something that made me believe you were not safe. This is nothing to worry about and I would talk to you about this if I felt this needed to happen.

#### When will the project begin and end?

You will be involved in the first part of the research process, this will take place in XXXX, XXXX or XXXX. The research project will overall take up to 14 months until it is written up in summer 2023. If you have any questions, please feel free to ask me (Nicole) or my research supervisor (Penny) using the contact details below. Please keep this information safe as you may want to read it again in the future. Nicole McMurdo (Researcher)

Penny Fogg (Research supervisor)

Email: <u>njmcmurdo1@sheffield.ac.uk</u>

Email: p.fogg@sheffield.ac.uk

Anthony Williams (Course Director) Email: Anthony.williams@sheffield.ac.uk

If you decide **you would like to take part** now you have read all the information and discussed it with your parents/carers, you will need to complete the consent forms. Once you and your parents/carers have completed the consent forms and signed them they can be returned to XXX (SENCo) or to me. Once all the consent forms have been returned a date will be give to you for the first 'introductory' session. I will look forward to meeting you.

A video of this information can be found on this link,

https://youtu.be/oorFC-ooeO0

## What is the legal basis for processing my personal data?

According to data protection legislation, I am required to inform you that the legal basis I am applying in order to process your personal data os that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6 (1)(e)). Further information can be found in the University Privacy Notice:

https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

As I will be collecting some data that is defined in the legislation as more sensitive, information about gender identity, I will also need to let you know that I am applying the

following condition in law: that the use of your data is 'necessary for scientific or historical research purposes'.

#### Who is organising and funding the research?

The research project is part of the requirements for completion of my Doctorate in Educational and Child Psychology and does not have any sponsorship or funding.

## Who is the Data Controller?

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

## Who has ethically reviewed the project?

The project has been ethically approved via the University of Sheffield's Psychology Department ethics review procedure. Should you decide to take part, you will keep this information sheet and be asked to sign a consent form. **Appendix 10:** Parent/carer information letter



Researcher: Nicole McMurdo <u>njmcmurdo1@sheffield.ac.uk</u> Researcher supervisor: Penny Fogg <u>p.fogg@sheffield.ac.uk</u>

Dear Parent or Guardian,

Thank you for taking the time to read this information sheet and let me introduce myself. My name is Nicole McMurdo and I am a Trainee Educational Psychologist. I am studying for a Doctorate in Educational Psychology at The University of Sheffield. I have over 15 years' experience as a teacher and have personal experience of autism, and of working with autistic girls.



I am really excited to be able to invite your daughter to take part in a research project about how autistic adolescent females make sense of their self and identity who attend mainstream secondary schools. Please take some time to read the information sheet and then discuss the project with your daughter to see if she would like to participate. If you agree to take part it would be great if you and your daughter can sign the forms to give consent to take part.

#### What is the research about?

The research aims to enable autistic adolescent females to have their voice heard which will inform school staff and professionals in how best to support them. The research aims to empower the young people involved by inviting them to be active participants, giving them agency as co-researchers. To participate in this project the girls should:

- 1. Be aged between 11-16.
- 2. In full time education.
- 3. Registered at school as female.
- 4. Have a diagnosis of autism or self-identify as autistic.

\*self-identify means someone who recognises themselves as being autistic but have not had any formal diagnosis.

Your daughter's well-being will be my upmost priority and so it will be important to consider whether your daughter is comfortable being identified as autistic and are happy to talk about this.

#### What will be required of my daughter if she participates?

Your daughter will work with me to create a collage that represent who she is, her interests, strengths, and any other aspects she feels are important to share about her identity. There will be four sessions in total lasting up to 60 minutes.

