A participatory research approach to understanding the experiences of Black, Asian and Minority Ethnic (BAME) autistic young people

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ABSTRACT

Autism is no longer considered a rare condition and is thought to affect one in 160 children worldwide (World Health Organisation, 2019), irrespective of culture and ethnic or racial groups (Tincani et al., 2009). While the growth of autism research has been exponential, the majority of existing research exploring the experiences of autistic young people is based on data from largely White ethnic backgrounds (Marks et al., 2000). There is a growing recognition that ‘race’ is more salient for BAME individuals therefore there is a need to study autism in BAME communities (Dovidio et al., 2009). The purpose of this study was to explore the views of BAME autistic young people using a participatory approach. The study aimed to (1) empower a BAME autistic young person as a co-researcher, and (2) explore the lived experiences of four BAME autistic young people.

Using Aldridge’s (2017) participation model, this research was planned and delivered alongside a co-researcher. Collaboratively the researcher and co-researcher identified a research topic that was of importance to the co-researcher’s lived experience. Following on from this, research questions and a schedule for a semi-structured interview were developed in collaboration. Interviews were then carried out with four BAME autistic young people with the aim of eliciting their experiences of being autistic and BAME.

The researcher and co-researcher analysed the data using Interpretative Phenomenological Analysis. This produced themes at an individual level as well as across-cases. Four superordinate themes emerged at group level based on participants’ experiences. Participants highlighted how *The BAME communities’ constructions of autism* often resulted in negative perceptions of their diagnosis due to lack of understanding and knowledge of autism. Participants also highlighted *Self and Autism* and the impact of their diagnosis on their self-concept. *Relationships with peers* emerged as a key area within the research as friends were found to be both a barrier and an asset to the participants’ sense of belonging. The final theme, *The importance of positive relationships at the different levels* highlighted friends, family and LSAs as support systems that have positively contributed to the experiences of BAME autistic young people. While there are similarities between the experiences of

BAME autistic young people and findings from the literature review, the current study highlights that autistic young people from BAME communities have experiences that are unique to them as result of their cultural and racial identity.

The research findings have implication for educational psychologists and school staff supporting BAME autistic young people including providing support that goes beyond autism and that encapsulates the cultural and racial identities of BAME autistic young people. The researcher and co-researcher hope that this study will contribute towards social justice by shifting the nexus of power as well as enabling participation and giving a voice to a marginalised group who have largely been neglected by autism research. Additionally, by describing and documenting how autistic young people can be involved in research successfully, the researcher hopes that it will contribute to increasing the participation of autistic young people in research, bridging the gap between theory and practice.

Key words: Participatory research; young people; autism; lived experiences; Black, Asian, Minority Ethnic.

DECLARATION

University of East London

School of Psychology

Doctorate in Educational and Child Psychology

This work has not previously been accepted for any degree and it is not being concurrently submitted for any degree.

This research is being submitted in partial fulfilment of the requirements of the Doctorate in Educational and Child Psychology.

This thesis is the result of my own work and investigation, except where otherwise stated. Other sources are acknowledged by explicit references in the text. A full list is appended.

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April 2021

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Finally, I would like to dedicate this thesis to my daughter, I cannot wait to meet you.

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TABLE OF ABBREVIATIONS

Abbreviation	Term
AS	Asperger Syndrome
ASC	Autistic Spectrum Condition
ASD	Autistic Spectrum Disorder
BAME	Black, Asian and Ethnic Minority
BLM	Black Lives Matter
BPS	British Psychological Society
DSM	Diagnostic and Statistical Manual of Mental
EP	Educational Psychologist
EPS	Educational Psychology Service
GDPR	General Data Protection Regulation
HCPC	Health and Care Professions Council
HFA	High Functioning Autism
IPA	Interpretative Phenomenological Analysis
LA	Local Authority
MSFG	Multi-Systemic Family Groups
NAS	National Autistic Society
PM	Participation Model
PR	Participatory Research
SSIs	Semi Structured Interviews
SENCo	Special Educational Needs Co-ordinator
TEP	Trainee Educational Psychologist
UEL	University of East London
UK	United Kingdom
WoE	Weight of Evidence
YP	Young People

Chapter 1: Introduction

1.1 Overview

This chapter introduces the key concepts relating to the lived experiences of Black, Asian, and Minority Ethnic (BAME) autistic young people. It does this firstly by providing definitions of key terminologies used in the research as well as contextual information relevant to the study. This includes explaining ethnic disproportionality at a national and local context in relation to autism diagnosis. Additionally, this chapter will present the concepts of social justice, race and racism and the psychological impact of racism on young people from BAME backgrounds. Finally, the participatory research approach will be introduced and explained in relation to how it was utilised within the study, before concluding with the unique contribution of the research.

1.2 Terminology used in the study

There are number of terms used in this study which warrant clarification, in particular autism and BAME.

1.2.1 Autism Spectrum Disorder

Autism spectrum disorder (ASD or autism) is a neurodevelopmental condition which “affects how a person communicates with, and relates to, other people” (Evans, 2011, p. 6). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM 5), ASD is characterised by a triad of impairment: difficulties with social communication, interaction and restrictive, repetitive behaviour and/or interest (DSM 5, 2013). The prevalence of ASD is thought to affect one in 160 children worldwide (World Health Organisation, 2019), irrespective of culture and ethnic or racial groups (Tincani et al., 2009).

Changes made to the DSM 5 autism diagnosis now means that there is only a single diagnosis of ASD and previous subcategories such as Asperger’s Syndrome (AS) are no longer a distinct diagnosis but rather fall under the term ASD. While ASD is the only name referred to within the DSM 5, it is worth highlighting that many different names exist such as high functioning autism (HFA), classic autism, Pathological Demand Avoidance (PDA) and often these names are preferred (as opposed to ASD) by individuals from the autism community (National Autistic Society [NAS], 2019). It is also important to acknowledge that there are differences in approach and preference in how an individual describes their diagnosis and the ordering of the word autism, for example, autistic person versus a person with autism. A study by Kenny et al., (2015) surveyed 3470 participants in the UK about their preferred ways of describing their autism. They found that autistic individuals, their families and friends preferred the term 'autistic' whereas this was considerably less favoured by professionals. On the other hand, the term 'person with autism' was favoured by more than half of professionals whereas autistic individuals and their families preferred this term less. These findings were shared with the co-researcher of the study and a discussion was had regarding how participants should be described and addressed. Based on the study by Kenny et al., (2015) and the co-researcher's preference, this study will use the term 'autistic' when referring to participants, for example, 'autistic young people'.

1.2.2 Black, Asian, and Minority Ethnic

For the purpose of this study, the term BAME will be used to describe individuals from "Asian/Asian British, Black/African/Caribbean/Black British, Mixed/Multiple Ethnic Groups and Other Ethnic Groups" (Office for National Statistics [ONS], 2011). This term has been selected to provide consistency in line with UK research and publications such as the NAS 'Diverse Perspectives: The challenges for families affected by autism from BAME communities' (NAS, 2013). While this study uses the term BAME, both the researcher and co-researcher recognise that the way individuals describe and label themselves is important and terms such as BAME can at times be problematic (Inc Arts UK, 2020). For example, a key criticism of the term is that often it groups individuals from non-white descents into a meaningless collective (Inc Arts UK, 2020). The researcher and co-researcher (who both identify as belonging to a BAME group) acknowledge these criticisms and hope that using this term endorsed by research and policy that individuals from diverse groups do not feel excluded or discriminated against.

1.3 Context

1.3.1 National Context

The United Kingdom (UK) is considered by many to be a diverse society that comprises individuals from varying ethnic backgrounds, religions, cultures and languages. However, according to the ONS (2011), individuals from BAME backgrounds only made up 14 per cent of the population whilst the remaining 86 per cent was made up of individuals from White backgrounds. Based on these statistics the setting for the current study is informed by the dominant norm of White western culture (Aspinall, 2002). The social and economic history of Britain sets a context in which stereotypes, elicited by race, give way to cultural hate crimes and racism (ONS, 2017). However, it is important to note that demonstrations and movements such as The Black Lives Matter (BLM), will also have an impact on the setting of this study. This is possibly the first-time many children and young people (CYP) will have witnessed the severity of racial injustice at such a global level (Agyeman & Lichwa, 2020).

In the UK, autism is the most commonly identified need among CYP with statements of Special Educational Needs and Disability (SEND) and is thought to account for a quarter of all Education, Health and Care Plans (Department for Education [DfE], 2015). There is growing research to suggest that the increase in diversity and cultural differences within the UK has given rise to ethnic disproportionality. Ethnic disproportionality exists ‘when an ethnic group is significantly more, or less, likely to be in the identified with SEN compared to the ethnic majority’ (Strand & Lindsay, 2018, p.1). For example, Strand et al., (2018) found that Black Caribbean pupils and Black others were substantially overrepresented in the identification of ASD when compared to White British pupils. Pupils from Asian groups such as Pakistan and India were underrepresented (by 50 per cent) when compared to White British pupils. Lindsey et al., (2012) found ethnic over and under representation in both the diagnosis of autism and Speech and Language Communication Needs (SLCN). In their study pupils from Asian groups were 50 per cent less likely to be diagnosed with autism compared to White British pupils, whereas, pupils from Black groups were almost twice more likely to be labelled as having SLCN. Other studies have found that when professionals assess CYP from BAME groups they are less likely to be given an autism diagnosis

(Mandell et al., 2007). While it is not yet clear the reasons for such disproportionalities, there has been a growing national attempt to improve the experiences of BAME groups by making psychological and diagnostic services more culturally sensitive (National Health Service [NHS], 2009).

1.3.2 Local Context

According to the ONS (2011) more than 83 per cent of families living in London are of BAME backgrounds, which is much higher than the rest of England. In the specific inner London Borough where this research was carried out, ethnic disproportionality has been an area of focus for the Educational Psychology Service (EPS) for several years now. In light of the current anti-racism movement and the systemic challenges faced by BAME CYP, the Local Authority (LA) has coordinated an anti-racist strategy 'Tackling Disproportionality Action Plan – 2021' (in order to keep the anonymity of the LA, this will not be referenced). This strategy aims to reduce the disproportionality faced by BAME CYP who EPs come into contact with via schools and statutory services and aims to improve their educational and social outcomes.

With regards to autism, the LA has drafted an autism and social communication needs strategy 2021 (in order to keep the anonymity of the LA, this will not be referenced). The strategy outlines key priorities for the service which includes, creating a positive relationship with families at the earliest opportunity and training staff to be aware of cultural differences in understanding and acceptance of autism. These priorities are in line with growing research that recognises that culture and diversity does impact on how certain communities conceptualise autism (Frederickson & Cline, 2015).

1.3.3 Listening to the voice of young people

Highlighted in legislation and guidelines is the principle that the voice of CYP should be heard and listened to. The introduction of the Children and Families Act (2014) and the SEND code of Practice (DfE, 2014) has given prominence to the voice of CYP within the field of education. This legislation ensures that the views of CYP are to be collected and use to inform decisions affecting their lives. Article 12 of the United Nations Conventions on the Rights of the Child (United Nations, 1989) highlights that CYP have the right to participate in a decision that affects their lives. According to the

Equalities Act (2010) professionals such as Educational Psychologists (EPs) have a responsibility to listen to the views and experiences of BAME young people and their families while being aware of SEND in BAME communities. While recent legislation emphasises the importance of hearing the voice of CYP, the extent to which this occurs varies and at times is thought to be superficial (Hawkins & Soni, 2018) or completely missing (Pellicano et al., 2013).

1.4 Social Justice

Social justice is a relatively new concept within educational psychology (Shriberg & Fenning, 2009). While there are varying definitions of social justice, this study adopts the perspective that social justice is the eradication of systemic oppression and barriers with the aim of securing equal access to resources and opportunities for all (Bell, 1997). Suggested in this definition is the move away from discrimination based on grounds such as race, age, disability and other forms of discrimination that have prevented diverse groups from accessing resources. Whilst social justice is a complex and multifaceted term, Schulze et al., (2017) propose three key principles that underline social justice: “advocacy, non-discriminatory practice and fairness” (p.57). These fundamental principles of social justice, which are in line with the researcher’s ethical beliefs, will be used as a framework to give voice to BAME autistic young people and ensure that this research is carried out in a socially just manner.

1.5 Race and Racism

Critical Race Theory (CRT) is a theoretical framework which challenges the contexts and discourses of racial oppression. CRT offers a useful lens to examine the ways in which racism impacts on everyday life. Race, in spite of being scientifically rejected as a biological concept, remains an uncomfortable, political and heated discourse for many. CRT recognises race as a social construct and a by-product of societal thoughts with legal, cultural, and interpersonal implications (Calmore, 1992). The social aspect and implications of race are what makes this phenomenon so central to many lives. The Oxford English Dictionary defines racism as, “the belief that all members of each race possess characteristic, abilities or qualities specific to that race, especially so as to distinguish it as inferior or superior to another race or races” (Collins English Dictionary, 2012). CRT argues that racism should be used to describe overt, discriminatory, unconcealed acts of hatred but also covert acts that encourage racial micro aggressions towards specific racial groups (Elias & Feagin, 2016).

1.5.1 White privilege

White privilege is the notion that individuals from White backgrounds are awarded advantages by virtue of their skin colour (Leonardo, 2004). A fundamental aspect of White privilege is having the option to dismiss or completely ignore the ways in which race impacts and structures the opportunities individuals are given (Rankin & Reason, 2008). For the purpose of the study, it is important to distinguish between Whiteness and White people. According to Leonardo (2002), Whiteness refers to a discriminatory form of discourse that is centred on benefiting White people, whereas, White people refers to a socially produced category constructed on an individual's skin colour. It is important to note that these two terms are not synonymous. Due to the way in which education institutionalises race, BAME and White pupils may have very different lived experiences of school and education (Hurtado et al, 2008). Therefore, it is important to recognise the role of White privilege within the study.

1.5.2 Psychological impact of racism

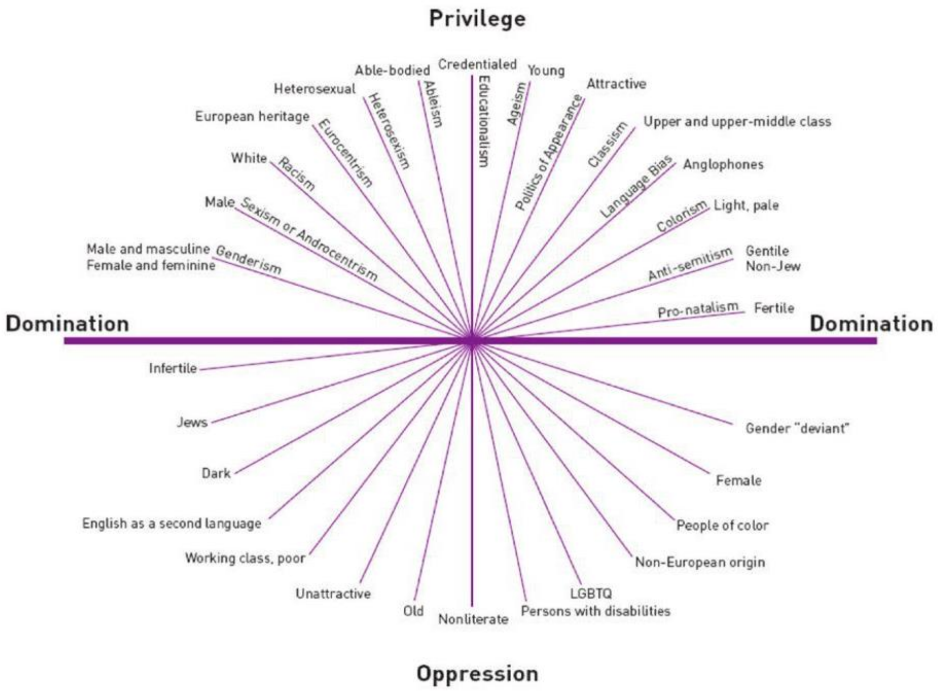
The field of psychology has generated a large body of literature which supports the negative impact of racism on the health and well-being of CYP and their families (Okazaki, 2009). Edward (2012) found that individuals that experience racism can have higher levels of stress and depression as well as lower levels of self-efficacy. The experience of racism, whether that is directly or indirectly, has been linked to racial trauma (Daniel, 2000). A recent study by Tynes et al., (2019) explored the impact of traumatic events online (TEO), such as the killings of unarmed civilians by the police, on the mental health of adolescents from African American and Latino backgrounds. In a sample of 302 participants, they found a significant correlation between viewing TEO and poorer mental health outcomes. They also found an association between girls who experienced race related TEO and increased levels of depression and Post Traumatic Stress Disorder symptoms. This study is of particular importance given the coverage in the news and social media of the deaths of black individuals such as Breonna Taylor and the impact it may have on participants' lived experience.

1.5.3 Intersectionality

Intersectionality (Crenshaw, 1991) is the concept that a person’s identity is multi-faceted and intertwined by social markers such as race, gender, class and sexuality. Intersectionality can be used to “describe analytic approaches that simultaneously consider the meaning and consequences of multiple categories of identity, difference and disadvantage” (Cole, 2009, p.171.) Intersectionality is of particular importance in this study as it provides a framework for understanding the systems of power and how the different facets place individuals (in this case research participants) in positions of disadvantage or oppression. It is worth highlighting that the intersectionality wheel (see Figure 1.1) does not account for neurodevelopmental conditions such as autism, instead it accounts for able bodies vs ableism. Using language such as ‘ableism’ to communicate about autism implies that they are “inferior to nondisabled people” (Bottema-Beutle et al., 2020, p1.) which in turn contributes to placing autistic individuals in a position of oppression. This study aims to use the intersectionality concept to consider the multiple and often overlapping layers of the young people involved in the research and the way in which different forms of oppression can take place at the same time (Acker, 2006).

Figure 1.1

Intersectionality wheel (adapted from Crenshaw, 1991)



1.6 Educational Psychologists and cultural competence

Educational psychologists (EPs) are applied psychologists who are primarily concerned with CYP’s learning, development and well-being. They work collaboratively in a variety of settings with staff, parents and CYP in order to promote positive changes. EPs are trained to adopt a holistic approach and draw on a range of psychology to consider the interaction between CYP and their environment (British Psychological Society [BPS], 2015).

Current growth in immigration and the overall population suggests that EPs will increasingly work and support CYP from BAME groups. Due to this, there is a growing need for culturally appropriate practice (often referred to as cultural competence) in order to meet the needs of diverse communities whose belief systems are often different from those of the dominant culture (Kusi, 2020). Cultural competence can be understood “as the ability to recognise one’s own racial and social identity” (Sue, 2016, p.226). EPs have an obligation to be aware of the impact of culture, equality and diversity on practice (Health and Care Professional Council [HCPC], 2015). Multicultural competence is given particular attention within the Educational Psychology training programmes (BPS, 2015) and all practitioner psychologists are expected to demonstrate cultural competence by meeting the Standards of Proficiency of HCPC (2015) at the end of their training programme.

With regards to autism, a key role for EPs is facilitating positive educational and social experiences for autistic young people (MacKay et al., 2017). One way of doing this is promoting the inclusion of BAME autistic young people whilst acknowledging their experiences and shifting the narrative around them. EPs are uniquely positioned (in schools and communities) to facilitate constructive and culturally sensitive dialogue that enables co-construction of shared understanding of strengths and needs. EPs can promote empowerment and address power imbalance by facilitating reflections on differences in belief, power and cultural assumptions (Dickson, 2012). The researcher and co-researcher, who both identify as BAME members, hope that this study goes beyond the research world and benefits the BAME community by raising the cultural practice of EPs and schools staff.

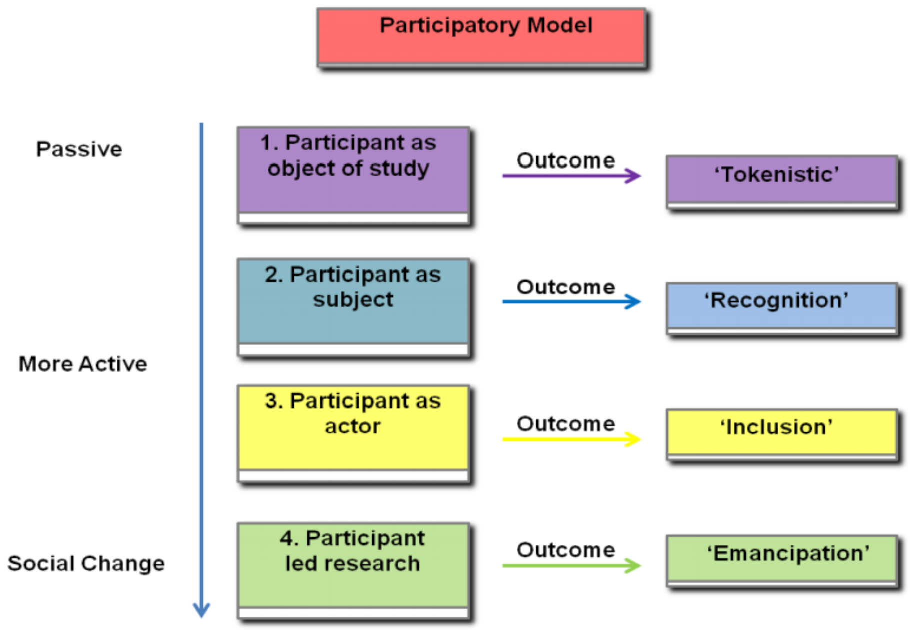
1.7 Participatory research

There are varying definitions of participatory research (PR), including but not limited to "user involvement" (Salway, et al., 2011, p.134). PR is often described as "attitude or approach" adopted within research as opposed to a particular method (Cornwall & Jewkes, 1995, p.1671). In the field of Educational Psychology there has been a growing interest in adopting PR approach (Pearson & Howe, 2017). The fundamental premise for PR is that it provides opportunities for young people – or other service users – to actively participate and engage in the research process. PR aims to readdress the balance of power within research by positioning young people as experts who are knowledgeable about their own lives and therefore ideally placed to guide research. PR also aims to be inclusive and relevant to its participants and the community involved (Bourke, 2009). Hart (1992) proposes that in order for a research project to meet the principle aims of PR, the researcher must collaboratively involve the community in every step of the research from the design stage through to dissemination. For the purpose of clarity, PR within this study refers to empowering a co-researcher, who is a BAME autistic young person, to work collaboratively with the researcher to design and carry out research on topics of relevance to the co-researcher's experiences.

There are numerous models of PR that can be used to guide research practice. This study adopts Aldridge's (2017) participation model (PM, please see figure 1.2). The PM provides a frame of reference which researchers can use in order to enhance "collaboration, inclusion and emancipation in research relationships" (Aldridge, 2017, p.26). The underlying principle of the PM is that any research involving young people (or service users) should move away from 'tokenistic' approaches that treat them as passive to ones which facilitate and encourage their voice thus empowering them to make social change. The PM also emphasises that the relationship between the researcher and participants should be based on mutuality, respect, trust and "that the voices of participants are prioritised over those of academic researchers" (Aldridge, 2017, p.32). Throughout the study the co-researcher has been encouraged to take an active role resulting in participant led research. This position prioritises social change outcomes and fits with the emancipatory and social justice aims of the research.

Figure 1.2

Aldridge's (2017) Model of Participation.



1.8 Researcher's personal background

As a Trainee Educational Psychologist (TEP) and researcher engaging in participatory research, it is vital to be transparent about how my beliefs and values may have influenced the interpretation of the participants' narratives and the dynamics between myself, the co-researcher and the research participants (Elliot et al., 1999). This section aims to provide transparency within the research by sharing my personal background and beliefs.

I am a Black-African, Muslim, cis-gender female. I was born in Somalia but came to the UK as a refugee with my family in early 2000 as a result of the civil war. My cultural heritage and Islamic faith are crucial aspects of my identity and self-concept as well as how I relate to the world around me. Throughout my educational experiences in the UK I have always felt cultural dissonance between my heritage and the country where I spent majority of my life. I find myself continually engaging in a process of integration between my dual identities, not always successfully but in a way that feels true and authentic to me.

Prior to starting the educational psychology programme, I had worked as a learning support assistant for a school funded by NAS for autistic young people. Additionally, I have previously engaged in autism research within the Somali community. Therefore, I have experience of not only working with BAME groups but also with supporting autistic young people with a range of communication levels. Although I am not an autistic young person, I am from a BAME background and therefore I bring some insider's perspective to the research that allows a better understanding of the BAME experience. Such shared understanding facilitated a culturally sensitive approach when working with the co-researcher and interviewing the participants. However, I recognise whilst this has it benefits there is also potential bias that might have been placed on the young people who have participated in the research.

1.9 Unique contribution of the research

While research exists exploring the educational experiences of autistic young people, they tend to mainly be from the perspective of parents' and teachers (Limbers et al., 2009; NAS, 2013). While these accounts are useful, they do not provide an insight into the experience of autistic young people from their perspective (Preece & Jordan, 2010).

Additionally, while some research exploring the lived experience of autistic young people exist, the majority of the participants tend to be from White British backgrounds (Mark et al., 2000). To the best of the researcher's knowledge, no academic peer-reviewed research has explicitly explored the lived experience of BAME autistic young people (this is the central finding from the literature review, please see Chapter 2). Subsequently, a strength of this research is that it explores the lived experiences of an under-represented and often marginalised group. The findings from this study will contributes to the small pool of research on autism and ethnic minorities.

The next chapter explores the available literature, relating to the educational experiences of autistic young people, carried out for the study.

Chapter 2: Literature review

2.1 Introduction

This chapter provides a systematic review of the existing research evidence relating to the educational experiences of autistic young people. The chapter outlines the process for identifying relevant studies followed by a critical analysis of the research findings. The main body of the chapter is divided into three themes: ‘self-concept’, ‘peer relationships’, and ‘school setting’. Each theme presents the identified studies and critically analyses the findings, along with the research designs. Following on from this, the researcher discusses gaps identified from the systematic review and the relevance of the current research within the existing literature. The chapter concludes with a summary of the literature.

2.1.1 Literature search strategy

A systematic literature review was carried out to locate studies that elicited the views of autistic young people to answer the following review question: What is currently known about the educational experiences of autistic young people?

The systematic review was guided by the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA), a checklist for identifying appropriate studies (Moher et al., 2009). The checklist provided an overview of the research in the area of autism and pupil voice as well as outlined the transparent process for identifying included studies. Guidance on how to carry out a systematic literature search was also sought from the specialist librarian from the school of psychology.

2.1.2 Identifying relevant studies

Eight databases (Academic Search Complete, British Education Index, Child Development & Adolescent Studies, Education Research Complete, Education Resource Information Centre, PsychARTICLES, Teacher Reference Centre and Scopus) were systematically searched first in October 2019 and then again in July 2020. These databases were selected as they were deemed to identify the large majority of relevant research on autism and pupil voice. The researcher’s initial review question related to the educational experiences of BAME autistic young people. An initial search was carried out using the terms relevant to the review question; ethnic minority, communication, autism, participants, education and experience. However, this did not produce any studies that met the inclusion criteria (the inclusion and exclusion criteria are displayed in Table 2.2). The researcher decided to expand the search by removing the term ethnic minority as it did not produce any articles. Terms such as ‘communication’, ‘autism’, ‘participants’ and ‘experience’ were broadened further by using EBSCO’s thesaurus. This produced variations on terms such as ‘perspective’, ‘ASD’, ‘child’, ‘perception’ and ‘education’. These terms were then combined to systematically search for papers (see Table 2.1).

Table 2.1.

Literature search terms

Terms related to communication	Terms related to Autism	Terms related to participants	Terms related to education	Terms related to experience
Communicat*	Autis*	Child*	Experienc*	School
Participat*	ASD	Pupil*	Evaluation	Education
Perspective	Asperger*	Young Person	Perception*	College
Consult*	High	Youth		
Voice*	functioning	Young people		
Child voice		Teenager		
View*		Adolescen*		
		Teen*		
		Student*		

Note: * The asterisk is used as a ‘wildcard symbol’ that broadens a search by finding words that start with the same letters.

Table 2.2

Inclusion and exclusion criteria

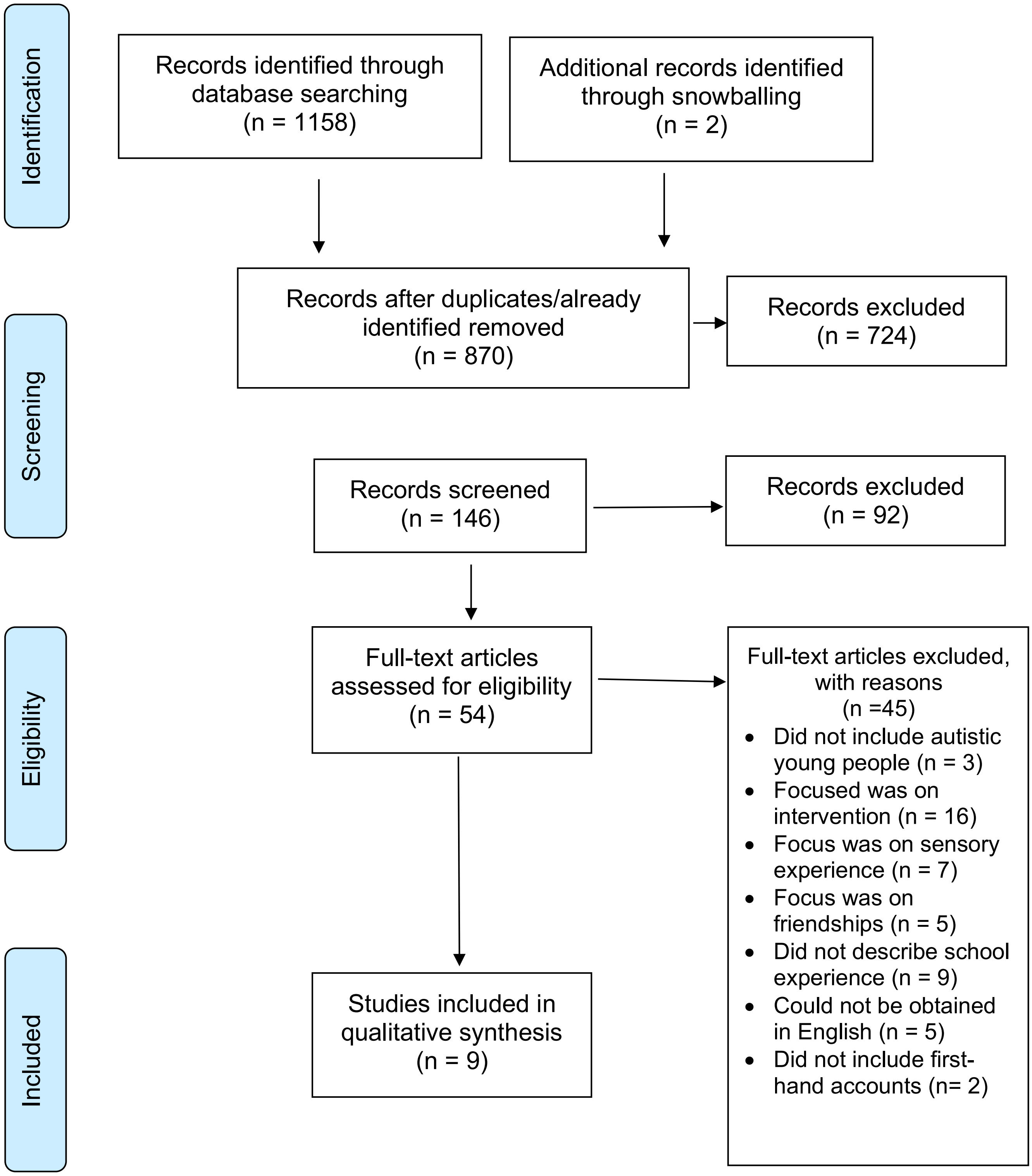
	Include	**Justification**	**Exclude**	**Justification**
Population	Diagnosed with autism or Asperger Syndrome	Ensure relevance to the literature review question	Not diagnosed with autism or Asperger Syndrome	Not relevant to the focus of the literature review question

Age	Age range: 11 – 25 years	Relates to participants within this research project	Outside the age range 11 – 25 years	Does not relate to the participants within this research project
Focus	Collected the views and perceptions of young people diagnosed with autism or Asperger Syndrome	Ensures relevance to the literature review question	Explored experiences of those not diagnosed with autism or Asperger Syndrome Explored experiences not relating to education.	Not relevant to the literature review question
Publication Date	Published papers between the years 2000-2019	Relevance to current theoretical beliefs about autism	Papers before 2000	Does not take into account key legislation such as the Children and Family Act (2014)
Source type	Published in a peer reviewed academic journal.	Studies will have a higher methodological quality		
Language of publication	Written in English	Accessibility	.	

A total of 1,158 studies were yielded from the search. After all the duplicates were removed, 870 studies remained. 724 studies were excluded as they were either: non-empirical papers, doctoral theses or meta/systematic analyses. The title and abstract of the remaining 146 studies were examined, this led to a further 92 studies being excluded due to the research focusing on family, parent or sibling experiences. An additional two studies were identified through snowballing; a technique that uses the reference list of studies that have been identified to search for additional relevant articles. This left 56 studies to be examined by reading full texts. A total of 45 were excluded as they did not meet the inclusion criteria. Of the 45 articles, three articles were excluded as autism was not named as the main area of need. Sixteen studies were excluded as the focus of the study was on evaluating a service or an intervention. A further seven studies were excluded as the main focus was on sensory experience. Five studies were excluded as the studies explored friendship experiences of young autistic individuals and a further nine were excluded as the studied did not describe educational experience. An additional five studies were excluded as the studies did not include first-hand account; finally, two studies were excluded as they could not be attained in English. The search found a total of nine studies that met the inclusion criteria (see Figure 2.1 for each stage of the literature search process). These nine studies were then assessed for quality. It is worth noting that no grey literature was included as it may be of lower methodological quality than published studies. However, the author recognises that this may mean some current views on the educational experiences of autistic young people may have been missed.

Figure 2.1

Prisma flow chart



2.1.3 Appraisal of studies

Gough's (2007) process for assessing research quality using Weight of Evidence (WoE) was used to judge the quality and relevance of the nine studies against the following criteria:

- **WoE A** (**Soundness of the study)**: Quality of execution of the study's 'soundness' and trustworthiness of the study (methodological quality).
- **WoE B** (**Study's design)**: Appropriateness of the study design and analysis for addressing the research question.
- **WoE C** (**Appropriateness)**: Appropriateness of focus of research for answering the review question.
- **WoE D** (**Overall WoE**): Judgement of overall weight of evidence (WoE) based on assessment made for each of the criteria A – C.

To support the assessment of methodological quality (WoE A), the researcher employed Critical Appraisal Skills Programme Checklist Items (Critical Appraisal Skills Programme International, 2019). Studies received a score of 1, 2 or 3 against WoE criteria A, B and C. For overall WoE D, studies that received a total score of between 0 – 3 were deemed 'low quality', 3 – 6 'medium quality' and 6 – 9 'high quality'. Of the included studies, three were rated high quality according to these criteria, and six were rated medium quality (Appendix 1.1).

Once all nine studies were assessed for quality, the researcher started the process of synthesising findings. To do this, the researcher followed the stages outlined by Trafford and Lesham (2008): summarise, synthesise, analyse and authorise. For example, studies were first summarised, then synthesis for ease, and then analysed at an individual level first then across studies. The final stage allowed the researcher to locate the current nine studies r within the existing literature and therefore to authorise her position held towards the current research.

2.2. Characteristics of the papers identified

The final nine studies included in the literature review were assessed in relation to research findings and limitations (Appendix 1.2). All nine of the studies identified were qualitative. Six studies were conducted in the UK (Connor, 2000; Browning et al., 2009; Humphrey & Lewis, 2008; Hill, 2014; McLaughlin & Rafferty, 2014; Goodall & MacKenzie, 2019). The remaining three studies were conducted in Australia (Saggers et al., 2011), Singapore (Poon et al., 2014), and the United States (Marks et al. , 2000). All nine studies used interviews to elicit the views of the participants, however, some of the studies also used observation (Poon et al., 2014), photo-elicitation (Hill, 2014), pupil drawing (Humphrey et al., 2008) and diamond ranking which involved participants ranking pre-written statements and arranging them in a diamond formation (Goodall et al., 2019). All nine studies aimed to represent the voice of autistic young people, but two of the studies (Connor, 2000; Marks et al., 2000) also represented the voice of the parents and school staff. It is worth noting, that only findings from the viewpoints of autistic CYP are drawn on in the themes below in order to answer the review question: What is currently known about the educational experiences of autistic young people?

2.3 Themes

Research studies identified from the systematic search were arranged into three broad themes of 'self-concept', 'peer relationships' and 'school setting' in order to answer the review question. These themes were selected after the researcher took the following steps: (1) an extraction of relevant statements of findings and key words from the identified studies, and (2) a consolidation of these statements into abstract findings. By taking these steps, the researcher ensured that the selected themes were strongly linked to the identified studies. Each theme is discussed below and critically considered in relation to focus of the study, research design and analysis.

2.3.1 Self-concept

The term 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). A central theme within the studies was the relationship between the diagnostic label of autism and pupils' understanding of and engagement with the term 'autism'. The studies reviewed suggests that depending on what the label 'autism' means to a pupil (and the degree to which this understanding form part of their identity) impacts how they make sense of their educational experience.

2.3.1.1 Identity

Humphrey et al., (2008) investigated the experience of 20 pupils (age range 11 – 17 years old) with AS across four mainstream secondary schools in the UK. Humphrey et al., (2008) used semi-structured interviews to collect the majority of the data, they also used pupil diaries to triangulate the data. Although not originally planned as part of their research design, they decided to include one of the pupil's drawings as a way of enhancing his verbal response. The data gathered was analysed using Interpretative Phenomenological Analysis (IPA) and to ensure social validity, the researchers invited pupils to comment on a "pupil friendly summary" version of their data before publication (Humphrey et al. 2008, p.29).

This study found that there was a divide between participants whose descriptions of themselves and their AS were characterised as negative versus participants who accepted their AS and saw it as "part of who they were" (Humphrey et al., 2008, p.32). Of those participants who viewed themselves and their AS negatively, the notion of wanting to be 'normal' appeared to underline their response. These participants described the negative impact of AS on their sense of self, terms such as "freak" or "mentally disabled" (Humphrey et al., 2008, p.31) were used when referring to how they saw themselves. In contrast, some participants spoke about celebrating and accepting their AS and not being able to imagine their life without it. For these participants, the researchers appear to suggest that their positive experience is a result of them having successfully integrated AS as part of their identity. However, it is not clear what percentage of participants viewed their AS and subsequently themselves positively or negatively. The small sample of participants means that the findings must be cautiously interpreted due to the lack of generalisability that can be made from a small exploratory study. Furthermore, the small sample is made more problematic by the lack of participant information. Besides age, the researchers fail to provide any information on participants including gender and ethnic background. Although the researchers provided a summary of the findings to participants, there appears to be no collaboration or involvement of the participants in any stage of the research.

McLaughlin et al., (2014) explored the lived experience of six young people with AS across two mainstream schools. Although the focus of the study was on how individuals make sense of their diagnosis, their participants exclusively discussed their educational experience. This study used semi-structured interviews to collect qualitative data. Participants consisted of five males and one female ranging from Year 10 to Year 13 (no specific ages were provided).

Similar to Humphrey et al., (2008) a key finding that emerged from this study was a desire to be 'normal'. The majority of the participants described themselves as being 'different' from peers, often in a negative way. These participants constructed their identity in relation to how "different from normal people" they were (McLaughlin et al., 20014, p. 68). The researchers found that some participants did not want others (i.e. peers and teachers) to know about their diagnosis in fear of being treated differently. Of the participants whose AS diagnosis was known publicly, they reported feeling disadvantaged in school as a direct result of their AS being known by peers and staff. Similar to the study by Humphrey et al., (2008) AS in this context was constructed negatively by participants, in addition participants' perception of difficulties associated with AS appears to be deepened by beliefs that their diagnosis is "permanent and unalterable" (McLaughlin et al., 2014, p.67). Not all participants, however, saw themselves or their AS in this way. While participants in the first study interpreted their perceived difference "as part of who they were" (Humphrey et al., 2008, p.32), some participants in this study saw their diagnosis as 'unproblematic' (McLaughlin et al., 2014). A notable exception in both studies is that some participants attributed having friends and academic achievement as reasons for their positive perception, suggesting that their self-concept is more about what they can do, instead of what they believe that cannot do as a result of their diagnosis (Humphrey et al., 2008 & McLaughlin et al., 2014).

This study adopted an IPA approach which lends itself to small and purpose sampling of participants (n=6). A real benefit of IPA is its idiographic method of inquiry which enables an in-depth and close reading of the data to explore how participants describe their lived experience. Other limitations include the lack of triangulation of data (the researchers only interviewed their participants once) and similar to Humphrey et al.,'s (2008) study there appears to be no collaboration in any part of the study between the participants and the researchers. Although the researchers report offering the participants an opportunity to discuss the outcome of analysis, all six participants declined. This brings into question the trustworthiness of the findings. The research questions appear to be driven by the authors' interest as opposed to the needs and interests of the participants. Additionally, both studies (Humphrey et al., 2008 & McLaughlin et al., 2014) examined pupil experience in mainstream secondary schools. It is worth noting that the heterogeneity of autism was not represented in either study as all of the participants were diagnosed with AS. Therefore, the findings reported only speak to enhancing the educational experience of verbally able autistic young people in mainstream settings.

2.3.1.2 Interests

Mark et al., (2000) investigated the experiences of individuals with AS. The study was carried out in the US and involved interviews with three young people diagnosed with AS and their parents. Interestingly, this was the only study in the literature review that provided participants' characteristics in relation to ethnic background. This study included an Asian American female aged 13 and two Caucasian males age 15. The questions used in the semi-structured interviews were devised in a focus group that consisted of service providers. Using thematic analysis, the researchers synthesised the data collected (from pupils and parents) into a portrait for each participant. The portraits were organised into three broad categories; school life, interests and social life.

Mark et al., (2000) found that all three pupils had strong interests from early on but as they grew older the topic of their interest changed. For example, parents reported peculiar and repetitive interests such as a fascination with doors or ceiling fans (Mark et al., 2000). But as the pupils grew older, parents reported that these interests became more 'mainstream' such as hockey, the civil war or electronical items. Furthermore, parents reported that these strong interests eventually shaped their child's personality. For example, "I like to take apart stuff…VCRs, TVs, stereos, tape records, anything that has to do with electricity" (Mark et al., 2000, p.8). Pupils in this study reported feeling and behaving different from their peers as a result of their narrow interests which often isolated them from peers. Other studies have found divergence in participant experience relating to their special interest. For example, Humphrey et al., (2008) found that for some participants their interest fascinated their peers and in turn aided their confidence, “people are often questioning me…how do you know all this, how do you know all that?...I often feel proud of myself” (Humphrey et al., 2008, p.32). For others, their special interest caused difficulties and at times led to arguments as peers could not understand how the participants could sustain such an interest in one area (Mark et al., 2000). These interests often led to a need for routine in their daily lives (Humphrey et al., 2008).

While the study by Mark and colleagues (2000) supports the commonly held view that autistic young people may have a narrow array of interest, this study is not without limitations. Firstly, the voice of the pupils was not well represented within the portraits. Although the pupils were quoted, parent voice certainly resonated louder within the study. Additionally, the researchers drew many of their conclusions based on accounts and experience of the parents as opposed to the pupils. While it is important that parents feed into giving a holistic account of young people’s experience it does indicate a need for research to fully explore the experience of autistic young people.

2.3.1.3 Summary on studies that have explored self-concept

The finding from the three studies suggest that participants actively construct their perceptions of AS by drawing on feedback from peers. As such, sense-making about themselves in relation to their typically developing peers plays an important role in shaping their self-identity. Within the identified studies there appears to be lack of collaboration between the researcher and participants in directing the focus of the research. Additionally, some of the studies have neglected the voice of the young person in favour of their parents. A gap therefore exists in hearing about the experience of autistic young people about topics of interest to them through their lens.

2.3.2 Peer relationships

Another key theme that emerged from the studies is peer relationships. Three studies were identified which explore peer relationships from the perspective of bullying and having a friend. The studies found suggests that relationships with peers can act as both a barrier and an asset to pupil experience of education.

2.3.2.1 Bullying

Goodall et al., (2019) used a multi-method approach to explore the educational experience of two autistic girls in Northern Ireland. Participants (Ro and Sarah-Jane) aged 17 and 18 provided retrospective accounts of their educational experience in mainstream primary and secondary school settings. Both participants have a diagnosis of AS in addition to auditory processing (Sarah-Jane) and a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD, Ro). This study was a part of a wider study, however only Sarah-Jane and Ro (out of a possible five girls) gave consent to be part of this study. The selected research design employed was first considered by the Children's Research Advisory Group (CRAG), which was made up of autistic young people. The researchers employed a range of different techniques to capture the educational experience of Ro and Sarah-Jane. Using inductive thematic analysis, the researchers presented their findings into two strands; 'impact on wellbeing' and 'bullying and friendship'.

For both Sarah-Jane and Ro being bullied was their main worry when it came to mainstream education. They both reported peer victimisation, including "verbal, physical and… sexual" (Goodall et al., 2019, p.507). In the 'beans and pot' activity both participants selected 'true' for the statement "I feel different from other children here" (Goodall et al., 2019. P. 508). Sarah-Jane reported feeling targeted by others due to judgement about her disability and being seen as 'different' by peers. Unfortunately, reports of bullying are not exclusive to Sarah-Jane and Ro. Other studies such as Humphrey et al., (2008) found that characteristics linked with AS appear to increase the risk of being victimised. They also found that for their participants name-calling and physical violence occurred regularly, and sometimes verbal abuse continued for seven days straight. This persistent level of bullying meant that some participants experienced emotional distress and anxiety. Both studies (Goodall et al., 2019 & Humphrey et al., 2008) report participants feeling socially isolated from peers as a result of bullying.

