# "It's like the only way I have ever lived, I can't think of anything else": An interpretative phenomenological analysis of the lived experiences of adolescent autistic girls from minoritised ethnic backgrounds

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## Summary

This thesis is divided into three key chapters: a review of the literature, an empirical chapter, and a critically reflexive account. The first chapter provides a narrative review of the educational experiences of autistic girls as well as the relationship between culture and autism including detailed explanation of relevant terminology and consideration of the current context. Secondly, the empirical chapter presents a qualitative study which employed semi-structured interviews and child-friendly resources to explore the views and experiences of five autistic girls from minoritised ethnic backgrounds. Following analysis of the data using Interpretative Phenomenological Analysis (IPA), this chapter discusses the findings in relation to the broader literature and considers implications for practice and future research. Finally, the reflective chapter provides a critical account of the researchers' research journey, with a particular focus on the process of designing, conducting, and analysing the current study. This chapter also explores plans for dissemination.

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## List of acronyms

**AEP:** Association of Educational Psychologists

**A-Levels:** Advanced Level

**APA**: American Psychiatric Association

**AS:** Asperger Syndrome

**ASC:** Autistic Spectrum Condition

**ASD:** Autistic Spectrum Disorder

**BAME:** Black, Asian, Minority Ethnic

**BPS:** British Psychological Society

**CT:** Critical Theory

**CYP:** Children and Young People

**DfE:** Department for Education

**DoH:** Department of Health

**DSM:** Diagnostic and Statistical Manual of Mental

**EP:** Educational Psychologist

**EPS:** Educational Psychology Service

**EST:** Ecological Systems Theory

**GCSEs:** General Certificate of Secondary Education

**GDPR:** General Data Protection Regulation

**HCPC:** Health and Care Professions Council

**HFA:** High Functioning Autism

**IPA:** Interpretative Phenomenological Analysis

**LA:** Local Authority

**NAS:** National Autistic Society

**SEN:** Special Education Needs

**SENCo:** Special Educational Needs Co-ordinator

**SEND:** Special Educational Needs and Disability

**SSIs:** Semi Structured Interviews

**TA:** Teaching Assistant

**TEP:** Trainee Educational Psychologist

**UEA:** University of East Anglia

**UK:** United Kingdom

**UNCRC:** United Nations Convention on the Rights of the Child

**YP:** Young Person/Young People

# Chapter 1: Literature review

## 1.1 Introduction

Literature reviews aim to provide an overview of current knowledge and ascertain what has been achieved previously in a particular area (Grant & Booth, 2009). This prevents duplication and allows the researcher to identify relevant theories, methods and gaps in existing research. There are several types of literature reviews including systematic and narrative reviews (Grant & Booth, 2009). The former offers a summary of research evidence which answers a well-defined question (Higgins et al., 2022). This is achieved by using “systematic and explicit methods to identify, select, and critically appraise relevant research” (Higgins et al., 2022, p.4). On the other hand, narrative reviews are generally “comprehensive and cover a wide range of issues within a given topic, but they do not necessarily state or follow rules about the search for evidence” (Collins & Fauser, 2005, p.104). Narrative reviews also “link together many studies on different topics, either for purposes of reinterpretation or interconnection,” (Baumeister & Leary, 1997, p. 312). While both types of reviews are useful, the researcher felt that a systematic review would not be appropriate for this piece of research as its narrow focus and prescriptive approach would not allow for comprehensive coverage of the topics being explored in this thesis (Collins & Fauser, 2005). A narrative review was deemed as the most appropriate for this piece of research as it allowed for links to be made between studies exploring different topics (e.g., autism and gender and autism and culture). A narrative literature review was conducted which aimed to explore the experiences of autistic girls as well as the intersections between culture and autism.

### 1.1.1 Literature search strategy

As a narrative review was conducted, this chapter will be less explicit about the search strategy and the studies included (Bryman, 2012). However, in order to ensure transparency and rigour, details about the literature search including search terms, date ranges and exclusions are outlined below. Additionally, appendix 1 provides a summary of the key studies reviewed. A number of key databases relevant to autism research (Academic Search Complete, British Education Index, Child Development & Adolescent Studies, Education Research Complete, Education Resource Information Centre, PsychARTICLES, Teacher Reference Centre and Scopus) were searched between January 2022 and March 2023.  A ‘snowballing technique’ which involves identifying articles from reference lists (Jalali & Wohlin, 2012) was also used to identify further relevant articles. An initial search was conducted using terms relevant to the research topic e.g., minoritised, ethnic minority, Black Asian and Ethnic Minority (BAME), autism, girls, females, participants, education and experience. However, this did not generate any relevant studies. Thus, the researcher conducted separate searches, one relating to the educational experiences of autistic girls, and another one which focused on the intersections between autism and culture. Terms such as ‘autism’, ‘participants’ and ‘experience’ were broadened by using EBSCO’s thesaurus. This produced variations on terms such as ‘perspective’, ‘Autism spectrum condition (ASC)’, ‘child’, ‘perception’ and ‘education’. This literature review includes “grey literature” such as government statistics and unpublished theses. Unpublished theses can be particularly helpful when exploring topics which have not been widely researched (Hartling et al., 2017). Unpublished theses were deemed suitable as they were presumably reviewed through the process of external examination. Due to the limited research which focused on autistic girls’ experiences, studies examining autistic women’s retrospective experiences of education were included. Studies conducted outside of the United Kingdom (UK) were also included. Studies that focused solely on the experiences of parents and professionals were excluded. Moreover, studies which explored gender dysphoria or transgenderism within autistic children and young people (CYP) were excluded as it was felt that such studies added an extra layer of complexity to understanding autistic girls and thus were outside of the scope of the current literature review. Date limits were not set due to the lack of literature in this area of research.

### 1.1.2 Structure of review

This review starts with a detailed explanation and justification of the terminology adopted for this research. A narrative review of the existing research evidence relating to the educational experiences of autistic girls is then provided. This review is organised thematically and is divided into three key themes: relationships, school environment and mental health. This chapter also provides a brief narrative review of the literature exploring the relationship between culture and autism. The chapter concludes with a summary of the literature including gaps identified through the narrative review.

## 1.2 Terminology

This review uses several terms which are deemed complex. The following section aims to define and contextualise these terms. It is acknowledged that language is continuously evolving and that it shapes and reflects one’s understandings of one’s social environment (Kincheloe & McLaren, 2005).

### 1.2.1 Autism

Autism is commonly defined as a life-long neurodevelopmental condition which affects social communication and interaction, interests, behaviour and sensory sensitivities (American Psychiatric Association [APA], 2020). However, it is important to note that this is only one way of understanding autism (Happé & Frith, 2020). Autism was originally identified within a medical and deficit-focussed context (Kanner, 1943; Asperger ,1944). While the definition and aetiology of autism has changed over the years (see Happé & Frith, 2020 for a comprehensive overview of the evolution of autism as a construct), the medical model of autism still carries significant social capital and continues to be the most popular view of autism (Begon & Billington, 2019). Indeed, autism is currently diagnosed using the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM- 5, APA, 2013) or the International Classification of Diseases (ICD-11, World Health Organization [WHO], 2022), both of which focus on quantitative deficits. However, the neurodiversity movement has challenged the pathologizing and medicalisation of autism (Chapman, 2019) and several autism researchers and advocates are starting to describe autism differently (Begon & Billington, 2019; Jaarsma & Welin, 2011), stating that it is a ‘difference’ rather than a ‘disorder’ (Kapp et al., 2013; Latif, 2016). For example, Milton, an autistic researcher, advocates for the creation of discursive spaces “where autistic development is not framed from the outset as ‘disordered’” (Milton, 2017, p. 461). While the present research privileges alternative critical constructions of autism, positioning autistic individuals at the centre (Begon and Bilington, 2019), it is recognised that the neurodiversity movement has been criticised for failing to represent all autistic individuals. According to Jaarsma and Welin (2012), the neurodiversity movement is only applicable to a subgroup of the autistic community. They note that this movement overlooks autistic individuals who have an intellectual disability as well as those who have limited verbal skills, and/or who have pronounced co-occurring conditions. Jaarsma and Welin (2012) argue that these individuals may benefit from the medical model of disability, which recognises their autism as a ‘disorder’ rather than a ‘difference’. As such, some autistic individuals may view their autism as a ‘disorder’ or a disabling condition, whereas other autistic individuals may reject this view. As autism is an evolving construct that is changing overtime, the language used around it is constantly evolving. Autism is usually referred to as Autism Spectrum ‘Condition’ (ASC) or ‘Disorder’ (ASD) (Wing & Gould, 1979; Frith, 1991; Roth & Barson, 2010). Roth and Barson (2010) explained that clinicians and professionals often use the term ASD in the context of diagnosis and clinical practice. On the other hand, autistic individuals seem to have a preference for ASC as it is thought to be a more neutral term. In line with this preference, this research will interchangeably use the terms autism and ASC. There is also an ongoing debate regarding identity-first (e.g., autistic person) or person-first (e.g., person with autism) language. However, recently, Adams and Liang (2020) noted that while ‘…no consensus exists, and the ultimate choice is each individual’s, there is a general preference within the autistic community towards identity-first language…’ (p. 10). Additionally, a study conducted in the United Kingdom (UK) by Kenny et al., (2015) found that autistic individuals, their families and friends prefer the term ‘autistic’, whereas most professionals prefer the term ‘person with autism’. These findings underpinned the researcher’s decision to adopt the term ‘autistic’ when referring to participants, for example, ‘autistic girl’.

A recent study suggested that around one in 57 (1.76%) CYP in the UK have a diagnosis of autism (Roman-Urrestarazu et al., 2021). Autism accounts for a third of all Education, Health and Care Plans in England (Department for Education [DfE], 2022). Previous research indicates that the educational experiences of autistic CYP can be significantly worse than those of non-autistic CYP, especially when appropriate support is not in place (Humphrey et al., 2015). One may argue that autism is a national priority as the education of autistic CYP has received increasing attention, particularly in regard to educational interventions, policy and research (Bond et al., 2016; Pellicano et al., 2018; House of Commons, 2020).

### 1.2.2 Sex and gender

Before exploring literature relating to sex differences in autism, it is prudent to differentiate between the concepts of ‘sex’ and ‘gender’. The former refers to the biological attributes which define male and female whereas the latter is defined as “the socially constructed characteristics of women and men – such as norms, roles and relationships of, and between groups of women and men" (WHO, 2018, para1). As such, the key distinction between sex and gender is that "sex is related to anatomical structure, gender is related to an imposed or adopted social and psychological condition" (Diamond, 2002, p.321). While these concepts are complex and arguably require further exploration including consideration of the potential overlap between sex and gender, this is outside of the scope of this review. In line with previous studies (e.g., Sedgewick et al., 2018), the researcher adopted the term 'gender differences'. This review will use the terms female or girl in reference to sex assigned at birth. Previous studies in this area, considered gender as a binary construct. However, it is acknowledged that autistic individuals are more likely to identify as gender diverse (Bevan, 2017).

Research has established that there are gender differences in autism (Lai et al., 2015; Mandy et al., 2012). Historically, autism has been conceptualised as a male condition and evidence appeared to suggest that the condition was more common amongst males. For example, a ratio of 4:1 (in favour of males) was previously referenced by theorists and professionals (Baird et al., 2006; Rivet & Matson, 2011). However, other studies suggest that the actual ratio of autism diagnoses is roughly 2:1 (Dworzynski et al., 2012). The most recent estimates suggest a ratio of 3:1 (in favour of males) (National Autistic Society [NAS], 2021). Some theorists have argued that these conflicting prevalence estimates are due to male-biased diagnostic tools. This reflects the general gender bias in healthcare (Wesolowicz et al., 2018; Samulowitz et al., 2018; Westergaard at al., 2019). Mussey et al. (2017) argued that the prevalence estimates are more balanced when one does not rely on such tools. This supports the Female Autism Phenotype theory which posits that there is a specific female autism phenotype that is not detected by the current diagnostic criteria (Bargiela et al., 2016; Lai et al., 2015; Mandy et al., 2012). According to this theory, autistic girls present differently to autistic boys, for example autistic girls exhibit less restricted and repetitive behaviours and interests (RRBI) than autistic boys (Hartley & Sikora, 2009; Van Wijngaarden-Cremers et al., 2014). Autistic girls often have the same interest as non-autistic girls such as pop stars (Dean et al., 2017; Gould & Ashton-Smith, 2011; Hiller et al., 2014). The only difference is the intensity of such interests. Autistic girls experience more internalising difficulties, such as anxiety and depression (Hartley & Sikora, 2009; Holtmann et al., 2007) and are more likely to have high levels of anxiety than autistic boys (May et al., 2014). Although this is a plausible theory, theorists have put forward alternative explanations for the underdiagnosis of autistic girls (Lockwood et al., 2020). For example, the Female Protective Effect theory proposes that females require a greater combination of both environmental and genetic factors in order to exhibit autism, compared to males (Hull & Mandy, 2017). Moreover, the Camouflaging Hypothesis states that autistic girls and women are more likely to camouflage their autistic traits, therefore they are underdiagnosed (Cook et al., 2021). Camouflaging will be explored in more detail below.

Research has also shown that there are gender differences in mean age at diagnosis with boys being diagnosed at a younger age than girls (Begeer et al., 2013; Shattuck et al., 2009; Duvekot et al., 2017; Gould & Ashton-Smith, 2011; Mandy et al., 2012; Rynkiewicz et al., 2019). Begeer et al. (2013) conducted a large-scale study in the Netherlands and found that the mean age for girls diagnosed with autism was 1.8 years older than the mean age for boys. They added that key factors such as socio-economic status (SES) and ethnicity might play a role in the diagnosis for girls. However, these factors were not examined in their study. Likewise, a UK study found that girls are diagnosed 2 to 3 years later than boys (Russel et al., 2021). Notably, research has shown that cognitively able females are more likely to remain undiagnosed than females with intellectual disability (Baldwin & Costley, 2016; Rynkiewicz et al., 2019; Zener, 2019). Furthermore, autistic girls and women are commonly diagnosed with mental health conditions such as anxiety, obsessive compulsive disorder and depression before they eventually receive an autism diagnosis (Feist, 2013; Hull et al., 2017; Lai & Baron-Cohen, 2015; Milner et al., 2019; Tierney et al., 2016). At present, it is unclear whether these girls and women are misdiagnosed with these mental health conditions as suggested by some researchers (Begeer et al., 2013; Feist, 2013; Gould & Ashton-Smith, 2011; Hull et al., 2017; Milner et al., 2019); or whether they develop secondary mental health conditions (Beteta, 2009; Cook et al., 2018; Cridland et al., 23 2014; Feist, 2013; Gould & Ashton-Smith, 2011; Tierney et al., 2016) as a result of being ‘undiagnosed autistics’ and managing the challenges associated with this. Nonetheless, recent evidence suggests that there has been an increase in the number of girls and women diagnosed with autism in the last few years (Lai et al., 2015).

### 1.2.3 Culture, Ethnicity, ‘Race’ and Minoritised

The terms culture, ethnicity and ‘race’ are often used interchangeably. However, while these terms are somewhat related, they refer to distinct constructs. Culture is a “complex and multi-dimensional” construct (Urdan & Bruchmann, 2018, p. 124) which can be difficult to define (Spencer-Oatey, 2013). In 1952, Kroeber and Kluckohn (1952), critically reviewed definitions of culture and compiled a list of 164 definitions. Within this research, culture will be defined as “the social norms, roles, beliefs, values and traditions that influence the behaviours of a particular social group” (King et al., 2018, p. 1032). On the other hand, ethnicity is related to group identity and a sense of belonging to a particular ethnic group (Fernando, 2019). Individuals within the same ethnic group often share a common language, place of origin, traditions, values and beliefs (Jones, 1997). An individual’s ethnic and cultural identity is complex and is understood to be highly fluid and personal (Slade, 2014). Interestingly, while everyone possesses ethnicity and culture, these terms are often only used in relation to “minority” groups or “the other” i.e., non-white individuals (Patel et al., 2000; Fernando et al., 2005). ‘Race’ refers to “a group of human beings socially defined on the basis of physical characteristics such as skin colour, hair texture and facial features” (Cornell & Hartmann, 2007, p.25). However, it is now widely acknowledged that ‘race’ is more closely linked to power and oppression than to biological differences (Patel et al., 2000). For example, Du Bois (1903) argued that the concept of ‘race’ was created to provide a biological justification for oppression. Thus, within this research, the term ‘race’ has been used with inverted commas to highlight the fact that it is a social construction which is underpinned by racist historical acts and systems such as colonialism, slavery and apartheid (Durrheim et al., 2009). The current research primarily focuses on culture and ethnicity. However, due to the complex nature of these constructs, it is acknowledged there will be some overlap between ethnicity, culture and ‘race’.

In the UK, the acronym ‘BAME’ (Black, Asian and minority ethnic) has commonly been used by government departments, public bodies and the media to refer to individuals who belong to a ‘minority’ group. Consequently, the acronym has been used extensively within UK research and publications. For instance, the NAS ‘Diverse Perspectives: The challenges for families affected by autism from BAME communities’ (NAS, 2013). However, this term is problematic for a number of reasons. Firstly, it reduces individuals to acronyms. Secondly, it fails to encompass the diversity within these groups (Okolosie et al, 2015) as it groups all individuals from non-white descents into a meaningless collective (Inc Arts UK, 2020). For example, Asian is a very broad term and does not distinguish between 'South Asian' and 'East Asian' or 'Pakistani' and 'Chinese'. Thirdly, it has been argued that the term is used to mask the unique inequalities which specific ethnic and racial groups face (Okolosie et al., 2015). For example, the educational outcomes for CYP from Indian heritage backgrounds is very different from those from third-generation Caribbean backgrounds. This demonstrates that ethnic inequalities do not impact all minoritised communities equally. Another criticism of the acronym BAME is that it potentially creates a hierarchy as it names some ethnic groups (e.g., Black and Asian) over others. It is also important to note that this acronym was not chosen by those it applies to. Thus, individuals have been deprived of the opportunity to exercise their autonomy, which is vital for psychological well-being (Deci & Ryan, 2000). Due to these criticisms, in March 2021, the Commission on Race and Ethnic Disparities recommended that the government stop using the term BAME (HM Government, March 2021). As such, alternatives terms were considered for this research. For example, the terms ‘ethnic minority’ and ‘minority ethnic’ are commonly used in the UK but are seen as equally problematic (Aspinall, 2002). This is because the term ‘minority’ can be misinterpreted as meaning “less important or marginal” (Aspinall 2002, p. 804). Additionally, ethnic groups that are minorities in the UK are in fact majorities in the global population i.e., global majorities (Aspinall, 2002). Alternative terms such as ‘people of colour’ which are commonly used in the United States (US) are becoming increasingly popular in the UK, but they are also subject to criticism (Aspinall, 2002). Essentially, all the terms considered above centre whiteness and reinforce the idea that ‘whiteness’ is the norm and everyone else is the ‘other’ (Patel & Keval, 2018). However, such terms are useful as they provide a lens to explore social injustices and ethnic inequalities. Nevertheless, it is important to recognise that in order to dismantle structures of oppression, one must also dismantle the language that maintains such structures (Lorde, 2018). A recent survey conducted by Inc Arts UK (2020) found that individuals who belong to a “minority” group prefer terms such as “African Diaspora people”, “South Asian diaspora people” and “ethnically diverse” (diaspora refers to people who settled away from their homelands). However, it is not clear whether CYP took part in this survey.

Ultimately, the researcher opted to use the term ‘minoritised’ which was coined by Yasmin Gunaratnum in 2003. This term was thought to be more appropriate because it “gives some idea of the active processes of racialisation at work in classifying certain features of groups in particular situations as being in a minority.” (Gunaratnam, 2003, p.15). In other words, this term suggests that individuals do not inherently exist as a minority (as the term ethnic minority implies) but instead that they are actively minoritised by others. Minoritisation is therefore a social process influenced by power (Predelli & Halsaa, 2012). The term minoritised also better reflects the fact that ethnic groups that are considered minorities in the UK are in fact majorities in the global population i.e., global majorities. However, the researcher acknowledges that the term ‘minoritised’ refers to a process rather than an identity. It is important to ‘name and recognise’ individuals’ preferred identities (Selvarajah et al., 2020). Thus, where possible, the researcher will strive to be specific about the cultural and ethnic background of the participants of the reviewed literature. Nevertheless, it is acknowledged that some of the terms used in this thesis e.g., ‘White’ and ‘Black’ are ambiguous.

The UK is often considered a multicultural country. However, 82% of the population is from a White background compared to 18% from minoritised backgrounds (Office of National Statistics [ONS], 2021). Therefore, the dominant norm is White western culture (Patel et al., 2000). Autism affects individuals from all ethnic backgrounds (Roman-Urrestarazu et al., 2021). However, Frederickson and Cline (2015) argued that there are ethnic disparities in special educational needs and disability (SEND), specifically autism. Ethnic disproportionality refers to “when an ethnic group is significantly more, or less, likely to be in the identified with Special Educational Needs (SEN) compared to the ethnic majority” (Strand & Lindsay, 2018, p.1). For example, Black Caribbean and Black others CYP are considerably more likely to be diagnosed with autism when compared to White British CYP (Strand & Lindsay, 2018). Conversely, CYP from Asian groups such as those from the Pakistani and Indian diaspora are underrepresented when compared to White British CYP. More specifically, CYP from Asian groups were 50 per cent less likely to be diagnosed with autism compared to White British CYP (Strand & Lindsay, 2018). A more recent study, which explored the prevalence of autism within the school population in England, indicated that Black CYP have the highest prevalence (2.11%) whereas Roma/Irish

Travelers CYP have the lowest prevalence (0.85%) of autism (Roman-Urrestarazu et al., 2021). While the reasons for such disproportionalities remain unclear, theorists have argued that the following factors are likely to play a role: culturally biased diagnostic assessments, lack of cultural humility within autism diagnostic services and stigma within some minoritised communities (Papadopoulos, 2016). These factors will be explored in more detail within this chapter. Nationally, there is a drive to make diagnostic services more culturally competent and thus improve the experiences of minoritised individuals (National Health Service [NHS], 2019).

## 1.3 The educational experiences of autistic girls

A narrative review of the existing research evidence relating to the educational experiences of autistic girls is provided below. This review is organised thematically and is divided into three key themes: relationships, school environment and mental health.

### 1.3.1 Relationships

One key theme which emerged from the literature was relationships. Within this theme, three areas were identified: friendships, social motivation, camouflaging and social exclusion and bullying. These will be considered in detail below.

#### 1.3.1.1 Friendships

Previous research has highlighted differences between male and female friendships. For instance, girls typically have smaller and more intimate friendship groups than boys (Blatchford et al., 2003; Freeman & Kasari, 1998). Sedgewick at al., (2019) used self-report questionnaires and interviews to examine the friendship experiences of 102 young people in mainstream secondary schools in the UK (including autistic and non-autistic girls and boys). They found that autistic female friendships were more similar to non-autistic females than autistic males, particularly in terms of companionship, closeness, help and security. This suggests that gender is more pertinent than diagnosis when it comes to differences in friendships. Both autistic and non-autistic girls in this study were able to name at least one ‘best friend’ in school and most reported that they saw their friends outside school. However, they also reported experiencing ‘relationally aggressive’ behaviours. For example, gossiping, being excluded and having their trust betrayed. Such behaviour was not reported by both autistic and non-autistic boys. This fits with previous research which highlights differences in how boys and girls demonstrate aggression. In other words, girls tend to use subtler and more sophisticated social techniques (Card et al., 2008) which require more relational interpretive skills (Dean et al., 2014). As a result, autistic girls and women have stated that they find it difficult to navigate adolescent relationships and particularly manage conflict within these relationships (Cook et al., 2018; Cridland et al., 2014; Myles et al., 2019; Sedgewick et al., 2019; Tierney et al., 2016; Vine Foggo & Webster, 2017). They struggle to spontaneously learn the implicit social rules which underpin the social world of adolescent non-autistic girls (Edwards, 2012; Logsden, 2010; Moyse & Porter, 2015). For example, Rainsberry (2016) found that autistic girls struggled with the lack of predictability of peer interactions and the need to read social cues. This is also supported by one of the participants in the Myles et al. (2019) study who reported that she had to explicitly learn the hidden social rules. The complexity of friendships amongst adolescent girls was also highlighted by one study which included parental perspectives. Mothers in this study believed that the social difficulties experienced by their autistic daughters were greater than those experienced by autistic boys (Cridland et al., 2014). However, this study has a number of limitations. Firstly, the voice of autistic girls was not fully captured within this research. In fact, 93% of quotes used in this research were from mothers rather than autistic girls themselves (Jackson, 2019). This suggests that parental voices were favoured. Whilst parental perspectives are valuable, there is a lack of research which fully investigates the experiences of the autistic girls themselves. Secondly, this study was conducted in Australia thus findings must be considered with caution as they might not be applicable to autistic girls in the UK. Thirdly, the study used a small sample which lacked homogeneity. In fact, only one of the autistic girls in this study had a diagnosis of ASC while three had a diagnosis of Asperger Syndrome, and one had a diagnosis of Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). This is pertinent because, although Asperger Syndrome now comes under the umbrella of autism, being diagnosed with Asperger Syndrome was usually associated with positive connotations in comparison to autism (Huynh, 2020). Thus, one may argue that Asperger Syndrome was previously seen as a distinct identity to ‘autistic’ (Huynh, 2020). There was also lack of homogeneity in terms of the educational settings of the participants as some participants were in mainstream school while others were in specialist settings or units attached to a mainstream school. This is particularly pertinent because the type of educational setting is likely to influence autistic girls' experiences of friendship. The lack of homogeneity within the sample is incompatible with the analysis used i.e., Interpretive Phenomenological Analysis (IPA). Although some studies appear to suggest that autistic girls are more socially skilled than autistic boys, one study proposed that this apparent social success may be due to autistic girls using camouflaging behaviours such as maintaining proximity to their peers in order to mask their social challenges (Dean et al., 2017).

#### 1.3.1.2 Social motivation

As well as differences in friendships between autistic boys and girls, research has highlighted differences in motivation for friendships and social interactions. Cook et al. (2018) conducted a study with 11 autistic girls and their parents in the UK. They found that, unlike autistic boys (Cook et al., 2016), autistic girls demonstrated a motivation to have friends. This motivation to have friends has been reported by autistic girls and women from different ages and countries (Beteta, 2009; Gaffney, 2020; Kock et al., 2019; Milner et al., 2019; Myles et al., 2019; Rainsberry, 2016; Tierney et al., 2016; Vine Foggo & Webster, 2017). Rainsberry (2016) also found that autistic girls were motivated to have friendships and described how friendships were a source of comfort, support and belonging for two of the participants. Similarly, all autistic girls in the Myles et al (2019) study acknowledged the value of friendships. However, they also expressed a preference for smaller groups and often chose to stay on the 'periphery' of larger groups (Myles et al., 2019). Similarly, in Vine Foggo and Webster's (2017) study, seven Australian autistic girls reported that social interaction (and the associated mental health benefits) was important to them. Yet, three of the girls also highlighted the need for time alone so that they can self-regulate. Interestingly, this need for alone time was previously misunderstood as a lack of social motivation (Kanner, 1943). This further emphasises the need to include autistic girls in research as interpretations from researchers, professionals (and even parents) can be incorrect (Brownlow, 2010).

#### 1.3.1.3 'Camouflaging'

There is a wide body of literature which reports that autistic girls tend to engage in camouflaging (Lai et al., 2017; Schuck et al., 2019). Camouflaging refers to when an autistic individual employs strategies, (either consciously or unconsciously) to hide autistic characteristics (Hull et al., 2017; Lai et al., 2011). An example of camouflaging is when an autistic individual mimics facial expressions or forces themself to make eye contact and to stop talking about an interest. Camouflaging is also commonly referred to as compensation, masking or adaptive morphing. Compensation is a fairly recent term (Livingston & Happé, 2017) and it refers to when an autistic individual utilises alternative cognitive strategies to compensate for the socio-cognitive and behavioural difficulties associated with autism (Livingston et al., 2019). For instance, an autistic girl might compensate for theory of mind difficulties by using executive function strategies to learn to recognise facial expressions. While the researcher recognises that not all camouflaging involves alternative cognitive strategies, the term camouflaging has been used throughout this research as a broader term which includes compensation.

Before exploring the research concerning autistic girls and women’s tendency to camouflage, it is important to note that camouflaging is not exclusive to autistic girls and women. Indeed, autistic individuals of all genders report using a wide range of camouflaging behaviours and strategies in order to navigate the demands and expectations of a predominantly non-autistic world, often at great personal cost (Cage & Troxell-Whitman, 2019; Hull et al., 2017). For example, autistic individuals report camouflaging in order to build and maintain friendships, and prevent bullying (Cage & Troxell-Whitman, 2019; Hull et al., 2017). Likewise, it is also important to note that camouflaging is not specific to autism (Lai et al., 2020). Non-autistic individuals also use techniques to manage how others perceive them and facilitate positive interactions i.e., impression management or self-presentation behaviours (Goffman, 1959). Goffman (1959) describes how non-autistic individuals usually put on a “performance” by adopting a "front" (p. 22). However, the key difference between autistic and non-autistic individuals when it comes to the use of camouflaging strategies is that autistic individuals are more likely to experience a mismatch between their ‘authentic self’ and the expectations of a non-autistic social world. The consequences of not employing such strategies are also more severe for autistic individuals, this includes stigmatisation and discrimination (Lai & Baron-Cohen, 2015; Mandy, 2019; Perry et al., 2022). Qualitative research also highlights that camouflaging varies with age (Dean et al., 2017; Halsall et al., 2021; Hull et al., 2017). These age-related differences in camouflaging may be due to a number of factors including changes in cognitive development and age at diagnosis (Hull et al., 2021). Later age at diagnosis may lead to a greater tendency to camouflage (Lai & Baron-Cohen, 2015). On the other hand, those diagnosed at a younger age have more time to develop a strong autistic identity and therefore may feel less pressure to conform to the demands of a non-autistic social world (Cage & Troxell-Whitman, 2020).

Despite the fact that camouflaging affects both autistic and non-autistic males and females, the term is often used in relation to autistic girls and women and is presented as a possible explanation for the increased rates of missed or late diagnosis amongst autistic girls and women (Duvekot et al., 2017; Dworzynski et al., 2012; Head et al., 2014; Kirkovski et al., 2013; Lai & Baron-Cohen, 2015; Lehnhardt et al., 2016; Shattuck et al., 2009; Whitlock et al., 2020). Historically, autistic women themselves wrote about camouflaging. For example, Liane Wiley explained that, prior to receiving her diagnosis, she pretended “to be normal” (Willey, 2006). However, autistic women’s accounts of their own lived experiences were not always considered by clinicians and academics. This further highlights the importance of eliciting the voices of autistic girls and women as assumptions made by professionals may be inaccurate. Lehnhardt et al. (2016) argued that autistic girls and women have a greater ability to camouflage (compared to their male autistic counterparts) due to sex-related differences in cognitive profiles. However, other researchers and theorists argued that the increased tendency to camouflage seen amongst autistic girls and women is related to gender-based societal expectations (Kreiser & White, 2014; Pearson & Rose, 2021). Because of these societal expectations, autistic girls and women feel more pressure to fit in socially and thus resort to camouflaging strategies. This means that autistic girls and women feel more pressured than autistic boys to display the ‘right’ behaviours (Kreiser & White 2014; Lai et al., 2015). In less-pressured situations, autistic girls may not feel the need to employ camouflaging strategies. This may account for variation in perceived social communication difficulties across different contexts and environments as autistic girls can present differently across different environments such as home, school or in clinical assessment (Solomon et al., 2011). This may also account for variation in perceived social communication difficulties over time as the complexity of social situations changes across developmental stages as outlined above. Therefore, autistic girls may be able to camouflage their difficulties during simpler social interactions, but their difficulties may become more apparent as these interactions become more complex, particularly during adolescence (Lai et al., 2011; Mandy et al., 2018).

Several studies have qualitatively examined camouflaging in autistic girls and women. For example, through interviews with autistic girls and their mothers, Cridland et al. (2014) found that some autistic girls imitate their non-autistic peers' social behaviours and interests thus reducing the appearance of autistic characteristics. Tierney et al. (2016) conducted interviews with 10 adolescent autistic girls in the UK and found that the girls often used camouflaging strategies in order to hide autistic characteristics and therefore develop and maintain friendships. The use of such strategies negatively impacted their psychological wellbeing and arguably hindered access to appropriate support as their difficulties were concealed. Though the small sample size of this study means that the findings cannot be generalised to all autistic girls, such findings provide valuable information particularly when considered alongside other studies (e.g., Cridland et al., 2014). Furthermore, qualitative studies with late-diagnosed autistic women (Bargiela et al., 2016), autistic young women and their parents (Milner et al., 2019; Sedgewick et al., 2019; Bassett, 2022) and autistic adolescent girls (Jordan, 2021) generated similar findings.

#### 1.3.1.4 Social exclusion and bullying

Research has shown that autistic CYP are more likely to be bullied than non-autistic CYP (Cappadocia et al., 2012; Cook et al., 2018). Sterzing et al (2012) found that autistic individuals are four times more likely to be bullied than their non-autistic counterparts. In particular, autistic CYP who present as socially skilled are more likely to be bullied (Rowley et al., 2012). This may be due peers having higher expectations for those who present as socially able/skilled. These autistic CYP are then 'punished' for failing to meet such expectations. This means that autistic girls are particularly vulnerable to bullying as they are likely to present as more socially able due to camouflaging as well as the sex differences between autistic boys and girls outlined above. In line with this, bullying was a common theme in many studies exploring the experiences of autistic girls and women (Bargiela et al., 2016; Beteta, 2009; Cook et al., 2018; Cresswell & Cage, 2019; Cridland et al., 2014; Goodall & MacKenzie, 2019). These studies showed that autistic girls tend to experience relational bullying (e.g., being ignored) rather than overt bullying (e.g., shoving) which can be less obvious to adults and the girls themselves (Myles et al., 2019). In one study (Cook et al., 2018), autistic girls attending both mainstream and specialist settings described other examples of relational bulling including being picked last in PE or not being invited to parties. Moreover, using peer-nomination data, Dean et al. (2014) found that both autistic and non-autistic girls were less likely to be overtly rejected. However, autistic girls were also less likely to be listed as a friend or as a member of a group. This suggests that while autistic girls are not overly rejected like their male autistic counterparts, they are easily overlooked. This fits with other studies which show that the social behaviour of autistic girls superficially resembles that of non-autistic girls, and that the social-communication difficulties of autistic boys are more evident (Dean et al., 2017). However, when explored more closely, it becomes apparent that both autistic girls and boys experience social challenges, have fewer social connections and are less likely to have a mutual friend (Dean et al., 2014). Numerous other studies suggest that autistic girls are more likely to be shunned by peers and thus experience isolation, loneliness, 'social misfit' and bullying (Cook et al., 2018; Cridland et al., 2014; Honeybourne, 2015; Sproston et al., 2017; Moyse & Porter, 2015). Both Cook et al. (2018) and Sedgewick at al. (2019) found that autistic girls often developed relationships with girls who were also seen as different in some way, for example they may also have SEN.

Using self-report measures from 105 autistic girls and boys as well as parental reports, Greenlee et al. (2020) found that the negative impact of bullying is more detrimental to autistic girls compared to autistic boys, as autistic girls are more likely to internalise these experiences. However, it is important to note that the self-report measures used in this study were validated with non-autistic CYP. This is relevant as there is evidence to suggest that autistic CYP conceptualise bullying differently to non-autistic CYP. In other words, autistic CYP may not relate to the examples of peer victimisation used on bullying questionnaires (Fisher & Taylor, 2015). A major consequence of bullying for autistic girls is increased difficulties with attending school (Cook et al., 2018).

Goodall & MacKenzie (2019) used a range of tools to explore the educational experiences of two autistic girls aged 17 and 18 in Northern Ireland. Participants reported that their main concern regarding mainstream education was bullying. Both participants reported several forms of peer victimisation, including "verbal, physical and… sexual" (Goodall & MacKenzie, p.507). One of the participants reported feeling targeted by peers and being seen as 'different'. This study found that autistic girls felt socially isolated from peers because of bullying and that incidents of bullying led to emotional distress and anxiety.

#### 1.3.1.5 Summary of studies that have explored relationships

The literature emphasised that, despite their motivation to interact with peers and build friendships and their apparent social success, autistic girls experience a number of challenges in this domain including difficulties in understanding social expectations and rules, feeling different, dealing with conflict and bullying and social isolation (Beteta, 2009; Cook et al., 2018; Cridland et al., 2014; Feist, 2013; Goodall & MacKenzie, 2019; Kanfiszer et al., 2017; Logsden, 2010; Milner et al., 2019; Moyse & Porter, 2015; Rainsberry, 2016; Sedgewick et al., 2019; Tierney et al., 2016; Vine et al., 2017). Many of the studies explored above failed to provide demographic information about participants (particularly their ethnic, cultural and racial background) and generally there was a lack of participants from minoritised backgrounds. Moreover, some of these studies favoured parental voices therefore neglecting the voices of autistic girls.

### 1.3.2 School environment

Another key theme which emerged from the literature was the school environment. Within this theme, three areas were identified: accessing the school curriculum, the physical environment and support from school staff. These will be explored in detail below.

#### 1.3.2.1 Accessing the school curriculum

There is a wide body of research which suggests that autistic CYP are more likely to underachieve academically than non-autistic CYP (Howlin, 2005). This is often due to autism-specific challenges such as executive functioning difficulties rather than academic ability (Kirkovski et al., 2013). Some researchers have argued that autistic girls and women experience more difficulties with executive functioning than their autistic male counterparts and non-autistic individuals (Lemon et al., 2011). Although, this finding has not been replicated quantitatively by some studies (Nydén et al., 2000), a more recent study found that 53% of 82 autistic women self-reported difficulties with attention and concentration (Baldwin & Costley, 2016). Autistic women in this study added that these difficulties were overlooked by school staff thus resulting in underachievement. However, this study was conducted in Australia and focused on the retrospective accounts of autistic adult women regarding their school experiences. Hence, this may not be applicable to the school experiences of autistic girls currently studying in the UK. Nevertheless, the findings and conclusions of this study are supported by UK studies such as Tomlinson et al. (2021) and Moyse and Porter (2015). In another Australian study (Jarman & Rayner, 2015), participants reported difficulties with understanding, organisation, planning, time management, and prioritising; thus, strengthening Kirkovski et al.'s (2013) findings regarding executive functioning difficulties.

The social aspects of learning such as group tasks were also highlighted as an area of difficulty for autistic girls (Tierney et al., 2016). Moyse and Porter (2015) investigated the effect of the 'hidden curriculum' (i.e., social norms that most non-autistic individuals generally learn implicitly, but autistic individuals require explicit teaching) on three autistic girls by using interviews and observations. They also interviewed their parents, class teachers and Special Educational Needs Coordinators (SENCOs). They found that some of the girls' difficulties accessing learning were underpinned by their misunderstanding of social expectations. For instance, the autistic girls struggled to understand that classroom rules were directed at all children, cope with inconsistent instructions from school staff, and work alongside peers or complete tasks if rules and criteria were not explicitly explained to them. However, when these factors were addressed, particularly when consistent and clear expectations and rules were implemented, autistic girls experienced success at school (Moyse & Porter, 2015). Despite a small sample size, this study offered a rich analysis of the experiences of these three autistic girls. The concept of 'double empathy problem' is relevant here. This concept suggests that non-autistic and autistic individuals struggle to understand and interact with each other due to a mutual lack of understanding (Milton, 2012).

#### 1.3.2.2 Support from school staff

School staff play a key role in defining the school experiences of children and young people including autistic girls' experiences (Rainsberry, 2016; Tomlinson et al., 2021; O'Hagan, 2020). Moyse and Porter (2015) found that school staff were not aware of the impact of the hidden curriculum on autistic girls. Consequently, they did not always support autistic girls effectively. For example, they failed to implement key strategies such as explicitly communicating expectations, setting consistent class rules and checking the girls' comprehension. The study also found that school staff often overestimated how well the girls were managing and enjoying school. For example, one of the girls' teachers believed that she enjoyed school 'very much'. However, the girl only rated her experience of school as 'slightly higher than okay'. This further highlights the importance of eliciting the voices of autistic girls themselves as the views of professionals/adults around them are not always a true reflection of their experiences. This discrepancy between the girls' and their teachers' views is likely due to the girls' tendency to mask and internalise their difficulties. This is likely to impact the level and type of support that they receive from school staff. In fact, the lack of observable difficulty even led some teachers to question their diagnoses.

Likewise, Milner et al. (2019) conducted a study with 18 autistic girls and women (11-55 years) and four mothers of autistic girls in the UK. Recruiting participants of different ages allowed the researchers to explore varied experiences. Some of their participants reported that teachers did not understand their strengths and needs, therefore labelling them as 'naughty' or a 'slow learner'. However, it is important to note that these comments were shared by older participants (aged 30 years or older). Therefore, it is likely that these findings may be a reflection of the socio-political context at the time of the participants' schooling. Moreover, as girls and women are less likely to receive an autism diagnosis, this study included two self-diagnosed autistic women. While this research recruitment strategy is likely to become more common due to the increased number of self-diagnosed women, this may lead to questions regarding the homogeneity of the sample.

Jarman and Rayner (2015) conducted an online survey with 30 autistic women (aged 18 and older) and 15 mothers of autistic girls. The aim of this study was to examine what participants wished teachers knew. While this study took place in Australia and focused on Asperger Syndrome specifically, it generated similar findings as the Milner et al.'s (2019) study including lack of understating regarding needs and teacher scepticism regarding diagnosis. This suggests common experiences across Western cultures. While one may argue that, similarly to the Milner et al's study, the socio-political context at the time of the participants' schooling may have affected its applicability to the current context, it is important to note that one third of the participants were mothers of current students thus the findings are likely to be applicable to the current socio-political context. This study also found that autistic girls and women were often reluctant to ask for help from school staff as they did not want to inconvenience or upset them. One limitation of this study is that 25 of the 30 autistic women, received a diagnosis of autism in adulthood thus they were unable to provide meaningful insights into school staff's understanding of their diagnosis. Additionally, parental voice dominated this research. In fact, only 26% of the quotes used in this study were from autistic women themselves. Therefore, it could be argued that this study provides a second-hand recount of autistic girls' lived experiences. Moreover, this study took place in Australia, thus it may not be directly applicable to the experiences of autistic girls in the UK. Nevertheless, negative experiences with staff were highlighted in other studies which explored the experiences of autistic girls and women. For example, in Baldwin and Costley's (2016) online survey, 46% of autistic girls and women identified 'lack of support' as one of the worst things about their school experience. Additionally, other studies found that teachers often misinterpreted autistic women and girls' needs as bad, rude or lazy behaviour (Rainsberry, 2016; Bargiela et al., 2016).

However, Jarman and Rayner's (2015) study also highlighted positive experiences with school staff. In fact, one of the themes identified in this study was 'helpful attitudes and actions of teachers'. Participants described how some teachers made them feel valued and liked by showing an understanding of their individual needs, taking a personal approach, making necessary adaptations and communicating with parents. Likewise, in Rainsberry's (2016) research, autistic girls described how teachers had put adjustments into place to support their needs, for example attending extracurricular clubs and eating lunch in a quieter space. This study explored the school experiences of three autistic girls in years 8, 9 and 11 over a one-month period. Data collection involved written, illustrated diaries. One strength of this study was that it elicited the voice of autistic girls themselves. Despite this, the study had a number of limitations including a lack of interpretative analysis as no explicit analytical method was specified, a small sample size, and the fact that one participant was unaware of her diagnosis. This raises questions about whether participants truly understood the research. Additionally, in Baldwin and Costley's (2016) online survey, 32% of participants stated that the support they received was one of the three best things about their school experience. A key limitation of this study is that it used anonymous data which means that it was not possible to verify whether participants were genuine and/or met the eligibility criteria.

