

**Addressing Intersectional Invisibility:
Exploring the lived experiences of Black
African mothers raising an autistic child in
the UK**

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Abstract

Whilst autism is an extensively researched area, the vast majority has focused on participants from a White Western background. Findings derived from such research have therefore been applied to the experiences of parents of autistic children from the global majority. However, there is increasing emphasis on the important role of culture, ethnicity and race in people's beliefs, views, and experiences. Research exploring lived experiences of the global majority is therefore needed to diversify current knowledge. The purpose of the study was to explore the lived experiences of Black African mothers raising autistic children in the UK.

This study adopted the participatory model by recruiting a Black African mother of an autistic child as a co-researcher to work collaboratively with during the research process. Semi-structured interviews were conducted with Black African mothers to gain their views and experiences of raising an autistic child. Interpretative phenomenological Analysis (IPA) was used for the data analysis to gain a deep understanding of the participants' lived experiences. Firstly, individual-level themes were produced for each participant. Group-level themes across participants were then produced, reviewed, and finalised with the co-researcher.

Five superordinate group themes emerged from the mothers' lived experiences, which seemed to have an underlying cultural link. The first theme was *cultural construction of autism*. Participants expressed a strong narrative about the negative perceptions of autism within their communities that stemmed from a reduced awareness and understanding of autism. Participants also highlighted *accessing support* as a key experience explaining that initially, they disengaged from professional services due to shock and denial. However, once mothers felt more accepting of the diagnosis, mothers described difficulties in gaining support for their children. *The role of religion* played a significant and often conflicting part in the mothers' lives, acting as both supportive but also blocking their full acceptance of the autism diagnosis. Religion was also believed to contribute to the negative views of autism within their culture. *The role of race* was another theme that emerged from participants. Many wondered if being racialised as Black negatively impacted their experiences, and there were hopes for more culturally specific parent support groups. The final theme, *positives*, highlighted strengths noted by mothers in their autistic children and the personal growth participants felt they had gained from being a parent to an autistic child.

The study's findings are important for EPs and others working with global majority families and children. There is a clear need to offer culturally sensitive support encompassing racial and cultural identity. The findings add to emerging research into autism from the perspective of global majorities. It is hoped this research acts as a form of social justice by empowering a Black African mother as a co-researcher

and providing an opportunity for the voices of a marginalised group to be centred and heard.

Keywords: autism, mothers, Black African, lived experiences, culture, participatory research

Declaration

University of East London School of Psychology

Doctorate in Educational and Child Psychology

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 reference list is provided.

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Table of Abbreviations

Abbreviations	Term
ASC	Autism Spectrum Conditions
ASD	Autism Spectrum Disorder
BAME	Black, Asian and Ethnic Minority
BLM	Black Lives Matter
BPS	British Psychological Society
CRT	Critical Race Theory
CYP	Child and Young Person
DfE	Department for Education
DSM 5	Diagnostic and Manual of Mental Disorders
EHCP	Educational, Health and Care Plan
EP	Educational Psychologist
EPS	Educational Psychology Service
HCPC	Health And Care Professional Council
ICD-10	International Classification of Diseases
IPA	Interpretive Phenomenological Analysis
LA	Local Authority
PR	Participatory Research
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SEND	Special Educational Needs and Disabilities
SSIs	Semi Structured Interviews
TA	Teaching Assistant
TEP	Trainee Educational Psychologist
UEL	University of East London
UK	United Kingdom
USA	United States of America

Chapter 1: Introduction

1.1 Overview

The chapter will introduce the focus area of the research study. It will define key concepts linked to the lived experiences of Black African mothers raising autistic children. The national and local context and the rationale for selecting participants will be explained. The conceptual, theoretical and researcher's positioning underpinning the research will also be identified. Lastly, the chapter will discuss the study's rationale before concluding with the personal background, aims and research question for the study.

1.2 Key Terminology

The terms used in the research study are defined below to provide a clear understanding of how they were utilised during the study.

1.2.1 Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) or autism is described as a lifelong neurodevelopmental condition that impacts how a person interacts and communicates with others (Murray, 2012). In the United Kingdom (UK), a person must meet the criteria outlined by the Diagnostic and Statistical Manual of Mental Disorders (DSM 5) or International Classification of Diseases (ICD-10) in order to receive a diagnosis of ASD. The diagnostic criteria for ASD highlights a dyad of impairments where individuals demonstrate varying degrees of difficulties in social communication and interactions, and fixated interests or repetitive behaviours which may include unusual sensory behaviours (DSM 5, 2013). It is estimated that around 1 in 160 children have ASD worldwide (World Health Organization, 2021).

Interestingly, prior to the DSM 5, the diagnostic criteria referenced a triad of impairment which separated social communication and social interactions. However, it is now recognised that the two are inseparable. Additionally, sensory issues were also not taken into consideration (Samadi et al., 2022).

Furthermore, the DSM 5 also removed subcategories such as autistic disorder, Asperger's disorder, and Pervasive Developmental Disorder, leaving only a single possible diagnosis of ASD. However, although the DSM 5 only refers to ASD, other terms are preferred and used by some groups (Kenny et al., 2016). For example,

Autism Spectrum Conditions, Asperger's, or Pathological Demand Avoidance (PDA) are some of the terms that may be preferred and/or used by various professionals. Moreover, there are notable different stances on the use of language when speaking about autism. Two main perspectives exist; the use of identity first (e.g., autistic person) or person-first (person with autism) language. Kenny et al., (2016) study found that a large majority of autistic adults, their parents, family, and friends preferred the identity first language. Professionals however were found to mostly prefer the person first language in their description of autism. Based on Kenny et al., (2016) findings this study will use identity first language throughout the research to align with autistic people and families' preferences.

Within autism research there are several current debates and topics of interest. Historically autism knowledge has tended to stem from cisgendered boys and therefore omitting girls, nonbinary or other marginalised gender identities. This appears to have impacted the assessment and diagnostic criteria that is drawn on when identifying autism (Navarro-Pardo et al., 2021). Consequently, it has been argued that there is limited understanding of how autism may present in girls and has led to an underdiagnosis of autism in girls and women. This has been attributed to the fact girls are reported to have camouflaging or masking abilities which enables them to blend in socially although it should be noted this can impact on their wellbeing (Hull et al., 2017, 2020). Additionally, research implies that girls may display subtler autistic characteristics as well as for example holding better abilities in expressive language skills like reciprocal conversation, initiating interaction and have fewer unusual stereotypical or repetitive behaviours (Young et al., 2018). Moreover, statistics suggests that when girls do recent a diagnosis, there are more likely to have significant learning needs and delayed language skills than their male counterparts again suggesting that the subtle nature of autistic traits in girls may be more likely to be missed (Lai & Szatmari, 2020).

Another key debate in autism in recent years, is the increase in the number of people diagnosed with autism within the UK. Russell et al, (2021) looked at autism diagnoses over 20 years between 1998 and 2018 and found a 787% rapid increase

in incidence of autism diagnoses. They reported that the increases were greatest in females and adults, with the authors concluding this is likely the result of greater awareness and recognition.

Another potential reason for the increase in diagnosis has been said to be the widening of the spectrum to include autistic people who perhaps would not have been included before. As discussed early the previously used terms such as Asperger's has now been removed. Also, there is growing awareness of neurodiversity paradigm which includes many people who are said to think differently from neurotypical people.

However, there are cultural differences with some societies notably stating that neurodiversity or autism does not exist within their cultures. Research has suggested that many global majority countries hold the belief that autism does not exist and often have no name for it within their own languages (Slade, 2014).

1.2.2 Ethnic Minority

As this research was conducted in the UK, the study adopted the UK government's definition of an ethnic minority to remain consistent with current research and data. In their definition an ethnic minority "refers to all ethnic groups except the White British Group. Ethnic minorities include White minorities such as Gypsy, Roma and Irish Traveller groups" (Race Disparity Unit, 2021). However, it is accepted that this term can be problematic as it positions whiteness as the norm and is arguably rooted in systemic racism and White privilege (which are discussed in more detail further on in this chapter), which marginalises 'non-White' people (Campbell-Stephens, 2021). The term 'global majority' has been suggested as a more appropriate term as it encapsulates the fact that those who tend to be described as minorities actually make up the majority both globally and locally in some contexts within the UK. The shift in language aims to empower individuals labelled as ethnic minorities and remove the negative connotations of the term minority that could imply subordinate status to their White counterparts (Campbell-Stephens, 2020). Nonetheless,

Campbell-Stephens (2020) advised people should be provided the opportunity to self-identify their racial, ethnic, and cultural background. Therefore, this study uses the term global majority rather than ethnic minority but ensures participants' self-identified terms and labels are used in regard to their racial, cultural, and ethnic group. However, the term ethnic minority is used within the literature review and when referring to existing research as this reflects the language used by the authors.

1.2.3 Black African

In England and Wales, the term Black African is typically used to refer to individuals of African heritage originating from sub-Saharan Africa. This study used this definition in the participant inclusion criteria. However, it is acknowledged that this term can be problematic as it ignores the heterogeneity of people from different countries regarding beliefs, values, and practices (Agyemang, 2005). Notably, the recent 2021 census added an optional 'write in' response box in the ethnic group of 'Black African' to allow for the addition of a specific country of origin. With this in mind, this study will use the term Black African to remain consistent with England's ethnic categorisations, research, and policies. However, participants were given the opportunity to also state or write their ethnicity more specifically by asking about the country of heritage, for example Kenyan. This allowed for cultural differences to be explored among different regions or countries of Africa.

1.2.4 Culture

Culture is a complex term which refers to a set of beliefs, values, attitudes, and norms held by a group of people which is often passed down through generations. Culture influences how a person perceives and understands themselves, others, and the world around them (Matsumoto, 2001). The importance of culture will be explored further in the cultural competence section below.

1.2.5 Mother

The Cambridge dictionary defines 'mother' as the female caregiver to their child or children (Cambridge Dictionary, 2023). This study includes females who are cis-gendered or those who self-identify as being the female.

1.3 Context

1.3.1 National Context

The 2021 census indicated much of the United Kingdom (UK) population identified as White (81.7%) making the global majority around 18.3% of the population (Asian, Asian British or Asian Welsh 9.3%; Black, Black British, Black Welsh, Caribbean or African 4%; Mixed or Multiple ethnic groups 2.9%; and Other ethnic group 2.1%).

Looking more closely at the 'Black, Black British, Black Welsh, Caribbean or African ethnic' groups the census suggests that Black African make up 2.5% of the population, whilst Black Caribbean are around 1.0% and Black Other is 0.5% (Office for National Statistics, 2022).

As the dominant ethnic group is White, a key context for the study is the norms of White Western culture. This includes individualism, where there is a heavier focus on the self and immediate family compared to more collectivist societies that emphasise closer relationships and the inclusion of extended family and the community.

Evidence suggests that cultures in non-Western countries such as those in Africa tend to be more collectivist in nature (Hofstede et al., 2010).

Furthermore, historically the UK has been described as institutionally racist, creating another important context (Macpherson, 1999). UK establishments and organisations were argued to have 'processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness, and racist stereotyping which disadvantage minority ethnic people' (Macpherson, 1999 p.369). Controversially however, the Commission on Race and Ethnic Disparities report (March 2021) concluded that the UK was no longer institutionally racist. This received widespread criticism including from the UN Working Group of Experts on People of African Descent and prominent racial injustice campaigners in the UK (Day et al., 2021). Another notable context is the Black Lives Matter (BLM) movement. The media focus on police brutality against Black Americans and particularly the murder of George Floyd, led to worldwide recognition and discussion about racial injustices in society. This also prompted several professions to actively

examine their practices and address inequalities in the hopes of moving towards anti-racist practices (Agyeman & Lichwa, 2020).

Moreover, another key context is the heightened focus on immigration in the UK (Martins, 2021). Immigration continues to receive heavy media coverage and is at the forefront of public and political debate. In the UK, the Leave vote in the Brexit referendum 2016 was arguably driven by immigration concerns (Meleady et al., 2017). This has debatably led to an increase in anti-immigration attitudes, and there has been a rise in reported discrimination and hate crimes against global majority and immigrant groups (Home Office, 2022). More recently, the current management of the Calais to Dover crossing has again propelled immigration into the spotlight. This anti-immigration attitude has reportedly led some global majority groups to feel unwelcome and unsafe within particular communities in the UK (Carr et al., 2020).

In the UK, around 700,000 people are estimated to be autistic, with 1 in 100 children diagnosed with ASD (British Medical Association, 2021). ASD is the most identified need among Children and Young People (CYP) with statements of Special Educational Needs and Disability (SEND). Additionally, over a quarter (31%) of all Education, Health, and Care Plans (EHCP) list ASD as a primary need (Department for Education (DfE), 2021). The prevalence of ASD is similar across ethnicities (Tincani et al., 2009). However, there is some evidence of ethnic disproportionality in the diagnosis of SEND. This is suggested to be linked to growing ethnic diversity. For example, Strand and Lindorff (2018) found an underrepresentation of CYP from Asian backgrounds with an ASD diagnosis compared to their White counterparts. However, those from Black Caribbean and Black other were overrepresented in the diagnosis of ASD. Additionally, pupils from mixed White and Black Caribbean backgrounds were found to be overrepresented in Social, Emotional and Mental Health diagnoses (Strand & Lindorff, 2018). Furthermore, CYP from Black backgrounds were found to be almost twice as likely to be labelled as having Speech, Language and Communication Needs (Strand & Lindsay, 2012).

1.3.2 Local Context

London is the most ethnically diverse region of the UK, with 40.2% of residents identifying as being from a global majority background, with some boroughs having up to 83% of residents from Black or Asian groups (Office for National Statistics, 2022). In the Local Authority (LA) Educational Psychology Service (EPS), where the researcher is currently on placement, a main priority is its response to the BLM movement. The EPS is reviewing practices and services with the aim of embedding anti-racist procedures. During EP meetings, there is a running agenda item on challenging racism & discrimination where EPs are invited to share and reflect on any good practice, experiences or research that reflects anti-discriminatory practices. It is hoped that a better understanding of the local challenges and needs of global majority communities will help improve access to services and enhance educational and social outcomes.

In regard to autism, the LA currently has a well-established autism diagnosis service, including a Senior EP who has responsibility and specialism within the team. The EPS also works closely with the LA's Autism Advisory Service as well as parent advocacy and support groups run by volunteer parents of children with SEND, including autism. One of the groups has created a Black, Asian and Ethnic Minority (BAME) sub-group specifically to support parents and CYP from global majority backgrounds.

1.4 Race

Several theoretical and conceptual frameworks underpinned this study. These connected the research and theory, allowing for the exploration, understanding and creation of meaning from participants' experiences.

1.4.1 Critical Race Theory (CRT) and Social Justice

CRT is a theoretical framework which examines race-based oppression. CRT identifies race as a social construction and explores how "structural arrangements inhibit and disadvantage some more than others" (Treviño et al., 2008 p.8). CRT highlights the importance of recognising not only overt racism but also covert or subtle microaggressions faced by marginalised groups. CRT aims "not only to name but to be a tool for rooting out inequality and injustice" (Treviño et al., 2008 p.8). CRT

will be helpful in exploring ways in which racism may impact the research participants' experiences.

An aim of CRT is social justice. This is a complex concept to define as it has varying meanings to people. Nevertheless, there is a consensus understanding around the link to fairness and justice (E. Smith, 2018). This study will take a communitarian viewpoint of social justice that highlights "principles of desert (i.e., what is deserved), need (i.e., what is required), and equality (i.e., what is equivalent)" (Speight & Vera, 2009 p.83). From this standpoint, social justice is achieved when processes or institutions upholding inequalities are transformed and barriers to resources are removed (M. Fox, 2015). Key to this is working collaboratively with stakeholders, advocating and challenging biases and raising awareness (Rogers & O'Bryon, 2008). This definition will be used as a framework to give participants the space to voice their experiences and work "with" rather than "on" them (Creswell, 2013 p.24). The framework also aligns with my values aiding a 'just' way of conducting the research.