- The first session will take place in school with a trusted adult and the other
  participants from your daughter's school. There will be an informal 'getting to know
  you' session initially which will last approximately 30 minutes. This session will
  provide an opportunity to ask any questions and get to know me. At the end of the
  session your daughter will be asked to collect any images, photos or drawings that
  represent her interests, strengths, favourite places and people. It can be any pictures
  from magazines, books, printed off the internet and photos that can be brought to
  the next session.
- The second session I will meet your daughter and ask her to complete a visual collage to tell me about herself and her identity. She can use drawings, words or images from what she has collected. I will bring different materials, magazines etc... that can also be used. There is no requirement to have any level of artistic ability, it will be a relaxed session where I can provide support with the collages. At the end of the session, I will give your daughter some questions to help her think about her collage work before I meet again. Your daughter will have the opportunity to opt out of any questions she feels does not want to answer.
- The third session is where we will talk about the collage that your daughter has
  produced. I will share some questions to help her reflect on what she has created.
   The questions will cover topics such as her strengths and likes, what she enjoys
  doing, how people may describe her, experiences that have influenced how she feel
about herself. The sessions will be audio recorded so that I can listen to what has been said and your daughter can have a trusted adult in the session if she would prefer. I hope this session will be a positive experience and your daughter will be able to make decisions such as how we sit, whether she wants background music, refreshments, or a trusted person with her.

- During the last session I will share some ideas with your daughter about her collage and what I think it tells me. I will ask her what she thinks about this, her views will be valued. I will then share a typed 'I statements' that I have selected from the typed transcript of our discussion from the previous session. I will support your daughter in creating an 'I Poem' which helps represent who she is from the statements once your daughter has checked she is happy with them.
- The collages and I Poems will be used to create an animation that can be shared as
  part of the dissemination of the research and to amplify the participants voice within
  the research. Your daughter does not have to take part in creating the animation
  unless she wishes to be involved with this stage. Any voices in the animation will be
  provided by myself however your daughter will be able to contribute to the decisions
  about the animation and help create the characters and artwork that will form the
  presentation.

I will be contactable by the email included on this information sheet throughout the project and following its completion.

#### Are there any risks?

All personal details including anything your daughter says during the interview will remain confidential. The only time this would change is if your daughter told me something that made me believe she was not safe.

My aim is for the research experience to be a positive one where your daughter will feel involved as we work collaboratively together rather then the research being 'done to' her. I will use a colour card system to ensure your daughter can say if she would like a break at any time during the process or if she would like it to stop altogether. I aim to create a positive experience where the interviews will feel like a conversation that your daughter enjoys and find the process interesting. I want your daughter to feel as comfortable as possible and so will discuss with them how they would like the interview to be carried out e.g., table and chair layout, playing background music, bringing a trusted adult. The questions will have been seen prior to the interview to prepare what answers may be shared to reduce the risk of any surprises or unexpected responses. The questions mainly explore positive aspects which may reduce the risk of your daughter becoming upset. There will be staff available to support your daughter in school throughout the research and I will ensure she has an information sheet which will include support services contact details should you need it. Your daughter's well-being will always be the priority throughout the process, I really want her to enjoy working with me.

#### What are the benefits of my daughter's involvement?

There are no direct benefits from being involved in the research. My aim is to make the experience both positive and enjoyable. Participants in research like this often find it is helpful for their own reflection and interesting. As your daughter will be a participant in

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participatory research this will help her to be involved in suggesting changes and enable her to have a 'voice' within the research. It is hoped that the findings will help to improve provision for autistic females' wellbeing and experiences.

#### What happens if I or my daughter change our minds?

You or your daughter can withdraw your consent at any time during the project and up to 7 days after completion. You can do this by emailing me or my supervisor on the email addresses above. You are not required to give any reason, there are no penalties for withdrawing. Any data already collected about your daughter would be destroyed, unless she consented to it being kept.

#### Can I see the results once completed?

Yes. I will email a copy of a summary to all the participants once completed.

#### What will happen to the data?

All of the data, both personal and the data collected in the project, will be loaded onto a secure google drive which requires a two-factor authentication process to access. The collages will be kept in a locked in a filing cabinet until the end of the projects when your daughter can then take them home if they wish or will be destroyed. The data will be accessed only by the researcher, Nicole McMurdo and shared with Dr Penny Fogg once anonymised. All data will be stored in accordance with the Data Protection Act. You can find more information about the act here

#### https://www.gov.uk/government/collections/data-protection-act-2018.

In line with the University's policy on the management of research data, only data that is anonymised will be gathered in this research. It may be preserved and made available publicly for others to consult and reuse. The results of the study will be written up as part of my Doctorate thesis, and may be presented at national and international conferences, in written articles and reports. If you so wish I can send you copies of these electronically. The anonymised data will be used as part of my dissemination of my research, with consent this will include quotes, the I poems and the collages.