#### 1.3.2.3 Physical environment

Many studies have explored the sensory experiences of autistic individuals (e.g., Saggers et al., 2020; Sciutto et al., 2012). Although such studies are largely based on male samples, autistic girls and women also experience sensory sensitivities, which can influence their experience of school (Davidson, 2007). Autistic girls and women have reported that their sensory sensitivities impact them negatively (Milner et al., 2019; Tierney et al., 2016). Sensory difficulties within the school environment were highlighted by several studies (Honeybourne 2015; Jarman & Rayner 2015; Moyse & Porter 2015). In Rainberry's (2016) study, certain areas of the school such as corridors and lunch halls were described as sensorily overwhelming due to noise levels. The general proximity to people was also a sensory trigger as autistic girls in this study highlighted the need for personal space at specific times during the school day, for example breaktimes. Similarly, in Jarman and Raynan's (2015) study, sensory aspects of the school environment were also identified as a major challenge by autistic women and parents of autistic girls. Participants in this study noted that sensory factors such as fluorescent lights (and associated headaches) made the school environment stressful and overwhelming especially when coupled with a lack of understanding from school staff regarding the impact of sensory difficulties/sensitivities (Jarman & Rayner 2015). Other sensory triggers such as disliking the material of the school uniform and the impact of auditory sensitivities on concentration, and thus academic performance were also highlighted by other researchers (Feist, 2013). Nevertheless, other studies provided a more positive account of the sensory experiences of autistic girls within schools. For example, through interviews with eight adolescent autistic girls, Myles et al. (2019) found that sense of belonging, which was linked to friendships and level of support received within school, was a protective factor for autistic girls and helped them to cope with the sensorily overwhelming school setting. Likewise, reasonable adjustments such as providing alternative quiet rooms during lunch time, helped to reduce stress and anxiety for autistic girls (Jarman & Rayner, 2015). Autistic girls themselves also used a number of strategies and modifications to reduce the impact of sensory sensitivities, for example coming into class early from breaks (Moyse & Porter 2015). Some studies even described how sensory sensitivities can in fact be positive experiences. For example, an autistic woman reported that music led to a positive and euphoric feeling (Milner et al., 2019). Similarly, an autistic girl noted that her synaesthesia was positive and boosted her musical ability (Feist, 2013). Synaesthesis occurs when one sense is processed as another, for example hearing colours. This is thought to be more common amongst autistic individuals compared to non-autistic individuals (Baron-Cohen et al., 2013).

#### 1.3.2.4 Summary of studies that have explored school environment

The literature suggests that support from school staff plays a key role in autistic girls' experience of education. However, the literature demonstrates that autistic girls often feel unsupported in their educational settings as teachers lack an understanding of their needs. Some autistic girls are reluctant to ask for help due to fear of upsetting or inconveniencing school staff. Therefore, they mask their difficulties in order to appear 'normal'. This leads to further unrecognition and lack of support from school staff. The literature also demonstrates that similarly to autistic boys, autistic girls struggle to access the school curriculum due to executive functioning difficulties. Additionally, previous studies found that autistic girls experience a range of sensory experiences within their educational settings which can be both positive and negative.

### 1.3.3 Mental health

Another key theme which emerged from the literature was mental health. Research has demonstrated that autistic individuals are more likely to develop mental health conditions than non-autistic individuals (Cage et al., 2018; Lai et al., 2015; Rynkiewicz et al., 2019) especially during adolescence (Vickerstaff et al., 2007). Within the autistic community, there is evidence to suggest that autistic females are more susceptible to develop mental health conditions (Baldwin & Costley, 2016; Lai & Baron-Cohen, 2015; Rynkiewicz et al., 2019; Zener, 2019). In Baldwin and Costley's (2016) study, 85% of autistic women reported having a mental health condition (compared to 68% of males). Additionally, a study in Denmark found that autistic girls have 4 times higher rates of suicide attempts (Kõlves et al., 2021). It has been argued that the educational experiences of autistic girls have a negative impact on their mental health including high levels of stress and anxiety (Cook et al., 2018) and feelings of depression (Honeybourne, 2015), which are seen as a direct consequence of their propensity to internalise their difficulties (Jarman & Rayner, 2015; Moyse & Porter 2015). Stewart (2012) conducted a case study of four autistic girls (aged between 10 and 15) and their mothers. Three of the girls in this study attended mainstream secondary school while one attended a specialist provision. They found that autistic girls experience anxiety within the school context and display a number of symptoms and behaviours associated with this including insomnia, self-harm, refusal to attend school and consistent emotional outbursts (Stewart, 2012). Further, in line with autistic girls' tendency to mask their difficulties, this study indicated that anxiety-related behaviours/symptoms were more visible at home. This fits well with findings from other studies which indicate that autistic girls supress their difficulties at school and ‘melt down’ as soon as they get home (Moyse & Porter, 2015). It is likely that there is a relationship between this and the growing number of adolescent autistic girls missing from education. In fact, Moyse (2021) found that adolescent autistic girls are significantly more likely to be persistently absent from school, in comparison with both their non-autistic counterparts and autistic boys.

Williams et al. (2017) completed a metasynthesis of qualitative studies which explored how the experiences of autistic CYP in mainstream schools contribute to their self-concept. Self-concept refers to “the individual's belief about himself or herself, including the person's attributes and who and what the self is” (Baumeister, 1999, p.11). They noted that the majority of papers “represented largely the voice of verbally and cognitively able, male pupils in mainstream secondary schools in Western societies” (p. 11). Autistic girls’ educational experiences, particularly in terms of their social relationships are likely to have an impact on their emotional well-being and identity formation (Collins & Laursen, 2004) as peers are very influential during this period i.e., adolescence (McElhaney et al., 2008; Smith, 2016). In one study, two autistic young women reported that they felt “different from other children” (Goodall & MacKenzie, 2019. P. 508). In addition, Gaffney (2020) conducted an IPA study to explore how six adolescent autistic girls made sense of their autism diagnosis and how this impacted on their sense of self and identity. She found that some adolescent autistic girls maintained a positive sense of self and separated themselves from their diagnosis whereas others experienced low self-esteem and depression due to being different. More recently, Morgan (2023) used interviews and journal/blog entries to explore the discourses of ten autistic adolescent girls in terms of their self-concept and social identity. She found that adolescent autistic girls constructed themselves using three key discourses, namely diagnostic, individualistic and normativity. Participants saw autism as a core part of their identity, viewing diagnosis as a way to legitimise their identity as an autistic person (diagnostic discourse) but also emphasised their uniqueness as an autistic individual (individualistic discourse) and constructed themselves as outside of normativity as they felt that they did not fit-in in normative environments (normativity). Additionally, two unpublished theses, explored adolescent autistic girls’ identity and sense-making (Carver, 2020) as well as their sense of belonging (Brennan De Vine, 2022). This suggests that research exploring the emotional well-being of autistic girls is growing.

## 1.4 Culture and Autism

Most autism-related research studies do not adequately provide information regarding participants' cultural, racial or ethnic background. Pierce et al. (2014) found that in three preeminent ASC-related journals, 72% of the studies did not provide participants' cultural, racial or ethnic background and 54% of studies did not consider these constructs in their findings and discussions. In the rare occasions when researchers provided details about the race, ethnicity and/or cultural background of participants, 63.5% of those participants were identified as white (West et al., 2016). These studies illustrate how, for many years, the 'white male identity' has saturated and dominated our understandings about autism (Matthews, 2019). This is of relevance because research can have extensive implications for instructional practices and educational policies (Abedi et al., 2004; Simpson & Sasso, 1992; Stahmer & Mandell, 2007). Thus, omitting details about participants ethnic and cultural background is likely to hinder advancements in terms of diagnosis and access to effective interventions for minoritised autistic individuals (Shanawani et al., 2006). The existing research evidence relating to the relationship between culture and autism sits within four key areas: the impact of culture, explanatory models, minoritised families' experiences and the experiences of minoritised autistic CYP.

### 1.4.1 Impact of culture

The lack of consistency in reporting participants' cultural background within research studies is relevant as there is a growing body of evidence which suggests that culture influences how different communities conceptualise autism (Frederickson & Cline, 2015). For example, within the Somali community residing in the UK, the term 'Western disease' is sometimes used to describe autism because there is no word for autism in their native language, and many believe that autism does not exist in Somalia (Decoteau, 2017). Culture is an important aspect to consider when exploring the experiences of autistic girls because the diagnostic criteria for autism was developed within Western cultures (Masi et al., 2017), thus it can be argued that such tools are not only gender-biased but also culture-biased. For example, these diagnostic tools often involve observation, which do not take into account variation within and between cultures for aspects such as level and intensity of eye contact (Bernier et al., 2010).

For example, Perepa (2013; 2014) argues that in some Nigerian families in the UK, giving direct eye contact is considered rude whereas in western cultures eye contact is a ‘must’ during social interactions. This suggests that social understanding and development are heavily influenced by cultural factors (Dyches et al., 2004). Thus, what is deemed appropriate social behaviour differs depending on one’s culture. Therefore, it follows that for one to be able to effectively interpret social behaviour, one must be familiar with the social customs, rules and norms of the particular culture (Burton et al., 1995). Professionals involved in the autism diagnostic process must therefore have an appropriate level of cultural competence and humility. This also raises concerns regarding the suitability/appropriateness of some social interventions for minoritised autistic CYP as the skills taught within these interventions e.g., giving eye contact may not be compatible with the child’s family’s cultural norms (Dyches et al., 2005). There is also evidence which suggests that culture impacts on the presentation of autistic traits. For example, researchers in the US found that even when accounting for socio-economic background, minoritised and majority groups differ from each other on the clinical presentation of autistic characteristics on standardised tests (Tek & Landa, 2012). Culture may also influence which behaviours are perceived as autistic traits. For example, in communities where CYP are expected to have a passive role, some autistic traits such as repetitive questioning or echolalia may be perceived as more challenging by the parents (Dyches et al., 2007). These differing perceptions are likely to impact on whether or not a family seeks support, and when they do so. UK and US research has shown that some minoritised parents of autistic CYP seek support from their families first, instead of looking for professional advice (Burkett et al., 2015; Fox et al., 2017; Luong et al., 2009), and their families often advised them not to be alarmed (Fox et al., 2017; Jegatheesan et al., 2010). However, research has also shown that when minoritised families do seek professional advice, they often experience difficulties relating to language barriers and lack of familiarity with systems (Fox et al., 2017). The Somali parents in Fox et al’s (2017) research displayed a “widespread concern that their child would be taken away from them if they were seen to be having difficulty coping with the demands of raising a child with autism” (p. 312). Likewise, Hussein et al. (2019) found that Somali parents in the UK did not trust western medicine and the explanatory models of autism commonly adopted by western societies. It is sometimes suggested, by a range of services, that minoritised communities are ‘hard to reach’ (Darko, 2023). However, it is important to note that communities are only ‘hard to reach’ if services fail to reach out and engage with them. Thus, instead, one may argue that these communities are ‘hardly reached’.

### 1.4.2 Explanatory models

In the UK, research exploring the relationship between culture and autism has focused primarily on parental perspectives including those of the Somali community (Fox et al., 2017; Hussein et al., 2019), African immigrant mothers (Munroe et al., 2016), the South Asian Muslim community (Gilligan, 2013) and the UK Jewish community (Sher et al., 2022). These studies found that minoritised families adopted a range of cultural and religious explanations for autism. For instance, Hussein et al. (2019) found that some Somali parents in the UK believed that their child’s autism was either the will of Allah, a test of faith or result of a *jinn* entering their child’s body. The jinn is an Islamic concept which refers to a supernatural spirit which is believed to cause illnesses (Lewis, 1998). The moral and/or religious model of disability is of relevance here. This model is not as widely recognised as the medical and social models of disability. However, it is arguably the oldest model of disability and is found in a number of religious traditions (Pardeck & Murphy, 2012). This model sees disability as an act of God (either as a punishment for a sin, a test of faith, an opportunity for character development or as a special calling/blessing) (Retief & Letšosa, 2018). While the moral/religious model of disability is not widely prominent in Western cultures, it is still the predominant view in certain cultures (Dunn, 2015). These religious explanatory models may be employed to avoid the stigma associated with genetic explanations (i.e., the idea that the family has ‘bad blood’) (Sarrett, 2015). However, it is important to note that research exploring religious views of autism is still in its very early stages. Therefore, one should not generalise the findings of these very small number of studies or assume that all religions (and their members) hold these views. Another study found that South Asian Muslim mothers were led to believe, by others within their community, that their child’s autism was caused by their behaviour or diet during pregnancy (Gilligan, 2013). Munroe et al. (2016) found that African immigrant mothers in the UK mostly rejected the explanatory models for autism prominent in some African communities (within some of these communities autistic CYP are often seen as being ‘possessed’, ‘mad’ or naughty). The mothers in this study found it difficult to make sense of the explanatory models employed by their countries of origin and the explanatory models employed in the UK. Consequently, they felt marginalised from both cultures and struggled with their cultural identity. These differing explanatory models adopted by minoritised communities are likely to impact if, when and how they seek support (as well as the interventions they adopt) and thus impact on the experiences of minoritised CYP. For example, Hussein et al. (2019) found that Somali parents in the UK tried to combine interventions based on faith with advice from professionals.

### 1.4.3 Minoritised families' experiences

Research has shown that minoritised parents experience social stigma as well as difficulties in accessing autism-related services (Fox et al., 2017; Hussein et al., 2019). This can lead to social isolation and exclusion (Kinnear et al., 2016) and mental health difficulties (Papadopoulos et al., 2019). A recent report from the University of Birmingham (Perepa et al., 2023) uncovered widespread discrimination, biases, and lack of resources available for marginalised families with autistic CYP. The researchers interviewed marginalised families and the teachers who support them. They found that professional beliefs, cultural stigma, and confusion navigating the system were barriers to accessing diagnosis. Additionally, after diagnosis, marginalised families struggled to navigate the educational systems, find an appropriate educational setting, and access relevant guidance and support. Families attributed this to several factors including bias and racism, a lack of diversity in the school workforce and an under-resourced system. As a result, these families experienced isolation. The concept of minority stress can be applied here. This concept posits that, while everyone experiences general life stress, those from minoritised backgrounds have to deal with additional stress (linked to their minoritised status in society) (Meyer, 2003). These stressors are likely to impact on the well-being of marginalised families and their autistic CYP. Essentially, the results of this study suggest that marginalised families (and their autistic CYP) have experiences that are unique to them due to their ethnic, cultural and/or racial identity. However, it is important to note that, in this study, marginalised families included those who belonged to a minoritised ethnic community, whose first language was not English, from economically disadvantaged backgrounds and those who were in the care systems.

Thus, these findings may not be applicable to minoritised communities as a whole. Nevertheless, these findings broadly support the findings of previous studies in this area (Fox et al., 2017; Hussein et al., 2019). Overall, these studies suggest that there is a need for culturally sensitive services including ensuring that information is available in multiple languages. While the findings of these studies are helpful, it is important to note that all of these studies focused solely on parental perspectives and did not explicitly consider gender differences in autism. Furthermore, Happé and Frith (2020) stated that the impact of culture and ethnicity on autistic individuals has not yet been explored sufficiently.

### 1.4.4 The lived experiences of minoritised CYP

A recent UK study (an unpublished doctoral thesis) explored the experiences of minoritised autistic CYP and found that while there are similarities between the experiences of minoritised autistic CYP and their White-British counterparts, minoritised autistic CYP have experiences that are unique to them as result of their cultural, ethnic and racial identity (Hussein, 2021). For example, minoritised autistic CYP noted how lack of understanding and knowledge of autism within minoritised communities often led to negative perceptions of their diagnosis. Unlike previous studies, this study explored the views of minoritised autistic CYP themselves. However, similarly to previous research exploring the intersections between culture and autism, this study did not explicitly consider the experiences of minoritised autistic girls. Some minoritised autism advocates (e.g., Simmonds, 2021) have argued that the experiences of minoritised autistic people differ from their white autistic counterparts as they wear a ‘triple mask’. Simmonds (2012) argued that black autistic people mask their ‘blackness’ in ‘white spaces’. She argued that they also mask in autistic spaces because such spaces are predominantly ‘white spaces’. Thirdly, black autistic people mask their autism in ‘black spaces’ because there is limited understanding of autism within the community. Having considered the detrimental impact of masking, one can deduce how this may influence individuals with multiple marginalised identities such as minoritised autistic girls. This relates closely to the concept of double consciousness. This concept was first introduced by W.E.B. Du Bois in The Souls of Black Folk (1903), it refers to the psychological challenges of reconciling multifaceted and conflicting identities.

### 1.5 Summary of the literature review and future research directions

While this review shows that there has been considerable progress in the area of autism and girls, there is limited knowledge and insight into the educational experiences of autistic girls in the UK. In particular, the literature exploring the experiences of autistic girls (from their own perspectives) is limited. Some studies which explore the experiences of autistic girls seem to be dominated by parental or professional perspectives, as researchers demonstrate a tendency to obscure the lived experiences of autistic girls. For example, Cridland et al. (2014) gave more emphasis to parental perspectives and Dean et al. (2017) only used autistic girls' data to supplement the quantitative data which they had already collected. Autistic individuals are the experts of their own lived experiences (Gillespie-Lynch et al., 2017) thus research exploring the experiences of autistic girls, should aim to elicit and privilege their own voices.

In addition, while most studies considered within this review provided valuable information about the educational experiences of autistic girls, several methodological weaknesses were identified, including the lack of details regarding participants' cultural, racial and ethnic background. Thus, it is difficult to assess the range of girls to which the findings might be relevant.  In the few studies where information regarding participants' cultural, ethnic and racial background was provided, it was clear that these studies had been carried out with all- or majority-white British samples, meaning that the findings may not be representative of minoritised autistic girls' experiences. The exclusion of race, ethnicity and culture within mainstream autism research seems to imply that culture, race and ethnicity are not of importance to the autistic experience (Hussein, 2019). However, as evidenced within the literature, there is a growing body of evidence which suggests that culture influences how different communities conceptualise autism (Frederickson & Cline, 2015). Thus, it is plausible that culture influences one's experience of autism. For example, Hussein (2019) found that that minoritised young people have experiences that are unique to them due to their cultural and racial identity. No studies were identified which exclusively looked at the lived experiences of minoritised autistic girls. This indicates that the voices of minoritised autistic girls are not adequately represented and that current understandings of autism in girls are therefore primarily based on research conducted with White-British participants. Minoritised autistic girls are effectively invisible in the current literature. Given the national context of the current research, with over 34.5% of students in England classified as “minority ethnic” (DfE,2022), it is paramount that research examines the experiences of this underrepresented group.

# Chapter 2: Empirical chapter

## 2.1 Abstract

There is a lack of research in the UK which elicits the voices of minoritised autistic girls and explores their lived experiences, including their educational experiences. The present study explored the lived experiences of minoritised autistic girls with a particular focus on their educational experience. Semi-structured interviews were conducted with five minoritised autistic girls (aged 14 to 16), which were analysed using Interpretative Phenomenological Analysis (IPA). Child-friendly resources were used within the interview process to support autistic girls to share their experiences. Although each participant had unique experiences, five Group Experiential themes (GETs) emerged from the analysis: ‘journey to diagnosis’, ‘making sense of autistic identity’, ‘making sense of cultural identity’, ‘school/college life’ and ‘relationships. The findings suggest that, in some respects, the experiences of minoritised autistic girls are similar to those of White-British autistic girls. However, minoritised autistic girls also have experiences that are unique to them as result of their cultural and ethnic identity. These findings are relevant to educational professionals (including EPs), so that the needs of these girls are better understood. Key implications and areas for future research are identified.

## 2.2 Introduction

Autism is commonly defined as a life-long neurodevelopmental condition which affects social communication and interaction, interests, behaviour and sensory sensitivities (APA, 2013). However, alternative critical constructions of autism challenge this notion and suggest that autism is a ‘difference’ rather than a ‘disorder’ or ‘condition’ (Chapman, 2019). Recent research indicates that around one in 57 (1.76%) CYP in the UK have a diagnosis of autism (Roman-Urrestarazu et al., 2021). Research also indicates that the educational experiences of autistic CYP can be significantly worse than those of non-autistic CYP, especially when appropriate support is not in place (Humphrey et al., 2015). Extensive research has shown that there are gender differences in autism (Lai et al., 2015). Despite this, most studies exploring the experiences of autistic CYP tended to focus on males (Gould, 2017). However, there has been a recent shift towards research which focus specifically on understanding the experiences of autistic girls and young women (Cridland et al., 2014; Moyse &

Porter 2015). Such research has shown that, in some respects, the experiences of autistic girls and young women are similar to those of autistic boys and young men. For example, similarly to their male counterparts, autistic females experience difficulties managing noisy school environments (Honeybourne 2015; Moyse & Porter, 2015), accessing the curriculum (Jarman & Rayner, 2015), managing transitions (Moyse & Porter, 2015) and social relationships (Cridland et al., 2014; Dean et al., 2017; Honeybourne 2015). Despite these shared experiences, research has also shown that there are key differences between autistic boys and girls which should be taken into account. For example, it is thought that autistic girls are more likely to mask their difficulties than their male peers (Attwood, 2007). This often leads to school staff underestimating the level of difficulty experienced by autistic girls and reflects their increased tendency to internalise their difficulties (Mandy et al., 2012). Whilst there are some studies which explore the educational experiences of autistic adolescent girls, such studies are mostly dominated by parental and professional voices rather than autistic girls themselves (Tomlinson et al., 2019).

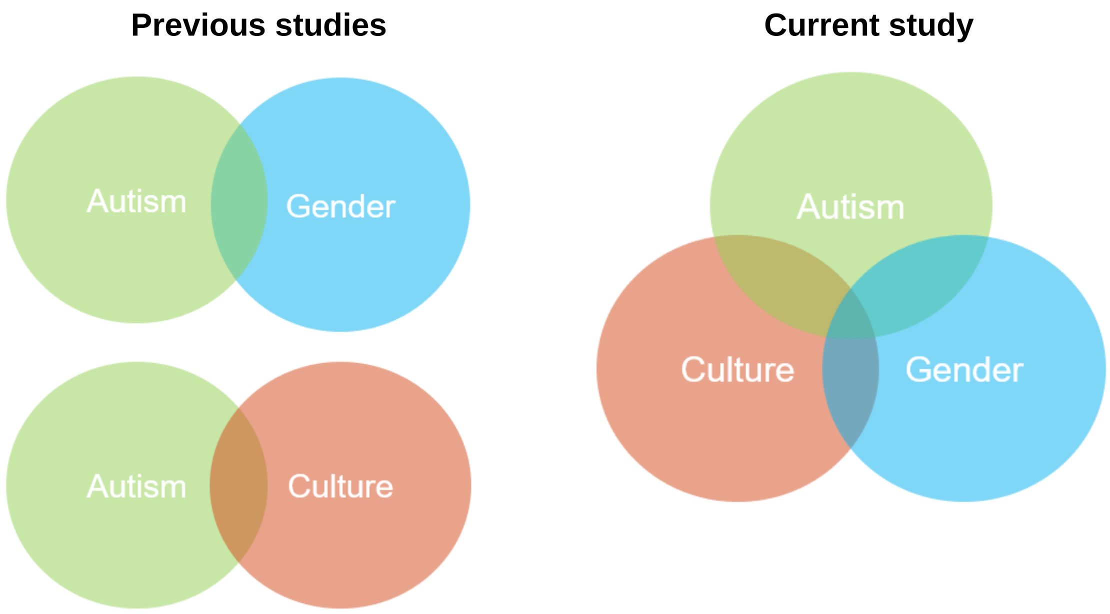
Most research exploring the educational experiences of autistic girls fails to specify the cultural, ethnic and/or racial background of participants. When this information is provided, it is clear that the samples consist largely of White-British participants. This indicates that the voices of minoritised autistic girls are not adequately represented and that current understandings of autism in girls are therefore primarily based on research conducted with White-British participants. The exclusion of culture, ethnicity and 'race' within autism research seems to suggest that culture, race and ethnicity are not of importance to autistic experience (Hussein, 2021). However, there is growing evidence that suggests that culture influences how different communities conceptualise autism (Frederickson & Cline, 2015). Culture is a "complex and multi-dimensional" construct (Urdan & Bruchmann, 2018, p. 124) which can be difficult to explain. However, it can be defined as "the social norms, roles, beliefs, values and traditions that influence the behaviours of a particular social group" (King et al., 2018, p. 1032). Examples of differing cultural conceptualisations of autism include the fact that, within the Somali community residing in the UK, some use the term 'Western disease' to describe autism because there is no word for autism in their native language, and many believe that autism does not exist in Somalia (Decoteau, 2017). Since the mid-2000s, there has been a surge in research investigating the intersection between culture and autism. These are largely UK and US-based studies focusing on ethnic disproportionality (Tincani et al., 2009; Travers et al., 2011), parental views and experiences (Barrio et al., 2018; Kim et al., 2020), participation in research (Robertson et al., 2017; Shaia et al., 2020), and culturally competent autism-related interventions (Davenport et al., 2018). In the UK specifically, research exploring the relationship between culture and autism has focused primarily on parental perspectives including those of the Somali community (Fox et al., 2017; Hussein et al., 2019), African Immigrant mothers (Munroe et al., 2016), and the South Asian Muslim community (Gilligan, 2013). Such studies highlighted that family perceptions of autism are influenced by lack of knowledge and that minoritised parents experience social stigma as well as difficulties in accessing services (Fox et al., 2017; Hussein et al., 2019). This can lead to social isolation and exclusion (Kinnear et al., 2016) and mental health difficulties (Papadopoulos et al., 2019). Overall, these studies suggest that there is a need for culturally sensitive services including ensuring that information is available in multiple languages. While the findings of these studies are helpful, it is important to note that such studies focused solely on parental perspectives and did not explicitly consider gender differences in autism. A more recent UK study explored the experiences of minoritised autistic CYP and found that while there are similarities between the experiences of minoritised autistic CYP and their White-British counterparts, minoritised autistic CYP have experiences that are unique to them as result of their cultural, ethnic and racial identity (Hussein, 2021). For example, minoritised autistic CYP noted how lack of understanding and knowledge of autism within minoritised communities often led to negative perceptions of their diagnosis. Unlike previous studies, this study explored the views of minoritised autistic CYP themselves. However, similarly to previous research exploring the intersections between culture and autism, this study did not explicitly consider the experiences of minoritised autistic girls. Autistic girls and women were previously described as “research orphans” (Bazelon, 2007) and while research in this area has increased in the last few years (Tomlinson, 2019), one may argue that minoritised autistic girls still remain ‘research orphans’. Given the national context of the current research, with over 34.5% of students in England classified as “minority ethnic” (DfE, 2022), it is paramount that research examines the experiences of this underrepresented group.

## 2.3 Aims and rationale

As outlined above, some researchers have previously explored the intersections between autism and gender while others have focused on the intersections between autism and culture. However, no research has explicitly explored the intersections between these three differing identities. This research seeks to address this gap by exploring the experiences of minoritised autistic girls. Minoritised autistic girls have three interacting identities that can influence their experiences – being female, being autistic, and being from a minoritised ethnic background. Figure A illustrates the aims of the current study. Research can be explanatory, exploratory, descriptive and/or emancipatory (Creswell, 2013; Robson 2002). Polit et al. (2006) state that an exploratory approach should be adopted if there is scarce information available in an area. As there is no research (both published and unpublished) that has explicitly focused on the experiences of minoritised autistic girls, the primary purpose of this research is exploratory in order to gain an understanding of the experiences of these girls. Exploratory research focuses on gaining new insights, particularly in under-researched areas (Robson, 2002). This research also has an emancipatory goal as it hopes to create an opportunity for the voices of these girls to be heard. Emancipatory research entails producing information that can benefit marginalised or disadvantaged groups (Noel, 2016). By adding the voices of minoritised autistic girls to the research base it is ultimately hoped that professionals, particularly educational professionals such as EPs and teachers can better support their needs in educational settings.

**Figure 1**

*Aims of the current study*



The central research question that this research seeks to answer is:

1. What are the lived experiences of minoritised autistic girls?

There are two sub-questions:

2. How do minoritised autistic girls experience and make sense of their identities?

3. How do minoritised autistic girls describe their educational experiences?

These questions have intentionally been kept broad. This is in line with the researcher's ontological and epistemological position (Critical Theory), as well as the aim of this research, which is to hear the experiences of these girls, in their own words.

## 2.4 Theoretical Frameworks

There are several psychological and sociological theories and concepts which are relevant to the current research. However, the following theories were identified as particularly pertinent: Critical Theory (and associated strands outlined below), Ecological systems theory and Epistemic oppression.

### 2.4.1 Critical Theory (CT)

CT is "an umbrella term for a set of theories that aim to make social structure visible through an analysis of power relations" (Paradis et al., 2020, p.843). Essentially, CT is concerned with power relations within society and the interaction of race, class, gender, education, economy, religion and other social institutions that contribute to a social system (Guba & Lincoln, 1994). The following strands of CT are particularly relevant to the current research: feminist theory, intersectionality and DisCrit.

#### 2.4.1.1 Feminist theory

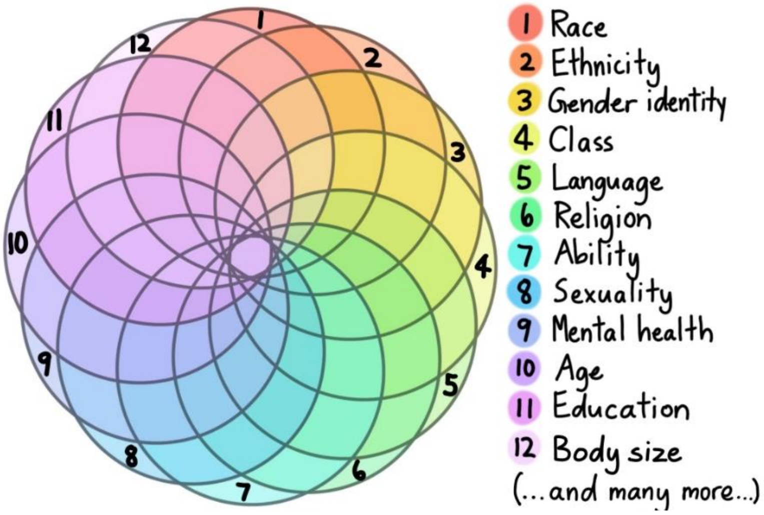
The use of feminism as a theoretical perspective has increased exponentially in the last few decades (Travers, 2001). Feminism focuses on understanding, challenging and eliminating women's oppression. Feminism acknowledges and welcomes the subjective element of research (Letherby, 2003) and strives to eradicate the power imbalance between the researcher and the participants. A feminist standpoint ensures that women are at the core of the research. Feminist research aims to 'challenge the passivity, subordination and silencing of women' (Maynard & Purvis, 1994, p. 23) by encouraging them to share their lived experiences (Roberts, 2016). In line with the feminist standpoint, the aim of the current research is to generate research that is 'on, by and for women' (Maynard & Purvis, 1994). However, traditional feminist standpoints have been criticised for centring White, middle class, able-bodied, heterosexual women (Zinn & Dill, 1996) and failing to address the needs of women with multiple marginalised identities. Thus, the traditional feminist standpoint alone would fall short in exploring the lived experiences of minoritised autistic girls. To counter this short-coming, intersectionality theory has also been adopted.

#### 2.4.1.2 Intersectionality

Intersectionality (illustrated in Figure 2) was originally developed in order to examine black women's oppression in America. However, this theory is now widely used within many disciplines (Crenshaw, 1989). Intersectionality has been defined as "a way of understanding and analysing the complexity in the world, in people, and in human experiences" (Collins & Bilge, 2016, p. 2). Intersectionality examines how the interaction between distinct oppressed identities leads to multiple barriers due to inequality in structures within society (Liasidou, 2013). It proposes that differing social identifies (i.e., disability, ethnicity, and gender etc.) are interdependent (Annamma et al., 2016; Collins, 2019) and that different structures and systems of oppression in society work simultaneously (Bowleg, 2008; Taylor, 2017). Collins (2019) argues that simply naming participants' social identity does not warrant intersectionality. Instead, García and Ortiz (2013) posit that using intersectionality as a framework for transformative research involves incorporating appropriate theories, using identity-focused comprehensive participant descriptions, and employing research reflexivity. While there have been explicit calls for intersectionality in studies relating to autism (Happé & Frith, 2020), few autism researchers have responded and meaningfully acted upon this request. The narrative review demonstrates that the current research base has failed to support intersectional analysis of autistic girls' experiences. There is therefore a need for research which uses intersectionality to gain an understanding of the relationship between autism and other social identities (Happé & Frith, 2020). Drawing on intersectionality theory, this study will capture the views of girls with multiple marginalised identities to gain a better understanding of how different power structures interact in the lives of minoritised autistic girls.

**Figure 2**

*An Illustration of Intersectionality theory*



### 2.4.1.3 Dis/ability critical 'race' studies (DisCrit)

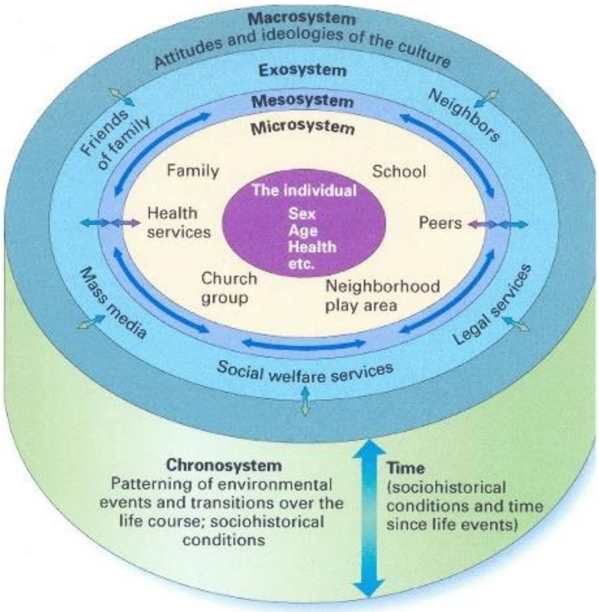
Dis/ability critical 'race' studies (DisCrit) is underpinned by critical race theory (CRT) and disability studies (DS). DisCrit incorporates both 'race' and ability (Annamma et al., 2016). HernándezSaca et al., (2018) argued that DisCrit centres the "false and oppressive ideology of Whiteness and heteronormativity with that of normalcy and ableism" (p. 304). This theory recognises that both 'race' and 'disability' are social constructions, however it also recognises that being labelled as raced or dis/abled has a real psychological impact on individuals. Thus, DisCrit aims to understand how racism and ableism impact the day-to-day lives of minoritised CYP with dis/abilities. According to DisCrit, the experiences of minoritised CYP with dis/abilities are qualitatively different than the experiences of white CYP with dis/abilities (Annamma et al., 2013). Similar to intersectionality theory, DisCrit discards singular notions of identity and instead privileges multiple identities. DisCrit places a key emphasis on amplifying the voices of marginalised communities, particularly those who are not traditionally acknowledged within research.

### 2.4.2 Ecological Systems theory (EST)

Bronfenbrenner (1979) argued that ‘conception of the developing person, of the environment, and especially of the evolving interaction between the two’ (p. 3) impacts CYP’s development over time. EST (illustrated below) suggests that there are several interconnected concentric environmental systems around a child or young person (Bronfenbrenner, 1979). The closest concentric system to the individual is the microsystem, which refers to the individual’s immediate setting such as family and school. The following system is the mesosystem which represents the relationships between the microsystems such as the relationship between family and school. The exosystem describes structures which indirectly influence the child or young person such as their parents’ workplace. Although the child is not part of this structure, it still has an indirect impact on them. The macrosystem encompasses attitudes and ideologies of culture. The chronosystem describes environmental changes over the lifetime. The current research will focus on interaction between minoritised autistic girls and the educational setting within the microsystem, as well as family and peer influences. The macrosystem is also vital as it can be argued that minoritised autistic girls in the UK live in a largely white, patriarchal and neurotypical world.

**Figure 3**

*Diagram of Bronfenbrenner's EST*



### 2.4.3 Epistemic oppression

Epistemic oppresion refers to oppression through restrictions on knowledge creation (Dodson, 2014). This concept posits that power is maintained through unequal participation in the construction of knowledge (Dotson, 2014). Differing power structures such as research institutions and educational systems lead to some groups, in this case minoritised autistic girls, being understudied and arguably underserved. The white male identity has dominated autism-based research while autistic individuals with marginalised identities such as minoritised autistic girls continue to be "absent presences of raced and disabled bodies" (Artiles, 2013, p. 331). Pellicano et al. (2018) argue that "it is not right that one group holds all of the influence and power" when it comes to autism-related research (p. 82). We currently have a white-normed understanding of autism (Brown, 2017). Thus, our current understandings must be challenged with critical epistemologies. In other words, epistemologies must shift to accurately reflect the experiences of minoritised autistic girls.

## 2.5 Methodology

### 2.5.1 Ontological and epistemological stance

Carter and Little (2007) argue that the researcher's ontological and epistemological stance is a fundamental component of research as it plays a direct and key role on the methodology chosen, and in turn, the methods used to gather data. Ontology is concerned with the nature of reality whereas epistemology is concerned with the nature of knowledge (Willig, 2013). There are several ontological and epistemological positions which a researcher may adopt. These positions are on a continuum from absolute realism (objectivism) through to absolute relativism (and subjectivism) (Willig, 2013). Critical theory (CT) was adopted as the ontological and epistemological position for this research. CT is concerned with power relations within society and the interaction of race, class, gender, education, economy, religion and other social institutions that contribute to a social system (Guba & Lincoln, 1994). CT assumes an ontology of historical realism. In other words, it is assumed that reality exists, but it acknowledges that this has been shaped by cultural, political, ethnic, gender and religious factors which interact with each other to create a social system. This theory assumes a transactional/subjectivist epistemology i.e., it suggests that knowledge cannot be 'value-free' or 'theory-free' (Guba & Lincoln, 1994). Researchers adopting this epistemological stance must therefore be self-conscious of their own epistemological assumptions and communicate them clearly so that "no one is confused concerning the epistemological and political baggage they bring with them to the research site" (Kincheloe & McLaren, 2005, pp. 305-306). CT proposes that knowledge endorsed by those in power should be viewed critically. In the words of Kincheloe (2008), researchers should ask themselves: "How did I get stuck with this body of knowledge and these lenses through which to see the world?" (p.21). Most critical theorists argue that language is both shaped by reality and it constructs reality (Kincheloe & McLaren, 2005). This theory posits that language reflects power structures, and therefore it cannot be neutral. Thus, critical theorists, who generally adopt qualitative designs, pay close attention to the linguistic features of their data, as well as their own role co-constructing data and their meaning. CT is critical of both interpretive and positivist approaches as it suggests that they are "enmeshed in dominant ideology… neither has an interest in changing the world, and neither has an emancipatory goal" (Scott & Usher, 2010, p. 35). Further, CT proposes that social change should be the primary goal of all research. The aim of CT is not only to explain or understand society but to change it (Patton, 2002). Critical theorists are thus concerned with inequitable power relations, they intend to promote consciousness and emancipate oppressed groups. This fits well with the goal of the current study which uses research as a social justice tool (Lorenzetti, 2013) and seeks emancipation for minoritised autistic girls.

### 2.5.2 Qualitative methodology

In line with the researcher's ontological and epistemological position, a qualitative design was adopted. A qualitative design was deemed appropriate as it has been utilised successfully in previous studies to explore the experiences of autistic CYP (e.g., Humphrey and Lewis, 2008; Huws and Jones, 2008, 2015) including autistic girls (e.g., Cridland et al., 2014; Tierney et al., 2016). This design also fits well with the aim of the current research which is to explore the experiences of minoritised autistic girls instead of looking for cause-and-effect relationships (Willig, 2013). More specifically, Interpretative Phenomenological Analysis (IPA) was selected. This approach has been increasingly used within autism research (Howard et al., 2019). IPA is an experiential qualitative methodology which aims to "explore in detail how participants are making sense of their personal and social world" (Smith & Osborn, 2007, p.53). IPA is underpinned by three key philosophical principles, phenomenology, hermeneutics and ideography (Smith, 2011). Phenomenology is the "study of human experience and the way in which things are perceived as they appear to consciousness" (Langdridge, 2007, p. 10). Thus, phenomenology is concerned with engaging with lived experience. According to Husserl (1931), one of the earliest phenomenological philosophers, researchers should "go back to the things themselves". In other words, researchers should strive, as much as possible, to 'bracket' their previous experience, bias and belief systems during the research process. The second theoretical component of IPA is hermeneutics, which refers to the "practice or art of interpretation" (Dallmayr, 2009, p. 23) and includes "the restoration of meaning" (Ricoeur, 1970, p. 8). The hermeneutic circle (Smith et al., 2012) focuses on the "relationship between the part and the whole" (p. 28). Smith et al., (2012) noted that IPA involves a 'double hermeneutic' because the researcher is essentially making sense of the participant who is also making sense of his or her own experience. IPA sees participants as the experts of their own lived experiences and aims to “establish an equality of voice” between the researcher and the participants (Howard et., al 2019, p.2). In this particular study, the goal is therefore to reduce the power imbalance between the non-autistic researcher and the autistic participants. However, IPA acknowledges that the researcher’s interpretation is inevitably affected by his or her preconceptions and prior experiences. The third theoretical component of IPA is idiographic which is concerned “with the particular” (Smith et al., 2012, p.29). Most research methodologies are nomothetic and focus on making claims at a population or group level. In contrast, IPA adopts an idiographic approach which focuses on the particular. As such, IPA analysis focuses first on the individual participants in the study by conducting a case-by-case analysis before moving to a cross case analysis which involves looking for both convergence and divergence across participants. The steps involved in IPA analysis will be discussed in more detail below.

### 2.5.3 Participants

#### 2.5.3.1 Recruitment

The recruitment process for the current study involved advertising the study on social media platforms such as Twitter and Facebook groups for parents of autistic CYP as well as through relevant autism-related charities such as Autism Voice and Autism Girls Network and on the Association of Educational Psychologists’ (AEP) newsletter (see research advert in appendix 2). The researcher also emailed 140 Special Educational Needs Co-ordinators (SENCOs) of several schools and colleges in the most ethnically diverse regions of England (e.g., London, West Midlands and East of England) according to the 2021 Census (Office of National Statistics [ONS], 2021) (see email sent to schools/colleges in appendix 3). In order to attain a reasonable degree of homogeneity (Smith et al., 2022), purposive sampling was used. Purposive sampling involves deliberately choosing participants who can provide an insight to the research questions being explored (Bryman, 2012). This sampling method is particularly suitable for exploratory research (Neuman, 2006). Table 1 outlines the participant inclusion criteria.

**Table 1**

*Participant inclusion criteria and justification*

| Participant inclusion criteria | Justification for criteria |
|---|---|
| (1) assigned female at birth | All participants who took part in this study were assigned female at birth and identified as female. However, participants, did not have to identify as female to take part in this study. This is in the light of recent research which suggests that autistic individuals are more likely than non-autistic individuals to identify as non-binary gender (Strang et al., 2020). |
| (2) aged between 12 to 18 years old | This research focused on adolescence as this has been identified as a critical period for autistic females (Cridland et al., 2014). Furthermore, it was felt that younger girls may struggle to discuss in detail topics relating to their cultural identity. |
| (3) have a diagnosis of autism | Participants were required to have a clinical diagnosis of autism. This neglected girls who did not have a clinical diagnosis. However, it was decided that to ensure sufficient homogeneity, this criterion was necessary. |
| (4) from a minoritised ethnic background (including mixed heritage) | This study sought girls who identified as from a minoritised ethnic background. This includes having at least one biological parent who identifies as from a minoritised ethnic background. |
| (5) currently attending an educational setting in England | Participants needed to be from one country to further support homogeneity by enabling a relatively matched socio-environmental context. |

| | |
|---|---|
| (6) able and willing to share their experiences | Participants needed to have the necessary communication and attention skills to be able to engage in an interview. |

**2.5.3.2 Participant characteristics**

In total, five minoritised autistic girls, aged 14 to 16 took part in this study (see table 2 for further information about participants' characteristics). While the number of participants may appear small, Smith & Eatough (2012) state that IPA studies require small sample sizes as the key goal "is to do justice to each participant's account (case) and detailed case-by-case analysis is time consuming" (p. 444). Smith et al. (2009) recommend between four and ten participants for doctoral research. Each participant in this study was given a pseudonym of a minoritised female superhero.