1.4.2 White Privilege

White privilege is the idea that people who are racialised as White have advantages in society based on their skin colour. These privileges are grounded in systemic racism and uphold whiteness (Leonardo, 2002). Whiteness is focused on the structures that create White privilege, which differs from White people, the socially constructed category based on skin colour (Lindner, 2018). Collins (2018) identified three privileges underpinning White privilege. Firstly "the power of normal" (p.4), "Where public spaces and goods seem catered" for White people whilst marginalising the needs of minority groups into "special sections" (p.5). Secondly, the power of the benefit of the doubt states that White people are more likely to be humanised, receive compassion and be given second chances. Conversely, minority groups are more likely to be racially stereotyped and receive less compassion in society. The power of accumulated power is another privilege described as White people "having greater access to power and resources than people of color [in the same situation] do" (Collins 2018 p.8). Finally, White privilege was identified as

having the power or choice to remain silent or dismiss racial inequities (Collins, 2018).

CRT and White privilege are valuable frameworks to consider for the present study as the research was conducted in the UK, where society tends to categorise individuals racially. Moreover, the population is predominately White. Research has suggested that there is a lack of representation of global majority groups in autism research, which may add to existing health and healthcare disparities (Maye et al., 2022). Additionally, there have also been findings to suggest that anti-Black racism and White privilege may be negatively impacting on the experiences of Black autistic people and their families from the diagnostic process, interactions with healthcare services and access to support services (Onaiwu, 2020; Straiton & Sridhar, 2022).

It was therefore important for the research study to consider the construction of race and White privilege as a lens to explore Black mothers' lived experiences of raising an autistic child.

1.4.3 Intersectionality and Intersectional Invisibility

Crenshaw, (1991) described intersectionality as the ways social and political identifiers such as race, gender, sexuality, and class overlap and produce privileges or discrimination in society. This framework will be useful in understanding how the systems of power may negatively impact participants' identities. Additionally, the framework can explore how different forms of oppression may occur simultaneously due to having overlapping social identities, in this case, being Black, female, and associated with disability.

Similarly, Purdie-Vaughns and Eibach (2008) presented the idea of intersectional invisibility, referring to how individuals who hold multiple marginalised group identifiers can become 'invisible' compared to those with a single marginalised identity. Such people are viewed as non-prototypical members of their respective identity groups, experiencing a unique set of societal advantages and disadvantages. This non-prototypical status is argued to be based on androcentrism, ethnocentrism and heterocentrism, where being male, White, and heterosexual are

seen as the prototype from which the norms are set in Western European societies. Purdie-Vaughns and Eibach (2008) stated that those with multiple intersects often have their characteristics misrepresented to align with frameworks for the prototype of the marginalised identity group. Examples of such groups include ethnic minority women or ethnic minority gay men. This framework is useful for the study as the research participants are ethnic minority women parenting autistic children. This study aims to give a voice to and explore the experiences of a group that may be experiencing multiple types of marginalisation and thus often 'invisible' in research.

1.5 The EP Role

As applied psychologists, EPs use their knowledge of psychology and child development to help support the learning and well-being of CYP. EPs adopt a collaborative and holistic approach, working with CYP, parents, and teachers to jointly problem-solve and consider the impact of the systems around the CYP on their development (BPS, 2021).

1.5.1 Legislation

EPs are governed by several laws and guidelines to ensure that practice remains ethical and aims to create positive outcomes for clients. A fundamental principle from such guidance is ensuring CYP's and their parent's increased autonomy. The Children and Families Act (2014) and The SEND Code of Practice (Department for Education (DfE) & Department for Health, 2015) highlight that professionals, including EPs, should actively involve CYP and parents/carers in decisions that impact on their lives. Furthermore, it highlights that professionals must listen to the perspectives and opinions of CYP and their families from global majority backgrounds. Professionals are required to be aware of both the prevalence and recognition of SEND in such communities.

1.5.2 Cultural Competence

With the population becoming increasingly diverse, EPs will likely support many more CYP and families from a global majority background. Consequently, there is a necessity for culturally responsive practice, often known as cultural competence, to ensure that the needs of such groups are efficiently met. This refers to 'the awareness, knowledge, and skills necessary to work effectively and ethically across cultural differences' (Pope & Reynolds, 1997 p.270). EPs are advised to illustrate

cultural competence, which includes being actively aware and curious about potential cultural factors impacting clients' experiences and integrating this into practice (BPS, 2018; HCPC, 2016). Laws such as the Equality Act (2010) highlight the necessity for professionals to tailor services to fit the requirements and needs of global majorities to improve access to services.

EPs can play a vital role in improving the educational and social experiences of autistic CYP and families from global majority backgrounds. Being able to work within different systems (schools and wider communities) makes EPs well-placed to facilitate collaborative discussions, allowing for the exploration of culture and beliefs that can lead to a mutual and holistic understanding of the CYP's strengths and needs. Additionally, EPs can foster the empowerment of global majority parents by having reflective conversations about power dynamics related to culture, knowledge, and beliefs by providing space for them to share their views.

1.5.3 Participatory Research

Participatory Research (PR) involves including those affected by the topic being studied in the research process. Rather than a design, PR can be viewed as an 'approach' to research (Schratz & Walker, 1995). The degree of this inclusion can vary greatly, but an underlying principle is actively engaging participants in the research process (Cornwall & Jewkes, 1995). PR enables power imbalances between the researchers and participants to be addressed. The aim is to equalise power by positioning parents as the experts in their lives and therefore the best people to direct the research (Wang et al., 2016). This study used PR principles to empower a co-researcher who identifies as a Black African mother to work in partnership with the researcher. The co-researcher was trained to conduct research and given the freedom to decide the level of involvement they wanted in the study.

1.6 Personal Background

I am a Black-African female born in Uganda. I came to the UK aged 3 with my family in the early 1990s. My cultural background, values and beliefs are essential parts of my identity. Growing up, I sometimes felt clashes between my Ugandan values and British culture. I often found myself navigating between the two, which sometimes proved challenging.

Before starting on the Trainee EP course, I spent several years working closely with autistic CYP in various roles, including as a Learning Support Assistant, Assistant Psychologist, and as an Inclusion Manager. Furthermore, I am a mother of two boys with additional needs, one of whom is autistic. I have therefore gained a deep passion for this topic area.

Sharing the same ethnicity and gender as participants and having experience raising an autistic child in the UK may be beneficial for the research. I believe this may aid in building rapport and trust with participants and provide an insider perspective, allowing for a stronger understanding of the global majority experience. Additionally, I may be well positioned to facilitate culturally sensitive working with the co-researcher and participants. Nevertheless, I acknowledge the potential bias my personal background may have on my interpretations. To mitigate the potential bias the researcher worked with a co-researcher to design the interview schedule and review the main group themes. I also had discussions and checks with my supervisor and sought support from other Trainee EP (TEP) with experience in IPA. I have also attended a PR action group. Lastly, I have kept a reflective diary as part of my research process.

1.7 Research Rationale

Although ASD has been widely researched, most participants have tended to be from White Western backgrounds (Slade, 2014). ASD research has arguably often taken an absolutist position where it is assumed people are psychologically similar and human phenomena are the same across different cultures. Thus, findings are assumed to be universally applicable to all (Perepa, 2019). However, this position ignores culture's crucial role in shaping people's views, beliefs and understanding of the world.

Heer et al., (2012) suggested that immigrant or ethnic minority families with children with disabilities undergo a "minority experience" (p.951) that differs from their White counterparts. This minority experience is influenced by language, beliefs, religion,

and acculturation. These shared values shape perceptions, understanding and responses to disabilities. Similarly, Ravindran and Myers, (2012) urged an understanding of disability in cultural contexts. They highlighted autism as a particularly complex label and concluded UK based research did not accurately represent ethnic minorities as it has been based largely on the dominant White perspective.

Recently there has been some interest in researching autism through the lens of ethnic minority participants and exploring the influence of culture on experiences (Perepa, 2019). However, such research is minimal. Previous studies have highlighted the need for further exploration of the global majority experience of ASD to diversify current knowledge. Furthermore, mothers were highlighted by previous research to be more often negatively impacted whilst raising their children, often experiencing blame and alienation from family and their wider community (F.Fox et al., 2017; Ijalba, 2016; Lovelace et al., 2018; Munroe et al., 2016; Selman et al., 2018). This study provides valuable information on an under researched area, with its focus detailed below. Additionally, the study can also provide a theoretical contribution in the areas of autism, culture, and race, helping to shape a new understanding from the direct experiences and views of Black African parents raising autistic children. Importantly the study aims to aid further development of cultural competence by highlighting the cultural values and beliefs held within this community which could be used to enhance and inform anti-racist practice.

1.8 Research Aim

The study aims to explore the lived experiences of Black African mothers raising a junior-aged (6-12 years) autistic child in the UK. It is hoped this would give a voice to a marginalised group and help identify any distinct needs for this community to aid the movement towards culturally competent EP practice.

1.9 Research Question

What are the lived experiences of Black African mothers with an autistic child living in the UK?

1.10 Chapter Summary

This chapter introduced the present study by identifying key terminology and exploring the background and context of the research. The theoretical and conceptual frameworks underpinning the research study and the role of the EP were discussed. The researcher's background was included, and the research rationale was outlined. This highlighted key reasons for further investigation into the research topic. Finally, the research aims, and research questions were shared. The next chapter will examine existing literature exploring the lived experiences of global majority parents of autistic children.

Chapter 2: Literature Review

2.1 Overview

This chapter presents a systematic review of current research on the lived experiences of global majority parents' experiences of raising an autistic child. The chapter begins by outlining the process of finding the relevant research and is followed by a critical analysis of the findings. Key themes will then be considered before a discussion about the gaps in the literature. Finally, the chapter will conclude with a summary of the literature.

2.2 Literature Review Process

A systematic literature review was undertaken to identify studies exploring the experiences of global majority parents with an autistic child/ren. The studies were reviewed to address the review question: What is currently known about the lived experiences of global majority parents raising an autistic child?

The researcher used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) to direct and inform the systematic review. This evidence-based checklist aided in identifying relevant research studies to include

and helped provide a transparent and replicable process for the studies included (Moher et al., 2009).

2.2.1 Identifying Relevant Studies

Several databases were searched to find relevant studies around the lived experiences of global majority parents raising autistic children (Academic Search Ultimate, Child Development & Adolescent Studies, PsychINFO, Scopus). A search was carried out using EBSCO's thesaurus, using terms such as minority groups, life experiences, and ASD. The full list of search terms is presented in Table 2.1.

Table 2.1*Literature Search Terms*

Terms related to Autism	Ethnicity	Terms related to participants	Terms related to experience
ASD	African	Caregivers	Events
Autism	Asian	Carers	Experiences
Autism Spectrum conditions	Asian people	Fathers	Life events
Autism Spectrum Disorder	BAME	Guardians	Life experiences
Autistic	Black African	Mothers	Lived experiences
	Black Asian and Minority Ethnic	Parents	
	Black people		
	Ethnic minorities		
	Ethnic minority backgrounds		
	Ethnic Minority groups		
	Minority ethnic		
	Minority ethnic backgrounds		

From the search, 1135 studies were identified through database searches of different combinations of search terms. Following the removal of duplicate studies, 749 remained. The inclusion and exclusion criteria were then applied. A further 506 studies were removed as they were not peer-reviewed. The remaining 243 studies' titles and abstracts were examined to determine relevance to the focus of the literature review. This led to another 192 studies being excluded as they did not primarily focus on parental experiences of raising an autistic child. Fifty-one studies were then read in full. Thirty-nine of these articles did not meet the inclusion criteria and were therefore excluded.

Reasons for exclusion included focusing on the perceived appropriate social behaviour of autistic children rather than on parental experiences of raising their children, evaluating services rather than focusing on parents' perspectives and having parents of children with other disabilities but grouping findings together making it difficult to know what results related to those raising autistic children.

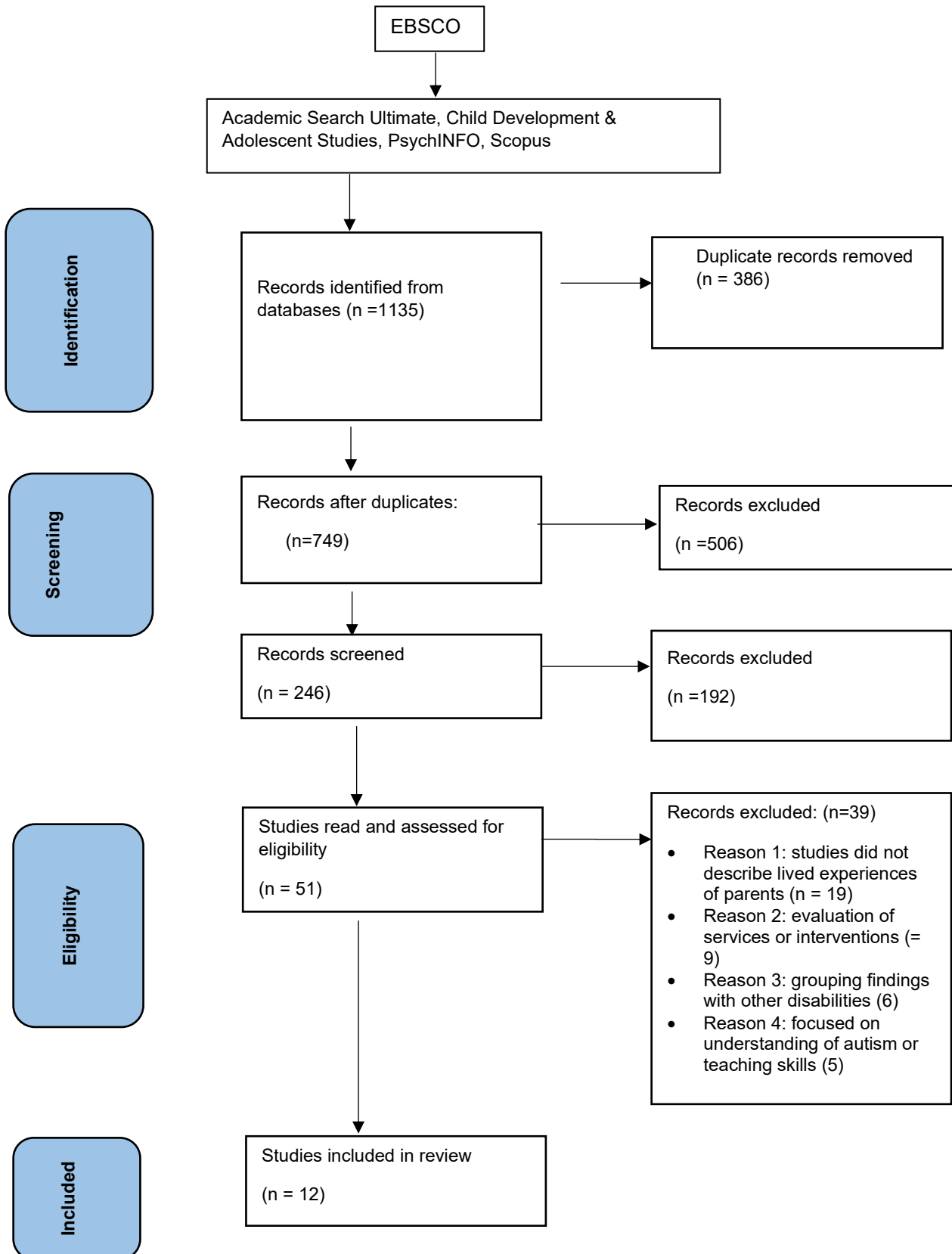
This left a total of 12 studies which met the inclusion criteria. These studies were then assessed for their quality.