## What happens if something goes wrong?

In the unlikely case of a concern or complaint, you can contact Dr Penny Fogg, University of Sheffield, at <u>p.fogg@sheffield.ac.uk</u> or Dr Anthony Williams, Course leader at the University of Sheffield at <u>Anthony.williams@sheffield.ac.uk</u>.

## What should I do next?

If you have any further questions, please contact me on <u>njmcmudo1@sheffield.ac.uk</u>. If you are happy for your daughter to take part and she consents, please complete both the parent/carer and participant consent form, sign and return to XXX (SENCo) or to me. I do hope that you will support your daughter's participation in this research project. This research project has been approved by the School of Psychology Research Ethics Committee. What this means is that my research follows the standard of research ethics set by the British Psychological Society. The University has appropriate insurances in place. Full details are available on request.

A video version of this information can be found on this link:

# https://youtu.be/oorFC-ooeO0

Thank you for your time and I look forward to hearing from you.



## Appendix 11: Participant Consent Form

Title of the project: What it means to be you? Exploring autistic adolescent female's

constructs of self and identity, a participatory approach to research using the creative arts.

Name of researcher: Nicole McMurdo

Participant pseudonym:.....

Please make sure you have read/watched/listened to the information sheet before

completing this form. Please read the statements below and put your initials at the end if

you agree with them.

I understand the information that I have read/watched or listened to on the information sheet dated XXXX for the above study.	1	
I have had the opportunity to ask questions, have them answered and have had time to think about my involvement in the research.	C. C	
I confirm that I am taking part in this project by choice and have not been pressured. I understand that taking part in this project will involve me making a collage and talking about myself. Interview sessions will be recorded.	$\bigcirc$	
I understand that I can withdraw from the research at any time, up to 7 days after the project has ended. I will not have to give a reason. If I withdraw my data will be destroyed.	$\diamond$	
I understand I do not have to answer any questions that I do not want to or feel able to. I can use the cards to indicate this and will not be pressured for a reason.	00 5.	

I understand that as part of the	research the thing	s I talk about will be	
written in a report. My name w	vill not be used in t	he report. There may	
be extracts of what I said used i	n quotes to illustra	te certain points, but	
no names will be included.			
Yes I agree to take part in the p	roject.		
			<u>I</u> I
Name of participant	Date	Signature	
Lead Researcher	Date	Signature	

Copies: Once this has been signed by all parties, the participant should receive a copy of the signed and dated participant consent form, the information sheet and any other written information provided to the participants. A copy for the signed and dated consent form should be placed in the project's main record (e.g. site file), which must be kept in a secure location.

Contact details

Nicole McMurdo (Researcher)

Dr Penny Fogg (Research supervisor)

Email: njmcmurdo1@sheffield.ac.uk

Email: p.fogg@sheffield.ac.uk

Dr Anthony Williams (Course Director)

Email: <u>Anthony.williams@sheffield.ac.uk</u>

Consent forms for parent and participant.

Title of Project: What it means to be you? Exploring autistic adolescent female's constructs

of self and identity, a participatory approach to research using the creative arts.

Name of Researcher: Nicole McMurdo

Participant pseudonym: .....

If you consent for your child to participate in this research, please read each statement

below, indicate your response and sign below to give your consent.

Please tick the relevant column.	Yes	No
Participating in the project.		
I have read the project information sheet or watched the information video		
and understand what it involves. (If you answer no to the statement you do not		
need to proceed with completing the form until you fully understand what		
participation in the research means).		
I have been given opportunity to ask questions about the project.		
I agree for my child to take part in the project. I understand this will involve		
creating a collage about how they understand who they are and their		
identity. They will talk about this collage and their understanding with me. I		
understand my daughter will create an 'I poem' from the transcripts.		