**Table 2**

*Participants' characteristics*

| **Name (pseudonym)** | **Age (at time of interview)** | **Gender (as identified by the participant)** | **Ethnicity (as described by the participant)** | **Age when diagnosed** | **Type of educational setting (and year group)** | **Location** | **Length of interview (in minutes)** |
|---|---|---|---|---|---|---|---|
| Wonder Woman | 16 | Female | Black British* | Secondary school (Year 7/8) | Mainstream sixth form college (Y12) | London | 87 |
| Cat Woman | 16 | Female | Mixed ("black and white")* | Primary school (Year 1) | Mainstream secondary school (Y11) | London | 19 |
| Storm | 14 | Female | Biracial (Mauritian, Italian, Irish and Antiguan) * | Primary school (Year 4) | Independent special school for autistic CYP (Y9) | London | 64 |
| Shuri | 15 | Female | British | Secondary school (Year 7/8) | Mainstream secondary school (Y10) | London | 35 |
| Gamora | 16 | Female | Mixed (English and Irish, Indian Kashmiri) * | Secondary school (Year 10) | Mainstream secondary school (Y11) | Home county | 140 |

*****N.B.: *Most participants alluded to the complexity of language surrounding their ethnic and cultural identity. Some participants used several terms to refer to their ethnic/cultural identify. For the purposes of succinctness, the researcher used the first term that the participants used to describe themselves. However, it is acknowledged that participants used other terminology throughout their interviews. Please refer to the Findings section for further discussion relating to this.*

### 2.5.4 Data collection

#### 2.5.4.1 Semi structured interviews (SSI)

In terms of data collection, semi-structured interviews (SSIs) were conducted. This method of data collection fits well with IPA as it invites “participants to offer a rich, detailed, first-person account of their experiences” (Smith et al., 2009, p. 56). This is key given the lack of research which centres the voices of minoritised autistic girls and explores their lived experiences. SSIs were chosen because they give a voice to autistic individuals (Humphrey & Lewis, 2008), enable the researcher to build rapport with the participant (Cridland et al., 2014) and allow the participant to direct the interview thus providing them with agency (Huws & Jones, 2015). An interview schedule (appendix 4) was created in order to elicit the voices of minoritised autistic girls in a non-judgemental way (Pavlopoulou & Dimitriou, 2019). This was achieved by devising open-ended, short and neutral questions. In line with recommendations by Smith et al. (2022), the interview schedule included different types of questions such as descriptive, contrast and evaluative questions. Smith et al. (2022) also suggest avoiding over-empathetic, manipulative, closed and leading questions. This was paramount in the current study due to participants’ social communication differences. The interview schedule, which was discussed and reviewed with the research supervisor, included a series of questions exploring four key areas: participants’ identity, experiences of education, relationships and plans for the future. Exploring these four areas enabled the researcher to obtain a holistic and rich picture of participants’ experiences. At the start of the interviews, the researcher clarified the purpose and structure of the interview. Participants were encouraged to direct the conversation and prompt questions were only used when further information was required. The researcher also tried to expose the obvious as suggested by Smith et al. (2022) by asking seemingly obvious questions rather than inferring/assuming. Moreover, one of the last questions in the interview schedule gave participants the opportunity to add anything that they deemed relevant to the interview. The considerations outlined above enabled participants to share their voices and experiences, while reducing the researcher’s influence (as much as possible).

The researcher recognises that while autistic people share common characteristics, each autistic individual has their own needs and preferences (Happé et al., 2006). Therefore, as an attempt to cater to individual needs, participants were given two choices of interview format: face-to-face or synchronous (‘real-time’) online interviews. Both formats have been used successfully within IPA research (Murray & Rhodes, 2005; Reynolds & Lim, 2007). All participants chose face-to-face interviews. Thus, all interviews were conducted face-to-face at participants’ educational settings. Interviews were conducted between January 2023 and March 2023. The length of the interviews varied between 19 minutes and 140 minutes. However, on average, interviews lasted 69 minutes. All interviews were audio-recorded.

#### 2.5.4.2 Child-friendly resources

Although semi-structured interviews are a common method to capture the voice of CYP, they are not always as effective in eliciting the views of autistic CYP due to differences in social interaction and communication (Mandleco, 2013). Additionally, Losh and Capps (2006) argued that CYP may find it difficult to share their views on emotionally complex matters especially when working with an unfamiliar person, in an unfamiliar context and under limited time. This highlights the importance of employing data collection methods which facilitate the engagement and participation of autistic individuals and allow them to express their ‘authentic voice’ (Danker et al., 2016). Previous research utilised several child friendly resources to support autistic CYP to articulate their experiences and voices in a way that suits them thus ensuring that they engaged meaningfully with the research process (Winstone et al., 2014). In line with this, the current study incorporated a number of child-friendly resources to support the girls to effectively communicate their views. These child-friendly resources aimed to scaffold participants’ responses and allowed them to respond to the interview questions using their preferred method of communication e.g., writing, drawing or talking. This approach promotes agency (Parsons et al., 2020), and empowers autistic CYP to share their constructs and stories (Pavlopoulou & Dimitriou, 2019; Benford & Standen, 2009). It was also hoped that using these resources would alleviate the ‘double empathy problem’ (this theory posits that non-autistic and autistic individuals struggle to interact due to a mutual lack of understanding) (Milton, 2012). The child-friendly resources used in this study are outlined below in more detail (see appendix 4 for an example of each child-friendly resource used). These resources were used flexibly depending on participants’ preferences; therefore, some participants chose not to use these (and others only used them partially). Resources used by participants can be found in appendices 5, 6, 7 and 8.

#### 2.5.4.2.1 Grid Elaboration Method (GEM)

The Grid Elaboration Method (GEM) is a visually oriented method which involves asking participants to write and/or draw their associations to a particular topic. This tool is suitable for autistic CYP as its concrete, visual and structured nature can help to reduce anxiety and facilitate dialogue (Joffe & Elsey, 2014). Additionally, this tool fits well with the exploratory purpose of this research because it elicits data that is unexpected by the researcher (Joffe & Elsey, 2014). Participants were provided with "a grid containing four empty boxes and requested to write or draw in each box any image, word or feeling that comes to mind when they hear or think of the term under study" (Joffe & Elsey, 2014, p.178). In this particular study, participants were asked to draw and/or write in each box any image, word or feeling that comes to mind when they hear or think of the word 'autism'. Following this, participants were asked to verbally explain their drawings and/or writings. Participants' GEMs can be found in the Findings section.

#### 2.5.4.2.2 Person-centred thinking tool 1: Good day/ bad day

Person-centred thinking tools are a set of simple templates which are utilised to structure conversations (Sanderson & Lewis, 2012). This particular person-centred thinking tool helps to structure conversations about what a good day and bad day is like, for the participant. This allows the researcher to learn about what is important to the participant including both what must be present in their day and what must not happen. This tool was used when asking participants about their educational experiences. Participants were asked to describe a good or bad day at school/college, either verbally or through drawing and/or writing.

#### 2.5.4.2.3 Person-centred thinking tool 2: Relationship circles

This person-centred thinking tool provides a way of identifying who is important to the participant, and to explore any key issues around their relationships. This tool was used when asking participants about their relationships with others including, family, peers and school/college staff. Participants were asked to describe their relationships either verbally or through drawing and/or writing.

### 2.5.5 Data Analysis

Data was analysed using IPA. The researcher followed the seven-step process recommended by Smith et al. (2022). While this process is presented step-by-step, it is recognised that this is an iterative process. Please note that this research uses the new terminology introduced by Smith et al. (2022) in the second edition of their book.

#### 2.5.5.1 Prior to 'officially' starting analysis

Immediately after each interview, the researcher wrote down her initial thoughts and impressions in a research diary (see extract in appendix 9). These aided reflexivity during the later stages of the analysis process. The interviews were transcribed verbatim. Although IPA analysis focuses on the content of the interview, non-verbal communication (e.g., laughter and pauses) were recorded in the transcripts in order to support interpretation.

#### 2.5.5.2 Step one: 'Reading and re-reading'

The first step of the IPA process required the researcher to immerse herself in the data. Initially, this was achieved by listening to the audio-recording while reading the transcript for the first time. Subsequently, the transcript was read and re-read multiple times. This promoted active engagement with the data and ensured that the participant became "the focus of the analysis" (Smith et al., 2012, p.82). During this stage, the researcher also recorded her initial impressions of the transcript in a research diary.

#### 2.5.5.3 Step two: Exploratory noting

The second step of the IPA process required the researcher to "explore the semantic and language content on a very exploratory level" (Smith et al., 2022, p.79) while staying close to the participant's account. This involved writing exploratory notes on one margin of the transcript (refer to appendix 10). As suggested by Smith et al. (2022), the text was not divided into different meaning units, instead the researcher aimed to conduct a free textual analysis. In this step the researcher begins to identify how the participant thinks, understands and talks about the phenomenon being explored.

#### 2.5.5.4 Step three: Constructing experiential statements

The third step of the IPA process required the researcher to consolidate and crystalise her thoughts by developing experiential statements (analysing exploratory notes to develop experiential statements whilst preserving the complexity). This was achieved by focusing on the exploratory notes, rather than the transcript. An experiential statement is a statement that articulates the main claim that the researcher is making about the meaning of the participant's experiences around a particular phenomenon.

These statements reflect both the participant’s original words and the researcher’s interpretations. Refer to appendix 11.

#### 2.5.5.5 Step four: Searching for connections across experiential statements

This step required the researcher to look for connections between experiential statements. In practice this involved cutting the experiential statements into separate pieces of paper and scattering these on the floor in no particular order. The researcher then proceeded to cluster related experiential statements together. This involved spending a considerable amount of time looking at the experiential statements, moving them around and trying different clustering. See appendices 12 and 13.

#### 2.5.5.6 Step five: Naming the Personal Experiential Themes (PETs) and consolidating and organising them in a table

This step involved assigning a title to each cluster of experiential statements. These clusters then became the participant’s Personal Experiential Themes (PETs). Following this, the researcher created a table to organise and consolidate the PETs. This table presented PETs (and associated sub-themes) specific to the participant and included evidence from the original transcript e.g., quotes and page numbers of the transcript (Smith et al., 2022). Appendix 14 shows a table of PETs for Wonder Woman. At this stage, the researcher wrote a profile of the participant (based on their PETs). This profile was then shared with the participant in order to ensure that it reflected her experience. This was done via the process of member checking (see appendix 15).

#### 2.5.5.7 Step six: Continuing the individual analysis of other cases

The sixth step of the IPA process involved moving to the next participant’s transcript and repeating the process. In line with the idiographic principle of IPA, the researcher made a conscious effort to ‘bracket’ her ideas and assumptions from the previous case so that each case could be treated on its own terms. It is acknowledged that the findings from the previous case will inevitably influence the current case. However, in order to reduce this, Smith et al., (2022) recommends following the steps outlined above systematically for each participant.

#### 2.5.5.8 Step 7: Working with Personal Experiential Themes (PETs) to develop Group Experiential Themes (GETs) across cases

Once the researcher analysed all the transcripts individually and identified PETs for each participant, the aim is to generate Group Experiential Themes (GETs) (see appendix 16). This required the researcher to look for patterns of convergence and divergence across the PETs. As suggested by Smith et al. (2022) the researcher placed each table of PETs in a large surface and looked across them to find patterns and connections (see appendix 17).

## 2.6 Ethical Considerations

This research received ethical approval from UEA's Research Ethics Committee in June 2022 (see appendix 18) and adhered to guidance from the British Psychological Society's Code of Human Research Ethics (2021). Particular attention was paid to respect, trust, informed consent, confidentiality and the reduction of potential harm.

### 2.6.1 Informed consent

Before conducting interviews, potential participants and their parents/carers were provided with a comprehensive information sheet (see appendix 19 and 20) which outlined what the study would involve. This enabled participants (and their parents/carers) to fully consider their participation before agreeing to take part in this study. Prior to conducting any interviews, the researcher obtained written consent from both participants and their parent/carer. At the start of each interview, the researcher went through the information sheet with the participant in order to reiterate the aims and purpose of the study as well as seek additional verbal consent (including consent for audio-recording the interview). Throughout the interview process participants were reminded that they had the right to withdraw at any time. In fact, participants were given multiple opportunities to ask questions, raise concerns and withdraw from the study. By reiterating these key issues throughout the interview process, the researcher hoped to allow adequate time for participants to fully process and understand this information. Thus, obtaining informed consent was seen as an ongoing process, rather than a one-off event (Usher & Arthur, 1998; Lewis & Porter, 2004).

### 2.6.2 Confidentiality

Participants' data was handled in accordance with the General Data Protection Regulation Act (2018) and the University of East Anglia (UEA) Research Data Management Policy (2019). Participants' data, including personal and contact details, were only used for purpose that participants and their parents agreed to, and will be destroyed upon completion of the doctoral programme. Audio-recordings were encrypted and stored securely in the university's OneDrive, and transcripts were fully anonymised to ensure confidentiality. During the transcription process, participants were only referred to by number and all of their personal information was removed.

### 2.6.3 Duty of care

The researcher recognised that the topics being explored during the interview i.e., autism and culture/ethnicity could potentially cause some distress or discomfort for participants, particularly if they had negative experiences relating to their ethnicity/culture and/or autism. In order to reduce, any potential for psychological harm, distress or discomfort, participants were advised, at the beginning of the interview, that they could take a break or end the interview at any time. An appropriate member of school/college staff was also identified prior to all interviews in case of distress during the interviews. Additionally, at the end of the interviews, participants were provided with a debriefing sheet (see appendix 21) which included contact details of key support organisations for autistic people particularly autistic girls and minoritised autistic CYP. Lastly, the researcher adhered to the duty of care and safeguarding procedures defined by the Health and Care Professions Council (HCPC) (HCPC, 2016).

## 2.7 Quality of the research

Hefferon and Gil-Rodriguez (2011) suggest using Yardley's criteria (2000) to assess and demonstrate the validity of IPA research. These measures are sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

### 2.7.1 Sensitivity to context

This research considered sensitivity to context at all stages. In line with this principle, the researcher conducted a comprehensive review of the literature which enabled exploration of existing empirical and theoretical literature and formulation of research questions which addressed a gap in the literature. Secondly, this research ensured sensitivity to context by providing participants with a choice regarding the format of the interview (face-to-face or online) and the language used around their identity. Similarly, this research ensured sensitivity to context by providing participants with different means to share their views and experiences e.g., through drawings, writing or verbally. The method of data collection was therefore sensitive to the participants' social communication preferences/differences. The needs and preferences of autistic individuals were considered at all stages of the research (Howard et al., 2019). At the start of every interview, participants were asked if they felt comfortable and if they required any accommodations. Some participants requested minor accommodations, which included closing the blinds in the interview room and having a copy of the interview schedule with them during interview. The researcher also ensured sensitivity to context during the analysis process by not allowing her expectations to interfere with this process (Yardley, 2008). Moreover, by making use of direct quotes, the researcher ensured that participants' accounts remained central to the findings.

### 2.7.2 Commitment and rigour

Commitment and rigour were promoted by engaging in a thorough exploration of the research topic and completing an in-depth data collection and analysis. The researcher met regularly with the research supervisor to discuss the research topic. The analysis of the data was conducted using IPA, as described by Smith et al. (2022). Participants were given the opportunity to comment on the data analysis to ensure that the researcher's interpretation was reflective of their lived experiences. Member checking strengthens rigour as it "ensures that the participants' own meanings and perspectives are represented and not curtailed by the researchers' own agenda and knowledge" (Tong et al., 2007, p.356).

### 2.7.3 Transparency and coherence

Transparency and coherence were demonstrated by providing enough detail to enable the reader to gain a full understanding of what was done (and why it was done). This was achieved by providing a thorough discussion of the research questions, recruitment process, and data analysis processes (please refer to the appendices) (Ritchie & Lewis, 2003). Reflexivity is key in the process of transparency (Yardley, 2008). Adopting reflexibility allowed the researcher to acknowledge the potential impact of the 'double empathy problem' in the current study (Howard et al., 2019). Within this study, reflexivity was promoted by bracketing interviews, making use of a research diary, engaging in though-provoking conversations with both the research supervisor and peers and reflecting on own preconceptions (please see Reflective Chapter for further discussion on this).

### 2.7.4 Impact and importance

Yardley (2000) argues that “there is no point in carrying out research unless the findings have the potential to make a difference” (p. 268). The researcher believes that the current research addressed the importance of eliciting the voice of CYP in line with national and international policy such as the SEND Code of Practice ([SEND CoP] DfE, 2015) and the United Nations Conventions on the Rights of the Child ([UNCRC] United Nations, 1989). More specifically, the SEND CoP (DfE, 2015) stipulates that the views of CYP should be sought and used to inform decisions affecting their lives. Similarly, Article 12 of the UNCRC (United Nations, 1989) emphasises that CYP have the right to participate decisions which affect their lives. However, theorists have argued that this legislation is not always adhered to (Pellicano et al., 2013) and that eliciting CYP’s voice is often done in a superficial or tokenistic way (Hawkins & Soni, 2018). For instances, the literature review showed that the voices of autistic girls have consistently been neglected at the expense of other voices (such as parental and professional voices). This research ensured that the voices of autistic girls themselves were gathered. In particular, this research has given a voice to minoritised autistic girls, who traditionally have been excluded from research. Secondly, this research addressed the need for cultural competence and humility in EP practice. Due to increasing cultural diversity in the UK, there is a growing need for culturally competent practice in order to meet the needs of minoritised CYP and their families (Kusi, 2020). In fact, consideration and sensitivity to minoritised experiences features prominently in professional standards for EPs (BPS, 2018). Thirdly, the current study addresses the need to improve outcomes for autistic CYP as it has been documented that outcomes for autistic CYP are generally poor (Rosenblatt, 2008; Ambitious about Autism, 2017; Smith et al., 2012). The Findings and Discussion sections of this thesis further outline the usefulness of this study (in terms of adding to the understanding of the experiences of minoritised autistic girls).

## 2.8 Findings

This section outlines the phenomenological and interpretative findings of the current study. In order to keep with IPA’s idiographic principle and remain close to each individual’s experience, the researcher’s individual analysis of each participant is presented first (in the form of a participant profile), before moving onto the cross-case analysis. It should be noted that, when considering this section, the reader will bring their own fore-conceptions thus adding an extra layer of interpretation to the participants' and the researcher's sense-making process (Smith et al.,2022).

### 2.8.1 Participants' profiles and GEMs

#### 2.8.1.1 Wonder Woman

Wonder Woman is a 16-year-old girl who identifies as a Black-British. Wonder Woman is studying A-levels Art, English and Sociology at a mainstream sixth-form college in London. Wonder Woman has two older sisters and a younger brother. Wonder Woman lives with her mother and siblings. Wonder Woman was diagnosed with autism when she was in secondary school (in year 8/9) as she was experiencing difficulties at school, particularly around sensory sensitivities. Wonder Woman explained that her mother suspected that she was autistic for many years but did not want her to be "*labelled*", because, as a social worker, she had seen the impact of labelling. Wonder Woman agreed with this 'wait and see' approach and hypothesised that being diagnosed earlier would have led to her having a "*disdain*" for autism. Wonder Woman welcomed her diagnosis as it provided an explanation for her experiences and enabled her to access support. Prior to diagnosis, Wonder Woman saw autism as "*something out of reach*" as she thought that it was only applicable to those on the more "*severe*" side of the spectrum. Wonder Woman described herself as "*low needs autistic*", highlighting the importance of specifying one's level of need and perhaps a need to differentiate or distance herself from others who she may see as being on the more "*severe*" side of the spectrum.

During the GEM activity (see figure 4 below), Wonder Woman drew shapes; she said that these shapes represented "*order and structure*", alluding to the rigidity of some of her behaviours e.g., following rules and eating specific foods. She also spoke about how her autism makes her appreciate the "*small things*" such as "*nice weather*" and "*listening to music*", describing this as "*really euphoric*" (she wrote the word 'appreciation' during the GEM activity). Wonder Woman reflected on how her autism interacts with her other conditions e.g., asthma and allergies leading to added stress (she wrote the word 'stress' during the GEM activity).

Wonder Woman demonstrated some hesitation when responding to questions regarding her cultural background noting that it is not something that she usually thinks about. When asked about her cultural identity, she paused and said, "*I guess Black-*

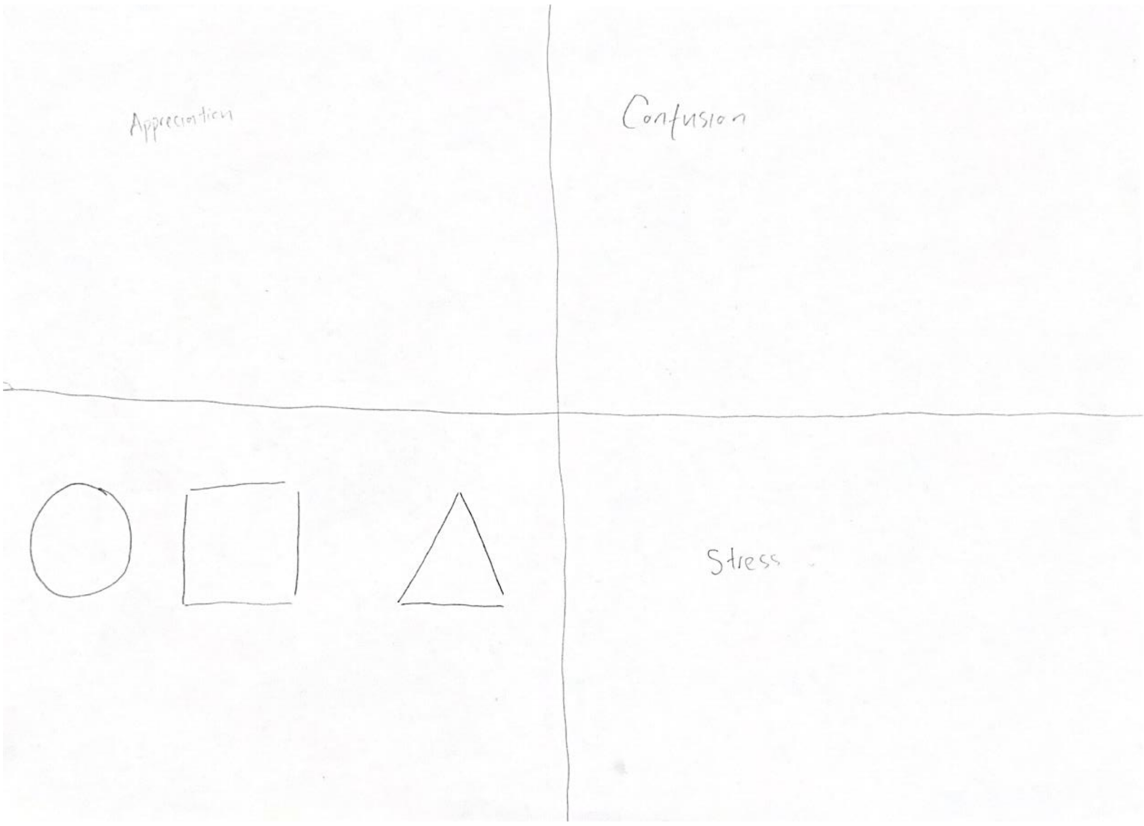
*British*". Her response suggested that her cultural identity did not feature within her everyday use of language. As the conversation unfolded, Wonder Woman reflected further on her cultural identity and concluded that her family may identify more as Black-Caribbean (particularly Jamaican), but she sees herself as Black-British. She alluded to the complexities around her cultural identity which were underpinned by migration. For example, she explained that her mother moved to the UK from Jamaica. She also referenced Canada as some of her extended family live there. Wonder Woman stated that her mother is a Catholic but she herself did not subscribe to any specific religion. She described religion as "*very dodgy*", and questioned the veracity and source of religious information, she said "*how do you know all of this information?".* Wonder Woman recounted that she was "*a bit worried*" about Catholicism when she was younger as she assumed that her mother, as a catholic, would tell her "*off*" due to her sexuality (Wonder Woman is bisexual). However, she noted that her mother was positive about this. During the member checking process, Wonder Woman noted that she now recognises that Catholicism and bisexuality "*can co-exist depending on the person*". Wonder Woman shared that she is exposed to Patois at home and that she speaks more "*formally*" at college compared to at home, highlighting perhaps a perceived expectation to speak formally at college. Wonder Woman talked at length about the way that she does her hair (in "*plaits*" and "*afros*") and how this is influenced by her heritage. Throughout her account, Wonder Woman referred to her immediate family, particularly her mother, as supportive and accepting. Wonder Woman's mother's influence was evident as her mother emerged in her narrative frequently. Wonder Woman recognised that she is "*lucky*" to have neurodiverse family members (her mother herself believes that she has "*Asperger's*"), expressing a great sense of gratitude for how this has shaped her lived experience. However, Wonder Woman recalled occasions where aspects of her autism, for example fleeting eye contact, were seen as "*rude*" and "*disrespectful*" by extended and older members of the family. Wonder Woman also expressed a sense of guilt in not always being able to fully participate in family and cultural events due to her sensory sensitivities (she explained that she usually sits in the corner or wears headphones to avoid the "*strong*", "*shouty*" and "*loud*" accents). For Wonder Woman, there was a sense of an inner conflict in wanting to participate in these events but also wanting to protect her wellbeing.

Wonder Woman spoke at length about how she previously struggled to understand social boundaries within relationships with peers at college, explaining that she constantly sought social interactions with peers but that these were not always reciprocated (e.g., peers did not respond to her texts or requests to "*hang out*"). Wonder Woman attributed these difficulties to her own misconceived ideas of what it means to be a friend, which were based on a previous friendship (during secondary school she had one best friend who she spent most of her time with). Wonder Woman asserted that she has now learnt to enjoy her own company and she believes that this will be a good skill to have when she eventually goes to university. However, she described this process, of having to learn to enjoy her own company, as "*very hard*". She also recognised that talking to peers still contributed to a good day at college for her (see appendix 6 for Good day/Bad day sheet). Likewise, she expressed wanting a social space at college highlighting that she is still very socially motivated. Wonder Woman talked about frequently feeling confused (she wrote the word 'confusion' during the GEM activity) about the social world and recognised that she will always feel this way due to her autism. While she described this as "*annoying"*, she also viewed it as positive aspect of her autism related to her ability to think critically. In this way, she reframed a challenge associated with autism as a strength. Wonder Woman found it hard to reflect on what it meant to be a Black-British autistic girl. However, she said "*I guess there is more nuance to me than like just being one thing or the other*", eventually concluding by saying "*it's like the only way I have ever lived, I can't think of anything else*". She noted that she does not see many girls when it comes to autistic representation, which she thought was related to the fact that people usually interpret girls' behaviours as simply being quiet or shy.

In the future, Wonder Woman aspires to study linguistics at university and "*get a job that doesn't stress me out (…) I just want to live a life that doesn't stress me out"*. During the interview process, although outside of the recorded interview, Wonder Woman noted that she had not previously considered many of the topics explored during the interview and that having the opportunity for reflection was helpful. Wonder Woman reviewed and approved this summary.

**Figure 4**

*Wonder Woman's GEM*



### 2.8.1.2 Cat Woman

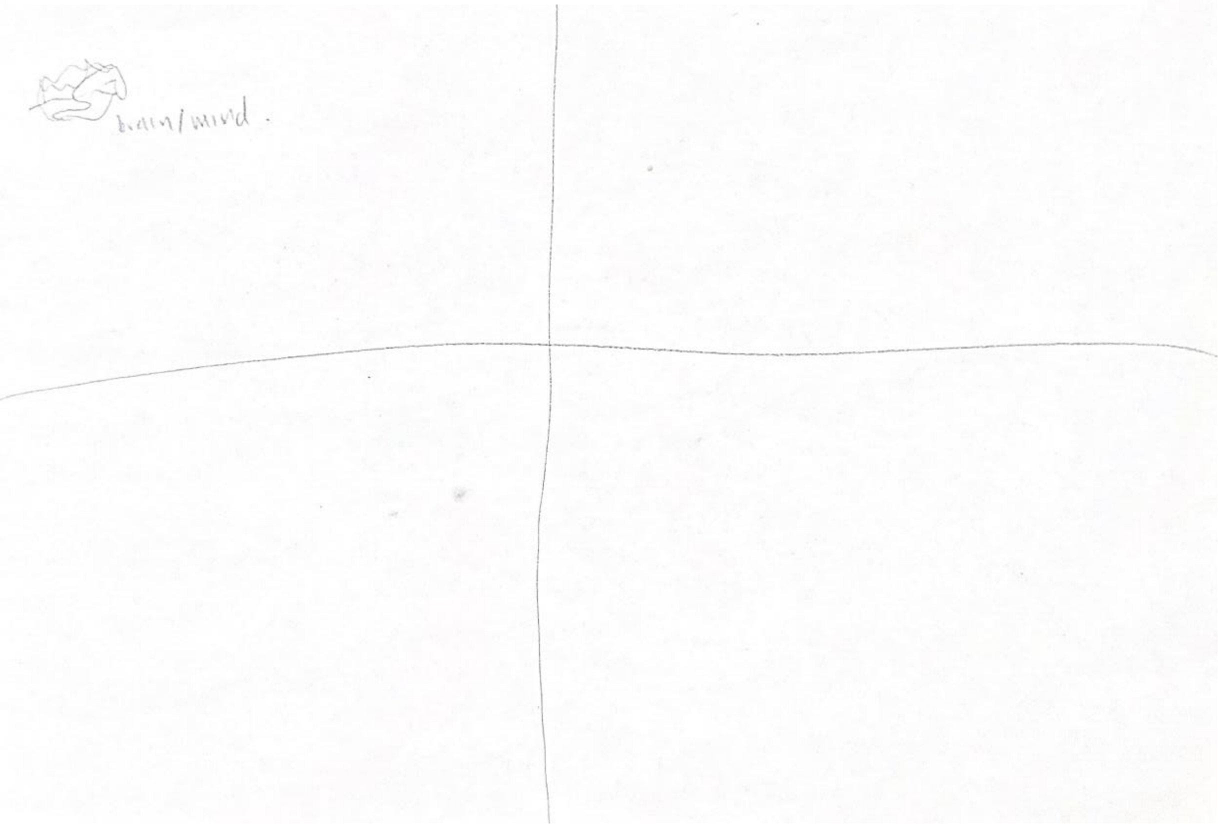
Cat Woman's interview was the shortest interview. Cat Woman generally answered questions very succinctly. Throughout our discussion, Cat Woman demonstrated a reluctance to share, often answering "*I don't really know*" and "*I am not really sure*". This was unsurprising as, prior to the interview, Cat Woman's mother informed me that Cat Woman is quite reserved. Despite this, Cat Woman was still able to share some of her experiences. Cat Woman is currently studying General Certificate of Secondary Education (GCSEs) at a mainstream secondary school in London. Cat Woman lives at home with her parents and one younger sibling. Cat Woman is 16 years old and identifies as "*mixed*". She said, "*my dad is black, and my mum is white*". She explained that on some occasions she has to clarify more about her identity because people assume that she has Nigerian heritage due to her mother's surname. Cat Woman conveyed a sense of conviction when talking about her cultural identity, generally answering questions about this quickly and in an assertive way. She reported that she is comfortable with the various terms used to describe people from minoritised backgrounds (she referenced the term "*people of colour*") but noted that she does not like outdated terminology such as "*coloured*".

Cat Woman explained that she was diagnosed with autism when she was 4 years old, but she only found out about this when she was 8/9 years old. During the interview, Cat Woman stated that she is "*just autistic*". She viewed early diagnosis as positive and recognised that many girls are diagnosed later. Thus, she viewed herself as privileged for knowing that she is autistic. During the GEM activity, Cat Woman drew a brain representing her mind (see figure 5 below). She explained that autism affects how she thinks and feels about situations, noting that she takes things "*more personally*" and "*more extremely*" than others, referring specifically to her sensitivity to sound. She described autism as "*certainly something that does intervene with my life on a daily basis*". When asked to think about the best thing about her autism, Cat Woman required further prompting and encouragement. Perhaps this is because she does not usually think of autism as a something associated with strengths. Cat Woman reflected on instances where she witnessed peers at school using "*autism as an insult*". She stated that people "*need to be taught that autism is relatively a normal thing*". These experiences seemed to cause her great discomfort, but she did not speak up, perhaps because she did not want to implicate herself. Cat Woman's reluctance to speak up was also present within her everyday school experiences, for example not asking for a replacement 'time out' card despite being entitled to one. Cat Woman recognised that she is "*scared*" to involve herself in "*stuff*". She said, *"that kind of draws attention to myself and I don't really want attention on myself"*. Cat Woman also reported finding social interactions with unfamiliar people tricky. She finds it easier to communicate with her friends, particularly those who are also autistic.

Throughout her account, Cat Woman referred to her family, particularly her mother and aunt, as "*tolerant*" and "*accepting*" attributing this to the fact that they both have autistic children, hence highlighting neurodiversity within her family. However, she recognised that her extended family would be less tolerant and knowledgeable about autism but hypothesised that they "*would not say anything bad about it*". Cat Woman made a distinction between her mother's side of the family and her dad's side of the family, stating that she is not aware of the attitudes of her dad's side of the family. Cat Woman highlighted that she uses the internet to make sense of aspects of her identity and gain a better understanding of the autistic female experience. For example, she noted that she found out online that girls and *"POC*" are more "*difficult to diagnose*".

**Figure 5**

*Cat Woman's GEM*



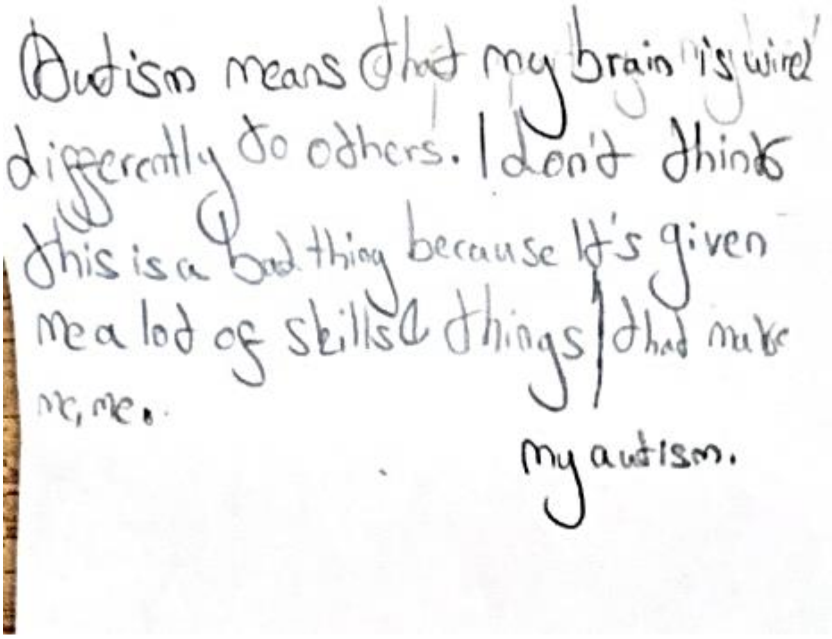
### 2.8.1.3 Storm

Storm is currently in Y9 at an independent special school for autistic CYP in London. Storm lives with her mother and two younger siblings. Storm is 14 years old and identifies as “*biracial*”. She explained that she is “a quarter Mauritian, Antiguan, Italian and Irish”. Storm uses British sign language (BSL), and sometimes speaks Creole with her grandmother. At the beginning of her interview, Storm asserted that her culture is “*very important*” to her. Storm recalled a time when someone failed to acknowledge the different parts of her cultural identity, which led her to become upset. She noted that “*it was like taking away a part of myself in a way”.* This suggests that how others describe her is important. However, Storm noted that she now usually describes herself as *“British”*, especially when she deems that the person asking requires a “*definitive*” answer. Thus, it seems that Storm now changes the language around her cultural identity to accommodate others. Later during the interview, Storm noted that she does not see language (both in terms of her autism and culture) as important unless it is relevant to the context of the situation, which seemed to directly contradict her earlier statement. Storm also stated that she often uses the term POC because she knows that some people dislike the term BAME. Overall, Storm's decisions about the language used to describe her identity around her autism and culture, were heavily influenced by other people's preferences.

Storm was diagnosed with autism when she was 9 years old following "*troubles*" at school. Storm explained that her journey to diagnosis was "*long*" and "*rough*" (partly due to unhelpful professionals) to the point that her mother considered paying for a private diagnosis. Additionally, family issues at the time meant that this period was very stressful for Storm. In particular, Storm referenced the Windrush scandal and described how her grandfather was at risk of deportation at the time of her autism diagnosis. Storm regularly referenced her mother and grandparents throughout the interview, highlighting the significant impact that they have in her life (see Relationship circles sheet in appendix 8). Initially Storm did not understand what her autism diagnosis meant, and while she has a better understanding of this now, she still believes that autism is something that cannot be fully understood. For Storm, autism means that her "*brain is wired differently to others" (see GEM below)*. Whilst Storm recognised that being autistic causes her to experience some challenges, particularly in terms of "*socialising*" and "*organisation*", she expressed that, for her, there are numerous positives associated with autism particularly "*good memory*" and "*empathy*". Storm stated, "*I really like being a person of colour and autistic cuz they are both parts of who I am*", she added "*I am like a superhuman*". Thus, her cultural and autistic identity were seen as very positive parts of her identity. This was in part attributed to the fact that in her family "*autism is seen as good thing*". During the interview process, though outside of the recorded interview, Storm asked the researcher whether she had come across as "*too pessimistic*". It appeared that it was important for her to convey the positive aspects of her experience as an autistic girl. In the future, Storm aspires to foster or adopt children. She has four careers options that she is considering: writer, musical artist, teacher and film maker, although she is currently leaning more towards teacher and filmmaker.

**Figure 6**

*Storm's GEM*



Autism means that my brain is wired differently to others. I don't think this is a bad thing because It's given me a lot of skills & things that make me, me.

My autism.

*Note. "Autism means that my brain is wired differently to others. I don't think this is a bad thing because it's given me a lot of skills & things that make me, me. - My autism."*

### 2.8.1.4 Shuri

Shuri is a 15-year-old girl who is currently in Y10 at a mainstream secondary school in London. Shuri has 3 older siblings and one younger sibling. When prompted to discuss her cultural identity, Shuri struggled to grasp this concept, asking "*How do you mean?"* and subsequently saying "*I don't know",* suggesting that cultural identity is not a part of her everyday language. When prompted to discuss her cultural identity further, Shuri could only talk about this in terms of food, stating that her family often eats "*Afro-Caribbean food*". When asked if she identified as Afro-Caribbean, Shuri stated that she is "*just British*". Shuri also noted that her parents were born in the UK. Shuri spoke about the role that Christianity plays in her life, seeing it as something that allows her to bond with her family (i.e., through prayer sessions before bed) but also describing church services as "*long*".

Shuri was diagnosed with autism when she was in Y7/Y8 as she was experiencing some difficulties at school, she explained that she was getting in "*bare trouble at school*". However, during the recorded interview, Shuri told me that she had been diagnosed "*2 months ago*". This was clarified outside of the recorded interview during discussion with Shuri and a member of school staff. Throughout her account, it was evident that Shuri had not yet processed nor accepted her diagnosis. This was evident in a number of ways: 1) a reluctance to provide an honest account of her diagnostic journey during the recorded interview, 2) an unwillingness to share her diagnosis with her friends, 3) a reluctance to speak about her diagnosis at home, stating "*I don't like talking about it, it's just weird*" 4) an inability to identify any positive aspects about her autism, 5) viewing autism as a "*disability*". Additionally, throughout the interview, Shuri demonstrated a sense of distance and vagueness in her responses. This distance and vagueness were also reflected in some of the language that she used. For example, instead of using first-person language, she often used the words "*them*" and "*they*" when referring to autistic people. In doing so, Shuri distanced herself from autistic people. Shuri chose not to complete the GEM activity, instead she stated that she views autism as a disability and that autistic people are "*different*" to "*normal people*". It appears that despite attempts from her older sister to reframe autism as a positive, Shuri continues to view her autism in a negative light. Shuri briefly mentioned that some of her friends make "*jokes*" about autism. Shuri explained that when this happens, she does not say anything and simply "*sticks*" to her "*side*", reflective of her reluctance to disclose her diagnosis or perhaps her belief that the topic of autism is not of relevance to her (as she rejects the diagnosis). Shuri stated that she does not have a preference regarding the language used to describe her autism, but later during the interview, she noted that she prefers the term autistic as it "*just sounds better*". There were a few staff members that Shuri liked and spoke about fondly, especially a couple of teachers and her teaching assistants (TAs) that she relied on daily to help her manage any difficulties. Shuri highlighted the importance of teachers listening to students and adopting a nurturing approach. In the future, Shuri wants to be a footballer. If she does not achieve this goal, she would like to become a midwife.

#### 2.8.1.5 Gamora

Gamora is a 16-year-old girl who identifies as "*mixed*". She explained that her mother is "*English and Irish*", and her dad is "*Indian Kashmiri*". Gamora used several terms such as "*British-Indian"* and "*biracial"* to describe herself, stating that the exact terminology she adopts often depends on the context and who she is speaking to. She also mentioned that she does not mind which term people use to describe her cultural identity, as long *as such terms "are coming from a positive source"*. Gamora's parents are divorced, and she lives with her mother. Gamora stated that she speaks "*a bit of Urdu*" and that she can also say greetings in Kashmiri. Gamora described her dad as a "*Sunni Muslim*" and her mother as a "*self-describing Christian*". Gamora reflected that it was difficult to grow up between these "*opposing yet similar religions*", noting that while her mother encouraged her to find her own path, her father, who she described as a "*strict Muslim*", hoped for her to be a "*traditional Muslim girl*". Gamora spoke at length about her tricky relationship with her father which she believes is underpinned by a mismatch between his cultural and religious expectations and the fact that she is usually not able to meet such expectations due to her autism (and comorbid conditions). Gamora noted that she had great respect for her father's culture and faith and expressed a desire to devote more time to explore this, but her mental health difficulties prevent her from doing so. Despite this, Gamora explained that she celebrates Eid every year, prays occasionally and goes to the mosque with her father. Gamora spoke about how her father does not understand how her autism impacts on her ability to take part in these religious events, for example, she recounted a situation when she was not allowed to use ear defenders at the mosque and therefore struggled to cope. She reported that she received judgement ("*side eye*") from members of the mosque.

Gamora is currently studying GCSEs at a mainstream secondary school in a home county. However, she does not attend lessons with most of her peers, spending most of her time in the SEND department. Gamora's experiences of masking (and the sense she makes of this) pervaded the interview. She included this in her GEM (see below), noting its detrimental effects, including high expectations from others and not truly knowing herself. Additionally, at the beginning of the interview process, although outside of the recorded interview, Gamora told the researcher that she planned to make a conscious effort not to mask during the interview. This appeared to be underpinned by a desire to showcase her true self to aid the researcher to make sense of her experiences. Gamora also spoke at length about her mental health difficulties, stating that she was diagnosed with Attention- Deficit-Hyperactive-Disorder (ADHD) and autism in Year 9 as she was struggling to cope at school and using unhealthy coping strategies such as self-harm and experiencing suicidal ideation. Her mother paid for a private diagnosis so that she could access support before her GCSE exams.