Goodall et al., (2019) is the only identified study within the review that focuses exclusively on the experience of AS girls. Furthermore, this study used multi methods, reviewed by CRAG, to enhance participants' engagement. Despite these efforts, this study is not without limitations. Firstly, this study is part of a larger research which is mentioned at the start. However, the research aims of this study are not clearly outlined and therefore it is difficult to know whether this study has met its aims. Additionally, the researchers report informal accuracy checks were carried out with participants during the data collection, however, it is not clear what this involved.

Browning et al.,'s (2009) study used interviews to compare autistic pupils' perceptions of stress and coping abilities to that of pupils without autism in the context of transition. Seventeen participants all in their last year of secondary school were interviewed. Of the ten participants, ten had a diagnosis of autism and the remaining seven were categorised as neuro-typically developed (NTD). The researchers selected autistic participants that had a "relatively high level of language ability" (Browning et al., 2009, p.37). The reason stated for this was that content analysis required participants to provide information that can be analysed; therefore, it was necessary from the researchers' perspective to recruit verbally able participants.

The study found that autistic participants were more likely to stress about incidents that caused them 'actual harm' in the educational context. For example, 26 per cent of these participants worried about encounters with bullies and more specifically they worried about being 'scratched' and 'punched' by bullies. In comparison, no participants in the NTD group named 'actual harm' as a concern, instead 23 per cent of these participants' main concern was 'cognitive pressures' as a result of schoolwork.

This study has several limitations which need to be addressed including the researchers' use of content analysis (CA). CA is often criticised for describing and analysing the data at a surface level and for not extracting meaning from the data pattern (Stemler, 2001). This often means that the coding used is too simplistic as it does not lead to a thorough analysis of participants' experiences. These limitations will have an impact on the interpretations of the findings as well as the generalisability of the study. Another limitation is that the researchers provided limited information on participants and their educational context; this makes it difficult to transfer these findings to the wider population and to know which group of young people the findings may be relevant for. Secondly, autistic participants were not randomly selected instead they were volunteers that contribute to research. This will affect the generalisability and conclusions that can be drawn from the findings as these participants may not be representative of autistic young people. This is also true in relation to the researchers purposely selecting autistic participants who are verbally able. Finally, it is worth noting that this study measures perception of stress rather than actual stressors that young people experience. This raises questions regarding the validity of the study.

2.3.2.2 Having friends

Poon et al., (2014) used qualitative research methodology to explore the views of pupils with High Functioning Autism (HFA). This was achieved through semi-structured interviews with four pupils attending two different mainstream secondary schools in Singapore. To reduce any potential anxieties participants were given the option to have a familiar adult with them during the interview. Participants consisted of three males and one female aged between 12 and 17 years old. The researcher attempted to get to know their participants by engaging in different activities before the interview. The researchers used IPA to analyse the data collected. Although the study focused on general experience, participants mainly discussed their educational experience.

A key theme that emerged from this study was participants' views on friendships. Pertinent to this view is the notion of what an ideal friendship should look like. Some participants described positive experiences of friendship based on their ideals. For example, one participant shared what having a friend was like for him: "we actually understood each other very well… we are like a hand. Without fingers we can't do anything, but together as a hand we can do anything". (Poon et al., 2014, p. 1076). The researchers propose that positive relationships can reduce social problems linked with HFA as they facilitate peer interaction. Other studies have also reported benefits of having a friend which includes feeing positive about themselves (Humphrey et al., 2008). The McLaughlin et al., (2014) study found that for participants the most crucial role a friend can play is supporting them to counteract their 'difference' by accepting them as they are. Poon et al., (2014) study also found that having a friend can provide a source of support especially when being bullied.

While Poon et al.,'s (2014) study may have yielded similar findings on friendship to Humphrey et al., (2008) and McLaughlin et al., (2014), it is important to remember that this study is based in Singapore. As such, there will be differences not only in the education context of the participants but also in peer relationships and how young people are supported. These differences mean that the findings from this study will need to be cautiously interpreted. As stated by the researchers this study is not representative due to the sample size (n =3) and only takes into account the experience of HFA individuals. However, the study does use IPA which calls for a sample size "between three and six participants" (Smith et al., 2012, p.51) due to the detailed analysis of each case that is required. Although interviews were conducted by a researcher more than half the participants were accompanied by a familiar adult. This may result in social desirability bias as participants may respond to questions based on what they think the familiar adult would like to hear as opposed to what they feel. Social desirability could have resulted in over-reporting of positive experiences of friendships leading to potentially inaccurate depictions of the experiences of autistic young people. Finally, the researchers acknowledge a limitation to their study is trustworthiness as participants were only interviewed once and findings were not corroborated by participants.

2.3.2.3 Summary of studies that have explored peer relationships

Findings relating to peer relationships highlight an interplay between how pupils see themselves (compared to their peers), difficulties linked to autism and the attitudes and beliefs of peers. The research proposes that peer victimisation - bullying and physical violence - can exacerbate difficulties and feelings of being different, contributing to a negative self-perception. Equally, positive and supportive friendships can stimulate a positive sense of self and feelings of being accepted.

2.3.3 School setting

The third theme to be explored is 'school setting'. Within the literature there appears to be a link between sensory difficulties, physical environment (of the school) and the need for order and predictability.

2.3.3.1 Physical environment

Hill (2014) explored the lived experience of autistic young people attending mainstream secondary school. A qualitative design was used by the researcher to enable a rich insight into the participants' experience. The researcher used photos as a tool to aid autistic young people to participate in the research process by enabling them to direct discussions based on their interest. Participants consisted of six young people from two different mainstream secondary schools. The researcher met with participants on four different occasions to collect data. The initial meeting consisted of building a positive rapport with participants as well as introducing the method of photo elicitation. The second meeting consisted of participants taking pictures of places that are significant to them. The third meeting involved the participants selecting one photo for them to discuss with the researcher. The final meeting consisted of the researcher asking participants if they were any photos, they wished they had taken. Once data was collected, the researcher used IPA to analyse all 13 interviews.

A dominant theme within this study is the physical environment and how it can impact on the accessibility of the school for autistic young people. Hill (2014) found that for some participants navigating corridors at schools can cause anxiety and stress as this environment can often present with challenging situations. For example, “This is the reception areas. I go through in the morning…cos in other entrances there's quite a lot of people. Sometimes they can be rough, and you don't know what other students are like (pause). Or what they are going to do” (Hill, 2014, p. 84). For others, they can experience sensory processing difficulties such as the sound of the bell at the end of the lesson. Social interaction in corridors and other parts of the school building which is often unpredictable and unstructured coupled with the noise and crowd appear to be a great source of anxiety and stress for participants. The researcher suggests that corridors and bells at the end of the lessons signify transition and change which could be adding to participants' anxiety. Other studies have found that noise sensitivity can further distance autistic pupils from their peers as often they avoid crowded places like the dining hall and corridors in search for quiet and less populated space (Humphrey et al., 2008). Hill (2014) reported that sensitivity to noise can impact on learning, as they are unable to concentrate due to the noise in the classroom which also impacts on how they work with peers. The researcher also found that it can be difficult for autistic young people that have intense interest with objects to concentrate or engage in school activities.

There are a number of steps taken by the researcher within this study that should be commended including the use of photos and the collection of data at four different points. These steps enabled and facilitated a richer dialogue and exploration of the lived experiences of the participants. The use of IPA in addition to the steps outlined meant the researcher examined the phenomenon from the individual level enabling an interpretation of the phenomena at a deeper level. Despite the strengths of the study, there are limitations including the researcher omitting information on the characteristics of the participants which in turn makes it difficult to know whether these findings relate to all autistic pupils or if it is more specific to autistic pupils who are unfamiliar with their environment (i.e. Year 7) due to transition. Moreover, the researcher has not provided any information on participants' gender which is problematic as there is growing research to suggest that autistic females present differently to boys (Goodall et al., 2019).

2.3.3.2 School curriculum

Saggers et al., (2011) explored the lived experience of autistic young people in a school in Australia. Using qualitative inquiry, the researchers examined inclusive education from the perspective of nine autistic pupils. Participants included seven boys and two girls ranging between the ages of 13 and 16-year-old. Data was gathered exclusively via interviews, once at the middle of the school term and then again two weeks later. Data was then analysed using constant comparative methods.

School curriculum emerged as a key issue for autistic young people and how they experienced school. Saggers et al., (2011) reported that eight out of the nine participants had difficulties with tight deadlines associated with assignments and exams. Other difficulties involved handwriting, with the majority of the participants reporting that they found writing notes exhausting, “my fingers gets a bit sore because I, you know, I've got a callous here…And well it just sort of hurts my arm when I write a lot” (Saggers et al., 2011, p. 180). Participants suggested being able to type their schoolwork as opposed to writing out notes as a way of reducing some of this pressure. The researchers also found that the work assigned to participants was received differently; for some participants the work was hard for others it was easy, but for one particular participant his response seems to suggest that he was receiving a balance between easy and hard work. Other studies such as Hill (2014) reported a correlation between levels of anxiety and certain subjects. For example, five out of the six participants in this study showed a preference for subjects that were more practical such as Design and Technology (DT). The researcher suggests that one possible reason for this preference is that it reduces the pressure of "getting the wrong answer" (Hill, 2014, p. 84). Additionally, it may also take the pressure off from the need to socially interact with peers as subjects like DT often do not require group work.

It is important to note that the Saggers et al., (2011) study was conducted in Australia. Differences in educational context, as well as cultural and social factors, may mean that findings may not be applicable to autistic young people in the UK. Additionally, it is worth repeating that the heterogeneity of autism was not represented, as all the participants were diagnosed with AS.

Connor (2000) used qualitative self-report to explore the day-to-day school experience of young people with AS. Participants consisted of 16 pupils (15 boys and one girl) attending comprehensive schools ranging from Year 7 to Year 11. The views of nine Specialist educational needs coordinators (SENCos) were also captured in the research.

Similar to Saggers et al., (2011) study, Connor (2000) found that DT was the most liked subject by participants. The self-report ranking showed a preference for activities that were practical. There appeared to be a dominant shared view by participants that subjects that required a significant amount of reading or social interaction were least liked and therefore rated low. Some of the participants reported to learning best when they "…have a choice of activity" (Connor, 2000, p. 291). Additionally, the majority of participants emphasised the importance of having teachers that understood them and their needs. However, other studies such as Saggers et al., (2011) found that participants wanted teachers to support them with tasks discreetly so that they would not attract attention and appear different to the rest of the classroom. This approach was also highlighted by other studies as participants wanted to 'fit in a little better'

(Humphrey et al., 2008; McLaughlin et al., 2014). Connor (2000) found that interviews with the SENCos revealed the difficulty of making sure that all teachers had an appropriate understanding of AS and how it impacts young people.

While the focus of this study (Connor, 2000) was the general experience of young people with AS the analyses of this paper appeared to be shaped largely by researchers' interpretations of SENCos' reported experience, with the majority of themes being drawn solely from SENCos rather than pupils. The participants' voices were obscured by the use of semi-structured interviews with pre-determined questions, as such the voices of young people with AS were not well represented. There appears to be insufficient extracts from the textual data as such the presentation of the findings appeared to lack transparency. Furthermore, the analytic procedure used in this study was not reported and therefore it is not clear how the researcher interpreted and drew themes from the study.

2.3.3.3 Summary on studies that have explored school setting

The findings from the reported studies suggest that autistic young people who experience sensory difficulties can miss out on crucial opportunities for peer interactions such as socialising outside the classroom or group work in lessons. These missed opportunities can further distance autistic young people from their peers. Additionally, the literature suggests that autistic young people tend to prefer subjects that are more practical. Moreover, none of the studies found were emancipatory in their approach. A gap, therefore, exists in empowering autistic young people to share their experiences.

2.4 Summary and conclusion of the literature review

The systematic review identified three, interconnecting, themes relating to the educational experience of autistic young people: self-concept, peer relationships and school setting. While efforts have been made by researchers to explore the voice of autistic young people, research is still within the emerging stages. This is highlighted by the relatively small pool of available literature as only nine studies met the inclusion criteria. The overall weight of evidence (WoE D; Gough, 2007) was also relatively weak as only three studies were judged as high quality (Humphrey et al., 2008;

Saggers et al., 2011; Goodwell et al., 2019). Additionally, this systematic review found that the available literature does not represent the heterogeneity of the autism population. This is because the majority of studies represented the views of largely Western cultures and verbally able male pupils with AS or HFA. The lack of description of the participants' ethnic background in the majority of the studies, suggests that the ethnic backgrounds of the participants were not considered by the researchers. Due to these limitations, it makes the findings difficult to transfer to other cultures and populations highlighting a gap within the literature.

The present systematic review focuses exclusively on qualitative studies it does highlight challenges relating to methodology in this area namely: (1) the methods employed to elicit the voice of autistic young people and (2) the fundamental ways in which autistic young people contribute to research. The review highlights that the majority of the research designs selected to elicit the experiences of autistic young people are still being administered 'to' participants rather than 'with' participants. This results in power imbalances which influence how participants engage with the research process and the knowledge produced (Milton, 2012). One way of addressing the power imbalance is to position autistic young people as experts in their own lives and to actively encourage them to be involved in all aspects of research. In this way, they can inform the future direction of research within the field of autism.

Given the findings, it is possible that adopting a participatory approach could shift how autistic young people are viewed within the research by reframing the dominant view that they cannot be actively involved in all aspects of research. Additionally, describing and documenting how autistic young people can be involved in research successfully could contribute to increasing their participation in research. Such documentation could also serve as a link between research and practice as it could provide a framework for researchers and practitioners alike to use when eliciting the views of this population. With this in mind, it appears that there is scope for in-depth participatory research exploring the views of BAME autistic young people.

2.5 Chapter Summary

This chapter provided a comprehensive and systematic review on the available on the literature on pupil voice, autism and educational experience. The chapter provided details on the literature search process as well as a critical analysis of the research findings. The three identified themes and related studies were discussed and critically analysed from several different perspectives. The methodological limitations of the studies identified provide a basis for the next chapter on Methodology.

Chapter 3: Methodology

3.1. Introduction

Having reviewed the literature relevant to autism and pupil voice, chapter three presents the methodological design adopted within the current study. The chapter starts with the ontological and epistemological positions of the researcher and how the researcher's worldview influences the method and design of the study. The theoretical and conceptual frameworks of social justice and Bronfenbrenner's ecological model (1994) are presented as lenses to engage the stories of the research participants with. The chapter also provides a rationale for selecting a qualitative participatory research design and outlines the recruitment, training and the role of the co-researcher. The chapter will then go on to discuss the procedure of carrying out the interviews with the participants, the process of carrying out IPA, explain ethical considerations before concluding with a review of the quality of the research.

3.2 Epistemological and ontological positions of the current research

To understand the methodological design selected for this study, it is imperative to first explain the ontological and epistemological assumptions that frame the research. Drawing upon Guba and Lincoln (1989), ontology is concerned with understanding the nature of reality, whereas epistemology is concerned with how knowledge is produced (Matthews, 2003). There are five distinct research paradigms, each differing in their ontological and epistemological assumptions, that can be adopted when carrying out research within social sciences. A researcher's chosen paradigm governs how the research should be carried out and the methods that should be used. This research was carried out from a social constructionist position with consideration to symbolic interactionism. Social constructionism takes a "critical stance towards taken for granted knowledge" (Burr, 2015, p. 2). Researchers adopting this position are cautious about assumptions relating to their understanding of the world and how it appears to them.

In contrast to a positivist position which views reality as a singular universal truth, this study adopts a relativist ontological position and rejects the notion of a 'true' reality (Braun & Clarke, 2013). Social constructionism suggests that multiple realities of our understanding of the world exist and our knowledge about categories and concepts are socially constructed and a by-product of history, language and culture (Burr, 2015). This is crucial when considering autism, particularly given that the triad of impairments of social communication, social interaction and repetitive and restricted behaviour is viewed as a problem within society. However, across a different time, culture and context these characteristics associated with autism might not exist. Additionally, social constructionism would propose that race is a social construct as one's racial category or status can change depending on the social and political context in that time. Consideration is also given to symbolic interactionism, which is the view that as individuals we construct and make sense of our world through social interactions (Burr, 2015). We exist in relation to others and as such we affect and are affected by our social interactions and more specifically our use of language. In this study, there is an assumption that young people may have been exposed to a discourse about their diagnosis and ethnicity that reflects those around them (parents, teachers, peers and society) and that their lived experience and perception is influenced by their historical and cultural context. The lived experience of the individuals is therefore subjective and based on social interactions and understanding of the world. This leads to individuals having a range of interpretation of concepts such as autism and race.

Social constructionism has been selected for this study as it places emphasis on listening to the individual to understand how they construct a reality that applies to them in their social and cultural context. According to this position, by adopting interviews as a method we can gain knowledge of subjective realities constructed by individuals. Therefore, initiating an exploratory study using qualitative interviews to explore the lived experience of BAME autistic young people is consistent with this ontological and epistemological position. By adopting a social constructionist position there is an acknowledgement that the choices and the interpretation made within this study are formed by the researcher's culture, beliefs, and history as well as the lived realities of the co-researcher and the participants. This research is therefore interpretative and recognises that others may construct alternative interpretation of the findings based on their worldview. By holding this in mind, the researcher has been able to curiously challenge personal biases relating to her experience and understanding of the world by remaining conscious and self-aware of how subjectivity may have impacted on this study.

3.3 Aims and purpose of the research

The aims of the current study were to:

1) Empower a BAME autistic young person as a co-researcher; and
2) Explore the lived experiences of BAME autistic young people

The researcher hoped by having clear research aims, that this study would contribute towards social justice by shifting the nexus of power as well as enabling participation and giving a voice to a marginalised group.

By adopting a participatory approach, it is hoped that this study will have a number of benefits for the co-researcher including:

1. developing new research skills;
2. having their voice heard on things that matter to them; and
3. a chance to create change in ways that will be beneficial to them.

3.3.1 Purpose

Polit et al., (2001) state that the purpose of research should be to adopt an exploratory approach if there is an indication that there is limited information available in an area. From a review of the literature available, there appears to be no published research that has explicitly focused on the experiences of BAME autistic young people. Consequently, the primary purpose of the study was exploratory in order to develop an insight and understanding into the experience of BAME autistic young people. In this way, the findings can be used to develop EP practice and inform future research (Robson, 2011).

Another key purpose of this study was emancipatory, in line with the participatory principles adopted within the study. The concept of ‘emancipatory’ research involves “the facilitating of a politics of the possible by confronting social oppression at whatever level it occurs” (Oliver, 1992, p.101). The researcher carefully considered and applied the principles of emancipatory research advocated by Stone and Priestley (1996). For example, they propose that a cornerstone of emancipatory research is positioning participants and not the researcher as “true knowers” (Stone et al., 1996, p. 699). Within this study, participants were positioned as expert of their lived experience, additionally power imbalance that arises as result of traditional research, were considered and reflected on. This study aims to facilitate greater collaboration between the researcher and the research participants and adopt methods that promotes self-advocacy and empowerment. Another principle is ensuring that research is only undertaken where there is or will be a ‘practical benefit’ to the group being researched (Stone et al, 1996). By exploring the lived experience of BAME autistic young people it is hoped that the findings can be used to support and improve the experience of this group of young people. Stone et al., (1996) advocate that research should directly empower the individuals involved in the research process. Within this study this is done by adopting a PR design, which means that a BAME autistic young person is recruited, trained and empowered as a co-researcher.

This research also has a transformative purpose as it encourages the engagement of BAME young people while focusing on increasing social justice. In line with Merten’s (2010) definition of transformative paradigm, the assumptions adopted within the study are “enhancement of social justice, furtherance of human rights, and respect for cultural norms” (Merten, 2010, p.470).

3.4 Theoretical and Conceptual Framework

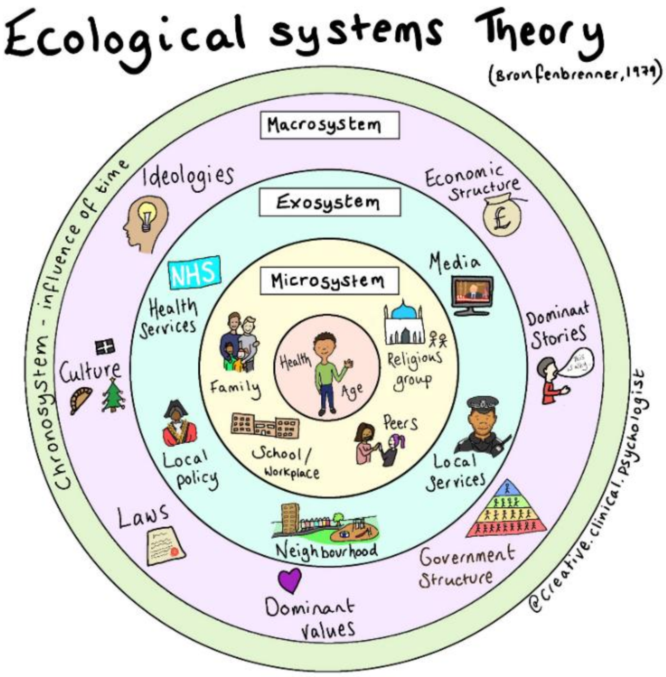
The purpose of this section is to present the theoretical and conceptual frameworks that provide critical lenses through which to engage the stories of the research participants.

3.4.1 Ecological Model

Loveland (2001) proposes that “autism is not a static condition existing within a person, but a developmental process that can only be understood as taking place through the interaction of person and environment” (p. 22). The ecological model proposes that the behaviours of autistic individuals are the outcome of the interactions between the individual and the multiple different systems. As such, this model attempts to explain the individual in relation to their interaction with their family, community and larger systems. Bronfenbrenner’s ecological model (Bronfenbrenner, 1994, Figure 3.1) provides a helpful framework for research for understanding the interrelationships and systems an autistic young person interacts with. It can be argued that the lived experiences of BAME autistic young people should be considered using this framework as this model emphasises equal attention to the individual and the environment in order to understand the phenomenon under study.

Figure 3.1

Bronfenbrenner's (1994) Ecological Model.



3.5 Interpretative phenomenological analysis

Interpretative Phenomenological Analysis (IPA) is a distinct qualitative approach that aims to, "explore in detail how participants are making sense of their personal and social world" (Smith & Osborn, 2007, p.53). IPA first emerged in the 1990s as a way of offering a qualitative analysis that focused on exploring individual lived experience on its own terms. By its very nature, IPA is valuable for gaining an insight, through detail exploration, into the lived experience of autistic individuals. IPA also aligns well with PR and using these approaches together can bring new knowledge and understanding to the field of autism. To understand the current IPA study which employs a PR approach, it is essential to first present IPA's three main philosophical influences: phenomenology, hermeneutics and ideography (Smith et al., 2012). The researcher describes the process of 'doing the analysis' later in the chapter.

3.5.1 Phenomenology

Phenomenology can be defined as ‘‘the study of lived experience’’ (Van Manen, 1997, p. 9). Grounded in psychology and philosophy, the aim of phenomenological studies is to first describe the participant’s experience of the phenomenon and then to gain an insight into the participant’s world (Smith et al., 2012). According to phenomenological philosophers such as Husserl (1927), researchers carrying out descriptive phenomenological research should adopt a ‘bracketing’ approach whereby previous experience, bias and belief systems are put aside during the research. Husserl (1927) proposed ‘bracketing’ the researcher’s previous experience in order for the phenomena under study to be seen clearly and without the impact of the researcher’s interpretation. This approach is known as the epoché (Smith et al., 2012). In contrast, Heidegger (1962), a student of Husserl’s, questioned the ability of individuals to be able to put aside influences from previous experiences. Heidegger (1962) developed an alternative to Husserl’s original descriptive phenomenology and proposed the concept of ‘inter-subjectivity’ which refers to “the shared, overlapping and relational nature of our engagement in the world” (Smith et al., 2012, p.17). He argued that as human beings, we are inseparable from the world in which we live and exist and therefore interpretation of individuals’ sense making is vital for phenomenology. Despite these differences, phenomenological methodologies adhere to a key concept of ‘reduction’ i.e. maintaining an open mind and returning to; “the original sources of peoples experiences’’ (Heinonen, 2015, p. 35) to ensure that researchers capture the uniqueness of each individual’s experience of the phenomenon under study.

3.5.2 Hermeneutics

The second influence of IPA is hermeneutics, which refers to the theory of interpretation (Smith et al., 2012). In the beginning, hermeneutics were to interpret biblical texts; subsequently philosophers used the theory to interpret transcriptions of interview data. IPA adopts Heidegger’s (1962) notion of ‘appearing’ to conceptualise the process of interpretation; this involves the researcher shining light on the phenomenon and using detective work to uncover what is being said and then making sense of it by engaging in close interpretation. Smith et al., (2012) proposed that researchers should engage in reflexive practice in order to recognise the impact of their previous experience on their interpretation of the data.

3.5.2.1 Hermeneutic circle

The hermeneutic circle (Smith et al., 2012) describes the process of interpretation and is concerned with the “relationship between the part and the whole” (p. 28). Heidegger (1962) proposed that as human beings we are situated in context and our relation to the world is both relational and interpretive. This means that to understand any part of the experience, the researcher needs to understand the whole experience i.e. the bigger picture, and therefore factors such as culture and language become crucial. Neither the part nor the whole can be understood in a single form or without reference to each other – this is known as the hermeneutic circle.

3.5.2.2 Double hermeneutic

Smith et al., (2012) suggest that the process of doing IPA involves a ‘double hermeneutic’. Double hermeneutic refers to the process whereby the researcher is making sense of and interpreting the participant’s attempt at making sense of their experience. This illustrates the dual role of the researcher in that the researcher is like and unlike the participant (Smith et al., 2012); they have access to the participant’s experience of the ‘phenomenon’ but seeing this experience through the lens of a researcher (Smith et al., 2012). By engaging with the data in this manner, IPA recognises that the researcher’s interpretation is influenced by the researcher’s experience, psychological thinking and understanding. IPA dictates that this is a necessary process in order to be able to interpret and make sense of participants’ experiences of the ‘phenomenon’. Therefore, IPA requires both the double hermeneutic and phenomenological insight as “without phenomenology, there would be nothing to interpret; without the hermeneutic, the phenomenon would not be seen” (Smith et al, 2012, p.37).

3.5.3 Ideography

The third major influence of IPA is ideography which is concerned “with the particular” (Smith et al., 2012, p.29). Unlike some other psychology research methodologies which are concerned with making claims about a phenomenon at a group level, IPA is committed to examining phenomena at an individual level. IPA is explicitly idiographic in that analysis occurs at a detailed and deep level of each case before moving to more general claims. To do this, IPA proposes undertaking a small sample size or even single cases to examine the phenomenon from the perspective of the individual, which in turn enables the researcher to interpret the particular phenomena at a deeper level.

3.5.4 Why IPA?

IPA promotes detailed and rich exploration of the phenomenon at an individual level and considers how it is contextualised by society, history and the cultural forces (Lopez & Willis, 2004). This is particularly pertinent to BAME autistic young people, whose triad of impairments are often defined by their social, historical and cultural context. According to William (1996) autism is largely assessed from an ‘outside’ perspective and not from the ‘‘inside according to how it is experienced’’ (p.14). As such, access to ‘inside’ interpretations of this phenomenon is crucially missing (Pellicano et al., 2013). However, by adopting IPA to explore such phenomenon it has the potential to bring forth ‘inside’ interpretation and reveal new understanding. Additionally, it seems appropriate to employ the holistic approach of IPA, focusing on the self, to explore how BAME young people experience the term autism, whereby “sense-making may require accommodating (or rejecting) an externally imposed identity” (MacLeod, 2019, p. 50).

IPA was also selected as it aligns with the researcher’s social constructionist position. By considering symbolic interactionism the researcher was able to explore the lived experience of BAME autistic young people at a deeper and more meaningful level with each participant. This approach is believed to be the best way to understand a phenomenon as it fits with the objectivities of the study. IPA has a strong theoretical basis which can be used to explore how BAME young people perceived their autism diagnosis and what being BAME and autistic means to them. Finally, IPA combined with the principles of PR allows for an interpretative phenomenological analysis to be carried out with a co-researcher. The experiences of the individual participants are interpreted through the lens of both the researcher and co-researcher. This allows for a deeper interpretation of the phenomena.

3.6 Research design: methodology

The purpose of the current study is to explore the lived experience of BAME autistic young people. The researcher required a design that would allow for detailed investigation of individual experience as well as a flexible design that would support rapport building in order for the researcher and co-researcher to access and make sense of the participants' inner world (Morgan, 2007). A qualitative research design was chosen as it utilises language as a vehicle to give voice to individuals, in turn addressing the research questions and guiding the data collection. In order to carry out the current research using a robust research design, the researcher utilised Patton's (2000) strategic framework for qualitative inquiry, integrating key qualitative and constructionist epistemological assumptions.

3.6.1 Participatory qualitative method

This research adopts the principles of PR outlined in Chapter 1 and uses Aldridge's (2017) PM as a frame of reference to carry out the research. The rationale for adopting this approach is to generate opportunities for marginalised groups, in this case BAME autistic young people, to have a 'voice' (Humphries, 2005) and to contribute to defining 'truth' and generating 'knowledge' (Cornwall & Jewkes, 1995). This study utilised participatory qualitative methods to enable the researcher and co-researcher to identify social problems, and then plan, implement and evaluate research around that problem in order to generate new knowledge. In this way, research is carried out 'with', rather than 'on' the BAME autism community.

3.7 Recruitment and selection of the co-researcher

In order to empower the voice of BAME autistic young people, access richer data and enable effective implementation of the findings, a co-researcher was recruited to the study. Given the timescales and demands associated with the doctoral training programme it was felt by the researcher that there was only capacity for one co-researcher.

The inclusion criteria for the selection of the co-researcher were as followed: (1) aged between 12 to 25 years old, (2) a known diagnosis of autism and (3) from a BAME background. A recruitment email was sent out to two sixth forms and one secondary school in the LA where the research took place. The email outlined information about the role of the co-researcher and asked staff to contact the researcher if any young people came to mind or if they were willing to support the recruitment of a co-researcher. The SENCo at one of the sixth form colleges indicated via email that there were several young people within the college that meet the criteria and who would potentially be interested in the role of the co-researcher. In order to select a co-researcher, all three potential co-researchers, their Learning Support Assistant and the SENCo were invited to a presentation about the research project. The presentation covered: the role of the co-researcher, the nature of participatory research, stages and timescales of the research as well as the benefits of being a co-researcher (Appendix 3.1). Of the three possible co-researchers, one expressed an interest in being involved in the research project. At this point, the potential co-researcher was provided with a written information sheet and consent form. Consent was sought both verbally and in written form before any involvement began.

3.7.1 Introducing my co-researcher

My name is Superman and I am 19 years old. I live with my mum and my elderly grandad. I want to be a counsellor for people with disabilities in the future.

This section introduces the co-researcher and reflects on his position within the research, for the purpose of introducing the co-researcher, he is referred to as Superman in this section of the thesis.

The pseudonym name Superman was selected by the co-researcher. The researcher supported the selection of the name Superman as it captures the co-researcher's bravery and commitment to the research. Superman identifies as a Black-Caribbean male young person. He was diagnosed with autism when he was 9 years old. During our first meeting, Superman shared with me his experiences of growing up as an autistic black male in the UK. He told me about his school experiences which included incidents of bullying and feeling like an outsider because of his autism label. Despite these experiences Superman was optimistic about the research and shared that he wanted to be involved in order to help other young autistic people.

It was important to the researcher that Superman was positioned within the research as an expert of his lived experience. PR is more than simply ‘taking part’ in research, it involves supporting young people like Superman to be actively involved in expressing their voice in ways that make a difference (Batsleer, 2008). The researcher’s position is that PR is as much as a process as it is a principle and engaging with young people in research models a social participatory approach as set forth by Friere (1972). By involving Superman in this way, he develops skills that would have previously been considered as ‘expert’ or ‘professional’ knowledge, reserved primarily for researchers (Healy, 2000).

3.7.2 Co-researcher training

Taking into consideration the researcher’s position on PR, it was deemed necessary to train the co-researcher on the fundamentals of research and its techniques, in order for him to be authentically involved and have his voice heard. The lesson structure and aims outlined in Kellet’s (2005) textbook were used to train the co-researcher. It was felt, however, that the interactive elements suggested for teaching the lesson aims were not always age appropriate for the co-researcher. As such, much of the delivery of the content was adapted and personalised for the co-researcher. The training consisted of eight one-hour virtual sessions, which occurred every Monday over a period of eight weeks (the lesson structure and plans used can be found in Appendix 3.2).

As a practitioner-researcher designing the training sessions, it was important that the first session was dedicated to building rapport with the co-researcher. The researcher recognises that building trust from the onset is crucial to the successful involvement of the co-researcher. Throughout the training sessions, the researcher reflected on the steps taken to establish and maintain trust (Appendix 3.3). To deliver the aims of the lessons, a range of methods were used such as discussions, mind maps, videos, role play and a sorting activity. The co-researcher engaged positively with the teaching methods and appeared to gain confidence over the sessions; for example, at the start of the training the co-researcher shared that he did not want to be involved in collecting data. However, by the end of the training, the co-researcher felt that he had developed enough skills to be involved in collecting data. Despite the co-researcher’s increased confidence, he did not appear to lose his lay perspective and was able to challenge and contribute his ideas throughout the research study.

3.7.2.1 Evaluating the training

As a research-based profession (Edward, 2002) the importance of evaluation is well documented in EP practice. With this in mind, the researcher employed scaling and questioning as a way of seeking feedback from the co-researcher. Scaling was used after each session whereas questioning was used to concept check and ensure that the co-researcher was able to apply the skills learnt to the research setting. Feedback was used to tailor subsequent sessions to the co-researcher. At the end of the training, the co-researcher was asked to complete an evaluation form (Appendix 3.4), the co-researcher rated the overall training as a 10, and fed back that he had “really enjoyed the sessions”.

3.8 Co-researcher’s level of participation

The researcher applied the principles from Aldridge’s (2015) PM to ensure that this study was co-researcher led and that the voices of the participants and co-researcher were prioritised. Within this model, the participants are positioned as expert in their lived experience and the researcher is the facilitator of this expertise. The researcher used Aldridge’s (2015) PM to facilitate and support the co-researcher to make decisions relating to the research. In order for the co-researcher’s involvement to be authentic, the level of participation was determined by the co-researcher. Table 3.1 outlines the stages of research and the level of participation from the co-researcher.

Table 3.1

Stages of research with levels of participation

Stages of research	Level of participation from the co-researcher
Stage 1: Designing research questions and interview schedule	• The researcher introduced a broad idea of what the research could focus on to the co-researcher.

	- The co-researcher alongside the researcher refined the topic of interest for the purpose of the research. - Co-researcher and researcher collaborated on developing the research questions. - The co-researcher in collaboration the researcher developed the interview schedule.
Stage 2: Pilot interview and finalising the interview schedule	- The co-researcher along with the researcher carried out the pilot interview. The researcher facilitated a reflective space for the co-researcher to share his thoughts on the pilot interview. - The co-researcher decided on the final interview schedule that was used in the study.
Stage 3: Recruitment and data collection	- The researcher sent out recruitment emails and finalised the interviews dates. - The co-researcher was involved in carrying out the interviews for all participants.
Stage 4: Data analysis	- All interviews were transcribed by the researcher and then anonymised transcribes were shared with the co-researcher. - The co-researcher was involved in the data analysis including selection of final themes.
Stage 5: Data dissemination	- Both the researcher and co-researcher were involved in data dissemination which included delivering a PowerPoint presentation of findings to the co-researcher's college.

3.9 Research questions

Prior to development of the research questions, the co-researcher received training on how to frame and develop appropriate and measurable research questions (please see the section on co-researcher training and Appendix 3.2). Kellet (2005) suggests that the process of developing and refining research questions can empower and encourage the co-researcher to feel ownership over the research project, which in turn can significantly motivate them to be actively involved until completion of the research project. With this in mind, the development of the research questions was led by the co-researcher supported by the TEP.

It is worth noting that prior to the involvement of the co-researcher, the researcher presented a broad concept and idea of what the research could entail (such as friendships, culture and school experiences), to the co-researcher. The researcher explained that she was interested in the experience of autism from the perspective of BAME individuals. However, it was made clear to the co-researcher the focus of this experience would be up to him to decide.

The ‘funnelling down’ approach was used to first explore the co-researcher’s interest; this was then narrowed down until a research topic was identified. The research topic was selected by the co-researcher after careful consideration of other topics such as friendships. The selected research questions were chosen as the co-researcher was keen to explore whether his lived experiences were shared by other young autistic people. More specifically whether his experience as a black young autistic person was shared by others BAME autistic young people. A discussion on the BLM movement (which was prevalent in the media at the time) revealed that my co-researcher believed that his experience of autism differed compared to White autistic young people. The co-researcher expressed a desire to explore whether his experiences and perceptions of race are shared by other BAME young autistic people. To ensure that the research questions were appropriate, the co-researcher was supported with the wording of the research questions by the TEP.

The final research questions are as followed:

What are the lived experiences of Black, Asian and Minority Ethnic (BAME) autistic young people?

Sub-questions:

1. How does a diagnosis of autism impact on their sense of self?
2. How do young people see their experience of being BAME and autistic?
3. What relationships have supported their experiences?

3.10 Data Collection

When selecting a method for collecting data for IPA studies, the researcher and co-researcher held in mind that IPA is best suited to methods which invite participants to "offer rich, detailed, first-person account of their experience" (Smith et al., 2012, p.56). In-depth interviews and diaries are two methods that would enable such access to participants' lived accounts (Willig, 2008). However, interviewing participants was deemed more practical and better suited to the nature of study as it would allow the researcher and co-researcher to collect stories of the participants in 'real time' (Patton, 2000). Additionally, adopting interviews as a data collection method is more inclusive as there is no reliance on writing.

3.10.1 Semi Structure Interviews (SSIs)

The purpose of semi-structure interviews (SSIs) is ''to obtain descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomena" (Kvale, 1996, p.5). As the current study is concerned with the lived experiences of BAME autistic young people, SSIs was deemed the most appropriate method for collecting data as it would allow participants to openly share their stories. Additionally, this method allows for the researcher and co-researcher to be responsive and curious about participants' experiences using probing methods. A key strength of SSIs is that they offer opportunities for the researcher and co-researcher to digress from the schedule and respond to individual differences. This is particularly important as following a structured interview approach could mean that some of the participants experience of the phenomenon could be lost, resulting in missing an opportunity to offer new ways of considering the experience of BAME autistic young people.

Prior to COVID-19 restrictions, the researcher and co-researcher intended to collect data face to face using SSIs. To maintain the safety of participants and the co-researcher, a decision was made to collect data virtually. Initially, some reservations were held by the researcher in regard to the implications of rapport building if the interviews were conducted virtually. However, advances in technology have meant that the way in which young people communicate about their personal experience has changed over the years. A study by Weller (2015) found that carrying out interviews remotely can facilitate a greater level of communication from young people regarding their lived experience. Furthermore, the study found that the informality associated with online interviewing and the physical absence of the researcher fostered a greater sense of ease. Carrying interviews online has been shown to facilitate a “greater (emotional) connection through participants’ increased sense of ease with the setting” (Weller, 2015, p.625). With this in mind, the researcher and co-researcher decided that all interviews including the pilot interview would be carried out virtually using Microsoft Teams.

3.10.2 Designing the interview schedule

Smith et al., (2012) recommend developing an interview schedule in order to facilitate a relaxed interaction with participants to enable them to share detailed accounts of their lived experiences. The interview schedule for this study was developed in collaboration with the co-researcher and followed the stages recommended by Rubin and Rubin (2005). The co-researcher and researcher took into account a number of considerations with regards to interviewing autistic young people. Firstly, findings show that autistic young people often display concrete thinking resulting in the development of literal language (Hobson, 2012). Therefore, at the start of the interview the researcher and co-researcher spent some time developing a shared meaning of key concepts such as BAME and culture with participants to ensure that there was no ambiguity or misrepresentation during the data analysis stage. This is a fundamental aspect of employing qualitative interviewing in research as the subjectivity of interviews can lead to exploring multiple and at times conflicting perspectives that arises from interviews (Warren, 2001). Secondly, in light of research that shows that autistic young people find new and unpredictable environment difficult to manage (Vicker, 2007), the researcher and co-researcher at the start of the interviews participants were provided with a visual outlining the different stages of the interview and how long each stage would last. Additionally, visuals of activity one and two (scaling and Bronfenbrenner, 1994, ecological model) were shared with participants to aid in the understanding of the questions being asked. Thirdly, to put the participants at ease it was decided that the questions would be asked by the co-researcher and where it was necessary the researcher would use prompts to support the participant to communicate their experiences or to expand their responses further. Phrases such as ‘anything else’ were also applied at appropriate times as advocated by Robson (2011). Finally, the practitioner-researcher held in mind the principles of attuned interaction when building rapport and carrying out the interviews (see Appendix 3.6 for the final interview schedule).

3.10.3 Pre-pilot practice interview

The researcher arranged a pre-pilot interview with an EP (who identifies as Asian-British) with experience of working with autistic young people. The EP was asked to answer the interview questions as though she was a young BAME autistic person. There were several reasons for arranging a pre-pilot interview including facilitating an opportunity for the researcher and co-researcher to: (1) become familiar with asking the interview questions, (2) practise interviewing skills and (3) obtaining feedback from the EP on the interview questions and process. The EP fed back that she felt that it would be helpful to get a reminder of the purpose of the research before the interview begins to ensure transparency and remind the participants that there was no hidden agenda. On considering this feedback, the researcher and co-researcher decided that they would collaboratively develop a statement explaining the purpose and aims of the research that would be shared with participants at the start of the interview. Additionally, the EP shared that whilst the visuals presented for activity two were helpful, she wondered whether the visual could remain on the screen when being asked subsequent questions. Both the researcher and co-researcher agreed that this would be helpful going forward as such included a reminder on the schedule to keep the visual on the screen when asking subsequent questions. The EP reported that she ‘really liked’ the last question as it left her feeling positive. Overall, the EP reported feeling at ease and respected during the interview process.

3.10.4 Pilot study

Carrying out a pilot study is particularly useful in PR and IPA studies, this is because firstly it allows the researchers to determine the feasibility of the research, assess any potential issues that may arise as well as gain a practical sense of the phenomenon in order to develop understanding. Kezar (2000) proposes carrying out a pilot study to enable the researcher to gain a ‘real world’ experience which in turn improves the research design. Wethington et al., (2007) found that carrying out a joint review of a pilot study increased the participatory nature of the study. For this study, a pilot was carried out to test the following: (1) feasibility of the research, (2) any ambiguity with the interview schedule and (3) the online data collection method.

In keeping with the theme of superheroes for pseudonym names, each participant was asked to select a superhero pseudonym name that reflected them and their journey. The pseudonym name Hulk was selected by the young person with whom the pilot study was carried out with. Hulk is an 18-year old male who identifies as a Black Caribbean autistic young person. Hulk was introduced to the researcher by the Post 16 Pathways and Employment Co-ordinator at the LA where the research was taking place. The researcher was told that Hulk previously contributed positively to autism events in the LA and was known to be vocal about the rights and treatments of autistic young people within the LA. Hulk was keen to be involved in the research project and reflect on his experience as a BAME autistic young person. Van Teijlingen and Hundley (2007) propose that using the findings from the pilot study within the main findings can lead to "contamination of the data" (p.36). The researcher and co-researcher therefore decided not to include Hulk's experience of the phenomenon as part of the main findings. As such the interview was not transcribed instead the researcher and co-researcher used it as an opportunity to test the aims of the pilot as well as reflect on the process and how it *felt* for Hulk. Hulk reported that he has not been asked questions about his background in relation to his autism and that he found the whole process 'therapeutic'. Upon hearing this feedback, the researcher and co-researcher decided that the interview schedule would remain the same.

3.11 Research participants

There are two sets of research participants in this study;

1. One co-researcher who identified as BAME autistic young person who has been trained to carry out research and;
2. Four BAME autistic young people positioned as experts in their own lived experiences.

3.11.1 Recruitment of participants

Participants were recruited using a purposeful sampling strategy, which involved identifying and selecting participants who were information-rich and who can provide an insight into the phenomenon being researched (Cresswell, 2014). Participants were recruited via schools and colleges within the LA and through the autism specialist teacher (AST) for the Borough. The researcher sent out emails to SENCos and the AST detailing the research and asked them to identify any participants who meet the following inclusion criteria: (1) aged between 12 to 25 years old, (2) Have a diagnosis of autism including what was formally known as Asperger Syndrome, (3) from a Black, Asian and Minority Ethnic Group and (4) able to share and discuss their experience of autism.

Following the SENCos and AST identification of pupils, consent form and information sheet were sent out to parents and potential participants. The researcher offered to answer any questions about the research to parents and participants via email and phone. Once consent forms were received, the researcher scheduled the interviews ensuring that the dates and times were suitable for both the participant and the co-researcher. The co-researcher and researcher discussed consent with the participants at the start of the interviews and were informed of their right to withdraw without any consequences.

3.11.2 Participant characteristics

In total, four BAME autistic young people, aged 14–19 took part in this study. Participants included in this study had a formal diagnosis of autism or Asperger's Syndrome. A pilot study was also carried out with an 18-year-old male who identified as a BAME autistic young person. While the number of participant (n=4) may appear small, IPA studies require a small sample number due to its idiographic method of inquiry which enables rich data to be gathered for analysis. For more information on participants' characteristics please see table 3.2.

3.12 Procedure

The data for this study was collected using SSIs via audio and/or video on Microsoft Teams. Interviews were carried out between October and December 2020. On average interviews lasted 48 minutes. At the beginning of each interview, participants were invited to look over the participant consent form to see if they had any questions and to check that they still wanted to take part in the research. They were also given a brief introduction into the purpose of the research, including definitions of key terms. Participants were reminded that they could ask questions they had throughout the interview. The researcher and co-researcher then proceeded through the schedule with the participants. At the end of the interview, participants were given the opportunity to share anything additional regarding their experience as a BAME autistic young person.