Table 2.2*Inclusion and Exclusion Criteria*

Criteria	Inclusion	Exclusion	Rationale
Participants	Parents/carers are Black African or from the global majority	Parents/ carers not Black African or from the global majority	The focus is on Black African mothers
Purpose of study	The study explores lived experiences of raising their autistic children.	The study does not explore lived experiences of raising their autistic children.	The study explores experiences around raising an autistic child.
Publication date	Published papers after 2012	Papers before 2012	Aligns with current theoretical beliefs about autism and released after key legislation, e.g., SEND Code of Practice (Department for Education and Department of Health, 2015) and the Equality Act (2010)
Language	Written in English	Papers not written in English	For accessibility
Source type	Peer-reviewed academic journals	Research that is not peer-reviewed	Peer-reviewed research has higher methodological quality

Figure 2:1

Prisma Flow Chart



Name and Titles of Papers:

1. F. Fox et al., (2017) 'It was like walking without knowing where I was going': A Qualitative Study of Autism in a UK Somali Migrant Community
2. Gordillo et al., (2020) Mothers' Adjustment to Autism: Exploring the Roles of Autism knowledge and culture
3. Habib et al., (2017). Pakistani mothers' experiences of parenting a child with autism spectrum disorder (ASD) in Ireland
4. Hussein et al., (2019). Understanding and awareness of autism among Somali parents living in the United Kingdom.
5. Ijalba (2016). I Immigrant Mothers of Young Children With Autism Spectrum Disorders: How Do They Understand and Cope With Autism?
6. Khanlou et al., (2017). Access Barriers to Services by Immigrant Mothers of Children with Autism in Canada.
7. Lewis, et al., (2022). The creator did not give me more than I can handle: Exploring coping in parents of Black autistic children.
8. Lovelace et al., (2018). Experiences of African American Mothers of Sons with Autism Spectrum Disorder: Lessons for Improving Service Delivery.
9. Munroe et al., (2016). The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed with an autism spectrum disorder: An interpretive phenomenological analysis.
10. Selman et al., (2018). 'You are labelled by your children's disability' – A community-based, participatory study of stigma among Somali parents of children with autism living in the United Kingdom.
11. Slade (2014). Diverse perspectives The challenges for families affected by autism from Black, Asian and Minority Ethnic communities.
12. Theara & Abbott (2015). Understanding the experiences of South Asian parents who have a child with autism.

2.2.2 Appraisal of research studies

The Critical Appraisal Skills Programme Checklist (Critical Appraisal Skills Programme, 2022) was used to assess the relevance and quality of the 12 research studies. Based on the checklist. The following categorisation was used:

- **0-3:** low quality
- **4-6:** medium quality
- **7-10:** high quality

From the studies included, 6 were considered high quality, 5 were deemed medium quality and 1 as low quality (See Appendix A). After assessing the selected studies, the author utilised the four-stage process by Trafford & Leshem (2008) to aid engagement with the literature. Firstly, the researcher began by summarising the research papers before synthesising the study' findings. The researcher then

analysed the research papers. Once these stages were completed, the researcher could place the studies within the current literature and authorise her position towards the present study.

2.3 Characteristics of the Research Studies

Six studies were conducted in the UK (F.Fox et al., 2017; Hussein et al., 2019; Munroe et al., 2016; Selman et al., 2018; Slade, 2014; Theara & Abbott, 2015); four in the United States of America (USA) (Gordillo et al., 2020; Ijalba, 2016; Lewis et al., 2022; Lovelace et al., 2018), and the others in Canada (Khanlou et al., 2017) and Ireland (Habib et al., 2017). Although the current research study took place in the UK, it was felt that including studies from outside was appropriate as these countries are considered as Western societies. Therefore, it was felt that the prominent values, beliefs, and culture would be relatively comparable to those from the UK. Nonetheless, it should be noted that different countries have different structures, processes, and resources in relation to autism diagnosis and support available. All the studies included aimed to give the views of parents. The main focus of studies included:

- How autism is understood and conceptualised (F. Fox et al., 2017; Hussein et al., 2019;)
- The lived experiences of having an autistic child (Gordillo et al., 2020; Habib et al., 2017; Ijalba, 2016; Munroe et al., 2016; Slade, 2014; Theara & Abbott, 2015)
- Accessing support and services (F. Fox et al., 2017; Khanlou 2016)
- Coping strategies used by parents raising an autistic child (Lewis et al., 2022; Selman et al., 2018)
- The impact of race on raising an autistic child (Lewis et al., 2022; Lovelace et al., 2018)

Themes from the existing research were identified to answer the review question: What is currently known about the lived experiences of global majority parents on raising an autistic child?

The theoretical and conceptual frameworks of the studies may have influenced the methodology used and, thus, the findings. Habib et al., (2017), Munroe et al., (2016) and Theara and Abbott (2015) all held a social constructionist position leading them

to consider how autism may be a social construction. F. Fox et al., (2017) and Selman et al., (2018) conducted community-based participatory research (CBPR), allowing direct work with Somali families. Having resources to permit collaborative working provided valuable insights to the community. It would have been helpful if themes were crosschecked by the participants in these studies to increase their trustworthiness and validity and remain consistent with PR principles.

Several studies explored the experiences of homogenous ethnic or racial minority groups, including Somali (F.Fox et al., 2017; Hussein et al., 2019; Selman et al., 2018), Pakistani (Habib et al., 2017), Black African American (Lovelace et al., 2018) South Asian: Pakistani, Indian and Sri Lankan (Theara & Abbott, 2015), Hispanic immigrant: Mexican, Dominican, Ecuadorian, and Peruvian (Ijalba, 2016) and African: Sierra Leonean, Ethiopian, Nigerian and Ugandan (Munroe et al., 2016). The remaining four studies included parents from various backgrounds, such as Black/African American, Latina/Hispanic, White/Caucasian (Gordillo et al., 2020), Asian, Europe Latin America and the Caribbean (Khanlou, 2017), Black African, White and Latina (Lewis et al., 2022) and Asian, Black, White, Middle Eastern (Slade, 2014).

Most studies concentrated on mothers' or primary female caregivers' experiences (Gordillo et al., 2020; Habib et al., 2017; Ijalba, 2016; Khanlou et al., 2017; Lewis et al., 2022; Lovelace et al., 2018; Munroe et al., 2016). Moreover, it should also be highlighted that of those that did include fathers or male caregivers; they were notably fewer in number, ranging from 2 fathers (Hussein et al., 2019) to 24 (Slade, 2014) compared to a range of 3 (Lovelace et al., 2018) and 106 (Slade, 2014) for female participants. The sex difference also appeared in the participants' children. Of those who stated the sex of the children, most studies had more boys than girls (F.Fox et al., 2017; Hussein et al., 2019; Ijalba, 2016; Khanlou et al., 2017; Selman et al., 2018). Furthermore, Lovelace et al., (2018) and Munroe et al., (2016) studies involved participants who only had sons. It is possible therefore, that sex may be an important factor influencing the reported findings.

Some researchers disclosed that they shared the same ethnicity as the participants (F.Fox et al., 2017; Habib et al., 2017; Hussein et al., 2019; Lewis et al., 2022; Lovelace et al., 2018; Selman et al., 2018; Theara & Abbott., 2015) and some were also parents of autistic children (Habib et al., 2017; Lewis et al., 2022; Selman et al., 2018). This may have strengthened rapport building and provided an insider perspective, which arguably increased the trustworthiness of the data as participants may have felt more comfortable sharing their experiences. Nonetheless, this may have also increased the possibility of biased interpretations, although some studies mentioned ways in which they attempted to limit this bias, such as using the essentialist framework (Hussein et al., 2019), where findings are reported without attempts being made to fit them to pre-existing codes or researchers' assumptions. Other studies also had a team review to check codes (F.Fox et al., 2017; Lovelace et al., 2018; Lewis et al., 2022; Selman et al., 2018). Interestingly, the lead author in Munroe et al., (2016) was White British and was conscious of the possibility of power imbalances. To mitigate this, the researcher reported being reflexive through supervision, keeping a reflective diary and speaking with colleagues about positioning and motivation.

All of the previous research has utilised appropriate qualitative methods, including in-depth interviews (F.Fox et al., 2017; Gordillo et al., 2020; Habib et al., 2017; Hussein et al., 2019; Ijalba, 2016; Khanlou et al., 2017; Lewis et al., 2022; Lovelace et al., 2018; Munroe et al., 2016; Selman et al., 2018; Theara & Abbott, 2015) and focus groups (Slade, 2014) to give ethnic minority parents a space to explore the influence of culture on their experiences of raising an autistic child. However, Slade (2014) analysed ethnic minority parent's data as a whole, making it difficult to ascertain specific racial or cultural characteristics or factors impacting parental experiences. Furthermore, as is common with qualitative studies, the number of participants was low, ranging from 3 (Lovelace et al., 2018) to 130 (Slade, 2014). The limited numbers, therefore, make it difficult to make generalisations. Nonetheless, the studies produced some detailed and rich findings through thematic analysis (F.Fox et al., 2017; Gordillo et al., 2020; Habib et al., 2017; Hussein et al., 2019; Khanlou et al., 2017; Selman et al., 2018), grounded theory (Lewis et al., 2022; Lovelace et al., 2018; Theara & Abbott., 2015) and IPA (Munroe et al., 2016).

2.4 Themes

From these studies, three main themes appeared to be linked directly to ethnic minority lived experiences and cultural influences. These were the construction of autism, challenges related to being an immigrants/ethnic minority parent, factors enabling positive experiences and faith/religion. Each theme will be outlined below and critically analysed regarding the research focus, research design and data analysis.

2.4.1 Construction of Autism

How ethnic minorities understand autism appears closely linked to culture and ethnic identity. Several studies have found that a lack of awareness of autism exists within ethnic minority groups, which can impact how it is viewed and understood.

2.4.1.1: Lack of Autism Awareness

The National Autistic Society report found that a lack of awareness of autism in the BAME community hindered access to early diagnostic services (Slade, 2014). However, these findings need to be interpreted with caution as the CASP identified this study to have low methodological quality due to a lack of details around how data was analysed. Likewise, Gordillo et al., (2020) found that Latina mothers who had immigrated to the USA had not known or heard about autism before their arrival. Similarly, Munroe et al., (2016) found that most parents were unaware of autism before their children were diagnosed. Similarly, findings were also uncovered in the Somali community, with some parents having never heard of it before arriving in the UK (Hussein et al., 2019). This suggested that awareness of autism was limited in African immigrant communities. Moreover, this was echoed by Ijalba, (2016) who interviewed Hispanic immigrant mothers of autistic preschool children and who shared that they did not have any knowledge of autism until after their child's diagnosis. Ijalba's (2016) study's use of phenomenological interviews gave parents the opportunity to be interviewed 3 times potentially increasing rapport and providing an opportunity for parents to express their experiences in-depth.

2.4.1.2: Wider Family Influence on Acceptance of Diagnosis and Accessing Support

Gordillo et al., (2020) found that most Latino mothers stated that when they informed others of their children's autism diagnosis, their immediate and extended family and

the wider community tended to reject the diagnosis, often denying or downplaying differences in the child's development. This impacted Latina mothers' construction and beliefs about autism, often leading to delays in accessing professional services. Gordillo et al., (2020) study enabled participants to choose to be interviewed in either Spanish or English allowing for greater inclusion of mothers who may not speak fluent English who may have otherwise been missed. Additionally, the use of interviewers from the same ethnic and cultural background, as well as the transcription and analysis being conducted in Spanish may have also enriched and increased the accuracy of the findings by allowing mothers to share nuance cultural experiences in their mother tongue without it being lost in translation (Choi et al., 2012).

Likewise, a small-scale study of 3 Black African American mothers (Lovelace et al., 2018) and 15 Somali parents (Selman et al., 2018) also shared experiences of family members' difficulties in understanding autism and denying its existence. When developmental differences were acknowledged, family members frequently advised the parents that the behaviours would be something the children would outgrow. Additionally, parents expressed at times getting blamed for their children's behavioural traits or being labelled as bad parents because of the lack of understanding of autistic traits (Lovelace et al., 2018; Selman et al., 2018). Similarly, Habib et al., (2017) also held semi-structured interviews with 9 Pakistani mothers and found they had experiences of extended family dismissing autism altogether and viewing it as behaviour the children would outgrow.

All three of these studies (Habib et al., 2017; Lovelace et al., 2018; Selman et al., 2018) had researchers who shared the same ethnic and racial background as participants which arguably added an insider perspective and increased the richness and depth of the findings. Moreover, Selman et al., (2018) also used aspects of PR to involve participants directly in the research. However, these three studies did not discuss how potential bias or influences that may arise from sharing same backgrounds with participants were mitigated. Nonetheless the CASP revealed that

the studies had relatively good methodological quality with Habib et al., (2017) in particular being rated as high quality.

Moreover, Parents in Habib et al. (2017) study reported that extended family discouraged seeking professional input when their children displayed atypical development. Furthermore, parents explained that some traits of autism were viewed as typical behaviour for children in Pakistan, and therefore family members often saw no need for professional advice. Likewise, Latina mothers also held broad views of developmental milestones, particularly language development, sharing that children in their cultures often spoke later or had a family history of late talkers, such as the fathers of their children reportedly speaking later in childhood. This often led to extended family members advising that parents wait before seeking professional input, causing delays in children receiving an autism diagnosis and accessing early intervention (Habib et al., 2017; Gordillo et al., 2020; Selman et al., 2018).

Moreover, Theara and Abbott (2015) held in-depth interviews with 9 south Asian parents of autistic children and found some parents disregarded the term autism entirely due to the wide spectrum and presentation of autism. The authors concluded that understanding of autism might be low in the south Asian community, impacting their access to services.

2.4.1.3: Belief in a Cure

Another key finding from current research is the suggestion that ethnic minority parents held a belief that autism can be cured. When differences in a child's development had been detected, some parents reported that their families and wider community had believed something caused such differences and therefore sought to find a cure (Slade, 2014).

2.4.1.4: Medical Model of Autism

Theara and Abbott (2015) found that parents favoured the medical model perspective in their construction of autism. This view was linked to cultural values, as parents reported that the medical profession was highly respected in their community. Therefore, when medical practitioners gave diagnoses, they held their word in high regard. Additionally, parents reported seeking treatments for their children due to links between the diagnosis and the medical profession.

Furthermore, families reported witnessing poverty and hardships in their home countries with no equivalent to social services for support. This created a strong drive to succeed economically, which they explained was linked to social hierarchies. Parents reported viewing disabilities as a risk to achieving such success and were therefore highly motivated to help their children overcome perceived obstacles through treatments. Additionally, the lack of public services in their home countries often led such families to disregard and disengage with services viewed as providing the social model of autism (Theara & Abbott, 2015). Similarly, research into Hispanic (Ijalba, 2016) and Latina mothers' experiences (Gordillo et al., 2020) found that a large majority tended to view the progress made by their children when accessing interventions or support services as evidence that they were outgrowing or no longer having autism fuelling their belief that autism may have a cure.

2.4.1.5: Negative View of Autism

Another salient point from the literature suggested that ethnic minority groups tend to hold a negative view of autism. Both Munroe et al., (2016), who interviewed 6 immigrant mothers from different African countries and Theara and Abbott (2015) study with south Asian mothers and fathers found that parents were likely to view autism negatively due to cultural views of disabilities and the construction of autism through the medical model. Parents reported that disabilities were viewed negatively due to their association with stigma, prejudice, and fear. Many parents shared that the negative link made them attempt to conceal or hide their children's needs (Selman et al., 2018; Theara & Abbott, 2015). Likewise, Munroe et al., (2016) found that parents reported negative attitudes and stigmatisation of disabilities in their communities, leading to feelings of shame, embarrassment, and blame. Munroe et al.'s, (2016) study holds high methodological qualities, outlining in detail the methods used with clear rationale making the findings more robust.

Moreover, Gordillo et al., (2020) noted that Latina mothers felt stigmatised by their community because of their children's autism diagnosis. This also created feelings of internalised stigma in parents who struggled to accept the children's diagnosis and often made attempts to reason why it may not be valid such as a mistrust in the diagnostic process. This also aligned with Lovelace et al. (2018) who explored experiences of 3 Black mothers and found that negative views of autism were held in the African American culture. Often parents felt blamed as family members viewed

their autistic children's behaviours were due to a lack of discipline and boundaries being provided by the parents. This further created internalised shame in the mothers for needing and accessing support services. These findings were also supported by Selman et al., (2018), who found Somali parents were often made to feel different or othered due to them being parents to an autistic child and at times blamed for causing the autism.