The diagnostic process is therefore still ongoing for Gamora as she is still waiting her NHS diagnosis. Gamora played an active role in her diagnosis, recognising her symptoms when she read about ADHD. Initially, she did not believe that she was autistic because she thought that this was only applicable to those with higher support needs. However, she noted that she always knew she was "*different*" because she was "*part of nurture groups*" throughout her education. Gamora described finding it difficult to "*emotionally empathise with others"*. However, during the member-checking process, Gamora explained that she does experience "*cognitive empathy*". She noted that she has a drive to help others as she likes to solve problems, but she often struggles with the reassurance and comforting side of things and needs others to clearly communicate what they want from her when they seek comfort. She added "*when someone is sad, I don't feel sad with them*" and noted that she struggles to put herself "*in their shoes*". Gamora identified educational professionals including teachers, counsellors and office staff who have supported and encouraged her, describing her counsellor as her "*rock*" (see Good day/Bad day sheet in appendix 5). Gamora described autism an essential part of who she is, highlighting a strong preference for the term "autistic" and stating that she had to learn that she is "*different, not less*". Gamora spoke at length about her co-morbid conditions including ADHD, Anxiety, Depression and Developmental Trauma. She also explained that she has hypermobility issues. Gamora reflected that her experiences are influenced by the interactions between these differing conditions rather than just autism. Gamora believes that her autism diagnosis was a positive turning point as she is now accessing support and using a range of resources to make sense of her autism and discover her true self. However, she also shared how she has experienced changes in adults' expectations of her capabilities post-diagnosis, recounting a time when a receptionist at a hospital treated her "*very childishly*". Gamora's account demonstrated a high level of self-awareness, with a clear understanding of who she is, her strengths and challenges, as well as which accommodations she needs in order to "*thrive*". Throughout her account, Gamora's use of language was often remarkable, as she used sophisticated and academic terminology e.g., mirroring, comorbidity and related this to herself. In the future, Gamora hopes to become a veterinary nurse and have lots of animals. Another career option for Gamora is nutrition. Gamora reviewed and approved this summary.

**Figure 7**

*Gamora's GEM*

## 2.8.2 Cross-case analysis: Group Experiential Themes (GETs)

Five GETs and fifteen sub-themes emerged from the data (see table 3). The five GETs are: ‘journey to diagnosis’, ‘making sense of autistic identity’, ‘making sense of cultural identity’, ‘school/college life’ and ‘relationships’. Each GET and sub-theme is outlined below with verbatim quotes from the participants in order to capture the nuances of their experiences and stay close to their accounts. Whilst themes are presented separately, it is important to recognise that they are highly interrelated. This is because, as exemplified by the hermeneutic circle, to understand individual ideas, one must look at the whole, and to understand the whole, one must look at individual parts/ideas (Smith et al., 2022). To aid the reader’s understanding, participants’ quotes are presented as follow:

- Verbatim quotes are italicised

- Participants’ pseudonyms preface quotes
- Contextual information is denoted by “[]” for example [laughs] or [pause]
- Emphasised speech is denoted by the use of capital letters

**Table 3**

*Overview of GETs and sub-themes*

**GET 1: Journey to diagnosis**

- Diagnosis in a problem context
- Involvement in the process
- Emotional reaction

**GET 2: Making sense of autistic identity**

- Strengths associated with autism
- Challenges associated with autism
- Identity first vs person first language
- Accessing online resources

**GET 3: Making sense of cultural identity**

- Cultural identity and labels as contextual and complex
- Navigating cultural and religious pressures and dynamics
- Understanding of intersectional identities

**GET 4: School/college life**

- Social relationships and interactions
- Sensory overwhelm
- Adjustments

**GET 5: Relationships**

- Immediate family as supportive
- Role of school/college staff

### 2.8.2.1 GET 1: Journey to diagnosis

During the interview, participants were asked to share their diagnosis stories. This GET describes participants' varying experiences of receiving an autism diagnosis. This included factors underpinning diagnosis, their involvement within this process and how they reacted to their diagnosis. Wonder Woman, Shuri and Gamora were all diagnosed with autism during secondary school. Storm was diagnosed in primary school whereas Cat Woman was diagnosed at age four.

**Table 4**

*Prevalence of sub-themes related to the GET 'Journey to diagnosis'*

| | Diagnosis in a problem context | Involvement in the process | Emotional reaction |
|---|---|---|---|
| Wonder Woman | ✓ | ✓ | ✓ |
| Cat Woman | | ✓ | ✓ |
| Storm | ✓ | ✓ | ✓ |
| Shuri | ✓ | ✓ | ✓ |
| Gamora | ✓ | ✓ | ✓ |

#### 2.8.2.1.1 Sub-theme: Diagnosis in a problem context

Wonder Woman, Storm, Shuri and Gamora all described that their autism diagnosis was triggered by difficulties at school, more specifically secondary school for most participants. Thus, for these participants, autism diagnosis was situated within a problem context. For example, Wonder Woman said:

> ***Wonder Woman**: Well in secondary, I think things like sensory issues were really getting to me. I had a lot of issues regulating my emotions and like if I was having a bad day already and then let's say it was raining outside and all of that just was really like…. I just couldn't cope. And that added with things like exams well even like the exam halls I just didn't like the layout, it made me stressed out. And then there was… like…. it was just very small things like that, that just built up to like me feeling low in mood all the time*

Here, Wonder Woman explains how a number of difficulties at secondary school namely sensory and emotional regulation prompted a autism diagnosis. The extent of

Wonder Woman's difficulties is apparent through her use of phrases such as "*really getting to me*" and "*I just couldn't cope*". Interestingly, Wonder Woman shared that her difficulties were underpinned by "*very small things*" that "*built up*" thus highlighting the gradual nature of her difficulties. Similarly, Gamora described how difficulties at secondary school triggered her autism diagnosis. She said:

> **Gamora:** *Especially once I got to secondary school, that is when the massive sort of bombshell hit that 'wow I am struggling'. Cuz I got to secondary school and the expectations completely changed. They went from gentle, go at your own pace to come on you need to study, you need to get the work done so that you can get your GCSEs and go out into the world, and I was like 'wow I am year 7, what happened?' and these high expectations led to me falling behind, going in lower sets.*
>
> **Gamora:** *I was experiencing loads of burn out, I was experiencing loads of like feeling overwhelmed and feeling tired. I hated school.*

In the first passage, Gamora's use of the words "*massive bombshell*" illustrates the significance of the revelation that she was struggling. She conveys a sense of surprise and shock at this realisation. This unexpected realisation was underpinned by the sudden change in expectations in year 7. Gamora was not prepared for this change. The detrimental impact of this sudden change of expectations is clear as Gamora used multiple words to describe this, i.e., "*overwhelmed*", "*tired*" and "*burn out*". One word is not enough to encompass the extensive impact of this. She also used the word "*hated*" to convey her intense, extreme dislike towards school at the time. The use of this word in the past tense highlights a progression of her feelings about school.

Shuri and Storm also referred to "*troubles at school*". However, for Shuri these troubles started in secondary school whereas for Storm, they started in primary school. Storm had a particularly tricky diagnostic journey, describing it as "*rough*" and "*long*". Unlike other participants, Storm experienced added difficulties at the time of her diagnosis as she was dealing with family issues related to the Windrush scandal:

> **Storm:** *Yeah, like it was very rough and especially since that was like a very rough time during … like it was like 2018… so like very rough for my family… like… yeah so.. like … hearing all of that.*

> **Interviewer:** *And when you say it was very rough for your family, do you mean the whole journey to diagnosis or were there other things going on?*
>
> **Storm:** *Yeah like do you know the Windrush scandal?*
>
> **Interviewer:** *Yeah*
>
> **Storm:** *Yeah it affected my grandad so. Like having that and me getting diagnosed and troubles at school and yeah so like it all… like I [inaudible] club like it was all like very messy.*
>
> **Storm:** *Early 2018 like grandad got a letter saying that he would… that he was gonna get deported. And so, like we were like trying to… like we were going to different parliaments… and like my mum and my grandad had different meetings and talked to the news.*

Storm's phrase "*very rough*" is used to indicate the significant negative impact of this period of her life. There is a sense of real chaos in Storm's account, this is captured by her use of the word "*messy*". This chaos is undermined by several factors including the threat of deportation of her grandfather and troubles at school. Furthermore, Storm's use of the word "*we*" suggests that she was (or at least she felt that she was) very much part of the 'battle' to stop her grandfather's deportation.

### 2.8.2.1.2 Sub-theme: Involvement in the process

All participants described varying levels of involvement within the diagnostic process. For Shuri, Storm, Cat Woman and Wonder Woman, their mothers were the main drives for diagnosis. Shuri shared:

> **Shuri:** *Like my mum was just concerned that I was getting in bare trouble at school so they referred me to him.*
>
> *Interviewer: What kind of trouble were you getting into?*
>
> ***Shuri****: Just trouble, like normal things at school*
>
> *Interviewer: Can you give me an example?*
>
> ***Shuri:*** *Getting like kicked out of lessons and getting into fights*
>
> *Interviewer: What were you doing to get kicked out of lessons?*
>
> ***Shuri****: Speaking and making noise.. and yeah*

In this excerpt, Shuri used the term “*they*” expressing a sense that she was not involved in the diagnosis process and that “*they*” had more of a say in this situation than she did. It was unclear whether “*they*” referred to her family or both her family and school. When prompted to explain further about why she was getting into trouble at school, Shuri said “*normal things at school*” suggesting that perhaps she did not see her troubles as a big concern (perhaps not concerning enough to warrant a referral and subsequently a diagnosis). Wonder Woman also noted that she was not involved in the diagnosis process and that her mother was the main drive for diagnosis:

> **Wonder Woman**: *She realised that I was like having some issues with like … I don’t know… I was just… She saw that I needed the diagnosis to help me with in life. So that’s what happened.*

Similar to Shuri, Wonder Woman also described how her mother was the main drive behind her diagnosis. However, unlike Shuri, Wonder Woman, appears to agree with and understand the value of her diagnosis, adding “*I needed a diagnosis to help me with in life*”. Diagnosis is therefore seen by Wonder Woman as a means to flourish in life. Cat Woman was diagnosed much earlier than other participants (at around age 4) thus her recollections were vaguer than other participants. She said:

> **Cat Woman:** *I think I got diagnosed when I was like four. I think like my mum had this meeting at school and I was like in y3 or 4. And I was kind of confused on why she had the meeting with my teacher.*

Cat Woman used the word “*think*” when recounting her diagnosis journey, indicating not only that she was not actively involved in the diagnostic process but also that she is not certain about specific details surrounding this.

Gamora was the only participant who was fully involved in the diagnostic process. As a result, she was able to provide a rich and detailed account of her diagnostic journey. Gamora described how she played an active role in her diagnosis by researching and contacting her General Practitioner (GP). However, she noted that she was initially seeking an ADHD diagnosis:

> **Gamora:** *I think I was probably 13 and cuz I always loved research and I was doing some stuff on psychology cuz that’s what I was enjoying, and I came across ADHD, and I was like ‘oh what’s this?’*

> **Gamora:** *And then I done loads and loads of research for months and months and months and then I said to my mum I think I might have ADHD. And then I called the GP I told all about my experiences, what I thought linked up with this, the symptoms I was having. And hilariously, he replied with 'OK great, so we will book you in for a face-to-face consultation, it sounds like you've got ADHD most likely autism as well'.*

Gamora repetitious use of the word "*months*" suggests that she completed extensive research on ADHD. Unlike other participants, Gamora uses the word *"I"* (first person) several times when describing her diagnostic journey, alluding to her significant involvement in this process. Gamora went on to describe the diagnostic process as "*long*" as she is still awaiting her NHS diagnosis (she has a private diagnosis that her mother paid for so that she could access appropriate support in time for her GCSE exams).

#### 2.8.2.1.3 Sub-theme: Emotional reaction

All participants noted that receiving an autism diagnosis evoked a range of emotional reactions and responses. These ranged from positive, negative and conflicting emotions. Despite difficulties around obtaining a diagnosis Gamora described how being diagnosed enabled her to understand herself better:

> **Gamora:** *Personally within myself, it was just…It sparked a really good sort of [inaudible] of finding and understanding myself, of course that was very difficult for me because I now understood I have this difference, I am being assessed for it bla bla bla I am not being myself humm so what is myself?, and I had to do a lot of self-studying like realising this behaviour means this and that means that again loads of loads of personal research*

Here, Gamora described how diagnosis prompted a journey of self-discovery which involved *"a lot of self-studying".* While she sees this as largely positive, Gamora also acknowledges the difficulty around having to re-discover oneself and working out her true self *"so what is myself?"*. Like Gamora, Wonder Woman also welcomed her diagnosis. She saw it as *"an answer"* for her experiences:

> **Wonder Woman:** *I guess it is nice to have like something there just to say, like… this is… like, it's like an answer. Because I had always been questioning things. So even though…at that point in time I was like it probably is autism.*

> *Just to have it like say like yeah it is autism.*

Here Wonder Woman, appears to suggest that having a diagnosis, not only provides an answer but it also legitimises her experiences. There is a sense that the autism diagnosis, provides reassurance and stops the *"questioning".* Being diagnosed with autism also evoked an emotional response for Shuri. However, her response was less positive than other participants. When asked what she felt when she found out that she was autistic, Shuri said:

> **Shuri:** *I don't know, I was shocked*

Despite prompts to expand on her answer, Shuri was unable to offer an explanation as to why she was shocked. Shuri's inability to expand on this suggests that she is still perhaps shocked.

Both Storm and Cat Woman expressed that they did not fully understand the concept of autism at the time of their diagnosis attributing this to their age and maturity at the time. Cat Woman said:

> **Cat Woman:** *I think I understood but not like to the same extent that I would understand now*

In this excerpt, Cat Woman highlights the progression in her understanding of autism suggesting the evolving nature of her understanding of autism and perhaps her identity as an autistic girl. Storm added to this notion:

> **Storm:** *I didn't fully understand but like I don't think me at that age was meant to, you get me?*

Here, Storm's use of a question *("you get me?"),* suggests that she is perhaps seeking reassurance that it was OK not to have a full understanding of her diagnosis at the time. She went further to add that she does not yet have a full understanding of autism and believes that no one can fully ever understand it, suggesting that she sees autism as a something beyond comprehension:

> **Storm:** *I don't think anyone can really understand, like they might have like a high knowledge of it but like you can never properly know anything.*

### 2.8.2.2 GET 2: Making sense of autistic identity

This GET refers to the impact of participants' autism diagnosis on their self-constructs. During the interview, participants were asked what their autism meant to them and what language they preferred to use in terms of their identity around their autism. Most participants identified both strengths and challenges associated with their autism, thus presenting a balanced or at times conflicting view. For some participants, these views appeared to be influenced by information that they had accessed online. It is important to note that while participants were asked about the best things about being an autistic girl, they were not directly asked about the challenges associated with autism. In terms of language used around their identity, most participants preferred identity-first language. However, their reasons for this differed.

**Table 5**

*Prevalence of sub-themes related to the GET 'Making sense of autistic identity'*

| | Strengths associated with autism | Challenges associated with autism | Identity first vs person first language | Accessing online resources |
|---|---|---|---|---|
| Wonder Woman | ✓ | ✓ | ✓ | |
| Cat Woman | ✓ | ✓ | ✓ | ✓ |
| Storm | ✓ | ✓ | ✓ | ✓ |
| Shuri | | ✓ | ✓ | |
| Gamora | ✓ | ✓ | ✓ | ✓ |

#### 2.8.2.2.1 Sub-theme: Strengths associated with autism

During the interview, participants were asked about the best things about being an autistic girl. Most participants identified strengths associated with their autism. Overall, Wonder Woman, Gamora, Cat Woman and Storm understand their autism as an advantage in some ways. For example, Gamora identified two key strengths associated with her autism:

> **Gamora:** *I am able to be very hum practically helpful.* And very knowledgeable on certain subjects.
>
> ***Gamora:*** *I probably know more than you and your dietitian about how to take care of your dog and I probably know more rare animal species than you and I probably know a lot more about how to care for a dog than you do, and I know a lot more about snakes than you do.*
>
> ***Gamora:*** *And I am able to help someone without being biased or affected by my emotions. So, while you are sitting there upset crying with the person or being affected that you witnessed some gruesome fight between two people, I will be the one helping clearing up and taking care of them without being affected by it. So yeah, I think those are two very positive things.*

In these extracts, Gamora identified her strengths by comparing herself to others, she appears to use the word "*you*" in reference to non-autistic individuals. Her use of comparative language (e.g., "*more than*") conveys a sense that, at least within these domains, she possesses characteristics that non-autistic individuals often lack, in this sense she perhaps saw herself as superior to non-autistic individuals. Interestingly, when discussing her strengths, Gamora also mentioned areas that she struggled with, e.g., 'although I am not able to X, I can Z'. This indicates that having these strengths balances out her challenges/difficulties.

At times, some participants reframed challenges associated with autism as strengths. For example, Wonder Woman identified an aspect of her autism which she saw both as a strength and as a challenge. For example, Wonder Woman said:

> **Wonder Woman:** *Sometimes I just like… it's like a lot of the times... I just like see people doing things and I am just like "why?" like not in a bad way, but like… I remember in school; I will see people like on their phones and they are on Instagram... I don't know... I think it was Snapchat. I think they were taking pictures of each other and they were doing [inaudible]. And I was thinking why are you doing that? And I just didn't get it and I don't think I ever will... sometimes I feel like things confuse me more than they should and sometimes I don't see it as a bad thing. Like I see it as a good thing because it's like I can think more critically… like the more you think about things I think is better than just taking things at like face value and just accepting, but is quite annoying*

In this passage, Wonder Woman alludes to the duality of some aspects of her autism. Being confused is not just a strength or a challenge – it is both. On one side, it enables Wonder Woman to *“think more critically*” but on the other hand it is also *“quite annoying”.*

Cat Woman and Storm recognised similar strengths associated with their autism, namely empathising with other marginalised groups. They said:

> **Cat Woman:** *Hummm… I feel like it’s made more empathetic towards other people with disabilities and stuff*
>
> **Storm:** *And also like it helps me like with my empathy I think because I … if like… if I wasn’t autistic myself I don’t know if like I could relate to people with… like different people with autism and like different autistic people and like I don’t know if I would been as empathetic and like to other people’s struggles as I am being …. If I wasn’t autistic.*

While both participants provided a similar answer, it is important to noted that Cat Woman initially struggled to answer this question, requiring prompts to think about it further. This may be because she does not usually think about autism in this way i.e., as something associated with strengths. In contrast, when asked this question, Storm said “*ah there is a lot of things in this”* indicating that she can readily identify numerous strengths associated with her autism and that perhaps this is something that she thinks and reflects about frequently. For example, in addition to empathy, she identified good memory as a strength associated with her autism. She said:

> **Storm:** *To be able to like make people, give people the illusion that you know a lot, but you don’t [laughs]*
>
> **Interviewer:** *What do you mean? Tell me a bit more about that.*
>
> **Storm:** *Because I have very good memory so like I can remember the most, like I can remember like crazy facts so when I am talking to people, they think I know stuff. And like I just heard it because I watched a YouTube video.*

Shuri was the only participant who did not identify any strengths associated with her autism. When asked if there is anything good about being an autistic girl, she said *“nothing*”. This is perhaps related to her reluctance to accept her diagnosis.

#### 2.8.2.2.2 Sub-theme: Challenges associated with autism

Although participants were not directly asked about this, all participants identified at least one challenge associated with their autism. However, the extent to which participants focused on these challenges throughout their interview, varied considerably between participants. There were also key differences in how participants made sense of and dealt with these challenges. Most participants' challenges related to their social interaction and communication skills as well as sensory difficulties. Additional difficulties identified by participants included feeling different and organisational difficulties. For example, Shuri viewed autism as a *"disability"* which affects how she thinks:

> **Shuri:** *Different… I feel like some autistic people think different to like other normal people*

Here, Shuri refers to autistic people in the third person, perhaps suggesting that she does not see herself as autistic. She also uses the word "*normal people*" to refer to non-autistic people hence suggesting that she sees autism as something abnormal. Storm identified organisational difficulties as a challenge associated with her autism. She said:

> **Storm:** *My organisation is a flop*
>
> **Interviewer:** *What does that mean? Tell me a bit more.*
>
> **Storm:** *Like it's like my mind is like completely like air and that like I keep on forgetting stuff and I can't keep my room clean like I am like yeah, I am like called, like some people, my family joke around that I am a tornado because of like yeah*

Storm provides a powerful comparison, associating her mind to "*air*" seemly highlighting her difficult to maintain and organise information in her mind. Like a tornado, Storm's organisational difficulties cause disruption and mess, and perhaps affects those around her (in this case her family).

#### 2.8.2.2.3 Sub-theme: Identity first vs person first language

Participants were asked about their preference regarding language used around their autistic identity. Gamora, Wonder Woman and Cat Woman shared a preference for the term autistic. Cat Woman said:

> **Cat Woman:** *I am just autistic.*

Cat Woman uses the word *"just"*, indicating that perhaps, for her, there is no question or uncertainty about this. She is simply autistic. Gamora explained why she preferred identity-first language:

> **Gamora**: *Cuz obviously you know autism is a neurotype, it's the way your brain is made up, it's not something on the side, like I haven't got a broken leg like it's not something that can either go away or is separate from myself like I am not carrying a handbag, it's the way my brain is made up. So, I think definitely autistic person fits better with me because like I see it as, it's how I am.*

In this excerpt, Gamora uses powerful comparisons to highlight the fact that her autism is an inherent part of her identity rather than an add on (unlike a *"handbag"*). She also says *"fits better with me"* which emphasis the highly personal nature of this preference. Gamora goes on to say:

> **Gamora:** *I think that for me the reason why using the correct terms is important probably boils down to the fact that it has taken a long time for me to figure it out so being able to voice that and have other people use those terms for me makes it feel very validating even in my own identity and how I describe myself.*

Here, Gamora highlights that language around her autism identity is particularly important to her as she considers herself to be *"late diagnosed*". Thus, it took a long time for her to make sense of her identity. There is a sense that using the correct terminology around her autistic identity perhaps validates or legitimises her autistic self. Again, Gamora uses terms such as *"for me"* highlighting the highly personal nature of her choice for identity-first language. Wonder Woman also showed a preference for identity-first language and highlighted the importance of specifying one's level of need, identifying herself as *"low needs autistic".* She shared:

> **Wonder Woman:** *I also think maybe like low needs autistic would be more specific because I know that like it's a spectrum.*

Here, by specifying her level of need, Wonder Woman seems to be distancing herself from other autistic people who she perhaps sees as on the more *"severe side"* of the spectrum. There is therefore a 'us versus them' attitude within the spectrum. She goes on to explain that the level of specificity depends on the context or situation:

> **Wonder Woman:** *Well, I guess it depends on the situation because if someone is talking about like implementing something for autistic people in general then maybe you should be more specific with that. Or like if you are speaking about your experience sometimes maybe just like specifying like "oh I am non-verbal" to like help give more context or like how something can impact you. Other than that, I think if you say you are autistic then people usually think of the most common attributes like sensory issues and things like that*

Both Storm and Shuri said that they did not mind either term (person with autism or autistic person):

> **Storm:** *I don't mind, autistic, person with autism*
>
> **Shuri:** *I don't know it is up to you. I don't mind*

However, this appeared to be for different reasons. Throughout her interview, Storm conveyed a desire to please people or avoid inconveniencing people. This was apparent in her willingness to adjust the terminology used around her identity to accommodate others/for the ease of others. On the other hand, Shuri's initial indifference in terms of the language used around her autism, was perhaps underpinned by her rejection of her diagnosis. After being prompted further, Shuri stated that she preferred the term autistic person because "*it just sounds better",* thus suggesting that she is not as indifferent as she initially portrayed to be. However, her response highlights that this is perhaps a superficial preference.

#### 2.8.2.2.4 Sub-theme: Accessing online resources

Most participants reported using online resources e.g., social media and autism-related websites to understand and make sense of their autism and to understand the experiences of minoritised autistic girls. For example, Storm shared:

> **Storm:** *I feel like my community like masks a lot well based on what I researched because I like researching. I think it is very interesting because of how like people of colour and autistic girls are like two of the most like two like both of them are very big masking communities because you have to like, like you have to be and then having them both together is probably, you get me?*

In this excerpt Storm uses the term *"my community*", conveying a sense that she identifies with such community. She seems to suggest that masking is a requirement or expectation *("you have to"*) for both autistic girls and POC. She also reflects on the possible complexities of being a minoritised autistic girl (*"having both of them together").* Interestingly, Storm's use of the word *"having"* suggests that one *'has autism'* and *'has POC'*. Her use of the word *"probably"* also suggests that she is not certain about it as it is perhaps not reflective of her own experience but rather something that she has researched. When asked to expand on this further, Storm struggled to articulate her response, suggesting that she is not always able to either make sense of or articulate information which she has researched, and which is not personal to her. Cat Woman also speaks about reading about this matter online:

> **Cat Woman:** *I just like heard of like how other like… white people and boys are like easier to diagnose, and that people are diagnosed the wrong thing when they are really autistic and stuff*
>
> **Interviewer:** *Where did you see or read this?*
>
> **Cat Woman:** *I just heard of people saying online and stuff*

Cat Woman's use of the word *"other people"* suggests a distinction between herself and other autistic individuals. She, a mixed autistic girl, is different to autistic *"white people boys",* who are *"easier"* to diagnose. Her use of the word *"easier"* suggests that there is something inherent about white people and boys that makes them easier to diagnose. Gamora echoed this distinction between autistic boy and girls. She said:

> **Gamora:** *I think there are differences between boys and girls because of studies*

In this excerpt, Gamora indicates that her views about autistic girls and boys are shaped by studies which she has read.

### 2.8.2.3 GET 3: Making sense of cultural identity

During the interview, participants were prompted to speak about their cultural identity. This GET refers to how participants view and make sense of their cultural identity. Most participants mentioned basic aspects about their family's heritage, their religion, and other aspects that make up their culture. Cultural identity and labels were seen by most participants as contextual and complex. Some participants also spoke about difficulties navigating cultural and religious pressures as a result of their autism.

**Table 6**

*Prevalence of sub-themes related to the GET 'Making sense of cultural identity'*

| | Cultural identity and labels as contextual and complex | Navigating cultural and religious dynamics and pressures | Understanding of intersectional identities |
|---|---|---|---|
| Wonder Woman | ✓ | ✓ | ✓ |
| Cat Woman | ✓ | | ✓ |
| Storm | ✓ | | ✓ |
| Shuri | | ✓ | ✓ |
| Gamora | ✓ | ✓ | ✓ |

#### 2.8.2.3.1 Sub-theme: Cultural identity and labels as contextual and complex

Some participants particularly those with mixed heritage (e.g., Cat Woman, Storm and Gamora) seemed to welcome the space to explain or provide more detail about their cultural background rather than focusing just on one label. When asked about her cultural identity, Cat Woman initially said:

> **Cat Woman:** *I think I would describe myself as mixed normally*

Cat Woman provided a succinct and prompt response, suggesting that she is confident about how she describes herself in terms of her cultural identity. However, her use of the word *"normally"* suggests that she perhaps also adopts other terms and labels to describe herself in terms of her cultural identity. When prompted to discuss her cultural identity further, Cat Woman added:

> **Cat Woman:** *When it comes to like… like if people ask about my surname because, like my dad like… basically, my surname is like from my mum's side, but my mum is like mainly white and it's like a Nigerian surname but like my dad is not Nigerian so its kind confusing*

Here, Cat Woman's use of the word *"confusing"*, alludes to the complexity of cultural identity.

Storm and Gamora stated that how much information they provide regarding their ethnic identity usually depends on the context. For example, Storm initially said "*I am biracial. I am a quarter Mauritian Antiguan Italian and Irish".* However, she explained that she usually just says *"British"* following this incident:

> **Storm:** *I was in Madame Tussauds and then like there was this person that was hosting a game and he kept asking where I was from and then I kept on saying those four countries, and then he ended up just saying one at random which I got upset by and then I talked to mum about and she just said just use the word British so that's what I use.*
>
> **Interviewer:** *Why did you get upset?*
>
> **Storm:** *Like… I felt like it was like taking away a part of myself in a way. Yeah, because like my culture is very important to me and makes part… like a portion of who I am so.*

Here, Storm alludes to the importance of her of cultural identity and sees this an inherent part of who she is. By not recognising her full heritage, others are denying and *"taking away"* this crucial part of herself. This encounter had significant lasting impacts for Storm, as she has subsequently changed the way she identifies herself. It appears that, for Storm, others have the power to deny or validate her identity. Storm shared how she identifies now:

> **Storm:** *I say biracial, and I say which countries I am from but like if they want me to give a definitive answer, I say I am British.*

In this passage, Storm uses the word "they" which suggests that the terminology that she uses to describe her ethnic identity is determined/dependent on the person asking the question. Gamora echoed this idea, stating "*Well if it's just anyone I would say I am half English half Indian, but if it's someone that knows a bit about culture, I would say, well I am half British and half Jammu Kashmiri so but that's just what I would say depending on so I don't mind, whatever is easiest or feels comfortable for you*".

Congruent with this idea of ethnic labels/language/terminology as contextual, Cat Woman, Storm and Gamora noted that they do not mind the terminology used around their ethnic identity, particularly terms used to describe ethnic diversity more generally (e.g., POC, BAME etc.). Storm said:

> **Storm:** *I don't mind, anything is cool. I just use People of Colour because I know people not liking the term BAME and I want to make sure that like yeah*

Here Storm conveys that she is happy with any terminology others prefer to use. However, she generally uses the term POC as this is what she perceives most people prefer, again highlighting how she changes the language around her identity to appease others. Interestingly, the term POC was also referenced by Cat Woman and Gamora.

Cat Woman also displays a somewhat unfazed approach towards terminology used to describe her in terms of her ethnic identity. However, she rejects outdated terminology:

> **Cat Woman:** *I don't think I am really against anything but mixed just makes the most sense to me.*
> **Interviewer:** *Ok, are there any terms that you've heard that you are not really keen on?*
> **Cat Woman:** *Humm I feel like the terms I wouldn't be keen on are just the terms that shouldn't be used nowadays*
> **Interviewer***: Ok like what?*
> **Cat Woman:** *Like coloured and stuff*

In this excerpt, similar to Storm, Cat Woman conveys somewhat an indifference towards the terminology used to describe her. However, she effectively draws the line and identifies *"terms that shouldn't be used nowadays"* perhaps due to the racist connotations associated with these terms. For Cat Woman, these terms are outdated and therefore should not be part of the current vocabulary. Gamora takes a similar perspective and acknowledges that:

> **Gamora:** *I think they are all valid terms; I mean so long as they are coming from a positive source that's what matters cuz obviously words only have meanings because of the intention you have behind them.*

Here Gamora suggests that the meaning of a word can change depending on the intention of the speaker. So, while words themselves have a dictionary definition, their meaning can also be influenced by the speaker's intention and the circumstances in which they are used.

Similar to other participants, Wonder Woman also seemed to require space to explain or provide more detail about her cultural background. However, this was for slightly different reasons. When first asked about her cultural identity, Wonder Woman said:

> **Wonder Woman:** *[pause] I guess Black-British*

In this extract, Wonder Woman’s pause/hesitation to response suggests that she needed time to think and reflect on her cultural identity. Furthermore, her use of the word *“guess”* suggests that she is uncertain about her response. Additionally, her mention of both Black-British, seems to be a way of encompassing both cultures. Later during the interview, Wonder Woman reflected further on her ethnic identity particularly in relation to her family’s ethnic identity:

> **Wonder Woman:** *I'm not really sure about the British when I think about it because most of my family don't like… whenever I talk to my mum… she goes ‘oh when I was in Jamaica’ ‘it’s not like oh…’ if anything I am like the… like my family is more Caribbean oriented and even there is things like Canada as well because majority of them moved to Canada. But like when I talk to them about things its mainly like … they talk about Jamaica and things like that so that’s more like relevant to them than like I guess being British and Caribbean.*
>
> **Interviewer:** *But for you, what would you say is more relevant?*
>
> **Wonder Woman:** *I am not sure; it’s just I don’t like even though I do have some friends that are British like Caribbean. I like… I just feel like I don't really like talk to many people about it. Like it is not really something that like, like there is not many people that I just like talk to or like … I don’t know how to explain it but like… I don’t really feel like I am involved in Black Caribbean culture in like the UK.*

Here, Wonder Woman alludes to the complexities of her cultural background due to migration. Wonder Woman recognises her family connections to Jamaica and Canada, but she does not necessarily connect with either of those identities. There is therefore uncertainty around her cultural identity. Wonder Woman also shared that her cultural and cultural identity is not something that she usually thinks about:

> **Wonder Woman:** *I don't see it as something that comes up a lot. Like in my mind … thinking … but I can see how it can impact me in different ways.*

In this extract, Wonder Woman suggests that her cultural identity is not something of great significant importance to her, although she does acknowledge how it can impact her. Similar to this, Shuri appears to lack an understanding on her cultural identity and requires lots of prompts to think about this:

> **Interviewer:** *So, I am going to start by asking you a few questions, the first question is what words would you prefer me to use when talking about your identity around culture or ethnicity? So how would you describe yourself?*
>
> ***Shuri:*** *How do you mean?*
>
> **Interviewer:** *So, if someone asked you what is your ethnicity or your culture, how would you describe yourself? What would you say?*
>
> ***Shuri:*** *I don't know.*
>
> **Interviewer***: Were your parents born in the UK?*
>
> **Shuri***: Yeah*
>
> **Interviewer:** *Do they have any heritage? Heritage is about things like traditions, values, cultures and maybe the types of food they eat.*
>
> **Shuri:** *I eat things like… my mom like… has like different brothers and stuff… so I eat like Afro-Caribbean food.*
>
> **Interviewer:** *Do you identify as African or Caribbean?*
>
> **Shuri:** *No, I am just British*

In this passage, Shuri appears to struggle to grasp the meaning of concepts such as one's ethnicity and culture. She asserts that she is *"just British",* nothing more, nothing less.

#### 2.8.2.3.2 Sub-theme: Navigating cultural and religious dynamics and pressures

Wonder Woman, Gamora, and Shuri highlighted pressures associated with their cultural and religious background. Gamora spoke specifically about her experiences taking part in religious events as an autistic individual.

> **Gamora:** *I went into the mosque with my headphones, and he [Gamora's dad] was like 'oh Gamora you can't wear those during prayer' and I was like 'I am going to have to cuz it's too loud for me'. And he was like 'oh you can't do this it's against the rules it's it's it's gonna be really difficult you can't do that. What will the people of the mosque think? What will they say to me?'. And I was like 'right ok then' so then I took my my headphones off and I left them in the car, and I literally struggled through the whole of the prayer so I couldn't do anything I just sat there next to this girl, and I was like 'I can't pray' and she was like 'OK that's fine I am sitting here too'. And the aunties all around me they were just staring at me like giving me the side eye, and I was like WHAT DO I DO? I CAN'T COPE!*

In this passage, Gamora uses the term *"the aunties"* in reference to older women in the community rather than her parents' sisters. Gamora shares the difficulties coping in religious events without accommodations, namely her headphones. She states that *"the aunties"* were giving her *"side eye"* suggesting that perceived judgement from others made her feel uncomfortable. The vivid language used and the dramatic tone that Gamora employed *("I CAN'T COPE")* seems illustrate the considerable impact of this experience. It is unclear whether she cannot cope due to not having her headphones or because of the perceived judgement from the aunties, or a combination of both. Similarly, Shuri alluded to difficulties keeping up with religious events. Shuri explained that her family is Christian but when asked if she herself was Cristian, she said:

> **Shuri:** *Half half, I like it but like… yeah…. Half half*
>
> **Interviewer:** *Half half, tell me a bit more, what does half half mean?*
>
> **Shuri:** *Like I like learning stuff about it but not all the time*
>
> **Interviewer:** *So, you like learning stuff about it but sometimes?*
>
> **Shuri:** *Yeah... it gets a little bit too much*

> **Interviewer:** *What gets too much?*
>
> **Shuri:** *Like church stuff. I didn't really use to go to church but now my mum has started to say to come… it's alright*

Shuri's use of the term *"half half"* suggests that she has mixed or conflicting feelings about her religion. On one side, she enjoys learning about it but on the other side she describes Christianity as *"too much".* She later adds:

> **Shuri:** *It's just long, services are long*

Despite seeming ambivalent about it, Shuri reflected on how her religion is a positive part of her life in other ways:

> **Shuri:** *Sometimes like me and my little sister and my mum before we like go to bed sometimes, we like pray and stuff and like have our little reunions*

Here, Shuri describes how her religion enables her to connect and be close with her family, namely her mother and sister. Later in the interview she also stated that she likes socialising with people at the church services, stating that she feels "*comfortable speaking around them*". This indicates the duality of religion in Shuri's life.

Wonder Woman also spoke about religion and the importance of this for her family, particularly her mother. However, Wonder Woman herself expressed some scepticism towards religion. She said:

> **Wonder Woman:** *Well I think about it and I don't really have much thoughts like I don't think I necessarily agree with Catholicism because I just think like religions and stuff with like books, they are just too specific, but it seems very dodgy like how do you know all this information? where did you get it from? And I just think like if something happens, something happens and like, I guess there is like higher being or something that could be, but like I don't know.*

Here, Wonder Woman uses a number of questions indicating perhaps an ongoing internal/personal questioning/inquiry of religion. Later during the interview, Wonder Woman added:

> **Wonder Woman:** With identity, [pause] with Catholicism and like religion, I was a bit worried when I was like growing up a bit because I am bisexual, so I was

> like worried about my mum telling me off about that because of Catholicism, but she is actually really open to it which is really nice.

In this extract, Wonder Woman adds further context to understanding her scepticism of religion. Wonder Woman pre-empted disapproval from her mother due to her religious beliefs.

In addition to navigating specific religious dynamics and pressures, Gamora and Wonder Woman talked about wider cultural dynamics that they have had to learn to manage. Gamora said:

> ***Gamora:*** *so one thing that is difficult is that [pause] I suppose, it doesn't necessarily apply just to culture but one thing I found is that cultural expectations and traditions can sort of affect people like me who are autistic so… and I think definitely for my dad it has been difficult because I think in my culture there is a lot about tradition and honour and respect and I think it's like that in a lot of cultures so there is a lot of respect and understanding and sort of you know uh expectation for tradition and doing things that fit in like the cultural standard I guess.*

In this extract, Gamora highlights the importance of tradition, honour and respect within her culture, particularly the need to do things which *"fit"* in the *"cultural standard*". Gamora appears to suggest that it can be *"difficult"* to fit within these cultural standards as an autistic individual.

Wonder Woman spoke about not always being able to take part in cultural events due to her autistic traits and feeling a sense of guilt about this.

> **Wonder Woman:** *Another thing is like when I met like other family and like... I don't know…because some of them have like really strong accents, it sounds very shouty and it sounds very loud. And I don't know… like when I went to like some family gatherings and I had my headphones on, they were like "oh Wonder Woman you always have your headphones on" and I don't know how to respond to that and sometimes things would be really loud, and I just sit down in the corner and just like try to wait for like it to be finished. But at the same time, I felt bad because like this is my family like I shouldn't be seeing them as like a drag or anything but sometimes the family parties just go so long and it's*

> *really stressful and there is music playing and there is lots of people walking around and then you have to like say hi to everyone.*

In this excerpt, Wonder Woman alludes to elements of her culture which may not be congruent with her autism, particularly the "*strong accents*" which she describes as "*shouty*" and "*loud*". While Wonder Woman highlights difficulties in managing these cultural events, she also displays conflicting feelings. On one hand, she finds the environment overwhelming, on the other side, she conveys a sense of guilt in not being able to fully participate in such events. Wonder Woman also alludes to questions and comments from people in her culture regarding her autism. She goes on to recount another similar experience:

> **Wonder Woman:** *I have an aunt right and she has moved to Canada now, but she used to live down the street from me and I would see her all the time. And she was a very nice aunt it's just that she was a bit scary, so I didn't like, like looking at her. I didn't like talking. And she'd be like 'oh Wonder Woman, you know it is a bit rude to not look at me' and things like that. And I just like felt bad.*

Here, Wonder Woman explains that some autistic traits are seen as rude by some people in her culture. Again, Wonder Woman appears to express a sense of guilty in not being able to reciprocate the eye contact.

#### 2.8.2.3.3 Sub-theme: Understanding of intersectional identities

Participants were asked how participants view and make sense of their three differing and intersecting identities (autistic, girl and from a minoritised cultural background). All participants struggled to understand and make sense of these intersecting identities when prompted to do so. In other words, when asked what it meant to be an autistic girl from their cultural background, they found it difficult to articulate this. Gamora said:

> **Gamora:** *humm…That's actually a very difficult question.*
>
> ***Gamora:*** *Because… I mean I have thought about like the implications of the different sides of it. But I have never thought about what it means to me.*

Here Gamora explains that she has given some thought to the differing sides of her identity, but she is unsure about what it means to her. Although she describes the question as *"very difficult",* her responses suggest that she understands the question, but simply finds it hard to relate to her personal experiences. In a similar vein, Storm shared:

> ***Storm****: Ah that's hard... I never really think of it…*
>
> **Storm:** *It's just that like when I think of it, I don't like… if it's something to do with me and like what does it mean to you like yeah but like with my autism is fine because I do it normally but like yeah… I don't really normally get asked that question like I think like I think it's me and like I don't it's really like think is that much of a big thing because like that's just me. It's like yeah…*

In these extracts, Storm appears to suggest that she is used to and comfortable with reflecting on her autistic identity. In contrast, she does not see her other identities e.g. gender and culture as *"that much of a big thing"* because it is just her. This highlights a hierarchy of identities in that she perhaps sees some parts of her identity as more significant than others. Congruent with this idea of some identities being more significant than others, Cat Woman said:

> ***Cat Woman:*** *Hum…. I think it just like means that… I don't know… like… I am just …... like I am autistic, but I am also mixed. I think I am happy to know that I am autistic. Because I know like a lot of people don't normally know that they are autistic until later on.*

In this extract, Cat Woman highlights two key components of her identity stating, *"I am autistic but I am also mixed",* she however, does not consider her identity as a girl, perhaps indicating that this is not as important as her autistic and mixed identity. Similar to Cat Woman, when asked this question, Shuri initially found it difficult to articulate her answer:

> **Shuri***: Nothing.*
>
> **Interviewer:** *Nothing?*
>
> **Shuri:** *Nah…. Well, not nothing but like… it's there… I don't know… it's like different. I think it's like different to other people*
>
> **Interviewer:** *In what sense?*
>
> **Shuri:** *Like they don't think the same or like act the same and then their emotions and stuff*

In this passage, Shuri acknowledges that her experiences are different to others, but it seems that she attributes this solely to her autism and does not consider other elements of her identity. This sense of being different is echoed by Wonder Woman:

> **Wonder Woman:** *I think it means… it means that… like.. I guess there is more nuance to me than like just being one thing or the other. Like sometimes I don't feel like I fit in with other. Like for example my sisters, I feel like I don't really fit in with them when it comes to being like that….. they…. they… well I am not sure.*
>
> **Wonder Woman:** *I understand that…like…. hum… I can understand how those things would change how I live my day-to-day life but like…. it's like the only way I have ever lived, I can't think of anything else.*
>
> **Wonder Woman:** *yeah, I don't really have anything else to compare it to*

In these passages, Wonder Woman acknowledges that she has multiple identities which can have implications for her daily life. However, she struggles to think of what this means to her as she does not have anything to compare it to. Despite this, later during the interview, Wonder Woman was able to provide a striking account of how her differing identities shaped some of her experiences, particularly around recognition of autistic traits. She reported:

> **Wonder Woman:** *I think that's when like ethnicity plays like a really huge part because I feel like with girls in general, because like I know that like girls are. Like usually when you think of autism you usually think of boys. But with girls is usually seen as like… because like... when I was younger and I was quiet, it wasn't seen as like oh maybe its autism. It's just that Wonder Woman is quiet. Like Wonder Woman is just quiet. Like Wonder Woman doesn't like loud things. I am not sure you could've… it's difficult to attribute it to things but like I feel like I don't really see much girls when it comes to autistic representation. And depending on your culture, if like in your culture, you being like an obedient child and not really saying much or not really doing much and things like that. Like when I was younger, like I just liked to stay quiet because I didn't really like the thought of like… I am quite a talkative person but there would be times where I was just like OK, I don't want to speak. That could be perceived as me just being a good child instead of oh maybe there is something else with that.*

> *Or me avoiding eye contact like maybe that is just with me being shy instead of something else.*

Wonder Woman acknowledges that her ethnicity/culture and gender are likely to have played a key role in how some of her behaviours were perceived by others. Wonder Woman's lengthy reflection is indicative of the level of thought she has given to this topic.