Table 3.2

Participant details

Name (pseudonym)	**Age**	**Gender** (as identified by participant)	**Ethnicity** (as described by the participant)	**Religion** (as named by the participant)	**Age when 'diagnosed'**	**Education / Employment status**	**Length of interview**
Hulk (Pilot)	18	Male	Caribbean	Christian	Primary school (Year 4)	Undergoing supported internship at the LA	. 42.03
Wonder woman	14	Female	British-Somali	Muslim	Primary school (Year 6)	Year 9 in a mainstream secondary school	55:22
Storm	19	Female	Black British African (Eritrean)	Muslim	Secondary school (age 13)	College / supported internship	55:02
Catwoman	16	Female	African-British (Ghanaian)	Christian	Primary school (age 6)	College	31:18
Wolverine	19	Male	British-Indian	Hindu	Primary school	Second year of university	55:09

3.13 Data Analysis ‘The process of carrying out IPA’

To ensure an active and reflective engagement with each of the participant’s interview data, the researcher followed the recommended six-step process described by Smith et al., (2012).

3.13.1 Step one: ‘Reading and re-reading’

The researcher began the IPA process by immersing herself in the data, this was done firstly by listening to the audio-recording before reading and re-reading the transcript. To ensure that the participant “becomes the focus of the analysis” (Smith et al., 2012, p.82), the researcher’s reflections and initial impressions were recorded in a research diary (please see extract example on Appendix 3.3).

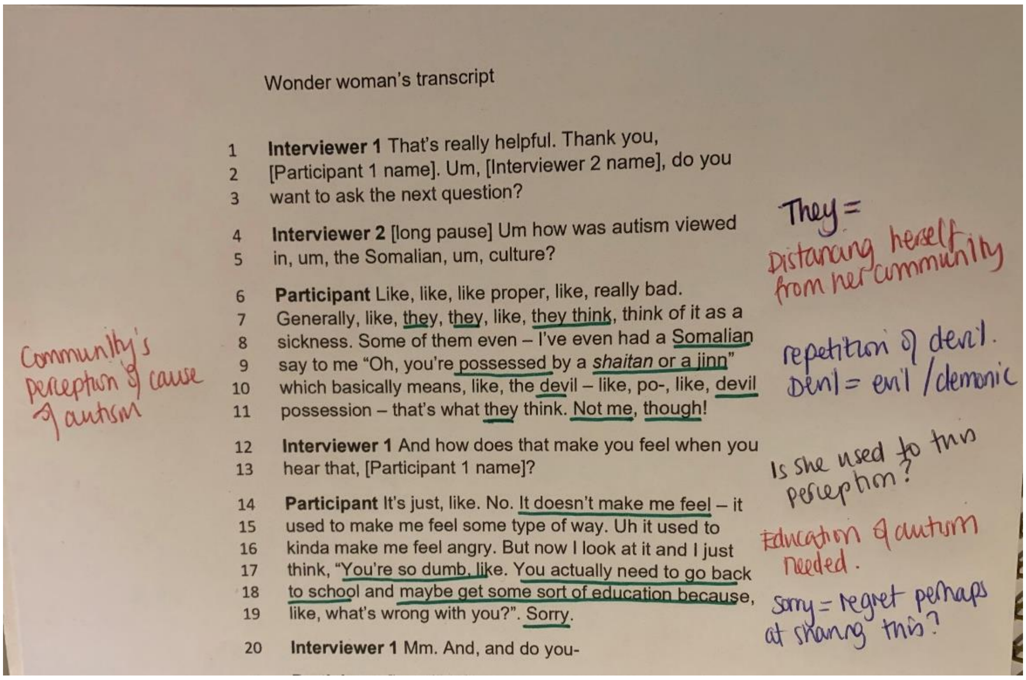
3.13.2 Step two: Initial noting

Step two involves making initial notes alongside the right-hand side of the margin. At this stage, in order to become more familiar with the transcript the researcher made notes on the semantic and language content used on a very exploratory level. In line with IPA’s approach to data analysis, there were three levels of analysis were carried out (Smith et al., 2012):

1. Descriptive (focusing on the content of what the participant said or the subject discussed),
2. Linguist (commenting on the way language was used by the participant) and
3. Conceptual (engaging with the data by questioning concepts and ideas by taking an interrogative approach).

At this point initial notes in relation to these three areas were made in the right-hand column of the transcripts (please see picture 1 as an example of initial note taking). The researcher’s reflective skills as a practitioner-researcher supported the shift from superficial interpretation of the participant’s word to the interpretive.

Picture 1: Initial notes on Wonder woman's transcript



Wonder woman's transcript

Interviewer 1 That's really helpful. Thank you, [Participant 1 name]. Um, [Interviewer 2 name], do you want to ask the next question?

Interviewer 2 [long pause] Um how was autism viewed in, um, the Somalian, um, culture?

Participant Like, like, like proper, like, really bad. Generally, like, they, they, like, they think, think of it as a sickness. Some of them even – I've even had a Somalian say to me "Oh, you're possessed by a *shaitan* or a jinn" which basically means, like, the devil – like, po-, like, devil possession – that's what they think. Not me, though!

Interviewer 1 And how does that make you feel when you hear that, [Participant 1 name]?

Participant It's just, like. No. It doesn't make me feel – it used to make me feel some type of way. Uh it used to kinda make me feel angry. But now I look at it and I just think, "You're so dumb, like. You actually need to go back to school and maybe get some sort of education because, like, what's wrong with you?". Sorry.

Interviewer 1 Mm. And, and do you-

Community's perception of cause of autism

They =
Distancing herself from her community

repetition of devil.
Devil = evil / demonic

Is she used to this perception?

Education of autism needed.

Sorry = regret perhaps at sharing this?

3.13.3 Step three: Developing emergent themes

The next step of the analysis process involved the researcher going back to the initial notes from the transcript in order to develop emergent themes. Smith et al., (2009) stress the importance of the analysis being grounded not only in the researcher's interpretation but the participant's original words. This stage involved the researcher analysing the initial comments in order to map the "interrelationships, connections and patterns between" (Smith et al., 2012, p.91) whilst preserving the complexity of the data. This process led to the researcher producing several emergent themes across the transcript. At this stage, the emergent themes were shared with the co-researcher and a discussion took place on how these themes emerged.

3.13.4 Step four: Searching for connections across emergent themes

This stage involved identifying patterns and connections between the themes. To do this, the researcher adopted several approaches including:

1. Abstraction – identifying patters and then grouping them under a superordinate them (Smith et al., 2012).

2. Contextualisation – identifying the contextual aspects of the narrative whilst attending to the “temporal, cultural and narrative” (Smith et al, 2012, p.98) in a proactive manner.
3. Numeration – identifying the frequency of the occurrence of the theme in the participant’s narrative.

Once the themes were grouped into subordinate themes, it was then shared firstly with the co-researcher and then the participant in order to ensure that the theme identified reflected the experience of the participants. This was done by organising a meeting with the co-researcher to go through the themes together and decide on the emerging themes. For the participants this was done via the process of member checking (see Appendix 4.2).

3.13.5 Step five: Moving onto the next case

In line with the idiographic principle of IPA, participants’ transcripts were analysed case by case. To keep the individuality of each case, the researcher made an effort to bracket the ideas and assumptions from the previous case to ensure that each case was treated on its own terms. However, the researcher does acknowledge that despite efforts of bracketing, it is inevitable that previous experience (i.e., from the participant before) will influence the current case. To reduce this, Smith et al., (2009) recommends following the step six outlined systematically as it will ensure scope for bracketing between analysis.

3.13.6 Step six: Looking for patterns across cases

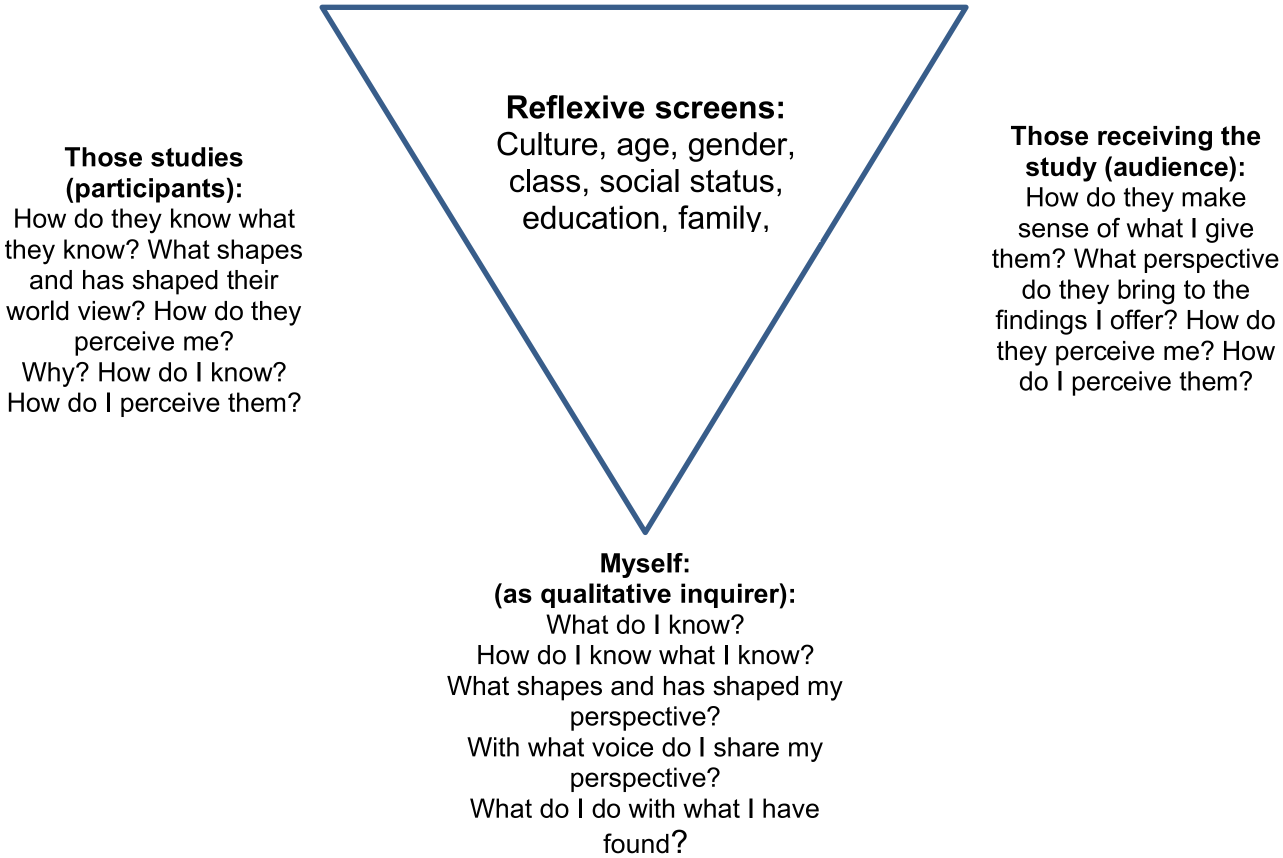
Once the researcher analysed the transcripts at an individual level, patterns and connections were looked for between the participants. The researcher followed the recommendation of Smith et al., (2012) of laying out the emergent and superordinate themes of the participants and looking across to explore any potent themes as well as instance of higher-order superordinate themes. Exploring the data in this way allows for exploration of meaning-making present in the participants’ transcripts. Patterns and connections identified were shared and discussed with the co-researcher and participants, amendments were made following this (see Appendix 4.2). The final result of this approach is captured in chapter 4 (Results).

3.14 Reflexivity

A core part of the researcher’s professional responsibility is to maintain a reflexive approach by adopting a self-aware position in both research and practice. Reflexivity is “the turning back of the experience of the individual upon her or himself” (Mead, 1934, p.134) which is imperative within IPA research as it promotes the voice of marginalised communities. It is worth noting that the engaging in reflexivity does not guarantee a reduction of the researcher’s values in research (Gough, 2008), instead it allows the researcher to consider how their previous experience may have influenced the research process and interpretation of the data. For IPA researchers, the depiction of participants’ words involves ‘double hermeneutics’ (Smith et al., 2012), this is because the researcher is making sense and interpreting the participants’ attempt at making sense of their experience. It is vital for IPA researchers to be conscious of the values and beliefs that they hold and its influence on the research process and its outcomes (Etherington, 2007). By involving the ‘self’ in the research process, the researcher acknowledges their role as a subjective researcher (Etherington, 2007). To encourage reflexive validity throughout the research, the researcher used Patton’s (2002) reflexive questions (see Figure 3.2)

Figure 3.2

Reflexive Questions, Triangulation Inquiry (Patton, 2002)



The researcher maintained a reflective diary and used this model to reflect on her role, position and any power imbalance within the study (please see Appendix 3.3, for an example extract). Supervision (on placement and at university) was also utilised as a contained and safe space to reflect on principles such as mutual respect between the researcher, co-researcher and the participants. The researcher also facilitated a space for the co-researcher to reflect on his experience of carrying research and any emotions or feelings that arises as result of the study or hearing the participants stories. The co-researcher shared that he has not previously been asked to share his thoughts so openly and that he appreciated the space to talk after each interview.

3.15 Ethical considerations

Prior to the research commencing, ethical approval was obtained by the University of East London's (UEL) Ethics Committee (Appendix 3.7) and the LA where the research was carried out (Appendix 3.8). Ethical guidelines from relevant agencies such as the BPS Code of Ethics and Conduct (BPS, 2018), BPS Code of Human Research (BPS, 2014), UEL Code of Practice for Research Ethics (UEL, 2015), and HCPC Code of Conduct, Performance and Ethics (HCPC, 2016) informed this research. Research that involves young people may have the potential to impact in a harmful or detrimental way, therefore, careful safeguards were put in place to ensure that this research was carried out ethically.

3.15.1 Informed consent: Co-researcher

Ethical practice advocates that researchers engaging in PR should seek to secure "provisional and then ongoing consent" (Flewitt, 2005, p.4). This study adopts this model of consent by first gaining provisional consent from the co-researcher and then employing informal and formal process of checking ongoing consent. It was explained to the co-researcher on the information sheet (Appendix 3.9), research presentation (Appendix 3.1) and verbally that he could withdraw or change his involvement at any time. The co-researcher was reminded that his involvement in the research was determined by him. Once provisional consent was gained, the co-researcher was provided with several formal opportunities (i.e., during and at the end of the training sessions as well as the analysis stage) to withdraw from the research at any point without consequence. The co-researcher also gave informal consent during the research at several points without prompting.

3.15.2 Informed consent: Participants

Careful ethical consideration was also applied to participants. Consent to participate in this study was outlined in the following documents; participant information sheet (Appendix 3.10), participant consent form (Appendix 3.11) and parents' consent form for participants under the age of 18 (Appendix 3.12). It was made clear to participants (both verbally and in written form) that they had the right to withdraw from the study at any point without consequence. It was made clear to parents and participants, that if they withdraw from the study, their contribution (e.g. any audio recordings and interview transcripts) will be removed and confidentially destroyed. However, if the two-week 'cooling off' period had passed, it was explained that their anonymised data would be used. This information was also reiterated in the debriefing sheet (Appendix 3.13). During the recruitment stage, the researcher found that the co-researcher and participant 'Wonder woman' knew each other previously from college. Informed consent to participate was sought from both the participant and the co-researcher and it was explained that either of them could withdraw from the interview if they wanted. However, both the participant and the co-researcher were happy to proceed with the interview.

3.15.3 Confidentiality

All data relating to this study was collected in line with the requirements set out by the Data Protection Act (2018) and General Data Protection Regulation (GDPR) (European Commission, 2018). The researcher also followed the Data Management Plan (DMP) approved by the University, which included ensuring that consent forms were scanned and uploaded onto the researcher's laptop immediately after the interview. Data stored electronically was encrypted and saved on the UEL H: Drive (using the researcher's password). The researcher transcribed all interviews (removing identifiable information), pseudonymised names of participants at the point of transcription and then deleted all audio recordings. All participants were assigned an anonymous ID number which was then stored on an encrypted USB stick, which can be used to re-identify a participant if needed. To ensure that no data is lost, the researcher ensured that working data is backed up weekly on an external hard drive. Although anonymised transcripts were shared with the co-researcher and supervisor at UEL for the purpose of analysis, the co-researcher did not have access to password protected data. Any information or quotations used in the thesis write up and subsequent publications were anonymised. It was explained to participants and the co-researcher verbally and in the consent form that confidentiality would only be breached if the researcher was concerned about their safety.

3.15.4 Duty of care

The researcher recognised that there was a possibility that the topic of autism and race may cause some participants distress, particularly if they have experienced marginalisation due to their race or their autism. To manage any emotional distress following the interview, the participants were provided with a debriefing sheet (Appendix 3.13) which included contact details of relevant support organisations for autistic young people. At the beginning of the interview, participants were reminded that they could ask for a break at any time or opt to end the interview early if they wish to.

Throughout the research process, careful attention was given to ensure that the co-researcher felt empowered, respected and listen to. Power imbalances between the co-researcher and researcher were reflected on carefully (Appendix 3.3). The researcher positioned herself as a non-expert when working with the co-researcher and assumed the position of a facilitator. Additionally, the researcher applied the principles of attuned interaction to build rapport with the co-researcher and participants. Finally, the researcher followed the duty of care and safeguarding procedures outlined by the HCPC (HCPC, 2016).

3.16 Trustworthiness of the study

For the purpose of clarity, trustworthiness in this thesis refers to the reliability and validity of the study. In order to assess and maximise the trustworthiness of the current study, the researcher applied the four principles of validity by Yardley's (2000): "sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance" (Yardley, 2000, p.219). Hefferon and Gil-Rodriguez (2011) recommend using Yardley's principles to evaluate and demonstrate the validity of IPA research. With this in mind, Yardley's (2000) criterion was selected by the researcher as these principles were theoretically neutral, aligned with the researcher's social constructionist position and complemented the use of IPA. Yardley's (2000) four principles were applied consciously throughout the research.

3.16.1 Sensitivity to context

During the time the research was carried out, COVID-19 was prominent and the UK went into a second national lockdown. The researcher was sensitive to this and supported participants that had questions about the national lockdown and / or COVID-19. Additionally, the researcher was sensitive to the context of autistic young people and sought to only expand (and not repeat) the findings from the relevant literature and theoretical perspective. Recruiting a co-researcher ensured that the research questions developed were appropriate and sensitive to the participants' contexts. Finally, the interview schedule developed enabled the participants to share openly and freely about their lived experience (Thomson, 2011).

3.16.2 Commitment and rigour

Commitment and rigour were applied within this study firstly by adopting PR principles and involving a co-researcher to the study. The researcher not only worked closely and collaboratively with the co-researcher throughout the different research stages, but also maintained communication with the research participants even after the data collection stage. Secondly, commitment and rigour were achieved by allowing participants to lead the discussions and share their lived experience of autism. The researcher's training on consultation and attuned principles enabled her to listen and look out for body cues of participants to better understand how they felt. This is often referred to as testimonial validity. Finally, the co-researcher and participants were involved in selecting the final themes reported in the write up of this study which can be argued to facilitate a greater insight to the experience of BAME autistic young people, in turn enhancing the trustworthiness of the study (Thomas & O'Kane, 1998).

3.16.3 Transparency and coherence

The researcher ensured transparency within the study by providing detailed information on how data was collected and analysed. Throughout the study, the researcher and co-researcher kept in mind the aims and objectives of the study and used these to guide the interpretation of the data. To ensure inter-rater reliability (Smith, 2008), the researcher and co-researcher verified the codes with a fellow TEP who acted as a critical friend. The fellow TEP has experience of carrying out IPA research and was able to provide feedback on the process of analysis. The researcher reported textual passages that disconfirmed emergent themes. This was done by searching through the data to identify ‘negative’ or ‘deviant’ cases. These instances have been presented at appropriate points in Chapter 4 (Results). To increase the social validity and credibility of the study the researcher sent a draft of the findings to participants and asked them to comment on the interpretation made by the researcher and co-researcher as well as the accuracy in capturing their voices. The direct quotations used in the write up of the study was agreed by the participants. This is known as credibility checking, a technique that carries significance in an autism, participatory and IPA study. The researcher attended a peer supervision group for IPA once a month. The researcher engaged in reflectivity in order to report accurate and detailed accounts of participants experience. A reflective diary was kept which included the researcher’s reflections on carrying out research using a participatory design as well as thoughts and feelings related to the interpretation of the data (Johnson & Christenson, 2014).

3.16.4 Impact and importance

The impact and importance of the current study is that it has empowered a BAME autistic young person as a co-researcher, by giving them the skills to carry out research. It has also given a voice to the lived experience of BAME autistic young people, who traditionally have been excluded from research. By adopting the principles of PR and recruiting a BAME autistic young person, Staley (2009) suggests that ‘community validity’ is achieved. Community validity is when a member of the public, in this case a co-researcher, helps to ensure that the research is appropriate and relevant as well as it being significant to the community, for this research that would be BAME autistic young people. By involving a BAME young person in the research process it is more likely that the research is more valid and representative of that community (Staley, 2009). The data collected has implications for how BAME autistic young people are supported. This is further discussed in Chapter 6.

3.17 Chapter summary

This chapter provided an overview of the research paradigm adopted within the study including the researcher's ontological and epistemological positions. This was followed by a detailed description of the rationale and justification for why this research was needed. The use of qualitative participatory research alongside IPA is presented and explained. This chapter also outlines the recruitment of participants and the co-researcher as well as the training and role of the co-researcher. The collaborative research procedure of conducting SSIs and analysing the data with the co-researcher is provided. The chapter closes with ethical considerations before concluding with a review of the quality of the research.

Chapter 4: Results

4.1. Introduction

This chapter presents the phenomenological and interpretative narrative findings of the research. The researcher and co-researcher's interpretation of the findings is first presented at an individual level before analysis is brought together and common themes across cases are presented.

4.2 Development of individual themes

In order to identify individual themes for each participant, the researcher and co-researcher followed the IPA process as recommended by Smith et al., (2012 for further information please see section 3.11). The co-researcher involvement in the IPA process was as followed:

1. Reviewing and finalising emergent themes (stage 3),
2. Reviewing and finalising grouped subordinate themes (stage 4), and
3. Reviewing as well as finalising patterns and connections identified across cases (stage 6).

Through following the process of IPA, distinct superordinate themes were developed to explore the ideographic 'parts' related to the phenomenological 'whole' of each participant's lived experience. The superordinate and subordinate themes that are pertinent to the research questions are included in the findings. In order to increase the social validity and credibility of the study, the researcher sent a draft of the findings to participants and asked them to comment on the interpretation made by the researcher and co-researcher as well as the accuracy in capturing their voices (please see Appendix 4.2)

4.3 Case one: Wonder woman

Wonder woman is a 14-year-old female who identifies as a British-Somali young person. Wonder woman was diagnosed with autism when she was in Year 6. Wonder woman shared that when she is at home, she alternates between speaking English and Somali depending on which member of her family she is conversing with. Wonder woman named being kind and friendly to others as some of her strengths. In the future, Wonder woman aspires to go to university, get a job and *"down the line,* [have] *a husband" (1-2, p.27).*

Table 4.1

Wonder woman's Superordinate and subordinate themes

Superordinate and subordinate themes	Transcript line numbers / Page number	Key words or phrases
1. The complexity of faith		
God made me this way	40-41 (p.9), 1-5 (p.10).	Issue, God, believe, created.
For some autism means being possessed by Jinns	6-11 (p. 9), 31 (p.9).	Possessed, Jinns, shaitan, devil.
Not a religious Muslim	7-10 (p.7), 14-19, 1-3 (p.10).	Religious, hijab, abaya, fasting, praying.
2. Who am I?		
Being a 'retard'	35-42 (p.7), 19 (p.8), 12-21 (p.10).	"That what I used to think", "retarded thing".
Others defining who you are.	17-21 (p.10).	Arabs, Somalis, White girls

4.3.1 Superordinate theme: The complexity of faith

Close interpretation of Wonder woman's lived experience led to the formation of the superordinate theme one – The complexity of faith. Initially, this theme was named 'expression of faith' however after discussions with the co-researcher it was renamed as 'the complexity of faith' as this was felt to be a more accurate depiction of Wonder woman's relationship with her faith.

4.3.1.1 Subordinate theme one: God made me this way

A narrative that came across in Wonder woman's transcript was the way in which her faith enables her to accept her autism. References to God or Allah appeared in Wonder woman's interview transcript more than five times.

> *"But really if, in reality, if you believe in the will of Allah, then why all of a sudden, is the way God created me an issue to you?" (3-5, p. 10).*

In this extract, there appears to be a strong correlation between faith and acceptance of autism. Wonder woman's use of the phrase, *"the will of Allah"* is of interest as this translates to nothing happens unless decreed by Allah, including Wonder woman's autism. Wonder woman's use of questioning in the extract**, "***is the way God created me an issue to you?"* can be interpreted as her willingness to accept her autism as part of God's decree whilst questioning why those of faith have an *"issue"* with how she was created. Wonder woman's use of the phrase, *"if you believe"* further adds to support the idea that strong faith enables acceptance of autism.

4.3.1.2 Subordinate theme two: For some autism means being possessed by Jinns

Wonder woman shared the belief held by some members of the Somali community that autism is a result of 'jinns'[1] or 'shaitan'[2]. Wonder woman's perception of her community's construction of autism featured strongly in her transcript.

> *"Some of them even – I've even had a Somalian say to me "Oh, you're possessed by a shaitan or a jinn" which basically means, like, the devil – like, po-, like, devil possession – that's what they think. Not me, though" (8-11, p.9).*

Wonder woman shares that in the Somali community, autism is often seen as being possessed by "*the devil".* The use of the word, *"devil"* is interesting here as it infers

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[1] Jinn are beings of flame who are able to assume human or animal form.

[2] Shaitan are evil spirits in Islamic belief

feelings of evil and demonic influences. Wonder woman's use of the phrase *"Not me, though",* makes it clear that she does not subscribe to the commonly held beliefs in her community that autism is caused by *"jinn".* The distance that Wonder woman is putting between her and her community is further strengthened by her use of the third-person plural *"they"*. I wondered whether because there is no direct translation for the word autism in the Somali community, if words like *"shaitan"* or *"jinn"* is the only available language to describe the behaviour associated with autistic individuals.

4.3.1.3 Subordinate theme three: Not a religious Muslim

Wonder woman offers an explanation of the type of Muslim she is and how she differs to other Muslims.

> *"I'm Muslim, like. But [long pause] To be honest, I wouldn't say I'm, like, a, a religious Muslim. Like, I'm not those Muslims that, Muslims that would stand, like, in a Hijab and Abaya" (7-10, p.7).*

Wonder woman declares *"I'm Muslim"* at the start of the extract, however, this is followed by a long pause, perhaps indicating hesitation. Wonder woman appears to be distinguishing herself from other Muslims by stating, "*To be honest, I wouldn't say I'm, like, a, a religious Muslim",* it is interesting she is using the word *"religious"* as this infers to the degree to which she practices her faith. She further separates herself by stating, "*I'm not those Muslims",* however what is not clear here is whether she feels different to *"those Muslims*" because she does not wear *"a Hijab and Abaya"* or whether she is hinting at the strength of her faith being different. I wondered whether a possible reason for her need to separate herself from *"those Muslims"* was because of the commonly held views about her autism in her community.

4.3.2 Superordinate theme: Who am I?

Wonder woman's construction of autism and how this forms part of her identity lead to the formation of this superordinate theme two – Who am I? The subordinate themes explored here are at an individual level as well as a community level acerbating negative perception of autism.

4.3.2.1 Subordinate theme one: Being a ‘retard’

Wonder woman associated autism with being a *“retard”*. This subordinate theme arose three times.

> *‘‘From when I was younger, I used to hear it. I think, like, um. I feel so bad for saying this but, like, “retard” – that’s what I used to think. But when I actually first found out I got it, like, when I was in year 6, I was eleven years old. Like, I, I, I kind of thought of myself as a retard, as well.” (35-40, p.7).*

Wonder woman’s use of the phrase, *“I used to hear it”* suggests that the language *“retard”* was commonly used to describe autistic individuals and that became part of her vocabulary. Her statement, “*I feel so bad for saying this”* appears to show remorse that she used to think of others with autism as being a *“retard”.* The reference to “*year 6, I was eleven years old”* appears to be of significance to Wonder woman, as this is when her association of autism as a *“retard”* shifted from others onto herself.

4.3.2.2 Subordinate theme two: Others defining who you are.

A strong and consistent narrative which was present in Wonder woman’s transcript was how others from different communities constructed and defined autism. For example, Wonder woman shared how autism is often referred to as “crazy” by different communities.

> *“I feel like it’s just Somalis and, like, Arabs generally but [pause] I feel like the whole “crazy” and “mental” stigma around it is in all communities. Even white people. I’ve seen white girls come to me with, “Oh, so you’re crazy?” [pause] Like, “No”! [snorts]” (17-21, p.10).*

This extract gives an insight into the labelling and stigma associated with the word autism in certain communities. Wonder woman’s use of words such as *“mental”* and *“crazy”* suggests that often these communities see autism as a mental illness. What is interesting in her comment, “*Even white people”* is that this community is no different to that of *“Somalis”* and *“Arabs”* despite her expectations being higher for *“white people”.* Wonder woman is sharing her personal experience when she says, “*I’ve seen* *white girls come to me"* which is perhaps her way of confirming that these communities do hold the same view of autism and is not just her thinking. However, she appears to be rejecting the stigma that autism means you are *"crazy",* by her response, "*No!"* [*snorts]"* indicating her disapproval in others' views.

4.4 Case two: Storm

Storm is a 19-year-old female who identifies as an Eritrean young person. Storm was diagnosed with autism when she was 13 years old. Storm is the youngest of four children, at home she speaks English and Arabic. Currently, Storm is undergoing a supported internship within the LA where the research was carried out. Storm named travelling independently and speaking Arabic as some of her strengths. In the future Storm aspires to become *"a news reporter or a writer" (20-21, p.19).*

Table 4.2

Storm's Superordinate and subordinate themes

Superordinate and subordinate themes	Transcript line numbers / Page number	Key words or phrases
1. Seeking social connectedness online		
Reality versus social media	1-9 (p.9), 35-39 (p.13), 1-4 (p.14).	Friends, acquaintances or people
Knowing the safety rules of meeting 'friends' offline.	15-23 (p.9).	Boundary, meet, parent or carers.
2. Left stranded by Covid-19.		
Social distancing is like being in prison	38-39 (p.14), 27-36 (p.14).	Prison, stop, social distancing, so annoying.
Impact of lockdown on wellbeing	7-16 (p.14), 18-24 (p.14).	"lockdown is coming again", triggers, anything.

3. Feeling the impact of social injustice		
Every life matters	22-24 (p.18), 33-36 (p.18).	Black life, Muslim life, Asian life. Treated equally.
Fear of the police	38-42 (p.18), 1-6 (p.19), 9-11 (p.19).	Worry, die, hands, police.
Shukri Abdi	24-30 (p.19), 32-41 (p.19), 1-12 (p.20).	Shukri, drowning, upset, innocent Muslim woman, life taken.

4.4.1 Superordinate theme: Seeking social connectedness online

Interpretation of Storm's transcript led to the formation of the superordinate theme one – 'Seeking connectedness online'. The related subordinate themes explore Storm's desire to create relationships online, whilst remaining safe.

4.4.1.1 Subordinate theme one: Reality versus social media

Storm shared some of the difficulties associated with making friends on social media. Storm referred to social media in relation to friendships five times in her interview.

> *"Um social media is a bit tough because when you add all those people, like, I think they seem nice, but in reality, like, when I go, oh, in reality, I don't know what they're actually like" (6-9, p.9).*

"In reality" implies that Storm is aware that often people's social media persona may often be different from who they are in real life, which is further emphasised by her use of the phrase *"actually like".* Linguistically the repetition of the phrase *"in reality"* suggests that Storm has a good perception of what is reality and what is social media.

4.4.1.2 Subordinate theme two: Knowing the safety rules of meeting ‘friends’ offline.

Storm described an influencer she met online and her desire to meet her in real life while remaining safe. Although Storm only mentioned online safety rules once, it was deemed significant enough to warrant a subordinate theme as it captured Storm’s desire to seek social connectedness online.

> *“Also, on social media, I have made friends with a woman named, um, [woman’s name] she is a-, [woman’s name], she is from, she’s from Iraq, but she’s living uh, somewhere in [city name]. I follow her blog, [blog name], but I have never met her in real life, but I’d like, like- she seems nice, but, one day I’d like to meet her, but I have like, a boundary, like, I’ll come and meet her, only if I bring a parent or carer with me” (15-23, p.9).*

It seems that Storm is aware of the possible dangers of meeting people offline by her use of the phrase, “*only if I bring a parent or carer with me”.* I wondered whether Storm was repeating a script taught to her about meeting people offline. It seems that Storm is aware that whilst this person may *“seem nice*” online, this might not be the reality.

4.4.2 Superordinate theme: Left stranded by Covid-19.

These subordinate themes have been grouped together as they describe Storm’s experience of Covid-19 and the impact it has had on her.

4.4.2.1 Subordinate theme one: Social distancing is like being in prison

Storm describe the impact of social distancing as result of Covid-19. References to the restriction imposed by Covid-19 arose three times in Storm’s transcript.

> *“Can I mention the social distancing rule with ASD, like, when I want to see people fr-, when I see like, people fr-, who I haven’t seen in a long time, like family, friends, like in public, I really want to go and give them a hug and say I missed them a lot. I find it hard when like, I’m told, “d-d-d-d-d-, stop” I’m told “d-d-d-d-, social distancing”. Instead, I have to, like, I have to like say hello from*

> *far. It's so, like, annoying. I can imagine, social distancing, it's like [pause] being in prison". (29-39, p.14).*

The linguistic use of a simile *"like a prison*" serves to highlight that for Storm the restrictions of social distancing is similar to being in prison. It seems that for Storm the absence of not being able to connect with her friends and families physically has been restricting for her.

4.4.2.2 Subordinate theme two: Impact of lockdown on wellbeing

Storm reflects on the impact of the previous national lockdown on her autism.

> *"Also, also the news as well, like [pause] like, hearing about th-, the news has affected me with my ASD, like, hearing about the lockdown, when I hear "lockdown is coming again", that triggers me a lot, like, I cannot literally do anything, I'm so restricted from like, doing the activities and the hobbies that I'm really interested in. Like, I love swimming a lot, like, I can't go to my leisure centre, and [pause] I can't go to my leisure centre and swim to release all the stress that's in my body" (7-16, p. 14).*

For Storm, the return of a national lockdown appears to be anxiety provoking as it suggests a loss of familiar routines. "*I cannot literally do anything"* invokes feelings of being trapped which links to Storm's previous theme of feeling like she has been imprisoned by Covid-19. What is interesting in this extract is that Storm is aware of the impact that *"swimming"* has on her wellbeing, which raises the question what happens if she is unable to "*release all the stress"* that is in her body.

4.4.3 Superordinate theme: Feeling the impact of social injustice

Close interpretation of Storm's transcript led to the formation of the superordinate theme three – 'Feeling the impact of social injustice'. The related subordinate themes were grouped together because they relate to the psychological impact of social injustice felt by Storm.

4.4.3.1 Subordinate theme one: Every life matters

A consistent narrative that appeared in Storm's interview was the treatment of individuals from BAME communities by society. This subordinate theme arose three times.

> *"Eritreans with autism shouldn't be singled out, no matter what religion they are. They should be treated equally 'cos every life matters. Black life, Muslim life, Asian life" (33-36, p.18).*

Storm appears to be advocating for the equal treatments of all lives. She specifically mentions *"Black", "Muslim"* and *"Asian"* suggesting that perhaps she is aware of the treatment and marginalisation of these groups within society. I wondered whether Storm was referring to herself in the statement, "*Eritreans with autism shouldn't be singled out".*

4.4.3.2 Subordinate theme two: Fear of the police

Storm provided a detailed description of her fears regarding police brutality. Even though this description appeared once, it was enough to be considered as a subordinate theme due to how deeply she was affected by it.

> *"That's what's triggering me the most, like, I'm living in Britain, I see the police everywhere, I worry that I might die in the hands of the police" (3-6, p.19).*

Prior to this statement, Storm mentioned feeling traumatised from watching a video of a black autistic American man who was killed by the police. While Storm appears to be aware that this video was recorded in America there is still, for her, a genuine fear of the possibility of dying as a result of police brutality. What is of interest here is that Storm's lived experiences does not include negative encounters with the police, yet she expresses rooted fear.

4.4.3.3 Subordinate theme three: Shukri Abdi

Storm commented on the treatment of BAME individuals and the impact of bullying several times in her transcript. For example, she shared how she felt upon hearing about the death of Shukri Abdi[3]. References to Shukri Abdi arose seven times.

> *"Hearing about Shukri Abdi's death has upset me. I- has upset me a lot, because, being a, being an African Musl-, being a Muslim, and coming, and a refugee in this country, um [pause] being a refugee in this country, she was being treated differently to like her peers, they singled her out. They have allowed her to suffer, like, I- [pause] allowed her to suffer. Her drowning has like, her drown-, Shukri drowning has made me feel upset because a young innocent Muslim woman had her life taken away from her at the click of her fingers, for no reason" (1-12, p.20).*

Storm stating, *"I- [pause] allowed her to suffer"* emphasises perhaps a deep sense of anguish felt by Storm and how society has failed Shukri. The use of word *"allowed"* is of interest, as this suggest that from Storm's perspective, Shukri's suffering and ultimate death was done with intent. I wondered whether Storm (who also identifies as a black, Muslim and an immigrant) saw herself in Shukri and her suffering.

4.5 Case three: Catwoman

Catwoman is a 16-year old female who identifies as a Ghanaian young person. Catwoman was diagnosed with autism when she was six years old. Currently, she is attending sixth form and resitting her GCSEs. Catwoman named being generous and kind as two of her strengths. In the future Catwoman aspires to go *"to university and become somebody" (8-9, p.13).*

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[3] Shukri Abdi was a young person who drowned in the River Irwell, England, on 27 June 2019. Aged 12, she was a refugee from Somalia who had lived in a refugee camp in Kenya until moving to England in 2017.

Table 4.3

Catwoman's Superordinate and subordinate themes

Superordinate and subordinate themes	**Page / Line**	**Key words**
1. Making sense of my autism		
Autism is a lifelong condition	3-4 (p.6), 9-11 (p.6).	Reversable, stay, forever, continuing
Loving your autism	14 (p.8), 17-23 (p.8).	Love, yourself, always, achieve, goals, "live with autism".
2. A desire for friendships		
Shunned by others	13 – 15 (p.7), 21 (p. 7), 24 (p.7), 28-30 (p.7).	Shun, "it's because of my autism",
Online friends	34 (p.13), 1-3 (p.14), 6-10 (p.14).	Online, easier, chat, instant message.

4.4.1 Superordinate theme: Making sense of my autism

Interpretations of Catwoman's transcript led to the formation of the superordinate theme one – 'Making sense of my autism'. The related subordinate themes were grouped together as they capture Catwoman's attempts to accommodate autism in her life.

4.4.1.1 Subordinate theme one: Autism is a lifelong condition

Catwoman shared how she once thought that her autism was reversable.

> *"Like, um [pause, sharp exhale] at once I thought it's gonna to be reversable, but now it's gonna stay here for like forever. That's all" (9-11, p. 6)*

Catwoman's sharp exhale indicates perhaps discontentment at the fact that she once thought her autism was *"reversable".* In this extract, Catwoman demonstrates a shift in thinking regarding the treatment of autism. Catwoman's use of the word *"forever"* suggests a sense of permanence and perhaps an awareness that autism is a lifelong condition with no cure. The use of the phrase, *"that's all"* is of interest, because it suggests perhaps an urgency to end the conversation.

4.4.1.2 Subordinate theme two: Loving your autism

Catwoman shared that focusing on the positives relating to her autism meant that she was able to love herself with autism. This subordinate theme arose three times and was a central part of Woman woman's identity.

> *"Because, um [pause] like, things in life, it's very, very [pause] you have to keep your head up high. And, you know, um [pause] you always have to like achieve your goals to live with autism. And um autism yeah, it's very common, in general. Like, um [pause] it's about, who you are, like, you have to love yourself" (17-23, p.8).*

What is of interest in this extract is Catwoman's response to the prevalence of autism, *"it's very common"* suggesting perhaps an attempt by her to normalise autism. I wondered whether Catwoman has previously heard someone state that autism is *"common",* and whether she has internalised this dialogue.

4.4.2 Superordinate theme: A desire for friendships

Close interpretation of Catwoman's transcript led to the formation of the superordinate theme two – 'Desire for friendship'. These subordinate themes capture Catwoman's attempts at friendships and socialising.

4.4.2.1 Subordinate theme one: Shunned by others

Catwoman reflects on the emotional impact of wanting to socialise with others but yet feeling rejected and at times bullied. Catwoman gave several examples of feeling rejected for example, when she tried to *"mingle"* with her peers.

> *"Um, like when I tried to mingle with people, they just shun on me, like they wouldn't talk to me or something" (28-30, p. 7).*

From this extract, Catwoman appears to be socially motivated to engage with others. The conceptualisation Catwoman presents that others reject her despite her desire for interaction is of interest. In the previous response on her transcript, Catwoman linked feelings of being shunned to her autism.

> *"Yeah, I think it's because of my autism" (24, p.7).*

The initial interpretation of this extract reflects the sense of loneliness that Catwoman may have felt during school. Catwoman attributes peers not wanting to engage with her and her loneliness to her autism diagnosis.

4.4.2.2 Subordinate theme two: Online friends

The subordinate theme 'online friends' arose five times. Catwoman shared that she finds interacting with peers easier when online compared to in-person.

> *"It's easier to make friends online" (34, p.13).*

Catwoman was able to elaborate on what makes online interactions easier for her.

> *"Like, um, like I ask them how are they doing? And like they [pause] said they're doing fine. And um [pause] to be honest, that [pause] um [pause] like, you can still chat to them online [pause] by using um, like, instant messaging" (6-10, p.14).*

From this extract there is the suggestion that Catwoman is able to engage in dialogue with others online more successfully than in person. I wondered if Catwoman felt more success with social interactions online because computer mediated conversations strip away social cues such as facial expressions, sensory demands and tone of voice. Perhaps interacting in this way feels more natural for Catwoman and therefore she is able to experience success in her social interaction in a way that she would not in person.

4.5 Case four: Wolverine

Wolverine is a 19-years old male who identifies as a British-Indian young person. Wolverine was diagnosed with autism when he was in Primary school. Wolverine is currently completing his second year of university and is renting a house with his friends off campus. Wolverine mainly speaks English with his family however, he does have some language in Gujarati. Wolverine named understanding people and academic achievement as some of his strengths.

Table 4.4

Wolverine's Superordinate and subordinate themes

Superordinate and subordinate themes	**Page / Line**	**Key words**
1. From old me to the now me		
Struggling with a sense of self	10-5 (p.12), 26 - 29 (p.12).	Apprehension, different, negative, why me.
Adults as a support to accepting autism	13 (p.13), 32-33 (p.19).	Supportive, "they're really gonna be there for you".
Normality is a spectrum	26-34 (p.12), 26-27 (p.6).	Learned, being normal, everyone, their own normality.
2. Advocacy		
There is power in sharing lived experience	3-16 (p.23), 18-27 (p.23), 18-23 (p.22).	Social media, my autism, documentary, progression, story.
Representing autism at the different levels.	1-8 (p.22), 30-36 (p.4).	Massive advocate, ambassador, mental health, autism.

4.5.1 Superordinate theme: From old me to the now me

Interpretation of Wolverine’s transcript led to the formation of the superordinate theme one – ‘From old me to the now me’. These subordinate themes were grouped as they capture Wolverine’s journey to his current thinking.

4.5.1.1 Subordinate theme one: Struggling with a sense of self

At the beginning of Wolverine’s interview, he was asked about his feelings regarding when he was first diagnosed with autism.

> *“I used to be so negative about it, when I was little. Um, I always asked myself, why am I so different to others? Why is this happening to me? What's going on with me? Why, why are others like, like that, and I'm like this. You, there's a lot of self-doubt when you're little, because you don't have that knowledge” (10-15, p.12).*

The initial interpretation of this extract is that Wolverine’s negative feelings and self-doubt were a result of his lack of knowledge regarding what autism is. Wolverine was able to articulate his struggles about what was happening for him prior to him accepting his diagnosis. The theme title ‘self’ refers to the psychological construct of ‘self’, Wolverine alludes to how he struggles with his sense of self prior to gaining knowledge. What is of interest is Wolverine’s use of time, *‘when you’re little’* which suggests that for him self-doubt and confusion existed in that time period.

Wolverine goes on to explain how feedback from his friends has supported him to develop a stronger sense of self.

> *“And all my friends realised that I had something unique” (27-28, p.4)*

The use of the word, *“unique”* infer this notion of being one of kind and extraordinary. This extract gives an insight into the importance of friends facilitating and supporting a positive sense of self.

4.5.1.2 Subordinate theme two: Adults as a support system to accepting autism

Wolverine reflected on the support he received from learning support staff and the impact it had on him. References to adult support, given by learning support staff and his parents, featured heavily throughout Wolverine's transcript.

> *"And it's worked wonders for me. With-, without that learning support, I wouldn't be in the same place where I am right now. Because they've been so supportive. At [mid-teens] I became so much more embracive. My friends like became more embracive" (10-14, p.13)*

The linguistic interpretation of the extract highlights that Wolverine's lived experience at secondary school was positive because of the support he received from learning support. The domino effect described by Wolverine is of particular interest as it underlines the support, he received which enabled him to embrace his autism, in turn allowing his friend to embrace him.

Wolverine's reflections on the support he received was not limited to just school. He shared how his family was there for him.

> *So that's that first perception, where you feeling "ah crap, I have a mental health condition and it's not great and none of my other family does, and you're a misfit" but you're really not because they're really there, they're really gonna be there for you, which is quite unique" (27-33, p.19).*

What is significant in this extract is the conceptualisation that Wolverine presents in which the support he received from his family is *"quite unique".* This builds on previous narrative from Wolverine that his family as *"British-Indians"* (*19, p.5*) are more accepting of his autism than traditional Indian families.