I understand that taking part is voluntary and I can withdraw my child from the	
study at any point, up to 7 days after completion. I do not have to give any	
reasons for why I no longer want my child to take part and there will be no	
adverse consequences if I choose to withdraw.	
I agree for my child to take part in creating an animation to present the work	
that they have created in the project. I understand this will involve clips of their	
work, their I poem or quotes whilst remaining anonymous. I understand that	
any voices used in the animation will not be provided by my child.	
I understand that taking part in the creation of the animation is voluntary and I	
can withdraw my child from this stage of the research. I do not have to give any	
reasons for why I do not want my child to take part in this stage of the project.	
How my information will be used during and after the project:	
I understand that any personal details for my child such as name, age, phone	
number and address etc. will not be revealed to people that are outside of the	
project.	
I understand that quotes from what my child says in response to the questions	
may be used in publications, reports, web pages and other outputs for	
research. I understand that my child will remain anonymous and not be named	
in these outputs.	
I understand and agree that other authorised researcher's may use the data	
from the research including your child's contribution in reports, publications,	
webpages and other research outputs, on the condition that they preserve the	
confidentiality of the information that they require, as requested in this form.	

So that the information you provide can be legally used by the researchers:	
I agree to assign the copyright I hold in any materials generated as part of this	
project to The University of Sheffield.	

Name of parent/carer	Date	Signature
Lead researcher	Date	Signature
Lead researcher	Date 	Signature

(To be signed and dated in the presence of the participant)

Copies: Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the information sheet and any other written information provided to the participants. A copy for the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location

Contact details

Nicole McMurdo (Researcher)

Dr Penny Fogg (Research supervisor)

Email: <u>njmcmurdo1@sheffield.ac.uk</u>

Dr Anthony Williams (Course Director) Email: Anthony.williams@sheffield.ac.uk Email: p.fogg@sheffield.ac.uk

# Appendix 12: Project Guidance booklet

# What it means to be you?

# Exploring autistic adolescent female's constructs of self and identity, a participatory

approach to research using the creative arts.



# Session 1

This is a chance to get to know each other. Here is something you might like to know about

me.



This is me! My name is Nicole.

I used to be a teacher and now I am a student.



I am training to be an Educational Psychologist.



I have two pugs called Minnie and Mickey.



I love listening to country music.

Here are some ideas that you could complete before the next session.

1.....

2.....

3.....

Remember to collect any photos, magazine cuttings, materials, leaflets or drawings that you

feel represent you and who you are for the next session.

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## Session 2 – Group Session

Today we are going to make our collage pictures that are your artistic representation of who you are. You can use a combination of colour, drawing and sticking. I have added some pictures of examples of collage. There is no right or wrong in this as it is completely your own work and ideas.



In the next session we are going to talk about your collage. Here are some questions that

you might want to think about to help you.

How do you like to spend most of your free time currently? What do you most enjoy / are you
most interested in right now?
How would you describe yourself?
What do you think your strengths are?
How would your family describe you?
How would your friends describe you?
What would your teachers say if I asked them to tell me about you?
How do you feel when you are doing things you enjoy?
Is there anything you try not to do? Are there things you don't do or avoid doing?
What helps you to be yourself?
Can you tell me when you feel happy? Relaxed?
What would you like to get better at?
Were there any specific experiences that have influenced how you feel about yourself?
Were there any specific people that have influenced how you feel about yourself?
If the young person raises being autistic or indicates, they would like to talk about it
Can you tell me what being autistic is like for you?
Is there anything that has been left out that you feel is important?

Remember you don't have to answer any questions that make you feel uncomfortable, or

you do not know the answer to.

# Session 3

Today we are going to talk about your collage and work through the questions. Remember

you can use the cards to communicate how you are feeling.



The green card will show that you are ready to begin the interview and happy to continue to talk.



The yellow card will show me you are starting to feel uncomfortable. I can move on to the next question when I see this.



If you want to stop the interview for today, I will end the questioning immediately when I see this. You will not have to give a reason for this unless you want to.



If you do not understand a question just show this card and I can ask it in a different way.



If you need to take a break just show this card and we will take a <u>comfort break</u>. When you are ready to start again place the <u>green</u> card next to the clock. If you want to stop for the <u>day</u> you can show your <u>red</u> card.

## Where can I get help?

If you would like support following your interview or involvement in the research you can speak to XXXXX in school. There are a number of contacts listed below if you would like further help or prefer to talk to someone else.