#### 2.8.2.4 GET 4: School/college life

This GET describes participants' experiences of education. All participants reported aspects of education that they found challenging, namely social relationships and interactions and the sensory environment. Participants also referenced the importance of adjustments at school and college and identified ways that their needs could be better met.

**Table 7**

*Prevalence of sub-themes related to the GET 'School/college life'*

| | Social relationships and interactions | Sensory overwhelm | Adjustments |
|---|---|---|---|
| Wonder Woman | ✓ | ✓ | ✓ |
| Cat Woman | ✓ | ✓ | ✓ |
| Storm | ✓ | ✓ | |
| Shuri | ✓ | ✓ | ✓ |
| Gamora | ✓ | ✓ | ✓ |

##### 2.8.2.4.1 Sub-theme: Social relationships and interactions

All participants highlighted difficulties with social interactions and relationships at school/college. Both Gamora and Storm talked about finding it difficult to interact with others and often employing masking techniques. Storm said:

> **Storm:** *When I see people my age interacting, I get a little … I get like a little confused and that like… yeah. And yeah, like when I go and talk to people my own age like I end up like mirroring behaviours yeah but like.*

> **Interviewer:** *What do you mean by mirroring behaviours?*
>
> **Storm:** *Like its copying like [pause] like seeing …. Like… I am just gonna show you like if somebody is laughing, I will laugh if someone is walking, I will follow them because I don't really know what to do in that situation.*

In this passage, Storm notes that she finds interactions with people her age confusing, suggesting that interactions with people of other ages are perhaps easier for her to manage. Storm says, *"I end up like mirroring behaviours",* conveying a sense that mirroring is not necessarily a conscious choice but rather something that just happens. Gamora also spoke about mirroring:

> ***Gamora:*** *A lot of the times I will either consciously or unconsciously mirror the behaviours or personality of the person in front of me because I am unsure of how to act, I don't know the social cues, so I will just copy whatever they are doing and try and hope for the best that that is the right thing. And like I will do things like in the mirror I will practise conversations, or I will practice faces and stuff and like how to smile.*

Gamora shares a similar experience to Storm as she also engages in mirroring but, unlike Storm, Gamora indicates that she mirrors both during her interactions with others and before/after these interactions. For Gamora, mirroring is more than a one-off event. It requires practise. Gamora consciously and unconsciously builds new personas depending on who she is with. Her statement "*hope for the best that that is the right thing*" also suggests that there is an element evaluation of her mirroring skills, she either gets it right or wrong. This also demonstrates the extent of Gamora's uncertainty of how to act in social situations, the only option that she has is to mirror others and "*hope for the best*". Both Gamora and Storm described mirroring as tiring. Storm stated that it is **"***mentally draining*" as "*it's hard to try and be someone else*". Similarly, Gamora stated *"masking to me can be a comfort blanket but overall, it has done a lot of damage to me because I have not been able to express myself and even still it's a hard thing to work through psychologically because you will unconsciously do it and then wonder why you are tired at the end of the day".*

Cat Woman expressed some anxieties around social interactions particularly people she does not know:

> ***Cat Woman:*** *And like when people that I don’t talk to talk to me that kind of scares me a lot.*

Here Cat Woman outlines how much being approached by unfamiliar people distresses her, stating that it *“scares”* her *“a lot”.* It is OK to talk with familiar people but interactions with unfamiliar people cause fear.

Like other participants, Wonder Woman also expressed difficulties with social interactions and relationships. However, her difficulties were related to understanding appropriate boundaries around friendships rather than social anxiety or masking. She expressed a strong desire to interact with peers socially but felt that this was not reciprocated. She provided a rich account of her attempt to manage these difficulties, particularly when she first transitioned to college:

> **Wonder Woman:** *So, I came to the school with the expectation or just like thinking that I am gonna meet someone who I am going to click with, and we are going to like hang out with each other all the time and revise together and such and such. And when that wasn’t happening, I was like ‘oh what is happening?’. And then like I tried to do things like ‘oh like if I like try to like message so and so to say like oh if they respond’ or if I like try to like say… I don’t know... if I just try to like seem available all the time maybe that’s when like… it would work. Because I had seen lots of people in like big groups of friends. Just people grouped all together and just like say do you want to go to this place or like just talking to each other and things like that. And I just being by myself, so I just tried messaging people. And I just felt like I was bothering everyone. Like no one outwardly said it but it just felt like that because it’s like an issue meeting people… I don’t know… like I just look at the chat history and it would just be me saying ‘oh are you free?’. And again, and again. And I just think oh this doesn’t seem right. Oh, this seems very tiresome. Like I was getting tired of it.*

Wonder Woman had expectations of what it meant to have friends, and when this was not reciprocated at college, she began questioning *“oh what is happening?”.* She employed a number of strategies to seek out social interactions, but these were not reciprocated. Her ongoing/numerous attempts to seek out social interactions highlight the significance of this for her. Wonder Woman’s motivation to interact with others was further fuelled by the fact she had seen *“big groups of friends”* in college. There was therefore a sense of comparison to others. Wonder Woman wanted that for herself, but her numerous attempts to attain this were not successful, leading to a feeling of tiredness. It is almost as if Wonder Woman felt defeated.

Cat Woman, Shuri and Storm talked about negative interactions with peers. Storm briefly recounted incidents of bullying:

> **Storm:** *I used to get like made fun of*

Storm uses the past tense, indicating that this is not a current occurrence. However, Storm’s short answer and unwillingness to explore this topic further is perhaps suggestive of her desire to want to avoid the difficult feelings associated with this experience. Cat Woman did not directly recount incidents of bullying, but she recalled instances where peers at school expressed negative views of autism. She said:

> **Cat Woman:** *I wished that people like my age would use autism as an insult less. It’s really awkward.*
>
> **Cat Woman:** *Because like yesterday I think someone was using… she was like ‘oh you are so autistic’ to someone. And I was like right there and it was pretty awkward. I didn’t say anything, but I just felt really bad*
>
> **Cat Woman:** *I just don’t understand why people use that stuff as an insult*

Here Cat Woman’s use of the word *“wished”* indicates a strong desire for her peers to stop using autism as an insult, but it also conveys a sense that she sees this as something difficult to attain. It is a wish, the likelihood of it becoming reality is miniscule. The impact of witnessing peers using autism as an insult is significant for Cat Woman as she stated that she *“felt really bad”.* Despite this impact, Cat Woman remained silent, perhaps because she did not want to implicate herself or because she did not know how to deal with this *“awkward”* situation. When asked what needs to happen for her wish to come true, Cat Woman added:

> **Cat Woman:** *I think people just need to be taught that autism is like relatively a normal thing and it’s like I don’t know.*
>
> ***Interviewer:*** *What do you mean by normal thing?*
>
> **Cat Woman:** *I don’t know... like its probably more common than they assume it to be. And that like… like there is probably like people they are offending by using it as an insult. I think that goes to other disabilities as well.*

Cat Woman rejects these negative views about autism, describing it as a *"a normal thing".* Here, Cat Woman is trying to normalise autism by drawing on its prevalence. It is common so it must be normal. Shuri also recounted similar experiences of witnessing peers discussing autism in a negative way. She said:

> **Shuri:** *Like my friend has like … My friend's cousin has an autistic friend and then she speaks about how…. how she like speaks to autistic people sometimes.*
>
> **Interviewer:** *Ok, and does she talk about in a positive way? In a neutral way?*
>
> **Shuri:** *Sometimes they speak about it in a positive way, sometimes negative way as in like jokes and stuff*
>
> **Interviewer:** *Ok, how does that make you feel?*
>
> **Shuri:** *I don't know, I don't really say nothing, just when they speak about that stuff, I just stick to my side*

Similar to Cat Woman, Shuri remains silent when witnessing peers discussing autism. However, the reason for this appears to differ from Cat Woman's. There is a sense that Shuri "*sticks"* to her *"side"* because the conversation is not pertinent to her as she does not see herself as part of the autistic community. It is also possible that she *"sticks"* to her *"side"* because she does not want to disclose her diagnosis to her friends.

#### 2.8.2.4.2 Sub-theme: Sensory overwhelm

Most participants described difficulties coping with the sensory environment at school/college. For example, when asked what a good day at school would look like for her, Cat Woman stated:

> **Cat Woman:** *I feel like a good day would be one where like I have like subjects I like and like ones that… like the food is good ….and like the lessons go well. And they are not loud.*

The level of noise appears to be of particular importance for Cat Woman as it was one of the few things that she referred to when thinking about a good day at school. Similarly, Gamora wrote (on her good day/bad day sheet) that a good day for her is when "*it is quiet in the SEN room*" suggesting that levels noises also impact on her experience of school. Shuri also highlights sensory difficulties, but these are not limited to noise levels. When asked to describe a bad day at school, she recounted a specific occasion:

> **Shuri:** *Like I was coming to school and then I just wanted to come to school and chill and just sit on my desk and everybody just keeps shouting and calling my name and then everyone is just pushing and… then... I don't know…*

In this extract, Shuri explain how a combination of sensory stressors including noise levels, the crowdedness and having others pushing can greatly impact her enjoyment of her day at school.

#### 2.8.2.4.3 Sub-theme: Adjustments

All participants spoke about things that they would change in school/college to enable them to have a better experience at school/college. Some of these changes related to specific accommodations relating to individual needs, whereas other changes largely focused on relationships with staff. The later will be explored further in another GET. For example, Cat Woman stated:

> **Cat Woman:** *I would say that it would be nice to have like …. I don't know… like I think some people… people get like time out cards and stuff if they are overstimulated and stuff.*

Cat Woman refers to a time out card which suggests that she values the opportunity to have a break from the classroom. In contrast, Wonder Woman's desired accommodations were all somewhat related to social aspects of college. This further reflects her motivation to interact with others. She said:

> **Wonder Woman:** *I think I would change like maybe like I don't know… The workload. Like I know that we are here for work, and I know that we are here for education but when I think about it, like I am only gonna be here for 2 years. I'd like if you know there would be times where I could feel less guilty for like having fun and like just be happy. I do feel that like when I hang out with other people or when I go to clubs. I do feel happy. There's a club I joined and we've only had one meet up and there's just tests and because most of the upper years are not gonna be here after September, they are gonna do their A-levels*

> *we have only met up once what is the point of the club existing. It just seems pointless. I just wish we could meet up more*
>
> **Wonder Woman:** *Maybe we could add like…. another place to work …. I don't know… a place like… I don't know… this school can get really busy… very busy…. There have been times where its just like…. there's so many people… and like there is places where you can like sit down and talk to other people…. Like there is the [redacted ] but we are not meant to sit down and talk to people. We are meant to like sit down and do work. So it is sometimes a struggles to try to meet up with people and like find out somewhere to like just hang around. Like there are places but those place you are not really meant to be because they are meant to be for learning. And because this school gets so busy like its sometimes a bit difficult.*

Storm also identified accommodations that she would like her school to put in place. Similar to Wonder Woman, she focused on the social aspects of school. She said:

> **Storm:** *Probably like get more support with some topics*
>
> **Interviewer:** *What subjects?*
>
> **Storm:** *Like socialising, like no not like any subjects in general like more like sociali- being social and like having to like yeah*
>
> **Interviewer:** *How would that look like?*
>
> **Storm:** *Them paying more close attention to me more and like yeah*

In this extract, Storm expresses a desire for support with *"socialising".* This is an area that she previously highlighted as a challenge for her. Her initial use of the word *"topics"* highlights that she views socialising in the same way that she views subject topic. Learning about social skills is therefore comparable to learning about history for example.

Gamora explained why accommodations were important for her. She noted:

> **Gamora:** *My items help me thrive. So having the right support items or having things in place means that I can enjoy things like everyone else cuz without them it means that I won't be as fulfilled, and I won't be able to succeed. Like under the umbrella of equality, you also need justice and modifications.*

Here, Gamora’s use of words such as *“thrive”* indicates the significance of her *“items”.* Her items allow her to do thrive, and without them she is cannot *“enjoy things like everyone else”,* feel *“fulfilled”* and *“succeed”*. Therefore, the impact of not having her items is enormous. There is a sense that Gamora’s items enable her to explore and experience things *“like everyone else”,* which she wouldn’t have been able to otherwise. Having access to the right support is therefore seen as an *“equality”* and *“justice”* issue.

#### 2.8.2.5 GET 5: Relationships

This GET refers to the importance of relationships in different systems. All participants highlighted how their immediate family shaped their experiences. All participants also referenced the importance of staff at school and college, highlighting the key role that they play in their lives but also suggesting ways that staff could support them further.

**Table 8**

*Prevalence of sub-themes related to the GET ‘Relationships’*

| | Immediate family as supportive | Role of school/college staff |
|---|---|---|
| Wonder Woman | ✓ | ✓ |
| Cat Woman | ✓ | ✓ |
| Storm | ✓ | ✓ |
| Shuri | ✓ | ✓ |
| Gamora | ✓ | ✓ |

##### 2.8.2.5.1 Sub-theme: Immediate family as supportive

All participants described their family, particularly their mothers as supportive. Cat Woman described how her mother supported her to understand her diagnosis:

> **Cat Woman:** *She [Cat Woman’s mother] just started talking about how I was just a little more special than the rest [laughs]… and than some people normally are. And that we are all special [laughs]*
>
> **Cat Woman:** *I don’t know… like they [Cat Woman’s mother and aunt] are pretty accepting of it.*

In this excerpt, Cat Woman recounts how her mother attempted to frame autism diagnosis as a positive. The use of the word *"special"* is particularly interesting as Cat Woman laughed each time that she used this word, highlighting perhaps some uncomfortableness with this word. Cat Woman also describes her mother and aunt as *"pretty accepting"* of autism suggesting that they are more accepting than other people. Cat Woman then goes on to explain that this is because both her mother and aunt have autistic children. It seems that Cat Woman believes that her mother and aunt's proximity to autism makes them more accepting of it.

Gamora also described ways that her mother has supported her. However, she focused on slightly different aspects of her relationship with her mother. She described how her mother continues to fight and advocate for her. She also described how she feels safe enough not to mask around her mother. She shared:

> **Gamora:** *I don't mask around my mum anymore.*
>
> **Gamora:** *So, at times when I am finding it difficult to explain things for myself, having people like my mum, she is probably my biggest advocate, explain to others why I am feeling a certain way or like send a disclaimer saying like Gamora may display these behaviours and this is how she wants you to deal with that.*

The first passage implies that there is something about Gamora's mum that enables her not to mask. Gamora later disclosed that her mother recently received a diagnosis of ADHD. Perhaps this shared neurodiversity means that she is able to unmask in front of her mother. In the second passage, there is a real sense that Gamora's mother 'backs her' and speaks up for her when she is not able to do so herself. It's them against the (neurotypical) world.

Storm spoke about her mother and grandparents as key supportive figures in her life:

> **Storm:** *In my family being autistic is like a good thing by the way because you can express who you are, and like you can learn and like you can like you can like yeah*

In this passage, Storm attempts to explain why autism is seen as a "good thing" in her family. Being able to express oneself is raised as a reason but Storm struggles to articulate further why autism is a good thing in her family. Nevertheless, the idea that autism equals “a good thing” seems to be prominent in Storm’s family. Storm conveys the idea that her family is different to other families as they adopt a positive view of autism.

Shuri mentioned how her sister helped her to make sense of her diagnosis:

> **Shuri:** *Yeah, she [Shuri’s sister] just told me that some people don’t know that they are autistic and stuff so it’s not really bad*

Shuri recounted that her sister attempted to reframe autism as *“not really bad”.* This suggest that Shuri perhaps viewed (or still views as suggested by her responses throughout the interview) as *“bad”*.

Wonder Woman considers herself *“lucky”* to have a supportive family system:

> **Wonder Woman:** *I think I am quite lucky that I was born into a family where my mum is very like aware of like autism and how it can impact you and I have some family members who are like autistic or have like special needs and things that. And my mum actually suspects that she has Asperger’s. So, with that. I think that's helped me a lot.*

In this passage, Wonder Woman expresses a sense of gratitude about having a neurodiverse family. The significance of this clear as Wonder Woman stated that having neurodiverse family members helped her *“a lot”*.

#### 2.8.2.5.2 Sub-theme: Role of school/college staff

Relationships with school and college staff were highlighted by all participants. For example, when asked what a bad day at school would look like for her, Shuri focused largely on the teachers that she has built close relationships with. She said:

> **Shuri:** *The teacher that I like to speak to is not in, and like when I am angry… and teacher’s not in that I speak to... and when Ms X [Shuri’s teacher] is not in it’s like hard for me sometimes, because like when I have like …. When she [Shuri’s teacher] is not in, I can’t go to her.*

Here Shuri conveys a sense of not knowing what to do when specific teachers that she has built strong relationships with are not in school. There is a sense that she perhaps feels lost when this happens. These teachers seem to play a key role in helping Shuri to regulate a range of emotions e.g., when she is *"angry".* Shuri also described her teaching assistants (TAs) as *"helpful".* She said:

> **Shuri:** *I like that…. like I have like 3 to 4 of them like because they understand me, and they help me and that's nice.*

Shuri expresses a real sense of appreciation for her TAs. Gamora also identified key relationships with staff as a vital component of her educational experience:

> ***Gamora:*** *I have a good relationship with a few of my teachers, so I have like a… I have like a network of trusted people within the school which is really helpful, and I have a very good relationship with them, so I am very comfortable around them.*

Like Shuri, Gamora used the word *"helpful"* to describe the staff who support her, thus highlighting their supportive nature. Gamora uses the phrase "*a network of trusted people"* which suggest that there is group/collective endeavour to support her. She also states that she is *"comfortable around them"* suggesting perhaps that she is better able to be her true self. Wonder Woman also spoke about the role of school/college staff. However, she focused on a specific relationship, with her school counsellor. She shared:

> **Wonder Woman:** *I'd get taken out and I would just talk with the counsellor and we'd just like play uno and stuff like that and it was really nice, and I looked forward to it. And it was just something that like made me feel like it's just something that I looked forward to and it's just like made my day.*

Here Wonder Woman recounts her experiences of working closely with and building a relationship with a member of school staff. There is a real sense of appreciation in having the opportunity sit down and *"just talk*" with the school's counsellor.

Other participants highlighted things that staff should do to build or strengthen relationships with autistic girls. For example, Gamora highlighted the importance of staff asking questions and finding out more about her needs. She said:

> **Gamora:** *If I am displaying a behaviour and you are not sure why I am doing it or maybe you are worried that it means that I am upset instead of happy, just*

> *ask. And it doesn't matter how it comes across to me because you are literally asking a question and I can explain it and you can go away understanding it*

Gamora's use of the phrase *"just ask"* suggests that she sees this as an easy task for school staff. Asking is a simple action which can support staff to understand her better. Storm spoke about the importance of staff taking an interest in her as an individual. She said:

> **Storm:** *Like make an effort to go and like get to know me.*
>
> **Storm:** *Like talking to me, like playing games just like interacting to me. You can't really truly understand someone if you don't know someone, yeah, you get me?*

In these passages, Storm suggests that knowing someone is a prerequisite to understanding their needs. You cannot have one without the other. She also appears to suggest that the onus is on the adults to get to know her – they should *"make an effort".* Shuri also identified things that staff could do to support autistic CYP further:

> **Shuri:** *Like just ask how their day has been… just ask if they are ready to talk like now*
>
> **Interviewer:** *And when do you think they should ask that?*
>
> **Shuri:** *Outside of the classroom because what if they like they don't want the class to know?*

In this excerpt, similarly to Storm, Shuri suggests that staff should make an effort to get to know autistic CYP. Although one may presume that these suggested strategies are directly relevant to Shuri's experience, her use of the words *"they"* and *"them"* reflect her continual attempted to distance herself from autistic individuals. Shuri goes on to suggest that staff should talk to autistic CYP outside of the classroom as they may not want the rest of *"the class to know"*. This highlights the importance of a discreet approach for Shuri which is likely to be related to how the class perceives this support. In a similar vein, Cat Woman stated:

> **Cat Woman:** *I mean I think I like it when the teacher actually comes up and asks me but like I wouldn't really want help with doing that [asking for help] for*

> *me. Because that kind of draws attention to myself and I don’t really want attention on myself.*
>
> **Cat Woman:** *I am too scared. Then people would be asking me why I have help and that would be even more awkward.*

Here Cat Woman suggests that she likes when staff approach her, thus highlighting that having a relationship with staff is important to her but she noted that, similarly to Shuri, she values when this is done in a discrete manner. The potential negative consequences of openly receiving support from staff are twofold, first it draws unwanted attention to Cat Woman; secondly it may require her to explain why she is receiving such help. Cat Woman expresses a real fear at this possibility.

### 2.9 Discussion

This section discusses the findings of the current study in relation to the research questions, situating these within the context of the broader literature. Following this, limitations of the study and suggestions for future research will be considered. Lastly, implications for EPs and other educational professionals (based on the girls' perspectives) are detailed.

#### 2.9.1 Central research question: What are the lived experiences of minoritised autistic girls?

All GETs were relevant to this research question. However, the GETs most relevant to this research question were: 'Making sense of cultural identity', and 'Relationships'.

This study sought to explore the lived experiences of autistic girls from minoritised ethnic backgrounds. This was achieved by conducting semi-structured interviews with five autistic girls from minoritised backgrounds. Subsequently, the data were analysed using IPA and five GETs were identified. The findings of the current study demonstrate the heterogeneity of participants' experiences, thus highlighting the importance of adopting a person-centred approach when considering the needs of autistic girls (Bond & Hebron, 2016). This heterogeneity of participants' experiences also challenges the way in which autistic CYP are traditionally portrayed in autism research i.e., as a homogenous group. However, despite reported differences, the cross-case analysis highlighted similarities in the experiences of all five girls. Notably, some of these experiences (particularly their educational experiences) were congruent with the experiences of White-British autistic girls detailed within the broader literature. Nonetheless, the present research also showed that minoritised autistic girls have unique experiences related to their cultural and ethnic identity. While this study did not aim to compare the experiences of minoritised autistic girls and White-British autistic girls, it is prudent to highlight the similarities and differences between these two groups in order to gain a better understanding of their experiences.

The girls within this study highlighted the importance of relationships at different levels. The EST (Bronfenbrenner, 1979) is relevant here as it was evident that the concentric systems closest to the girls' e.g., the microsystem played a key role in their lived experiences. Firstly, the girls identified close family members (particularly, but not exclusively, their mothers) as a key source of support. Through the girls' account it was evident that their mothers made noticeable contributions to their lived experiences. The mothers of the autistic girls in this study supported them in a numerous ways including by acting as an advocate. For example, Gamora noted that her mother was her "*biggest advocate*". In addition to the role that mothers played in advocating for the girls in this study, they also appeared to play a key role in supporting them to construct a positive autistic identity, through acceptance of the girls' diagnosis. For example, Wonder Woman, Cat Woman and Storm all highlighted the key role that their mothers played in helping them to make sense of their identity. Storm described how "*being autistic is seen as good thing*" in her family. This is of relevance as previous studies demonstrate that autistic individuals' identity is largely determined by how others perceive them (Pearson & Rose, 2021). Similarly, Riccio et al. (2020) found that autistic CYP whose parents openly discussed autism were more likely to have a positive autistic identity. Thus, the mothers of autistic girls can play a key role in shaping their autistic identity. This is particularly salient during this period i.e., adolescence when autistic girls start to make sense of who they are (Blakemore, 2018). These findings are in line with findings from previous studies which explored the experiences of autistic girls. For instance, in previous studies such as Cridland et al. (2014), mothers of autistic girls described how they had to 'fight' to get their concerns addressed and taken seriously. Moreover, autistic girls in Beteta's (2009) study reported that their mothers influenced their lives in numerous ways. For instance, one participant shared that her mother often protected her by helping her to avoid anxiety-inducing situations. Likewise, Tierney et al. (2016) found that one mother had to go as far as training school staff to look beyond her daughter's outward smile (due to her tendency to mask her difficulties). Overall, it is evident, from the current study and the existing literature, that mothers play a crucial role in the lives of autistic girls (Cook et al., 2018; Cridland et al., 2014; Jarman & Rayner, 2015; Milner et al., 2019; Rainsberry, 2016). However, it is acknowledged that it is not only mothers who play an important role in autistic girl's life experiences. In the present study, Shuri described how her older sister helped her to make sense of her autism diagnosis, stating "*She [Shuri's sister] just told me that some people don't know that they are autistic and stuff so it's not really bad".* Generally, research has shown that sibling relationships can play a pivotal role in the social emotional and mental health development of CYP with neurodevelopmental conditions such as autism (Buist et al., 2013; Dirks et al., 2015; Kramer, 2014)

Relationships with school and college staff were also given special prominence within the girls' accounts. It was apparent that some participants (e.g., Gamora and Shuri) valued the relationships that they had developed with educational staff, this included teachers, TAs, counsellors and office staff, while others (e.g., Storm) expressed a desire to build relationships with school staff. In particular, the girls highlighted that they valued when staff showed an interested in them. Relationships with staff were thus integral to creating a positive educational experience for this group of girls. This finding is supported by previous studies, both those exploring the experiences of autistic CYP (Sproston et al., 2017) and those specifically focusing on the experiences of autistic girls (Jarman & Rayner, 2015; Goodall & Mackenzie, 2019). A more recent study found that autistic CYP appreciate when school staff understand their needs and support them appropriately (Hummerstone & Parsons, 2021). Positive relationships with educational staff can impact CYP's wellbeing (Milton & Sims, 2016). In fact, a global research project found that the wellbeing of CYP in England "was lower than all but one other country" and that "poor relationships between teachers and students'" was a contributing factor (Reay, 2016, p.326). Furthermore, Moyse (2021) noted that lack of positive relationships with educational staff, is associated with numerous detrimental consequences including absenteeism. This illustrates the significant impact of positive relationships with staff for autistic girls. This finding is also pertinent as there is a misconception that autistic individuals are not usually motivated to interact and form relationships with others (Chevallier et al., 2012). However, the girls in this study expressed a desired to want to interact and form relationships with educational staff. Interestingly, the findings of the current study highlight the importance of relationships at all levels of the educational setting, rather than just relationships with teaching staff. For example, some participants (e.g. Wonder Woman and Gamora) referred to positive relationships with office staff and counsellors as key.

This study suggests that some autistic girls from minoritised cultural backgrounds find it difficult to navigate religious expectations, suggesting a potential incompatibility between autism and places of worship. For example, Shuri noted that she struggled with church services as they are *"too long".* Likewise, Gamora, expressed difficulty in attending the mosque without her headphones due to the level of noise. Places of worship may be tricky to manage, not only for autistic girls but for autistic individuals in general. This is because places of worship can be sensorily overwhelming, as they usually include one or more of the following: loud music, vivid artwork, crowds, strong smells and sometimes an expectation for physical touch. The expected religious clothing may also be uncomfortable for autistic individuals. Places of worship also usually require individuals to stay still and quiet for extended lengths of time. Previous research showed that religious spaces are not accepting of autistic CYP and found that members of some places of worship, including African churches and mosques, lacked awareness and tolerance of autism in particular, atypical behaviours in places of worship (Slade, 2014). This lack of awareness and tolerance was picked up by some of the girls in this study. For example, Gamora reported how "*the aunties*" gave her "*side eye*" when she was struggling to cope at the mosque. It is possible that members of places of worship adopt a moral model of disability. However, it is important to note that, as mentioned previously, those who attend places of worship can hold both positive and negative views of autism, similar to the general population (Waldock & Forrester-Jones, 2020). Thus, one should not assume that these views are underpinned by religion or exclusive to religious communities. Other participants, namely Wonder Woman, found it difficult to conceptualise and understand religion, leading to scepticism. This is in line with previous research which has shown that autistic individuals are more likely to be agnostics or atheists and reject religion in favour of their own independently constructed religious belief system (Caldwell-Harris et al., 2011). Despite difficulties experienced at places of worship, some participants e.g., Shuri, also recognised the value that religion brought to their life (for Shuri, this was related to the opportunity to bond with family members through prayer). Research has shown that religion plays an important and positive role in autistic people's lives (Liu et al., 2014; O'Hanlon, 2013; Turner et al., 2004) as it promotes a sense of belonging (Baumeister & Leary, 1995).

In addition to managing religious dynamics, some girls also reported having to navigate broader cultural dynamics. For example, Wonder Woman spoke about how some autistic traits such as fleeting eye contact are seen as *"rude"* or *"disrespectful"* within her community. She also struggled to attend cultural events due to loud noises (and *"shouty", "loud" and "strong"* accents). For Wonder Woman, this meant that she often experienced a sense of guilt as she felt that she should be taking part in these family/cultural events and adopting the behaviours expected of her. This is in line with research conducted by Hussein (2021) which found that lack of understanding of autism within minoritised communities meant that minoritised autistic CYP felt pressured to behave in a socially desirable way. This finding regarding difficulties associated with navigating cultural and religious expectations has not previously been highlighted in studies which examined the experiences of autistic girls. This is perhaps because these experiences are unique to minoritised autistic girls or because previous studies did not explicitly explore these issues.

### 2.9.2 Research sub-question 1: How do minoritised autistic girls experience and make sense of their identities?

The GETs most relevant to this research question were: ‘Journey to autism’, ‘Making sense of cultural identity’ and ‘Making sense of autistic identity’.

Humphrey and Lewis (2008) argued that a “central issue in any research that examines the lived experiences of individuals who have some kind of diagnostic label applied to them is their understanding of and engagement with the label itself.” (p. 30). For most of the girls in the current study, the diagnostic process was triggered by difficulties at school such as academic difficulties and sensory issues. Thus, their diagnosis was situated within a problem context. Despite this, some participants e.g., Gamora and Wonder Woman highlighted that their autism diagnosis was a positive turning point as it promoted self-understanding, provided an answer for their difficulties and enabled them to access support. This is in line with previous studies which suggest that this self-understanding prompts validation and acceptance of the self (MacLeod et al., 2013; Mogensen & Mason, 2015). Gamora and Wonder Woman compared themselves favourably to others who have higher support needs thus making a ‘downward social comparison’. Previous literature (Huws & Jones, 2015) posit that these downward social comparisons increase subjective well-being and improve self-esteem. Moreover, Huws and Jones (2015) found that autistic CYP view their autism as less severe than other disabilities.  Participants in this study made sense of their autism in different ways, however their responses generally indicated that they all recognised that autism had impacted on their sense of self. Participants acknowledged that their autism was associated with some challenges but also recognised its strengths. All girls identified challenges associated with their autism which often related to social interaction and relationships, namely mirroring, social anxiety and understanding appropriate social boundaries, but other challenges were also identified, including organisational difficulties, and thinking and being different to "*normal people*". However, most girls were also able to reflect on the strengths that they possessed as a result of their autism (e.g., ability to think critically, good memory and empathy), highlighting that they had a balanced and perhaps, at times, a conflicting view of their autism. Overall, most participants in this study highlighted that autism was an important part of their identity. This supports previous literature which showed that some autistic adolescents claim autism as a core part of self (Cridland et al., 2015; Gaffney, 2020; Humphrey & Lewis, 2008; Huws & Jones, 2015; MacLeod et al., 2013; Mogensen & Mason, 2015). Shuri was the only participant who overtly rejected her diagnosis, seeing it as a "*disability*" and something that she does not want to talk about at home or school. Shuri's construction of autism is in line with previous research which demonstrated that some autistic CYP view autism as 'being different/not normal' (Humphrey & Lewis, 2008). This construction of autism is likely to be underpinned, at least in part, by the perceptions that society holds of autistic CYP. Research has shown that autistic people's construction of autism is largely influenced by professionals, the media as well as cultural and family perceptions (Huws & Jones, 2010). This is supported by Cooley's (1902) 'looking-glass self' theory, which posits that interpersonal interactions shapes one's self-concept. Hence, the information that autistic CYP are exposed to during, and after their diagnosis impacts how they incorporate autism into their identity (Bagatell,2007; Leedham et al., 2020). Most girls in this study demonstrated a preference for identity first language. This is in line with previous research which shows that those with an autism diagnosis often prefer identity first language as they see autism as being an inherent part of their identity (Kenny et al., 2016). Previous studies also suggest against the use of person-first language (Bagatell, 2010; Davidson & Henderson, 2010; Hurlburt & Chalmers, 2002) as such language reinforces the idea that autism is a 'wrong' or 'faulty' way of 'being' (Kenny et al., 2016). However, one participant within this study stated that she does not have a preference. This highlights the importance adopting a person-centred approach and asking individuals their preferences rather than making assumptions (Bond & Hebron, 2016). Adopting a person-centred enables autistic CYP to play an active role in decisions relevant to their life (Pellicano et al., 2013).

Adolescence is a critical developmental period as it is often during this period that adolescents construct a personal and social identity (Erikson, 1968). This is also the period when adolescents explore and construct their ethnic identity (Phinney, 1993).

Most of the participants in the current study used several terms to describe their cultural identity. This was underpinned by a number of factors. For some participants there was a level of complexity to their cultural identity (either because of mixed heritage or migration). For other participants, the context seemed to play a key role on how they identified themselves. Thus, cultural identity was seen as both complex and contextual for most participants. Gamora and Wonder Woman referred to themselves as British-Indian and Black-British respectively, thus encompassing two cultures. However, Wonder Woman had two cultures as a result of migration whereas Gamora had two cultures as a result of her mixed heritage. Interestingly, Perepa (2019) argued that autistic individuals may struggle to navigate this fluidity of culture due to their rigid constructions of the world and inflexibility of thought. Shuri simply identified herself as British. Research suggests that those who have been in the UK for longer are more likely to identify as British (Manning & Roy, 2010). As Shuri's family was established in the UK, she was comfortable to identify as British. Interestingly, cultural identity was not a familiar concept for some participants (e.g., Shuri and Wonder Woman). Phinney (1993) developed a model of ethnic identity development that includes three key stages: unexplored ethnic identity, ethnic identity search, and achieved ethnic identity. It could be argued that some of the girls in this study are at the earlier stages of this model. Most girls in this study portrayed a sense of indifference towards the terminology used to describe cultural diversity, although some referenced terms such as POC. It is likely that this term was referenced as it is fairly popular on social media at the moment. Overall, the girls in this study demonstrated that their cultural identity is complex and contextual. Thus, how they make sense of their cultural identity is essentially determined by the context, including the person asking the question and the purpose of this question. Remarkably, most girls in this study more readily identified with and reflected on their autism-based identities compared to their cultural identity.

Most girls alluded to using the internet particularly social media to understand and make sense of their identities, particularly their autistic identity. Thus, their understanding was heavily influenced by input that they had accessed online from social platforms such as TikTok. Autistic women and girls have previously reported using social media to connect with other autistic individuals and access information about autism (Feist, 2013; Leedham et al., 2020; Logsden, 2010; Webster & Garvis, 2017). This has a number of benefits including reduced isolation and increased well-being (Milton & Sims, 2016; Webster & Garvis, 2017). Learning about other autistic girls and women online may also help autistic girls to construct a positive ‘autistic identity’ and challenge the predominant understandings of autism as ‘deficit’ (Bagatell, 2007; Davidson, 2007). In fact, Logsden (2010) found that autistic girls who accessed autism-related resources (e.g., reading relevant books) were more accepting and aware of their diagnosis. Fostering a positive ‘autistic identity’ is key as it improves self-esteem and psychological wellbeing (Milton & Sims, 2016; Tan, 2018). While there are many benefits associated with using the internet to make sense of one’s identity, there are also some limitations. For example, the unregulated nature of online content means that autistic girls may access information that is not evidence based.

### 2.9.3 Research sub-question 2: How do minoritised autistic girls describe their educational experiences?

The GET most relevant to this research question is: ‘School/college life’.

Notably, the girls’ educational experiences were vastly similar to the educational experiences of White-British autistic girls outlined within the broader literature. In line with previous research, the girls in the present study reported difficulties navigating the school environment, particularly due to sensory issues and difficulties with social interactions. This finding aligns with previous studies which focused specifically on the experiences of autistic girls (e.g., Goodall & Mackenzie, 2018; Sproston et al., 2017) as well as studies which explored the experiences of autistic CYP more generally (e.g., Humphrey & Lewis, 2008). In particular, the girls found it difficult to cope with the noise levels at school/college. This is congruent with other studies which found that autistic girls struggle with “sensory overload” (Tierney et al., 2016; pp. 80-81) at school. School triggers for sensory overload identified within the literature include (but are not limited to) the levels of noise in corridors and lunch halls, crowding (Rainsberry, 2016); uniform material (Feist, 2013); lighting, and difficulty holding pens (Jarman & Rayner, 2015).

Participants in the current study also reported difficulties with understanding the behaviour of others and found the social environment overwhelming. Difficulties with social relationships and interaction were identified as a significant struggle for Wonder Woman, Cat Woman, Gamora and Storm. This finding support previous studies (e.g., Cridland et al., 2014; Tierney et al., 2018), further highlighting the need for specific support for girls to enable them to navigate increasingly complex adolescent female relationships (Jamison & Schuttler, 2017). Some participants described being part of friendship groups (e.g., Shuri and Cat Woman) and others were highly motivated to have friends (e.g., Wonder Woman), as seen in previous studies (e.g., Cook et al., 2018; Sedgewick et al., 2016). Shuri, Cat Woman and Storm reported difficult interactions with peers. Storm recounted incidents of bullying at her previous school whereas Cat Woman and Shuri spoke about how autism is sometimes used as a *"joke"* or an *"insult*" at school. This is unsurprising as bullying was a common theme in many different studies with autistic girls and women (Bargiela et al., 2016; Beteta, 2009; Cook et al., 2018; Cresswell & Cage, 2019; Cridland et al., 2014; Goodall & MacKenzie, 2019). Research has also shown that the general population lacks an understanding of autism (Cage et al., 2019). These negative views can make autistic CY, for example Shuri, reluctant to disclose their diagnosis. This, in turn, has been shown to have a detrimental impact on psychological wellbeing (Thomas et al., 2020).

In line with previous research on autistic girls (Bargiela et al., 2016; Halsall et al., 2021; Tierney et al., 2016) the girls in this study reported using masking strategies such as mirroring during social interactions at school. Tierney et al (2016) found that autistic girls closely observed peers' social behaviour and mirrored these during social interactions. The literature suggests that autistic girls engage in masking as they are motivated to interact and build relationships with peers (Cook et al., 2017; Tierney et al., 2016). The girls in the current study reported that they 'mirrored' due to being unsure about how to act. For some, mirroring was an unconscious act whereas others did this consciously at times. Storm acknowledged the detrimental impact of masking describing it as "*tiring*" and stating that it is "*hard trying to be someone else*". This is congruent with previous studies in which autistic girls reported that masking requires a great amount of energy and leads to them feeling exhausted (Cook et al., 2017; Hull et al., 2017; Tierney et al., 2016). The literature has also shown that masking leads to a number of mental health difficulties including self-harm and suicide (Camm-Crosbie et al., 2019; Cassidy et al., 2020; Hunsche et al., 2020). Furthermore, Gamora acknowledged the impact of masking on her identity, leading her to question "*who is me?*". Interestingly, the impact of masking on autistic girls' identity has not been examined sufficiently within research. However, Pearson and Rose (2021) noted that masking leads to ‘detachment from the self’ and subsequently psychological distress.

The girls in this study highlighted the importance of adjustments within their educational setting to enhance their educational experience. These adjustments ranged from specific support items to support with social interactions. This is congruent with previous research which has explored the experiences of autistic girls. For example, participants in Rainsberry’s (2016) study identified a number of helpful adjustments, including attending clubs, and eating lunch in a quiet space. Likewise, other researchers noted that accommodations should be put in place even if autistic girls are not overly struggling at school (Moyse & Porter, 2015; Tomlinson et al., 2021). This is to address their tendency to mask. However, in this study, Cat Woman noted that some adjustments may not be appropriate and may exacerbate levels of anxiety. This again, highlights the importance of adopting a person-centred approach when supporting autistic girls.

## 2.10 Implications

### 2.10.1 Implications for EPs

Referring back to the concept of epistemic oppression, it is evident that EPs are in a privileged position, as their knowledge and opinions are often well regarded within society. Thus, they are well placed to bring about systemic change, and support autistic CYP from all cultural backgrounds and genders. As EPs work with different concentric systems around the YP, e.g., families and schools, they can amplify the voices of minoritised autistic girls to ensure that they succeed and achieve positive outcomes. EPs are not only well placed to elicit the voices of minoritised autistic girls but also to support them to advocate for themselves (if they feel comfortable to so do) (SEND CoP, DfE, 2015). They could draw on a number of child-friendly resources similar to the ones used in this study, e.g., person centred planning tools and the GEM to achieve this.

During consultations and planning meetings with college and school staff, EPs can act as critical friends. Costa and Kallick (1993) stated that a critical friend is a trusted person who offers a critical but non-judgemental perspective while supporting schools through change. As critical friends, EPs could challenge staff’s views regarding presentation of autism as it has been found that their views are generally shaped by a male-based (Gray et al., 2021) and arguably westernised presentation of autism. Minoritised autistic girls may not fit either of these presentations and thus are likely fall under the radar. EPs can also provide whole-school level training in this topic (i.e., autism and girls). When doing so, it is important that EPs highlight and consider the needs of all autistic girls, not just those from the majority-cultural group. This can be achieved by encouraging school staff to adopt an intersectional lens, for example through the use of the Social GRRAAACCEEESS framework (Burnham, 2012). Delivering whole-school training, encourages acceptance and understanding thus ensuring that all educational professionals within the setting are better equipped to meet the needs of autistic girls. This is paramount as literature has shown that teachers often do not have access to appropriate training on how to support autistic girls (Critchley, 2019). By training and upskilling other professionals, EPs demonstrate their commitment to working with other professionals as outlined in the SEND CoP (DfE, 2015).

EPs often make recommendations regarding appropriate evidence-based interventions for autistic CYP. However, it is important to note that such interventions (namely social skills interventions) are based on research conducted with mostly white autistic boys rather than autistic girls (Jamison & Schuttler, 2017). Thus, such interventions may not be appropriate for autistic girls from minoritised cultural backgrounds. EPs are well placed to adapt existing interventions to ensure that these are appropriate both in terms of gender and cultural identity. EPs could also recommend interventions which were specifically designed for autistic girls. The ‘Girls’ Night Out’ (GNO) model (Jamison & Schuttler 2017) is a good example of an intervention which was specifically developed to tackle the unique needs of autistic girls. This intervention focuses on social skills and self-care. In the UK, similar interventions have also been devised such as “The ASD Girls’ Wellbeing Toolkit An Evidence-Based Intervention Promoting Mental, Physical & Emotional Health” (Rae & Such, 2019). Importantly, EPs should take autistic girls’ views into account when considering appropriate interventions, as the girls can provide valuable insights about what is important for them. Essentially, like critical theorists, EPs should view knowledge endorsed by those in power critically. In the words of Kincheloe (2008), EPs should ask themselves: “How did I get stuck with this body of knowledge and these lenses through which to see the world?” (p.21). Thus, EPs should not rely solely on evidence-based practice but also consider practice-based evidence, and more importantly lived experience informed practice.