4.5.1.3 Subordinate theme three: Normality is a spectrum

Wolverine shared that previously he used to feel apprehensive about being different but now his thinking is that *“everyone is different*”. This subordinate theme arose five times. Wolverine referenced friends, family members and members of staff as key figures that have supported this way of thinking.

> *“And you learn that you're-, everyone's different. Everyone has their own personality, everyone has [pause] their own sort of, yeah, like I said, everyone has their own personality. So, there is no such thing as you being a normal person, because everyone's different” (30-34, p.12).*

An important concept for Wolverine was how he made sense of his autism. It was important for him to conceptualise his autism in the context of what is normal, hence the emergent theme ‘Normality is a spectrum’. Within this extract, there is a sense of empowerment and a development of self-worth through Wolverine’s use of the phrase, *“everyone is different’.* Employing the double hermeneutic, his questioning of normality, indicates that perhaps he is trying to find acceptance by discrediting what is normal.

4.5.3 Superordinate theme: Advocacy

Interpretation of Wolverine’s transcript led to the formation of superordinate theme two– ‘Advocacy’.

4.5.3.1 Subordinate theme one: There is power in sharing lived experience

Wolverine shared that he is in the process of creating a short film about his lived experience in order to raise awareness of autism. By documenting his journey and focusing on the positive associated with autism, Wolverine hopes to help other young people.

> *“I’m doing a documentary, putting it on YouTube, have a watch”. Uh, and it’s about sort of how my life has evolved, to, to give everyone the whole story, cos not everyone’s known the whole story, everyone’s just known bits and bobs, every-, some people have just known about my childhood, some peop-, some*

> *people just knew about my uni life, and I wanted people to really know about the progression. And that's the most important thing, the progression, of who you are" (8-16, p. 23).*

Focusing on the linguistic level of analysis, Wolverine's use of the word *"progression"* suggests that for him capturing his move towards acceptance of his sense of self is the important aspect of telling his story. The use of *"the whole story"* further builds upon this narrative of the journey to acceptance.

4.5.3.2 Subordinate theme two: Representing autism at the different levels.

Wolverine shared how he became an ambassador for mental health and autism at university.

> *"And then when I got to uni, I was a massive advocate towards it, because there's so many mental health societies and there's not a lot talked about on it. So, I became, uh, an ambassador towards, uh, mental health and autism" (32-35, p.4).*

There is a sense that despite there being many mental health societies at university, Wolverine did not feel represented. The linguistic interpretation of Wolverine stating, "*there's not a lot talked about on it"* suggests existing mental health societies were not discussing autism and Wolverine saw this gap as a reason for becoming *"a massive advocate".* Wolverine being able to represent and speak on behalf of young people with autism suggests that he feels safe at university to share his experiences.

4.6 Findings across participants

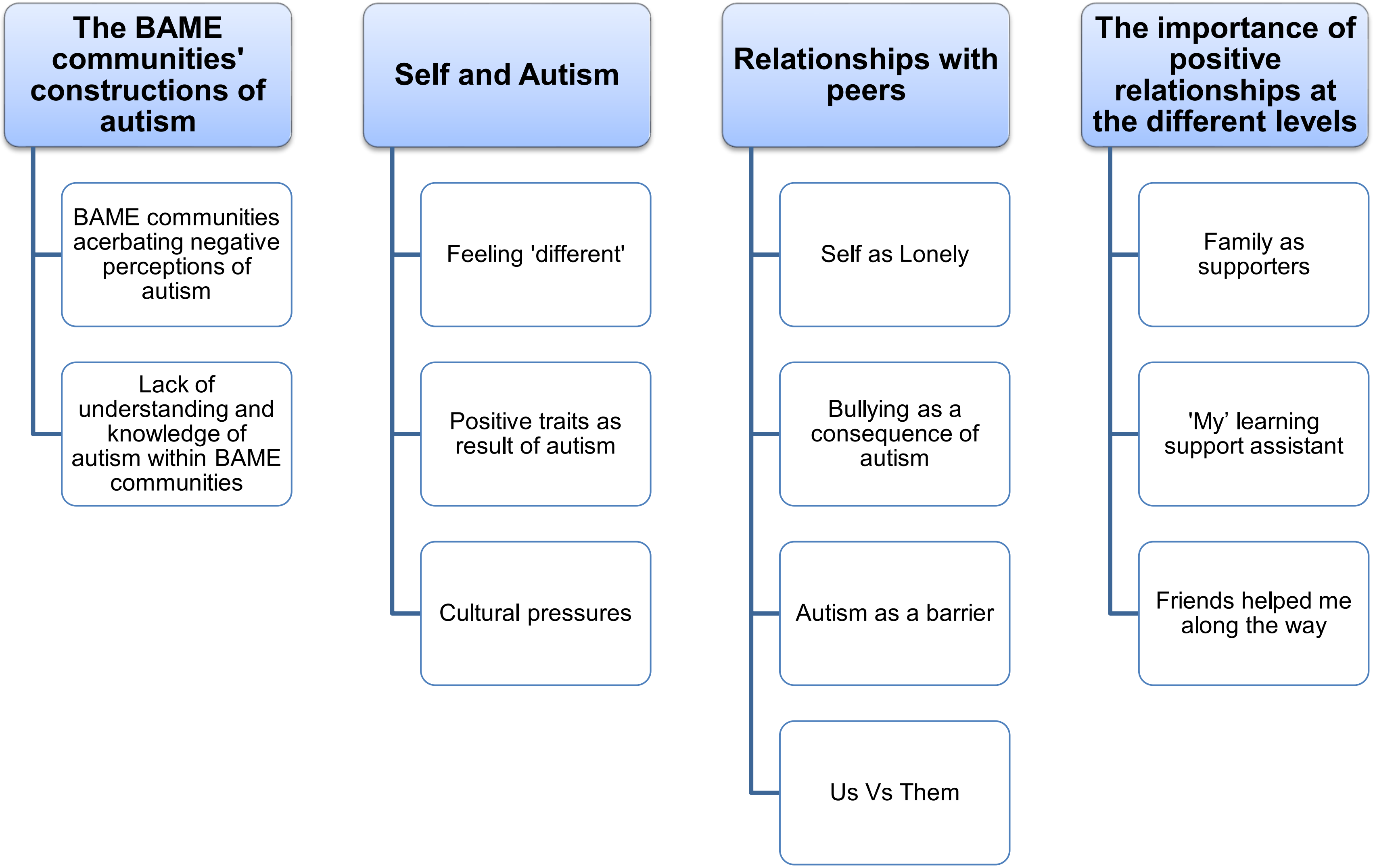
Once the case-by-case analysis was completed, the researcher looked for patterns across cases which led to the analysis and grouping of superordinate and subordinate themes at a group level. For trustworthiness, themes were only reported if they were identified in more than two participants' transcripts (i.e. 50 per cent). Additionally, interpretations made at a group level by the researcher and co-researcher were shared with the participants for feedback.

4.7 Analysis and Interpretation of Superordinate Group Themes

Four superordinate themes emerged from the analysis: The BAME communities' constructions of autism, Self and autism, Relationships with peers and The importance of positive relationships at the different levels (please see figure 4.1). The group superordinate and subordinate themes are presented in this way to tie in with the research questions and reflect the lived experiences of BAME young people with autism. Each superordinate theme is presented in a table and shows the related subordinate themes and the participants' that contributed to the themes.

Figure 4.1

Superordinate group themes



4.7.1 The BAME communities' constructions of autism

This superordinate theme reports on the challenges faced by the participants in relation to autism and how it is constructed in their specific community. A shared narrative between the participants was the negative perception of autism as well as the lack of understanding and knowledge of autism in their communities. In order to distance themselves from these commonly held negative views of autism in their communities, nearly all of the participants adopted a dual identity.

Table 4.5

Subordinate Themes Relating to Superordinate Theme 'The BAME communities' constructions of autism'.

The BAME communities' constructions of autism				
Subordinate Theme	Wonder woman	Storm	Catwoman	Wolverine
BAME communities acerbating negative perception of autism	✓	✓	✓	✓
Lack of understanding and knowledge of autism within BAME communities	✓	✓		✓

4.7.1.1 Subordinate theme one: BAME communities acerbating negative perception of autism

Participants were asked during the interview how autism was viewed in their specific community (i.e., Somali, Eritrean, Ghanaian and Indian). All four participants shared negative perceptions that they felt their community held regarding autism.

> *“Yeah, um, in traditional India, it's viewed as retardism, uh it's viewed as you being a failure, to your family” (Wolverine, 1-2, p.5).*

> *“…I think they'll say bad things about you. Like um, they said that you're not working well. You're like, mental, you’re like this, you’re like that. All sorts of things” (Catwoman, 27-30, p.4).*

All of the participants used negative words to describe or explain how autism is viewed in their communities. For instance, words such as *“failure”, “bad”, and “mental”* were heavily featured across the participants’ interviews. Wonder woman goes on to elaborate on the word autism having a “*negative”* meaning in her community.

> *“It’s literally, like, the word “autism” has very negative connotations around it in Somali community” (Wonder woman, 33-34, p.9)*

What is of interest is that all of the participants saw themselves as being part of, and not part of, their community. Although they all identified as belonging to their ethnic community, they also felt detached from the commonly held negative perceptions of autism in their communities. Both Wolverine and Wonder woman named themselves as British-Indian and British-Somali as a way of differentiating themselves.

> *“But, again, like I said, I'm a British Indian, we're a very modern Indian family. So, there's a lot of acceptance” (Wolverine, 19-20, p.5).*

An initial interpretation of this extract is that there is difference between being a *“British-Indian”* and an *“Indian”.* For Wolverine, there is a sense of pride associated with being a *“British-Indian”*. The use of the word *“modern”* implies an up-to-date way of thinking and ideologies which allows for *“acceptance”* in a way that perhaps you would not find in traditional India. Wolverine’s use of the phrase *“lot of”* implies that there is an abundance of acceptance for those who are different, when you are *“British-Indian”.*

4.7.1.2 Subordinate theme two: Lack of understanding and knowledge of autism within BAME communities

Catwoman, Storm and Wolverine discussed the lack of understanding and knowledge related to autism in their communities. They explained that the rarity and recognition of autism coupled with the lack of descriptors, often meant that autism was not understood by members of their community and as such viewed negatively.

> *"**Storm:** It would be a bit of a battle towards them, they have, it's hard explaining your disability to the Eritrean community, and they find it hard to understand.*
> ***Interviewer 1:** Mm, and why do they find it hard?*
> ***Storm:** It's because um, they weren't educated about um AS. They're, like, in my culture, like [pause] autism's quite rare in children but there are, I have, but there are s-, there are s-, there are some, there are some things describing ASD which is hard to understand in, it's hard to explain it to them in the language they're speaking, English, but it's, it's rare in their home language" (Storm, 10-22, p. 6).*

Storm's use of the word *"battle"* infers to the struggle she experiences when trying to explain autism. Storm is suggesting that it is hard for the "*Eritrean community"* to understand her *"disability"* because "*they weren't educated".* There is a sense that Storm is wanting to facilitate better understanding in her community about autism, when she goes on to state, "*it's hard to explain it to them"*. Although not directly mentioned by Storm, there is sense that part of this *"battle"* is because of a language barrier as there is no direct translation for the word autism in the Arabic language. However, I wondered whether a battle would continue to exist for Storm if *"they"* acquired the body of knowledge to understand autism better as suggested by Storm.

Similarly, Wonder woman expressed frustration towards the lack of knowledge surrounding autism in the Somali community.

> *"You're so dumb, like. You actually need to go back to school and maybe get some sort of education because, like, what's wrong with you? Sorry" (Wonder woman, 15-19, p.9).*

In this extract, Wonder woman is responding to members in the Somali community who refer to her autism as being *“possessed by a shaitan or a jinn” (Wonder woman, 9, p.9).* Wonder woman is instructing these members of the Somali community to *“go back to school”,* because these negative views can only be held by those without *“education”.* Wonder woman’s use of phrases such as *“what’s wrong with you”* and *“you’re so dumb”* is indicative of the lack of knowledge which is perpetuating negative perceptions of autism.

4.7.2 Self and autism

This superordinate theme reports on the impact of an autism diagnosis on the participants’ self-constructs. Many of the participants spoke negatively about their autism which often related to feelings of being ‘different’. However, the same participants were also able to reflect on the positive traits as a result of their autism which perhaps hints at their struggle with coming to terms with their autism. Some participants spoke about the cultural pressures they felt being autistic and belonging to BAME communities and how this contributes to their sense of self.

Table 4.6

Subordinate Themes Relating to Superordinate Theme ‘Self and autism’

Self and autism				
Subordinate Theme	Wonder woman	Storm	Catwoman	Wolverine
Feeling different	✓	✓	✓	✓
Positive traits as result of autism		✓	✓	✓
Cultural pressures	✓	✓		✓

4.7.2.1 Subordinate theme one: Feeling different

All of the participants, at one point, referred to ‘feeling different’ as a result of their autism. For example, Storm shared the following:

> *"…having a diagnosis does make, does uh make me feel singled out” (Storm, 31-32, p.9)*

She was able to elaborate further on what makes her feel different compared to others.

> *“…my behaviour is quite strange to others. Uh, I find it quite hard understanding social rules, uh, personal space, um [pause] um, the way of my communication, of how I speak to people. [pause] I blurt out things and I kind of say random stuff” (Storm, 10-15, p.5).*

Storm’s use of the phrase, *“quite strange to others”* suggests that her construct of herself and her autism is influenced by the feedback she has received from others. There is a sense that Storm’s understanding of *“social rules”* makes her different to others. She names her specific communication style which include saying “*random stuff”* to further emphasis her feeling different.

Wonder woman was also able to share her feelings of being different, for instance she states:

> *“I just, I just feel really different. I feel like an alien” (Wonder woman, 9-10, p.26)*

Wonder woman’s use of a simile, *“like an alien”* gives a vivid description of how different she feels. The use of the word *“alien”* is of interest in this extract as it suggests perhaps not belonging to this world. Wonder woman goes on to say:

> *“I just feel like, I’ve been given to the world with no manual.” (Wonder woman, 12-13, p.26)*

Wonder woman is communicating that she has no clear instructions of how to navigate herself in this world. There is a sense that perhaps Wonder woman is lost without a *"manual".*

4.7.2.2 Subordinate theme two: Positive traits as result of autism

Storm and Wolverine were the only two participants in the research to identify positive characteristic as a result of their autism. A key narrative that was shared, was that they both felt their autism was the reason for certain skills.

> *"…the best things about being autistic, is that you can have skills that hardly anyone else would have. So, for example, having perfect pitch. Not a lot of people have perfect pitch. It's very difficult to have perfect pitch. I have it, and I'm very lucky to have it. Photographic memory, not a lot of people have photographic memory" (Wolverine, 17-22, p.25).*

In this extract, there is a sense of pride for Wolverine with regards to the skills that he has acquired as result of his autism. Wolverine highlights having "*perfect pitch"* and *"photographic memory"* skills which are considered to be rare but present due to his autism. What is interesting here is Wolverine saying, "*hardly anyone else would have"* further adds to this idea of having extraordinary skill sets because of autism.

4.7.2.3 Subordinate theme four: Cultural pressures

Wonder woman, Storm and Wolverine all spoke about the cultural pressures they felt from their communities to behave in a socially desirable way. An interesting contrast made by Wolverine is the difference in treatment between typical and atypical development within the Indian community.

> *"You can have any type of condition other than autism, you can have ADHD, you can have ADD, you can have dyslexia. Um, but that will be always deemed as a failure. They want, there's so much expect-, there's a thing with this expectation" (Wolverine, 3-6, p.5)*

In this extract, Wolverine states that if you deviate from the norm of what is considered typical then you are deemed as a *"failure".* Wolverine's use of the word *"they"* is interesting as it separates him from those who subscribe to these expectations.

Wolverine also discusses the cultural expectations of career choices in Indian families and how not following these traditional expectations results in further disappointment.

> *"When you're from an Indian family to do- a ver-, it's a very stereotypical sort of point of view. So, you should become a doctor, you should become a businessman. You should be in those fields, cos that's what people perpetuate Indians as. When you're with a men- when you have a mental health condition though, you don't normally [pause] especially autism, you don't really, sort of, follow that field. So, in traditional India, that's [pause] classed you not following the tradition, so you get ridiculed, you get belittled, berated in school, you get berated at home. It's horrible. It's not nice at all. Um, I've had personal experiences from my friends back in India as well" (Wolverine, 6-18, p.5).*

There is a sense here that having autism classes you into a different subgroup resulting in the deviation from the conventional career pathways. Wolverine's repetition of the word *"berated"* highlights that these pressures exist across school and home. Additionally, Wolverine shares that the cultural expectation exists regardless of whether you are living in London or *"back in India".*

4.7.3 Superordinate theme: Relationships with peers

This superordinate theme explores relationships with peers and the difficulties participants experienced as a result of pragmatic and social communication difficulties, which acted as barrier when interacting with peers. Bullying was experienced by nearly all the participants at different levels of severity and regularity. Many of the participants named their autism as the key barrier for successful inclusion and positive peer relationships. Finally, some participants mentioned a difference in treatment between BAME autistic young people and white autistic young people.

Table 4.7

Subordinate Themes Relating to Superordinate Theme 'Relationships with peers'.

Relationships with peers				
Subordinate Theme	Wonder woman	Storm	Catwoman	Wolverine
Self as lonely	✓	✓	✓	
Bullying as a consequence of autism	✓	✓		✓
Autism as a barrier	✓	✓	✓	
Us Vs Them	✓	✓		✓

4.7.3.1 Subordinate theme one: Self as Lonely

Wonder woman, Storm and Catwoman reported that peers did not wish to befriend them because of judgements about their autism. These three participants shared that they struggled to make friends in school despite actively wanting friends and being socially motivated.

> *"I want to have friends. And just feel like, I'm, like, other kid" (Wonder woman, 35-36, p.15).*

Catwoman was able to share how not having friends made her feel lonely and socially isolated.

> ***"Catwoman*** *Yeah. Like I always felt a bit alone, like, trying to have some friends.*
> ***Interviewer 1*** *Mm-hmm.*

> ***Catwoman** [pause] Yeah, but [pause] When I tried to come near them, they just walked away. So, um, I have like difficulties in school" (Catwoman, 18-23, p.13).*

The initial interpretation of this extract suggests that there is a distinction between Catwoman and her peers and hints at Catwoman being an outsider. The use of the pronoun, *"them"* adds to this idea of an 'in-group' and 'out-group' and Catwoman's lack of belonging in school. Catwoman stated, "*when I tried to come near them, they just walked away",* suggesting that they are quick to denigrate her because perhaps she does not fit in to their social group. Catwoman appears to be looking inwards as a reason for why she does not have friends and later in the interview names her autism as the reason for why *"they walk away*".

Similarly, Wonder woman also shared feelings of loneliness due to lack of friends and names her autism as the reason why she is not fitting in.

> ***"Wonder woman** Cus they know I'm different and they know I have autism and they know, like, and they co- I feel like as I'm growing up, like, my autism is becoming more big, like, it's becoming more obvious.*
> ***Interviewer 1** In what way?*
> ***Wonder woman** Like, visible. Just generally, you can just tell more. I don't know. I just, I see myself and, like, I can just tell. That it's more obvious. (Wonder woman 12-19, p.15)".*

The statement, "*they know I'm different'* gives us an insight into Wonder woman's self-concept. What is interesting here is that often autism is referred to as a hidden condition, however, for Wonder woman her autism is visible for the world to see. Linguistic interpretation of the phrase, "*it's becoming more obvious"* suggests that Wonder woman is no longer capable of hiding her autism. Wonder woman's repetition of the word, *"obvious"* further emphasises that she feels her autism is evident for everyone to see because she can see it *"becoming more big".*

4.7.3.2 Subordinate theme: Bullying as a consequence

Wonder woman, Storm and Wolverine reported experiencing bullying and teasing as a consequence of their autism. The three participants provided an insight into their experiences of school and the impact that bullying had on them. Wonder woman was able to share the regularity with which she experiences bullying at school.

> *"I hate school, like. I just 24-7 get bullied and I hate it. I just [pause] I'm just so unhappy, like, it's my second- so, even, next year's not even a year, to be honest, like. I'm just gonna basically, yeah, I think, next year, like the bullying will kind of stop, because, obviously everyone's just more kind of busy with their GCSEs" (Wonder woman, 36-40, p.14 & 1-4, p.15).*

The use of time frame "*24-7"* suggests that Wonder woman feels the threat of bullying is constant. There is a sense that Wonder woman does not see school as a safe space. Of particular interest is Wonder woman's statement, "*like the bullying will kind of stop, because, everyone's just more kind of busy with their GCSEs".* There is a suggestion in this statement that Wonder woman sees GCSEs as a protective factor and a way of escaping her current experience of bullying. Wonder woman's use of the word *"next year"* implies that she has accepted her fate in being bullied this year and is waiting for everyone to become busy with GCSEs and lose interest in her.

Additionally, Wolverine shared how his experience of bullying, as a result of his autism, lead to him feeling depressed.

> *"But the last bit of bullying that I got, like, proper bullying, leading to depression, when I was [mid-teens], uh, for three months, and it was awful" (Wolverine, 27-29, p.17).*

Wolverine's use of the phrase, *"proper bullying"* is interesting as it suggests that there are varying degrees of bullying. Previously, Wolverine has stated that he found it hard to distinguish between bullying and teasing. There is a sense that for Wolverine some forms of bullying are acceptable but "*proper bullying"* is not. The seriousness of the impact of *"proper bullying"* is captured in the time frame of *"three months".*

4.7.3.3 Subordinate theme three: Autism as a barrier

For Wonder woman, Catwoman and Storm, a theme throughout their narratives, was how their autism acted as a barrier to forming relationships with others. For instance, Storm spoke about how her autism made it difficult to build close friendships.

> *"…it has like affected me like in making friends with people, like [pause] building a close bond, um, building a close bond with um some people, um I found it quite hard" (Storm, 36-39, p.9).*

Storm's repetition of the phrase, *"building a close bond"* suggests desire or a lack of absence of a close connection with others. Storm discussed how she struggles with observing clear personal boundaries.

> *" Uh, sometimes, uh, when I see people in public, I, say like children and babies, children and babies, I go and approach them, and some of the parents, they get very aggressive, like, [pause] [imitating a voice] "don't touch my children, leave us alone" [in usual voice] "leave us alone", like, it gets like, really annoying when they shout, it sometimes frightens, the parents, it frightens me. I didn't feel, I felt so scared" (Storm, 19-29, p.13).*

This extract gives an insight into Storm's difficulties in navigating social boundaries in a public setting. Storm appears to express confusion as to why parents have responded to her this way to her. There is a conflict between Storm's earnest intentions and the parents' fears and protectiveness over their child. Storm's literal interpretation of the situation hints at her difficulties with theory of mind (ToM) and her ability to interpret behaviour.

Wonder woman, on the other hand, shared the following statement:

> ***“Wonder woman**…I am kind of angry at the fact that I have autism because obviously I feel like it just stops me from doing so many things.*
> ***Interviewer 1** What kind of things do you think your autism stops you from?*
> ***Wonder woman** Like, just, just being like everyone else”. (Wonder woman, 36- 41, p.15)*

From this extract, there is a sense of blame directed at her autism for making her different to *“everyone else”.* This extract alludes to Wonder woman’s lived experience been different to that of her peers because her autism “*stops me from doing so many things”* and places restrictions in her life.

4.7.3.4 Subordinate theme four: Us vs Them

Throughout their narratives, Wolverine, Wonder woman and Storm, highlighted the treatment of BAME autistic young people. In particular, they mentioned how they felt that white autistic young people were treated better in comparison to BAME autistic young people.

> *“I can tell you a story relating to B-A-M-E, relates- but some of the whites [*autistic individuals*] are treated better” (Storm, 31-33, p.16).*

> *“I think, white people do get more help” (Wolverine, 4, p.19)*

Wonder woman was able to expand further on the differences in treatment between white and BAME individuals.

> *“Like, I feel like white people are, are more, like, open-minded. And that’s why, like, they get treated different. And when it comes to a black person, they’re not really open-minded” (Wonder woman, 5-8, p.25).*

Wonder woman uses the term *“open-minded”* to differentiate between the experiences of white and black individuals. Linguistically, being *“open-minded”* infers that you are not closed off suggesting that white people’s willingness to be *“open-minded”* allows for a better experience of autism. There is a sense from this extract that Wonder woman is holding the white community in higher regards compared to the black community.

4.7.4 Superordinate theme: The importance of positive relationships at the different levels

This superordinate theme explores the role of friends, families and learning support assistants (LSAs) on participants' experiences of school. A common narrative shared across the participants, which tied in with the theme of 'self and autism', were examples of support given to them by friends, families and LSAs. Participants shared how this support has shaped their lived experience and acceptance of autism. Table 4.8 shows how the subordinate themes were spread across the participants.

Table 4.8

Subordinate Themes Relating to Superordinate Theme 'The importance of positive relationships at the different levels'.

The importance of positive relationships at the different levels				
Subordinate Theme	Wonder woman	Storm	Catwoman	Wolverine
Family as supporters	✓	✓	✓	✓
'My' learning support assistant	✓	✓	✓	✓
Friends helped me along the way		✓	✓	✓

4.7.4.1 Subordinator theme one: Family as supporters

All of the participants were able to discuss specific family members that they felt supported them and the impact this had on them.

> *"…she's just generally been there for me" (Wonder woman, 14-15, p.19).*

> *"They have to make sure that I need to keep focused, or like, um, revise any notes I've been [pause] confused on, like [pause] um [pause] like they always wanted me to be like active" (Catwoman, 20-24, p.9).*

> *"I go out with my sister when my friends don't want to come out with me, which is often" (Storm, 33-35,p.11).*

The different ways in which family members supported the participants was most evident in Wolverine's interview.

> *"…they've helped me open up about feelings, they tau-, sort of like, helped me open up about anger, and sort of helped me sort of control, not just control anger, but to, sort o, get to a situation where, right, my emotions are here, I can emote them, and I can talk about them, how I feel. That was the main, that's the main things, I don't have tonnes of say about the family, because they've done pretty much everything for me" (19-25, p. 14).*

The conceptualisation Wolverine presents that his parents helped him develop his skills for emotional regulation is of interest. Wolverine attributes his ability to communicate emotions appropriately to his parents teaching him to *"control"* and *"talk"* about his emotions. Wolverine stating, "*they've done pretty much everything for me"* suggests a sense of gratitude towards his parents.

4.7.4.2 Subordinate theme two: 'My' learning support assistants

All the participants shared positive experiences they had with LSAs who took an interest in getting to know them. The participants appeared to take pride in naming their LSAs who supported them.

> *"[LSA's name], she's a mentor, but she talks to me, like. When me and her talk, she's just so sweet, like" (Wonder woman, 5-6, p.20).*

> *"I really want to go and give the LSAs a hug. There is one LSA named [LSA's name] in this college, the Lithuanian woman, whenever I see her, I want to build a friendship with her" (Storm, 8-12, p. 15*).

The use of the LSAs names in both Wonder woman and Storm's extracts highlights the important role they had in their lived experience. Wolverine and Catwoman spoke of the value they took from having LSAs that they felt understood them.

> *"He was 20 at the time, when I was in year 8, and he [pause] was in my learning support, he used to sit next to me in history all a time, we used to have conversations about the work, and he just like, not, made me feel really comfortable, it was really nice to have, an adult figure next to me instead of like, a classmate. Uh, so the learning support department were wonderful" (Wolverine, 28-34, p.16).*

Wolverine appears to attribute his positive experience to the LSA's ability to make him feel *"comfortable".* Wolverine shares key information about his LSA including his age revealing perhaps the close relationship he had with him. Their close relationship is further emphasised by Wolverine's preference in having his LSA next to him rather than a peer.

4.7.3.3 Subordinate theme three: Friends helped me along the way

Friendship was identified as a key support mechanism for more than half of the participants. Wolverine, Storm and Catwoman revealed that their experiences of school were influenced by having friends. Despite the difficulties experienced by Wolverine, Storm and Catwoman a key narrative that came through was the role of supportive friends as a coping mechanism in school. For instance, Catwoman spoke about her friendships with peers consisting of checking in on each other.

> *"Um, like, I just, uh, mingle with them, and, um, you know, like [pause] ask how their day's been going, like, what's stressing them out the most?" (Catwoman, 1-3, p.10).*

Wolverine, on the other hand, spoke in detail about how his friends helped him to develop an appreciation for humor.

> *"And they said the real reason, is because we know you're developing with your autism. We want you to have fun and be a little less serious about yourself. We want you to let your hair down, let loose and enjoy yourself and be happy. And that's why they joked around, and I sort of got it and I picked it up and everyone started taking the piss and sometimes, it was just good fun. And, it become like, less, you get, become less rigid about it" (Wolverine, 20-27, p.13).*

There is a sense from this extract that the social difficulties experienced by Wolverine is a result in navigating the complex language of humour. At a linguistic level, Wolverine stating, *"I sort of got it"* suggests a lack of confidence in his ability to engage in humor exchanges with peers. There is a suggestion that being autistic means being "*rigid"* and it takes his friends intervening to aid him to *"let loose"* and be *"less serious".*

4.8 Chapter Summary

This chapter has presented the researcher's interpretative analysis of the superordinate themes for each of the four participants as well as the overarching groups themes. The next chapter 'Discussion' explores the findings in relation to the research questions, previous literature and psychological theory.

Chapter 5: Discussion

5.1 Introduction

This chapter presents a consolidation of the themes identified by the participants in relation to the research questions. While the researcher mainly draws on themes identified at a group level, to keep with IPA's idiographic principle, relevant themes at an individual level will also be referred to and discussed in relation to existing literature and psychological theories. Following this, the chapter presents the strengths and limitations of the current study and how findings can be used to bridge the gap between theory and practice for both EPs and schools. Dissemination of the research as well as reflections on the research process and study designed will be presented before a conclusion of the research is offered.

5.2 Research questions

This research aimed to explore the lived experiences of BAME autistic young people. Research exploring the voice of autistic young people is still within the emerging stages, and where present has generally excluded young people from ethnic backgrounds. This research adopted a participatory approach and hopes by documenting how autistic young people can be involved in research successfully it can contribute to increasing their participation in research.

In order to analyse the findings from the interviews carried out, the next section of the thesis is organised in three parts which relate to the research questions, with the overarching research question being answered last.

What are the lived experiences of BAME autistic young people?

Sub-questions:

1. How does a diagnosis of autism impact on their sense of self?
2. How do young people see their experience of being BAME and autistic?
3. What relationships have supported their experiences?

5.3 Research question one: How does a diagnosis of autism impact on their sense of self?

The themes most relevant to research question 1 were: ‘Feeling different’, ‘Positive traits of autism’, ‘Self as lonely’, ‘Bullying as a consequence of autism’ and ‘Autism as a barrier’. These themes were selected as they provide an insight into how a diagnosis of autism has impacted participants’ sense of self, by this we mean how the participants view themselves. Feedback received from others as well as relationships with key individuals such as peers appeared to contribute to how participants saw themselves and their autism.

5.3.1 Feeling different

The current study highlights a range of feelings associated with the diagnosis and label of autism. Similar to Humphrey et al.’s (2008) study, the current research found a ‘divergence’ between BAME autistic young people’s description of autism and themselves. For example, Wonder woman used words like *“retard”* (*39, p.7*) and *“alien”* (*10, p.26*) to describe herself and her autism, which is indicative of her understanding and engagement with the label autism. Wonder woman’s experience mirrors findings in Huws and Jones’ (2009) study which found negative reactions experienced by participants as result of their diagnosis. Wolverine’s perception of autism on the other hand was negative as a child but as he grew older and understood the term autism this led to increased self-understanding and ultimately an acceptance of his difference. This is similar to Humphrey et al.’s (2008) study that found that some participants not only accepted but eventually celebrated their autism. Despite differences in their self-perception in relation to their autism, all the participants in the current study agreed that a diagnosis of autism has impacted on their sense of self.

For some participants, like Storm, their construction of themselves and their autism was influenced by feedback they received from others including peers. Murry (2006) found that autistic young people who received negative feedback due to their autism by peers or teachers begin to incorporate these perceptions into their self-concept. Humphrey et al., (2008) argue that due to the pathologizing of the term autism we should move away from viewing it as a disorder and instead view it as a ‘difference’. This is supported by other autism researchers that advocate referring to autism as “a normal personality variant" (Frit, 1991, p.23) as defining an individual by their diagnosis can lead to loss of individuality limiting what others expect of them (Molly & Vasil, 2002).

Some participants in the study identified positive traits associated with autism such as perfect pitch and good memory. They expressed feeling proud of these traits as well as a belief that these traits were a result of their autism. This is consistent with research that found autistic individuals who had special talent, such as attention to detail or music, were more likely to feel proud of their autism and in turn were more likely to have a positive sense of self (Gulec-Alan et al., 2013).

5.3.2 Self as lonely

A key narrative that arose from the current study was participants' feelings of being 'different' coupled with experiences of being shunned, socially excluded and bullied by peers. These experiences are consistent with previous autism research that found autistic young people are more likely to experience difficulties forming friendships (Mehzabin & Stokes, 2011), poorer quality of friendships (Bauminger & Kasari, 2000) and social rejection (Jones et al., 2010).

Difficulties with social communication (see 'autism as a barrier', in section 5.3.4) can make it hard for autistic young people to form and develop relationships (Calder et al., 2013), impacting on their sense of belonging (Slaten et al., 2018). Maslow's (1987) Hierarchy of Needs proposes that advancement towards the attainment of 'self-esteem' or 'self-actualisation' is reliant on individuals' need for 'love and belonging' being met. Baumeister and Leary (1995) propose the idea that belonging is a basic psychological need and a lack of belonging can lead to higher levels of loneliness, stress, and mental health problems. MacDonald and Leary (2005) reported that lack of a sense of belonging can be experienced by individuals in a similar way to physical pain. These findings support the notion that as humans we are motivated to develop secure, fulfilling relationships with others and not experiencing a sense of belonging can have a detrimental impact on our well-being.

In the current study, Storm, Wonder woman and Catwoman all shared feeling lonely as result of being socially excluded by peers. Margalit (1994) describes loneliness as an undesirable and negative feeling which arises from “unfulfilled desire to have friends” (p.34). Interestingly, this desire for friendship was only expressed by the female participants of the current study, which alludes to differences between autistic females and males. The notion that autistic females may be more socially motivated to have friends was investigated by Sedgewick et al., (2016). Using questionnaires and semi-structured interviews, they examined gender differences in social motivation and friendship experiences between autistic and non-autistic adolescents. They found that autistic girls had a similar social motivation for friendship when compared to non-autistic girls. The findings from the current study supports the notion that autistic girls may indeed be more motivated to have friends, however, it is importance to acknowledge that the current study was only based on a small number of participants.

5.3.3 Bullying as a consequence of autism

While it has been well-documented within research that CYP with SEND are more likely to experience bullying (Norwich & Kelly, 2004), autistic young people are disproportionally affected by bullying both in prevalence and outcomes (Humphrey et al., 2008). Three of the participants in the current study shared experiences of bullying (both verbal and physical) as result of their autism. It has been said that autistic young people are more likely to experience bullying due to social naivety (Humphrey et al., 2008) and the struggle of NT peers to empathise and understand behavioural difference between themselves and autistic peers given that ASD is a ‘hidden’ condition (Humphrey & Hebron, 2015). Tantam (2000) found that when autistic young people experience bullying, they do not always have the resilience skills to manage fallouts as such school can become a distressing place. This finding links with the current study, and more specifically with Wonder woman’s experience, *“I hate school, like. I just 24-7 get bullied and I hate it” (36-37, p.14).* Schafer (2004) found that the long-term effects of bullying can result in higher levels of depression and associated difficulties with mental health problem. Again, this links with the current study, as Wolverine shared that his experience of bullying led him to feeling depressed for three months (*27-29, p.17).*

It is clear from the literature and the findings from the current study that an eco-systemic approach (Bronfenbrenner, 1994) would be beneficial to better understand the experiences of autistic young people and to target support across the different systems.

5.3.4 Autism as a barrier

Participants in the current study named their autism as a key barrier to forming relationships and interacting with peers. Despite difficulties with social communication, more than half of the participants in the current study shared their preference for online interaction when initiating and sustaining conversations with friends.

Schalkwyk et al., (2017) proposes that online interaction can offer autistic young people an opportunity to expand their social engagements with peers via online platforms as it is more suited to their communicative style due to less reliance on interpreting nonverbal information such as facial expressions. Although not explicitly mentioned by participants there is a suggestion that the current participants' preference may be due to social cues being stripped away similar to Schalkwyk et al.,'s (2017) study. The findings from the current study suggest that participants find it easier to make friends online as it enables them to be able to engage with peers more successfully. This is consistent with research suggesting that the use of social media can support the development of high-quality friendships in autistic young people (Kuo et al., 2014), encourage positive interaction between autistic and non-autistic peers (Schalkwyk et al., 2017) and facilitate romantic relationships (Roth & Gillis, 2015). The current study and existing research support the notion of promoting the use of online platforms as a way for autistic young people to improve their quality of friendship and opportunities for interaction with peers.

5.4. Research question two: How do young people see their experience of being BAME and autistic?

The themes most relevant to research question 2 were: 'The BAME communities' construction of autism', 'Us Vs Them' and 'Cultural pressures'.

5.4.1The BAME communities' construction of autism.

A key theme that emerged from participants was the negative perception held about autism in their communities. Participants used words like, *"jinn", "failure", "mental"* and *"not working"* to communicate how autism was seen in their communities. Although no research has exclusively explored perceptions of autism in BAME communities from the perspective of autistic young people, there are a number of studies that highlight parents' of autistic children's experience of negative perceptions of autism in different BAME communities, including Asian Indian families (Zechella & Raval 2016), Somali families (Hussein et al., 2019) and African immigrant mothers (Munroe et al., 2016). Participants in the current study appear to receive conflicting messages regarding autism from their community. For example, Wonder woman shared that members of her community often drew on religion and referred to 'jinns' as an explanation for the cause of her autism. This was found to be common in research investigating explanatory models of autism within BAME communities from parents' perspectives. For example, Hussein et al.,'s (2019) study found that some parents from the Somali community believed that the cause of autism was 'jinns' possessing their child's body, whereas, Wang and West's (2016) study found that Asian American parents believed that the cause of autism was mothers violating pregnancy taboos.

Participants in the current study reported prejudice and discrimination from their own community. While there is no research that has exclusively explored BAME autistic young people's experience of stigma as a result of autism there are number of studies that have reported on social stigma experienced by parents with autistic children from BAME communities (Lui et al., 2015; Kinnear et al., 2016). Munroe et al., (2016) found that negative attitudes towards autism in the African community often meant that parents experienced prejudice and discrimination resulting in some parents hiding their autistic child. Mazumer and Thompson-Hodgetts (2019) carried out a scoping review into stigmatization of autistic CYP and their families and found that negative attitudes towards autism can result in stigma for the families which can then be internalised by autistic children and their families.

Three of the participants also highlighted the need for psychoeducation to increase understanding of autism. Participants in the current study specifically linked lack of education and knowledge as a contributing factor for negative perceptions and stigma within their community. This mirrors findings from research that suggests educating others about autism can improve perceptions (Broady et al., 2017) and associated stigma (Milacic-Vidojevic et al., 2014). Staniland and Byrne (2013) created an anti-stigma intervention programme to encourage the acceptance of autistic adolescent boys by their peers. The programme was found to improve the knowledge and attitudes of non-autistic peers; however, it did not affect the behaviour of non-autistic peers towards their autistic peers. It is worth noting that this programme only provides literacy around autism in order to improve attitudes and it did not consider cultural and religious factors often associated with autism in BAME communities. Additionally, there is growing research to show that BAME communities' experience of prejudice and stigma as a result of autism may stem from a range of cultural and traditional factors unique to that community. For example, Hussein et al.,(2019) found that in the Somali community prejudice and discrimination often came in the form of labelling. Parents with and without autistic children shared that the Somali community are quick to label those who are different. Unfortunately, there appear to be little research on negating stigma and prejudice of autism within BAME communities.

5.4.2 Us Vs Them

Perhaps the most compelling theme that emerged from the current study is the racial identity of the participants and how they viewed their position in society. Wolverine, Wonder woman and Storm highlighted differences in the treatment of BAME autistic young people when compared to White autistic young people. Dovidio et al., (2009) suggested that for CYP from BAME communities their racial identity is very much part of their self-concept and how they interact with the world, whereas, for White CYP their racial identity is much less salient. Therefore, it is not surprising that nearly all of the participants in the current study commented on the treatment of BAME autistic young people, as 'race' is seemingly an issue for people of colour and not a White problem (Banks & Banks, 2009). A noteworthy finding in the current study is that many of the participants appear to hold individuals from White backgrounds in higher regards than individuals from their communities. CRT (introduced in Chapter One) argues that racism is a universal condition embedded into society and not an individual pathology. Therefore, the participants' perception of Whiteness is a result of White privilege and its unearned benefit influencing how individuals from minority groups see themselves. A key tenet of CRT is supporting individuals to share their experiences of race and racism via storytelling (Vaught & Castagno, 2008). By applying the principles of social justice, this study had given voice to a marginalised group by facilitating an opportunity for the research participants to tell their stories.

Although the term racial discrimination was not explicitly mentioned by participants in the current study, they highlighted differences in treatment between BAME and White individuals. For example, at an individual level Storm highlighted the treatment of Shukri Abdi and how that was *'triggering'* for her (*3, p.19).* Hackett et al., (2020) found that individuals from BAME communities who witnessed or experienced racial trauma were more likely to experience poor mental and physical health. Using CRT as the theoretical framework, Lee (2018) offers guidance for educators on how best to support the experiences of BAME young people in order to reduce racial discrimination and trauma. The literature and current study highlight a need to combat racial discrimination in order to improve the psychological and physical health of BAME individuals.

Issues relating to racism and systemic oppression were also raised in the current study in the form of police brutality and BLM. At an individual level, Storm shared her fears of dying as result of police brutality. An inquest carried out in 2020, found that black people are twice as likely to experience injury or death during police custody and five times more likely than their White counterparts to experience excess use of force during custody (Inquest, 2020). Frederick and Shifrer (2019) found that disability also appears to be a strong predictor of the likelihood of experiencing police force, however, unlike the data on race, whether an individual has a disability is not always recorded. Frederick et al., (2019) argue that in order to understand the positionality of individuals such as BAME autistic young people an intersectional analysis is needed to highlight “how racism and ableism intertwine and interact to generate unique forms of inequality” (p.200). In other words, intersectionality can be used as a vehicle to promote social justice for BAME autistic young people whose chance of marginalisation is increased due to their multiple identities.

5.4.3 Cultural pressures

Participants in the current study highlighted differences between the culture they were born into and the culture of the UK. These differences meant that many of the participants held separate beliefs about the cause and perception of autism to those in their community. Although no research was found to have explored differences in perspectives of autism between autistic young people and their community a study by Munroe et al., (2016) found that African mothers with an autistic child often reported shame and isolation due to feeling disconnected from the culture of their community and the pressure of trying to fit into Western culture. However, the findings from the current study conflict those in Munroe et al., 's (2016) study, as participants in this study referred to themselves as British-Indian or British-Somali as way of encompassing both cultures.

Participants adopting more than one culture can be understood through Berry's (1997) acculturation strategies. The process of acculturation is when an individual from one culture adopts the values of another culture that is not originally their own. This results in the original culture of the individual remaining but changing as result of the acculturation process. Participants in the current study appear to engage in a transmutation strategy, which is when an individual combines two cultures to form a third culture consisting of a blend of old and new. Wolverine shared, *"like I said, I'm a British Indian not Indian" (19, p.5*). Many of the participants in the current study appear to adopt a dual cultural identity as a way of distancing themselves from the negative perceptions held regarding autism in their community. Engaging in the process of transmutation has given way to participants having experiences of being a 'Third Culture Kid (TCK)'. According to Pollock and Van Reken (1999), TCK are CYP whose cultures are different to those of their parents or community. Studies have found that TCK are more likely to possess greater intercultural sensitivity (Lyttle et al., 2011) and higher levels of cultural balance (Peterson & Plamondon, 2009). It is worth noting that no research has explored TCK with autism and their experiences.

Another aspect of culture that was raised by the participants in the current study was cultural expectations within their community with regards to behaviour and career choices. What is noteworthy is that the participants referred to how these cultural expectations were not adopted by their families and how their individual families were more accepting of them and their autism than traditional families ‘back home’. Ravindran and Myers (2012) found that cultural beliefs held by a family can influence the experiences and response to autism.

5.5 Research question three: What relationships have supported their experiences?

An eco-systemic approach (Bronfenbrenner, 1994) was taken to explore the different levels of support given to participants. The themes most relevant to research question 3 were: ‘Friends helped me along the way’, ‘Family as supporters’ and ‘My learning support assistant’.

5.5.1 Friends helped me along the way

Friendships, which can be defined as a “mutual and reciprocal relationship between two people” (Bagwell et al.,1998, p.141), featured strongly in the current study as peer relationships was both seen as a challenge by participants (see research question 1) as well as a support system. Findings from the literature review carried out suggest that having supportive friends can act as a buffer against social problems (Poon et al., 2014) and increase positive sense of self for autistic young people (Humphrey et al., 2008). The literature also suggests that having supportive friends can reduce incidents of bullying and peer victimisation (Poon et al., 2014). Participants in the current study were able to name friends and the support they provided, which included helping them to accept their autism diagnosis.

Within research, the role of friends has been found to be the most pivotal relationship to support the inclusion and sense of belonging of autistic young people in schools (Coverdale & Long, 2015). Ochs et al., (2001) suggests that “the practice of inclusion rests primarily on unaffected schoolmates rather than teachers” (p.341). Supportive friends can act as a protective factor for autistic young people with regards to mental health (Boyle & Allen, 2018). Furthermore, autistic young people who have positive friendships with peers are less likely to be withdrawn from school (Osterman, 2000). The findings from the current study supports research suggesting that positive peer relationships can promote a sense of belonging for autistic young people. Given the findings from research and the current study, supporting autistic young people to develop positive peer relationships should be considered a key priority.