2.4.1.6: Lack of Vocabulary Around Autism

A further prominent point from the research related to a negative view of autism was the lack of vocabulary and the perceived non-existence of autism within the ethnic minority community. Many parents tended to view autism as part of the Western world and not something that occurred within their cultures and communities. F. Fox et al., (2017) held in-depth interviews with 15 Somali immigrant parents of autistic children. Findings suggested parents had little awareness of autism, mainly due to there being no word for autism in Somali and disabilities primarily being associated with physical or visible difficulties. The wide and varying spectrum of autism made it difficult for parents to accept and understand it (F. Fox et al., 2017; Selman et al., 2018). Somali parents explained that anything that varied from typical development and behaviour was viewed and labelled as mental illness, which held highly negative connotations within their community. Furthermore, the language used to describe such differences in development were highly derogatory and offensive, adding to the stigmatisation (Selman., et al. 2018). Hussein et al., (2019) supported these findings as their participants also reported a lack of awareness of autism in the Somali community due to there being no word for it in Somali. Again, parents stated this was linked to the perceived lack of physical symptoms within autism. Consequently, the lack of understanding led to autism being regarded as a mental illness within Somali society. F. Fox et al., (2017), Gordillo et al., (2020) and Selman et al., (2018) studies were found by the CASP to have employed robust methodological approach to conduct their research included clear and approach qualitative methods making their research findings easily replicable

2.4.1.7: Belief Autism does not Exist

A further significant finding from the research linked to the perceived non-existence of autism within ethnic minority groups was that many parents had not heard of autism before their children's diagnosis. This tended to create confusion and

impacted on their construction of what it meant for their children. F. Fox et al., (2017) found that some parents believed that autism was caused due to the MMR vaccines and a lack of Vitamin D and sunshine exposure. They argued that as the MMR vaccine was not routinely given in Somalia and children have access to plenty of sunshine they believed autism did not occur there (Hussain et al., 2019). Comparably, Gordillo et al., (2020) found that some ethnic minority parents believed that autism only affected children in Western societies or children in the USA and did not exist in their cultural groups.

2.4.2 Challenges Related to Being an Immigrant/Ethnic Minority Parent

Parents from ethnic minorities reported having largely negative experiences of raising a child with ASD in Western countries, including the UK, USA, and Canada.

2.4.2.1 Emotional Impact and Social Isolation

Munroe et al. (2016) found that some Black African immigrant parents expressed feelings of physical and emotional exhaustion from having an autistic child. Moreover, receiving the diagnosis of ASD was described to be an extremely sad, shocking and confusing time for parents (F.Fox et al., 2017; Munroe et al., 2016; Theara & Abbott, 2015). This often caused parents to feel alienated and socially isolated (Ijalba, 2016; Khanlou, 2017; Slade, 2014; Selman et al., 2018). Many reported their children's behaviour as challenging to manage particularly in social settings. Some reported feelings of embarrassment, blame, judgement and rejection aimed mainly at mothers (F.Fox et al., 2017; Ijalba, 2016; Lovelace et al., 2018; Munroe et al., 2016; Selman et al., 2018). Some Somali mothers reported difficulties within or a complete breakdown of their relationships with their children's fathers due to difficulties accepting their child's autism (Selman et al., 2018).

Moreover, social isolation also caused mothers from various backgrounds who had immigrated to Canada to experience low self-esteem (Khanlou, 2017) or emotional withdrawal from others (Selman et al., 2018). Such social isolation was also a barrier to engagement with services and professionals (F.Fox et al., 2017; Theara & Abbott, 2015). Language barriers in particular impacted engagement and access to services, as parents often did not understand professional jargon (F.Fox et al., 2017; Slade, 2014). Additionally, the language barrier also impacted parents' ability to communicate their concerns about their child's development. Habib et al., (2017)

found that Pakistani mothers had difficulties sharing their concerns with professionals before they were fluent in English.

2.4.2.2 Stigma, Prejudice and Discrimination

Parents shared that they felt they had experienced prejudice and discrimination because of the negative perception of autism and the stigma linked to disabilities within their communities. This had led some parents to hide their children's diagnosis or withdraw from family and the wider community (Hussain et al., 2019; Selman et al., 2018; Theara & Abbott, 2015). Furthermore, Black African American mothers shared having to use self-control as part of a problem-solving strategy in coping with the challenges of raising an autistic child when engaging with professionals. Black mothers reported fears of being viewed and stereotyped as having "Black mama syndrome" (Lewis et al., 2022, p.5), referring to being perceived as angry. Likewise, parents reported "code-switching", where they attempt to mask their race or ethnicity when talking on the phone to professionals in an attempt to secure support services because of fears they would be disadvantaged because of their race (Lovelace et al., 2018). Additionally, Black African American mothers in their study also felt they had experienced covert and overt racism when engaging with professionals in the health and education sectors. Examples given included beliefs that their children were not receiving adequate provision or experiencing delays in receiving support in school due to their race. Mothers also reported feeling their voices were not heard or considered when speaking to professionals about issues with their children and when seeking a diagnosis. Many expressed that the diagnostic process and subsequent attempts to receive support were characterised by continuous struggles, fighting and delays. Parents believed their race had added to such challenges (Lovelace et al., 2018). Similarly, Somali parents also noted overt discrimination experiences, such as name-calling by parents of non-autistic children when out in the community (Hussein et al., 2019; Selman et al., 2018).

2.4.2.3: Mistrust of Professionals

Fear and mistrust of professionals and a limited understanding of available services also hindered engagement among south Asian parents (Theara & Abbott, 2015). Parents shared that they often were not readily provided information about available resources (Khanlou, 2017; Lovelace et al., 2018). This was echoed by Gordillo et al. (2020), whose findings suggested that Latina mothers also distrusted the diagnostic

process, which led to them questioning the validity of their child's diagnosis. Comparatively, Some African American mothers also reported weighing up the well-being of their children and accessing services because of a worry that their children may receive negative treatment (Lovelace et al., 2018). Furthermore, parents also expressed frustration at long waiting lists for diagnosis and access to services (Habib et al., 2017; Khanlou, 2017).

2.4.2.4 Impact of Immigration

Some parents spoke about the additional stress they felt in raising autistic children and having immigrated. Many had experienced family separation, which caused the loss of support networks, which had an emotional toll on parents (Habib et al., 2017; Khanlou, 2017). Some parents were also at risk of deportation due to having unauthorised immigration status, which created additional fears and uncertainty (Ijalba, 2016). For some parents, socioeconomic difficulties created further challenges when raising their autistic children. Khanlou (2017) found that many of their participants had financial difficulties, which directly impacted their ability to access some services. Findings from Khanlou (2017) should be taken with some caution however as the questions used within the interviews were specifically designed to concentrate on social support which may have limited what participants could discuss. Furthermore, the analysis also grouped results from participants together making it difficult to ascertain which findings relate to specific ethnic or racial groups. Moreover, immigrant mothers expressed that losing their primary earner due to deportation brought economic hardship, increasing their feelings of stigmatisation and social isolation. Parents reported they often could only afford to live in shared accommodation with people from their culture however the low awareness amongst the community often led to stressful incidents where their children's behaviours were attributed to poor parenting (Ijalba, 2016). Similarly, Black African American mothers also reported feeling additional pressures caused by being single parents, such as financial strain and difficulties committing to attending interventions and support services. Furthermore, parents that single parenthood also impacted their well-being as they often experienced feelings of loneliness (Lovelace et al., 2018).

2.4.3 Factors Enabling Positive Experiences

Although not explicitly explored, some positive experiences were revealed. Some parents spoke of having come to accept their child's ASD diagnosis and were hopeful for their futures (Munroe et al., 2016). Moreover, mothers also described feelings of satisfaction and contentment in raising autistic children (Habib et al., 2017; Lewis et al., 2022). Several parents also had great pride and appreciation of their children's strengths (F.Fox et al., 2017) and found joy in their children's abilities (Habib et al., 2017). Other parents focused on working hard to create and have a positive view of their children's future (Theara & Abbott, 2015). Many mothers also shared positive elements of raising their children, including the impact on them as people, such as making them more tolerant, sensitive, and sympathetic to others. Mothers described an increased resilience and ability to advocate for their children (Lovelace et al., 2018).

Furthermore, some mothers had positive experiences of schools meeting their children's educational needs, mainly linked to the support provided by teachers. Indeed, Habib et al., (2017) found that Pakistani mothers living in Ireland expressed that being able to communicate with teachers about their children's needs encouraged positive collaboration and allowed full participation in developing Individual Education Plans. The positive interactions also extended to health professionals, and the mothers felt empowered to proactively seek support and services for their children. This differs from the findings of Theara & Abbott, (2015), which the participants' backgrounds may explain; Habib et al., (2017) study involved professional working mothers who had achieved a high level of education and who confidently communicated with professionals and could access services easily. However, parents in Theara & Abbott (2015) reported more negative experiences, which may have been due to language barriers.

Lewis et al. (2022) explored mainly African American mothers' coping techniques when faced with live stressors. Parents also shared that they used positive self-talk and self-care as part of their coping strategies. They also found that parents engaged in planful problem-solving techniques to actively overcome problems they

faced due to their children's autism. For example, parents described seeking medical advice, adapting environments, or conducting their own research into autism. However, the CASP found Lewis et al., (2022) to be a medium quality study; the focus on coping strategies could have limited parental ability to speak about their experiences more broadly. Similarly, Somali parents also stated that engaging in their own research also helped them accept their children's needs and refute stigmatisation by providing them with a method to educate other parents (Selman et al., 2018). In addition, Somali parents reported that the increased awareness of autism in some of the community made it easier for their children to be accepted and understood. Furthermore, despite there still being stigma associated with autism, many parents reported that receiving a diagnosis of autism for their children gave them an understanding and explanation of their children's behaviours which lowered their internalisation of stigma (Selman et al., 2018).

Social support was also highlighted as a key strategy that was helpful to Black parents when coping with challenges. They identified informal support from partners, family and friends as providing emotional, informational, and tangible support, i.e., financial or babysitting. Parents notably identified other parents of autistic children as helpful and supportive; many had found such support online or through parent support groups (Lewis et al., 2022; Selman et al., 2018). However, Black parents reported that they sometimes felt disheartened by official support groups as they often felt underrepresented or found the space to be non-inclusive. African American parents shared that often they were the only Black parents in such groups and felt this at times meant they experienced a disconnect with the other parents due to a lack of shared experiences that took into account the intersectionality of race, gender, and disability. Parents expressed a desire to have specific groups for African American parents (Lewis et al., 2022; Lovelace et al., 2018). Similarly, single parents also felt excluded from support groups, as most parents were married or had partners. Therefore, such parents thought that some of their experiences and challenges of single parenthood were often omitted. Single parents also shared a wish for a targeted support group to meet their needs (Lovelace et al., 2018).

2.4.4 Faith and Religion

Religion appeared to be a key element and protective factor for parents raising autistic children. Often parents found their faith to be a consistent source of support

when experiencing negative lived experiences. Religion provided many parents with hope and helped them come to an acceptance of their child's ASD (F.Fox et al., 2017, Habib et al., 2017; Hussein et al., 2019; Munroe et al., 2016; Lewis et al., 2022; Selman et al.2018). Many parents reported believing it was "God's will" (Habib et al., 2017, p.74) and something that was predetermined and therefore out of their control. This appeared to give parents a coping strategy to mitigate internalised blame and shame (Munroe et al., 2016; Selman et al., 2018).

The hope provided by religion was, however, found to impact full acceptance of the lifelong nature of ASD. Parents reported praying for their children to "improve, or get better in the future" (F.Fox et al., 2017 p.310) and others believed their children would be cured through their religious faith (Ijalba, 2016). Furthermore, some studies reported that parents found faith groups and places of worship to be judgmental and held negative views of disabilities and autism (Slade, 2014). Likewise, some parents believed that autism was a curse or that their child had been possessed by evil spirits (Munroe et al., 2016). Similarly, other parents also shared the view that autism was caused by "jinn", believed to be a supernatural spirit that can cause physical and mental illness (Hussein et al., 2019, p.14). Moreover, many parents sought help and support through prayer and religious scholars to support their autistic children. Nevertheless, many parents also acknowledged the importance of accessing support from healthcare professionals alongside prayers (Hussein et al., 2019; Lovelace et al., 2018).

2.5 Summary of Literature Review

Four main themes were identified from the systematic literature review. These were the construction of autism, challenges related to being an immigrant/ethnic minority parent, factors enabling positive experiences and religion and faith in relation to the experiences of global majority parents raising autistic children. The research indicated an important link existed between a parent's culture and their understanding of autism and their experiences of raising an autistic child. The literature review only generated 12 studies that were deemed to meet the inclusion criteria suggesting that this is an area of research that is still emerging and therefore justifies the need for further exploration. Moreover, although the small sample sizes produced rich and detailed findings, this does not allow for them to be generalised to wider communities. Furthermore, the studies identified were qualitative in nature,

which appears to be the most appropriate method when exploring lived experiences. However, some methodological challenges were found in the existing literature. Firstly, all the studies used interviews to gain the global majority parents' views, which again was an appropriate tool. However, some studies focused on specific topics raising the possibility that other experiences may consequently be missed out. Secondly, parents seemed to have a limited degree of participation in the research process, mainly as the interviewee. Only one study contained elements of PR approaches. The remaining studies did not include members of the population being researched in any other stage of the research process other than as the interviewee during the interview itself. This could be interpreted as the research being done 'to' rather than 'with' participants. Consequently, may increase power imbalances and influence the knowledge that is generated (Aldridge, 2017). Furthermore, the existing research seems to demonstrate the importance of culturally sensitive research designs to successfully explore global majority parents' experiences. Some researchers identified as belonging to the same ethnic or racial group as the participants. Having an insider perspective within the research team seemed to have enhanced rapport and helped produce rich and detailed findings. Nevertheless, there appears to be a gap within the existing literature where PR principles are adopted alongside a culturally sensitive approach that positions global majority parents as experts and provides the opportunity to speak about their lived experiences. This could help inform future practice and advise professionals on how to better support parents from such backgrounds.

The literature review also suggested that mothers tended to be the primary caregivers of their autistic children and also shared mainly negative lived experiences. Moreover, Black parents were found to experience direct or overt discrimination, with most studies having been conducted in the USA. Research that predominantly focused on Black parents included three that focused on Somali parents, two on African Americans and one from various African backgrounds. Arguably, the direct nature of the discrimination particularly racism is likely to have a detrimental impact on parents. Moreover, the intersectionality of race, gender and disability is also under-researched, particularly as Black women often experience intersectional invisibility (Coles & Pasek, 2020). A way of further addressing this would be to investigate this intersectionality and specifically recruit participants that

fit the three characteristics of being Black, female and proximity to disability (raising an autistic child). This may allow Black African mothers to voice their views and inform a framework of how they could be actively included in future research.

Taking this into consideration, it appears that there is scope for an in-depth exploration of the views of Black African mothers in the UK, where Participatory Research principles are incorporated within the research design.

2.6 Chapter Summary

This chapter included a systematic review of the current research available that explored global majority parents raising autistic children and their lived experiences. Details of the literature review process and critical analysis of research findings were also provided. The emerging key themes were discussed and also critically analysed. Finally, a summary of the literature review was given. The limitations identified from the studies informed the next chapter on methodology.

Chapter 3: Methodology

3.1: Introduction

This chapter will focus on the methodological design of the current study. An outline of the ontological and epistemological position of the researcher and the influence this has on the study's choice of method and design will be discussed. The rationale for using a qualitative participatory research design will be provided, and the co-researcher role will be explained. The procedure and interview process with participants will be included along with the IPA process. Finally, ethical considerations will be highlighted, and the chapter will conclude with a review of the quality of the research.

3.2 Research Position

To understand the chosen methodological design of the current study, the ontological and epistemological positions underpinning the research need to be explained.

Ontology refers to the way in which the nature of reality is understood, whilst epistemology is concerned with the nature of knowledge and how the knowledge is created (Denzin & Lincoln, 2011). Five different research paradigms exist that vary in their ontological and epistemological assumptions. These paradigms can be adopted when carrying out social science research. Therefore, the chosen paradigm governs how the research is carried out and the methods that should be applied (Denzin & Lincoln, 2011).

This research took a relativist ontological position, assuming we cannot determine the 'true' nature of reality (Braun & Clarke, 2013). Moreover, the researcher adopted a social constructionist epistemological position arguing that multiple realities exist based on the social and cultural context, influencing how an individual constructs reality. This social constructionist position suggests that knowledge is gained through listening to people's experiences to understand how they construct their reality (Willig, 2013). When adopting this social constructionist paradigm, researchers are actively aware of assumptions related to their perception and view of the world. They take a "critical stance towards taken for granted knowledge" (Burr, 2015, p. 2). This is important for the current study as currently most knowledge of autism has stem

from a white western perspective and there is an opportunity for new knowledge and learning to be gained from working with Black African mothers of autistic children.