Another implication of this research is for EPs to support minoritised autistic girls to make sense of and develop a positive identity, both in terms of their autism and their culture. This is pertinent as theories of identity development stress the need to explore one’s sense of self, particularly during adolescence (Erikson, 1968). In terms of fostering a positive autistic identity, EPs could work alongside educational professionals, parents and autistic girls in order to help them to explore their diagnosis. This support could be provided in the form of workshops. Abdi (2015) suggests that EPs can play a key role in supporting positive ethnic identity formation. At the individual level, EPs can use tools such as the Tree of Life (Ncube,2006), Cultural Genograms (McGoldrick et al., 1999); Drawing the Ideal Self (Moran, 2002) and Multigroup Ethnic Identity Measure (MEIM; Phinney, 1992; Roberts et al., 1999) and the GEM to explore autistic girls’ constructions of their identity. EPs should also conceptualise cultural and ethnic identity in their case formulations and understand its importance to well-being not only for autistic girls but for all CYP whom they work with. At the group level, EPs could employ the “Identity project” intervention (Umaña-Taylor et al., 2018) which facilitates exploration of students’ ethnic identities and supports self-esteem. However, if EPs are to deliver such interventions effectively, they need to have a robust understanding of ethnic identity development. This illustrates the importance of teaching ethnic identity on EP training programmes. Furthermore, Agyeman and Lichwa (2020) propose that EPs can play a key role in supporting educational staff to “foster a sense of ethnic affirmation through ethnic–racial socialisation as a means to promote a healthy self-concept” (p.7). However, EPs should take into account that for some individuals, differing sides of their identity may be deemed more important than other parts of their identity. For example, for an autistic Indian girl, her Indian identity may be more important for her than her autistic identity (or vice versa). This was the case for some girls (e.g., Storm) in this study who focused more on their autism identity than their cultural identity. Thus, EPs must explore this without making assumptions.

EP work is often restricted to educational issues (MacKay, 2006). However, MacKay (2006) argues that “there can be no future for educational psychology within the narrow boundaries of special educational needs and the servicing of bureaucratic educational functions” (p.7). Thus, EPs should explore opportunities to work with communities (MacKay, 2006). Community psychology “attempts to make the field of applied psychology more effective in the delivery of [its] services and more responsive to the needs and wants of the communities” it supports (Bender, 1976, p.6). In line with this, it seems reasonable to suggest that EPs are well placed to work with local religious and cultural groups, to support them to develop an understanding of the needs and strengths of autistic girls. This would not only promote knowledge and understanding, but also reduce stigma.

EPs should also continue to use research as a social justice tool (Lorenzetti, 2013) by exploring and amplifying the voices of autistic CYP with multiple marginalised identities and disseminating the findings and use these to inform practice and policy.

### 2.10.2 Implications for educational professionals (based on the girls’ views):

The following recommendations closely align with the principles of good autism practice outlined by the Autism Education Trust (AET) (Guldeberg et al., 2019), where applicable, these principles will be referenced below.

1. Build attuned relationships: The girls in this study highlighted that they value when school and college staff show an interest in them and build positive relationships with them. Staff should therefore aim to develop attuned relationships with autistic girls. Research has shown that, in order to achieve this, staff need to: 1) provide opportunities for autistic girls to share their views and experiences (Moyse, 2021); 2) show an interest in their strengths and interests and celebrate these (Goodall & MacKenzie, 2019); 3) be nurturing and caring when interacting with them (Noddings, 2013); and 4) acknowledge and validate their needs (John, 1996). This includes supporting girls to develop a positive autistic and cultural identity by exploring positive aspects of their autism and cultural background. This recommendation closely relates to the following AET principles: “Understanding the strengths, interests and challenges of the autistic child and young person” and “Workforce development to support autistic children and young people on the autism spectrum”. A sample of the relevant quotes from the girls is provided below:

- **Shuri:** *Like just ask how their day has been… just ask if they are ready to talk like now*
- **Storm:** *Like make an effort to go and like get to know me.*

- **Storm:** *Like talking to me, like playing games just like interacting to me. You can’t really truly understand someone if you don’t know someone, yeah, you get me?*

2. Promote awareness and acceptance of autism at all levels within the school/college: Research has shown that while the general population now has a basic understanding of autism, this understanding is often superficial which means that some people are still hesitant to interact with autistic people (Cage et al., 2019). The girls in this study highlighted that some of their peers hold negative views of autism. School and colleges should adopt a whole-school/college intervention to promote acceptance of neurodiversity and reduce of stigmatising attitudes within the setting. This intervention should target both staff (including non-teaching staff) and students. This recommendation closely relates to the following AET principles: “An ethos and environment that fosters social inclusion for children and young people on the autism spectrum” and “Workforce development to support autistic children and young people on the autism spectrum”. A sample of the relevant quotes from the girls is provided below:

- **Cat Woman:** *I wished that people like my age would use autism as an insult less. It’s really awkward.*
- **Cat Woman:** *I think people just need to be taught that autism is like relatively a normal thing.*
- **Gamora:** *The lady at the desk immediately flipped her sort of way of addressing me, she started treating me very childishly and infantilising me quite a lot as if I am unable to do things.*
- **Gamora:** *A lot of people’s idea of being autistic, they think of someone who is mentally, perhaps, for lack of a better word, not there.*

3. Listen to autistic girls: The girls in this study were able to speak openly about their educational experiences. They provided useful insights which can be used to inform practice at different levels, thus it is important that educational settings continue to actively elicit the voices of these girls to enable them to shape decisions about their education. Research indicates that CYP with SEND can provide useful insights about their educational experiences (Parsons et al., 2009). This recommendation closely relates to the following AET principle: “Enabling the voice of the autistic child and

young person to contribute to and influence decisions". A sample of the relevant quotes from the girls is provided below:

- **Gamora:** *If I am displaying a behaviour and you are not sure why I am doing it or maybe you are worried that it means that I am upset instead of happy, just ask. And it doesn't matter how it comes across to me because you are literally asking a question and I can explain it and you can go away understanding it.*

4. Identify and implement person-centred adjustments: This includes adapting the sensory environment according to the girls' sensory profile, providing opportunities for adult-facilitated social interactions, time out cards and a safe space for the girls to self-regulate. It is paramount that these adjustments are agreed in conjunction with the girls as some adjustments may lead to further anxiety for some girls (see Cat Woman's quote below). This recommendation closely relates to the following AET principles: "Targeted support and measuring progress of children and young people on the autism spectrum" and "Adapting the curriculum, teaching and learning to promote well-being and success for autistic children and young people". A sample of the relevant quotes from the girls is provided below:

- **Wonder Woman:** *I think that some things that would really help is just a break*
- **Wonder Woman:** *Places where you can like sit down and talk to other people*
- **Cat Woman:** *I would say that it would be nice to have like …. I don't know… like I think some people… people get like time out cards and stuff if they are overstimulated and stuff….*
- **Cat Woman:** *I wouldn't really want help with doing that [advocating] for me. Because that kind of draws attention to myself and I don't really want attention on myself.*

### 2.11 Limitations and Future Research

Although the current research has made a significant contribution by capturing the voices and lived experiences of minoritised autistic girls, it is important to acknowledge its limitations. The first limitation of this study is the generalisability of the findings due to the small sample size (n=5). However, it is important to highlight that the aim of this research was not to generalise findings or generate nomothetic claims, instead IPA's idiographic method of inquiry was adopted to gain an insight into the experiences of minoritised autistic girls. While it is recognised that this approach greatly limits generalisability of the research findings, the researcher aimed to counter-act the overuse of nomothetic claims within the autism literature and instead move from general to specific as suggested by Macleod et al. (2017).

The methodology selected for this study required participants to have the necessary verbal skills to be able to take part (Willig, 2013). Thus, a second limitation of this study is that it only captured the views and perspectives of a subgroup of the autistic community i.e., those who are able to understand complex concepts such as ethnicity and culture and who are able to share their views and experiences verbally. As such, the voices of non-verbal minoritised autistic girls were not captured within the current study. It is acknowledged that the perspectives of autistic girls with limited language skills, who are often not represented within the literature, are essentially absent in the current study. Thus, one may argue that this study exhibits elite bias (Miles & Huberman, 1994). Elite bias refers to the notion that research participants are usually the most well-spoken and accessible individuals of a specific community. This further restricts limits the generalisability of the findings.  Future research should therefore aim employ creative tools such as the mosaic approach (Beresford et al., 2004) and talking mats (Rabiee et al., 2005) to elicit the voices of minoritised autistic girls with limited verbal skills.

Although this study, unlike most autism-related studies, collected key information about participants' cultural background, it did not collect any other demographic information. This may have been helpful in order to contextualise these participants' account. This is particular important for aspects such as socio-economic background as one may argue that a privileged socio-economic background may, to some extent, mediate the challenges associated with autism (Vernon & Swain, 2002). Further research could collect additional demographic information, to gain a true intersectional understanding of participants' experiences.

As mentioned previously, extensive literature has shown that autistic girls have a tendency to adopt masking strategies, particularly when they are worried about how others will perceive them (Moyse & Porter, 2015). Thus, it is possible that the participants in this study employed masking strategies and answered interview questions in a socially desirable way (Weber & Cooke, 1972). However, participants shared diverse experiences and perspectives ranging from acceptance to rejection of the diagnosis which suggests that social desirability did not have a significant impact in this study. All participants were recruited through contact with schools/colleges. It is possible that the girls felt pressured to take part in the study due to the power dynamics which exist in traditional adult-student relationships within educational settings. This may have been exacerbated by autistic girls' tendency to worry about how others perceive them.

Another limitation of this study is the lack of homogeneity in terms of the educational settings of the participants as some participants were attending mainstream secondary schools, one was attending a mainstream sixth-form college and another participant was in a specialist setting for autistic CYP. This is particularly pertinent because the type of educational setting is likely to influence autistic girls' experiences. For example, Storm's highly positive autistic identity is likely to be underpinned by the fact that she attends a setting which specifically caters to autistic CYP. There was also lack of homogeneity in terms of the cultural and ethnic background of participants. Some participants were of mixed heritage, and it has been found that the experiences of those with mixed heritage is intricate and complex and likely differs from those with single heritage background (Boyle, 2022).  The lack of homogeneity within the sample is incompatible with the analysis used i.e., IPA.

An additional limitation of this IPA study is the level of subjectivity involved during interpretation. One may argue that despite best efforts, the researcher's views may have influenced the interpretation to the point that the final findings are not reflective of what the girls originally intended it to be. In order to address this, all girls were given the chance to review and amend the researcher's interpretation of their accounts. While member-checking is seen as a controversial technique within most qualitative approaches (including IPA), it has been used previously in participatory autism studies (e.g., MacLeod et al., 2017), thus the researcher felt that it was appropriate to adopt this technique on this occasion. Nevertheless, it is important to note that only two girls took up this opportunity.

The current study used a binary approach to gender, distinguishing between autistic boys and girls. Although this approach is useful as it enables us to gain a better understanding of the experiences of autistic girls, it ignores non-binary or gender fluid autistic individuals (Cooper et al., 2018). Future research should aim to explore the overlap between sex and gender, particularly because autistic individuals are more likely to identify as gender diverse (Strang et al., 2020).

The findings of this study suggest that relationships at different levels play a key role in the lives of minoritised autistic girls.  Thus, future research should strive to capture the views and experiences of the key adults around minoritised autistic girls (e.g., their parents and teachers). Doing so would possibly address a common critique of IPA which relates to the fact that standard IPA does not consider participants' context (Willig, 2013). One way to counter this is to adopt a multi-perspective IPA and seek, not only the views of autistic girls but also the views of their teachers and parents. This would greatly complement and enrich the accounts of minoritised autistic girls; however, researchers should take great care not to overshadow the girls' views. Additionally, although the researcher recognised and attempted to minimise the potential impact of the 'double empathy problem' within this study, future research should aim to better address this problem by adopting a participatory approach and including members of the autistic community at each stage of the research process, (e.g., from devising research questions and designing the methods to the dissemination of findings) (Fletcher-Watson et al., 2018). A participatory approach will better reflect the 'new era in autism research' (Pellicano et al., 2018).

## 2.12 Conclusion

This is the first study in the UK to explore the lived experiences of minoritised autistic girls. As such, this study has not only contributed to the emerging body of autism research investigating the experiences of autistic girls, but it has also given a voice to a marginalised group who has largely been neglected within the literature. The findings of the current study challenge the way in which autistic CYP have traditionally been portrayed in autism research i.e., as a homogenous group and highlights the importance of adopting a person-centred approach when considering the needs of autistic girls (Bond & Hebron, 2016) as the girls in this study reported differing experiences. However, despite reported differences, the cross-case analysis highlighted similarities in the experiences of all five girls. Notably, some of these experiences (particularly their educational experiences) were congruent with the experiences of White-British autistic girls detailed within the broader literature. For example, the girls reported difficulties navigating the school environment, particularly due to sensory issues and difficulties with social interactions and relationships. They also highlighted the importance of relationships with staff and welcomed adjustments at school/college. Nonetheless, the present research also showed that minoritised autistic girls have unique experiences related to their cultural and ethnic identity. For example, the girls in this study reported difficulties navigating cultural and religious expectations due to their autism. These findings have key implications for educational professionals (including EPs).

## Chapter 3: Research-Practitioner: a critically reflexive account

This chapter is written in the first person to reflect my active role in the current research. Throughout this research project, I reflected on the process of conducting research through supervision and keeping a research diary. My research journey has been challenging, but it enabled me to learn and reflect on a deeper level about the research topic as well as the process of conducting research and my identity as a practitioner and researcher. This chapter provides a critical account of my research journey, with a particular focus on the process of designing, conducting, and analysing the current study. This chapter also explores plans for dissemination.

### 3.1 Choosing a research topic

Prior to gaining a place in the professional doctorate, I worked as Psychology Assistant for an Educational Psychology Service (EPS) and a Teaching Assistant (TA) in a number of specialist educational settings, including a special school for CYP on the autism spectrum. Thus, I have extensive experience working with autistic CYP. It was during my role as a TA in a special school for autistic CYP that I first became interested in the topic of autism and girls. When I started working in this setting, I noted that there were no girls on roll. By the time that I left my role within this setting, the number of autistic girls had only increased to 2 (out of roughly 70 students). I often wondered what it was like to be an autistic girl in a ‘boy’s world’. Following this I worked as a Psychology assistant for an EPS. Within this role, I took part in a ‘Learning Set’ which focused on autism and girls. As part of this learning set, I worked alongside other members of the EPS to create a guidance document with up-to-date literature and resources relevant to autistic girls. It was through conducting this brief literature review, that I notice that many of the studies exploring the experiences of autistic girls, did not specify participants’ racial, ethnic and cultural background, and the studies which provided this information included mostly White British participants. This further ignited my interest in the experiences of autistic girls particularly those from minoritised ethnic backgrounds. I took on an interest in this area and continued to read articles, attend webinars and engage with the autistic community through social media channels such as Twitter (for example via the hashtag #actuallyautistic), and again it was evident that issues regarding culture and ethnicity were never raised within the ‘mainstream autistic community’. In the early stages of designing this research, I considered employing participatory approaches as I had read a fascinating piece of research by a Trainee EP (TEP) who adopted this approach to explore the experiences of minoritised autistic CYP. Hussein (2019) adopted a fully participatory approach by recruiting an autistic co-researcher (an autistic young person) who played a key role at all stages of the research process. However, I recognised that, as outlined by many researchers and Hussein herself, adopting this approach is more challenging and time consuming than engaging in traditional research. As I was completing a professional doctorate, alongside placement and personal commitments, I made the decision to focus on carrying out ‘good enough’ research.

### 3.2 Positionality

“The qualitative researcher's perspective is perhaps a paradoxical one: it is to be acutely tuned-in to the experiences and meaning systems of others—to indwell—and at the same time to be aware of how one's own biases and preconceptions may be influencing what one is trying to understand.” (Maykut & Morehouse, 1994, p. 123). Throughout this research project, I often reflected on this quote and actively tried to find a balance between making sense of participants’ experiences while being aware of my own biases. To ensure transparency, I will now outline key elements of my background/identity which may have influenced this research. I am a Black-African, first-generation immigrant, cis-gender female from a working-class background. Although I do not have a diagnosis of autism, I am a woman from a minoritised background thus I believe that I share aspects of an insider’s perspective which enhanced this research. For example, when interviewing Wonder Woman, she spoke about the importance of her hair as a Black-British girl and used a number of terms such as ‘stockings’, ‘bonnets’, ‘afros’ and ‘plaits’. While researchers from majority-cultural backgrounds may be familiar or have a basic understanding of these terms, the cultural significance of ‘black hair’ may not be fully understood by all. This shared understanding was particularly useful within the interview process. It is possible this also alleviated the power imbalance between me and the participants. However, I recognise that having somewhat an insider’s perspective is also likely to have impacted my interpretations. For instances, I could have over- or underestimated the significance of ‘black hair’ due to my own experiences. However, use of a research diary as well as a commitment to asking clarifying questions during the interview process enabled me to ensure that I stayed close to participants’ accounts. Despite sharing a similar minoritised background with participants, I acknowledge that I am not autistic. In fact, throughout the research journey I questioned my ability to fully understand minoritised autistic girls when I am not autistic. In particular, I reflected on the potential impact of the double empathy problem. Using child-friendly resources and member checking enabled me to tackle some of this. My professional experience and interest in this topic also meant that I had plenty of preconceptions that needed to be bracketed. Luckily, I felt that years of reflective and reflexive practice within EP training (BPS, 2017) facilitated this process.

### 3.3 Ontology and Epistemology

During the initial stages of devising this project, I considered social constructivism as the ontological and epistemological stance for this research. However, when presenting my research proposal to a group of TEPs and tutors, I was advised by a tutor to explore CT as a possible alternative. I had never heard of CT prior to this and when I attempted to find out more about it, I could not find much information within the literature. In fact, CT appeared to be overshadowed by Critical realism. After extensive research, I decided that CT was a better fit for this research. I also felt that CT closely fit with my stance as a practitioner. Thus, I feel that I will continue to reflect on this theory throughout my professional life.

### 3.4 Issues with recruitment

My initial plan for this research was to recruit autistic girls (aged 14 to 16) who were attending mainstream secondary schools in the East of England. My aim was to achieve a reasonable level of homogeneity, thus I set myself a strict criteria in terms of age group, type of educational setting and area of residence. However, I experienced several issues with recruitment. This was despite the fact that I advertised the research on several social medial channels and autism charities. After 4 months of recruitment difficulties, I took the decision to expand the inclusion criteria to include girls aged 12 to 18 and from a range of educational settings in England. I also changed my recruitment strategy and focused on contacting school and colleges directly. I also shared my research with EPs across England via the AEP weekly newsletter. My hope was that they would share the research with their link schools and colleges. However, in the end, all participants were recruited through my own contacts with schools and colleges. My first interview was in January 2023. This led me to consider possible reasons for issues around recruitment. Some of the reasons provided by schools and colleges were: “We do not have any students that meet your criteria” and “Our students do not have the necessary language skills to engage in an interview". Throughout the recruitment process, I reflected on the ethical issues associated with contacting schools and colleges multiple times. My recruitment strategy involved emailing SENCOs and a total of two reminders were sent, where needed. I felt that this technique could potentially be viewed as an intrusion or unwelcome pressure. Additionally, throughout the recruitment process (and associated difficulties), I questioned my choice of research topic and considered adjusting it to simply focus on the experiences of the parents of minoritised autistic girls, as I felt that it would be easier to recruit parents. At one point, I even considered changing the research topic altogether. However, I reflected on Devlin's words (2013) "if you are going to survive as an educational psychologist, you have to learn to accept that there are things you cannot change but if you are going to survive as a person then you cannot stop trying to change things that you cannot accept" (p.223). I stayed committed to this research as I could not accept that the voices of these girls were not represented within the literature.

### 3.5 Terminology

The language used in this research to describe ethnic diversity changed multiple times throughout the research journey. The term ethnically diverse was initially considered in line with the results outlined in the survey by Inc Arts UK (2020). However, this term was discarded following feedback from peers and tutors regarding its ambiguity. Despite being fully aware of its drawbacks, I reluctantly chose the term BAME in order to maintain consistency with existing UK research and publications. Thus, all research documents (e.g., ethics form, research advert etc.) used the term BAME. In line with the emancipatory goal of the study, my plan was to explore this in interviews with participants and allow them to choose whichever term they preferred. Language surrounding these topics i.e., culture and ethnicity continues to evolve, thus it is crucial that the individuals and communities being addressed are given the opportunity to express their preferences. My personal preference was the term 'global majorities'. However, I did not choose this term as I felt that it is not a widely known term and therefore could negatively impact recruitment. Additionally, I was committed to ensuring that the language used in this research reflected participants' preferences rather than my own. Interestingly, when I posted the research advert on an autism-related Facebook group, a user commented:

**Figure 8**

*Comment regarding terminology on research advert*

[redacted]

[redacted]

Correct terminology is no longer BAME but People of the Global Majority. Or just Global Majority. Just thought it might help.

Look at Inc Arts

https://www.governmentevents.co.uk/bameover-a-statement.../

GOVERNMENTEVENTS.CO.UK

#BAMEOver - A Statement for the UK -

This led me to consider whether using the term BAME also impacted recruitment in a negative way, as it is evident that many people do not agree with this term. After interviewing participants, I quickly realised that most of them did not have a preference, and the terms which they did briefly mention e.g., POC appeared to be heavily influenced by their use of social media. While I considered using the term POC, I reflected, with support from my research supervisor, that the girls' brief reference of the term POC was perhaps reflective of their limited knowledge base in this area. Upon reflection, I feel that it would have been helpful to provide participants with an explanation of the different terminologies (e.g., POC, BAME, minoritised, diaspora, global majority etc.) during the interview to enable them to make an informed decision. The girls may be limited by their own knowledge base thus scaffolding and steering would have enabled them to make an informed decision. For example, it is unlikely that the girls have come across terms such as global majorities, minoritised and diaspora (as these terms are not widely used within social media). However, I personally felt that these terms were better suited as they are fairly neutral and do not centre 'whiteness'. I recognised that, as suggested by Lorde (1984), in order to dismantle structures of oppression, one must also dismantle the language that maintains such structures. Therefore, I drew on my professional expertise to choose a term which was neutral and appropriate. Through discussions with my research supervisor, the term minoritised was chosen. The term minoritised was chosen for a number of reasons (which have already been outlined in Chapter 1). Another reason for adopting this term, is that it may be more searchable (as closely relates to the term “minority” which is widely used within the literature).

### 3.6 Analysis

Prior to selecting IPA as the methodology for the current research, alternative methodologies namely Grounded Theory and Narrative Inquiry (NI) were considered. These methodologies were considered as they all focus on meaning and experience (Ritchie et al., 2013). Grounded Theory is an approach which aims discover new understandings in order to devise a theory (Bryman, 2012), this was discounted as the present research did not aim to develop a new theory. Both IPA and NI align with the research questions and aims of the current study as both approaches are interpretative and focus on first person accounts (Griffin & May, 2012). In the end, IPA was chosen as it positions participants as experts. While I am able to summarise each of these methodologies now, I remember feeling very confused when first trying to make sense of all of these choices. As a novice qualitative researcher, this led to feelings of conscious incompetence (Curtiss & Warren, 1973). I remember considering ‘just doing’ thematic analysis as I (wrongly) assumed that that was the easier and safer option. However, I reflected on the importance of using methods which fit not only the research questions but also the participants’ needs. Immersing myself in the work of other IPA researchers allowed me to become more comfortable with the idea of ‘doing IPA’. Additionally, Willig (2013) provided a simple overview of these different methodologies. Folkes (2022) argues that “qualitative research is messy, complex and contradictory, echoing the nature of human behaviour” (p. 15). Thus, as a novice qualitative researcher, starting data analysis was a daunting step. However, time constrains pushed me to ‘get on’ with this process.  During the transcription process, I often found myself judging my own interview skills. For instance, I thought of more suitable follow up questions which might have led to deeper exploration of the topic. I feel that this has influenced my practice as a TEP particularly when considering the best questions to ask to elicit deeper discussions during casework.

### 3.7 Epistemological violence

During the write up process, I noted that I often found myself needing to contrast or challenge potentially negative views of religion. I initially thought that this was perhaps underpinned my own experiences (I was raised as a Catholic and I am a believer). However, through further reflection I recognised that this was simply a conscious effort to avoid epistemological violence. Epistemological violence refers to “a practice that is presented in empirical research articles, chapters, and books in psychology (and the social sciences), when theoretical interpretations of empirical results implicitly or explicitly construct the Other as inferior or problematic, despite the fact that alternative interpretations, equally viable, based on the data, are available.” (Teo, 2014, p. 594). This violence often portrays those from marginalised communities, including minoritised cultural communities and autistic people as inferior. This commitment to avoid epistemological violence was (hopefully) presented throughout this thesis. For example, when discussing the concept of autism in the literature review, I drew on mainstream views of autism but also actively challenged this with alternative constructions of autism put forward by the autistic community.

### 3.8 Plans for dissemination

A key goal of this research was to produce information that could benefit marginalised or disadvantaged groups, in this case minoritised autistic girls (Noel, 2016). By adding the voices of minoritised autistic girls to the research base it is hoped that professionals, particularly educational professionals such as EPs and teachers can better support their needs in educational settings. In order to maximise the potential impact of the current study, the findings will be disseminated at various levels. More specifically, I plan to create an accessible one-page summary of the findings which can be shared with a range of stakeholders including participants and their educational settings. Some of the educational settings and charities which I contacted during the recruitment process (those that were not able to aid with the recruitment process), also expressed an interested in hearing about the findings of this study, with many requesting that I present the findings in their settings/organisations. I hope that conducting live presentations within these settings, rather than just sending a one-page summary of the findings, will ignite discussions and potentially prompt actions to better support minoritised autistic girls. Additionally, I am hoping to present the findings to my current EPS as well as on other key platforms, such as the Southend ‘EPS Reach Out’ YouTube channel. Finally, I hope to publish the research findings to the ‘Educational Psychology in Practice’ journal. This journal is particularly pertinent as it has previously published research related to autism and girls (e.g., Morgan, 2023;

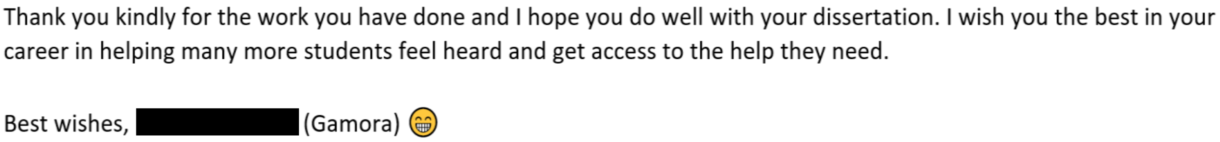
Gray et al., 2021) and it is accessible to EPs. However, other journals relevant to the research topic will also be considered.

### 3.9 Conclusion

Throughout this chapter, I hope to have provided a clear and detailed account of the rationale for this research project and the decisions which I made throughout this research journey. I have remained open and reflected on how my experiences and background may have impacted and guided the research process. I also reflected on the various challenges which I encountered throughout this research journey, particularly difficulties with recruitment as well as difficulties associated with conducting a doctoral research project alongside placement responsibilities. Despite such challenges, I have found this research journey to be highly valuable as it has enabled me to deepen my knowledge of the research topic and conversely gain a better understanding of how to best support autistic girls. This has greatly impacted my practice as a professional. In fact, many of the suggestions offered by the girls in this study will continue to guide my practice as a qualified educational and child psychologist. In addition, conducting this research project has enabled me to further my skills as a qualitative researcher. As I prepare to submit this thesis, I am experiencing a number of conflicting emotions. Above all, I feel immensely grateful to have had the opportunity to elicit and amplify the voices of these girls. Despite the numerous challenges encountered in this research journey, learning about these girls' experiences (and Gamora's feedback, which is outlined below) has made the process all worth it in the end:

**Figure 9**

*Feedback from Gamora*



Thank you kindly for the work you have done and I hope you do well with your dissertation. I wish you the best in your career in helping many more students feel heard and get access to the help they need.

Best wishes, [redacted] (Gamora) 😁

# Appendices

## Appendix 1: List of key studies reviewed

*Published research*

Baldwin, S., & Costley, D. (2016). The experiences and needs of female adults with high-functioning autism spectrum disorder. Autism, 20(4), 483–495. https://doi.org/10.1177/1362361315590805

Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. Journal of Autism and Developmental Disorders, 46(10), 3281–3294. https://doi.org/10.1007/s10803-016-2872-8

Cook, A., Ogden, J., & Winstone, N. (2018). Friendship motivations, challenges and the role of masking for girls with autism in contrasting school settings. European Journal of Special Needs Education, 33(3), 302–315. https://doi.org/10.1080/08856257.2017.1312797

Cook, J., Hull, L., Crane, L., & Mandy, W. (2021). Camouflaging in autism: A systematic review. *Clinical Psychology Review*, *89*, 102080. https://doi.org/10.1016/j.cpr.2021.102080

Cresswell, L., & Cage, E. (2019). ‘Who am I?’: An exploratory study of the relationships between identity, acculturation and mental health in autistic adolescents. Journal of Autism and Developmental Disorders, 49(7), 2901–2912. https://doi.org/10.1007/s10803-019-04016-x

Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2014). Being a girl in a boys’ world: Investigating the experiences of girls with autism spectrum disorders during adolescence. Journal of Autism and Developmental Disorders, 44(6), 1261–1274. https://doi.org/10.1007/s10803-013-1985-6

Dean, M., Harwood, R., & Kasari, C. (2017). The art of camouflage: Gender differences in the social behaviors of girls and boys with autism spectrum disorder. Autism, 21(6), 678–689. https://doi.org/10.1177/1362361316671845

Gaffney, J. C. (2020). ‘it’s autism, it’s just a name’: Exploring the impact of autism spectrum diagnosis with adolescent females using interpretative phenomenological analysis. *Educational and Child Psychology*, *37*(1), 136–149. https://doi.org/10.53841/bpsecp.2020.37.1.136

Goodall, C., & MacKenzie, A. (2019). What about my voice? Autistic young girls’ experiences of mainstream school. European Journal of Special Needs Education, 34(4), 499–513. https://doi.org/10.1080/08856257.2018.1553138

Gould, J. (2017). Towards understanding the under-recognition of girls and women on the autism spectrum. Autism, 21(6), 703-705. 136

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

Greenlee, J. L., Winter, M. A., & Marcovici, I. A. (2020). Brief report: Gender differences in experiences of peer victimization among adolescents with autism spectrum disorder. Journal of Autism and Developmental Disorders. Advance Online Publication. https://doi.org/10.1007/s10803-020-04437-z

Hull, L., & Mandy, W. (2017). Protective effect or missed diagnosis? Females with autism spectrum disorder. Future Neurology, 12(3), 159–169. https://mc04.manuscriptcentral.com/fm-fnl

Hull, L., Lai, M. C., Baron-Cohen, S., Allison, C., Smith, P., Petrides, K. V., & Mandy, W. (2020). Gender differences in self-reported camouflaging in autistic and non-autistic adults. Autism, 24(2), 352–363. https://doi.org/10.1177/1362361319864804

Hull, L., Mandy, W., Lai, M. C., Baron-Cohen, S., Allison, C., Smith, P., & Petrides, K. V. (2019). Development and validation of the camouflaging autistic traits questionnaire (CAT-Q). Journal of Autism and Developmental Disorders, 49(3), 819–833. https://doi.org/10.1007/s10803-018-3792-6

Hull, L., Petrides, K. V., & Mandy, W. (2020). The female autism phenotype and camouflaging: A narrative review. Review Journal of Autism and Developmental Disorders, 1-12.

Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C., & Mandy, W. (2017). “Putting on my best normal”: Social camouflaging in adults with autism spectrum conditions. Journal of Autism and Developmental Disorders, 47(8), 2519–2534. https://doi.org/10.1007/s10803-017-3166-5

Jarman, B., & Rayner, C. (2015). Asperger’s and girls: What teachers need to know. Australian Journal of Special Education, 39(2), 128–142. https://doi.org/10.1017/jse.2015.7

Kirkovski, M., Enticott, P. G., & Fitzgerald, P. B. (2013). A review of the role of female gender in autism spectrum disorders. Journal of Autism and Developmental Disorders, 43(11), 2584–2603. https://doi.org/10.1007/s10803-013-1811-1

Lai, M. C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. The Lancet Psychiatry, 2(11), 1013–1027. https://doi.org/10.1016/S2215-0366(15)00277-1

Livingston, L. A., Shah, P., & Happé, F. (2019). Compensatory strategies below the behavioural surface in autism: a qualitative study. The Lancet Psychiatry, 6(9), 766–777. https://doi.org/10.1016/S2215-0366(19)30224-X

Milner, V., McIntosh, H., Colvert, E., & Happé, F. (2019). A qualitative exploration of the female experience of autism spectrum disorder (ASD). Journal of Autism and Developmental Disorders, 49(6), 2389–2402. https://doi.org/10.1007/s10803-019-03906-4

Morgan, R. (2023). How do adolescent autistic girls construct self-concept and social identity? A discourse analysis. *Educational Psychology in Practice*, 1–23. https://doi.org/10.1080/02667363.2023.2181316

Moyse, R., & Porter, J. (2015). The experience of the hidden curriculum for autistic girls at mainstream primary schools. European Journal of Special Needs Education, 30(2), 187–201. https://doi.org/10.1080/08856257.2014.986915

Myles, O., Boyle, C., & Richards, A. (2019). The social experiences and sense of belonging in adolescent females with autism in mainstream school. Educational and Child Psychology, 36(4), 8–21.

Sedgewick, F., Hill, V., & Pellicano, E. (2019). "It's different for girls": Gender differences in the friendships and conflict of autistic and neurotypical adolescents. Autism, 23(5), 1119–1132. https://doi.org/10.1177/1362361318794930

Sedgewick, F., Hill, V., Yates, R., Pickering, L., & Pellicano, E. (2016). Gender differences in the social motivation and friendship experiences of autistic and non-autistic adolescents. Journal of Autism and Developmental Disorders, 46(4), 1297–1306. https://doi.org/10.1007/s10803-015-2669-1

Tierney, S., Burns, J., & Kilbey, E. (2016). Looking behind the mask: Social coping strategies of girls on the autistic spectrum. Research in Autism Spectrum Disorders, 23, 73–83. https://doi.org/10.1016/j.rasd.2015.11.013

Tomlinson, C., Bond, C., & Hebron, J. (2019). The school experiences of autistic girls and adolescents: A systematic review. European Journal of Special Needs Education, 1–17. https://doi.org/10.1080/08856257.2019.1643154

Tomlinson, C., Bond, C., & Hebron, J. (2021). The mainstream school experiences of adolescent autistic girls. *European Journal of Special Needs Education*, *37*(2), 323–339. https://doi.org/10.1080/08856257.2021.1878657

Vine Foggo, R. S., & Webster, A. A. (2017). Understanding the social experiences of adolescent females on the autism spectrum. Research in Autism Spectrum Disorders, 35, 74–85. https://doi.org/10.1016/j.rasd.2016.11.006 138

Fox, F., Aabe, N., Turner, K., Redwood, S., & Rai, D. (2017). "It was like walking without knowing where I was going": a qualitative study of autism in a UK Somali migrant community. Journal of Autism and Developmental Disorders, 47, 305–315.

Gilligan, P. (2013). The challenge of cultural explanations and religious requirements for children with autism spectrum conditions: South Asian Muslim parents in Bradford, England. Journal of Religion, Disability & Health, 17, 393–408.

Hussein, A. M., Pellicano, E., & Crane, L. (2019). Understanding and awareness of autism among Somali parents living in the United Kingdom. Autism, 23(6), 1408–1418.

Munroe, K., Hammond, L., & Cole, S. (2016). The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed with an autism spectrum disorder: an interpretive phenomenological analysis. Disability & Society, 31(6), 798–819.

*Unpublished theses*

Bassett, C. (2022). An exploration into the development of camouflaging behaviours adopted by girls on the autism spectrum in mainstream secondary schools: Perspectives of girls and their parents. [Unpublished doctoral thesis]. Institute of Education, University of London.

Beteta, L. M. (2009). A phenomenological study of the lived experiences of adolescent females with Asperger syndrome [Unpublished doctoral thesis]. Walden University.

Brennan De Vine, N. (2022). Exploring how a sense of belonging is constructed in the accounts of autistic girls who attend mainstream school in England. [Unpublished doctoral thesis]. Institute of Education, University of London.

Carver, H. (2020). “We are normal, we just have a different wiring”: A narrative inquiry into the identity and sense-making of adolescent autistic girls. [Unpublished doctoral thesis]. University of Bristol.

Edwards, K. (2012). Self-perceptions of a high school female adolescent with Asperger syndrome: A case history [Unpublished doctoral thesis]. Capella University.

Feist, N. A. (2013). “Too different to be accepted, too different to fit in”: Adolescent girls’ perceptions of living with ASD, as presented on YouTube [Unpublished master's thesis]. University of the Witwatersand.

Hussein, A. (2021). A participatory research approach to understanding the experiences of Black, Asian and Minority Ethnic (BAME) autistic young people. [Unpublished doctoral thesis]. University of East London.

Jackson, A. (2019). Using a participatory research model to investigate the friendship experiences of females with autism or social communication difficulties. [Unpublished doctoral thesis]. University of East London.

Jordan, D (2021). Autistic Teenage Girls’ Lived Experiences of Masking. [Unpublished doctoral thesis]. University of Essex

Logsden, L. (2010). The experiences of adolescence for females with asperger’s disorder [Unpublished doctoral thesis]. Alliant International University.

O'Hagan, G. (2020). Missing voices: The educational experiences of girls with autism. [Unpublished doctoral thesis]. Queen's University Belfast.

Rainsberry, T. (2016). An exploration of the positive and negative experiences of teenage girls with autism attending mainstream secondary school [Unpublished master's thesis]. The University of Birmingham.

## Appendix 2: Research Advert

University of East Anglia

# CALL FOR PARTICIPANTS

## THE EDUCATIONAL EXPERIENCES OF BLACK, ASIAN AND MINORITY ETHNIC (BAME)* AUTISTIC GIRLS.

My name is Edguelza and I am a Trainee Educational Psychologist. As part of my study, I would like to speak to BAME autistic girls (aged 12 to 18) who are currently attending school or college in England.

Taking part in this study would involve a one-to-one interview with myself. You can choose if you would like to meet virtually or in person.

The interview would last around one hour and would be voice recorded so that I can listen back to it.

***I recognise that many people do not identify with the term ‘BAME’. If you choose to take part in this study, you will be in control of the language used.***

For more information, please speak to your parent/carer and ask them to email me. My email address is **e.costa@uea.ac.uk**

## Appendix 3: Email sent to SENCOs

Dear SENCo,

I hope this email finds you well.

My name is Edguelza Costa and I am currently completing a doctorate in Educational and Child Psychology at the university of University of East Anglia (UEA).

I am writing to ask for your help with my current doctoral study. I am conducting research with autistic girls (aged 12 to 18) from Black, Asian, and Minority Ethnic (BAME)* backgrounds who are currently attending school or college in England. I am interested in talking with these girls (either remotely or in person) to find out about their experiences. The attached 'Research advert' (which is a brief overview) and 'Participant information sheets' (for parents and young people) offer more detailed information about my study.

*I recognise that many people do not identify with the term 'BAME'. Therefore, participants will be in control of the language used within this research.

As you may be aware, current research focuses mainly on the experiences of white British autistic girls, thus I am hoping to give BAME autistic girls a chance to have their voices heard. I would be very grateful if you could share my research advert with the girls in your school/college.

If you have any questions about this research study, please do not hesitate to contact me.

I look forward to hearing from you.