In the current study, Wolverine spoke about how his friends have helped him develop an appreciation for humour. Humour appreciation is “the ability of an individual to sense the funniness of information and recognise it as being humorous” (Ching-Lin et al., 2014, p.1387). According to the Theory of Weak Central Coherence (Frith, 1989) and the theory of mind construct (Baron-Cohen et al.,1985, 2001), autistic young people find it difficult to understand jokes when compared to NT peers (Samson et al., 2008). This is because autistic young people have difficulties with seeing the bigger picture due to the amount of focus given to smaller details as well as a lack of ability to recognise the mental state of others, which make it more difficult to understand the implications of jokes (Lyons & Fitzgerald, 2004). Difficulties with humour have been found to have an impact on social relationships as they lead to fewer opportunities for positive interactions with others (Carter, 2009). Wolverine shared that the more he practised humour, the more he “*become less rigid about it” (26-27, p.13),* which suggests that developing these skills can support and encourage autistic young people to engage in humorous exchanges. Samson et al., (2013) found that by supporting autistic young people to develop their skills in humour this can act as a buffer against negative comments made about them, in turn improving the interpersonal challenges they face.

5.5.2 Family as supporters

Family as a source of support was identified by all the participants as a pivotal part of their lived experience as autistic young people. Support offered by family members in the current study ranged from schoolwork, input around emotional literacy, self-regulation, and ‘being there’ for them. Gulec-Aslan et al., (2013) found that family played an influential role on young people’s experience of autism and that individual family members can act as a source of social support for autistic young people. In the current study, Storm spoke about how when her friends were unavailable, her sister usually stepped in to go out with her. *“I go out with my sister when my friends don’t want to come out with me, which is often” (33-35,p.11).* Studies have found that sibling relationships can play an important role in companionship as well as contribute to the development of SEMH (O’Neill & Murray, 2016). Tomeny et al., (2019) found that autistic young people who accepted social support from NT siblings were less likely to experience behavioural and emotional problems. Additionally, Ben-Itzchak (2019) found that having a sibling positively influenced the social skills and social functioning in autistic young people. The importance of family members providing opportunities to socialise has been found by other researchers (Krieger et al., 2012; Zukauska et al., 2009).

In the current study, Wolverine shared how his parents' acceptance of him being 'special' enabled him to accept his autism. "…*but there is something special about you. And your parents can see it, you would never see it" (47-3, p.8-9).* This idea of parents accepting their autistic child as 'different', has been documented in autism research (Preece & Jordon, 2010). Krieger et al., (2012) found when parents accepted their child's autism this fostered a positive, secure and protective relationship between the child and parent. In child psychology, these needs being met by parents can be understood from an attachment perspective. According to Bowlby (1988) children develop an internal working model in response to the quality of interaction between themselves and their caregiver. This interaction then becomes a prototype for all future social relationships and influences how a child perceives themselves, others, and their environment. The findings of this research point to supporting parents to accept their child's autism in order for them to develop a secure attachment and a positive sense of self.

5.5.3 'My' learning support assistant

All of the participants in the current study highlighted the support provided to them by their LSAs. Participants appeared to take pride in naming their LSAs and the level of tailored support they received. Having trusted adults who autistic young people can talk to about their individual experiences rather than autism more generally has been associated with positive school experience (Hummerstone & Parson, 2020).

Positive relationships with LSAs has been suggested to play a crucial role in the successful inclusion of autistic young people in schools (Emam & Farrell, 2009). Furthermore, having a positive relationship with an LSA or teacher in school is correlated with lower levels of social exclusion (Symes & Humphrey, 2012) and greater academic success (Burack et al.,1997). Wolverine shared that his positive relationship with his LSA was due to shared heritage which allowed for a deeper cultural understanding of his lived experience. Although no research was found that explored the relationships between LSAs and autistic young people from a cultural perspective, Wolverine's experience highlights the value of having an LSA who understands the culture and language associated with autism in BAME communities in order to better support BAME autistic young people. While, ideally, LSAs from all BAME communities would be represented in schools, this is not feasible. So instead, there is a need for more culturally sensitive practice and to train LSAs about BAME communities, specifically on different cultures and religions and how this influences the perception of BAME autistic young people and how they see themselves.

5.6 Overarching Research Question – 'What are the lived experiences of autistic BAME young people?'

This research aimed to explore the lived experiences of BAME autistic young people using a participatory approach. In doing so, it has highlighted that some of the experiences of the participants can be mapped onto the findings from the literature review. However, there are experiences that are unique to BAME autistic young people due to their cultural and racial identity. The aim of the current study was not to compare the experiences of BAME autistic young people against White autistic young people, but rather to highlight what the differences between these two groups are (from the perception of BAME autistic young people) in order to better understand their experiences. This study adopted an eco-systemic approach to highlight where participants felt particularly supported but also to recommend areas across the systems where support can be improved. Although this study has discussed social justice, intersectionality and CRT individually, they are all interconnected in their shared emancipatory endeavor.

As reflected in the literature review carried out, friendship (and lack of) was one of the main themes identified by participants. Relationships with peers were seen as taking the most pivotal role by participants in supporting a sense of belonging. However, where relationships with peers were not positive this resulted in social exclusion, loneliness and even bullying being experienced by participants. Difficulties in communication and interaction as result of autism were highlighted by the participants to be the main barrier for not being able to have friends. More than half of the participants shared that difficulties in social communication were less of a barrier when using social media platforms to communicate with peers.

Participants named LSAs that have supported them and the way in which this support was given. Unlike relationships with peers, participants only highlighted positive experiences with LSAs and shared how they were sources of support by listening to them and making them feel valued. One participant in particular highlighted the racial and cultural identity of his LSA and how having someone talk to him about autism in his community fostered a deeper connection. Participants also highlighted family as a source of support as they were able to facilitate participants to accept their autism and where friends were not available provide opportunities to socialise.

The impact of an autism diagnosis on the participants’ self-constructs was raised by participants. Many of the participants spoke negatively about their autism which often related to feelings of being ‘different’. However, the same participants were also able to reflect on the positive traits as a result of their autism which perhaps hints at their process with coming to terms with their autism. Despite differences in their self-perception in relation to their autism, all the participants in the current study agreed that a diagnosis of autism has impacted on their sense of self.

Throughout the research participants commented on the construction of autism within their specific communities. Participants shared that negative perceptions of autism meant that they experienced prejudice and discrimination from their own community. Unsurprisingly, participants rejected their communities’ negative perceptions of their autism and instead called for psychoeducation around what autism is in order to improve perceptions. The topic of ‘culture’ also fed into how participants experienced autism within their communities. Participants appear to adopt a dual cultural identity as a way of distancing themselves from the negative perceptions held regarding autism in their community. Finally, participants raised issues relating to racial discrimination, systemic oppression and police brutality. Participants demonstrated a strong awareness of their racial identity and highlighted their awareness of differences in treatment between themselves and white autistic young people.

5.7 Limitations of the Research

While this study has made important contributions to understanding the lived experiences of BAME autistic young people, it is not without limitations.

The first limitation for this study is the generalisability of the findings due to the small sample size. The researcher had difficulties accessing the research population and due to timescales (i.e. carrying out the research alongside fulfilling placement and academic components of the doctorate), the final study (n=4) involved three females and one male. Although IPA's idiographic method of inquiry supports a purposeful sample of four, it does however, place restrictions on the generalisability of the research findings. Participants were recruited because they could provide an insight into their experience of being a BAME autistic young person as a phenomenon of study (Smith et al, 2009). All the participants were from a BAME community, with a formal diagnosis of autism and from a similar geographical area, which improved the homogeneity of the population of study, but may have further placed restrictions on the generalisability of the findings. Throughout Chapter Four, an attempt has been made to provide information on the participants' background, strengths, level of education and their aspirations for the future. By doing this, the researcher hopes that this information would possibly allow for a theoretical generalisability to the greater BAME autistic community.

The participants' experiences captured in this study may only represent a subsection of the autistic population; those who are able to conceptualise the concept of race and who are willing and verbally able to share their experiences. Due to the selected methodology of SSIs, the voices and experiences of less verbally able autistic young people has been missed. All interviews were carried out virtually via MS Teams. Interviews are characteristically subject to demand characteristics; that is, the tendency for participants to take on apprehensive-participant role during the interview and answer questions in a socially desirable way (Weber & Cooke, 1972). Social desirability could result in over-reporting of positive experience of being autistic and BAME which in turn could lead to a false depiction of BAME autistic young people's experience. However, the varying experiences and beliefs shared by the participants during the interviews indicates that this method of bias may not have had a strong impact on the data collected. This is because participants discussed fear of police, feeling shunned by peers and concerns of social injustice. These concerns and fears perhaps would not have been shared by the participants if they were attempting to answer in a socially desirable way.

It is important to acknowledge the subjective role of the researcher in IPA studies (Smith et al., 2012). As previously stated, for IPA researchers the depiction of participants' words involves the process of 'double hermeneutics' which means that the same phenomena can be viewed in different ways by the researcher and participant (Smith et al., 2012). Therefore, a limitation of using IPA is that the researcher's experience, values or belief systems could potentially influence the interpretation so much that it moves the meaning away from what the participant originally intended it to be. To combat this, the researcher and co-researcher have made efforts to member check the interpretation of the findings with all the participants. Additionally, as part of this process participants were given an opportunity to correct or challenge interpretations that they felt were inaccurate or not reflective of their lived experience (see Appendix 4.2).

5.8 Unique Contribution

The experiences of autistic young people and the impact the label autism has on their identity, peer relationships and social wellbeing is an area of emerging psychological research. However, to the best of the researcher's knowledge, this is the first study in the UK to exclusively explore the lived experiences of BAME autistic young people. This study plays an important role in promoting the voices of BAME autistic young people within autism research, an area that has been largely neglected by researchers. This study adopted a PR approach which included recruiting a co-researcher (from the autism community) to collaboratively plan and deliver the research project. Carrying out research in this manner means that the findings from the current study are more relevant and provide a greater insight to the experience of BAME autistic young people, in turn enhancing the trustworthiness of the study (Thomas et al., 1998). Additionally, both the researcher and co-researcher are from a BAME background which further enhances the richness of the study as they were able to adopt an ‘insider perspective’ in order to facilitate a culturally sensitive approach to the research (Tillman, 2002).

The findings from the current study highlight that autistic young people from BAME communities have experiences that at are unique to them as result of their cultural and racial identity. This study also highlights the importance of intersectionality in supporting BAME autistic young people as often their multiple identities (i.e. race, gender, ableism etc) can mean that different forms of oppression can take place simultaneously. The researcher and co-researcher hope that the findings from the current study can provide EPs and schools working with BAME autistic young people an insight to their experiences in order to better facilitate tailored support that goes beyond autism and encapsulates culture and racial experiences.

5.8.1 Bridging the gap between practice and research

Due to concerns over the lack of representation of BAME young people in autism research as well as concerns over social justice and marginalisation of this group this study adopted a participatory approach and recruited a BAME autistic co-researcher to support the exploration of the lived experiences of BAME autistics young people. By engaging a co-researcher in this study, it highlights that autistic young people can actively be involved in all aspects of research with careful planning and training. Boyle and Lauchlan (2013) argue that EPs’ positions within the community and schools mean that they are able to take on the role of translating evidence-based best practice that has been established through psychological research into real change for CYP and their families. With this in mind, the researcher hopes by sharing documents such as the training manual and reflections on best practice, it can serve as a framework for researchers and practitioners to use when considering how to involve autistic young people in projects and research, in turn bridging the gap between practice and research.

5.9 Suggestions for Further Research

The majority of studies exploring the lived experience of autistic young people have either provided a lack of description of the participants’ ethnic background or have disregarded it (see Chapter Two), which gives the impression that race and culture is not of importance to autistic experience. However, this study has shown that the young people involved in the research have experiences that are unique to them due to their cultural and racial identity. The participants in the study have been able to reflect on their experience of being BAME and autistic. It will be important for future research to continue to place importance on the role of race and culture on lived experience and not just gender. Applying the principles of social justice becomes even more important in research in order to ensure that autistic individuals’ racial and cultural identity is recognised and considered by researchers.

While this study has provided some insight into the support BAME autistic young people value and want, future research can adopt a strength-based approach to investigate positive experiences of BAME autistic young people in order to advocate for the type of support they value most.

Participants in the current study shared that negative perceptions of autism meant that they experienced prejudice and discrimination from their own community. Yet, there appears to be little research seeking to reduce stigma and prejudice of autism within BAME communities. Findings from the study highlight the need for targeted and tailored intervention aimed at the wider community demonstrating prejudice toward BAME autistic individuals due to their race and ‘disability’ in order to combat the stigma and prejudice they experience.

This study has highlighted that peer relationships can be a barrier and enabler of a sense of belonging within school. Future research can explore this area in more detail by exploring the narratives around what friendships means for BAME autistic young people. Additionally, this study has highlighted the crucial role and support of LSAs and the impact they can have on autistic young people long after they have finished school. Future research could work with LSAs and BAME autistic young people to help identify educational practices that facilitate the participation and inclusion of this population in schools.

A topic that arose unprompted during the training session with the co-researcher was his experience of romantic relationships. Very little is known about the romantic experiences of autistic young people in general let alone of those from BAME backgrounds (Hendrickx, 2015). Future research could investigate this area using a participatory approach to ensure that the research topic and questions are led by the community and takes into consideration the cultural and racial identity of BAME autistic young people.

5.10 Implications for EPs and schools

According to Watts (2014), findings from small-scale studies can contradict or even undermine established understanding of a particular concept or question our current professional practice. The research findings in this study, despite only including the voices of four BAME autistic young people, highlight several implications and recommendations for EPs and school staff. In keeping with the principles of PR, it is important that BAME autistic young people are involved in all discussions relating to support for them as they are best placed to know what would make a positive difference to their experiences.

5.10.1 Implications for EPs

As applied psychologists, EPs are uniquely positioned to work across and within different levels of systems (i.e. individual, family, school, community and societal) in order to support young people's development, mental health, identity, relationships and wellbeing (Roffey et al., 2016). Given the way in which EPs work, they are well placed to support marginalised and often unrepresented communities (Dunbar-Krige et al., 2010).

Eliciting and listening to the voices of young people is a key aspect of the EP role (Mercieca & Mercieca, 2014). At an individual level, EPs are able to work with BAME autistic young people to support their sense of belonging in schools and give them a voice regarding plans being proposed for them. McLaughlin et al., (2014) found that EPs are expertly positioned to advocate for the voices of CYP and also to challenge assumptions about autistic young people's identity. Given that BAME young people have been traditionally excluded from autism research, EPs are in a position to be able to advocate on their behalf in order to bring about positive changes.

A core aspect of the EP role is to give away psychological research and theory (Cameron, 2006). At a school level, EPs are able to support school staff by bringing awareness to psychological theories such as ‘labelling theory’ (Russell, 2016); which highlights that biases and assumptions can be made about a young person based on the label ‘autism’. This in turn can lead to self-fulfilling prophecies (Rosenthal & Lawson, 1964) and risk difficulties being viewed as within-child, which in turn ignores environmental and developmental factors. Findings from the current study highlight the importance of giving consideration to young people’s cultural and racial identities. Agyeman and Lichwa (2020) highlight that EPs are able to support school staff to “foster a sense of ethnic affirmation through ethnic–racial socialisation as a means to promote a healthy self-concept” (p.7).

A key principle from the SEND Code of Practice (DoE, 2014) is listening to the voice of families and CYP. At a family and community level, EPs have a responsibility to listen to the lived experiences of BAME families as well as develop an awareness of the role of culture and religion in decision making relating to their child’s autism. Previous studies have found that families from BAME communities’ perception of autism can be negative and often there is a lack of appropriate language available to describe autism (Jegatheesan et al., 2010; Hussein et al., 2019). This study has found that these negative perceptions and descriptions of autism are then interpreted by young people from these communities. EPs can work with families and BAME communities to develop literacy around atypical development and empower them to increase their awareness of autism. One way this can be done is through delivering strength-based interventions such as Multi-Systemic Family Groups (MSFG). MSFG has been found to promote the engagement of BAME communities in a respectful and culturally sensitive manner by working with the young person, family and school (Fox et al., 2017).

Finally, EPs can contribute to autism strategies within LAs shaping the way in which BAME autistic young people and their families are supported.

5.10.2 Implications for Schools

Schools should be aware of the crucial role LSAs can play in supporting BAME autistic young people as participants in the current study spoke positively about the support offered to them by their LSAs. This support can be seen as a protective factor for BAME autistic young people. Schools should continue to foster positive relationships between BAME autistic young people and LSAs in school.

A narrative that emerged from the findings was participants' desire to have friends but yet feeling socially rejected by peers. School staff can support autistic young people by delivering evidence-based interventions such as 'Friends for Life' to help them develop social skills in order to manage relationships with peers effectively and develop secure friendships. 'Friends for Life' has been found to result in positive outcomes for young people including fostering a greater sense of belonging and connectiveness (Ruttledge et al., 2016). However, it is important to note that this intervention does not take into account the cultural and racial identity of CYP, therefore this intervention will need to be adapted to ensure that BAME autistic young people cultural and racial identity is considered when prompting social friendships and social skills.

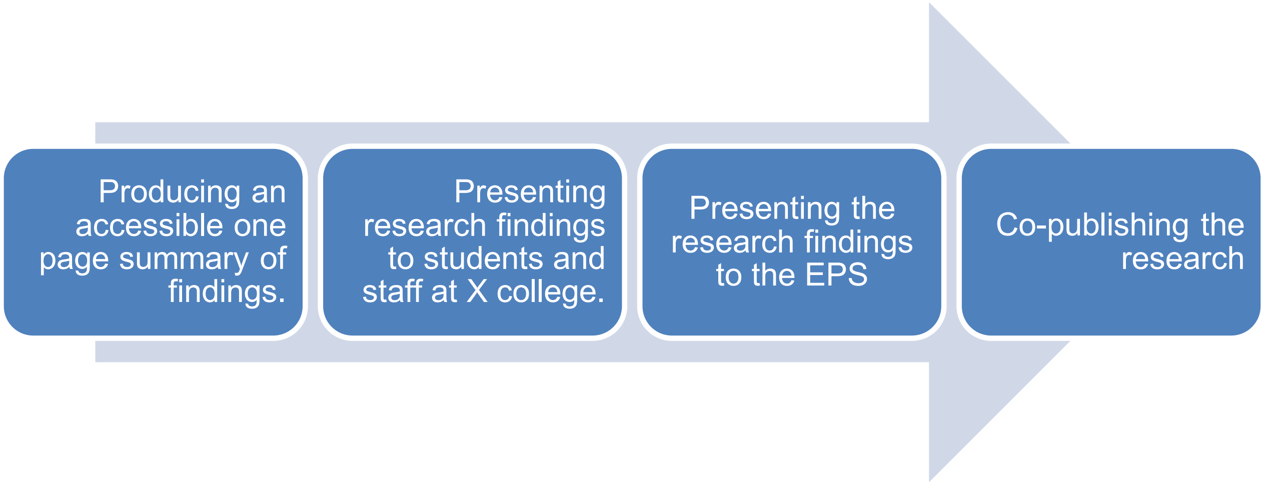
Finally, findings from the study show that autistic BAME young people are aware of the way in which society positions them due to their race. Nearly all of the participants mentioned being treated differently in comparison to white autistic young people. It may very well be that BAME autistic young people have questions about the treatment of black lives and their own racial identities. School staff can support young people from BAME communities by ensuring that their curriculum is culturally responsive. Teachers can facilitate safe and reflective spaces for young people to discuss movements like BLM and what this means. The researcher recognises that discussing race and racial issues can at times be uncomfortable for many, as such school can seek advice from EPs as they are able to support schools and staff to adopt an anti-racist practice.

5.11 Plans for Dissemination

PR advocates involving members of the community in the dissemination of research findings in order for it to be accepted as meaningful and valid (Staley, 2009). With this in mind, the co-researcher will be involved in all aspect of dissemination.

Figure 5.1

Stages of dissemination involving the co-researcher



Once the research project has been completed, the researcher and co-researcher intend on producing an accessible one-page summary of the findings to be sent out to participants with an invitation to speak about the project if they wish to. Additionally, the researcher and co-researcher have arranged to feedback the research findings to staff and students at the college where the co-researcher is currently attending. The research findings will also be presented to the EPS with hopes of it feeding into the draft autism strategy and improving the experiences of BAME autistic young people in the LA. Finally, the researcher and co-researcher hope to be in a position to publish the research findings so that other professionals who come in contact with BAME autistic young people are better informed of their experiences.

5.12 Reflections and reflexivity

In this final section of the thesis, the researcher will take a reflective position to explore the impact of the research on her practice as well as her positioning throughout the research. For these reasons, this section will be written in the first person (for further reflections on the research process please see Appendix 3.3).

5.12.1 Participatory Research

Prior to starting this research one of the questions I had was, ‘how can I confidently know what BAME autistic young people want when I am not an autistic young person?’ During a university lecture we were introduced to PR approaches and in that instant, I knew I wanted to incorporate the principles of PR into the research design of my doctorate thesis in order to answer my initial question. Throughout this research process I tried to go beyond a tokenistic approach to PR and dutifully apply the principles of PM as advocated by Aldridge (2017). I was conscious not to parachute in with my lack of understanding and knowledge of what it is like to be a young autistic person and carry out the research on a problem I think I see. I strongly believe that carrying out the current research using traditional methodology would have done a disservice to BAME autistic young people who have already been neglected in autism research.

Whilst I am proud of the research carried out, I think it is important to name that adopting a PR approach is more challenging than engaging in traditional research. The process of supporting the learning of my co-researcher took over eight weeks which had an impact on when the other stages of research can be carried out. Additionally, there has to be a conscious effort to consult with the co-researcher and collaboratively make decisions that impact on the research. It would have been much easier and less time consuming for me to have made these decisions on my own; but holding in mind the guiding principles of PR and what motivated me to carry out research in this way enabled me to be collaborative throughout the research. Carrying out research in this way has had a tremendous impact on my role as practitioner-researcher. I have learnt so much from working with my co-researcher that will forever influence my practice and how I elicit the voices of vulnerable young people (please see Appendix 5.1, for my key learning for future practice).

5.12.2 Power imbalance

Throughout the research process, I reflected on any power imbalances and interactions between myself, the co-researcher and the participants by revisiting the principles of attunement. Throughout the research process I maintained a self-aware position by reflecting on my positionality as a TEP and researcher and how this may impact on the relationships and the way in which the research was carried out. I am very aware that someone holding the title of EP and researcher can be seen as an expert in the field of autism, to remedy this I made sure that the co-researcher and the participants were aware that they were the experts in their lived experiences. I did this by taking a non-expert position and empowering participants to lead discussions during the interview and for the co-researcher empowering him to make decisions at different stages of the research process. I used supervision on placement and university as a space to consider any power imbalances that arose and how to address these. I was fortunate enough to be able to problem solve with my academic tutor and placement supervisor which enabled me to be transparent about decision making throughout the research process. Additionally, I employed the process of reflection on action and in action (Schön, 1983) to consider my role as a TEP and researcher.

5.12.3 Researcher's positioning

As previously stated, I am a Black-African, Muslim, cis-gender female. From the onset of the research I knew I wanted to explore the experiences of BAME individuals not only from the perspective of social justice but due to my own experiences as a member of the BAME community. I believe that these experiences allow me a certain level of unique insider perspective to bring to psychological research particularly given the small number of applied psychologists that are from the BAME community (Fatimilehin & Coleman, 1999). Reflecting on the analysis stage, I wondered whether my own racial and cultural identity was the main driving force behind some of the themes that emerged. Did my racial and cultural identity enable the participants to be more comfortable to discuss issues of marginalisation and racial discrimination with someone that looked like them? Putting aside my racial and cultural identity, having a co-researcher collaborate on this research project allowed for a high level of objectivity and rigour perhaps in a way that might not have been achieved if I carried this study out on my own. The co-researcher was able to support me to maintain a position of neutrality throughout the research in particular during the analysis stage. The co-researcher was able to support me in areas where I had blind spots (i.e. seeing what I wanted to see as opposed to what the data was showing) and hold in mind the reflective voices of the young people.

5.13 Concluding statement

This is the first study in the UK to explore the lived experiences of BAME autistic young people using a participatory approach. This study contributes to the emerging body of autism research investigating the voices of autistic young people. The findings from the current study highlight that while there are similarities between the experiences of BAME autistic young people and findings from the literature review there are some experiences that are unique to BAME autistic young people due to their cultural and racial identity. BAME autistic young people describe experiencing differences in the treatment of autism due to their skin colour, negative perceptions held about their autism in their community and cultural pressures. These findings have implications for EPs, clinical services, schools and policies including the importance of developing culturally competent professionals who are able to offer support that goes beyond autism and incorporates the cultural and racial identity of the young people. Additionally, the findings support the importance of raising the awareness of autism in order to negate any stigma experienced by young people in their community. It will be important that any support provided to BAME autistic young people is considered within an eco-systemic model (Bronfenbrenner, 1994) in order to ensure that consistent support is provided across the different systems. Finally, the researcher and co-researcher hope that this study will contribute towards social justice by shifting the nexus of power as well as enabling participation and giving a voice to a marginalised group who have largely been neglected by autism research.

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Appendix 1.1 – Weight of evidence (WOE)

	WoE A (Trustworthiness in terms of own question)	**WoE B** (Appropriateness of design and analysis for this review question)	**WoE C** (Relevance of focus for this review question)	**WoE D** (Overall weight in relation to review question)
Browning, Osborne and Reed (2009)	**1**	**2**	**1**	**Medium quality**
Connor (2000)	**1**	**1**	**1**	**Low quality**
Goodall and Mackenzie (2019)	**2**	**3**	**2**	**High quality**
Hill, L (2014)	**3**	**2**	**1**	**Medium quality**
Humphrey and Lewis (2008)	**3**	**2**	**2**	**High quality**
Marks, Scharader and Longaker (2000)	**2**	**1**	**1**	**Medium quality**
McLaughlin and Rafferty (2014)	**3**	**2**	**1**	**Medium quality**
Poon *et al.* (2014)	**2**	**1**	**2**	**Medium quality**
Saggers, Hwang, and Mercer (2011)	**3**	**2**	**2**	**High quality**

Appendix 1.2 –Critical analysis of identified studies

Author and country	**Objective**	**Participants**				**Study design: data collection method**	**Data analysis**	**Main findings / *Themes***	**Critical analysis**
		N	**Age**	**Gender**	**Diagnosis**				
Browning, Osborne and Reed (2009) **(United Kingdom)**	Post school transition of young people with and without autism.	**17**	Mean age = 15 years old.	8M, 2F = ASD / AS 4M, 3F = NTD	ASD AS	Semi structured Interview	Content analysis (Vaughn, Schumm & Sinagub, 1996)	Apparent differences between pupils with ASD and those without regarding: - their ability to cope with stress. - their source of stress. - concerns about their future. Participants with ASD were more likely to worry about interpersonal relationships and actual harm from bullies.	The heterogeneity of ASD was not represented. Researchers purposely selected participants with 'high language ability'. Only interviewed their participants once. Findings were not checked with participants. Limited information was provided regarding who the participants were. Ethnic backgrounds were not specified. Researchers did not state their ontological and epistemological positions.

Connor (2000) **(United Kingdom)**	Examined the experiences of students with Asperger syndrome at secondary school	**16**	11 – 16 years old	15M, 1F	AS	Semi structured interviews	Analytic procedure not reported; appears to be a Qualitative Content Analysis	Preferred activities at school, likes and dislikes, problems at school, activities at break or lunchtime, friendship, and post-school activities	Study did not involve any controls therefore uncertain whether similar answers would have been given by students with emotional or behavioural problems. Participants voices were obscured by the use of semi-structured interviews with pre-determined questions. Limited information was provided regarding who the participants were. Ethnic backgrounds were not specified. Analyses appeared to be shaped largely by researchers' interpretations of SENCos' reported experience, with the majority of themes being drawn solely from SENCos rather than pupils.

Goodall and Mackenzie (2019) **(United Kingdom)**	Explored the experiences of autistic girls in mainstream education	**2**	16 – 17 years old	2F	AS ADHD / APD	Semi structured interviews & participatory activities i.e. 'Good teacher, bad teacher', Beans and Pot activity & Diamond ranking	Thematic analysis (Braun& Clarke, 2014)	Bullying Friendship Fitting in – sense of belonging School environment class changes and negotiating chaotic, noisy corridor	Used participatory activities to make the research more inclusive Small sample of participants. Limited information was provided regarding who the participants were. Ethnic backgrounds were not specified. Researchers did not state their ontological and epistemological positions. The researchers report informal accuracy checks were carried, but unclear what this was? Part of a larger scale researcher. Unclear what the aims of this study are.

Hill, L (2014) **(United Kingdom)**	Explore the mainstream secondary school experience of young people with ASD	**6**	Not given	Not given	ASD	Photo elicitation followed by informal interviews. 4 separate interviews took place.	IPA (Smith et al. 2009)	Anxiety Environmental and social factor & Curriculum and learning factors Young people as active Agents. Making sense of self and other Emerging sense of independence Creative problem solvers Self	Limited information was provided regarding who the participants were. Ethnic backgrounds, gender and age were not specified. Researchers did not state their ontological and epistemological positions. Limitations of the study were not covered. Interviewed participants on four different occasions.

Humphrey and Lewis (2008) **(United Kingdom)**	Examined the experiences of individuals with ASD in mainstream secondary school	**20**	11 – 17 years old.	Not given	AS / HFA (terms interchangeably)	Semi structured interviews, diaries and pupil drawing	IPA (Smith et al., 2009)	Differences in how participants constructed their understanding of what their AS meant to them. Relationship with peers Preference for routine, predictability and low sensory stimulation Negotiating differences Anxiety and stress around sensory, exams, desire for privacy.	Limited information was provided regarding who the participants were. Ethnic backgrounds and gender were not specified. Described in detail how assent was sought from participants under the age of 18. Asked for feedback from participants schools' staff about the appropriateness of their interview questions before conducting the interviews. Triangulated the data from their participating pupil dairies. Invited participants to provide comments on a pupil friendly summary of their findings. Got to know their participants through engaging in various activities prior to interviews.

Marks, Scharader and Longaker (2000) **(United States)**	Examined the experiences of individuals with Asperger syndrome	**3**	13 – 15 years old.	Not given	AS	Semi structured interviews	Inductive analysis (Patton, 1990)	Narrow range of interest. Negative experience of school life – feeling isolated and loneliness. Social life – difficulties with making friends.	Parents voice resonates louder within the study. The researchers drew many of their conclusion based on account and experience of the parents as opposed to the pupils. Only study to specify participant's ethnic background. A small number of participants. Researchers did not state their ontological and epistemological positions

McLaughlin and Rafferty (2014) **(United Kingdom)**	Explored the lived experiences of young people with Asperger Syndrome	**6**	Year 10 to Year 13 (no specific age given)	5M, 1F	AS	Semi structured interview	Thematic analysis (Braun and Clarke, 2006)	Positive experience of AS: academic success, part of their identity. Negative experience of AS: anger over their diagnosis. Wanting to be 'normal' Fitting in – impact on peer relationships	Participant's characteristic including age and ethnic background were not specified. Described in detail how assent was sought from participants under the age of 18. Gathered their data exclusively by interviewing their participants only once. Researchers did not state their ontological and epistemological positions.
Poon *et al.* (2014) **(Singapore)**	Explored the views of students attending mainstream secondary school with High functioning autism	**4**	12 – 16 years old.	3M, 1F	HFA, AS	Semi structured interview Observation in school before the interviews	IPA (Smith et al., 2009)	Negative and positive construction of the label High Functioning Autism Peer relationships – difficulties with classmates Bullying School perceptions – fear of failure.	Only study to provide participant's cognitive abilities and academic performance. Provided participants with the option of having a familiar adult present during interview. Half of participants agreed to this. Possible impact on responses from participants?

								Anxiety and stress over academic work	Gathered data exclusively by interviewing participants only once. Researchers did not state their ontological and epistemological positions. A limitation identified by the researchers is trustworthiness of the study. Ethnic backgrounds of participants were not stated. Got to know their participants through engaging in various activities prior to interviews.

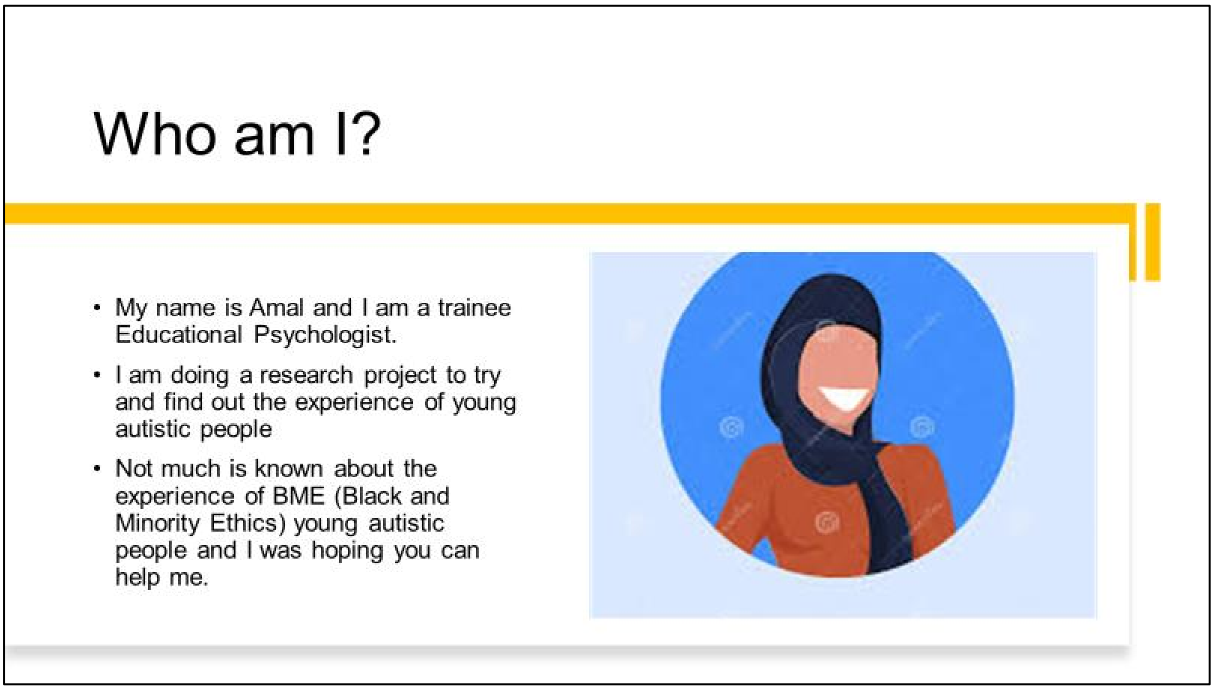
Saggers, Hwang, and Mercer (2011) **(Australia)**	Explored the educational experiences of adolescents with autism	**9**	13 – 16 years old.	7M, 2F	ASD	Semi structured interview; activity and 30 min home interview. Walking interview (at the college)	Constant Comparative Methods – GT (Glaser, 1992)	Bullying and being teased. Friendship with peers Teacher, curriculum and environmental characteristics	Nine students from a single high school in a metropolitan area. Issues around generalisability? Explored key themes they identified after the first interview. Limited information was provided regarding who the participants were. Ethnic backgrounds were not specified. Researchers did not state their ontological and epistemological positions

M: Male; F: Female; AS: Asperger Syndrome; ASD: Autistic spectrum disorder; GT: Grounded theory; HFA: High functioning autism; IPA: Interpretative Phenomenological Analysis; TA: Thematic analysis

Appendix 3.1 – Co-researcher presentation slides

Participatory research project

Amal Hussein (Trainee Educational Psychologist)

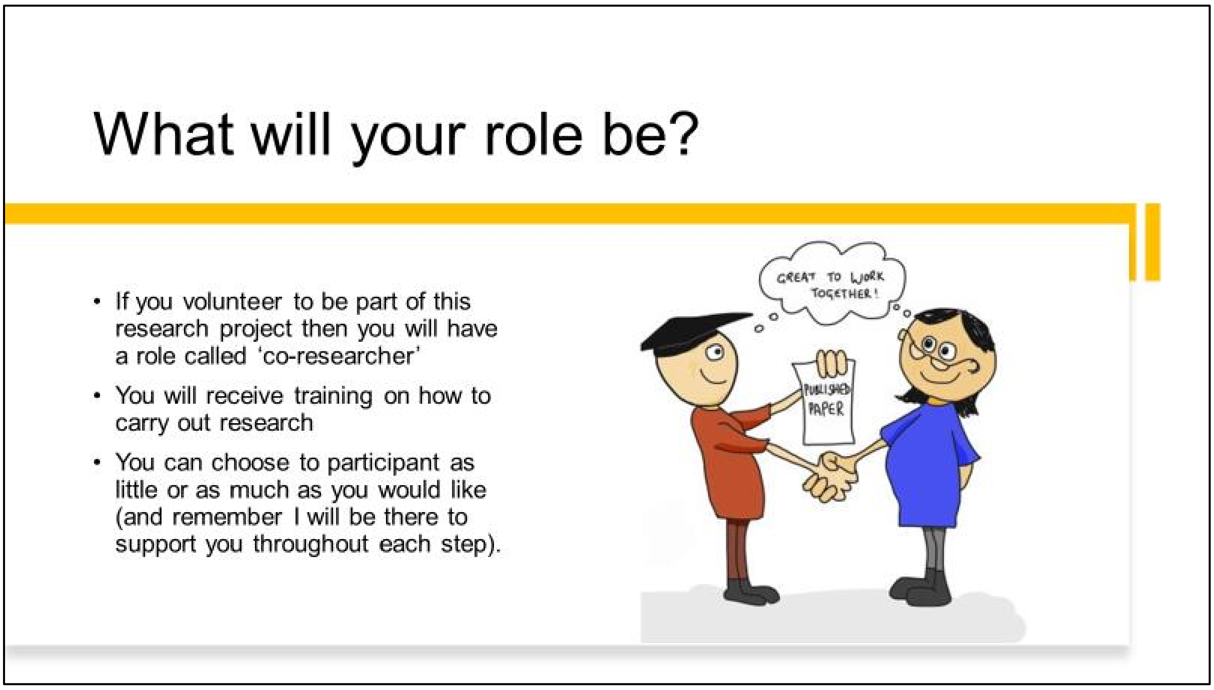


Who am I?

- My name is Amal and I am a trainee Educational Psychologist.
- I am doing a research project to try and find out the experience of young autistic people
- Not much is known about the experience of BME (Black and Minority Ethics) young autistic people and I was hoping you can help me.

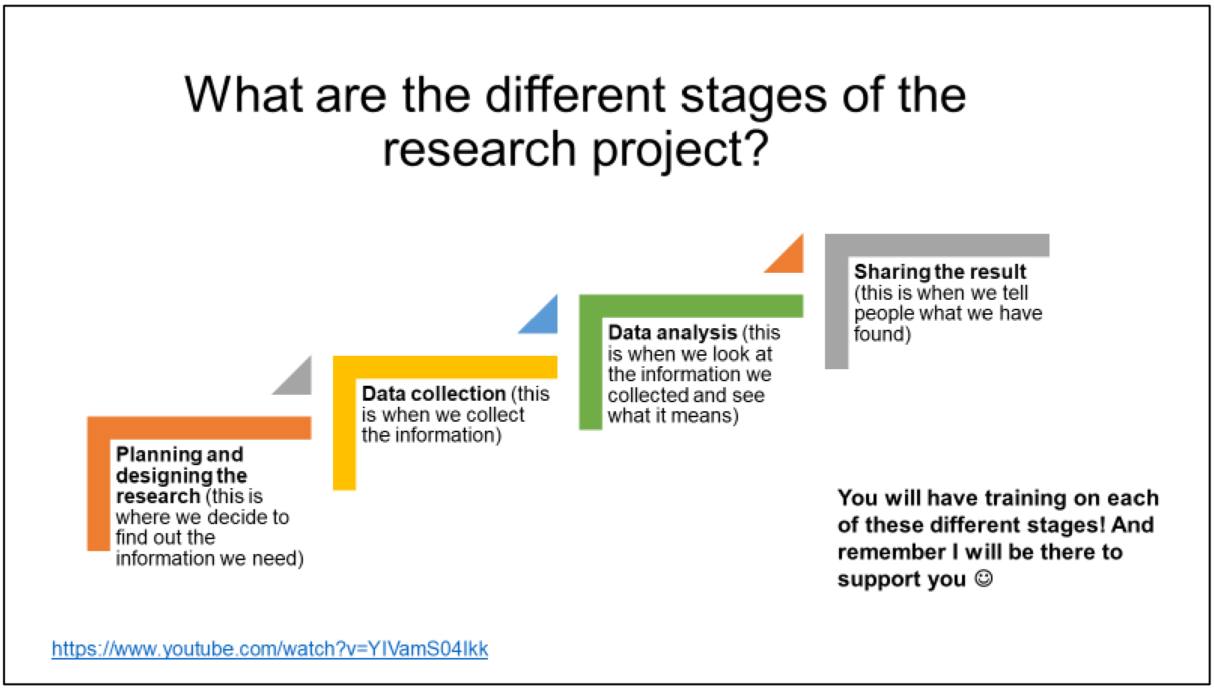
Doing research together

- By adopting an approach called 'PARTICIPATORY' research
- I hope to involve a young autistic person from a BME (Black and Minority Ethics) background to lead the project alongside me.
- That means that you can be involved in every stage of the project (I will explain these stages in more details later)



What will your role be?

- If you volunteer to be part of this research project then you will have a role called 'co-researcher'
- You will receive training on how to carry out research
- You can choose to participant as little or as much as you would like (and remember I will be there to support you throughout each step).



What are the different stages of the research project?

Planning and designing the research (this is where we decide to find out the information we need)

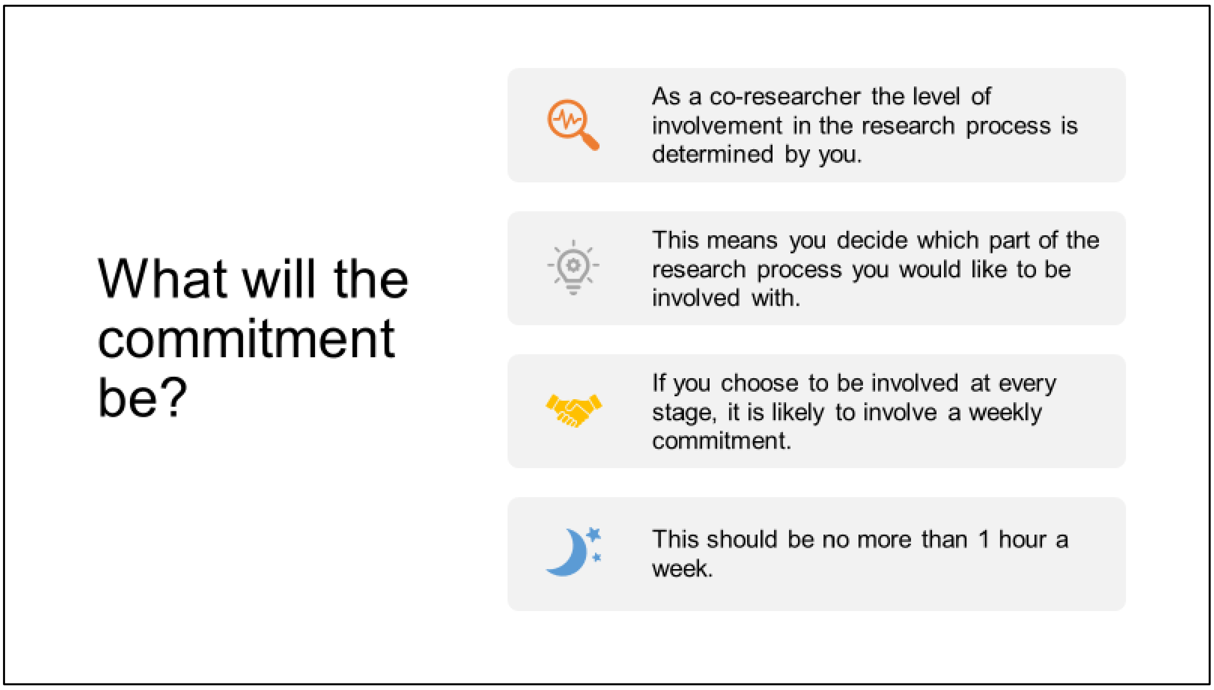
Data collection (this is when we collect the information)

Data analysis (this is when we look at the information we collected and see what it means)

Sharing the result (this is when we tell people what we have found)

You will have training on each of these different stages! And remember I will be there to support you ☺

https://www.youtube.com/watch?v=YIVamS04Ikk



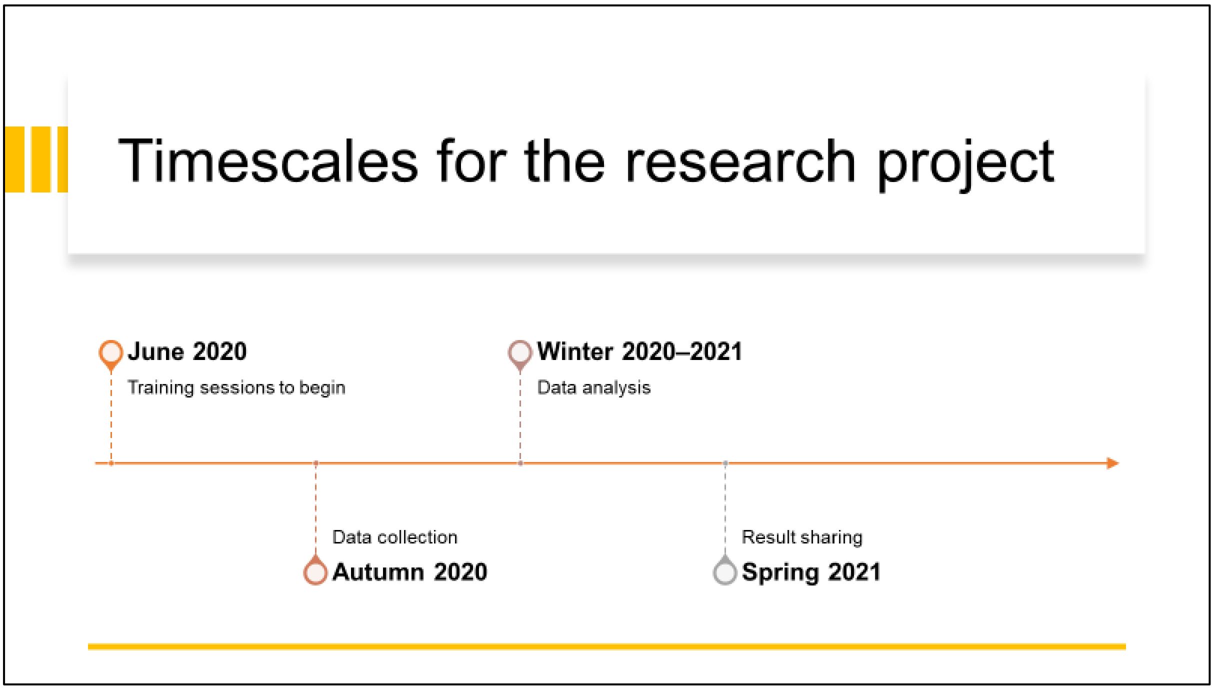
What will the commitment be?