The social constructionist position is important for this study when considering autism, the notion of multiple truths is important. Within the UK and arguably the Western world, the diagnostic criteria refer to a dyad of impairments that includes difficulties with social communication, social interactions, and repetitive behaviours (DSM 5, 2013), suggesting a positivist viewpoint in which a universal truth exists. However, as indicated by the literature review in chapter 2, when considering culture, context and time, the characteristics linked with autism may be viewed differently or even as non-existent. Likewise, race can also be understood as a social construct where people's racial category and associated status may change depending on the social and political context in which they live (Rubin & Rubin, 2005). This is important for this research study as the participants could be considered as being racialised as Black and it may be interesting to see how race may influence their experiences of raising an autistic Black African child.

Moreover, social constructionism is as it highlights the importance of listening to people to understand how they construct reality in the social and cultural context in which they are in. In line with this paradigm, using interviews as a method enabled the researcher to gain knowledge of the subjective realities constructed by participants. To align with the chosen ontological and epistemological position, this research conducted an exploratory study into the lived experiences of Black African mothers raising autistic children using qualitative interviews. The social constructionist paradigm acknowledges that the researcher's and co-researcher's own culture, beliefs, and the background will impact the choices and interpretations made (Willig, 2013). The research study is consequently interpretative, acknowledging that other people may construct differing interpretations of the findings founded on their own worldview. Subsequently, the researcher acknowledged the importance of being reflexive by identifying and challenging biases related to personal experiences, cultural background, values, and beliefs and

how this may have impacted the study. Reflexivity is discussed in more detail further in this chapter.

3.3 Aim and Purpose of the Research

3.3.1 Aims

This study aimed to:

- Empower a Black African mother of an autistic child as a co-researcher
- Position Black African mothers of autistic children as the experts in their lives and provide a space for them to share their lived experiences

It was hoped that by having such aims, the study's findings may promote social justice by shifting power dynamics and fostering the engagement of a marginalised group. Furthermore, by taking a participatory approach, the study aimed for the co-researcher to gain new research skills, the opportunity to voice things that were important to them and the prospect to produce change that could lead to enhanced support and improved experiences for this community (Willig, 2013).

3.3.2 Purpose of the Study

The primary purpose of this study was to take an exploratory look into the lived experiences of Black African mothers raising autistic children in the UK. The literature review revealed this is a very under-researched area; thus, it was hoped further insights could be gained and help advise EP practice and future research.

To align with participatory principles, another key purpose for this study was to be emancipatory in nature. Oliver (1992) describes emancipatory research as “the facilitating of a politics of the possible by confronting social oppression at whatever level it occurs” (Oliver, 1992, p. 110). A fundamental principle of emancipatory research is acknowledging the participants as the “true knowers” rather than the researcher (Stone & Priestley, 1996, p.687). Moreover, Stone & Priestley (1996) stated that research should aim to empower the group being researched directly. Consequently, during this study, participants were positioned as the experts in their lives and encouraged to feel empowered by emphasising collaborative work and adopting principles of PR.

A co-researcher was recruited and trained to conduct research to help equalise power dynamics that can occur in traditional research methods. Another fundamental principle of emancipatory research is to carry out research that may bring practical benefits to the group being studied (Stone & Priestley, 1996). By exploring the lived experiences of Black African mothers of autistic children, it is hoped the findings may help provide practical benefits leading to enhanced support and improved experiences for this community (Willig, 2013).

Finally, the current study aimed to have a transformative purpose. Transformative researchers aim to address power issues by intentionally positioning themselves and working with those with less power within society. The transformative paradigm is focused on increasing social justice for people from culturally diverse and marginalised communities (Mertens, 2009). This research study therefore aimed to foster the engagement of a marginalised group (Black African women of autistic children) and promote social justice (Creswell, 2013).

3.4 Cultural Insider Perspective

A cultural insider is someone with a similar background to the intended research population (Knopf et al., 2007). This is hypothesised to enhance the “likelihood that potential participants will feel comfortable participating in the study” (Renert et al., 2013, p.4) and assist in rapport building. Moreover, it has been suggested that having an insider perspective can help validate, interpret and understand cultural information (Tillman, 2002).

This study utilised the researcher’s and co-researcher’s cultural insider status to foster parent engagement in the interview process and better understand mothers’ experiences. The researcher and co-researcher shared ethnicity, sex, and cultural backgrounds, as well as being primary female caregivers of a Black autistic child. It was hypothesised that the shared knowledge and culturally sensitive perspective might help facilitate a culturally sensitive research approach.

3.5 Conceptual and Theoretical 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.

As outlined in Chapter 1, several theoretical and conceptual frameworks underpinned this research that focused on race and racism. These are CRT, White privilege, Intersectionality, and Intersectional invisibility (please see chapter 1 for further details on definitions).

3.5.1 CRT, White Privilege and Social Justice

CRT and White privilege are important frameworks, as the current study took place in the UK, where racial categorisation is used throughout society. Furthermore, most of the population identifies as White (Office for National Statistics, 2022). Within previous autism research, there has been limited focus on individuals and families from ethnic minority groups (Maye et al., 2022). Moreover, anti-Black racism and White privilege has been suggested to impact on the lived experiences of Black autistic people and their families (Onaiwu, 2020; Straiton & Sridhar, 2022). It was, therefore, important for the research study to consider the construction of race and White privilege as a lens to explore Black mothers' lived experiences of raising an autistic child.

An objective of these frameworks is to achieve social justice. This study was informed by the communitarian viewpoint. This emphasises the “principles of desert (i.e., what is deserved), need (i.e., what is required), and equality (i.e., what is equivalent)” (Speight & Vera, 2009, p.83). From this perspective, social justice is attained when processes or institutions maintaining inequalities are transformed, and barriers to resources are removed (M. Fox, 2015). An essential element in achieving this is working collaboratively with stakeholders, advocating, challenging biases, and raising awareness (Rogers & O'Bryon, 2008). The current study hoped this may be achieved by giving the co-researcher and participants the space to voice their experiences and work “with” rather than “on” them (Creswell, 2013, p.24).

3.5.2 Intersectionality and Intersectional Invisibility

Intersectionality (Crenshaw, 1991) and intersectional invisibility (Purdie-Vaughns & Eibach, 2008) were also key frameworks as this research focused on the lived experiences of Black African mothers of autistic children. Intersectionality can explore how different forms of oppression may occur simultaneously due to having overlapping social identities, in this case, being Black, female, and associated with disability. Furthermore, intersectional invisibility is particularly useful for the study as

the research participants are global majority women parenting autistic children who may be experiencing multiple types of marginalisation, making them 'invisible' in research (Purdie-Vaughns & Eibach, 2008). This study provided a space for the participants to voice their experiences.

3.5.3 Bronfenbrenner's (1994) Ecological Model

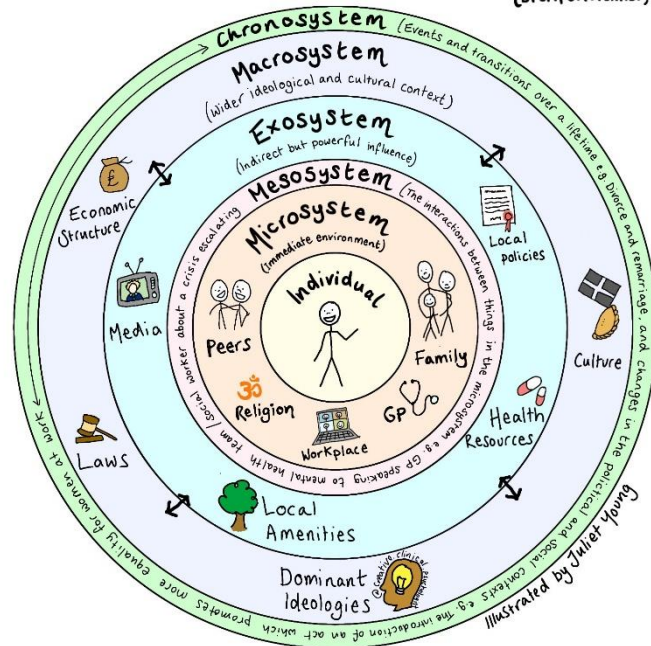
Unlike the individualised Western society that tends to emphasise the 'self,' the Black African community is more collectivist, placing a higher value on wider society (Hofstede et al., 2010). The ecological perspective takes into account the systems around the individual. The model suggests that Black African mothers of autistic children's behaviour result from the interactions between the individual and the different systems around them, including the family, community, and wider environment. Bronfenbrenner's ecological model (Bronfenbrenner, 1994, Figure 3.1) is a useful framework to help understand how the different systems interlink and influence Black African mothers of autistic children. The ecological model could be said to suggest that autism is conceptualised at the individual (micro) and cultural levels (macro). As such, the model is helpful when exploring culture and autism.

Figure 3.1

Bronfenbrenner, (1994) Ecological Systems Theory

Ecological Systems Theory

(Bronfenbrenner, 1979)



3.6 Interpretative Phenomenological Analysis (IPA)

IPA is a relatively new and increasingly popular qualitative approach that explores how people make sense of their lived experiences (J. A. Smith et al., 2012). This approach aligns well with the current study as it allows for an in-depth exploration of lived experiences of Black African mothers of autistic children. IPA also works well alongside PR, and by combining the two approaches, it is hoped that new knowledge may emerge in autism research and inform future practice.

IPA has three fundamental principles: phenomenology, hermeneutics, and ideography (Pietkiewicz & Smith, 2012). It is important to clearly outline these philosophical influences to understand the present research. The analysis process of IPA will be explained further on in the chapter.

3.6.1 Phenomenology

Phenomenology is “the study of experiences” (J. A. Smith et al., 2012, p.11). Phenomenologists are interested in what the human experience is “like,” particularly significant or important life events. The objective of phenomenological research is first to describe the participant’s experiences, followed by a detailed and rich insight into the individual world (J. A. Smith et al., 2012). Husserl was a prominent

phenomenological philosopher who argued that researchers need to identify the key components of an individual's experience that is unique from others.

Phenomenologists aim to get to the phenomenon's essence, what makes it unique or special, through a technique called eidetic reduction. Phenomenological studies also embrace a method called "bracketing," where taken-for-granted assumptions, biases and preconceptions are consciously held to one side to allow for the phenomena to be viewed in its own right without the influence of the researcher's interpretations (Pietkiewicz & Smith, 2012). This is the process of epoche (J. A. Smith et al., 2012). Husserl's ideas were built upon by his student Heidegger who argued that individuals could not entirely separate the influence of our own experiences during research. Heidegger put forward the concept of 'inter-subjectivity' to describe the interlinked and overlapping nature of "our engagement in the world" (J. A. Smith et al., 2012, p.17). Heidegger reasoned that interpretations of people's sense-making were key for phenomenology as it was not possible to separate people from the world in which they lived.

3.6.2 Hermeneutic

"Hermeneutics is the theory of interpretation" (J. A. Smith et al., 2012, p.21). IPA incorporated Heidegger's idea that the researcher is attempting to understand and highlight another person's experiences (but acknowledging this is not wholly possible). This occurs through an interpretative activity where the researcher pays close attention to the language used and mindset of the person to make sense of their experience, producing a translation of their message (Pietkiewicz & Smith, 2012). Therefore, the hermeneutic theory recognises a dynamic relationship between the whole and the part. Consequently, it is argued that to understand a part of an experience, you need to understand the whole experience and vice versa. The part and the whole are argued to be inseparable and can be understood only when both are considered; this is described as the hermeneutic circle (J. A. Smith et al., 2012). Furthermore, the IPA process includes a double hermeneutic. This refers to a dual interpretation where participants make sense of their world or experiences, and the researchers then attempt to translate or decode the participant's meanings and make sense of their interpretations. IPA researchers are said to try and gain insight into participants' experiences and see what it is like from their perspective (J. A. Smith et al., 2012). However, at the same time, they try to critically engage with what

is being said as a researcher. It is believed that IPA research may therefore contain interpretations that could enrich the data findings. IPA acknowledges that this process will be impacted by the experiences and understanding of the researcher, but it is a necessary process to be able to understand how the participants experience the phenomenon (Pietkiewicz & Smith, 2012).

To mitigate and acknowledge the influence of the researcher's experiences on interpretations, it is suggested that researchers practice reflexivity (J. A. Smith et al., 2012).

IPA thus combines phenomenology and hermeneutics to enable a descriptive method as it involves exploring how things are in their own right, and also an interpretative element as it acknowledges that both the participants and researcher are interpreting a phenomenon.

3.6.3 Ideography

Another fundamental theoretical underpinning of IPA is ideography. This refers to "the particular" (J. A. Smith et al., 2012, p.29) and involves the detailed and in-depth analysis of individual cases before making general assertions. This differs from other research methodologies where general statements are made at the group level. To abide by the Ideographic principles, IPA research recruits a small sample size or case study to explore a particular phenomenon through the lens of the individual, all for deeper interpretations to be generated by the researcher.

3.6.4 Rationale for using IPA

IPA fosters the examination of the phenomenon at the individual level to produce rich and detailed data and considers factors such as culture and society, which may influence how such a phenomenon is understood (Pietkiewicz & Smith, 2012). This is highly significant to Black African parents of autistic children as autism is frequently defined through the historical, cultural, and social setting. As stated early in chapter 1, research about autism has come mainly from a White Western perspective. Consequently, there is a lack of exploration from the viewpoint of ethnic minority groups (Maye et al., 2022). Using IPA to examine this phenomenon could produce new interpretations and create new understanding.

Additionally, IPA connects with the social constructionist position of the researcher. It enabled the researcher to explore the lived experiences of individual Black African

mothers of autistic children in greater and more meaningful ways. This was believed to be the best method of reaching the study's objectives and understanding the phenomenon. IPA allows for examining what it means to them to be a Black African mother and their perception of what it is like having an autistic child.

3.7 Research Design

The objective of this research study is to explore the lived experiences of Black African Mothers raising autistic children. The researcher needed a methodological design that would enable an in-depth examination of individual experiences. A qualitative research approach was selected in this study as it allows the exploration of complex everyday experiences. Additionally, language can be used as a means for individuals to tell their experiences. This would enable the researcher to explore the research question and direct the data collection (Willig, 2013).

The study's social constructionist position argues that people's construction of reality is affected by the context in which they live; therefore, multiple truths can be constructed. Additionally, the interpretive approach states that having different worldviews leads to varying interpretations of the same phenomenon. By adopting this research design, therefore, limits the possibility of generalisability. However, Denscombe (2010) stated that multiple realities are linked to the culture or society a person belongs to and are not completely individual. Consequently, findings from such a study could be used to understand the culture or group being studied. However, this current study did not aim to generalise findings but instead to provide a space for Black African mothers of autistic children to have their voices heard and highlight their lived experiences that may be able to help in creating new knowledge and inform future practice.

3.7.1 Participatory Qualitative Method

As summarised in chapter 1, principles of PR were employed in this study to ensure the research was conducted 'with' rather than 'on' participants and to promote advocacy for a marginalised group (Aldridge, 2017). This research study offered a space where participants could share their experiences. It is hoped these experiences will add to the knowledge base and widen understanding in the autistic field.

3.8 Recruitment and Selection of the Co-researcher

To promote the voice of a Black African mother of an autistic child and enhance the data findings, a co-researcher was recruited for the study.

The inclusion criteria for the co-researcher were:

- A mother of Black African heritage
- Have an autistic child between the ages of 6-12 years old
- The child was diagnosed in the UK
- The child has had their diagnosis for at least 2 years

A recruitment email was sent to local SEND parent/carer groups and autism advisory services in London LAs. The email provided information about what the role of a co-researcher would entail and how to contact the researcher should there wish to accept the role or find out more information. One potential co-researcher expressed interest in taking up the role. An initial meeting was held with the possible co-researcher to explain further what the role involved, the potential benefits of taking part, and information about PR, as well as the stages and timescales of the research (see Appendix B). Following the meeting, the potential co-researcher still wished to take the role and was given a written information sheet (see Appendix C) and consent form (see Appendix D). Consent was gained both verbally as well as in writing.

3.8.1 The Co-Researcher

The co-researcher identified as a Black African from Nigeria. In our initial meeting, she shared that she is the mother of 3 children (a boy and twins, a girl, and a boy). She explained that her firstborn son, who was 8 years old, was diagnosed as autistic at age 3 and a half. Her twins are neurotypical. She shared that as a mother of an autistic child, she felt her cultural background had significantly impacted her experiences. She expressed feelings of alienation, shame, and lack of understanding from her community. She was keen to have her experiences shared and hoped that doing so, it could help lead to more understanding of the global majority experience of raising autistic children, raise awareness within such communities and help inform better culturally sensitive practices.