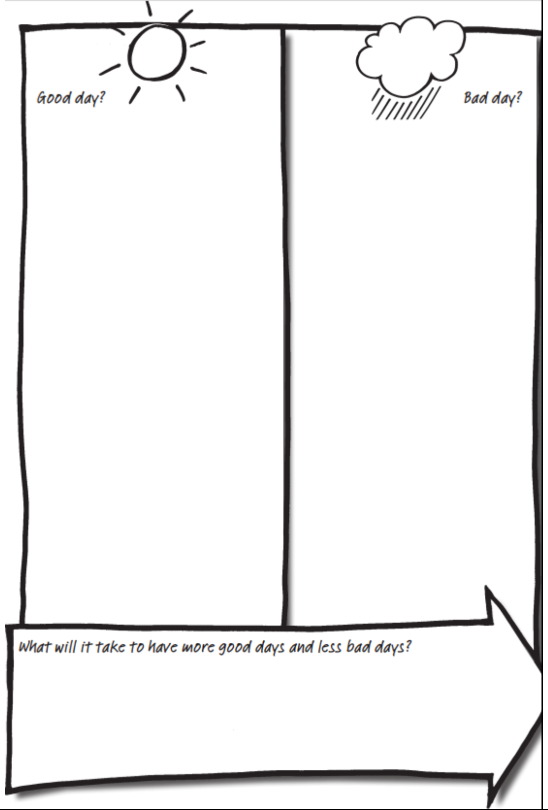
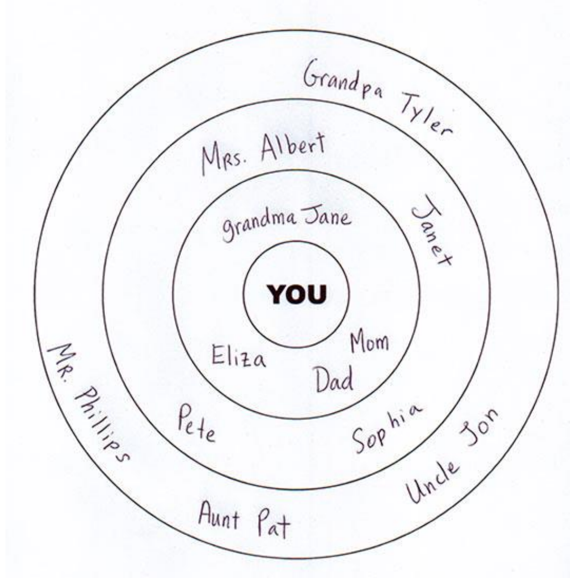
Best wishes,
Edguelza Costa

## Appendix 4: Interview schedule and child-friendly resources

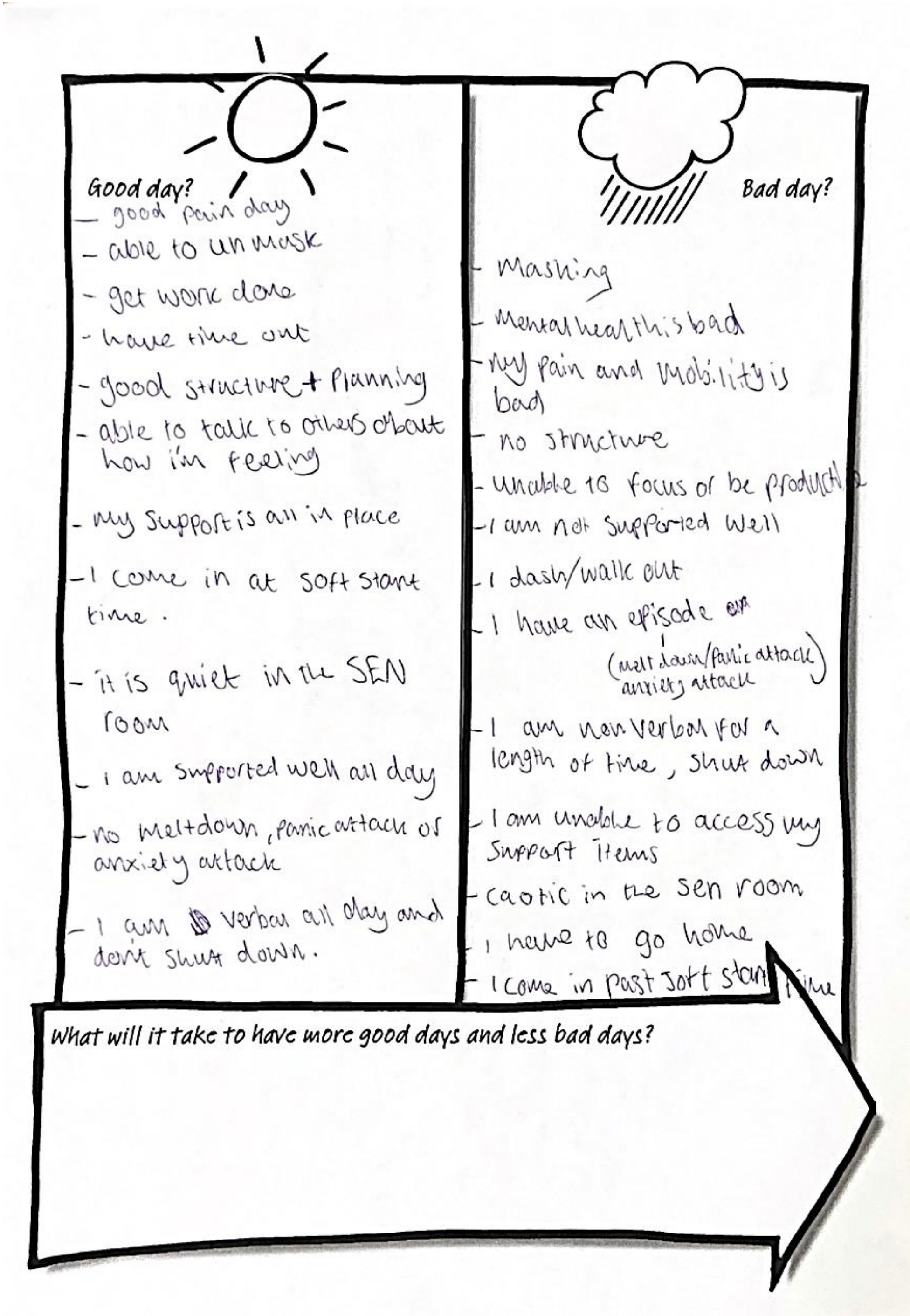
| **Topic** | **Possible main questions** | **Prompts** | **Child friendly resource/s** |
|---|---|---|---|
| Identity | • What words would you prefer me to use when talking about your identity around your culture?<br>• What words would you prefer me to use when talking about your identity around autism?<br>• When did you know that you were autistic?<br>• What does autism mean to you?<br>• What does being a ________ (name the cultural background the young person used to describe herself) autistic girl mean to you?<br>• How is autism viewed in _________ (name the cultural background the young person used to describe herself) culture?<br>• Do you think that there are differences for __________ (name the ethnic background the young person used to describe herself) autistic girls compared to autistic girls from other ethnic backgrounds?<br>• Do you think that there are differences between autistic boys and autistic girls? | • Prompt to find out about language spoken at home and religion<br>• What does it mean to you when people use the correct words? Is it important?<br>• Did you find out on your own? Did someone make you aware? How did it feel? How old were you? What did you think? When did you get diagnosed?<br>• Can you tell me a bit more about..?<br>• What would an older relative/aunt/uncle/grandparent say about autism?<br>• If yes, what are they? | Grid Elaboration Method (GEM) |
| School/College | • How is school/college for you?<br>• What are the main differences between a good day and a bad day at school/college?<br>• Would you change anything about your school/college if you | • What would you keep in a good day? What would you change about a bad day?<br>• If so, what would you change? | Good day/bad day sheet |

|  |  |  |  |
|---|---|---|---|
|  | could? |  |  |
| Relationships | • Can you tell me about your relationships with other people (peers, family, teacher)? | • Do you think autism has affected your relationships with these people? | Relationship circles |
| Moving forward | • What if anything, would you like to tell adults about what a person like you needs in order to feel happy, feel understood and be able to succeed?<br>• What are your plans for the future? | • Can you tell me a bitmore about that? |  |
| Extra questions | • Are there any questions that you think I should add to my list for other young people? Could you answer that question now yourself? |  |  |
| Positive question to end interview | • I am making a list of the very best things about being an autistic girl, I am wondering whether you can tell me the very best thing about your autism? |  |  |

**Description and examples of child-friendly resources**

| Name | Grid Elaboration Method | Good dady/Bad day sheet | Relationship circles |
|---|---|---|---|
| Example |  |  |  |
| Description | Participants are presented with a blank grid comprising four boxes on an A4 sheet of paper; they are then asked to represent with a word, image or phrase their "associations" to a given topic, that is, their first responses or "associations". | This person-centred thinking tool helps to have conversations about what a good day and bad day is like, for the participant. | This resource provides a way of identifying who is important to the participant, and to explore any important issues around those relationships. |

## Appendix 5: Gamora's Good day/Bad day sheet



Good day?

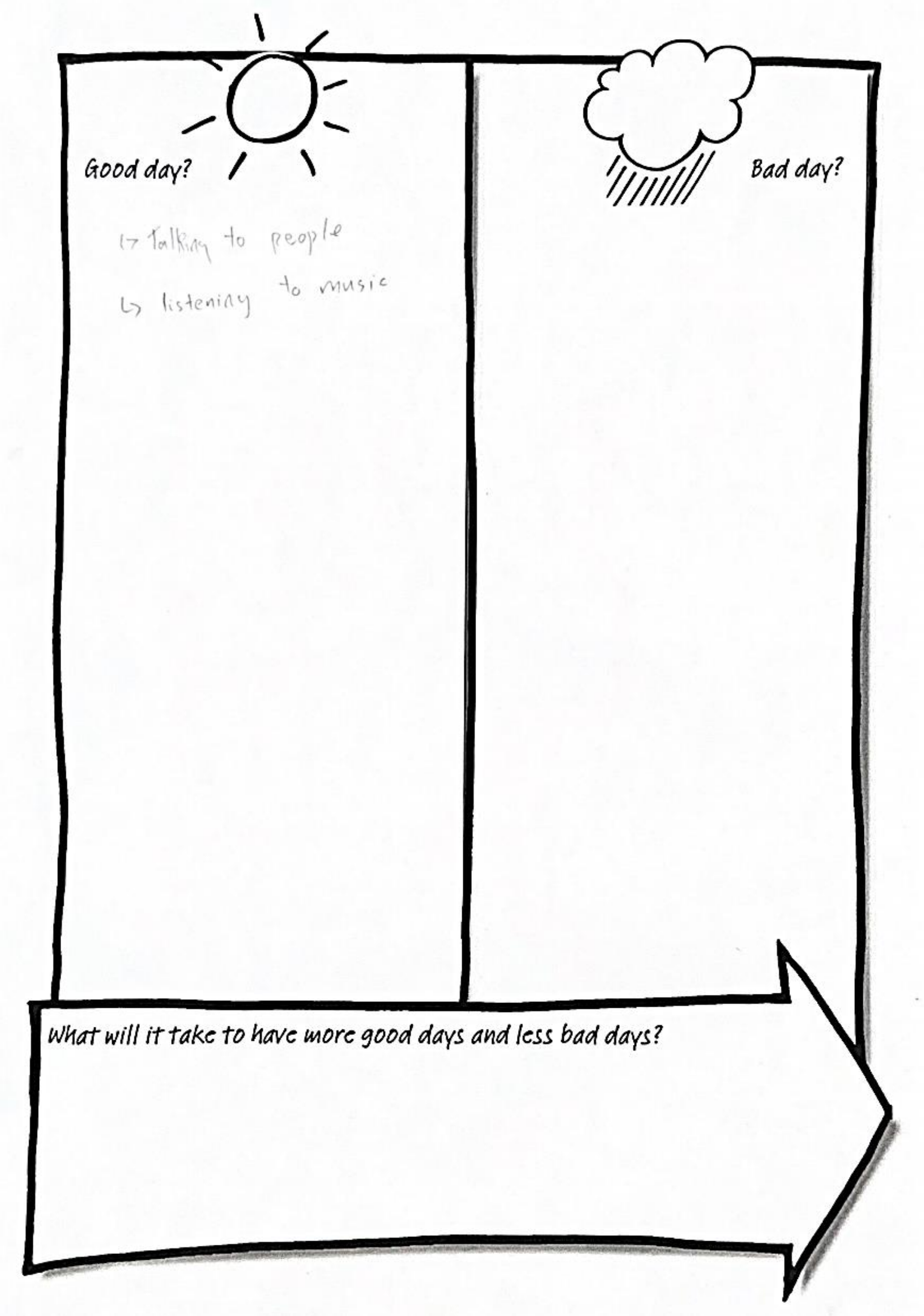
- good pain day
- able to unmask
- get work done
- have time out
- good structure + Planning
- able to talk to others about how i'm feeling
- my Support is all in place
- I come in at soft start time.
- it is quiet in the SEN room
- i am supported well all day
- no meltdown, panic attack or anxiety attack
- I am verbal all day and don't shut down.

Bad day?

- Masking
- Mental health is bad
- my pain and mobility is bad
- no structure
- unable to focus or be productive
- I am not supported well
- I dash/walk out
- I have an episode on (melt down/panic attack/ anxiety attack)
- I am non verbal for a length of time, shut down
- I am unable to access my Support Items
- caotic in the sen room
- I have to go home
- I come in past soft start time

What will it take to have more good days and less bad days?

## Appendix 6: Wonder Woman’s Good day/Bad day sheet



Good day?

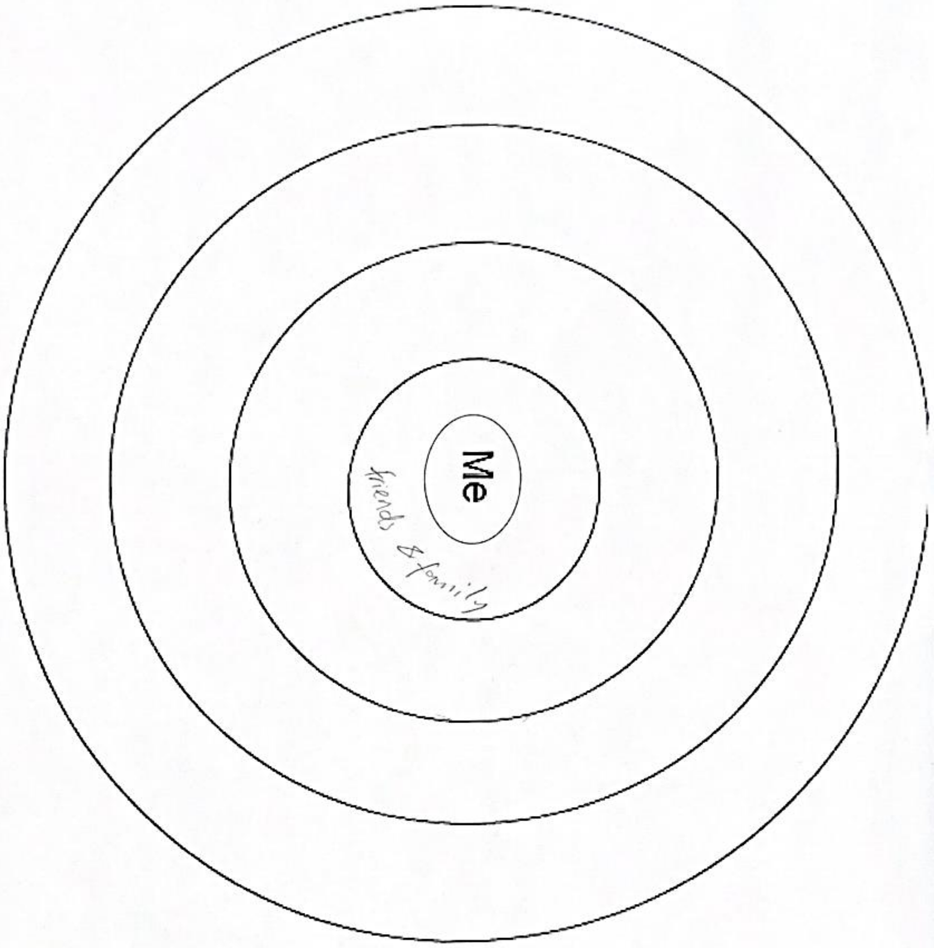
↳ Talking to people

↳ listening to music

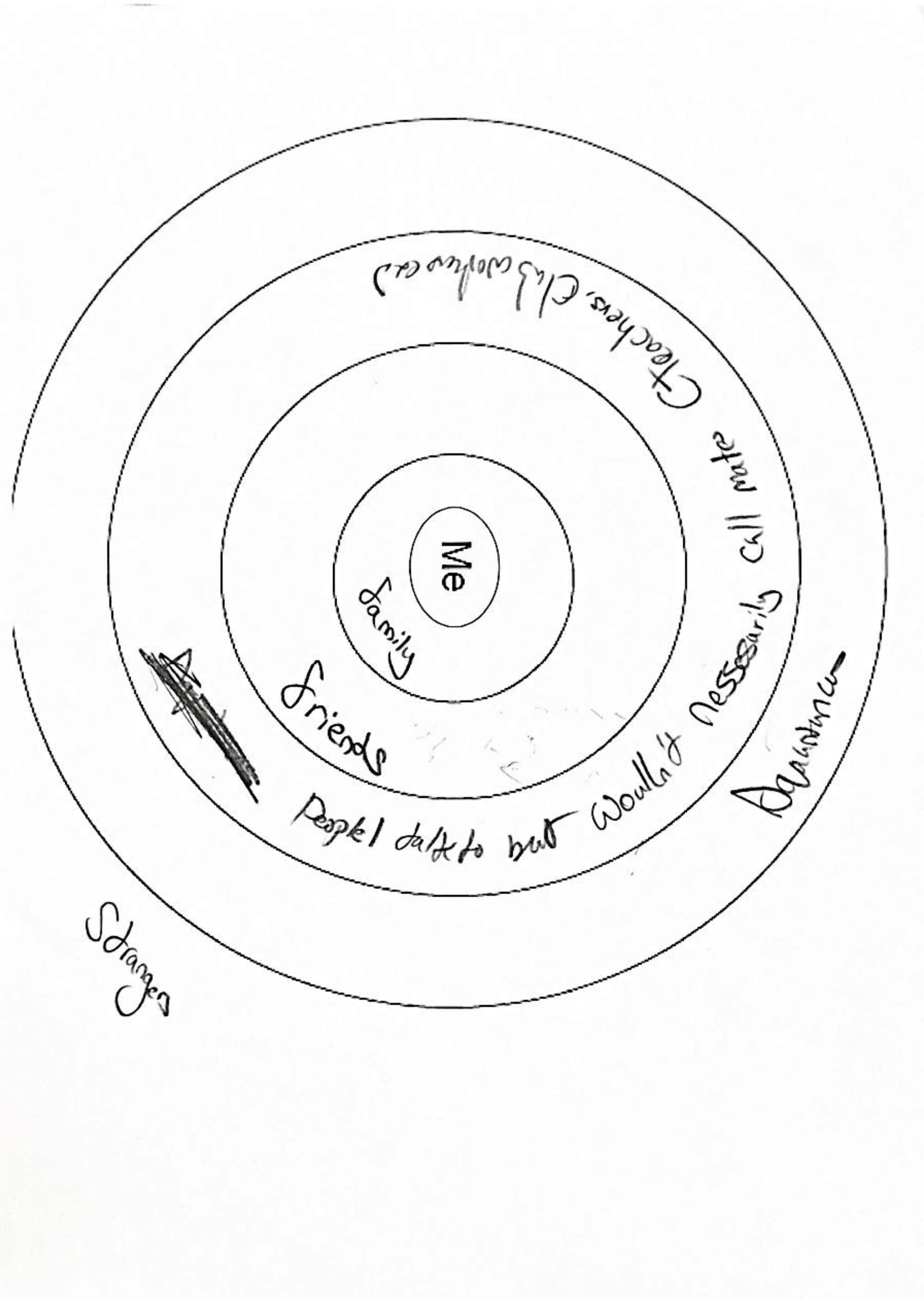
Bad day?

What will it take to have more good days and less bad days?

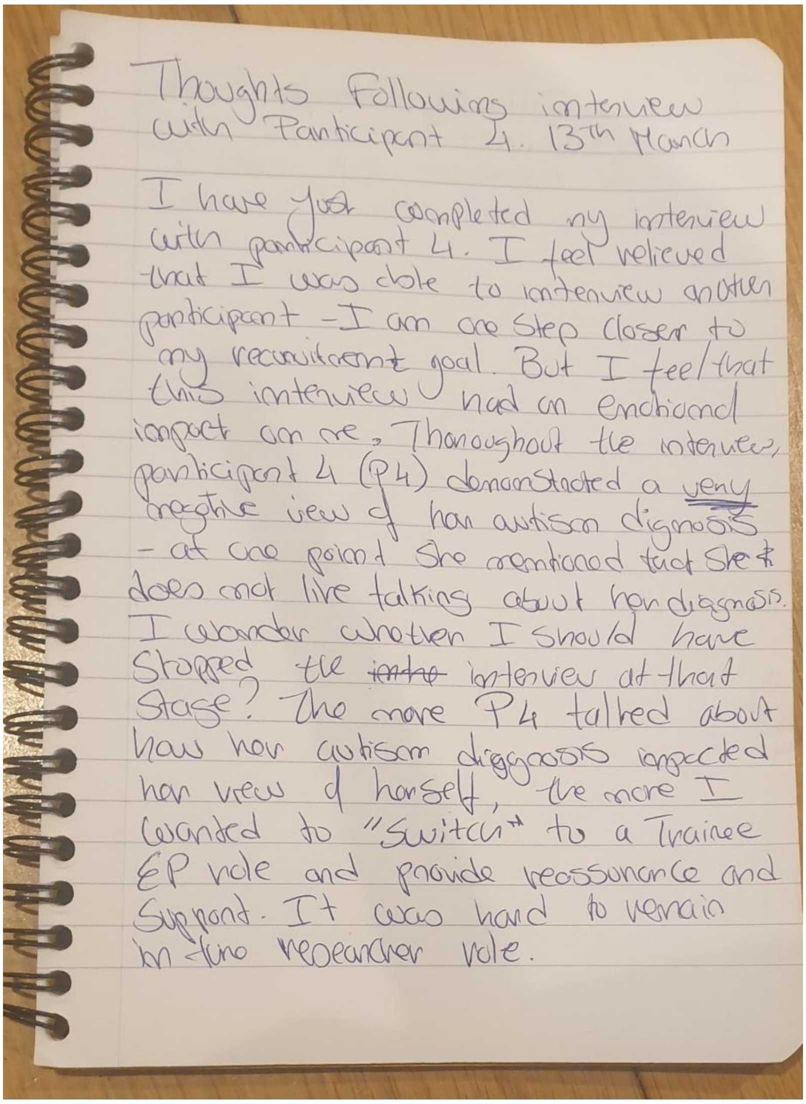
## Appendix 7: Wonder Woman’s Relationship Circles



## Appendix 8: Storm's Relationship Circles



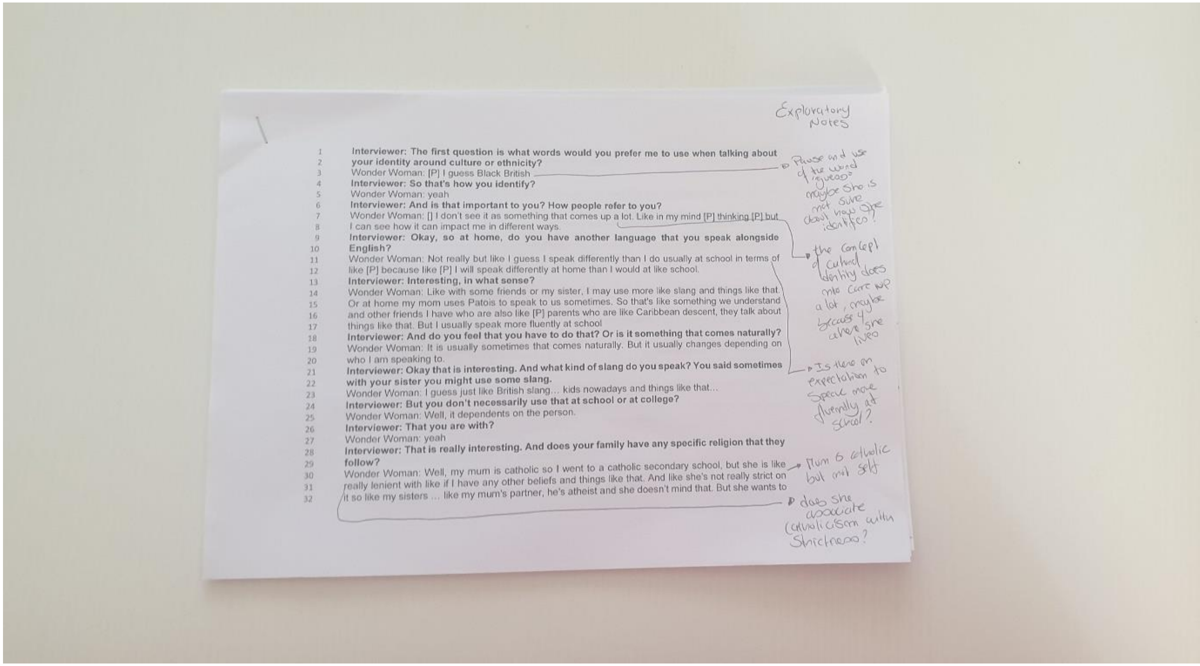
## Appendix 9: Extract from research diary



Thoughts Following interview with Participant 4. 13th March

I have just completed my interview with participant 4. I feel relieved that I was able to interview another participant – I am one step closer to my recruitment goal. But I feel that this interview had an emotional impact on me. Throughout the interview, participant 4 (P4) demonstrated a very negative view of her autism diagnosis – at one point she mentioned that she does not like talking about her diagnosis. I wonder whether I should have stopped the ~~inte~~ interview at that stage? The more P4 talked about how her autism diagnosis impacted her view of herself, the more I wanted to "switch"* to a Trainee EP role and provide reassurance and support. It was hard to remain in the researcher role.

# Appendix 10: Exploratory notes (Wonder Woman)



Exploratory Notes

**Interviewer: The first question is what words would you prefer me to use when talking about your identity around culture or ethnicity?**
Wonder Woman: [P] I guess Black British
**Interviewer: So that's how you identify?**
Wonder Woman: yeah
**Interviewer: And is that important to you? How people refer to you?**
Wonder Woman: [] I don't see it as something that comes up a lot. Like in my mind [P] thinking [P] but I can see how it can impact me in different ways.
**Interviewer: Okay, so at home, do you have another language that you speak alongside English?**
Wonder Woman: Not really but like I guess I speak differently than I do usually at school in terms of like [P] because like [P] I will speak differently at home than I would at like school.
**Interviewer: Interesting, in what sense?**
Wonder Woman: Like with some friends or my sister, I may use more like slang and things like that. Or at home my mom uses Patois to speak to us sometimes. So that's like something we understand and other friends I have who are also like [P] parents who are like Caribbean descent, they talk about things like that. But I usually speak more fluently at school
**Interviewer: And do you feel that you have to do that? Or is it something that comes naturally?**
Wonder Woman: It is usually sometimes that comes naturally. But it usually changes depending on who I am speaking to.
**Interviewer: Okay that is interesting. And what kind of slang do you speak? You said sometimes with your sister you might use some slang.**
Wonder Woman: I guess just like British slang… kids nowadays and things like that…
**Interviewer: But you don't necessarily use that at school or at college?**
Wonder Woman: Well, it dependents on the person.
**Interviewer: That you are with?**
Wonder Woman: yeah
**Interviewer: That is really interesting. And does your family have any specific religion that they follow?**
Wonder Woman: Well, my mum is catholic so I went to a catholic secondary school, but she is like really lenient with like if I have any other beliefs and things like that. And like she's not really strict on it so like my sisters … like my mum's partner, he's atheist and she doesn't mind that. But she wants to

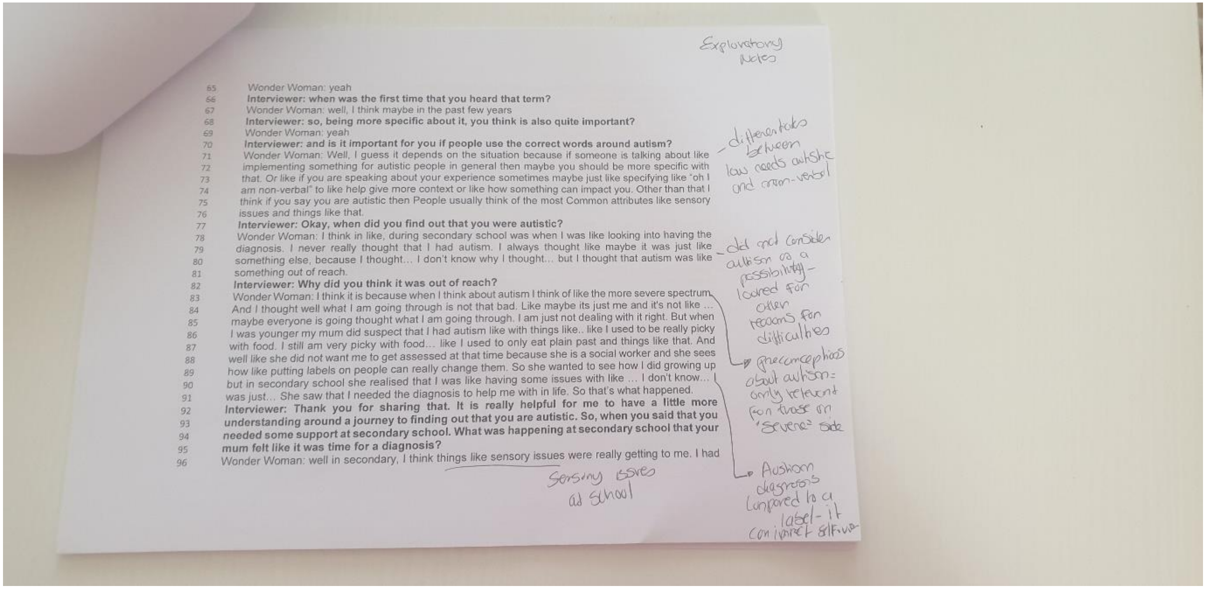
Pause and use of the word 'guess' maybe she is not sure about how she identifies?

the concept of cultural identity does not come up a lot, maybe because of where she lives

Is there an expectation to speak more fluently at school?

Mum is catholic but not self

does she associate Catholicism with strictness?



Exploratory Notes

Wonder Woman: yeah
**Interviewer: when was the first time that you heard that term?**
Wonder Woman: well, I think maybe in the past few years
**Interviewer: so, being more specific about it, you think is also quite important?**
Wonder Woman: yeah
**Interviewer: and is it important for you if people use the correct words around autism?**
Wonder Woman: Well, I guess it depends on the situation because if someone is talking about like implementing something for autistic people in general then maybe you should be more specific with that. Or like if you are speaking about your experience sometimes maybe just like specifying like "oh I am non-verbal" to like help give more context or like how something can impact you. Other than that I think if you say you are autistic then People usually think of the most Common attributes like sensory issues and things like that.
**Interviewer: Okay, when did you find out that you were autistic?**
Wonder Woman: I think in like, during secondary school was when I was like looking into having the diagnosis. I never really thought that I had autism. I always thought like maybe it was just like something else, because I thought… I don't know why I thought… but I thought that autism was like something out of reach.
**Interviewer: Why did you think it was out of reach?**
Wonder Woman: I think it is because when I think about autism I think of like the more severe spectrum. And I thought well what I am going through is not that bad. Like maybe its just me and it's not like … maybe everyone is going thought what I am going through. I am just not dealing with it right. But when I was younger my mum did suspect that I had autism like with things like.. like I used to be really picky with food. I still am very picky with food… like I used to only eat plain past and things like that. And well like she did not want me to get assessed at that time because she is a social worker and she sees how like putting labels on people can really change them. So she wanted to see how I did growing up but in secondary school she realised that I was like having some issues with like … I don't know… I was just… She saw that I needed the diagnosis to help me with in life. So that's what happened.
**Interviewer: Thank you for sharing that. It is really helpful for me to have a little more understanding around a journey to finding out that you are autistic. So, when you said that you needed some support at secondary school. What was happening at secondary school that your mum felt like it was time for a diagnosis?**
Wonder Woman: well in secondary, I think things like sensory issues were really getting to me. I had

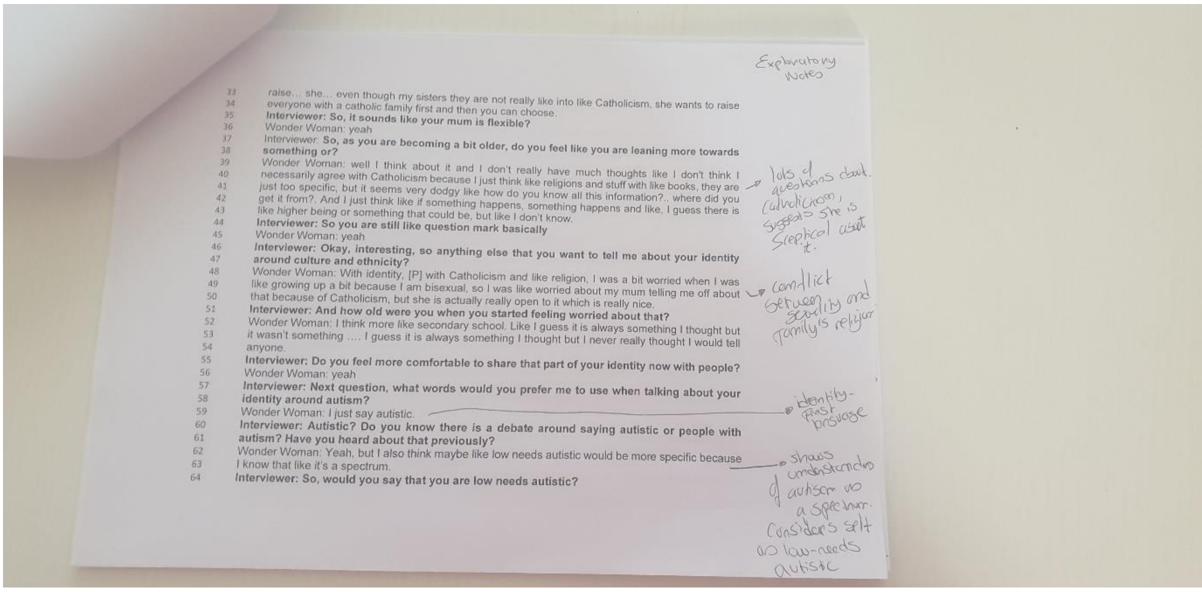
differentiates between low needs autistic and non-verbal

did not consider autism as a possibility - looked for other reasons for difficulties

preconceptions about autism = only relevant for those on 'severe' side

Autism diagnosis compared to a label - it can impact selfview

Sensory issues at school



Exploratory Notes

raise… she… even though my sisters they are not really like into like Catholicism, she wants to raise everyone with a catholic family first and then you can choose.
**Interviewer: So, it sounds like your mum is flexible?**
Wonder Woman: yeah
Interviewer: **So, as you are becoming a bit older, do you feel like you are leaning more towards something or?**
Wonder Woman: well I think about it and I don't really have much thoughts like I don't think I necessarily agree with Catholicism because I just think like religions and stuff with like books, they are just too specific, but it seems very dodgy like how do you know all this information?.. where did you get it from?. And I just think like if something happens, something happens and like, I guess there is like higher being or something that could be, but like I don't know.
**Interviewer: So you are still like question mark basically**
Wonder Woman: yeah
**Interviewer: Okay, interesting, so anything else that you want to tell me about your identity around culture and ethnicity?**
Wonder Woman: With identity, [P] with Catholicism and like religion, I was a bit worried when I was like growing up a bit because I am bisexual, so I was like worried about my mum telling me off about that because of Catholicism, but she is actually really open to it which is really nice.
**Interviewer: And how old were you when you started feeling worried about that?**
Wonder Woman: I think more like secondary school. Like I guess it is always something I thought but it wasn't something …. I guess it is always something I thought but I never really thought I would tell anyone.
**Interviewer: Do you feel more comfortable to share that part of your identity now with people?**
Wonder Woman: yeah
**Interviewer: Next question, what words would you prefer me to use when talking about your identity around autism?**
Wonder Woman: I just say autistic.
**Interviewer: Autistic? Do you know there is a debate around saying autistic or people with autism? Have you heard about that previously?**
Wonder Woman: Yeah, but I also think maybe like low needs autistic would be more specific because I know that like it's a spectrum.
**Interviewer: So, would you say that you are low needs autistic?**

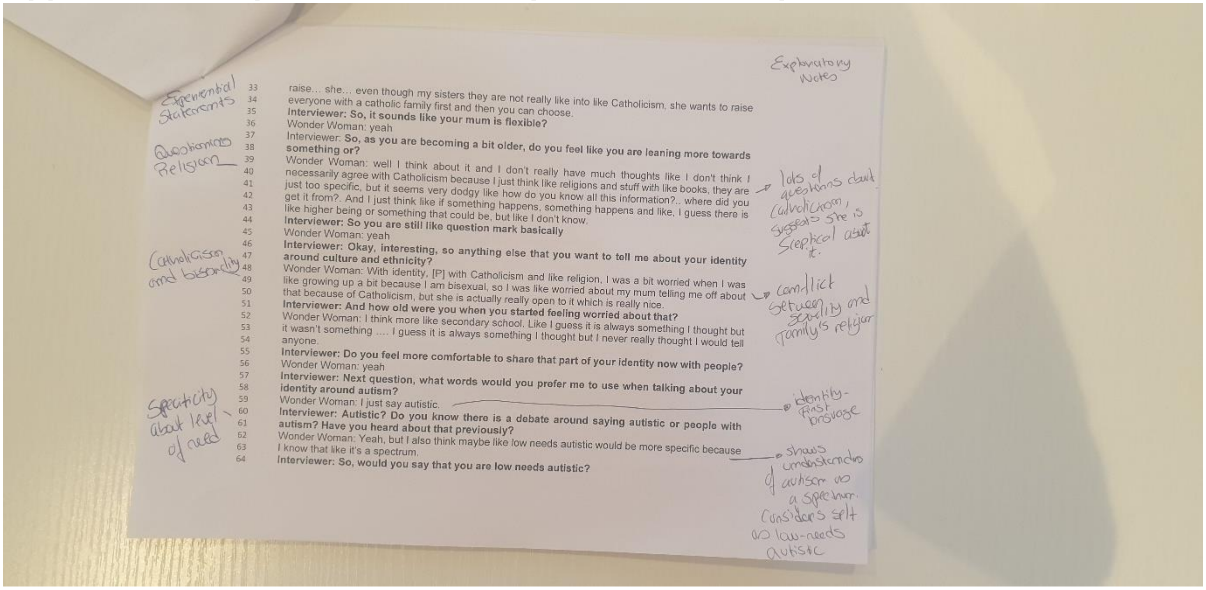
lots of questions about Catholicism, suggests she is sceptical about it.

conflict between sexuality and family's religion

identity-first language

shows understanding of autism as a spectrum. Considers self as low-needs autistic

## Appendix 11: Experiential themes (Wonder Woman)



Experiential Statements

Exploratory Notes

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**Interviewer: So, it sounds like your mum is flexible?**
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**Interviewer: And how old were you when you started feeling worried about that?**
Wonder Woman: I think more like secondary school. Like I guess it is always something I thought but it wasn't something …. I guess it is always something I thought but I never really thought I would tell anyone.
**Interviewer: Do you feel more comfortable to share that part of your identity now with people?**
Wonder Woman: yeah
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Wonder Woman: I just say autistic.
**Interviewer: Autistic? Do you know there is a debate around saying autistic or people with autism? Have you heard about that previously?**
Wonder Woman: Yeah, but I also think maybe like low needs autistic would be more specific because I know that like it's a spectrum.
**Interviewer: So, would you say that you are low needs autistic?**

Questioning Religion

Catholicism and bisexuality

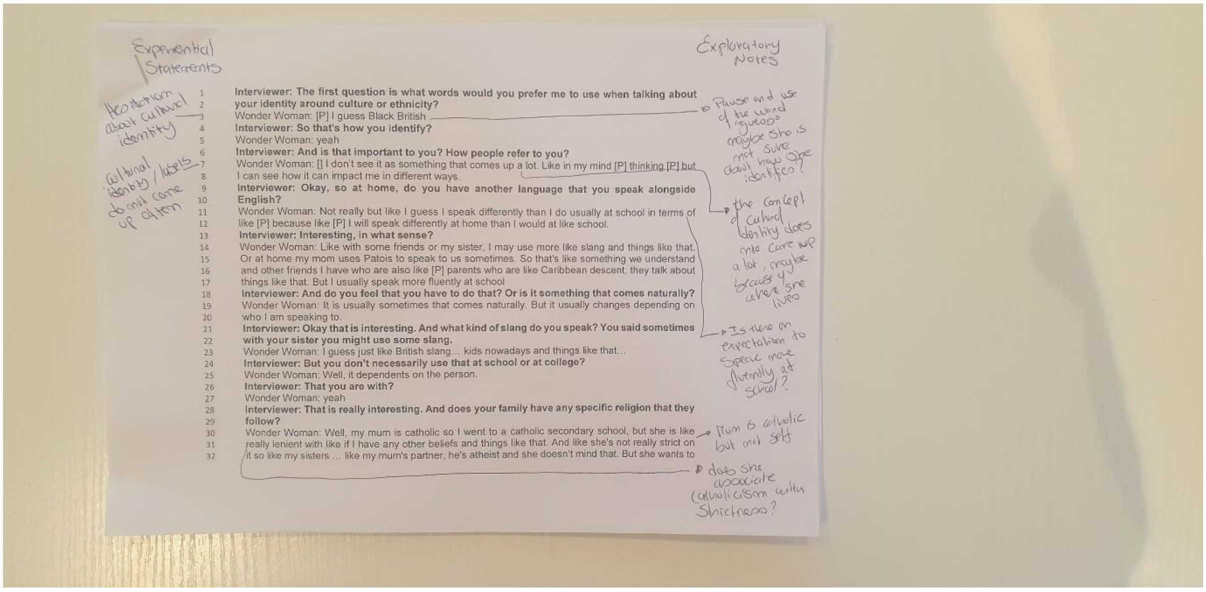
Specificity about level of need

lots of questions about Catholicism, suggests she is sceptical about it.

conflict between sexuality and family's religion

identity-first language

shows understanding of autism as a spectrum. Considers self as low-needs autistic



Experiential Statements

Exploratory Notes

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Wonder Woman: yeah
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Wonder Woman: [] I don't see it as something that comes up a lot. Like in my mind [P] thinking [P] but I can see how it can impact me in different ways.
**Interviewer: Okay, so at home, do you have another language that you speak alongside English?**
Wonder Woman: Not really but like I guess I speak differently than I do usually at school in terms of like [P] because like [P] I will speak differently at home than I would at like school.
**Interviewer: Interesting, in what sense?**
Wonder Woman: Like with some friends or my sister, I may use more like slang and things like that. Or at home my mom uses Patois to speak to us sometimes. So that's like something we understand and other friends I have who are also like [P] parents who are like Caribbean descent, they talk about things like that. But I usually speak more fluently at school
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Wonder Woman: It is usually sometimes that comes naturally. But it usually changes depending on who I am speaking to.
**Interviewer: Okay that is interesting. And what kind of slang do you speak? You said sometimes with your sister you might use some slang.**
Wonder Woman: I guess just like British slang… kids nowadays and things like that…
**Interviewer: But you don't necessarily use that at school or at college?**
Wonder Woman: Well, it dependents on the person.
**Interviewer: That you are with?**
Wonder Woman: yeah
**Interviewer: That is really interesting. And does your family have any specific religion that they follow?**
Wonder Woman: Well, my mum is catholic so I went to a catholic secondary school, but she is like really lenient with like if I have any other beliefs and things like that. And like she's not really strict on it so like my sisters … like my mum's partner, he's atheist and she doesn't mind that. But she wants to

Hesitation about cultural identity

Cultural identity / labels do not come up often

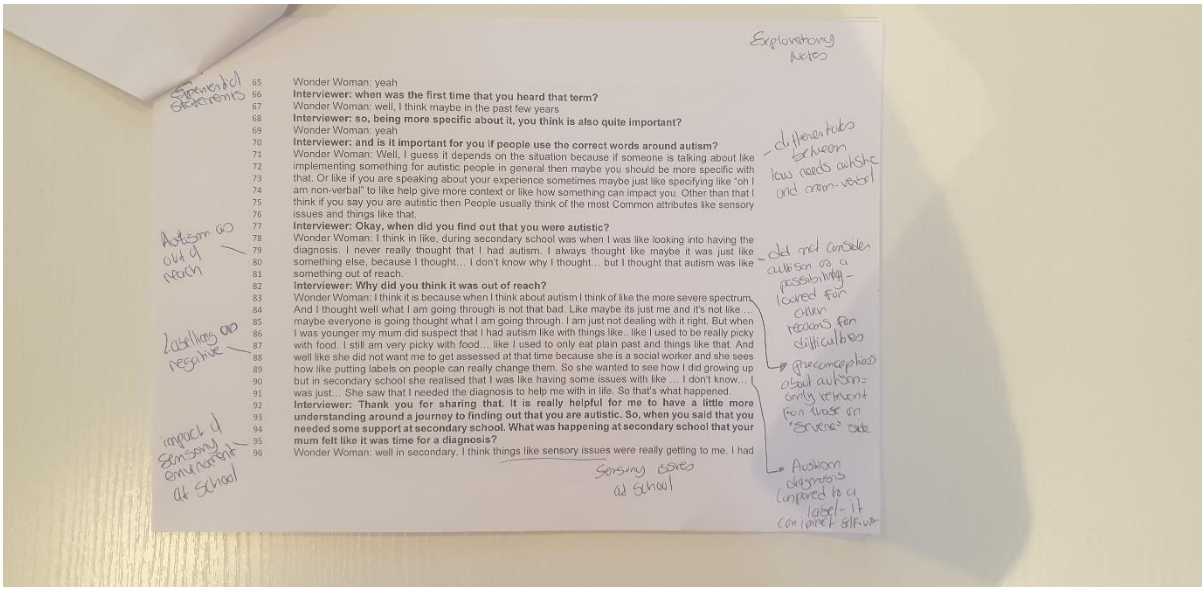
Pause and use of the word 'guess' maybe she is not sure about how she identifies?

the concept of cultural identity does not come up a lot, maybe because of where she lives

Is there an expectation to speak more fluently at school?

Mum is catholic but not self

does she associate Catholicism with strictness?