As a co-researcher the level of involvement in the research process is determined by you.

This means you decide which part of the research process you would like to be involved with.

If you choose to be involved at every stage, it is likely to involve a weekly commitment.

This should be no more than 1 hour a week.



Timescales for the research project

June 2020
Training sessions to begin

Data collection
Autumn 2020

Winter 2020–2021
Data analysis

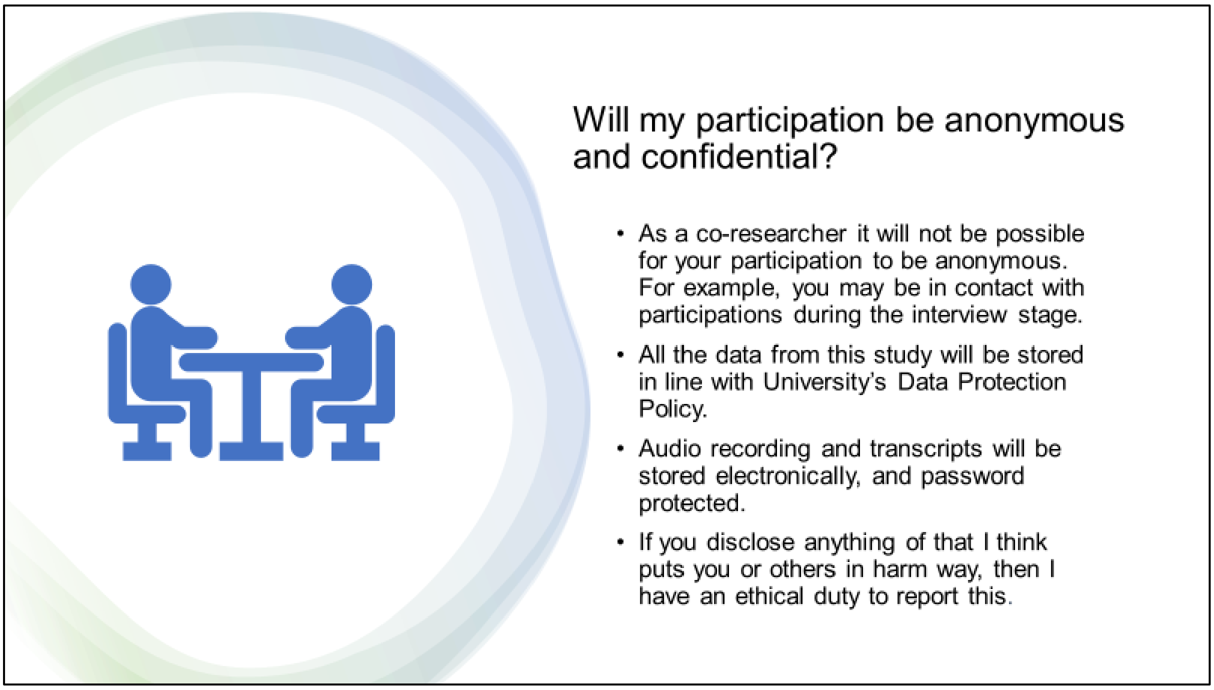
Result sharing
Spring 2021

What are the benefits of being a co-researcher?

YOU WILL LEARN NEW SKILLS IN CARRYING OUT RESEARCH

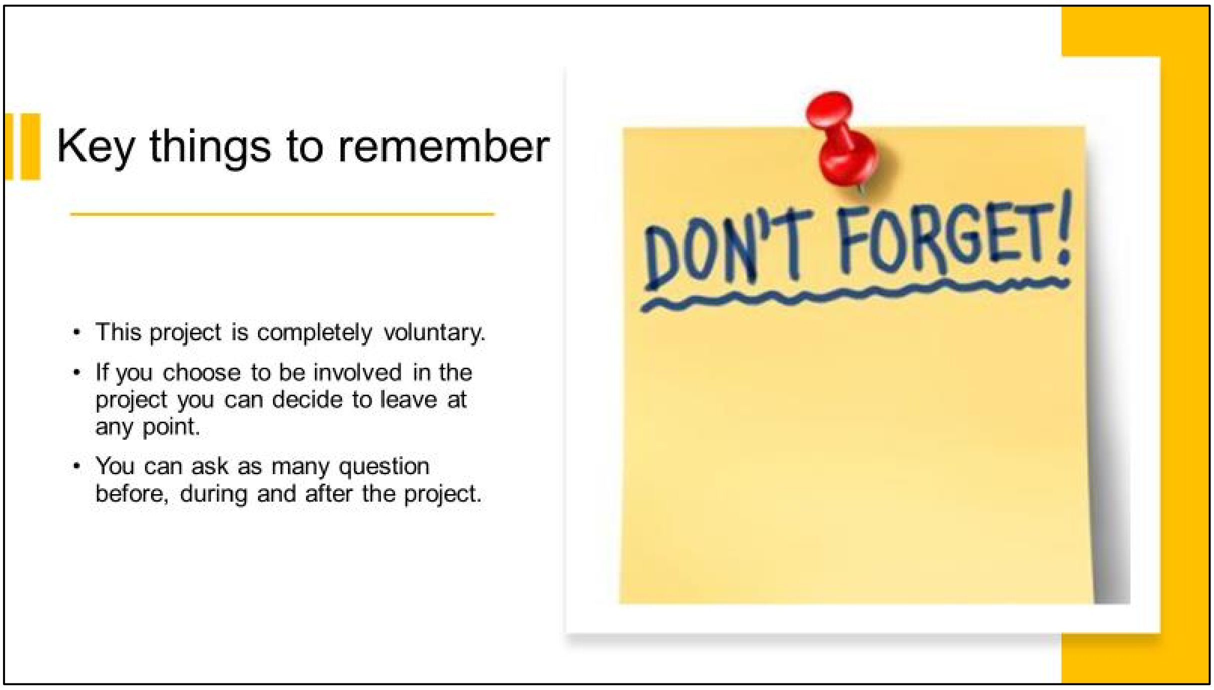
YOU WILL ALSO LEARN MORE ABOUT WHAT AN EDUCATIONAL PSYCHOLOGIST DOES AND HOW WE WORK AND SUPPORT YOUNG PEOPLE.

THE SKILLS YOU DEVELOP WILL BE USEFUL FOR YOU IN THE FUTURE (FOR EXAMPLE, COLLEGE AND UNIVERSITY APPLICATION)



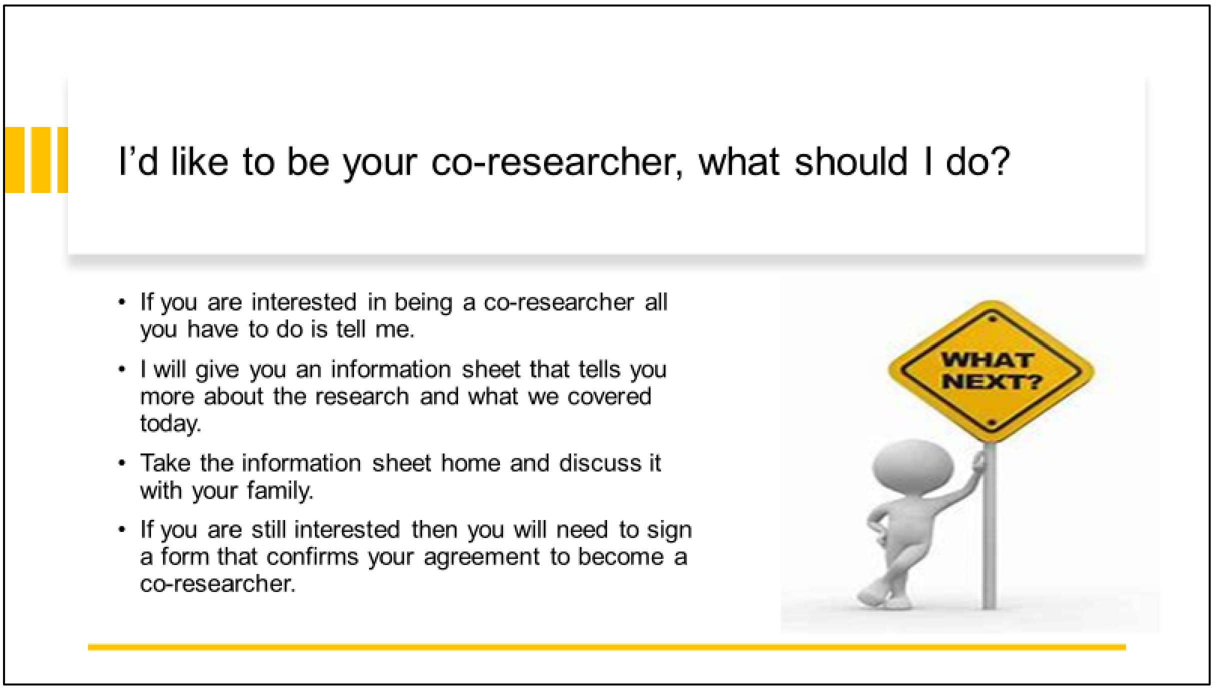
Will my participation be anonymous and confidential?

- As a co-researcher it will not be possible for your participation to be anonymous. For example, you may be in contact with participations during the interview stage.
- All the data from this study will be stored in line with University's Data Protection Policy.
- Audio recording and transcripts will be stored electronically, and password protected.
- If you disclose anything of that I think puts you or others in harm way, then I have an ethical duty to report this.



Key things to remember

- This project is completely voluntary.
- If you choose to be involved in the project you can decide to leave at any point.
- You can ask as many question before, during and after the project.



I'd like to be your co-researcher, what should I do?

- If you are interested in being a co-researcher all you have to do is tell me.
- I will give you an information sheet that tells you more about the research and what we covered today.
- Take the information sheet home and discuss it with your family.
- If you are still interested then you will need to sign a form that confirms your agreement to become a co-researcher.

I'm still not sure – what should I do?

- You could discuss taking part with a friend, family member or partner. They could also come with you whilst I explain the role of the co-researcher in more detail.
- You can also email me U1825079@uel.ac.uk. If you would like someone can contact me on your behalf and ask me any questions they will like about the process.
- If you decide that you would not like to be involved, that is completely okay! If you know another person who might be interested, you are welcome to let them know about this project


Questions
?
?
Answers
?

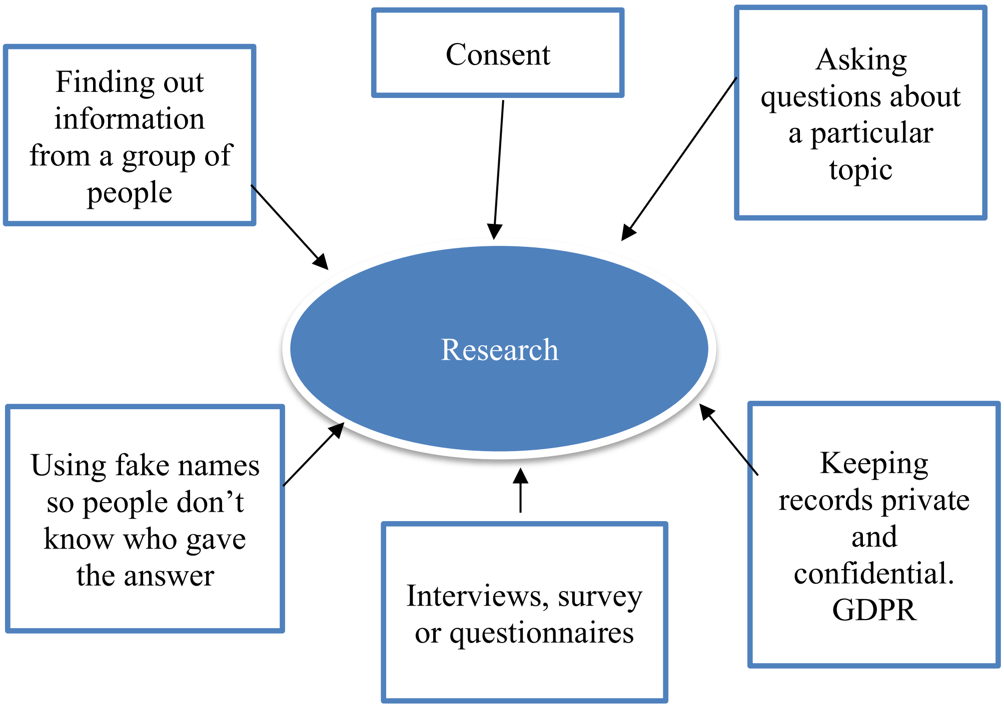
Appendix 3.2 – Lesson plans (training material)

Session 2: What is research?

Learning Aims	Knowledge content	Skills	Interactive element
Begin to develop an understanding of the nature of research	The nature of research/enquiry	Critical thinking Separating facts and opinion.	Discussions / Videos Word association game
Begin to have an appreciation of ethical issues in research	The importance of research / Different types of research and their main characteristics	Interpreting research findings	Mind map

Word association game

- What comes to mind when you hear the word research?



Video

- We watched an animated video on 'what is research' and discussed the key points from the video.

What is research? - YouTube

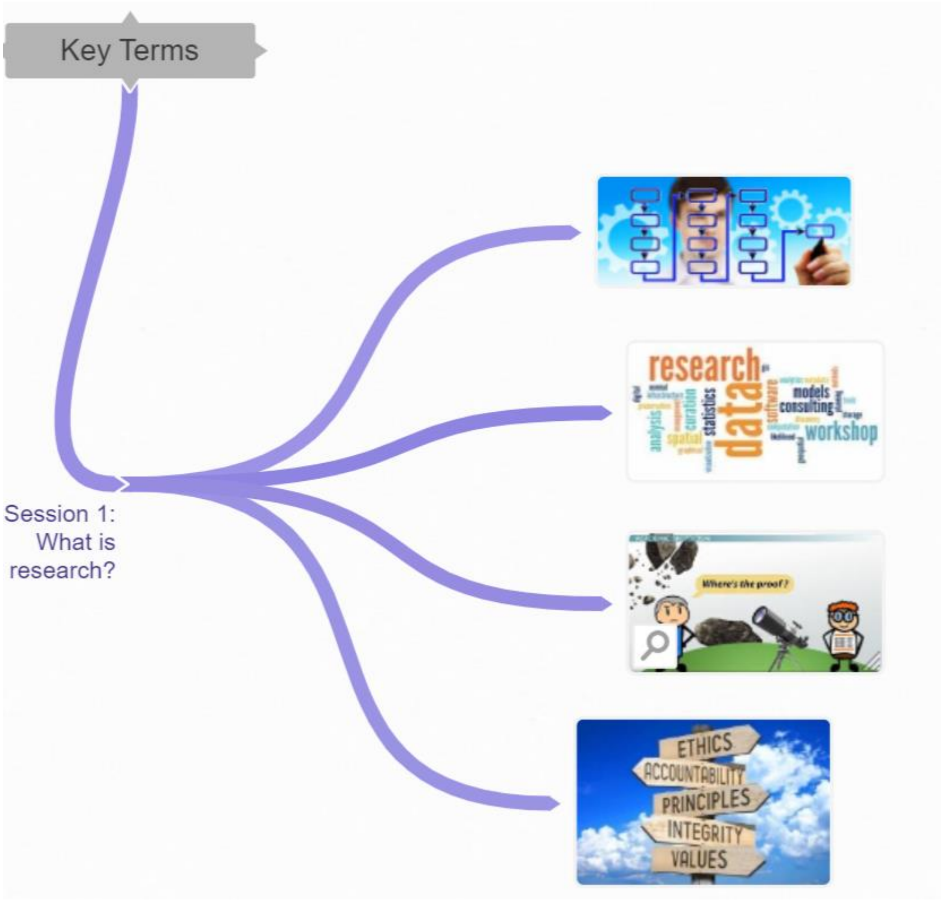
Overview of the 6-step **research** process-- Created using PowToon -- Free sign up at http://www.powtoon.com ...
26 Aug 2015 - Uploaded by Randall Meyer

Core activity:
The co-researcher was invited to highlight facts in one colour and opinions in another colour. Then we discussed the overall balance between facts and opinions and what this means for research.

UK fast-food diet producing ‘fat’ babies

New statistics out this month suggests that our obsession with fast food is now producing fat babies. This year a record number of babies – 103 – have weighed in at more than 12lb 12 oz. According to figures from the Office for National Statistics, 1.68% of babies weighed more than 10lb this year compared with 1.45% ten years ago. Boy babies weigh an average of 7lb 8oz, a rise of 2oz from 1973. Experts state that babies who are padded with fat all over their bodies – including, in some cases, their skulls – have a greater tendency towards obesity. In Japan where fast food is not as popular and the average diet includes an abundance of raw fish the average birth weight is 6lb 10oz and in India the average birth weight is less than 6lb.

Mind map activity:
To capture the key research terms, we created a mind map and key terms were added throughout the sessions. The pictures were selected by the co-researcher as a way of remembering what each term means. This week’s key terms: **data, ethical, sceptical, systematic**.



Session 3: Learning from Other People's Research

Learning Aims	Knowledge content	Skills	Interactive element
Begin to have an appreciation of good and poor research	The nature of research	Skim reading	Discussions
Understand the way a research paper is structured	Access to and orientation of research studies	Content sifting Critical reading	Mind map

Core activity: Finding your Way around a Research Paper

The title
A good title should reflect the content of the research paper and give enough information so that people are able to work out whether it is relevant to their area of interest.

The Introduction

- An introduction sets out the reasons a researcher is interested in their particular topic and a rationale for the study.
- This may include the literature review.
- It also sets out the particular question(s) that the study is going to explore.

Check for updates

Original Article

autism

Autism
2019, Vol. 23(6) 1408–1418
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Understanding and awareness of autism among Somali parents living in the United Kingdom

Amal M Hussein[1], Elizabeth Pellicano[2] and Laura Crane[1]

Abstract

Using vignettes and interviews, this study examined understanding and awareness of autism, and (a)typical development more broadly, among 32 Somali parents living in the United Kingdom. Results demonstrated that parents of both autistic (n = 16) and non-autistic (n = 16) children were just as likely to identify vignettes of typically developing children, yet parents of autistic children appeared more astute to signs of atypical development. Across the whole sample, parents commonly identified and labelled vignettes of autistic children, but experienced more difficulty labelling vignettes that described children with other forms of atypical development, sometimes mislabeling these children as autistic. This suggests that there is a need for greater support in recognising and identifying different types of atypical development in the Somali community (to mitigate the risk that the term 'autism' may take on its own meaning within the Somali community, becoming a euphemism for a range of developmental conditions). Analysis of interview data identified key sociocultural factors that either helped or hindered the inclusion of families with autistic children within the community, including the Somali community's: (1) perceptions of disability, (2) beliefs about the causes of autism in the Western world and (3) strong reliance on religious beliefs in understanding and accepting an autism diagnosis.

Keywords

attitudes, autism spectrum disorders, culture, migrant, qualitative research, Somali

In the United Kingdom, 1 in every 100 children, young people and adults are estimated to lie on the autism spectrum (Baird et al., 2006; Brugha et al., 2009), with worldwide autism prevalence thought to be approximately 1 in 160 (Elsabbagh et al., 2012). Yet, there are mixed views regarding the prevalence of autism in the Somali community. Hewitt et al. (2016) found that Somali and White children in Minneapolis, USA, were just as likely to be identified as autistic[1] (relative to Black and Hispanic children). In contrast, high rates of autism diagnoses have been reported in other communities. For example, Barnevik-Olsson et al. (2008) found that, in Sweden, the prevalence of autism was three to four times higher in Somali children compared to all other ethnic groups. In addition, elevated, but lower, prevalence rates have been reported in the United Kingdom, with Hassan (2012) finding that Somali, Black Caribbean and Black African children were twice as likely to receive an autism diagnosis relative to children from other ethnic groups.

While research is beginning to clarify the number of autistic children within the Somali community, there has been limited research on the views and experiences of Somali parents of autistic children. Fox et al. (2016) used semi-structured interviews to examine the experiences of 15 Somali parents of autistic children in Bristol, UK. This research highlighted how 'navigating the system' was a major challenge for Somali parents, as English tended not to be their first language. Even parents who were proficient in English struggled, as there is no word for autism in the Somali language. Parents added that they would have benefitted from having an interpreter present, or a Somali individual who had knowledge and awareness of autism, to support and enhance their understanding of the autism diagnostic and assessment process.

Reports of poor comprehension of autism, and a lack of appropriate language and vocabulary to explain autism,

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[1]University College London, UK
[2]Macquarie University, Australia

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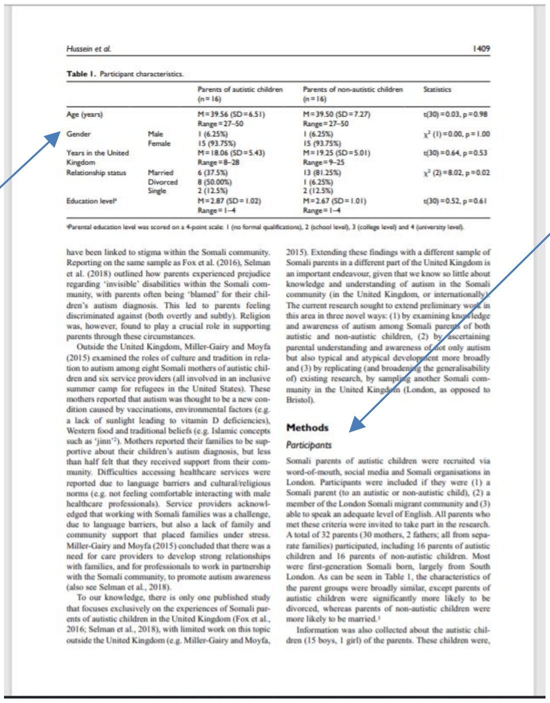
Email: L.Crane@ucl.ac.uk

The Abstract

- Most research papers have an abstract, which appears after the title but before the main body of the article
- This usually gives some background and rationale for the study, and may summarise the findings

Participant characteristic

- In this part, the author includes information about the participants that have been involved in their study.
- It is crucial that this section is clear and transparent.



Hussein et al. 1409

Table 1. Participant characteristics.

		Parents of autistic children (n = 16)	Parents of non-autistic children (n = 16)	Statistics
Age (years)		M = 39.56 (SD = 6.51) Range = 27–50	M = 39.50 (SD = 7.27) Range = 27–50	t(30) = 0.03, p = 0.98
Gender	Male	1 (6.25%)	1 (6.25%)	χ^2 (1) = 0.00, p = 1.00
	Female	15 (93.75%)	15 (93.75%)	
Years in the United Kingdom		M = 18.06 (SD = 5.43) Range = 8–28	M = 19.25 (SD = 5.01) Range = 9–25	t(30) = 0.64, p = 0.53
Relationship status	Married	6 (37.5%)	13 (81.25%)	χ^2 (2) = 8.02, p = 0.02
	Divorced	8 (50.00%)	1 (6.25%)	
	Single	2 (12.5%)	2 (12.5%)	
Education level[a]		M = 2.87 (SD = 1.02) Range = 1–4	M = 2.67 (SD = 1.01) Range = 1–4	t(30) = 0.52, p = 0.61

[a]Parental education level was scored on a 4-point scale: 1 (no formal qualifications), 2 (school level), 3 (college level) and 4 (university level).

have been linked to stigma within the Somali community. Reporting on the same sample as Fox et al. (2016), Selman et al. (2018) outlined how parents experienced prejudice regarding 'invisible' disabilities within the Somali community, with parents often being 'blamed' for their children's autism diagnosis. This led to parents feeling discriminated against (both overtly and subtly). Religion was, however, found to play a crucial role in supporting parents through these circumstances.

Outside the United Kingdom, Miller-Gairy and Moyfa (2015) examined the roles of culture and tradition in relation to autism among eight Somali mothers of autistic children and six service providers (all involved in an inclusive summer camp for refugees in the United States). These mothers reported that autism was thought to be a new condition caused by vaccinations, environmental factors (e.g. a lack of sunlight leading to vitamin D deficiencies), Western food and traditional beliefs (e.g. Islamic concepts such as 'jinn'[2]). Mothers reported their families to be supportive about their children's autism diagnosis, but less than half felt that they received support from their community. Difficulties accessing healthcare services were reported due to language barriers and cultural/religious norms (e.g. not feeling comfortable interacting with male healthcare professionals). Service providers acknowledged that working with Somali families was a challenge, due to language barriers, but also a lack of family and community support that placed families under stress. Miller-Gairy and Moyfa (2015) concluded that there was a need for care providers to develop strong relationships with families, and for professionals to work in partnership with the Somali community, to promote autism awareness (also see Selman et al., 2018).

To our knowledge, there is only one published study that focuses exclusively on the experiences of Somali parents of autistic children in the United Kingdom (Fox et al., 2016; Selman et al., 2018), with limited work on this topic outside the United Kingdom (e.g. Miller-Gairy and Moyfa, 2015). Extending these findings with a different sample of Somali parents in a different part of the United Kingdom is an important endeavour, given that we know so little about knowledge and understanding of autism in the Somali community (in the United Kingdom, or internationally). The current research sought to extend preliminary work in this area in three novel ways: (1) by examining knowledge and awareness of autism among Somali parents of both autistic and non-autistic children, (2) by ascertaining parental understanding and awareness of not only autism but also typical and atypical development more broadly and (3) by replicating (and broadening the generalisability of) existing research, by sampling another Somali community in the United Kingdom (London, as opposed to Bristol).

Methods

Participants

Somali parents of autistic children were recruited via word-of-mouth, social media and Somali organisations in London. Participants were included if they were (1) a Somali parent (to an autistic or non-autistic child), (2) a member of the London Somali migrant community and (3) able to speak an adequate level of English. All parents who met these criteria were invited to take part in the research. A total of 32 parents (30 mothers, 2 fathers; all from separate families) participated, including 16 parents of autistic children and 16 parents of non-autistic children. Most were first-generation Somali born, largely from South London. As can be seen in Table 1, the characteristics of the parent groups were broadly similar, except parents of autistic children were significantly more likely to be divorced, whereas parents of non-autistic children were more likely to be married.[3]

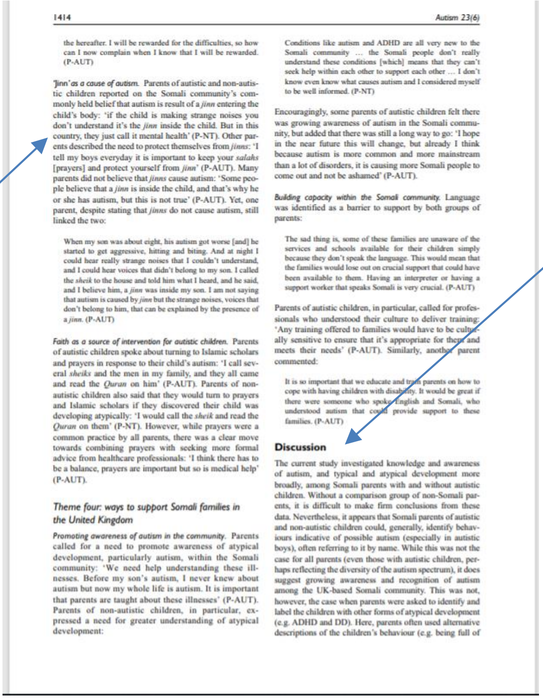
Information was also collected about the autistic children (15 boys, 1 girl) of the parents. These children were,

The methodology

- This is a crucial part of the paper. It must give enough information about how the research has been conducted that somebody else would be able to replicate it.
- It also needs to give enough info so people can judge the quality of the study.

The Findings

- This section tells us the data that has been found. This may be numerical, descriptive, or both.
- This section addresses the research question(s) that have been asked.
- It needs to be presented clearly and succinctly.



1414

Autism 23(6)

> the hereafter. I will be rewarded for the difficulties, so how can I now complain when I know that I will be rewarded. (P-AUT)

Jinn' as a cause of autism. Parents of autistic and non-autistic children reported on the Somali community's commonly held belief that autism is result of a *jinn* entering the child's body: 'if the child is making strange noises you don't understand it's the *jinn* inside the child. But in this country, they just call it mental health' (P-NT). Other parents described the need to protect themselves from *jinns*: 'I tell my boys everyday it is important to keep your *salahs* [prayers] and protect yourself from *jinn*' (P-AUT). Many parents did not believe that *jinns* cause autism: 'Some people believe that a *jinn* is inside the child, and that's why he or she has autism, but this is not true' (P-AUT). Yet, one parent, despite stating that *jinns* do not cause autism, still linked the two:

> When my son was about eight, his autism got worse [and] he started to get aggressive, hitting and biting. And at night I could hear really strange noises that I couldn't understand, and I could hear voices that didn't belong to my son. I called the *sheik* to the house and told him what I heard, and he said, and I believe him, a *jinn* was inside my son. I am not saying that autism is caused by *jinn* but the strange noises, voices that don't belong to him, that can be explained by the presence of a *jinn*. (P-AUT)

Faith as a source of intervention for autistic children. Parents of autistic children spoke about turning to Islamic scholars and prayers in response to their child's autism: 'I call several *sheiks* and the men in my family, and they all came and read the *Quran* on him' (P-AUT). Parents of non-autistic children also said that they would turn to prayers and Islamic scholars if they discovered their child was developing atypically: 'I would call the *sheik* and read the *Quran* on them' (P-NT). However, while prayers were a common practice by all parents, there was a clear move towards combining prayers with seeking more formal advice from healthcare professionals: 'I think there has to be a balance, prayers are important but so is medical help' (P-AUT).

Theme four: ways to support Somali families in the United Kingdom

Promoting awareness of autism in the community. Parents called for a need to promote awareness of atypical development, particularly autism, within the Somali community: 'We need help understanding these illnesses. Before my son's autism, I never knew about autism but now my whole life is autism. It is important that parents are taught about these illnesses' (P-AUT). Parents of non-autistic children, in particular, expressed a need for greater understanding of atypical development:

> Conditions like autism and ADHD are all very new to the Somali community … the Somali people don't really understand these conditions [which] means that they can't seek help within each other to support each other … I don't know even know what causes autism and I considered myself to be well informed. (P-NT)

Encouragingly, some parents of autistic children felt there was growing awareness of autism in the Somali community, but added that there was still a long way to go: 'I hope in the near future this will change, but already I think because autism is more common and more mainstream than a lot of disorders, it is causing more Somali people to come out and not be ashamed' (P-AUT).

Building capacity within the Somali community. Language was identified as a barrier to support by both groups of parents:

> The sad thing is, some of these families are unaware of the services and schools available for their children simply because they don't speak the language. This would mean that the families would lose out on crucial support that could have been available to them. Having an interpreter or having a support worker that speaks Somali is very crucial. (P-AUT)

Parents of autistic children, in particular, called for professionals who understood their culture to deliver training: 'Any training offered to families would have to be culturally sensitive to ensure that it's appropriate for them and meets their needs' (P-AUT). Similarly, another parent commented:

> It is so important that we educate and train parents on how to cope with having children with disability. It would be great if there were someone who spoke English and Somali, who understood autism that could provide support to these families. (P-AUT)

Discussion

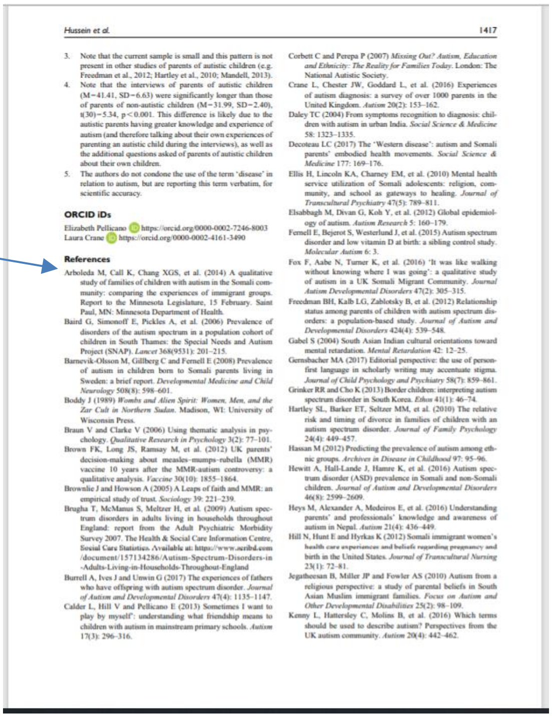
The current study investigated knowledge and awareness of autism, and typical and atypical development more broadly, among Somali parents with and without autistic children. Without a comparison group of non-Somali parents, it is difficult to make firm conclusions from these data. Nevertheless, it appears that Somali parents of autistic and non-autistic children could, generally, identify behaviours indicative of possible autism (especially in autistic boys), often referring to it by name. While this was not the case for all parents (even those with autistic children, perhaps reflecting the diversity of the autism spectrum), it does suggest growing awareness and recognition of autism among the UK-based Somali community. This was not, however, the case when parents were asked to identify and label the children with other forms of atypical development (e.g. ADHD and DD). Here, parents often used alternative descriptions of the children's behaviour (e.g. being full of

The Discussion

- In this part of the paper the author(s) analyse and discuss their findings.
- They will suggest implications of the study, including how this knowledge can further our understanding of the topic area, and how it fits into the context of other people's research.

References

- All research papers have a list of references at the end. This needs to include all the other research projects that the authors have referred to throughout their paper
- References must be done in a specific way that varies in different guidelines. However, it will always include the author(s) names, publication date, title of the paper, and where it was published (a book or a journal etc).



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3. Note that the current sample is small and this pattern is not present in other studies of parents of autistic children (e.g. Freedman et al., 2012; Hartley et al., 2010; Mandell, 2013).
4. Note that the interviews of parents of autistic children (M=41.41, SD=6.63) were significantly longer than those of parents of non-autistic children (M=31.99, SD=2.40), t(30)=5.34, p<0.001. This difference is likely due to the autistic parents having greater knowledge and experience of autism (and therefore talking about their own experiences of parenting an autistic child during the interviews), as well as the additional questions asked of parents of autistic children about their own children.
5. The authors do not condone the use of the term 'disease' in relation to autism, but are reporting this term verbatim, for scientific accuracy.

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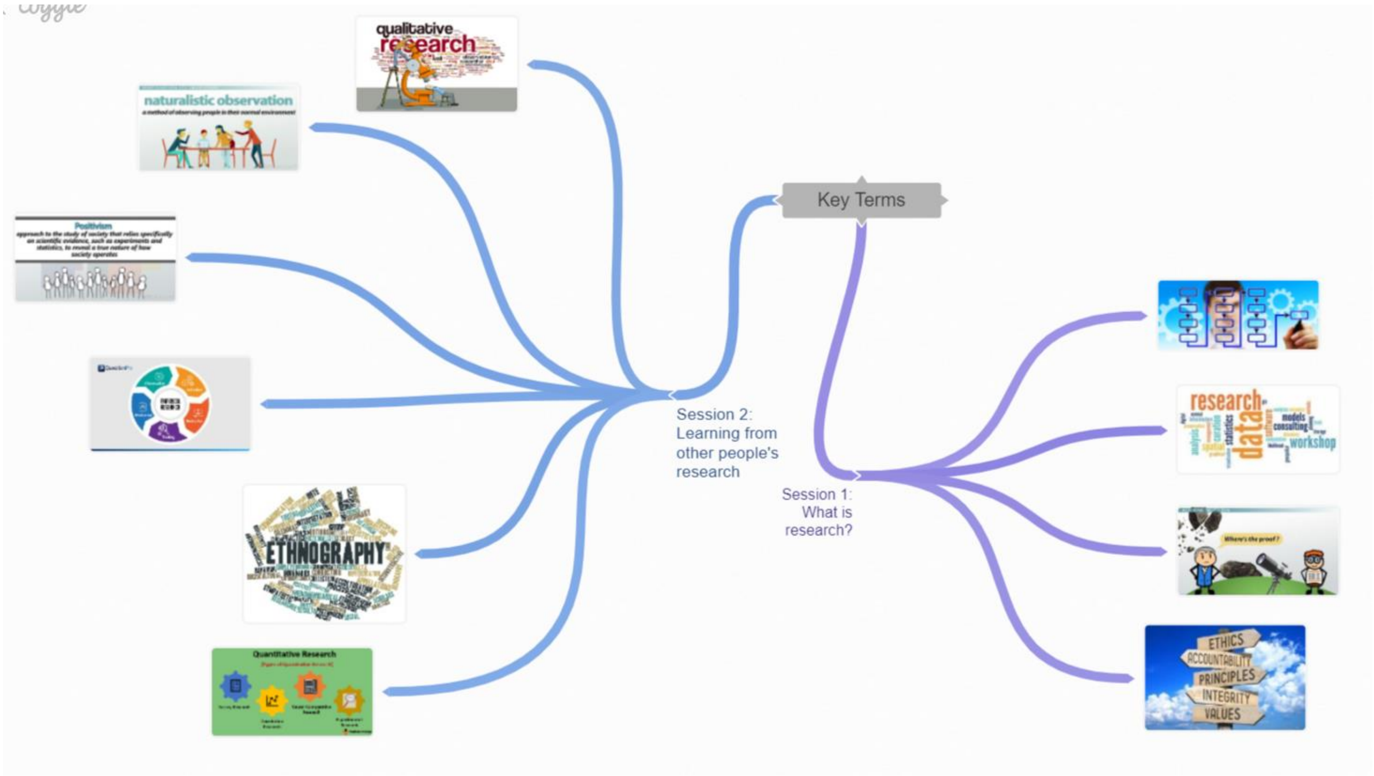
<u>Mind map activity</u>

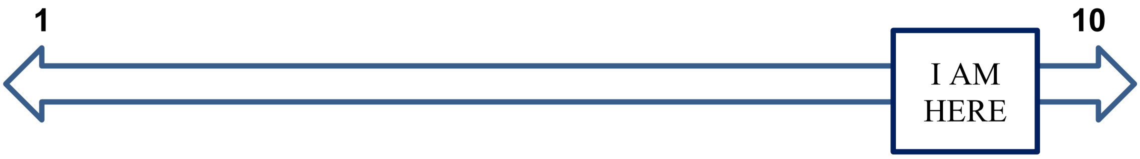
The following words were added to the mind map: **empirical, ethnography, naturalistic, positivist, qualitative, quantitative.**



Feedback on session from co-researcher using scaling:
The co-researcher was asked to rate the session on two part. Firstly, to rate his overall experience of the session and then the pace of the session. On a scale from 1(Bad) to 10 (Great). The co-researcher rated the overall session as a 10 and explained, “I really enjoyed talking about research papers as I never seen one before’. When I asked the co-researcher, what could make the session even better, he said ‘nothing’. Using the same scaling, the co-researcher rated the pace as ‘9’ and when I asked what could make it better, he told me “maybe if I had the paper before’. Feedback was incorporated into the next session.

<u>Overall session:</u>

<u>Pace of the session:</u>



Session 4: Research Ethics

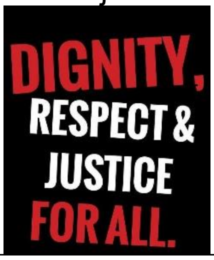
Learning Aims	Knowledge content	Skills	Interactive element
Understand the primary importance of ethics in research	Informed consent	Thinking skills Appreciating perspectives other than one 's own	Discussion Role play
Appreciate a given situation from another person's perspective	Human rights	Making balanced judgements	
Develop greater ethical awareness	Confidentiality/ Anonymity	Exploring moral and social values	

Video:

The co-researcher watched an animated video on psychological harm and how to reduce risk in research. After this we discussed what the co-researcher understood from the video.

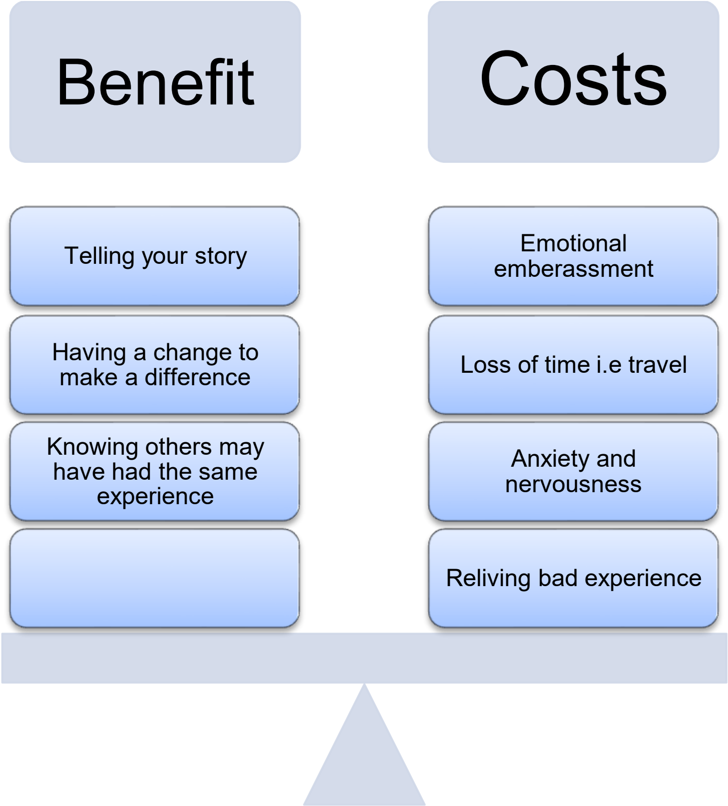
Guiding principles

This activity involved thinking about some of the guiding principle in research and what they would look like if someone applied these principles:

Principle	**What does it mean in research?**
Respect and justice  	Respecting participants' sensitivities and dignities. **What would this look like?** - Being kind to the participant - Listening to their story and their experience - If they don't want to talk about something not to push them.

Rights  	Participants’ rights to be protected from harm, to be fully informed and listened to. **What would this look like?** - Making sure that they give permission and if need be asking permission from their parents. - Making sure that our questions do not upset them.
Best outcomes 	To actively promote best outcomes for participants. **What would this look like?** - To help them if they have any questions. - To give them information of places to go and people to speak to if they need it. - Making sure our research helps them.

Activity: Listing the cost and benefit of engaging in research.



Benefit	Costs
Telling your story	Emotional emberassment
Having a change to make a difference	Loss of time i.e travel
Knowing others may have had the same experience	Anxiety and nervousness
	Reliving bad experience

Core activity.
Role play:

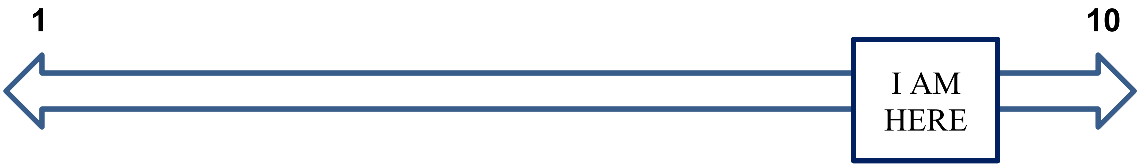
An ethical dilemma
An 11-year-old boy, Josef, is dying from a very rare form of cancer. There is no known cure and he only has a few months left to live. Researchers are in the process of developing a new drug which they think may be able to cure this cancer in the future if it could be caught at an early enough stage. The drug is not perfected yet and even if it were, Josef 's cancer is already far too advanced for it to be able to cure him. However, doctors could learn a lot more about the drug and its potential if they could test it out on Josef. Although this would not help Josef it could benefit many more children in the future. There is a possibility that there might be some side 128 effects from the drug, but the doctors cannot be sure as it has not been tested on humans before. Josef 's parents are against this and are refusing to give their consent. They want Josef to have the best possible quality of life and to be left in peace for the few months he has left. But Josef would like to help the doctors and says he wants to do some good with his life before he dies. Who should have the final say on his consent? Should Josef, aged 11, be allowed to overrule his parents or should his parent's wishes prevail? Who else might influence the decision-making process?

The researcher and co-researcher took it in turns to role play different characters:

Josef	Wants to have the drug and insists it's his body and his life.
Mother	wants Josef to be left in peace so that the family can make the most of the little time they have left together
Father	Angry the doctors should have approached them with this proposal, says this is emotional blackmail and that Josef is being exploited.
Doctor	Arguing for the possible benefits for other children

Feedback on session using scaling:
The co-researcher rated the overall session an 8 and said, 'I didn't really like the role play; I think we needed more people to do it well'. The co-researcher rated the pace of the session a 10 and said, 'I wouldn't change anything'.