The positioning of the co-researcher as an expert in her lived experience was essential to the study, as PR principles highlight the importance of actively involving

people so that their voice is able to make a difference. In this way, the co-researcher can gain skills traditionally viewed as 'professional' or 'expert' usually ascribed to the researcher (Cornwall & Jewkes, 1995).

3.8.1.1 Co-Researcher Training

To enable the co-researcher to fully participate in the research and promote her voice within the study, it was important to train her in the key areas of research and its techniques. The session structure and aims were adapted from Kellett (2005) using Howitt & Cramer's (2020) textbook to make it appropriate for adult learning. The lessons were one hour long and conducted virtually (See Appendix E).

As a practitioner-researcher, it was important that the first lesson was centred on building rapport to create trust and foster a good collaborative working relationship. Lessons were delivered using a variety of methods, including discussions and videos. Feedback was sought from the co-researcher at the end of each session through scaling and questioning to check understanding of key concepts and ideas.

3.9 Co-researcher's Level of Participation

To remain consistent with PR principles, the co-researcher was free to decide the level of participation she wanted in the study. Throughout the study, the researcher actively aimed to facilitate and support the co-researcher to lead and have their views and opinions prioritised. The co-researcher and participants were positioned as experts in their lives (Aldridge, 2017). The study stages and participation levels are highlighted in the table below.

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	<ul style="list-style-type: none"> • The researcher presented the overall focus of the research and potential research question to the co-researcher. • Time was taken to gain a shared understanding of key concepts, e.g., culture, autism, and experiences with the co-researcher. • The co-researcher and researcher agreed on the research question
Stage 2: The interview schedule	<ul style="list-style-type: none"> • The researcher shared potential questions for the interview schedule. • The co-researcher suggested the researcher ask her the questions, which she answered to help her reflect and generate possible further ideas. • The co-researcher proposed changes to wording and added further questions. • The co-researcher agreed on the final interview schedule used within the research.
Stage 3: Recruitment and data collection	<ul style="list-style-type: none"> • The researcher sent out recruitment emails and finalised the interview dates. • The co-researcher decided she did not want to conduct interviews of participants. • The researcher feedback to the co-researcher after interviews to keep her informed
Stage 4: Data analysis	<ul style="list-style-type: none"> • The researcher transcribed all interviews. • The co-researcher informed the researcher that she could not take part in the data analysis but wanted to look over the final themes. Her thoughts and feedback were used to finalise the group level themes.
Stage 5: Data dissemination	<ul style="list-style-type: none"> • The co-researcher was informed of the possibility of being involved in further publications

3.10 Data Collection

3.10.1 Semi-Structured Interviews

As this was an IPA research study, the data collection method needed to enable participants to share their experiences in great detail. The co-researcher and researcher agreed that using semi-structured interviews (SSIs) was the best method to provide a space for participants to share in-depth lived experiences. The open-ended questions allowed participants to share what is important and meaningful to them, creating richer and more detailed data. SSIs also permit the flexibility to respond to participants' answers and explore areas that may be missed using structured interviews (Willig, 2013). This could lead to new learning and knowledge about the participants' experience as a Black African mother of an autistic child.

The use of an interview schedule is recommended to promote a relaxed environment where participants feel free to share their stories and experiences (J. A. Smith et al., 2012). Utilising the stages suggested by Rubin & Rubin (2005), the co-researcher and researcher collaborated to devise the schedule used within this study, with the co-researcher agreeing on the final version (See Appendix F). The schedule was used as a guide for the interview, but participants were encouraged to lead the discussion and were free to divert from the questions.

When designing the SSI schedule, the co-researcher and researcher considered the language used to ensure it was simple and straightforward, so parents easily understood it. At the start of the interviews, it was highlighted that the purpose was to gain their views and experiences; therefore, there were no right or wrong answers. To promote consistency during the data analysis phase, time was also taken to establish a shared understanding of key concepts such as culture and Black African. Prompts and probes, such as phrases like 'anything more', were used to explore further and clarify views and experiences (Robson, 2016, p.289). This approach encourages the shift towards conducting research 'with' participants rather than 'on' them and fits within the PR principles. This also helped empower and position the mothers as experts in their experiences.

Participants were given the option to have their interview virtually over Microsoft Teams or face to face if COVID-19 restrictions allowed for this to enable them to select what is most comfortable for them. All participants opted to have virtual

interviews. The researcher drew on skills of attunement and consultation to build rapport and encourage collaboration to gain views in a meaningful way.

3.11 Participants

This study recruited two sets of research participants. Firstly, a co-researcher to promote the voice of a Black African mother with an autistic child/ren. Secondly, consistent with IPA, the study recruited a small sample size (6) of a homogenous group (Black African mothers with autistic children) to allow for rich and detailed data to be collected. Mothers were positioned as experts in their own lives and empowered to share their experiences as research has shown there are often the most negatively impacted as well as likely to experience intersectional invisibility (F.Fox et al., 2017; Ijalba, 2016; Lovelace et al., 2018; Munroe et al., 2016; Selman et al., 2018).

3.11.1 Recruitment

Purposeful sampling was utilised in this research study. This is a technique where a sample is built up of participants who met the inclusion criteria and, therefore, can offer insight into the phenomenon being studied (Robson, 2016). Participants were recruited through local SEND parent carer forums/groups, schools, and the autism advisory services within a LA. The researcher sent emails to SENCOs, the parent groups and the autism advisory service, which included information about the study and asking them to advertise and/or forward the participant information sheet (see Appendix G) to those who met the following inclusion criteria:

- Black African mothers with an autistic child/ren aged between 6-12 years old, diagnosed in the UK.
- The children would need to have had the diagnosis for at least 2 years to allow the opportunity to reflect on experiences.
- Mothers will need to be able to speak English and willing to share experiences of raising an autistic child in the UK.

The opportunity was provided for potential participants to ask questions via email. Consent forms were sent to parents who contacted the researcher wanting to participate in the study. Once consent was received, dates and times were selected

to meet for the interview. Consent was again sought before the interview started, and participants were reminded of their right to withdraw.

3.11.2 Participant Characteristics

In line with IPA, a small sample size of 6 Black African Mothers of autistic children partook in this study. This allowed for detailed and rich data to be collected for analysis. The table below shows further details of the participants' characteristics.

Table 3.2

Participants Characteristics

Participant	Ethnic Background	Religion	Marital Status	Autistic Child (ren) (Gender, Birth Order, Age, Age at Diagnosis)	Siblings
Aisha	Black African-Nigerian	Muslim	Single parent	Boy- 6 years old. Firstborn Diagnosed aged 3 and half	0
Keza	Black African-Rwandan	Catholic-non-practising	Married	Boy – 6 years old Firstborn Diagnosed aged 2	1 younger brother – 4 years old
Tiwa	Black African-Nigerian	Christian	Married	Boy – 6 years old second born Diagnosed aged 2	1 younger brother- 3 years old 1 older brother – 14 years old
Amma	Black African-Ghanian	Christian	Married	Boy – 6 years old Third born Diagnosed aged 4	1 older brother – aged 9 Sister- aged 8 1 younger brother – 10 months
Sanyu	Black African – Ugandan	Christian	Married	Boy – 7 years old Firstborn Diagnosed aged 4	1 brother, 5 years old 1 younger sister – 3 months old
Afia	Black African – Ghanaian	Christian	Married	Boy aged second born Diagnosed aged 3 and half	Older sister 12 years old Younger brother -7 years old

3.12 Procedure

Data was collected virtually on Microsoft Teams using SSIs. Interviews took place between April and May 2022. The interviews lasted an average of 1 hour and 3 minutes. Interviews began with revisiting the information sheet with participants and inviting them to ask questions if they wished. Verbal consent was then again sought. Participants were reminded that they were free to take a break at any point during the interview or could withdraw altogether. The purpose of the study was explained, and key concepts were defined. The interview schedule was followed, and a space was given to add any other information they felt may be relevant to know about their lived experiences. At the end of the interview, participants were sent a debrief sheet (see Appendix H) and the option to speak through anything they may be concerned about. Participants were also asked if they had a preferred pseudonymised name they would like to use for the purpose of the write-up.

3.13 Data Analysis

The current study followed the six steps of IPA suggested by J. A. Smith et al., (2012):

- Step One- Reading and Re-Reading

To start the process of IPA, the researcher immersed herself in the data by listening to the audio recordings and then reading and re-reading the transcripts. The researcher kept first impressions and reflections to keep the participants at the centre of the analysis.

- Step Two-Initial Notes

At this stage, the researcher made exploratory-level notes on the semantic and language content to become increasingly familiar with the transcript (See Appendix I). These initial notes were then added on the right-hand side of the margin (See Appendix J). The researcher conducted three different types of comments as outlined in J. A. Smith et al., (2012) p.84:

- Descriptive comments: focused on describing the content of what the participant has said
- Linguistic comments: focused on exploring the specific use of language by the participant

- Conceptual comments: focused on engaging at a more interrogative and conceptual level

- Step Three -Developing Emergent Themes

The third step entailed returning to the initial notes to generate emergent themes (see Appendix K). This involved concurrently maintaining the complexity of the data whilst also analysing the initial comments to map out patterns, connections, and interrelationships. A key element here is ensuring that the analysis is linked to the participant's original words and not just the researchers' interpretations (J. A. Smith et al., 2012).

- Step Four- Searching for Connections Across Emergent Themes

This stage aims to find connections and patterns between the emergent themes. The researcher utilised many approaches to achieve this, including:

- Abstraction: finding patterns and regrouping them into superordinate themes
- Polarization: looking at oppositional relationships between themes and focusing on the difference
- Contextualisation: identifying “the contextual or narrative element” and “attending to temporal, cultural and narrative themes in a proactive manner” (J. A. Smith et al., 2012, p.98)

The subordinate themes were shared with the co-researcher to confirm that they reflected the participants' experiences. Member checking was also completed with participants.

- Step five- moving on to the next case

Following the idiographic nature of IPA, cases were analysed individually in their own right. The researcher endeavoured to bracket ideas from the first case, although it is recognised that previous knowledge and findings for the case before will influence the current case. To mitigate this and enable new themes to arise, J. A. Smith et al., (2012) suggested systematically following the six steps outlined.

- Step Six- Looking for Patterns Across Cases

The final stage involves the researcher “looking for patterns across cases” (J. A. Smith et al., 2012 p.101). Here emergent and superordinate themes are examined to

explore potent or powerful themes and check for potential higher-order concepts or themes.

3.14 Reflexivity

As a researcher practitioner it is advised to adopt a reflexive approach by implementing a self-aware position (Drake & Heath, 2011). Arguably this is particularly important in IPA studies where the focus is usually on marginalised groups and aims to amplify their voices. Although it is accepted that being reflexive will not remove the researcher's values from the research, it is intended to encourage the researcher to examine how their previous experiences, cultural background and values may influence the research process and impact the interpretation of the findings. A key philosophical underpinning in IPA is the double hermeneutic, which recognises researchers are sense-making and interpreting the participants' attempts to interpret their experiences (J. A. Smith et al., 2012).

Therefore it is essential that when conducting IPA research that the researcher is actively aware of their beliefs, values and experiences and how they may impact the study and its outcomes (Etherington, 2007). By including the 'self' throughout the research process, the researcher accepts their role as a subjective researcher (Etherington, 2007).

To mitigate this and engage actively in reflexivity, the researcher took several steps throughout the research process. Firstly, the researcher kept a reflective diary (See Appendix L) to consider her positionality and response to potential power imbalances. The use of supervision both at university and on placement provided a reflective and supportive space to discuss the research study, feelings and thoughts that arose.

3.15 Ethical Consideration

Ethical approval was granted by the University of East London's Ethic Committee (see Appendix M), and the Principal Educational Psychologist provided approval from the LA (see Appendix N) and other identified gatekeepers before starting the study via email. The researcher followed relevant ethical guidelines, including the BPS Code of Ethics and Conduct (BPS, 2018), and the BPS Code of Human Research (BPS, 2021). UEL Code of Practice for Research Ethics (UEL, 2021) and HCPC Code of Conduct, Performance and Ethics (HCPC, 2016).

3.15.1 Informed Consent

Informed consent was gained in writing by providing the co-researcher and participants with an information sheet with details of the study and consent form. Participants were informed that they were free to contact the researcher at any time should they have any questions or inquiries. The information sheet, consent form, and debrief letter all highlighted the participant's right to withdraw at any point without any consequence or explanation, and this was reiterated verbally before the interviews. (BPS, 2018). However, participants were informed that the subsequent 3 weeks cooling off period following the interview, their data would not be able to be withdrawn, and their anonymised data would be used.

Concerning the co-researcher, ongoing consent was checked informally and formally throughout the research process. It was stated on the information sheet and research presentation that she could withdraw at any time or change the level of her involvement without disadvantage or consequence.

3.15.2 Confidentiality

All data collected was consistent with the Data Protection Act (2018) and General Data Protection Regulation (GDPR) (European Commission, 2018). The researcher followed the Data Management Plan approved by UEL. Data was pseudonymised through the use of pseudonymised names agreed with participants. Information and quotes used for the thesis or future publication will be pseudonymised. Consent forms explained that confidentiality would only be breached if there were any safeguarding concerns. Data was stored on a password-protected personal laptop only the researcher had access to. Information shared with the co-researcher and supervisor for analysis purposes was pseudonymised. Data was stored on UEL OneDrive for Business and accessed via a password-protected laptop.

3.15.3 Duty of Care

It was acknowledged that there was a possibility of emotional distress being felt by participants when discussing their lived experiences, especially if they have felt marginalised due to their intersectional identities. To minimise this, Participants were reminded that they could take a break at any point during the interview or withdraw altogether. Participants were also told of their right to withdraw their information after

the interview during the cooling-off period of 3 weeks. Information on support services was also provided to participants through a debriefing letter.

3.16 Trustworthiness of the Study

Yardley's, (2000) criterion was applied to address the study's trustworthiness or validity. Yardley (2000) suggests four characteristics that may increase the validity of qualitative research. This approach is theoretically neutral and supports the social constructionist position. It also aligns well with IPA. There are four principles:

- Sensitivity to Context

The researcher recruited a co-researcher to help ensure the research question and interview schedule were sensitive to the participants' contexts. Furthermore, as the researcher is from the same ethnic and racial group as well as a mother to an autistic child; It was hoped this would encourage participants to feel free to share openly about their lived experiences.

- Commitment and Rigour

By integrating PR principles through recruiting a co-researcher, collaborative working was achieved in various research stages. Furthermore, participants were encouraged to lead discussions when sharing their experiences. Skills gained through training in attuned interaction principles and consultation were used to aid active listening, deepen participants' understanding, and increase testimonial validity. Trustworthiness was also increased through actively including participants and the co-researcher in checking and selecting the final themes, which arguably enhanced insights into the experiences of Black African mothers of autistic children (Willig, 2013).

- Transparency and Coherence

Transparency was maintained by providing detailed information on how data was collected and analysed. The aims and objectives were considered throughout the study and used to inform the interpretation of the data.. To increase social validity, the researcher checked credibility by sending drafts of findings to participants to verify interpretations and provide an accurate reflection of their experiences (J. A. Smith et al., 2012). The co-researcher also reviewed and finalised the group level themes across the participants. The researcher also kept a reflective diary and had

regular discussions with the supervisor and fellow TEPs to engage in reflectivity (Willig, 2013).

- Impact and Importance

The current study empowered a Black African mother with an autistic child to become a co-researcher by training her to conduct research. Community validity may have been gained by having a co-researcher advise on how research can be applicable and meaningful to the Black African mothers' community with autistic children. Including a Black African mother in this research study may have increased the validity and be more representative of the community. Moreover, participants were positioned as experts and given the opportunity to speak about their lived experiences. The findings could therefore be used to advise professionals on better supporting parents from African backgrounds (Willig, 2013).

3.17 Chapter Summary

This chapter included a summary of the research position taken within this study, highlighting the researcher's ontological and epistemological positions. The rationale and justification for the need for the study were detailed. The chapter also explained the selection of a qualitative participatory research approach and the use of IPA. The recruitment process of both the participants and co-researcher was discussed, and the training undertaken by the co-researcher and her role was outlined. The procedure of using SSIs and the data analysis were also summarised. Finally, the chapter ends with ethical considerations and a review of the study's trustworthiness.