# childline

ONLINE, ON THE PHONE, ANYTIME

Call free on 0800 1111 for information and advice on lots of issues such as bullying, friendships, schools and relationships. Go online to <a href="https://www.childline.org.uk/">https://www.childline.org.uk/</a>



The place to go if you have any mental health or wellbeing worries. You will find separate sections for parents and young people. https://www.youngminds.org.uk/



This is a Lancashire based support page that guide you to the right place for support for a problem or to find out more about a particular subject. Call 0800 51 11 11 or text 07786 51 11 11 https://www.lancashire.gov.uk/youthzone/need-to-know/.



A support service that can help with whatever challenge you are facing from mental health-money, from homelessness to getting a job, from break-ups to drugs. You can talk via the online community, on social, using the free helpline or counselling service. https://www.themix.org.uk/

0800 808 4994 or text THEMIX to 85258

#### Session 4

#### **Analysis and I Poems**

This is the exciting part when you get to reflect on what you have shared during this process and what can be learnt from the information we have collected. Remember your views are valued and your voice is important.

We are going to follow these steps:

Step 1

Read the 'I statements' that I have taken from the transcript of the interview. Do you feel

the statements are accurate?

Step 2

We will put the statements together to create an 'I poem'. Read through the poem or if you would prefer I can read it aloud, do you feel this accurately reflects what you were communicating about you?

This is your poem so I would be really glad to hear any thoughts you may have or if you have any suggestions about the poem.

#### What is next?

You will have produced both a collage and an I Poem which will hopefully represent how you understand yourself.

What happens next is completely your choice. With your permission I would like to share the work we have done with others. You would remain anonymous under your chosen pseudonym.

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I would like to make an animation of the collages whilst the I Poems are being recited with your consent. If you would like to take part it is important that you complete the additional consent form which was shared with you at the beginning of the research project. If you have already completed this form I will check that you are still happy with all that you completed on the form.

**Appendix 13: Research Poster** 

# Want to be part of something exciting?



My name is Nicole McMurdo, I am a trainee Educational Psychologist and a student at The University of Sheffield.

As part of my training, I am doing a research project to understand how autistic adolescent females make sense of who they are and their identity. This is important as a lot of what we know about autism comes from autistic boys and not girls.

## What difference will this project make?

I am hoping that this project will help to raise awareness and understanding of what it can be like to be an autistic girl. This could help other autistic girls when they hear stories from others about how they understand who they are, and it can help professionals when they are working with autistic girls.

## Taking part is voluntary.

Taking part is voluntary, nothing will happen if you don't want to. You are not obliged to take part.

You can choose to not take part at any point in the project.

# What will I have to do?

I am looking for 4-5 girls aged 11-16 who have a diagnosis of autism or self-identify as autistic who would be happy to talk to me about themselves. You would be invited to be a co-researcher where you can help make decisions during the research. I will do my best to make sure taking part is a positive experience which you will enjoy by offering choices about how we communicate and work together.

You will be invited to 4 sessions which will include a group introduction, a group creative session where you will create a collage that represent how you see yourself and your identity. There will also be an individual interview.

If you are interested and would like to know some more information, please ask xxxxx for an information sheet for you and your parent/guardian.

Talk to your parent/guardian as they will also need to agree then you can let XXX or contact me to express an interest in taking part.

There will be a 'getting to know you' session where you can ask further questions and meet me.

njmcmurdo1@sheffield.ac.uk



Looking forward to meeting you.

## Appendix 14: Group rules that school provided.

- 1. Confidentiality- covers issues about what is shared outside the group. We agree that what is said or done in the group, stays in the group and is not repeated outside of the group permission.
- 2. Amnesty- confidentiality shared information isn't used against others during or after the group.
- 3. Put-ups, not put downs- everybody's contribution is valued and any question is encouraged.
- 4. Right to pass- it is ok if you don't want to say anything or talk.
- 5. Respectful listening- the group will listen with attention to someone who is sharing and that only one person talks at a time.
- 6. Feelings happen- people may experience feelings such as hurt, sadness, boredom or anger. We agree that we will show respect and create a safe space for anybody who wishes to express their feelings.
- 7. I-statements- people to speak for themselves and their own experience and not speak for others.
- 8. Personal accountability- the group can take charge of their own needs (bathroom break, taking a stretch, asking for help) and have fun during the process.

## Appendix 15: Phase 3 thematic map