Overall session:

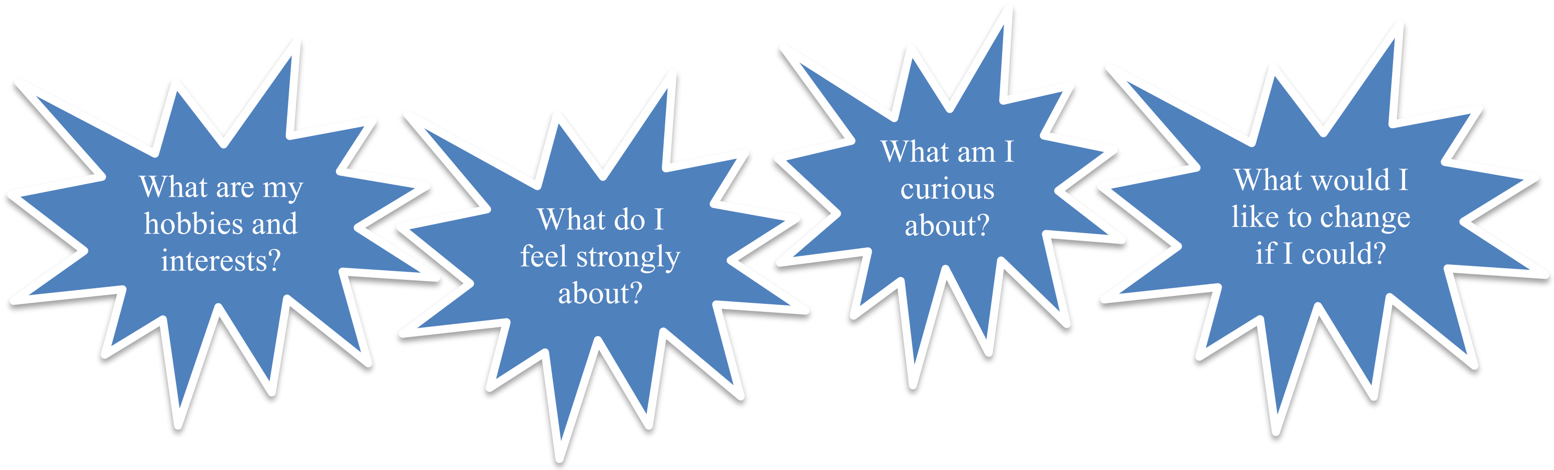


Pace of the session:

Session 5: Framing a Research Question

Learning Aims	Knowledge content	Skills	Interactive element
Begin to understand what a research question is and how it differs from a hypothesis	The pivotal place of a research question in the research process	Question framing	Discussion and completing 'Think Sheet'
Begin to understand how a research question informs the design and data collection method of a study		Sorting the essential from the peripheral and/or irrelevant	Go through one research papers and highlighting research questions

Core activity: Think Sheet (completed by co-researcher)



- I like football, photography and music. I would like to go to college and learn how to be a counsellor or mentor.
- I like helping others. I didn't have a nice experience growing up, so I want to help others like me.
- I am curious about the world and people, especially people like me who are autistic.
- I want everyone to feel equal and there be equal opportunities for everyone. No one should get less just because they have a disability. I also want to change the lack of opportunities for black people.

Topic Area: Autism

What aspect of this topic especially interests me?

What exactly am I trying to find out?

Where and how could I find this out?

- I am interested to know whether other autistic people have had the same experience as me. Growing up, I had a bad experience of being autistic and I was bullied a lot because of it. I wanted to know if other people were bullied because of their autism or whether their experience was different to mine.
- I want to find out about other autistic people like me and their experience.
- We could go to schools or colleges and ask questions. We can interview people like me.

Funnelling process:
The co-researcher decided that he is mainly interested in young people's experience of autism. This is the first stage of funnelling process achieved. Further stages of the co-researcher's funnelling process looked like this:

- *Am I interested in a particular age?*

Yes – if they are too little, they might not be able to tell us their experience. For some autistic children they might not be able to explain their autism and if they can't tell us about their autism we won't know about their experience.

- *Am I interested in comparing two age groups?*

No – as long as they can tell us about their experience how old they are does not matter.

- *Am I interested in finding out how autistic young people see themselves?*

Yes – it's not easy being autistic. I struggle because I am not like other people and I find things really hard because of my autism.

- *Am I interested in whether there are any ethnic or gender differences in experience?*

Yes and no – I am not sure about gender; I don't know many autistic girls, so I am not sure if there is a difference. There was a boy in my class who was also autistic, but he was white, but the teachers treated him different to me. He got extra help and I didn't get anything. Black people find things difficult look at George Floyd and everything happening with the BLM.

- *Are you interested in only black autistic young people?*

No – one of the boys in my school, I think he is Pakistani, and he really struggled like I did. So, it would be interesting to find out about him too.

* At this point the co-researcher and I had a discussion about the term BAME and BME. He said that he preferred the term BAME because. “it has the word Asian included and my friend is Asian and autistic”.

- *What about how young autistic people feel about their relationships with friends, teachers, parents etc*.

Yes – I would be interested about friendships definitely. I got bullied in school and was calling really bad names. And my dad he wasn’t around so my mum did everything for me.

From this initial exploration the co-researcher comes up with the research question:

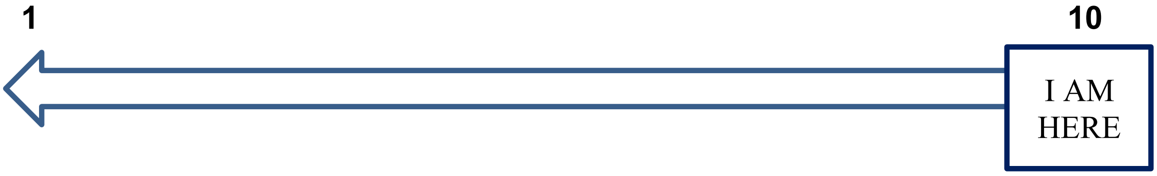
‘What are the experiences of young autistic people from BAME backgrounds”.

***At this stage the co-researcher and I generated our research questions and finalised the name of our project.**

<u>Feedback on session using scaling:</u>

The co-researcher rated the overall session a 10 and said, “I really enjoyed it and its starting to make sense”. When I asked how I could make the session better, he said “I can’t think of anything”. He also rated the pace of the session a 10 and said, “I really liked the speed it wasn’t too fast or too slow”.

Rating the overall session:



Rating the pace of the session:

Session 6: Data Collection, Interview Techniques and Open Vs Closed Questions.

Learning Aims	Knowledge content	Skills	Interactive element
To develop an appreciation of different interview structures and different question types	Framing Questions Question bias Structured interviews and surveys Semi structured interviews Unstructured interviews Group (focus) interviews	Opening questioning Closed questioning Nonverbal body language Avoiding interview bias	Discussion Mind map Sorting activity

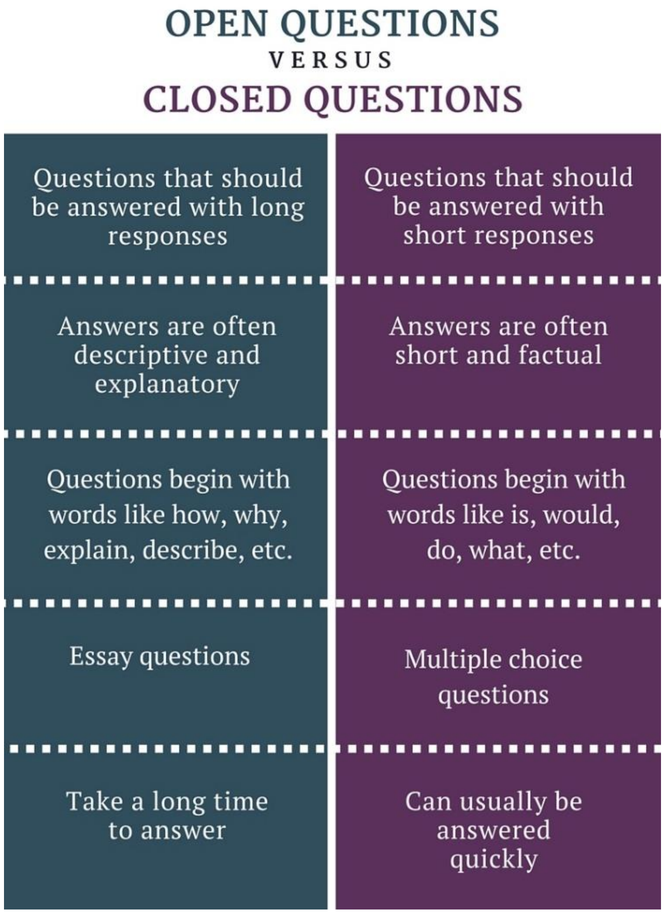
Sorting game: The co-researcher was provided with a number of different statements relating to different styles of interviewing. Together we sorted the statement into their appropriate section.

Structured interviews	If a researcher is interested in standardised answers, they will use this __________ interviews. They share some characteristics of a survey, although they are asked verbally rather than as a written questionnaire. Questions are asked in a way that allows some qualification of response without being too free.
Unstructured interviews	______ interviews are very open ended and designed to elicit individual and richly descriptive responses. There are no set questions and the role of the researcher is only to gently probe when appropriate to invite the interviewee to elaborate or clarify where necessary. _______ interview might open with a very general question about the topic matter.
Semi structured interviews	This type of interview is mid-way between a structured interview and unstructured interview. This interview type is very flexible. _______ interviews allow the researcher to pick up on individual responses and take the questioning in different directions where appropriate.

Group interviews	✚ This is where the researcher works with several people at the same time, rather than interviewing individually. ✚ These interviews can be structured, semi-structured or unstructured. ✚ The role of the researcher is more like a facilitator for steered discussion. ✚ The researcher's role is to steer and moderate the discussion, so it does not go too far off at a tangent but has enough flexibility to explore interesting trails.

Core Activity: Open/Closed Questions Learning Objective: Understanding the difference between open and closed questions.

Closed questions are ones that can only be answered with a yes/no response. For example, 'Do you like your school lunches?' Usually invites either a yes or a no.



OPEN QUESTIONS
VERSUS
CLOSED QUESTIONS

Questions that should be answered with long responses	Questions that should be answered with short responses
Answers are often descriptive and explanatory	Answers are often short and factual
Questions begin with words like how, why, explain, describe, etc.	Questions begin with words like is, would, do, what, etc.
Essay questions	Multiple choice questions
Take a long time to answer	Can usually be answered quickly

Open questions are ones that can be expanded upon as the answerer likes. For example, 'What can you tell me about your school lunches?

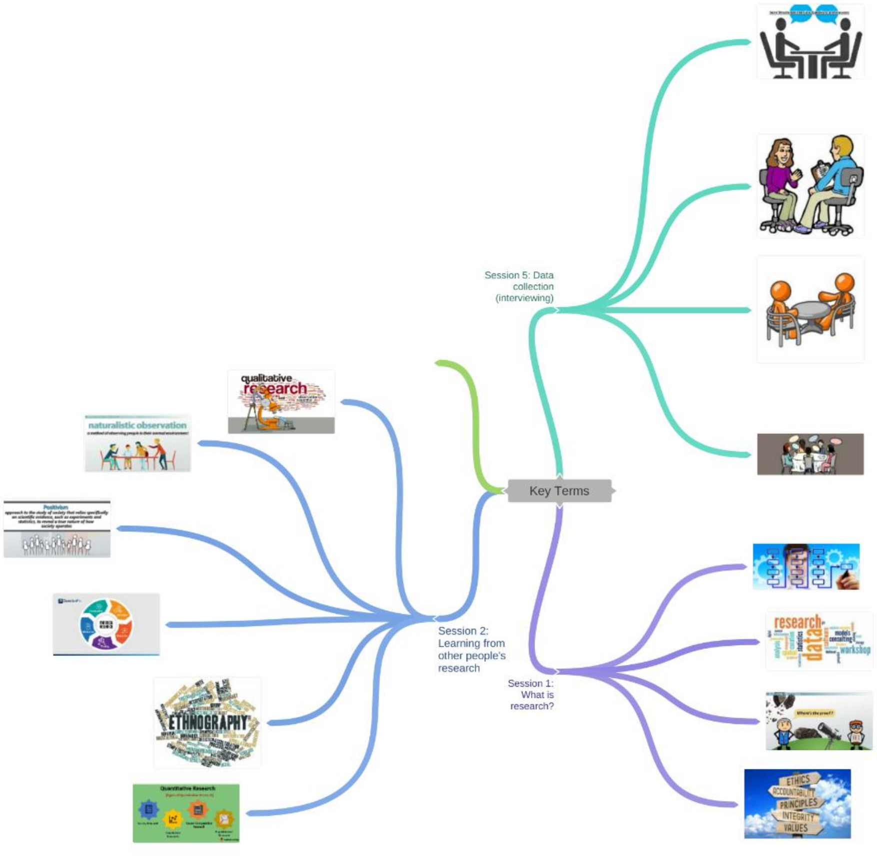
For our type of research, it is important that we ask open questions so that participants can tell us their views in depth.

Give me an example of one closed question relating to experience of young autistic pupils? (e.g. do you have lots of friends?)

Give me an example of one closed question that we can ask to find out about the experience of young autistic pupils? (e.g. how do you feel about friendships?)

Mind map activity

The following words were added to the mind map: structured interviews, unstructured interviews, semi structured interviews and group interviews.

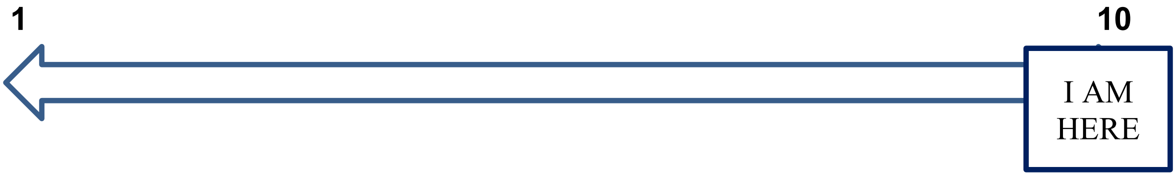


Feedback on session using scaling:

Using scale, the co-researcher rated the overall session as an eight and explained, “it wasn’t as fun as the other sessions”. When I asked what could have made it more ‘fun’ he suggested, “maybe watching video seeing examples of closed and open questions”. The co-researcher rated, the pace of the session as a ten.

Rating the overall session:

Rating the pace of the session:

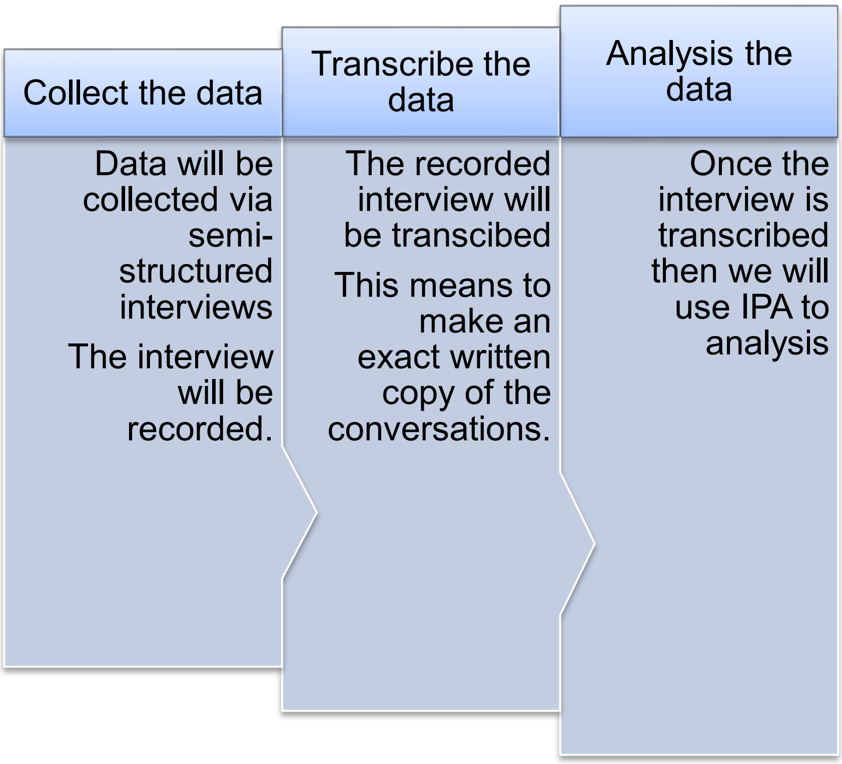


Session 7: Data Analysis

Learning Aims	Knowledge content	Skills	Interactive element
Begin to understand how to code and analyse qualitative data	Transcription Levels of coding Analysis of interview data	Organising, grouping and sifting large amounts of data Coding and categorising Memoing Theme abstracting	Discussion Mind map Video

Video: The co-researcher watched a video that explained phenomenological design and the use of Interpretative Phenomenological Analysis (also known as IPA) as data analysis tool. After watching the video, we discussed his understanding was.

Activity: The co-researcher and I discussed the different stages that are relevant to data analysis. We decided to create the bottom diagram to remind ourselves of the stage and what is expected.


Collect the data

Data will be collected via semi-structured interviews

The interview will be recorded.

Transcribe the data

The recorded interview will be transcibed

This means to make an exact written copy of the conversations.

Analysis the data

Once the interview is transcribed then we will use IPA to analysis

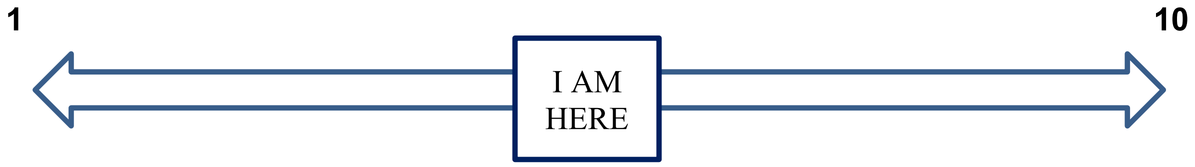
Core activity: The co-researcher and I discussed doing ‘IPA’ and what this looked like:

Phase	Description of phase
Familiarising ourselves with data	Reading the data following transcription. Sharing initial thoughts.
Initial note taking	This step involving making initial notes with textual commentary on what the participant is saying and our impressions of what is being said. We will start to make preliminary coding of the transcripts.
Developing emerging themes	This step involves searching for themes by mapping connects, patterns and interrelationships between exploratory notes. This involves the hermeneutic circle, remembering the ‘you’ in the process; the resulting analysis include the researcher interpretation of the participants words.
Searching for connections across emergent themes	This step involves looking across the themes established and developing a chart or mapping of how the identified themes linked together. At this stage the analysis is not

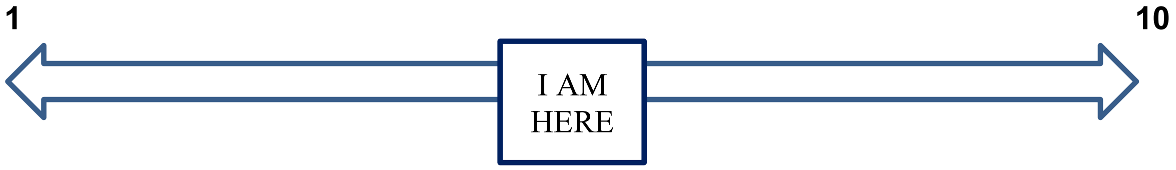
	prescriptive and its more about exploring and organising the themes. There are two ways to look for connections; - Type all the themes in a chronological order or - Print out the list of themes and lay them out so you can visually see how themes link together.
Moving to the next case	This step involves moving onto the next participant's transcripts and comparing and contrasting it with other participants transcripts
Looking for patterns across cases	This final stage involves looking for patterns across cases. Reviewing higher order themes but also recognising differences between participants. At this stage you are looking for the power of the themes to explain the phenomena.

Feedback on session using scaling:
Using scale, the co-researcher rated the overall session as a five, and explained "it was a bit confusing, not sure whether I really understood it". When asked what could make it better the co-researcher said, "I am not sure, it just seems complicated". Based on this feedback we agreed that transcribed produced for the pilot study will be used as an opportunity to practise the steps outlined above. The co-researcher also rated the pace of the session as five, and said, "I never heard of some the words before, so it was difficult".

Rating the overall session:



Rating the pace of the session:



Appendix 3.3 – Extracts from researcher's reflection diary

After the first training session with co-researcher:

I wondered about my style of checking for understanding with my co-researcher. I noticed that he was only giving me yes and no answer. Was my style of questioning populated by the use of too many closed questions? Was I only allowing for a yes or no response? Was I using enough open questions, should I be saying instead 'can you summarise to me what you understood based on what we just discussed'? I asked my co-researcher to tell me 3 things that went well in the session. He said, 'It was good', 'you made it fun' and 'you explained it well'. I also asked him what I could've done better, and his response was 'I did not see any faults in the session'. To encourage greater reflection, I wondered whether I could've directed him on specific things to feedback on, for example, pace, content or what he enjoyed the most. I wondered whether I should have used scaling to support his reflection. This made me think of my practice as TEP and the method and style of questioning I use to gain feedback from young people. Given that this was my co-researcher's first time engaging in research and he may not have prior experience and asking him to feedback on what I could've done better may have been difficult for him. Providing structure on how the research could feedback on the session will be an aspect I could develop on.

Maintaining boundaries with co-researcher:

Today I got a phone call from my co-researcher's mother asking if I can privately tutor her son with his studies. She shared that he feels that he has learnt a lot working with me and she wondered if she could pay me to support him with his learning as he is struggling in college. While it was lovely to receive such feedback, it was really important for both the co-researcher and his mother to understand my role and remit. I was really worried of offending either of them by saying no. I wondered whether because I previously helped him with his psychology homework whether I blurred the lines. Should I have said no when he asked for help with his work? Am I clear in my role in this research? Have I communicated this to my co-researcher efficiently?

Building trust with co-researcher:

Through this process I learnt and reflected on the importance of trust in a relationship between a researcher and co-researcher. I was really glad that the first session I had with my co-researcher was fun and designed for us to get to know each other. While I was worried that building rapport with him virtually would be difficult, I was happy at how much I felt we both knew about each other after the first session. I tried to use my training as TEP and previous work as LSA to really support me to build a relationship with him. I tried to actively listen and show him that I was listening to his ideas and concerns by using a range of listening techniques such as summarising what he was saying or encouraging him to say more. I always acted on any feedback he gave whether that was regarding the training session or how I can improve or support him better. Working with my co-researcher I felt we equally took enjoyment from working together.

Pilot interview:

I was so glad that we were able to carry out a pre-pilot interview prior to the pilot interview. It was so important for me that my co-researcher had a positive experience as this would determine our interviews going forward. Both my co-researcher and I enjoyed this experience, we were very please with how it went and how asked the questions. I was really conscious that I wanted to empower my co-researcher to lead the interview. I tried to engage in Reflection In Action while supporting my co-researcher when he felt suck with the questions. I found it particularly helpful using consultation and therapeutic skills to manage the discussions. The interviewee shared that he has not been asked about his autism in relation to his BAME background and I felt surprised by this. Our culture, diversity and ethnicity play a big role in who we are and how we interact with the world. Its surprising that he has managed to go 18 years without anyone asking about his autism in relation to his ethnic background. This really validated for me why I was doing this and the importance of studies that explore the BAME experience.

After the interview with Wolverine:

I was really impressed at how Wolverine was able to share his experiences and his journey with autism. It is clear that he is a strong communicator and charming young person. It was interesting that for him mental health and autism were synonymous, I *wondered whether this was because autism is diagnosis by the criteria set by DMS and refer to mental disorders? On reflection I should have unpicked this with him more during the interview. I was struck by Wolverine's capacity to advocate for others who are struggling with their autism. We ended the interview and I couldn't help but smile at how far Wolverine has come. It was clear that his parents and the adults that have helped him with his education have really left a mark on him.*

Analysis:

Throughout this process I tried to be mindful of that fact that my co-researcher said he didn't feel that confident with analysing the data. I really wanted to make sure that I was listening and respecting what he said. We discussed his confidence and agreed a way forward on how to work on the analysis together in a way that suited him and his needs. Whilst pulling together themes, I tried to hold onto the voices of the participates and whenever I was unsure, I found it helpful to speak to my co-researcher. This really helped to keep in sight the purpose of the study and really use the data to inform themes as opposed to selecting themes based on what I wanted to see. Being from a BAME community myself, I was really saddened but not surprised by the negative perception of autism held in their communities. All the participants were acutely aware of what their community thought of their autism. How can you feel like you belong to a community, if they refer to your autism as a failure or being possessed by the devil? I wondered if parents, teacher or professionals were aware that these young people were navigating through what they community said about their autism.

Appendix 3.4 – Overall feedback on the training sessions by co-researcher

1. **Using a scale from 1 to 10 (1 being bad and 10 being excellent). Please rate how you have found the overall training sessions.**

1 2 3 4 5 6 7 8 9 [✓ 10]

Response: 10, I really enjoyed working with you.

2. **What was your favourite thing about the training?**

Response: I really enjoyed all the sessions we had but my favourite session was when we were structuring the interview schedule and thinking of questions to ask.

3. **How did you find the overall pace of the training?**

Response: The pace was excellent! Not too fast and not too slow.

4. **What part of the training do you feel you may need further training on?**

Response: IPA session, I found this really hard. But I know when we get to this part you will help me.

5. **What, if any, improvement would you make to the training sessions?**

Response: I don’t have any improvements to make to be fair.

PLEASE RATE the following statements, from 1-5 (with 1 strongly disagree and 5 being strongly agree:

- I understand what research is and the difference between qualitative and quantitative research.

  1 2 3 4 [✓ 5]

- I understand which kind of skills are needed for research.

  1 2 3 4 [✓ 5]

- I feel confident to try out doing the different elements involved in carrying out research.

  1 2 3 4 [✓ 5]

Appendix 3.5 – Interview schedule

Reminder for researcher and co-researcher: *Clarifying and follow up prompts:*

- “Anything else”
- “What do you mean by…”
- “Can you tell me more about…”
- “Could you give me an example…”

Before starting the interview:

- Problem free talk.
- Go through the information sheet and answer any questions the participant may have.
- Explain the purpose of the research
- Explain key terms such as BAME and Culture.

Interview:

1. Can you tell us little about yourself? (prompt to find out strengths using strengths cards, age, gender, likes and dislikes).
2. How would you describe your ethnic background? (prompt to find out about ethnicity, language spoken at home and religion).
3. When did you first hear about autism? (Prompt: How old were they?)
4. How is autism viewed in X (name the ethnic background the young person used to describe themselves) culture?
5. When did you become aware of having autism? (Prompt: Did they find out on their own? Did someone make them aware? How did it feel? How old were they? What did they think?).

Activity 1: Present the participant with a scale ranging from 1-10. Explain that 1 indicates the unhappiest person in school and 10 represented the happiest person in school. Ask the participant where they felt they were on this scale.

6. Do you think that having an autism diagnosis has made a difference to the way that you feel about yourself? (If so, can you explain?).

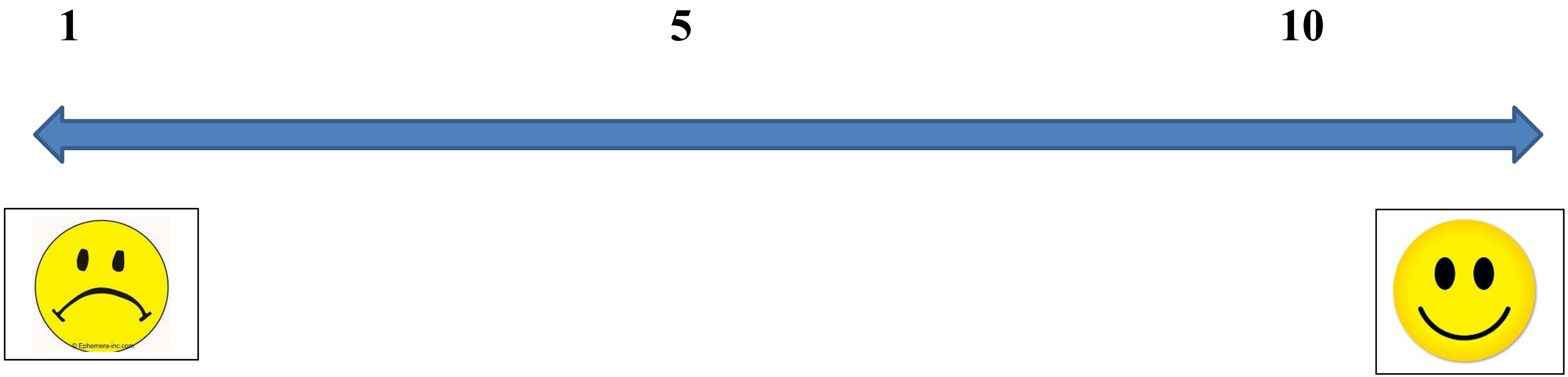
Activity 2: Draw the participant name in the centre and large circles drawn around it. Explain to participant that each circle represents four things: Home, School, Friends and the wider community. Ask them to tell you the names of people who have supported them in each circle. *(keep visual on the screen when asking question 7).*

7. Can you tell us how autism may have affected your relationships with other people? (peers, family, teachers).
8. Do you think that there are differences for BAME autistic young people compared to white autistic young people? (If yes, what are they?)
9. What if anything, would you like other people to know about what it is like to have autism as _________(name the ethnic background the young person used to describe themselves) young person?
10. What are your hopes as ____________(name the ethnic background the young person used to describe themselves) autistic young person?

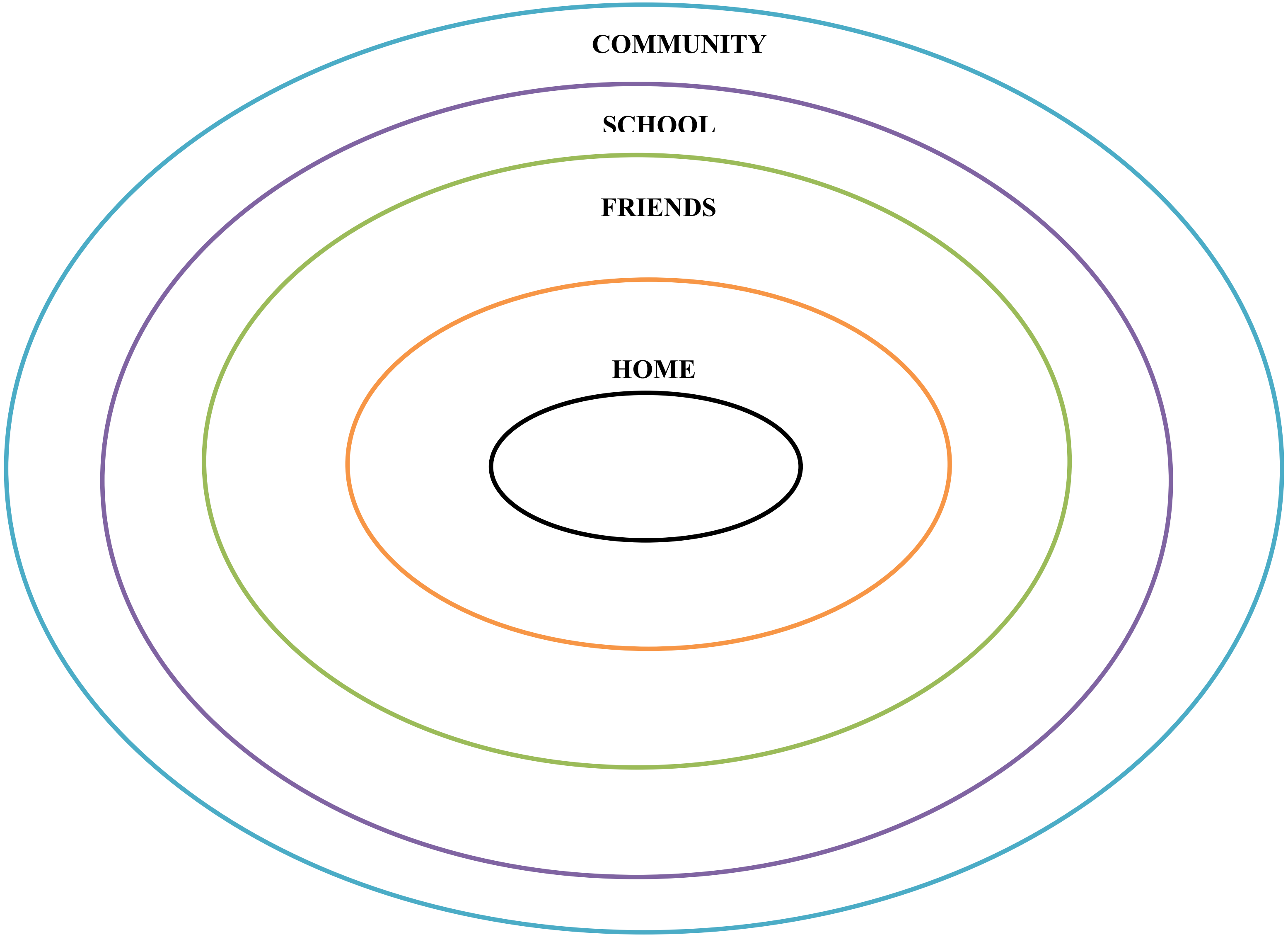
Close interview:

End with a positive question ("Would it be possible to ask you one last question before you? We are making a list of the very best things about being an autistic young person, we were wondering whether you can tell us the very best thing about your autism?)

Activity one:



Activity two:



Appendix 3.6 – Ethical approval

SCHOOL OF PSYCHOLOGY RESEARCH ETHICS COMMITTEE

NOTICE OF ETHICS REVIEW DECISION

FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

BSC/MSC/MA/PROFESSIONAL DOCTORATES IN CLINICAL, COUNSELLING AND EDUCATIONAL PSYCHOLOGY.

REVIEWER: Hanna Kampman

SUPERVISOR: Pandora Giles

STUDENT: Amal Hussein

Course: Professional Doctorate in Educational and Child Psychology

Title of proposed study: A participatory research approach to understanding the experiences of Black and Minority Ethnic young people with autism

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

APPROVED:

Minor amendments required *(for reviewer)*:

Major amendments required *(for reviewer):*

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

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

Student's name *(Typed name to act as signature):*
Student number:

Date:

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

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

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

YES

Please request resubmission with an adequate risk assessment

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

☐ HIGH

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

☐ MEDIUM (Please approve but with appropriate recommendations)

☑ LOW

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

Reviewer *(Typed name to act as signature)*: Hanna Kampman

Date: 06/02/2020

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

RESEARCHER PLEASE NOTE:

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

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

University of East London Psychology

REQUEST FOR TITLE CHANGE TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed title change to an ethics application that has been approved by the School of Psychology.

By applying for a change of title request you confirm that in doing so the process by which you have collected your data/conducted your research has not changed or deviated from your original ethics approval. If either of these have changed then you are required to complete an Ethics Amendments Form.

HOW TO COMPLETE & SUBMIT THE REQUEST

Complete the request form electronically and accurately.
Type your name in the 'student's signature' section (page 2).
Using your UEL email address, email the completed request form along with associated documents to: Psychology.Ethics@uel.ac.uk
Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.

REQUIRED DOCUMENTS

A copy of the approval of your initial ethics application.
Name of applicant: Amal Hussein
Programme of study: Professional Doctorate in Educational and Child Psychology
Name of supervisor: Dr Pandora Giles

Briefly outline the nature of your proposed title change in the boxes below

Proposed amendment	Rationale
Old Title: A participatory research approach to understanding the experiences of Black, and Minority Ethnic (BAME) young people with autism. New Title: A participatory research approach to understanding the experiences of Black, Asian and Minority Ethnic (BAME) autistic young people.	The propose new title was amended after careful consideration and discussion with the co-researcher (a young autistic individual). We felt that the research evidence plus his preference of being referred to as BAME(as opposed to BME) and autistic young person (as opposed young person with autism) warranted this change.

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	X	
Does your change of title impact the process of how you collected your data/conducted your research?		X

Student's signature (please type your name): Amal Hussein

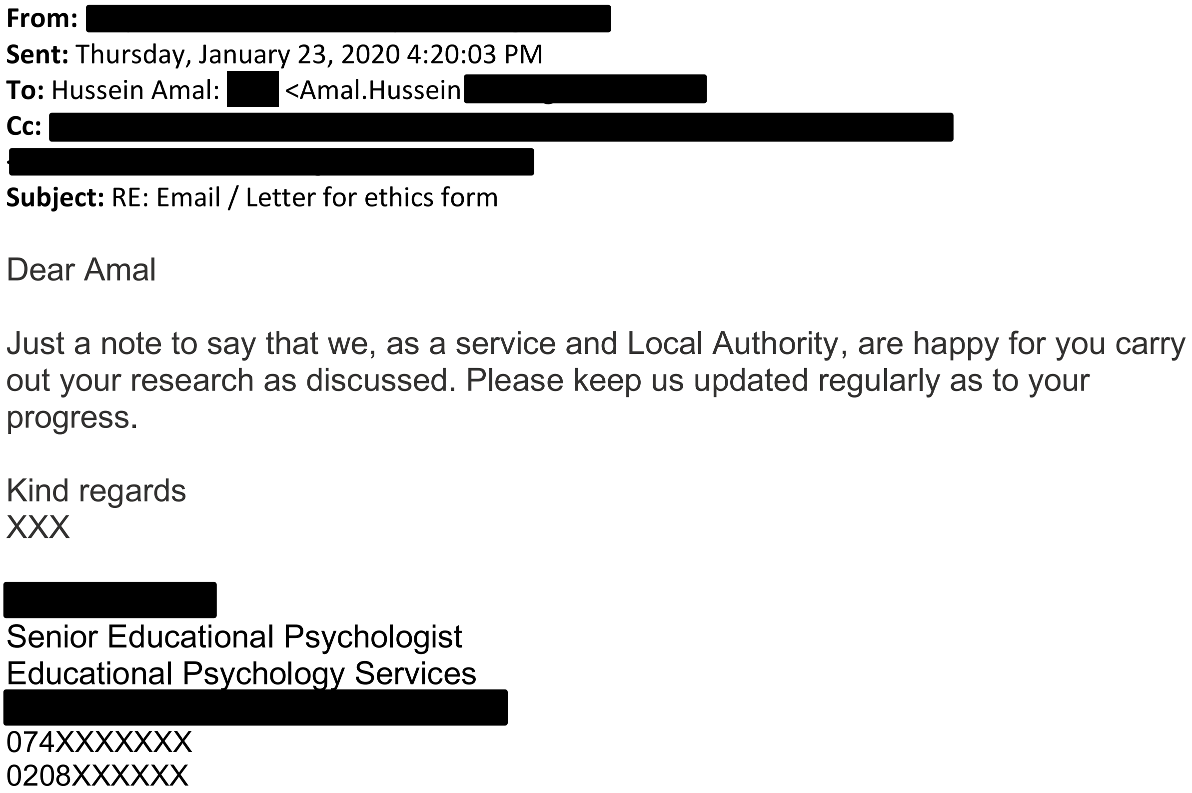
Date: 27/02/2021

TO BE COMPLETED BY REVIEWER		
Title changes approved	YES	
Comments		

Reviewer: Glen Rooney

Date: 26/03/2021

Appendix 3.7 – Email confirmation from Educational Psychology Service



From: [redacted]
Sent: Thursday, January 23, 2020 4:20:03 PM
To: Hussein Amal: [redacted] <Amal.Hussein[redacted]
Cc: [redacted]
Subject: RE: Email / Letter for ethics form

Dear Amal

Just a note to say that we, as a service and Local Authority, are happy for you carry out your research as discussed. Please keep us updated regularly as to your progress.

Kind regards
XXX

[redacted]
Senior Educational Psychologist
Educational Psychology Services
[redacted]
074XXXXXXX
0208XXXXXX

Appendix 3.8 – Information sheet for co-researcher

Become a co-researcher on a project exploring the experience of autistic young people

Who am I?

My name is Amal and I am a trainee Educational Psychologist.

Why am I contacting you?

I am doing research exploring the experiences of autistic young people. I am looking for a co-researcher to be involved in the research process.

Can I be the co-researcher?

Yes, if you are;

- A young person aged 12 to 25
- Diagnosed with autism.

What do I have to do?

As a co-researcher you can be as involved as you want to be. Once you agreed to becoming my co-research, I will train you on how to carry out research. From that point you can decide which part of the research process you would like to be involved with. Remember level of involvement in the research process is determined by you. Taking part in this study is low risk. If you find any part of the process stressful or upsetting, just let me know and I can support you or signpost you to other agencies.

What are the benefits of taking part?

You will be trained to be able to carry out research. You will also learn more about what an educational psychologist do and how we work and support young people.

What will happen once the research is completed?

The findings will be shared with others including the participants, colleagues and those interested in autism research. The research may also be published, and you can decide if you want your name in the paper.

Will my participation be anonymous and confidential?

As a co-researcher it will not be possible for your participation to be anonymous. For example, you may be in contact with participations during the interview stage. All the data from this study will be stored in line with University's Data Protection Policy. Audio recording and transcripts will be stored electronically, and password protected. If you disclose anything of that I think puts you or others in harm way, then I have an ethical duty to report this.

I'd like to be your co-researcher, what should I do?

That's great! You can email me on so we can arrange a time for us to meet. I will explain the research in more detail once we met. I will get you to sign a consent form.

I'm still not sure – what should I do?

You could discuss taking part with a friend, family member or partner. They could also come with you whilst I explain the role of the co-researcher in more detail. You can also email me If you would like someone can contact me on your behalf and ask me any questions they will like about the process. If you decide that you would not like to be involved, that is completely okay! If you know another person who might be interested, you are welcome to pass this information sheet to them.

Appendix 3.9 – Participant information sheet

	Hello! My name is Amal Hussein. I am a student at the University of East London. I am training to become an Educational psychologist.
	I am interested to learn and understand more about autistic children and young people from Black, Asian and Minority Ethnic backgrounds. I have asked an autistic young person to be my co-researcher and they will be working with me. We would like to invite you to take part in our research. If you are: - Age between 12 to 25 years old. - Have a diagnosis of autism. - From a Black, Asian and Minority Ethnic Group. - Able to share and discuss your experience of autism.
	Myself (and potentially my co-researcher) will organise a time to speak to you online via Microsoft Teams. We will record the conversation but it's up to you whether you want to show your face during the interview. I might make notes during our chat, if I do then you will be able to check them to make sure that they are accurate accounts if you wish.

	During this interview, you tell me what you like and what you do not like. As well as your experience of autism. Anything you tell me can help support other autistic young people like yourself.
	You can ask for the recording device to be stop at any time. If at any time you feel uncomfortable, you have the option to withdraw from the interview task or the research. If you feel that the process has upset you, then I will able to offer you support. Remember, you can ask to stop working with me at any time. It is important that you feel comfortable.
	I will use some of things you tell me in my research. But I will not use your real name or the name of your school / 6th form so nobody will know it was you in my research. I understand that once the researcher has started analysing the data, I will not be able to withdrawal data.
	I will store your data in a password protected filed on my university OneDrive serve. I will only share anonymised transcripts with my co-researcher and my supervisor.
	You can ask me any questions when we are working together. Or you can email me at U1825079@uel.ac.uk to ask any questions. Or you can email my supervisor p.giles@uel.ac.uk.

	If you are interested in being a part of research, then all you have to do is complete the consent form and return to me via email on Alternatively, you can call me to discuss this further on ***Please note, if you are under the age of 16 then your parents / guardians must also consent to you being apart of the research. If you don't have the parental information and consent sheet then pop me an email (or a call) and I can share it with you.*** **Thank you.**

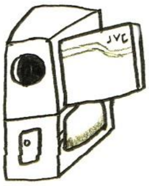
Appendix 3.10 – Participant consent form

UNIVERSITY OF EAST LONDON

Consent to participant in research study

Research Title: A participatory research approach to understanding the experiences of Black and Minority Ethnic autistic young people.

Please read the statement below carefully and tick **Yes** or **No**:

I can confirm I have read the information sheet, or had it read and explained to me?	☺ Yes	☹ No
 **I understand that this interview will be 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.		
Safeguarding Children If I tell the researcher that I or someone else is in danger they will have to let someone else know.		
 I know that the recording from the interview will be kept and stored safely for three years, then destroyed.		
 I would like to take part in this research.		

Your name: ………………………………………………………………………

Signature: ………………………………………..………………………..……

Date: ....………………………..…………………………..…………

Appendix 3.11 – Parent's consent form

UNIVERSITY OF EAST LONDON

Parent & Guardian Consent Form

Research Title: A participatory research approach to understanding the experiences of Black, Asian and Minority Ethnic autistic young people.

Researcher: Amal Hussein

Please read the statement below carefully and tick **Yes** or **No**:

I can confirm that I have read and understood the information sheet, or had it read and explained to me for the above study?	**Yes**	**No**
I freely and fully give consent for my child (name) to participant in this research, which has been explained to me.		
I give consent for a recording device to be used during the interview with my child. I understand that all names will be anonymised in the transcriptions.		
I understand that my child's participation in this study is voluntary. I understand it will not be possible for the researcher to remove my child's response from the written report once data has been analysed.		
The nature and purpose of the research has been explained to me. I understand that if I have any questions or concerns than I can contact the researcher.		
I understand that the response collected from my child may be published in anonymised doctoral thesis or journal.		

I understand the data collected on my child will remain strictly confidential and will only be seen by the researcher(s) involved in the study.		
I understand what will happen to the data collected once the research study has been completed.		

Name of Parent (BLOCK CAPITALS): ....

Parent’s Signature ....

Researcher’s Name (BLOCK CAPITALS) ....

Researcher’s Signature ....

Date: ....

Please return form to: or alternatively you can call me (the researcher) on

Appendix 3.12 – Debriefing form for participants

	Thank you for taking the time to be a part of my research. In this letter I will explain to you what will happen to the information 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.
	I will not use your name or the name of your school in my thesis, I will use a made-up name instead. I will share the findings with you, your parents, teachers and other professionals. But remember your actual name will not be included, no one but the researchers will know what you said.
	The information you have shared with us will be kept securely. Once I have finished my doctorate and written up the findings, I will destroy all the data.
	You can ask not to be involved in the research at any time. If you decide to withdraw before I have analysed your transcript, then it can be destroyed on your request. **BUT,** if I have started to type up your interview I will use the data for my research thesis.