Chapter 4: Findings

4:1 Introduction

This chapter will outline the phenomenological and interpretative narrative findings from the research. Firstly, the researcher's interpretations of the findings will be presented at the individual level, followed by an analysis across participants and the common themes presented at the group level.

4.2 Development of Individual Themes

Following the recommendations by J. A. Smith et al., (2012) on the IPA process, the researcher identified individual emergent themes for each participant (see section 3.13 in chapter 3 for further details). These were reviewed and finalised by the co-researcher. The researcher and co-researcher then identified and finalised emergent group themes by looking for patterns across participants' themes.

Superordinate themes were developed to explore the idiographic 'particulars' or 'parts' linked to the phenomenological 'whole' of the participants' lived experiences. The superordinate and subordinate themes that were relevant to the research question were presented in the findings. Social validity and credibility were enhanced by sending draft findings to the participants to allow them to comment on the interpretation made by the researcher and check the accuracy of how their views were represented (see Appendix O).

4.3 Mother One: Aisha

Aisha identified as a Black African Nigerian single mother of a 6-year-old boy who was first diagnosed as autistic at the age of 3 and a half. She shared that she was a practising Muslim and speaks both English and Yoruba. Aisha lives at home with her son but has extended family living nearby, whom she sees regularly.

Table 4.1:

Aisha's Superordinate and Subordinate Themes

Superordinate themes	Subordinate themes
The role of faith	Faith as a source of support Faith as an intervention

The role of Yoruba culture	Lack of autism awareness Negative views Stigma and blame Family as a supportive factor
Access to support	Impact of the diagnostic process Information not readily available
Positive experiences	Personal strengths Strengths in the child Relationships with professionals

4.3.1 Superordinate Theme: The Role of Faith

The first superordinate theme formed from closely interpreting Aisha's lived experiences was the role of religion and faith.

4.3.1.1 Subordinate Theme: Faith as a Source of Support

Faith appeared to play an important and positive part in Aisha's life. She seemed to find strength from her faith, and it is a motivator to support her son. "Obviously, faith plays a big part. It did. It does because that's one of the places I feel like I've got my strength from just succumbing to that." (70, p.11) This quote suggests that faith is an integral part of Aisha's life. The phrase "obviously, faith plays a big part" implies that Aisha may view her faith as a key source of support. The term "succumbing" is of interest as it seems to suggest that Aisha believes her son's autism is how God made him, and this is a powerful influence for acceptance. "It was hard to accept, but ...when you then add faith to it and know that... everything's got a plan. ... all of this isn't just happening." (120, p.25) This quote suggests a strong relationship between acceptance of autism and Aisha's faith in God. Aisha implies that her faith helped her get through the "hard to accept" diagnosis of autism, highlighting that it was when she added "faith to it" that she began to accept it. The phrase "everything's got a plan" suggests that Aisha believes her life has a purpose, including her son's autism. She seems to emphasise her belief in this purpose using the phrase "all of this isn't just happening". It supports the idea that she has conceptualised her son's autism as there being a deeper or spiritual reason for it, which appears to be a source of support and comfort.

4.3.1.2 Subordinate Theme: Faith as an Intervention

Aisha also seemed to believe that faith could be used to help support her son's development but within limits.

I think I went through that phase as well that I can pray it away. I mean, you can pray to a certain extent to have the, like, right support and not just going to go away, you still have to do your part as a parent, like get the necessary support. You know, that's when God will come to facilitate that role and bring people into your life and then make it better. (62, P.9-10)

Aisha appears to hold a narrative that although prayer can be supportive, it is not the only answer. She is moving away from perhaps more traditional views of her community to accept that support is also needed from social and health professionals.

4.3.2 Superordinate theme: The Role of Yoruba Culture

The second superordinate theme gained from exploring Aisha's transcripts was her Yoruba culture's role in her experiences.

4.3.2.1 Subordinate Theme: Lack of Autism Awareness

Aisha explained that in Yoruba, there was no word for autism, and this led to a lack of understanding within her community.

Umm, some people say it's the evil eye¹. Some people say it's, you know, sometimes it's what you didn't do as a mum because I went through that. Because I went through that guilt phase. Did I do something wrong? Did I hurt someone who put evil eye on me while I was pregnant? (62, p.9)

Aisha shared that some members of her community describe autism as being caused by the "evil eye" stemming from something "wrong" that the mother had done. The term "phase" suggests that Aisha went through many thought processes while trying to understand her son's autism diagnosis, initially aligning with her culture's belief of the possible cause of autism being linked to external influences such as the evil eye or a form of punishment. This suggests a strong connection between cultural beliefs, and how autism is conceptualised as well as faith and spirituality.

4.3.2.2 Subordinate Theme: Negative Views

Aisha spoke throughout her interview about the negative views of autism held within her culture.

¹ Evil eye: evil spirits or curses believed to cause illness, misfortune, injury, or death

I wouldn't blame them, there isn't much awareness about it... in Nigeria, now there is all these NGOs coming out, ... give this awareness of what autism is, ... it's not, ... this kids are not ill, they just have a different way of viewing things and life, and you just have to adapt to them, and they can learn just like every other child... just need to know what works for them (51, p. 7)

Aisha links the negative views to her culture's lack of awareness. She says she wouldn't blame them for this, perhaps because she may have felt it was the reason for her initial response to her son's diagnosis. Aisha seems hopeful that information about autism may increase awareness and shift how autism is understood and viewed.

4.3.2.3 Subordinate Theme: Stigma and Blame

Aisha explained that the lack of autism awareness within the Nigerian community seemed to lead to stigma and blame.

But when we go out, you know, parties and we get looks, especially when he starts to stim because he does verbal stimming... we get that. Umm, can you just shut him up? Umm, Like, I can't shut him up; it's what he enjoys doing! (55, p.8)

Aisha suggests that interactions within her community can be negative at times. She highlights that more noticeable differences can lead to judgements on her parenting and insinuations that she is not controlling his behaviour. However, Aisha seems empowered to advocate for her son by spreading awareness and sharing that he enjoys stimming.

The stigma and blame associated with autism also impacted Aisha's initial ability to accept her son's autism diagnosis. She felt this affected her marriage, as there were differing constructions of what was occurring with their child. "Yeah, the denial it's definitely there. But I, I accepted it for what it was way earlier on than he did. He is still struggling." (40 p.5)

This was a difficult time for Aisha, and she shared that it impacted her mental health, stating: "So umm, I mean, I went through a phase of depression because I was, you know, at the time of the diagnosis, I was going through divorce as well." (67, p.11) Aisha again refers to going through a phase of depression that she links to

simultaneously going through two stressful events (the diagnosis process and divorce).

4.3.2.4 Subordinate Theme Four: Family as A Supportive Factor

Aisha explains how her family's understanding of autism has been supportive.

I'm lucky My mum's side of the family...some of them are carers, some of them are nurses... My mum is a mental health nurse. She has ... siblings as well who work with, you know autism. Yeah, they they understand. I would say they understand. (55, p.8)

Aisha shared that she has a family that “understand” autism, and this seems to be supportive for her. She states that she is “lucky” to have this, perhaps acknowledging that this may be uncommon due to the lack of awareness within her community. Aisha explained that her family members worked in various healthcare roles, which she seems to link to their increased awareness and knowledge of autism.

4.3.3 Superordinate Theme: Access to Support

Aisha's transcripts suggest she found accessing support a complex and negative experience.

4.3.3.1 Subordinate Theme: Impact of the Diagnostic Process

Aisha highlights the process of diagnosis as mainly negative. “Exhausting...it wasn't so straightforward. ... I think I was; we were on the waiting list from when he was like, yeah, it was a long time. It was it was a really long time.” (63, p.10) Aisha speaks about the long waiting lists and is unable to put a timeframe suggesting she found it so lengthy she is unable to remember how long she waited. Aisha also repeats the word “long”, which again emphasises that she found the process exhausting and possibly tiring.

4.3.3.2 Subordinate Theme: Information Not Readily Available

Aisha indicated that information regarding support for her son and herself was not easily accessible.

I feel like the support is supposed to be all there. But you have to go on the internet and research like this huge Facebook group, like people suggested things like, do this and do that. Yeah, so I feel like we can benefit more in terms of input from professionals. (113, p.22)

Aisha shares that it was a struggle to find support following her son's diagnosis of autism. She references searching the internet and Facebook to find information and interventions to support her child. She seems frustrated and suggests the responsibility should have been with the "professionals" to ensure information is readily available post-diagnosis.

4.3.4 Superordinate Theme: Positive Experiences

Aisha also expressed some positive experiences of raising an autistic child.

4.3.4.1: Subordinate Theme: Personal Strengths

Aisha identified that she had gained some personal strengths from being a mother of an autistic child.

I used to be someone who never used to speak like; I was always keeping to myself. Now, I have this community of, like, people I just talked to, like, friends who are in the same situations... they have become friends. (121, p.25)

She explains that she has developed her social skills and is more willing to socialise with people, which has helped her create her own supportive "community". Having people experience similar life events appears to be significant to Aisha's wellbeing.

4.3.4.2: Subordinate Theme: Strengths in the Child

Aisha also shared her appreciation for the strengths she has noticed in her son. "He is smart... Femi never forget anything. If you take him somewhere one time. He knows that place." (123, p.25-26.) Aisha speaks about her son's memory skills which she associates with him being autistic. This seems to be a source of pride for Aisha and, again, supportive of her well-being.

4.3.4.3: Subordinate Theme: Relationships with Professionals

Aisha highlighted that having positive relationships with professionals helped her during the diagnostic process.

When we had a diagnosis, mmh, I had two, three appointment visits with a paediatrician. I think, and she tried her best to explain what it was and how, you know, our life was gonna change moving forward. Yeah, it was quite helpful. (66, p.11)

Aisha seems to have found having multiple visits with the same professional useful. Furthermore, Aisha also spoke about the paediatrician’s attempts to explain what autism was to her and how it may “change” their lives helpful. It suggests that the personalised nature of what the autism diagnosis may mean for her, and her son was beneficial for her.

Moreover, Aisha expressed that finding the “right” support for her son helped him settle well into school.

He loves Kiesha (TA). That's Mama in school. It's definitely been because school was struggling to find the right support, I would say...when she came, she definitely made things, you know, a lot more easier for him. ... he's settled well. (87, p.15)

The word “mama” shows that Aisha felt the TA took on her role, likely reassuring her. She equates this to making her son’s time in school “easier”. This highlights that having positive and trusting relationships with staff made Aisha feel secure and confident that her son was being well looked after.

4.4 Mother Two: Keza

Keza is Rwandan. However, as she is married to a Ugandan, she describes herself as East African. She is a mother of two boys. Her firstborn son is six years old. He received his first diagnosis of autism in the USA at one and a half years old and again at the age of 2 when the family relocated to the UK.

Table 4.2

Keza’s Superordinate and Subordinate Themes

Superordinate theme	Subordinate themes
The role of east African culture	Limited knowledge of autism Deeply negative views High expectations Stigma and judgment Impact on mental health
The role of religion	An interesting relationship Giving purpose
Support systems	Experiences with professionals and services Representation

4.4.1: Superordinate Theme: The Role of East African Culture

Through examining Keza's transcript, her East African heritage was a significant part of her experiences of raising an autistic child.

4.4.1.1: Subordinate Theme: Limited Knowledge of Autism

Keza explained that although she had heard of autism before her son's diagnosis, her knowledge was limited.

I had heard about it from, like, my aunt, the stuff about the MMR. And I always thought about it as like either they're geniuses or... They're low functioning. So that's all I really knew about it because I didn't ever think that it would affect me. (39, p.6)

Keza shared that she gained knowledge of autism through wider family, including linking autism to the MMR vaccine, although significant evidence suggests that such links do not exist.

4.1.1.2: Subordinate Theme: Deeply Negative Views

Keza explained that no word exists for autism in her community. Keza shared that the lack of autism awareness and the negative terms linked to autism fuelled negative views in some members of East African society.

Anyone that has any mental health issues is called shizong, like musiru, someone who's stupid. Do you understand how deep and how negative that is? ... they're all put in one like box, right? So, if anyone has any issues. 'Ohh, not that one; just dismiss it'. Right. They ignore that because that one has issues and is mad. (53, p.8)

Keza shares that the 'mental health issue' of which autism is often grouped within her community is described using derogatory terms such as "shizong" and "musiru", which translate to mean 'stupid' or 'mad'. Keza's rhetorical question portrays the deep hurt she feels from stigmatising labels within her society. She added that people viewed this way are rejected and overlooked, leading to alienation.

There's a huge stigma again around, like mental health issues. I mean, a lot of children who have mental health issues or special needs back home are either hidden. It's a taboo... They don't exist. ..In our culture, anyone that's different, that doesn't fit that perfect mould, is just dismissed. (Keza p.45 p.7)

Keza explained that the stigma around disabilities led to the community hiding children out of sight, likely to avoid judgement. Keza shares that it is taboo and “they don’t exist”, indicating that although special needs are present within the community, people act as though they do not occur to keep in line with the cultural expectations of sameness and excellence.

4.4.1.3 Subordinate Theme: High Expectations

Keza further discusses her belief that the dismissal of individuals who differ from their society’s “perfect mould” is due to the value placed on excellence.

I think that we come from a culture where excellence is like, you know, and the idea of you have to be excellent. Everything you have to be the best performer... it's actually sometimes unattainable and, frankly, very harsh. Right. So, if you don't fit that mould and you don't fit the idea of, like, you know, the overachiever who comes in and they're always getting into the best schools, the best grades, right, then you're kind of dismissed 'cause then you're just not... someone worth talking about. (115-117 p.17)

Keza feels that the high expectations valued within her community can be “unattainable”, describing it as “harsh”. She links some of the expectations to academic achievement, which suggest that Rwandans and Ugandans hold this in high regard. Consequently, individuals who do not achieve that type of “success” are seen as less desirable. Keza seems to imply that having autism may be viewed as a barrier to achieving excellence and therefore adding to the negative views.

4.4.1.4: Subordinate Theme: Stigma and Judgement

Keza identifies that she went through a denial phase when her son was diagnosed.

The denial also comes with blaming yourself because you're like, maybe I should have done something different. Was it cuz I had a really intense job when I was pregnant with him, and I said maybe I didn't take care of myself during the pregnancy, maybe because I also had forceps. ... maybe I did something wrong in my past? I don't know... You start believing in all those superstitions. (83, p.10)

Keza wondered what caused her son’s autism and struggled to come to an understanding or acceptance. She revealed a direct link to her culture’s beliefs led to

self-blame, stating she started believing in “those superstitions” about having done “something wrong” in a “past” life. Keza’s use of the phrase “You start believing in all those superstitions” also implies that she did not always hold these beliefs prior to having an autistic child, however in looking for an answer or understandings, her first thoughts aligned within her culture’s constructions.

Keza also shared that her community often judged parenting as a cause of their child’s behaviour. “You haven't raised your child well like his misbehaving.” (123, p.18)

She explained that community members often interpreted autistic traits as misbehaviour and blamed parenting style. Again, this highlights that the reduced awareness seemed to negatively impact Keza’s experiences, particularly as she explained she would be viewed as not meeting the high expectations of child-rearing within her culture.

The fear of judgement impacted Keza’s desire to socialise within her community.

Coming from a culture that we're in ...I'd literally say, I don't want to meet with certain people because I just don't want them to see that... to this day I still get a bit weird when I have new people around us... I don't want to have to explain... Sometimes I wish I didn't care as much, but because we've been raised, it's kind of ingrained in you as well (86-113, p.12-13)

It’s clear Keza felt she had to alienate herself from community members because she found it hard to deal with what might be said about her son’s autism. She seems to imply a sense of shame or embarrassment that she associates with her culture about having an autistic child which may be linked to the deeply held beliefs that difference, or disability, is undesirable.

4.4.1.5: Subordinate Theme: Impact on Mental Health

Keza shared that her mental health was impacted due to the experiences of raising an autistic child as a Black African mother.