Experiential Statements

Exploratory Notes

Wonder Woman: yeah
**Interviewer: when was the first time that you heard that term?**
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**Interviewer: so, being more specific about it, you think is also quite important?**
Wonder Woman: yeah
**Interviewer: and is it important for you if people use the correct words around autism?**
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**Interviewer: Why did you think it was out of reach?**
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**Interviewer: Thank you for sharing that. It is really helpful for me to have a little more understanding around a journey to finding out that you are autistic. So, when you said that you needed some support at secondary school. What was happening at secondary school that your mum felt like it was time for a diagnosis?**
Wonder Woman: well in secondary, I think things like sensory issues were really getting to me. I had

Sensory issues at school

Autism as out of reach

Labelling as negative

impact of sensory environment at school

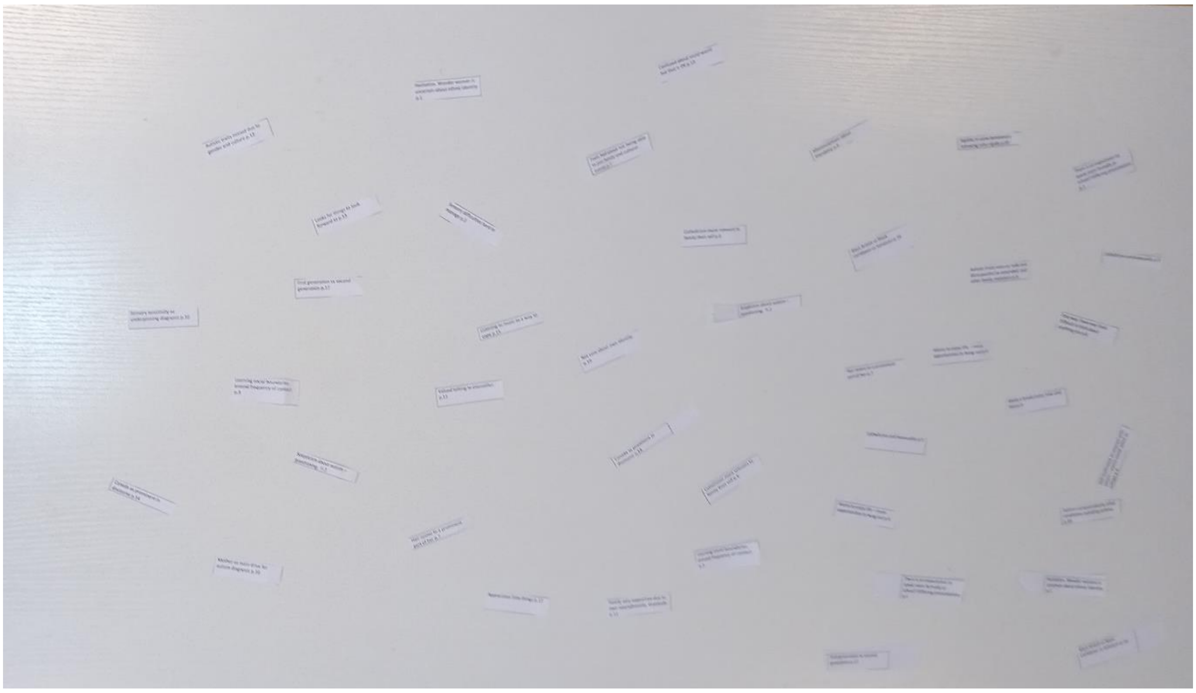
differentiates between low needs autistic and non-verbal

did not consider autism as a possibility - looked for other reasons for difficulties

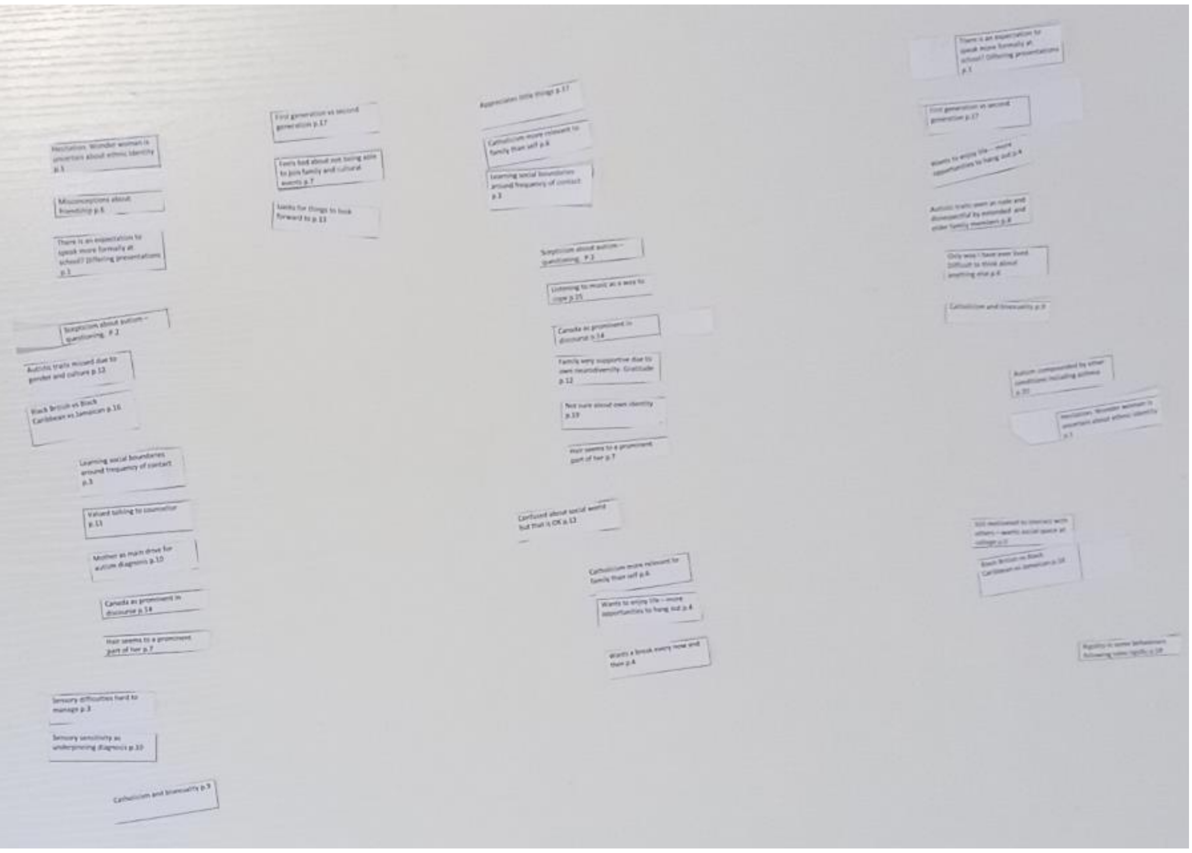
preconceptions about autism = only relevant for those on 'severe' side

Autism diagnosis compared to a label - it can impact self-view

## Appendix 12: Initial scattering of experiential statements in no particular order (Wonder Woman)



## Appendix 13: Clustering of experiential statements (Wonder Woman)



## Appendix 14: Personal Experiential themes (Wonder Woman)

**Table of Personal Experiential Themes (PETs) for Wonder Woman**

### A. THE COMPLEXITY OF CULTURAL IDENTITY

**Uncertain about her culture**

Hesitation about cultural identity p.1
"(pause) I guess Black British"

Cultural identity/do not come up often p.1
*"I don't see it as something that comes up a lot. Like in my mind … thinking"*

Identifies more with Black British culture than Black Caribbean p.10
*"I don't really feel like I am involved in Black Caribbean culture in like the UK"*

**Connections to multiple countries/cultures**

Different cultures - family dispersed in different countries p.9
*"Not all of my family live in the UK. Most of them live in Canada or Jamaica"*

Distinction between family cultural identity and one's cultural identity p.10
*"My family is more Caribbean oriented and even there is things like Canada as well"*

Jamaican culture as central for her family p.10
*"They talk about Jamaica and things like that so that's more like relevant to them than like I guess being British and Caribbean."*

**Navigating cultural events and expectations**

Sensory overwhelming parties/events p.10
*"Sometimes the family parties just go so long and its really stressful and there is music playing"*

Coping at parties/events p.10
*"I just sit down in the corner"*

Guilt about own views about family p.10
*"I felt bad because like this is my family like I shouldn't be seeing them as like a drag"*

Family accents as overwhelming p.10
*"Some of them have like really strong accent, it sounds very shouty and it sounds very loud"*

Autistic traits seen as rude by extended family p.11
*"She'd be like 'oh Wonder Woman, you know it is a bit rude to not look at me'"*

**Religion**

Questioning religion p.2
*"It seems very dodgy like how do you know all this information? where did you get it from?"*

Catholicism and bisexuality p.2
*"I was like worried about my mum telling me off about that because of Catholicism"*

**Afro Hair**

Importance of hair p.9

*"Like my mom when she does my hair she uses… we don't have a bonnet… we have like a stocking"*

### B. FAMILY SUPPORT

Lucky for mother's awareness of autism p.9
*"I am quite lucky that I was born into a family where my mum is very like aware of like autism"*

Gratitude for neurodiverse family members p.9
*"I have some family members who are like autistic or have like special needs and things that. And my mum actually suspects that she has Asperger's."*

Mother key source of support for triggering the diagnosis
*"Secondary school she realised that I was like having some issues" (Wonder Woman*, p.3*)*

### C. EVOLUTION OF VIEW AND EXPERIENCE OF AUTISM

**Before autism diagnosis**
Struggling to cope at school p.4
*"I just couldn't cope"*

Autism as out of reach p.3
*"I thought that autism was like something out of reach"*

Labelling as negative p.3
*"Putting labels on people can really change them"*

**After autism diagnosis**
Recognises the positives of being autistic p.6
*"I feel that I have a lot of appreciation for things"; "Like I can think more critically"*

Awareness of the difficulties related to her autism p.7
*"Sometimes I feel like things confuse me more than they should"; "is quite annoying*"

Autism as an answer p.5
*"I guess it is nice to have like something there just to say, like… this is… like, it's like an answer."*

Autism diagnosis provides access to support p.21
*"So what happened is I was getting some counselling sessions"*

Lack of girls in autistic representation p.13
*"I don't really see much girls when it comes to autistic representation"*

Autism compounds issues relating to other conditions p.8
*"It just all goes with each other and it's a bit annoying"*

**Language around autism**
Specificity about level of need – low need vs high needs autistic p.2
"I also think maybe like low needs autistic would be more specific"

**Autism and other identities**
Recognition of autistic traits impacted by culture and gender p.12
*"When I was younger and I was quiet, it wasn't seen as like oh maybe its autism"*

Multiple identities p.8
*"I guess there is more nuance to me than like just being one thing or the other"*

No comparison p.8
*"it's like the only way I have ever lived, I can't think of anything else".*

### D. SCHOOL AND COLLEGE EXPERIENCES

**Need to "hang out" with others**
Unrealistic expectation of friendships p.14
*"Like I have a best friend… and I thought that's what being a friend was"*

Self (alone) vs others (in big groups) p.14
*"Because I had seen lots of people in like big groups of friends"*

Continuous attempts to seek social interactions/relationships p.14
*"And then like I tried to do things like 'oh like if I like try to like message so and so"*

Impact of continuous attempts p.14
*"Oh this seems very tiresome. Like I was getting tired of it"*

Enjoying own company seen as a life skill p.14
*"I think it's really good because when it comes to like me going to like uni"*

Desire for additional social spaces p.19
*"Like there are places but those place you are not really meant to"*

**Balancing academics**
Academic workload restricts opportunities to have fun p.18
*"Times where I could feel less guilty for like having fun and like just be happy"*

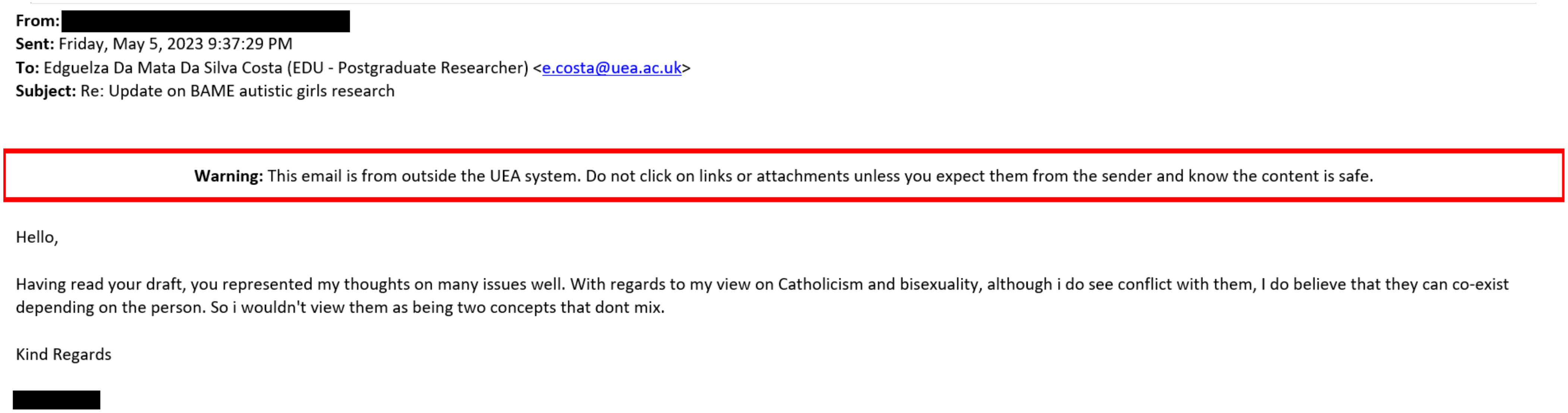
Values opportunities to have a break p.22
*"There has been times when I have been really stressed out and the only thing that has like really helped me if having space or time to think"*

**Relationships with staff**
Counsellor provides opportunities to talk p.21
*"I would just talk with the counsellor and we'd just like play uno and stuff like that and it was really nice and I looked forward to it"*

Pressure to follow rules p.21
*"Or like if I get told off for being late. Like it is something that really stresses me so I feel like I always try to appear like very…. Like up to standard and stuff when it comes to like relationships like teacher and stuff"*

**Sensory environment**
Impact of sensory environment at school p.3
*"I think things like sensory issues were really getting to me"*

# Appendix 15: Member Checking (feedback from Wonder W)



**From:** [redacted]
**Sent:** Friday, May 5, 2023 9:37:29 PM
**To:** Edguelza Da Mata Da Silva Costa (EDU - Postgraduate Researcher) <e.costa@uea.ac.uk>
**Subject:** Re: Update on BAME autistic girls research

**Warning:** This email is from outside the UEA system. Do not click on links or attachments unless you expect them from the sender and know the content is safe.

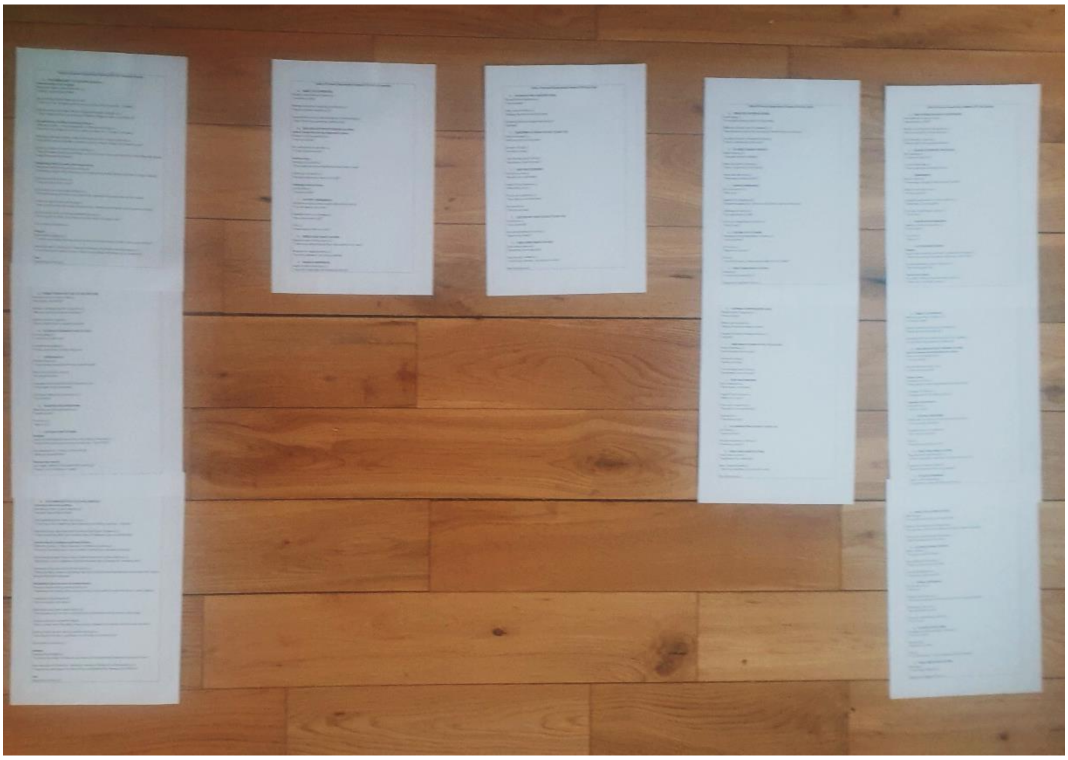
Hello,

Having read your draft, you represented my thoughts on many issues well. With regards to my view on Catholicism and bisexuality, although i do see conflict with them, I do believe that they can co-exist depending on the person. So i wouldn't view them as being two concepts that dont mix.

Kind Regards

[redacted]

## Appendix 16: Working with PETs to develop GETs across cases



## Appendix 17: Table of GETs

### Table of Group Experiential Themes (GETs)

### A. JOURNEY TO DIAGNOSIS

**Diagnosis in a problem context**

Struggling to cope at school
"*Well in secondary, I think things like sensory issues were really getting to me*" *(Wonder Woman, p.4)*

Troubles in primary school
"*And troubles at school" "it was all like very messy" (Storm, p.3)*

Trouble in secondary school
"*I was getting in bare trouble at school" (Shuri, p.2)*

Struggling to cope in secondary school
"*Especially once I got to secondary school, that is when the massive sort of bombshell hit that 'wow I am struggling*." *(Gamora, p.3)*

**Involvement in the process**

Others as main drivers for diagnosis
*"They referred me to him" (Shuri*, p.2*)*

Vague recollection of diagnostic process
*"I think like my mum had this meeting at school" (Cat Woman*, p.2*)*

Taking ownership of researching and initiating diagnosis
*"And then I done loads and loads of research for months and months" (Gamora*, p.3*)*

Mother triggered the diagnosis
*"Secondary school she realised that I was like having some issues" (Wonder Woman*, p.3*)*

Mother in charge of diagnosis
*"My mum was on the brink of having to go and pay for them to go and take me seriously" (Storm* p.5*)*

**Emotional reaction**

Diagnosis enabled self-discovery and understanding
*"It sparked a really good sort of [inaudible] of finding and understanding myself" (Gamora* p.5*)*

Autism as an answer
*"I guess it is nice to have like something there just to say, like… this is… like, it's like an answer." (Wonder Woman,* p.5)

Sense of shock
*"I don't know, I was shocked" (Shuri*, p.3*)*

Progressive understating of autism
*"I think I understood but not like to the same extent that I would understand now" (Cat Woman,* p.2*)*

Limited understanding of autism
*"I didn't fully understand but like I don't think me at that age was meant to, you get me?" (Storm,* p.3*)*

**B. MAKING SENSE OF AUTISTIC IDENTITY**

**Strengths associated with autism**
Positive attributes linked to her autism
*I am able to help someone without being biased or affected by my emotions (Gamora*, p.23*)*

Recognises the positives of being autistic
*"I feel that I have a lot of appreciation for things"; "Like I can think more critically" (Wonder Woman*, p.6*)*

*Being autistic leads to empathy towards others*
*"I feel like it's made more empathetic towards other people with disabilities and stuff" (Cat Woman, p.4)*

Good memory as a result of autism
*"I have very good memory" (Storm*, p.7*)*

**Challenges associated with autism**
Autism is linked to being different
*"Different… I feel like some autistic people think different to like other normal people" (Shuri*, p.5*)*

Being autistic impacts Storm's ability to organise herself
*"My organisation is a flop" (Storm p.5)*

Awareness of the difficulties related to her autism
*"Sometimes I feel like things confuse me more than they should"; "is quite annoying*" (Wonder Woman, p.7)

**Identity first vs person first language**
Simply autistic
*I am just autistic (Cat Woman, p.2)*

Autism as inherent part of self
*I think definitely autistic person fits better with me because like I see it as, it's how I am (Gamora*, p.3*)*

Language is of central importance
*It has taken a long time for me to figure it out so being able to voice that and have other people use those terms for me makes it feel very validating (Gamora*, p.3*)*

Specificity about needs – low need vs high needs autistic
*"I also think maybe like low needs autistic would be more specific" (Wonder Woman*, p.2*)*

Impartiality about terminology
*I don't mind, autistic, person with autism (Storm*, p.4*)*

Indifference: others can choose
*I don't know it is up to you. I don't mind (Shuri, p.3)*

(Superficial) reason behind preference
*I don't know it just sounds better (Shuri, p.3)*

**Accessing online resources**
Enjoys researching about masking communities
*"I feel like my community like masks a lot well based on what I researched because I like researching" (Storm*, p.9*)*

Learning about autism from people online
*"I just heard of people saying online and stuff" (Cat Woman, p.6)*

Studies shaped her knowledge of gender differences in autism p.
*"I think there are differences between boys and girls because of studies" (Gamora, p.14)*

***C. MAKING SENSE OF CULTURAL IDENTITY***
**Cultural identity and labels as contextual and complex**
Mixedness commonly adopted as key label
*"I think I would describe myself as mixed normally" (Cat Woman*, p.1*)*

Cultural label/identity can be confusing at times
*"It's like a Nigerian surname but like my dad is not Nigerian so its kind confusing" (Cat Woman*, p.1*)*

Different labels for different people
*"If they want me to give a definitive answer, I say I am British" (Storm, p.5)*

Consideration of others when choosing terminology
*"I don't mind, anything is cool. I just use People of Colour because I know people not liking the term BAME" (Storm, p.6)*

Mixed as primary (but not sole) label
*"I don't think I am really against anything but mixed just makes the most sense to me" (Cat Woman, p.2)*

Words and labels as subjective
*"Words only have meanings because of the intention you have behind them" (Gamora, p.9)*

Hesitation about cultural identity
*"[pause] I guess Black-British" (Wonder Woman, p.1)*

Cultural identity/do not come up often
*"I don't see it as something that comes up a lot. Like in my mind … thinking" (Wonder Woman, p.1)*

Identifies more with Black British culture than Black Caribbean
*"I don't really feel like I am involved in Black Caribbean culture in like the UK" (Wonder Woman, p.10)*

Unfamiliarity with discussions around culture/ethnicity
*"How do you mean?" (Shuri, p.2)*

Simply British
*"I am just British" (Shuri, p.2)*

**Navigating cultural and religious dynamics and pressures**
Judgement from others at the mosque
*"And the aunties all around me they were just staring at me like giving me the side eye, and I was like WHAT DO I DO? I CAN'T COPE!" (Gamora, p.18)*

Coping with church services
*"It gets a little bit too much" (Shuri, p.5)*

Length of church services
*"It's just long, services are long" (Shuri, p.5)*

Christianity enables bonding with family
*"Sometimes like me and my little sister and my mum before we like go to bed sometimes, we like pray and stuff and like have our little reunions" (Shuri, p.6)*

Questioning religion
*"It seems very dodgy like how do you know all this information? where did you get it from?" (Wonder Woman, p.2)*

Catholicism and bisexuality
*"I was like worried about my mum telling me off about that because of Catholicism" (Wonder Woman, p.2)*

*Expectations of tradition*
*"There is a lot of respect and understanding and sort of you know uh expectation for tradition and doing things that fit in like the cultural standard I guess." (Gamora, p.19)*

*Family accents as overwhelming*
*"Some of them have like really strong accent, it sounds very shouty and it sounds very loud" (Wonder Woman, p.10)*

*Autistic traits seen as rude by extended family*
*"She'd be like 'oh Wonder Woman, you know it is a bit rude to not look at me'" (Wonder Woman, p.11)*

**Understanding of intersectional identities**
Intersectional identities as complicated
*"humm…That's actually a very difficult question" (Gamora, p.20)*

Intersectional identities as less important
*"Ah that's hard... I never really think of it" (Storm, p.17)*

Intersectional identities mean Shuri is different to others
*I don't know… it's like different. I think it's like different to other people (Shuri, p.10)*

Recognition of autistic traits impacted by culture and gender
*"When I was younger and I was quiet, it wasn't seen as like oh maybe its autism" (Wonder Woman,* p.12*)*

Focus on some intersectional identities (and not others)
*"Hum…. I think it just like means that… I don't know" (Cat Woman, p.8)*

Multiple identities
*“I guess there is more nuance to me than like just being one thing or the other” (Wonder Woman,* p.8*)*

No comparison
*“it’s like the only way I have ever lived, I can’t think of anything else” (Wonder Woman,* p.8*)*

### *D. SCHOOL/COLLEGE LIFE*

**Social relationships and interactions**
Mirroring as unconscious
*“I end up like mirroring behaviours” (Storm, p.18)*

Mirroring as only solution
*I will either consciously or unconsciously mirror the behaviours or personality of the person in front of me (Gamora, p.21)*

Fear of talking to unfamiliar people
*“And like when people that I don’t talk to talk to me that kind of scares me a lot” (Cat Woman, p.9)*

Unrealistic expectation of friendships
*“Like I have a best friend… and I thought that’s what being a friend was” (Wonder Woman, p.14)*

**Sensory overwhelm**
Good day at school depends on noise level
*“And they are not loud” (Cat Woman, p.10)*

Quietness is of great importance
*“It is quiet in the SEN room” (Gamora, p.22)*

Sensory overwhelming classrooms
*“Everybody just keeps shouting and calling my name and then everyone is just pushing” (Shuri, p.11)*

*Impact of sensory environment*
*“I think things like sensory issues were really getting to me” (Wonder Woman, p.3)*

**Adjustments**
Opportunity for breaks from classroom
*“Time out cards and stuff” (Cat Woman, p.12)*

Welcomes social skills support
*“Like socialising, like no not like any subjects in general like more like sociali- being social” (Storm, p.19)*

Academic workload restricts opportunities to have fun
*“Times where I could feel less guilty for like having fun and like just be happy” (Wonder Woman,* p.18*)*

Values opportunities to have a break
*“There has been times when I have been really stressed out and the only thing that has like really helped me if having space or time to think” (Wonder Woman,* p.22*)*

Support items as key for success
*"My items help me thrive" (Gamora, p.20)*

### *E. RELATIONSHIPS*

***Immediate family as supportive***

Mother supporting to make sense of autism
*"She [Cat Woman's mother] just started talking about how I was just a little more special" (Cat Woman, p.2)*

Mother and aunt as most accepting
*"They [Cat Woman's mother and aunt] are pretty accepting of it" (Cat Woman, p.3)*

Mother enables her not to mask
*"I don't mask around my mum anymore" (Gamora, p.11)*

*Mother acts as an advocate*
*"Having people like my mum, she is probably my biggest advocate" (Gamora, p.11)*

Positive view of autism within family
*"In my family being autistic is like a good thing by the way" (Storm, p.15)*

Sister supporting to make sense of autism
*"She [Shuri's sister] just told me that some people don't know that they are autistic" (Shuri, p.8)*

Lucky for mother's awareness of autism
*"I am quite lucky that I was born into a family where my mum is very like aware of like autism" (Wonder Woman,* p.9*)*

Gratitude for neurodiverse family members
*"I have some family members who are like autistic or have like special needs and things that. And my mum actually suspects that she has Asperger's." (Wonder Woman,* p.9*)*

***Role of school/college staff***

Teacher's presence is paramount
*"When Ms X [Shuri's teacher] is not in it's like hard for me sometime" (Shuri, p.8)*

TAs as key source of support
"They understand me, and they help me and that's nice" (Shuri, p.8)

Asking question is key to gaining a better understanding of her needs
*"You are literally asking a question and I can explain it and you can go away understanding it" (Gamora, p.18)*

Desire to build relationships with staff
*"Like make an effort to go and like get to know me" (Storm, p.16)*

Value of informal conversations and relationships with staff
*"Like just ask how their day has been… just ask if they are ready to talk like now" (Shuri, p.9)*

Teacher support is welcomed
*"I like it when the teacher actually comes up and asks me" (Cat Woman, p.12)*

Fear of how adult support may be perceived by peers
*"I am too scared" (Cat Woman, p.12)*

## Appendix 18: Evidence of Ethical Approval

**University of East Anglia**

**Study title:** Working Title: The lived experiences of Black, Asian and Minority Ethnic (BAME) autistic girls attending mainstream secondary school: an interpretive phenomenological analysis (IPA) study

**Application ID:** ETH2122-1353 Dear

Edguelza,

Your application was considered on 5th July 2022 by the EDU S-REC (School of Education and Lifelong Learning Research Ethics Subcommittee).

The decision is: **approved**.

You are therefore able to start your project subject to any other necessary approvals being given.

This approval will expire on **1st August 2023**.

Please note that your project is granted ethics approval only for the length of time identified above. Any extension to a project must obtain ethics approval by the EDU S-REC (School of Education and Lifelong Learning Research Ethics Subcommittee) before continuing.

It is a requirement of this ethics approval that you should report any adverse events which occur during your project to the EDU S-REC (School of Education and Lifelong Learning Research Ethics Subcommittee) as soon as possible. An adverse event is one which was not anticipated in the research design, and which could potentially cause risk or harm to the participants or the researcher, or which reveals potential risks in the treatment under evaluation. For research involving animals, it may be the unintended death of an animal after trapping or carrying out a procedure.

Any amendments to your submitted project in terms of design, sample, data collection, focus etc. should be notified to the EDU S-REC (School of Education and Lifelong Learning Research Ethics Subcommittee) in advance to ensure ethical compliance. If the amendments are substantial a new application may be required.

Approval by the EDU S-REC (School of Education and Lifelong Learning Research Ethics Subcommittee) should not be taken as evidence that your study is compliant with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. If you need guidance on how to make your study UK GDPR compliant, please contact the UEA Data Protection Officer (dataprotection@uea.ac.uk).

I would like to wish you every success with your project.

On behalf of the EDU S-REC (School of Education and Lifelong Learning Research Ethics Subcommittee)

Yours sincerely,

Lee Beaumont

**Ethics ETH2122-1353: Miss Edguelza Da Mata Da Silva Costa**

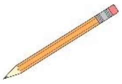
## Appendix 19: Participant information sheet and consent form

### Participant information sheet

You are being invited to participate in a research study. Before you agree, it is important that you understand what taking part would involve. This information sheet will try and answer any questions that you might have about the study so please take time to read it carefully. If you still have questions after you read it, you can email me (my email address is at the end of this sheet). This sheet is for you to keep.

**Title of study: "The educational experiences of Black, Asian, and Minority Ethnic (BAME)* autistic girls".**

**I believe that the way people describe themselves is important. I want to make sure that you feel comfortable with the words used in this study so, if you choose to take part, I will ask you about how you prefer to describe yourself. The words we use will be completely in your control.*

| | |
|---|---|
| **Who is doing this study?**<br>Hello. My name is Edguelza Costa. I am a doctoral student at the University of East Anglia. This is a photo of me. |  |
| **What is this study about?**<br>I am doing a study to find out more about autistic girls from Black, Asian, and Minority Ethnic (BAME) backgrounds. | ? |
| **Why am I asking you to take part in this study?**<br>You have been invited to participate in this study as someone who fits the kind of young person, I am looking for to help me explore the research topic. I am looking for BAME autistic girls aged between 12 to 18 who are currently attending school or college in England. |  |
| **Do I have to take part?**<br>You do not have to take part in this study. If you decide to take part, you can stop at any time. You do not have to explain why. It is your choice. |  |
| **What will happen if I choose to take part in this study?**<br>If you decide that you want to be in my study, I will:<br>✓ Organise a time to speak to you. You can choose to meet online or in person. If you choose to meet online, you can decide whether you want to show your face during the meeting. If you chose to meet in person, we will meet at your school/college.<br>✓ During this meeting, I will ask you some questions. You will also do some activities and a short drawing task. You do not have to answer all questions and can ask me to stop at any time. I want to know what you think – there are no right or wrong answers.<br>✓ I will record our meeting using an audio recorder so that I can remember exactly what you have said. Only I will hear the recording and it will be deleted at the end of the project.<br>✓ The meeting will last for about 1 hour. The exact time will depend on how much you want to say. | <br><br><br> |

**What happens after the meeting?**
When I have finished meeting you, I will also ask you to tell me what you think about being involved in the study. It is your choice to tell me what you think; you do not have to tell me if you do not want to.

I will also contact you after this meeting so that I can make sure that I have fully understood your experience in the way you want me to. I will tell you how I have understood what you said and ask you to correct me if you think I have misunderstood you. It is your choice to tell me what you think; you do not have to tell me if you do not want to.

**What will happen to my information?**
Everything you tell me during our meeting will be 'confidential'. This means that I will not tell anyone what we talk about. But if you say something which makes me worry about your safety or the safety of others, I will have to share this information.
All of the information that I have about you from the study will be stored in a password protected computer that only I have access to.

**Will people know that I took part in this study?**
I will use some of things that you tell me in my research. But I will not use your real name or the name of your school/college so nobody will know that it was you in my research.

**Who has checked this study?**
Before any research goes ahead it has to be checked by a Research Ethics Committee. This is a group of people who make sure that the research is OK to do. This study has been looked at by the University of East Anglia Research Ethics Committee.

**Are there any good things about taking part in this study?**
You might enjoy taking part in this study as it can be a chance for you to share what you think. Anything you tell me can also help support other autistic girls like you.

**Are there any bad things about taking part in this study?**
Because I will be asking you about personal things, there is a small chance that you may experience some unhappy thoughts. However, it is up to you to decide what you want to tell me. You will also have the option to access additional support from appropriate services if you feel that you need to.

**What if I want to withdraw (this means stop taking part)?**
You are free to withdraw from this study at any time without explaining or anything happening. If you do not want your answers to be used in my project, then you (or your parent) can withdraw from the study up to 3 weeks after taking part. I reserve the right to keep and use your data if analysis has begun.

**Will you tell me what you learned in the study?**
Yes, if you want me to, I will send you a one-page summary when I finish the study.

**What if I am not happy with the study or the people doing the study?**

If you are not happy with how I am doing the study or how I treat you, then you or your parent/carer can:

- Write an email to me. My email address is e.costa@uea.ac.uk
- Write an email to my supervisor. My supervisor is a teacher at my university and is helping me with my project. Her name is Imogen Gorman. Her email address is: i.gorman@uea.ac.uk
- Write an email to the Head of School. The Head of School is Professor Yann Lebeau. His email address is y.lebeau@uea.ac.uk

**What happens now?**

Talk to your parent/carer about whether you want to take part. If you do not want to take part in this study, you do not need to do anything. If you would like to take part in this study, please fill out the form on the next page and give it to your parent/carer to send back to me. If you have any questions you can email me. My email address is e.costa@uea.ac.uk.

## Participant consent form

**Title of study: "The educational experiences of Black, Asian, and Minority Ethnic (BAME) autistic girls".**

| Please read each statement carefully and tick 'yes' or 'no'. Once signed and dated, please **send** this form to the researcher. | YES | NO |
|---|---|---|
|  I can confirm I have read the information sheet, or had it read and explained to me. | | |
| I understand that this interview will be audio recorded, and I agree to this. | | |
| I understand that it is okay to stop at any time without giving a reason. | | |
| I understand that I can ask the questions about the research at any time. | | |
| I understand that no one will know who I am through this research as my name will not appear in any document or report. | | |
|  I understand that if I tell the researcher that I or someone else is in danger, she will have to let someone else know. | | |
|  I understand that my information will be kept and stored safely. | | |
|  I would like to take part in this research. | | |
|  I would like the researcher to send me a one-page summary when she finishes the study. | | |

**I would like to meet with the researcher:** ☐ **Online** **Face-to-face at school/college**

## Appendix 20: Parent/Carer information sheet and consent form

Edguelza Costa
Trainee Educational Psychologist

**Faculty of Social Sciences**
School of Education and Lifelong learning

University of East Anglia
Norwich Research Park
Norwich NR4 7TJ
United Kingdom

***Title of Study: "The educational experiences of Black, Asian, and Minority Ethnic (BAME)* autistic girls."***

### PARENTAL/GUARDIAN INFORMATION STATEMENT

**(1) What is this study about?**

Your child is invited to take part in a research study about autistic girls from Black, Asian, and Minority Ethnic (BAME) backgrounds. Your child has been invited to participate in this study because she fits the kind of young person, I am looking for to help me explore the research topic. I am looking for BAME autistic girls aged between 12 to 18 who are currently attending school or college in England.

****I believe that the way people describe themselves is important. I want to make sure that your child feels comfortable with the words used in this study so, if she chooses to take part, I will ask her about how she prefers to describe herself. The words we use will be completely in her control.***

This Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to let your child take part in the study. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary. By giving consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree for your child to take part in the research study as outlined below.
- ✓ Agree to the use of your child's personal information as described.
- ✓ You have received a copy of this Participant Information Statement to keep.

**(2) Who is running the study?**

The study is being carried out by the following researcher(s): Edguelza Costa, Trainee Educational Psychology Student, School of Education and Lifelong Learning, University of East Anglia.

This study will take place under the supervision of Imogen Gorman, Research Supervisor, Course Director, School of Education and Lifelong Learning, University of East Anglia.

**(3) What will the study involve for my child?**

Your child's participation in this study will involve them taking part in a one-to-one interview with the researcher (Edguelza Costa). This interview can be conducted online or face-to-face. It is up to you and your child to decide what she prefers. If you/your child opts for a face-to-face interview, this will take place at your child’s school/college. During the interview, I will ask your child about her experiences as a BAME autistic girl including her experiences of school/college. Your child may also complete a couple of activities including a short drawing task. With your permission I would like to use an audio recording device to record the interview.

**(1) How much of my child’s time will the study take?**
It is anticipated that your child will take part in one interview lasting between 30-60 minutes. Your child will also be given the opportunity to review her transcripts.

**(2) Does my child have to be in the study? Can my child withdraw from the study once they have started?**
Being in this study is completely voluntary and your child does not have to take part. Your decision will not affect your/their relationship with the researchers or anyone else at the University of East Anglia, The Association of Educational Psychologists, now or in the future. If you decide to let your child take part in the study and then change your mind later (or she no longer wishes to take part), she is free to withdraw from the study at any time up until the point that we have analysed and written-up the results.

**(3) What are the consequences if my child withdraws from the study?**
Your child is free to stop the research activity at any time. Unless you and/or your child say that you want us to keep them, any materials (e.g. images, recordings, text) will be erased and the information your child has provided will not be included in the study results. Your child may also refuse to take part in any of the activities that they wish. If you decide at a later time to withdraw your child from the study their information will be removed from our records and will not be included in any results, up to the point that I have analysed and published the results, and this would include the submission of the thesis for assessment purposes.

**(4) Are there any risks or costs associated with my child being in the study?**
Some young people may find it difficult to talk about their experiences if they have had a negative experience. I will be mindful of anything that might cause concern and no child will be required to speak if they don’t feel like it. If your child gets upset, I will stop the interview immediately. I will inform you of any difficulty or upset encountered during the interview. I will then provide details of organisations which can provide support for you and your child. In line with government legislation on safeguarding children if your child makes a disclosure that highlights a concern, I will report it to the local authority safeguarding team who will take charge. As a result, I may not be in a position to inform you as to the details of the safeguarding referral.

**(5) Are there any benefits associated with my child being in the study?**
I hope that your child will feel they have been listened to when talking about her experiences as a BAME autistic girl. I hope that what your child says about her experiences will add to wider discussions around autism as well as highlight the importance of including the voice of BAME autistic girls in conversations.

**(6) What will happen to information provided by my child and data collected during the study?**
Your child’s personal data and information will only be used as outlined in this Participant Information Statement, unless you consent otherwise. Data management will follow the Data Protection Act 2018 (DPA 2018) and UK General Data Protection Regulation (UK GDPR), and the University of East Anglia's Research Data Management Policy.

Your child's information will be stored securely and their identity will be kept strictly confidential, except as required by law. Study findings may be published. Although every effort will be made to protect your child's identity, there is a risk that they might be identifiable due to the nature of the study and/or results. In this instance, data will be stored for a period of 10 years and then destroyed.

### (1) What if we would like further information about the study?

When you have read this information, *Edguelza Costa (e.costa@uea.ac.uk)* will be available to discuss it with you further and answer any questions you may have about the study.

### (2) Will my child be told the results of the study?

You and your child have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by ticking the relevant box on the accompanying consent from. This feedback will be in the form of a one-page written summary. You will receive this feedback after August 2023.

### (3) What if I have a complaint or any concerns about the study?

If there is a problem, please let me know. You can contact me via the University at the following address:
*Edguelza Costa*
School of Education and Lifelong Learning
University of East Anglia
NORWICH NR4 7TJ
*e.costa@uea.ac.uk*

If you would like to speak to someone else, you can contact my supervisor:
*Dr Imogen Gorman via email* i.gorman@uea.ac.uk

If you or your child are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the Head of the School of Education and Lifelong Learning Professor Yann Lebeau via email y.lebeau@uea.ac.uk

### (4) How do we know that this study has been approved to take place?

To protect your safety, rights, wellbeing and dignity, all research in the University of East Anglia is reviewed by a Research Ethics Body. This research was approved by the School of Education and Lifelong Learning Research Ethics Committee.

### (5) What is the general data protection information my child needs to be informed about?

According to data protection legislation, we are required to inform you that the legal basis for processing your data as listed in Article 6(1) of the UK GDPR is because this allows us to process personal data when it is necessary to perform our public tasks as a University.

In addition to the specific information provided above about why your child's personal data is required and how it will be used, there is also some general information which needs to be provided for you:

- The data controller is the University of East Anglia.

## PARENTAL/GUARDIAN CONSENT FORM (First Copy to Researcher)

I, ............................................................[PRINT PARENT'S/GUARDIAN'S NAME], consent to my child ……………………………………………………………… [PRINT CHILD'S NAME] participating in this research study.

In giving my consent I state that:

- I understand the purpose of the study, what my child will be asked to do, and any risks/benefits involved.
- I have read the Parental/Guardian Information Sheet and have been able to discuss my child's involvement in the study with the researcher if I wished to do so.
- The researcher has answered any questions that I had about the study and I am happy with the answers.
- I understand that being in this study is completely voluntary and my child does not have to take part. My decision whether to let them take part in the study will not affect our relationship with the researcher or anyone else at the University of East Anglia now or in the future.
- I understand that my child can withdraw from the study at any time.
- I understand that my child may stop the interview at any time if they do not wish to continue, and that unless I indicate otherwise any recordings will then be erased and the information provided will not be included in the study results. I also understand that my child may refuse to answer any questions they don't wish to answer.
- I understand that my child may stop the research activity at any time if they do not wish to continue, and that unless I indicate otherwise any materials (e.g. images, recordings, text) will then be erased and the information provided will not be included in the study results. I also understand that my child may refuse to take part in any of the activities that they wish.
- I understand that personal information about my child that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about my child will only be told to others with my permission, except as required by law.
- I understand that the results of this study will be used for a thesis assessment and may be published but that the thesis and any publications will not contain my child's name or any identifiable information about my child.

I consent to:

| | | | | |
|---|---|---|---|---|
| Audio-recording of my child | YES | ○ | NO | ○ |
| My child reviewing transcripts | YES | ○ | NO | ○ |

I would you like to receive feedback about the overall results of this study? YES ○ NO ○

If you answered **YES**, please indicate your preferred form of feedback and address:

○ Postal: ______________________________________________

______________________________________________

○ Email: ______________________________________________

……………………………………………………………………………
**Signature**

………………………… ……………………………………………
**PRINT name**

……………………………………………………………………………
**Date**

## Appendix 21: Participant Debrief Form

| | |
|---|---|
|  | Thank you for taking part in this study.<br>In this letter I will explain to you what will happen to the information that you have shared with me. |
|  | Your recorded interview will be written up as a transcript and kept by me until I have finished my research project. Your data will be destroyed after the thesis is passed and any potential publication of the thesis (usually within ten years). |
|  | I will not use your name or the name of your school in my thesis, I will use a made-up name instead.<br>If you me want to, I will share the findings with you and your parents. But remember your actual name will not be included so only the researcher will know what you said. |
|  | The information you have shared with me will be kept securely. |
|  | You are free to withdraw from this study at any time without explaining or anything happening. If you do not want your answers to be used in my project, then you (or your parent) can withdraw from the study up to 3 weeks after taking part. I reserve the right to keep and use your data if analysis has begun. |
|  | If you have any questions, then you can email me. My email address is e.costa@uea.ac.uk.<br>If you are not happy with how I did the study or how I treated you, then you or your parent/carer can write an email to my supervisor (i.gorman@uea.ac.uk). |
|  | Here is a list of websites that you may find useful if you have any questions about autism.<br>• Autistic Girls Network<br>• Autism Voice<br>• National Autistic Society |

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