	If you would like further information about my research or have any questions or concerns, you can always email me. Name: **Amal Hussein** Email: If you have any questions or concerns about how the research has been done, then you can always email or write to my supervisor **Dr Pandora Giles.** School of Psychology, University of East London, Water Lane, London E15 4LZ, Email: p.giles@uel.ac.uk **or** Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas, School of Psychology, University of East London, Water Lane, London E15 4LZ.(Email: t.lomas@uel.ac.uk
ℹ	Here is a list of websites that you may find useful if you have any questions about autism. **NEMFLA (Network for Ethnic Minority Families Living with Autism):** http://www.stmichaelassociates.org.uk/services/index.html-nemfla **National Autistic Society:** http://www.autism.org.uk/?gclid=EAIaIQobChMI7un7q8OC2AIVDhHTCh3jZQ vrEAAYASAAEgIhcfD_BwE Or if you have any general questions about psychological research: **BPS Code of Ethics and Conduct:** https://beta.bps.org.uk/news-and-policy/bps-code-ethics-and-conduct **BPS Code of Human Research Ethics:** http://www.bps.org.uk/sites/default/files/documents/code_of_human_resear ch_ethics.pdf

Appendix 4.1 – Storm's transcript

Emergent Themes	**Storm's Transcript (Interview 1 = researcher, Interview 2= co-researcher)**	**Exploratory Comments**
	Interviewer 2: When did you first hear about autism?	
	Participant: Oh, I found out about six years ago when I was [early teens].	
	Interviewer 1: OK, and what did you find out?	
Knowing what autism is from others.	**Participant:** I found out that, um, I found out that my behaviours is quite strange to others. Uh, I find it quite hard understanding social rules, uh, personal space, um [pause] um, the way of my communication, of how I speak to people. [pause] I blurt out things and I kind of say random stuff. Also, with my ASD I don't like people who shout, I don't like shouty teachers, basically.	Feedback received from others appear to contribute to how she sees her autism. Self-concept – linked to other's perception. Aware of her sensory needs – Has she had a lot of shouty teachers?
	Interviewer 1: OK, helpful to know. Um, so when you first found out the word "autism", how did you find it, did somebody tell you it?	
	Participant: [pause, drinking water] I went and had a diagnosis.	
	Interviewer 2: Um [pause] how was autism viewed in Ethiopia?	
	Participant: Uh, Eritrea.	
	Interviewer 2: Sorry, Eritrea.	
	Participant: Well, autism in Eritrea is rare, is quite rare. I have met someone from Eritrea with ASD, but I have- oh yes, I have a family friend named [family friend name], he is autistic, but he is [pause] non-	Repetition of the word rare – does she feel like her autism is unique or unheard of in her community?

Lack of knowledge regarding autism in Eritrean community.	verbal, but [pause] [family friend name] is older than me by four years, he is [early 20s], he's got a disability. **Interviewer 1:** OK, thank you for sharing that. What do you think Eritrean people think of autism? **Participant:** Can you say the question again? **Interviewer 1:** Of course. What do you think Eritrean people would say about autism? **Participant:** It would be a bit of a battle towards them, they have, it's hard explaining your disability to the Eritrean community, and they find it hard to understand. **Interviewer 1:** Mm, and why do they find it hard? **Participant:** It's because um, they weren't educated about um AS. They're, like, in my culture, like [pause] autism's quite rare in children but there are, I have, but there are s-, there are s-, there are some, there are some things describing ASD which is hard to understand in, it's hard to explain it to them in the language they're speaking, English, but it's, it's rare in their home language. **Interviewer 1:** Is there a word for autism in the language? **Participant:** In Arabic, they can. It's a high functioning disability, um. It's a high functioning disability, there are children like, across the Middle East who suffer from disabilities, um, but some are rare. Some disabilities, like, in the Middle East, like, the government they fund, um, for SEN schools, they, they give the children the support they need.	Lack of understanding is a barrier "battle" may infer to the struggle she experiences when trying to explain autism. Lack of education means that Eritrean community does not understand. Advocating for psycho education? Possible language barrier? Is this making it harder? This is the first time she used HFA – is this the only term recognised in the Middle East? Comparison between funding systems in the Middle East and UK.

	Interviewer 1: OK. Thank you for sharing. [Interviewer 2]?	
	Interviewer 2: Um, when did you become aware of having autism?	
	Participant: Uh, like, when I was young, like at the age of six, I would, I would go to a- uh [name of centre] child development centre, um, it's, it's, it's next to the [name of major hospital], um, that's where children go for like family issues or diagnosis. They'd meet with, they'd meet with professionals there that do a lot with them, and then they'd get, the professionals would diagnose them and put the support in place for them in the educational backgrounds.	Does she see autism as a family issue? Autism is diagnosed by professionals / very factual description of the diagnosis process.
	Interviewer 1: OK, and when you were six, that was when you had your diagnosis, is that correct?	
Diagnosed in a problem context Being different to others.	**Participant:** I was, I was [early teens] when I was diagnosed, but at six I would go because I was behaving differently towards peers, um, I found hard making friends with them, uh, I'd sometimes like hit them, I'd sometimes hit them, uh [pause] I would [pause] but I don't come across, approaching like [pause] I found it hard, like, understanding personal space, barriers, all sorts.	Awareness of behaviour being different from peers. Concerns about behaviour led to the diagnostic process. Sense of Me vs Them? Attributing autism to difficulties with social boundaries and making friends.
	Interviewer 1: OK. And how did it feel to be diagnosed with autism when you were [early teens]?	
TA vs No TA	**Participant:** It was like I got a bit of a wake-up call. Um, having a disability was rare, like, I was ok, perfectly and [pause] I found it like hard having a diagnosis which ma- which has caused me to fall behind with schooling, um, having support staff, was like, during my time at high school, was a bit em-, having support staff during high school was a bit tough, like, I- it wasn't tough, it was needed, and, like, I didn't like	*"Wake up call"* – implies that the diagnosis of autism caused her to realise something or make change.

The role of TA	it some days when one of my TAs were off sick and I'd had to work on my own, I'd struggled doing the work by myself. **Interviewer 1:** Hmm. So it was helpful having the TAs? **Participant:** Having a teaching assistant like, a one-to-one is nice. Um, the one-to-one helps you with the work, like, sometimes you'd struggle when you're on your own when you're doing it. **Interviewer 1:** OK. Right, thank you. Um, so I'm just going to share a document with you, bear with me [long pause] I think I've found the right document [pause] yes [pause] Can you see that? **Participant:** Yes. **Interviewer 1:** Great. Um, so, this is a scale from 1 to 10, um, and the scale, number 1 indicates the most unhappiest person in college, or in school. And 10 represents the happiest person in school, or in college. Can you tell me where you would be on this scale? **Participant:** I'd be- I'd- it depends really, I go up and down, but I'd say number 5. **Interviewer 1:** OK. Why number 5?	Reframing how she sees TAs from *"tough"* to *"needed".* Able to reflect the difficulties she experiences without a TA. *"nice"* implies that it was a pleasant experience having a TA. Academic learning is easier with a TA. *"up and down"* = mood swings? Mental health difficulties?
Wellbeing and autism	**Participant:** Number 5, I'm in the middle, like one week I- like one week I feel depressed, and the next week my mood changes, I become happy. It depends really, on my mood. **Interviewer 1:** OK. What kind of things affect your mood? **Participant:** What's that again? Can you repeat the question again?	Drastic mood swings? Self-aware of her emotions.

	Interviewer 1: What affects your mood?	
Having routine means less mood changes. Social media and friendship Complexity of social media interaction.	**Participant:** Uhhh, what affects my mood is a change in timetable, ummm [pause] changing in a routine um, my mood is like, changing my mind at the last second, ummm [pause] oh, and there is one thing that does affect my mood is umm, one thing like, I, like with social media I, so one of my, one of my school friends um, they went to a wedding that was a Moroccan/Palestinian, I asked, can I like see the pictures, ‘cos I missed out, and like the moments of the wedding, the girl like made up an excuse which kind of let me down and she has said, um, the ph- [pause] like, she has like photos aren’t with her, they’re with the photographer, or, or her phone’s dead at that moment, she’d like make up an excuse. That would affect my mood, like, being misled by some people, or having to change stuff at the last minute.	Favours routines / predictability = more stable mood. Routine feels safe? Likes social media but has difficulties interacting on social media. Mood is affected by school friends not including her on social media. *“Misled*” implies being deceived or lied to.
	Interviewer 1: OK. Do you find “it easy” to make friends on social media, or would you say it’s more difficult?	
Reality vs social media.	**Participant:** Um, both sides really. Both sides, um. Making friends with actual people in real life is a bit harder, harder, ummm, is a bit harder because, um, the people you meet in real life, like, some of them are nice and others seem a bit impolite/rude. Impolite I mean. Um social media’s a bit tough because when you add all those people, like, I think they seem nice, but in reality, like, when I go, oh, in reality, I don’t know what they’re actually like.	Similar reasons are given – she is able to differentiate between social media and real life? She is aware that social media persona may often be different from who they are in real life, *“in reality”* perhaps hints at her awareness between real life and social media?
	Interviewer 1: OK. And have you met anybody from social media?	
E Safety rules when meeting people offline.	**Participant:** I have, like, I haven’t met, no, but like, I, I’ve met some of them, I follow, but not all. Also, on social media, I have made friends with a woman named, um, [woman’s name] she is a-, [woman’s name],	Able to make friends online / appears positive about her interaction with this international person.

	she is from, she's from Iraq, but she's living uh, somewhere in [city name]. I follow her blog, [blog name], but I have never met her in real life, but I'd like, like- she seems nice, but, one day I'd like to meet her, but I have like, a boundary, like, I'll come and meet her, only if I bring a parent or carer with me.	Aware of the possible dangers of meeting people offline? Is this a script that she has been taught and repeating?
	Interviewer 1: I think we are on question 6. OK. [Interviewer 2]? [long pause]	
	Interviewer 2: Do you think that having an autism diagnosis has made a difference to the way that you feel about yourself?	
Sense of self and autism	**Participant:** It has, yes.	No hesitation. Strong in her response.
	Interviewer 1: In what way?	
Feeling different Barriers as result of TA	**Participant:** In what way, um. Uh, having a diagnosis does make, does uh make me feel singled out. Ummm [pause] makes me feel singled out, um, having a lot of support staff, um, having a lot of support staff, um, like, coming to you every day, like [pause] um, it has like affected me like in making friends with people, like [pause] building a close bond, um, building a close bond with um some people, um I found it quite hard.	*"singled out"* implies a sense being different from others. Is TA support acting as a barrier to making friends? TA is perhaps making it more obvious that she is different?
	Interviewer 1: OK [pause] anything else?	
	Interviewer 1: Bear with me, hopefully it should share now. No, OK, that's fine, maybe we'll just ask you, then. Um, so, what I wanted to show you, was a big circle, OK. And the circle, in the middle it had your name. And in the middle, after having your name, it had things like home, friends, school, and the community.	

	Participant: Mm-hmm.	
	Interviewer 1: And then I was going to ask you, thinking about friends, can you name me some friends that have supported you?	
Pride in naming friends.	**Participant:** [pause] I’m thinking. Oh, oh, I’m, oh, I’m- [friend 1 name] she’s a school friend of mine, [friend 1 name].	Able to name many different friends.
	Interviewer 1: Mm-hmm.	
	Participant: [Friend 1 name], umm [pause]. [Friend 1 name] because I went to school with [friend 1 name] for five years.	Length of knowing someone determines friendship?
	Interviewer 1: Mm-hmm.	
The role of friends	**Participant:** I speak with [friend 1 name] like from, once a week on the phone to in between every now and again. Uhhhh [pause], [friend 2 name]. [Friend 2 name].	Indication of how she interacts with friends.
	Interviewer 1: Mm-hmm.	
The ups and downs of friendships	**Participant:** [Friend 2 name], she’s one of my high school friends [pause]. Uhh [pause] I’m trying to think as well. Uh, [friend 2 name], uhhh [pause]. [Friend 3 name]. [Friend 3 name] um, we’re friends, but sometimes we fall out, umm…	Providing an insight into her friendship
	Interviewer 1: OK. Why do you sometimes fall out with her?	
	Participant: With [friend 3 name] sometimes we say silly things and sometimes we fall out, but then we make up again.	Normalising falling out with her friend. Is this a cycle for her?
	Interviewer 1: OK.	

Friends and sense of self.	**Participant:** I'd say [friend 2 name]'s a friend, yes. I've known [friend 2 name] since the n-, since Year 9. Uhhhmmm, [friend 2 name], um, I'm just thinking of another friend. **Interviewer 1:** Thank you. **Participant:** I have, I have- quite a few, [friend 2 name], um [pause] trying to think, um, [friend 4 name] [pause] [friend 5 name] [longer pause], that's [pause] [friend 6 name]. [Friend 6 name] is from sixth form and here. Ummm [pause]. **Interviewer 1:** OK, amazing, that's a lot of friends **Participant:** So [friend 2 name] [pause] [friend 2 name] um, [friend 5 name], [friend 4 name], the three girls from my secondary school, they belong here, those are my three friends, um. And for family I've got my two brothers, my sister, my mum, my dad, and I also have my cousin. **Interviewer 1:** Amazing.	Continuing to name friends without prompt. Length of knowing the person is mentioned again. A sense of pride in naming multiple friends. Having friends impacts on sense of self? Does she have a more positive sense of self because of the number of individuals she was able to name as friends? Again, without prompt continuing to name friends.
Family as a support system / The role of sibling	**Participant:** So like three siblings, and my cousin from my mum's side of the family, he comes like a- [pause] once a week? Uh. I go out with my sister when my friends don't want to come out with me, which is often. [cousin name] she's my cousin living in Germany. [pause] Yep. **Interviewer 1:** And what about school? Is there anybody you can name in school that has supported you? [pause] **Participant:** [long pause] Uh, [person 1 name]. **Interviewer 1:** Mm-hmm.	Family acting as social partner. Sibling providing social opportunities.

	Participant: [Person 2 name].	
	Interviewer 1: Mm-hmm.	
	Participant: [Person 1 name] she supports [person 2 name] mainly but like when [person 3's name]'s um absent, she supports me and the other children in the class.	
The role of TA/LSA	**Interviewer 1:** Amazing.	Able name multiple individuals that support her in school.
	Participant: [Person 4's name]'s ma-, I had [person 4's name] help me in mathematics once, uh. Like [pause] like she's shown me methods of how to do calculations to get the answer, um, [person 5's name], [person 5's name]?	Insight into the type of support received by LSA.
	Participant: Yeah	Support is focused on academic support.
	Participant: [Person 5's name]. She's the maths teacher. Uhh, I'm thinking, um, [person 6's name].	
Supportive individual teacher	**Interviewer 1:** Mm-hmm.	
	Participant: [Person 7's name], um, s-, umm, there's um [person 8's name], but when [person 8's name]'s absent, there's sometimes [person 9's name].	
Naming LSAs	**Participant:** Supporting me, um, [person 5's name], and [person 4's name], [person 6's name], [person 7's name] and [person 8's name].	Similar to friends – listing names of those who supported her.
	Interviewer 1: Amazing. OK, [interviewer 2] shall we ask number 7?	
	Participant: Huh?	

	Interviewer 1: [Interviewer 2] is going to ask the next question.	
	Interviewer 2: Can you tell us how autism may have affected your relationships with people?	
	Participant: That’s the biggest part I want to talk about.	
	Interviewer 1: OK, yes please.	
Relationships and sense of self	**Participant:** [long pause, participant is writing] Over the last many years, over the last year, I have-	Relationships with others appears to be an important part of her lived experience. Relationships impacting on sense of self?
	Interviewer 1: Do you need to write this down? Or do you want to concentrate on what you’re saying?	
Difficulties with social communication. Literal interpretation.	**Participant:** Oh yeah. Over the last year, I have struggled with, um, understanding social cues, rules, and reading body language was quite hard. Uh, sometimes, uh, when I see people in public, I, say like children and babies, children and babies, I go and approach them, and some of the parents, they get very aggressive, like, [pause] [imitating a voice] “don’t touch my children, leave us alone” [in usual voice] “leave us alone”, like, it gets like, really annoying when they shout, it sometimes frightens, the parents, it frightens me. I didn’t feel, I felt so scared. My response is, I don’t like people who shout, like, it makes me jump.	*“over the last year”* implies that this is a recent development. Difficulty with ToM? Difficulties in navigating social boundaries in a public setting. Confusion as to why parents have responded to her this way to her. Literal interpretation of the situation. Fearful of how others respond to her.
	Interviewer 1: Mmm.	
	Participant: [pause] As well as social media, like, as we-, can I mention social media related to this?	

Social media - Friends or not friends. Covid-19 and wellbeing Social restrictions and Covid-19.	**Interviewer 1:** Yep. **Participant:** On social media, I have added, like, people from all over the world, like people living in UK, France, Germany, all over, who I've n-, completely never met before. I consider them like all my friends and they kind of start conversations with them. It's kind of, it's kind of like affected me, understanding if they are actually friends, acquaintances, or, people who [pause] who I think are my friends, it's kind of hard understanding. **Interviewer 1:** Hmm [long pause]. Is there anything else you want to share? **Participant:** Also, also the news as well, like [pause] like, hearing about th-, the news has affected me with my ASD, like, hearing about the lockdown, when I hear "lockdown is coming again", that triggers me a lot, like, I cannot literally do anything, I'm so restricted from like, doing the activities and the hobbies that I'm really interested in. Like, I love swimming a lot, like, I can't go to my leisure centre, and [pause] I can't go to my leisure centre and swim to release all the stress that's in my body. **Interviewer 1:** Hmm. **Participant:** Umm, I feel restricted of going to the gym, using the treadmill, running. Running does keep me a-, flowing, like [pause] like hearing the music at the gym, and running at the same time, it's making me come out of my comfort zone and [pause] the exercising helps me a lot, like [pause] weight loss and all sorts. **Interviewer 1:** How has it affected you in relation to friends?	Directed the conversation back to social media. Social media appears to be an important aspect of her lived experience. Difficulties with ToM makes it hard to determine whether those on social media are her friends. *"affected me"* implies the difficulties of trying to figure out whether these friendships are 'real' appear to be affecting her. *"trigger"* implies an awareness that this causes her stress or anxiety. "*I cannot literally do anything"* invokes feelings of being trapped. The restrictions of Covid-19 is impacting on her wellbeing and her routine. What are the effects of not being able to follow her normal routine? How is this affecting her? How is she managing her stress levels?

Social distancing means no physical contact.	**Participant:** [pause] relation to friends, I’m trying to think, oh. With my [pause] like with reading body-, like, can I mention the social distancing rule with ASD, like, when I want to see people fr-, when I see like, people fr-, who I haven’t seen in a long time, like family, friends, like in public, I really want to go and give them a hug and say I missed them a lot. I find it hard when like, I’m told, “d-d-d-d-d-, stop” I’m told “d-d-d-d-, social distancing”. Instead, I have to, like, I have to like say hello from far. It’s so, like, annoying.	Struggling with the physical restrictions imposed by Covid-19. Desire to physically contact with others. What impact, is the feedback from others reinforcing the rules, having on her?
	Interviewer 1: Hmm. I can imagine.	
	Participant: I can imagine, social distancing, it’s like [pause] being in prison.	
Social distancing is like a prison	**Interviewer 1:** Hmm. And I wonder, when you are in college, do you think having friends is easier, or more tricky?	*“like a prison*” highlight that the restrictions of social distancing is similar to being in prison
	Participant: A bit more trickier, because of my autism.	
	Interviewer 1: OK, in what way?	
	Participant: Trickier, like, getting on with people, um, finding the right group, like building relationships with people.	
Finding the right group of friends.	**Interviewer 1:** OK. And what about with teachers?	Findings friends that understand her is important.
My LSA	**Participant:** Teachers, like [pause] Oh my, when we talk about teachers from college, like, I really want to go and give the LSAs a hug. There is one LSA named [LSA name] in this college, the Lithuanian woman, whenever I see her, I want to build a friendship with her, like take the phone number, um, I want to grow a close bond with [LSA name] and like spend time with her outside of college, like going to a	Pride in naming her LSA. *“Grow close bond”* implies perhaps confusion over boundaries with LSA.

	park, jogging together, but, she says [puts on accent] “it’s not allowed”, um, “I have phone numbers, it’s not appropriate” [in usual voice] that’s what she says.	A desire for a close bond with LSA that goes beyond school. Boundaries and social rules are again reminded to her by others. How does this impact on her sense of self?
	Interviewer 1: [chuckles] That’s a great accent!	
	Participant: [putting on accent again] This is how Lithuanian people speak [in usual voice] sometimes.	
	Interviewer 1: [laughs] OK. And what about your family, your brothers and your sisters, how, has that affected your relationship?	
Close bond with family.	**Participant:** Oh, we have a very close bond, yes.	
	Interviewer 1: Right. [Interviewer 2]? Do you want t-	Proud of her relationship with her family.
	Interviewer 2: Yeah [interviewer 1]?	
	Interviewer 1: Do you want to ask number 8?	
	Interviewer 2: Do you think there’s a difference for BAME young people with autism compared to white young people with autism?	
BAME vs Non BAME	**Participant:** Um, Black ethn-, um, B-M, like in [name of college], there are some children with disabilities, they are, they are from different backgrounds, other than white. They are like, Black, Asian, like, and ethnic minorities. They’re so friendly, but some are non-verbal. Like with white autistic, there are, I, I know quite a few, like, in the college, a little percent, um, not, a little percent, um, whereas I went to, I went to an autistic school, um, for work experience, there was a lot of children with ASD, they’re from diverse, and like in the older years, there were a lot of white kids with ASD. But some have different spectrums.	Able to conceptualise the concept of race. Her lived experience includes both BAME and non-BAME autistic young people. I wonder what her experience of working in an autistic school was like for her? Did she see herself the same or different?

	Interviewer 1: And do you think there is a difference between having autism if you're white, and having autism if you're from a BAME background?	
	Participant: If you're white, wi-, and you have a disab-, if you're autistic, um, I don't know how to answer that question, because it's quite hard to describe it.	Difficulties in articulating the difference in treatment.
	Interviewer 1: OK. Do you think that there's a good difference, or a bad difference?	
Disparity in the presentation of autism between White and BAME autistic young people.	**Participant:** There, I would say, there is a bit of both, a good, a good and a bad. Like, with Black and ethnic, Asian minorities, kids with autism, they are more severe on the spectrum, whereas the others are, whereas the others are h-, are quite, whereas others are quite mild or severe. Like, with b-, like some of the kids who are from diverse backgrounds with ASD, the, some of them are verbal and non-verbal, it's hard understanding.	This hints at the difference in the presentation of autism between BAME and non-BAME young people. There is a suggestion that White autistic young people tend to be more verbal and HF compared to BAME autistic young people?
	Interviewer 1: OK. And do you think that BAME young people with autism are treated better, or worse?	
Treatment of BAME autistic young people.	**Participant:** In [pause] on the c-, I do not know the answer, but B-A, B-A-M-E, like some are treat-, I know quite of them are treated bad. I can tell you a story relating to B-M, B-M, B-A-M-E, relates- but some of the whites are treated better.	Is articulating that white autistic young people are treated better in comparison to BAME autistic young people.
	Interviewer 1: OK, did you want to tell us the story?	
	Participant: There is, like, a Lebanese family, who live in my area. They have a son who suffers with ASD. They are- [pause] they are ethnic mi-, they are minorities, yes? They were on a plane coming back	

	from Turkey to London. They flew with [name of airline]. [Name of airline] caused her family a, caused a Lebanese family a lot of grief. They, they said “we are not taking off th-, the plane is not going to take off from [Turkish city]” because the seatbelt was not fastened. Their seatbelt wasn’t fastened. The seatbelt, he, he found it hard to tigh-, fastening the seatbelt, it was a bit hard, on the plane. Like, the plane didn’t take off, they did the emergency, like, the plane had flown from [Turkish city] they, it landed in Copenhagen, Denmark. They used it, they used this emergency landing procedure, because he was disabled. [Name of airline] treated their family so badly, they wanted to sue the company, and take them to court, because they gave them a hard time. **Interviewer 1:** Hmm. [pause] OK, thank you. [Interviewer 2] do you want to ask number 9?	Telling a story to highlight the difference in treatment. There is a suggestion that Storm believes that this treatment on the plane occurred due to the family’s ethnic background.
	Interviewer 2: What, if anything, would you like other people to know about what it’s like to have autism, as a, um, Eritrean person?	
Advocating for increased awareness of autism	**Participant:** Yes. I would like everyone knowing about ASD. It’s a disability that is happening ar-, that it’s a disability around the world, that it’s affected families and other people. Whereas, whereas ASD is more important, ASD should spread awareness, not kept a secret, and like, the people should have more understanding towards people with high needs, rather than treating them differently. **Interviewer 1:** Hmm, that’s beautiful [participant name], I completely agree. What do you think people should know about being Eritrean and being autistic? **Participant:** Being Eritrean and what?	Does she also feel that her autism is a secret? Is she advocating for others as well as herself? Lack of understanding = difference in treatment. A need for psycho education?

	Interviewer 1: And being autistic	
Every life matters regarding of race	**Participant:** Being Eritrean is like [pause] coming from Eritrea makes me feel proud because that's my background and that's where my parents are from. Eritreans with autism shouldn't be singled out, no matter what religion they are. They should be treated equally 'cos every life matters. Black life, Muslim life, Asian life.	Advocating for the equal treatments of all lives. She is aware of the treatment and marginalisation of these groups within society? *"Eritreans with autism shouldn't be singled out"* is Storm referring to herself?
	Interviewer 1 Beautiful	
The impact of social injustice Fear of the police	**Participant**: Whereas in th- in America, there was uh, a person, there was a man, wi-, he was a Black African, he was autistic, he was wearing a hood, and ther- there was a man with a disability, he was going out shopping. The police asked him to remove his hood, but they, they thought he was a thug and they shot him, because of his disability. That's what's triggering me the most, like, I'm living in Britain, I see the police everywhere, I worry that I might die in the hands of the police.	Fear of the possibility of dying as a result of police brutality. Is this fear real for her as she sees herself as Black African and autistic.
	Interviewer 1: Do you think that's something that would happen to you?	
	Participant: Yeah [inaudible – audio cuts out briefly] and, I then, like, I worry that will happen to me, I get like, I get paranoid.	
Racial trauma and self	**Interviewer 1:** OK. And is that because of what you've seen on social media and on the TV?	Fears that the same fate will take place. Racial trauma of witnessing this video is having an impact on her mental health.
	Participant: I've seen it on the news, yes.	

	Interviewer 1: What you saw on the news, OK. Thank you. Um [pause] what would you say are your hopes [participant name], as a young, Eritrean, autistic person? What would you like to do in the future?	What is the impact of autistic young people watching injustice on social media?
Future aspiration Advocacy for people that look like me. Educating others	**Participant:** My hopes are like to become a news reporter or a writer. I like to fight for rights for Black, B-A-M-E people and Muslims. Their lives matter, like, with me, like, I like to write about what's going on in the world, like Shukri Abdi, fighting justice, like I want to educate the world that in our society, there are complicit teachers, who are white, and they have bullied, like they have bullied like Somalis in schools, and like, one, like some complicit teachers, they, they support bullying, they don't stop it, like, like rela- relating to Shukri Abdi, do you mind if I mention her?	A need to better the world for people that look like her. The social injustice of the world has inspired her to become a reporter or writer. *"I want to educate the world that in our society, there are complicit teachers"* suggests an investigator role
	Interviewer 1: Of course.	
Shukri Abdi	**Participant:** With Shukri Abdi, she was a Somali, she was a Somali refugee who, who died in the hands, who died from bullying, and in the hands of those complicit teachers. They knew Shukri was being bullied, bullied, um, they say they have [pause] they knew Shukri was being bullied, they haven't dealt with it properly, the complicit teachers in our society have bullied B-M, B-M, B-A-M-E students, and let them to suffer in silence, um, which has allowed them to die. [pause] That has hurt me a lot.	Has this story affected how Storm sees school and teachers? *"suffer in silence"* implies that teachers were aware but did nothing about it. Lack of accountability and injustice for Shukri.
	Interviewer 1: OK. Um, why do you…	
	Participant: Hearing about Shukri Abdi's death has upset me. I- has upset me a lot, because, being a, being an African Musl-, being a Muslim, and coming, and a refugee in this country, um [pause] being a refugee in this country, she was being treated differently to like her	

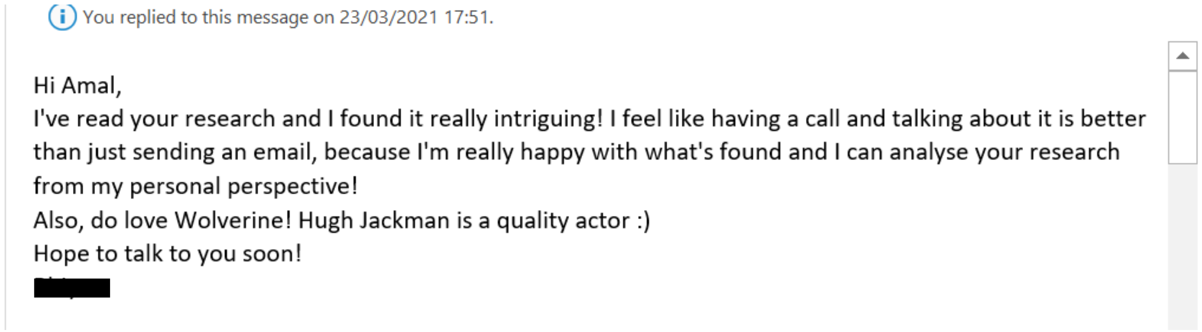
The impact of social injustice on wellbeing Shurki and I The impact of bullying. Fake friends pretending to be real friends.	peers, they singled her out. They have allowed her to suffer, like, I- [pause] allowed her to suffer. Her drowning has like, her drown-, Shukri drowning has made me feel upset because a young innocent Muslim woman had her life taken away from her at the click of her fingers, for no reason. **Interviewer 1:** And do you, have you ever experienced bullying? **Participant:** Oh yes I have in my high school like, some people have befriended me for money, and I didn't feel happy with that, um, I didn't feel happy with that and like, some students were asking me- some students like, made me feel uncomfortable, um [pause] kind of made me feel uncomfortable, um [pause, drinking water]. Sometimes like [pause] I have but like [pause] like there are some students who are a bit mean, I couldn't get on with and like, the fake friends [pause] I didn't like it when students were asking me "oh can I use your stuff?" Like, I'd give it and like, they would ask to use it again and again and it'd get really annoying. I found it hard saying no but like, I'm going to s-, like setting appropriate boundaries is what I'm working on. **Interviewer 1:** OK. Do you think that there are- [pause] so you mentioned Shukri Abdi, and that some teachers were compliant with the behaviour. Do you think that applies to autistic people as well? Or do you think th- **Participant:** Like, it's vice versa. **Interviewer 1:** Mm-hmm. : **Participant** It's a vice versa, and I find it hard to explain it, like maybe some children who are autistic, they like, some of them die, some of	Highlighting the injustice treatment of those who are different. *"I- [pause] allowed her to suffer"* emphasises perhaps a deep sense of anguish felt by Storm and how society has failed Shukri. I wondered whether Storm saw herself in Shukri and her suffering. This goes back to Storm difficulties with differentiating who is her friend and who is not. *"Fake friends"* = friends who keep asking you for things and wanting more from you. Hints at the difficulties Storm experiencing with social interactions.

Autism and bullying The best things about my autism.	them, some children with ASD find it hard to cope, they go through bullying and it like has an impact on their mental health. **Interviewer 1:** OK, right. Thank you. Um, so, would it be possible, so this is gonna be our last question before we will stop, so we wanna make a list of all the very best things about being an autistic young person. And we were wondering whether you can tell us the very best things about your autism. **Participant:** OK. [long pause] Oh, the best thing about mine was going to, to work experience in a SEN school, meeting children with ASD, giving them the support they needed. Uh, I learnt Makaton to communicate with them, um, err [pause] um, I, I like to go travelling with my ASD like visiting new places, I have routines of things that I want to see. Umm, going to fun fairs make me a bit happier. Eating a lot of crepes makes me happy with my ASD. Like, at times I struggle making like, crepes, and I end up burning my hand on the pan. **Interviewer 1:** OK [chuckles] [inaudible – possibly “I do too”?] Is there anything else that you would like us to know about before we stop the interview? **Participant:** Umm, I would like you to know that my favourite movies are Disney, and I like watching Arabic comedies. **Interviewer 1:** [laughs] That sounds like lots of fun.	The difficulties of coping of bullying when you are autistic. Bullying = impact on mental health and how someone sees themselves. Able to reflect on the positive experiences had as result of her autism. Learning Makaton appears to be a trait she is proud of. ASD = travelling.

Appendix 4.2 – Member checking (feedback from participants)

All participants were contacted and asked to make comments on the interpretation made by the researcher and co-researcher as well as the accuracy in capturing their voices at an individual level and group level. Given that member checking is optional, Wolverine and Storm were the only participants who engaged in this process.

Wolverine:



You replied to this message on 23/03/2021 17:51.

Hi Amal,
I've read your research and I found it really intriguing! I feel like having a call and talking about it is better than just sending an email, because I'm really happy with what's found and I can analyse your research from my personal perspective!
Also, do love Wolverine! Hugh Jackman is a quality actor :)
Hope to talk to you soon!
[redacted]

Email received from Wolverine confirming his preference to speak about the data as opposed to writing an email with his feedback.

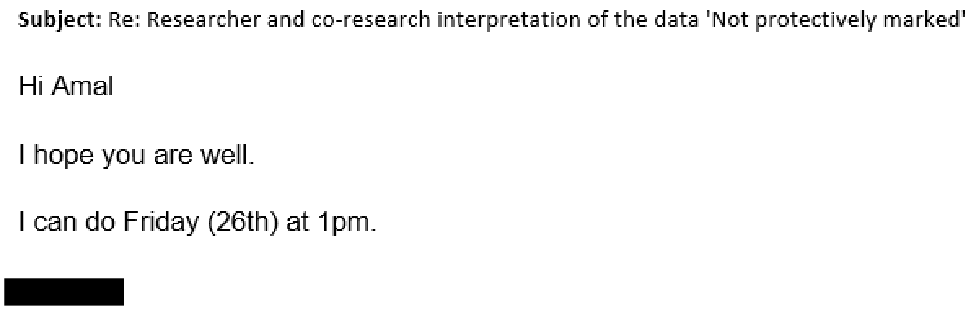
The researcher, co-researcher and Wolverine met on 26th March 2021 virtually to discuss his feedback regarding the findings. Please see below:

Feedback and comments from Wolverine regarding the data at an individual level	
Section / Theme	**Wolverine's feedback**
Introduction summary	• *I don't live on campus, but I am renting a house with my friend via private accommodation".* **This has been changed following feedback.**

Table summary of themes	• *"Everything here is fine. Nothing to add, it captures what I wanted to say so I'm happy with it"*
Subordinate theme one: Struggling with a sense of self	• *"This is accurate representation of how I was feeling when I was younger, you alluded to it very well*". • *"There was a lot of difference between me and my friends. My friends realised that I was different, and this made me unique. Educating people about differences has really helped. It has made a difference as it has reduced the rate of bullying. At University there is so much openness and people share their experiences and you can bond through those experiences. But this is only at University".*
Subordinate theme: Adults as a support system to accepting autism	• *"This is very very accurate as to what I would say. The support I received was sensational and I keep in contact with them. I had their support all throughout secondary school".* • "*The best LSAs I had were Indian and Middle Eastern. This is because they were on my wavelength. The LSA from India, told me stories about autism from people in my culture and her experience. She took me under her wing, and we connected because of our cultures".*
Subordinate theme: Normality is a spectrum	• *I am not finding anything wrong with your interpretation. It's what I would have said, everyone has their own normality and its who you are as a person. Its connected to your personality, for example if you are loud then that is normal for you".*
Subordinate theme: There is power in sharing lived experience	• *This is a recent development, in the last year or two. Growing up I didn't have lots of knowledge and I wanted to learn more about it before I started advocacy and sharing my autism".* • "*I want people to see who I was before and who I am now especially my university friends. They have only known me from 18 years old, they haven't seen or heard about all the difficulties I went through. They don't know I used to be timid and shy they only know the bubbly person I am now. I want them to know that going through challenges means you are progressing".*

Subordinate theme: Representing autism at the different levels	• *This is more reflective of first year then second year. Because of Covid – mental health and autism was more spoke about it. Uni have done a great job supporting BAME students to talk about their experience. Covid made this possible".*
Feedback and comments from Wolverine regarding the data at a group level	
Subordinate theme: BAME communities acerbating negative perception of autism	• *I would agree with the census of this time, 100 per cent".* • *"I stamp my authority of saying British-Indian as I am not Indian. I don't hold the same values as those of traditional Indian. This is not just about mental health but their views relating to gender issues and saying woman have to stay at home and cook and clean. But if you are British-Indian, then woman can go out and work and this is what you see in Britain".* • *"There is more acceptance in Britain. In Indian there is no acceptance and education about autism. In Britain there is more acceptance. Boris has invested 18 million into mental health services whereas there is nothing in Indian".*
Subordinate theme: Positive traits as result of autism	• *"I didn't know I had it initially but when I realise it, it made me feel proud to have these skills" and "I prefer looking at the positives because I want to have positive energy"*
Subordinate theme: Cultural pressures	• *"In traditional Indian – you can never fail because of your mental health. You fail because you don't put the work in".*
Subordinate theme: Bullying as a consequence	• *There are different waves of bulling. Name calling and cat calling. I got cyber bullied for 3 years and I got catfished once online. There is also peer pressure – a joke or banter which then turns toxic. I used to get pushed a lot but the cyber bullying was the worst. I haven't been bullied in the last 2 years since I started University".*
Subordinate theme: Us vs Them	• *All the BAME communities would agree with me. White people do get more help. I don't know the reason it's just seems that way. There are not a lot of people in BAME communities that have autism, and this is mainly because there are more white people in the UK than BAME individuals".*

Storm:



Subject: Re: Researcher and co-research interpretation of the data 'Not protectively marked'

Hi Amal

I hope you are well.

I can do Friday (26th) at 1pm.

[redacted]

Email sent by Storm confirming she is happy to virtually discuss the findings.

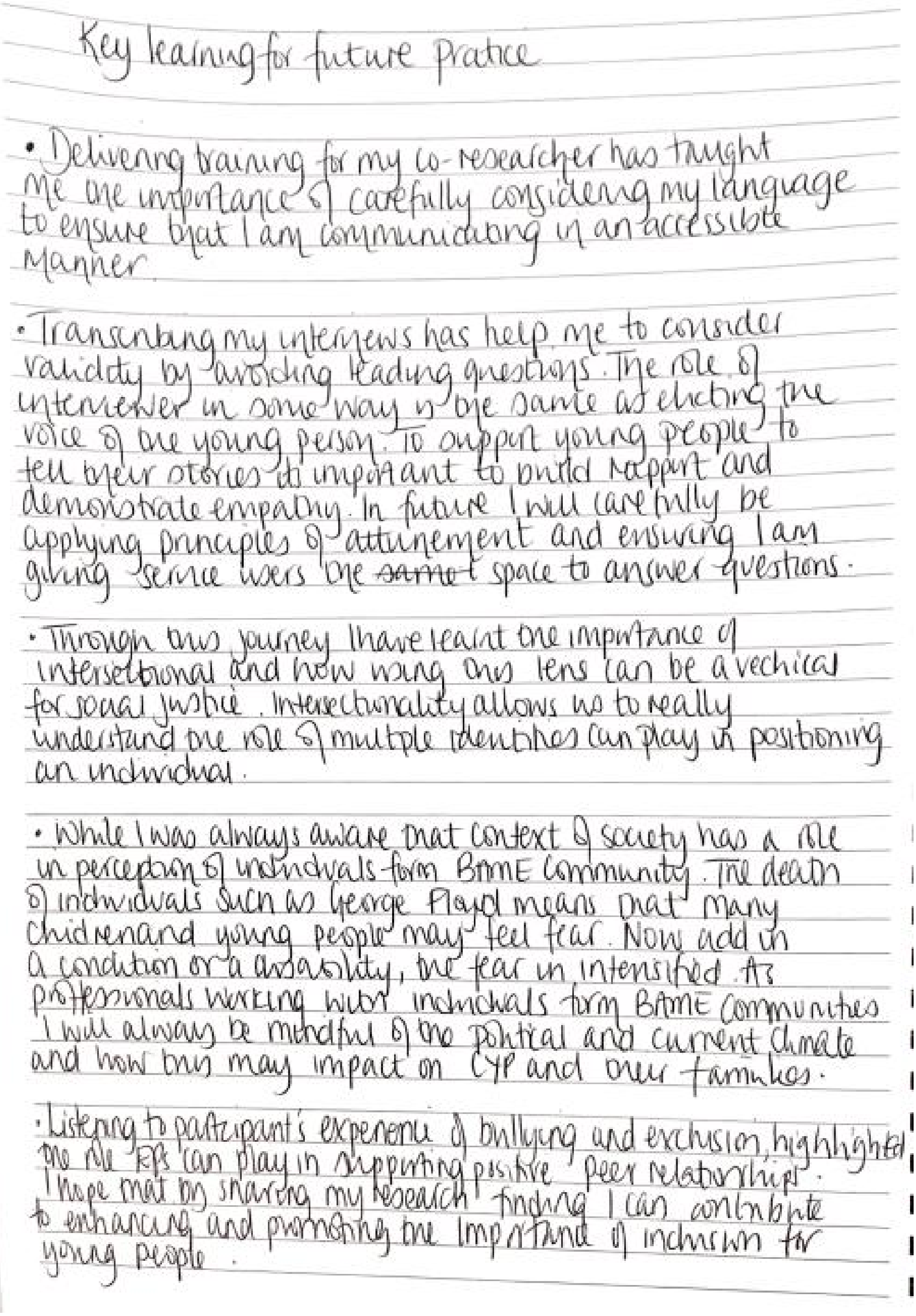
The researcher, co-researcher and Storm met on 26th March 2021 virtually to discuss his feedback regarding the findings. Please see below:

Feedback and comments from Storm regarding the data at an individual level	
Section / Theme	**Storm's feedback**
Introduction summary	- *"Happy with the name Storm"* - *"I want to add in I want to be a news reader"* - *"It shows my experience – I don't want to change anything"*
Subordinate theme: Reality vs social media	- *"I want to go into more detail. With social media I don't really understand how it affects mental health. I want to learn more about this and building healthy relationships in person".* - *"With online – I want you to add about safety and knowing what people are like behind closed doors. People are not always nice. My teacher told me about an 8-year-old who met a man, who she thought was a boy she gave him her address and he ended up killing her. Its trigging"*

Subordinate theme: Social distancing is like being in prison	- *"I agree with what you said here – I have an old friend from college. When I see her, I have the urge to hug her and she says no no no. It makes me feel upset being restricted from hugging her".*
Subordinate theme: Impact of lockdown on wellbeing	- *"Captures me experience - this is very accurate. I want you to know that I started doing bleep tests about 2 and 3 weeks ago. It helps me with stress and keep healthy".*
Subordinate theme: Every life matters	- *"Yes, I was talking about myself and another friend who is from Eritreans who is severally autism. We should be treated fairly".* - *"This is correct"*
Subordinate theme: Fear of the police	- *"I agree with this. Can you add that I went to the protest for those who lost their lives. I went to one in June 2020 about BLM and it was for George Floyd".* - *"I still have a feeling of fear with police, this hasn't changed".*
Subordinate theme: Shukri Abdi	- *I agree with this and what you wrote. But I think it is also about islamophobia and how they treat Muslim people. Did you know the school change the name after Shukri's death so they wouldn't be associated with it her death".*
Feedback and comments from Storm regarding the data at a group level	
Subordinate theme: Lack of understanding and knowledge of autism within BAME communities	- *"Half and half agree with this. The older generation find it hard to tolerant children with SEN. The younger generation are better regarding".*
Subordinate theme: Feeling different.	- *"I would agree with this and what you said. I also sometimes when I get on public transport, I get sensory overload. I can see that people are watching me having a meltdown".*

Subordinate theme: It's not me it's my autism	- *"I do find it difficult understanding people's behaviour, their body language and cues. I know this is because of my autism. People with autism find this hard"*
Subordinate theme: Autism as a barrier	- *"I already found building a bond with others hard and now Covid has made it even more difficult"*
Subordinate theme: Us Vs Them	- *"When I see people from white background, I notice that they were brought up loving parents. Black people are brought up differently".* - *"If you are from a white background, society is fairer to you".* - *"BAME kids who are autistic – they find it hard to fit in society they don't feel like they are part of the society. This is because of their skin colour and because of their disability"* - *"I don't feel like I am part of this society because of my personality and how I act. My skin colour also".*
Subordinate theme: Family as supporters	- *"I agree 100% - helping me with my homework, helping me budget. My sister and I are very close as well".*
Subordinate theme: 'My' learning support assistant	- *"This is true – I really liked my LSA a lot. She told me that when the restrictions lifted, I can start giving her hugs again. She was amazing to me".*
Subordinate theme: Friends helped me along the way.	- *"I have two friends have supported me, X and X"*

Appendix 5.1 Key learning for future practice



Key learning for future practice

- Delivering training for my co-researcher has taught me the importance of carefully considering my language to ensure that I am communicating in an accessible manner

- Transcribing my interviews has help me to consider validity by avoiding leading questions. The role of interviewer in some way is the same as eliciting the voice of the young person. To support young people to tell their stories its important to build rapport and demonstrate empathy. In future I will carefully be applying principles of attunement and ensuring I am giving service users the ~~samot~~ space to answer questions.

- Through this journey I have learnt the importance of intersectional and how using this lens can be a vechical for social justice. Intersectionality allows us to really understand the role of multiple identities can play in positioning an individual.

- While I was always aware that context of society has a role in perception of individuals form BAME Community. The death of individuals such as George Floyd means that many Chidren and young people may feel fear. Now add in a condition or a disability, the fear in intensified. As professionals working with individuals form BAME communities I will always be mindful of the political and current climate and how this may impact on CYP and their families.

- Listening to participant's experience of bullying and exclusion, highlighted the role EPs can play in supporting positive peer relationships. I hope that by sharing my research finding I can contribute to enhancing and promoting the importance of inclusion for young people.