You're constantly fighting those fears off cause. They literally this. It's so unknown. You're literally learning as you go. So, I think I'm in a better place. Mentally. I had to get counselling because it was a lot to deal with (93, p.13)

Keza says it is an ongoing “fight” managing the fears of the unknown future and the unfamiliarity of autism. This affected her mental health, and she required counselling to help her cope.

4.4.2: Superordinate Theme: The Role of Religion

Religion was another key theme that came from Keza’s interview.

4.4.2.1: Subordinate Theme: An Interesting Relationship

Keza explained that she has an interesting relationship with religion and shared that she was raised catholic. However, she currently views herself as a non-practising Christian but believes in a higher being, describing herself as spiritual.

I've an interesting relationship with religion, especially after my son's diagnosis... I was questioning a lot, and that's something that I'm still trying to figure out because I also want them to obviously have that grounding, you know because I feel like religion is grounding (4-6, p.1)

Keza pinpoints her son’s diagnosis as a significant experience of her changing relationship with religion. However, she still hopes her children will have religious elements within their lives, indicating she still values it. Her issues with religion seem to be intertwined with her cultural background.

you're paying back for the sins of your ancestors. Maybe your mum did something, and now this is coming back to haunt you... That's why I think I have a very, very interesting relationship with religion because I just feel like it's very not, just pray about it, and it will go away or just fast. Go take him to a prophet, and he will, like, you know, pray away the disease. And that's another thing it's seen as this disease. It's not seen as, as you know, they just look at the world differently. (46, p.36)

Keza appears to have a different construction of autism from members of her community. She seems uncomfortable with the connotations that link autism to “sins” or “disease” and the use of religion as an intervention to pray autism away or cure it.

4.4.2.2: Subordinate Theme: Giving Purpose

Although Keza has reservations about religion, it seemed to help her accept her son’s diagnosis.

It makes sense now that I was chosen to be his mother because I think that it's supposed to teach me because I've always been this kind of person. Where things just make sense... Teach you to just ride the wave... normalising it. Trying to fight that stigma. (168-172 p.23)

Keza believes she was “chosen” by God or a higher power to be her son’s mother to teach her to navigate the unpredictable world and do her best for him. She adds that she thinks the reason she had an autistic child was to make a positive change within her community for other autistic parents.

4.4.3: Superordinate Theme: Support Systems

Throughout Keza’s interview, she spoke about the significance of having support systems.

4.4.3.1: Subordinate Theme: Experiences with Professionals and Services

Keza highlighted getting support for her son as a challenging experience, which she found to be long and frustrating. “It was a difficult system to navigate because it's very slow. It's extremely slow. It's very bureaucratic. There's all these waiting lists and all these queues”. (62, p.9). She expressed a lack of forthcoming information, which made the process unclear. “I think the explanation wasn't as adequate...cause to this day, I don't think they explained the EHCP to me.” (77, p.11). Keza added that she often had to conduct self-research to gain information and help her make decisions. Moreover, Keza found that she had to seek private services to help in supporting her son as well as help with understanding the public systems. “What helped me, to be honest, was we got onto a program, a private program for speech therapy...They're still with us to this day. And so, they help me navigate the system.” (68, p.10)

Keza implies she felt that to gain support for her son, it was important to be able to “push back” and advocate for herself.

I think it also helps if the parent is informed, as in well informed, and they can push back, right? And they're able to just come in with the facts and say, this is what I think my child has. And this is what that support that I think they need. (64, p.9)

Keza suggests that she needed to be well informed to ensure the right support for her son. She implies a mistrust in professionals to provide transparent information about available supports and offer her son the right level of support.

4.4.3.2: Subordinate Theme: Representation

Keza's transcripts suggest that she found having families in similar situations helpful to her.

Actually, a group that we joined recently, that was exciting because for me, I was always looking for people who had similar stories and similar experiences, and that's extremely rare to find, especially in the area that we live in. (142, p.20)

Keza highlighted the significance of having support groups with families from the same cultural background, enabling her to "not have to explain" and feel understood because of shared lived experiences. she adds that this is hard to find due to her geographical location, highlighting her minority status as a Black African woman. "I would gravitate more towards like Africans who had children on the spectrum because for me it was. I want to not be able to explain certain things; like it's very nuanced." (144, p.20). Keza explains that she gravitates to those from a similar background, seemingly wanting a space where her cultural experiences are understood. This suggests her experiences in other spaces have meant nuances from her cultural background that impact her as an autistic mum are unknown or not understood.

Moreover, Keza shared her worries about the lack of representation she found while accessing health services and the impact this may have had on her experiences.

First of all, minorities are underrepresented, to begin with, within the healthcare system... A lot of parents, because you're adding that layer of, ...They don't understand what's going on with their children. You have the stigma. So, I think they have to, like, fight so many battles before they even come to the point of having to advocate for their child...So I think that the systems themselves are almost failing minority families because they're not putting that into consideration, right (190, p.27-28)

Keza seems to suggest that the lack of representation in the healthcare system may mean that cultural influences may be missed or not considered. She highlights the lack of awareness, and the stigma of autism as particularly significant “battles” parents are dealing with, which she felt were not considered by professionals. Keza felt that by missing out on cultural factors, minority families are being failed, seemingly suggesting early intervention is often not provided.

4.5 Mother Three: Tiwa

Tiwa is a married mother of 3 boys from Nigeria. She shared that her middle child aged 6, was diagnosed as autistic at 2.

Table 4.3

Tiwa’s Superordinate and Subordinate Themes

Superordinate Themes	Subordinate Themes
Cultural Influence	Autism is not Recognised Prejudicial Views Acceptance Difficulties and Judgements Impact on Mental Health
Positive Experiences	Availability of Strengths Recognition of Strengths Increased Understanding

4.5.1: Superordinate Theme: Cultural Influence

Tiwa’s transcript illustrated a strong relationship between her culture and her experiences of raising an autistic child.

4.5.1.1: Subordinate Theme: Autism is not Recognised

Tiwa explained that before her son’s diagnosis, she had limited knowledge of autism. She further shared that within her culture, there is no word for autism, and this seemed to add to the reduced awareness.

Well, say it’s not as recognised as it is here. Because, well, most of the autism kids are at home. People Will not.. would not even understand that it's autism. There might be calling it something else... they won't even place the name on like (66-70 p. 6-7)

Tiwa reveals that some Nigerians may not be aware of autism and may be referring to it in other terms. She adds that children who are autistic are “home”, implying that they are kept out of sight, therefore adding to autism not being recognised. This

suggests that autism is viewed negatively, possibly linking it to shame or something to hide from public view.

4.5.1.2: Subordinate Theme: Prejudicial Views

Tiwa shared that there were negatively held views of disability within the Nigerian community. “The child would be discriminated against because of his inability to talk or to communicate like his peer. So, the chance of that child to have a good future would be very slim.... he will be isolated.” (81-83 p.11-12). She explained that individuals who differ from their peers and struggle with communication are seen as less valuable or incomplete within society. She further states that such individuals are often discriminated against or isolated within the Nigerian community.

4.5.1.3: Subordinate Theme: Acceptance Difficulties and Judgements

Tiwa explained that she found it difficult to accept her son’s diagnosis and attributed this to her lack of knowledge of autism. “If I had been educated enough, umm, it wouldn’t be as strangely as it is right now, maybe I’ll be able to give him more and accept the situation more.” (208, p.25). Tiwa shares that she has found being an autistic mother strange and associates this with her limited knowledge of autism. This also seemed to lead to self-judgement and made her question whether she provided the right support. Likewise, Tiwa also explained that the negative view of autism in her community also led to judgement from others. “Immediately you be judged like your son's got disabled.... the way they look at you because it's something wrong. (211-213 p. 26) Tiwa highlights that disability is highly stigmatised within her community and leads to immediate judgement because of the view that something is “wrong”. Moreover, Tiwa seems to accept this notion and found the “look” people gave her difficult to manage.

4.5.1.4: Subordinate Theme: Impact on Mental Health

Tiwa’s difficulties accepting her son’s diagnosis and her community’s negative views seemed to impact her well-being. “It's not easy...what my child is going through, what that diagnosis is doing to him ... sometimes I feel sad... That he was not able to do things... I expected him to do” (137-141, p.16-17). Tiwa speaks of her sadness at the diagnosis and the loss of her expectations of what she thought her son would be like. Her use of the phrase “what my child is going through” suggests that perhaps she views her son’s experiences as negative and challenging, which she has found

to impact her emotionally. Tiwa's statement of "what that diagnosis is doing to him" seems to suggest that she conceptualises autism as being separate from her son and blames autism for making her son's life difficult. This also implies that she sees autism as a separate entity from him.

4.5.2: Superordinate Theme: Positive Experiences

Interpretations of Tiwa's transcripts led to the superordinate theme of positive experiences

4.5.3.1: Subordinate Theme: Availability of Support

Tiwa spoke about having found accessing support for her son a positive experience. "We get a lot of support... It was easily accessible." (252, p.31) More specifically, Tiwa speaks about the support she received from her son's school. She shared that the school was highly inclusive, and this was having a positive impact on her son. "His classmates love him.... the school...they make them aware that there's nothing wrong with them." (352, p.41)

Tiwa expressed her appreciation that the school spreads awareness of differences and felt that this had helped his peers accept him. Furthermore, Tiwa also shared that her family's support was another positive within her life. Speaking about her husband, Tiwa shared: "Oh, he's very supportive. He understands as well. And he's even more supportive than how I am, I would say... the child is more close to him than me... the family, in general, they're very supportive... they have to accept it anyway" (153-159, p.19-20) Tiwa's phrase "even more supportive than how I am" could imply that her husband may have accepted their son's autism easier than her, leading to a closer relationship. Tiwa also spoke about her wider family's acceptance of her son. The use of "they have to accept it" suggests that Tiwa felt that the family had little choice and may demonstrate her increasing understanding of the lifelong nature of autism.

4.5.3.2: Subordinate Theme: Recognition of Strengths

Tiwa identified strengths in her son that she appeared to add to her positive experiences. "I mean, he's very brilliant, and he's getting more time with the classmate in class... Right now, he can read.... even most of his classmates are not able to do that (187, p.21) Tiwa seems to value her son's academic progress and

achievements compared to his peers. She also seems to appreciate that he can spend more time in class, which implies that being with his peers is important to her.

4.5.3.3: Subordinate Theme: Increased Understanding

Tiwa spoke of her increasing understanding of autism, and this seemed to help her accept her son’s autism and empower her to continue supporting him. “Giving birth to an autistic child is not the end of the whole world... they need love and support, ... they can do almost everything that the other kids are doing.” (328-330, p.39-40) Tiwa appears to have found that increasing her knowledge of autism has made her understand that “it is not the end of the whole world” and normalised it for her. She expressed that she now believes that being autistic may mean you need additional support but can make progress.

4.6 Mother Four: Amma

Amma is a Ghanaian married mother of four children. Her 6-year-old son received a diagnosis of autism when he was 4. He is her third-born child.

Table 4.4

Amma’s Superordinate and Subordinate Themes

Superordinate themes	Subordinate themes
The role of Ghanaian culture	Autism doesn’t exist Difficulties accepting Stigmatised views Feelings of alienation
Professional engagement	Disengagement Powerlessness
The importance of faith	Judgement Faith and acceptance
Difficult accessing support	Race Parental support

4.6.1: Superordinate Theme: The Impact of Ghanaian Culture

Amma’s interview revealed that Ghanaian culture played a significant role in her experiences of raising an autistic child.

4.6.1.1: Subordinate Theme: Autism Doesn’t Exist

Amma explained that she had not heard of autism until she came to the UK and believed it did not exist or was extremely rare in Ghana. “I’m from Africa. And where I’m coming from...You don’t see those kinds of things.” (56, p.13) This lack of

awareness hindered Amma's ability to understand what professionals were referring to when speaking about autism. "But I can't see that in the boy. It doesn't look like those autistic children I have seen." (62 p.6) Amma's use of the phrase "it doesn't look like" seems to suggest she linked disabilities with visible or physical features, so she struggled to understand a seemingly invisible need in her son. Furthermore, Amma seemed to be using the term autism to describe another condition that has physically notable features.

4.6.1.2: Subordinate Theme: Difficulties Accepting

Amma's shared that she found it difficult to accept that her son may be autistic, and this impacted her engagement with professionals. "So, me, I don't believe so...I didn't believe in what that lady was saying, so far we didn't go." (62 p.6) Amma explained that a deep belief that her son was not autistic led her to disengage with services that she felt were mislabelling or misunderstanding her son.

Furthermore, Amma recalled that the wider family struggled to accept the diagnosis, impacting her willingness to work with professionals. "My siblings. Because my parents there old. So, I don't want to bother them... when I'm speaking to my sister, and she has said I shouldn't accept it (450, p.34) Interestingly Amma says she did not tell her parents because she did not want to "bother them", suggesting perhaps her awareness of the negative views of disability would be stressful. Also, Amma's wider family advising her to "not accept it" seemed to solidify her disengagement.

4.6.1.3: Subordinate Theme: Stigmatised Views

Amma shared that within Ghanaian culture, disabilities are stigmatised and believed to be caused by spiritual forces.

People will say you've done something wrong.... you used your child for rituals.... you sacrificed your child for riches, for money.... they will say maybe because I remember we struggle for children they may think maybe we went to a place for children, and they've given us such a boy... they may think you've gone for fetish priest². You maybe you've gone to we call something, Mami wata³ (197-204, p.16-17)

²Fetish priest: a person who serves as a mediator between the spirits and the living

³ Mami wata: (Mother Water) is a water spirit believed to appear in the form of a mermaid. She is said to be a powerful water goddess associated with seduction, fertility and wealth but can also be vengeful.

Amma expressed that her community thinks she may have done “something wrong”, leading her to have an autistic child. She explains that members of her community often believe that the causes of disability are due to engagement in African spiritual activities. She recalled that as she struggled with fertility issues, her community may say her son’s autism was due to this involvement.

4.6.1.4: Subordinate Theme: Feelings of Alienation

Amma voiced that such negative views often made her want to alienate herself from others. “When they behave like that, just you, you start to isolate... You take yourself out of them.” (439, p.33) Amma conveys that her way of managing the negativity was by avoiding being around them. she seems to see herself as different from her community because she has an autistic child and therefore distances herself.

4.6.2: Superordinate Theme: Professional Engagement

The transcripts show that Amma has had a difficult relationship with professionals. She connects this to her cultural heritage and the lack of awareness of autism.

4.6.2.1: Subordinate Theme: Disengagement

Amma shared that she stopped engaging with professionals when the possibility that her son may be autistic was raised by a speech and language therapist.

He says something. He suspects is autism... he shouldn't say that because autism scare people.... Even push us and scared us a lot..... I don't know anything about autism, and no mother; no mother will accept autism.... just taking your child to speech and language and then they say that.” (769-775, p.54-55).

This extract suggests that Amma found the ‘word’ autism scary as she did not know what that may mean for her son. The term seemed to have raised negative connotations, which she found hard to accept. Furthermore, Amma spoke about believing she was “just” going to speech and language therapy and seemed surprised that the possibility of autism was raised. This suggests she was unclear about the process or possible further referrals.

4.6.2.2: Subordinate Theme: Powerlessness

Amma explained that she felt she had to re-engage with professionals following a serious accident with their son that required the family to be supported by social care.

They came in the social, and everything came in... we are the parents, but we don't have control over the child anymore... we went back to the speech and language, and through that, we will refer to the autism team, and they diagnosed him as an autistic (102, p.8)

Amma seems to feel she lacked control during the diagnosis process and perhaps had feelings of powerlessness in decision-making. Amma further explains that this lack of control extended into her son's school life.

Up to now, he's not even going for full time... So, we are finding it very, very difficult... Somebody who qualify for six hours.... They gave him an hour, then an hour, 30 minutes, 2 hours. But then I was pregnant with my baby. You just drop him, and by the time you get home. They will call you. Ohh. Kojo is doing this. Can you come and pick him please?... Then you have to go and pick him... now they've given him four hours. (302-315, p.7-8)

Amma shares that her son is on a reduced timetable within school due to issues with managing his behaviour. She knows he is entitled to 6 hours; however, her use of the word "have to" suggests that she felt she needed to follow the request to pick him up. This indicates that she may view the school as holding power, and she feels unable to question this.

4.6.3: Superordinate Theme: The Importance of Faith

Amma's faith played a significant role in her life as a mother of an autistic child. Amma shared that she identifies as a practising Christian.

4.6.3.1: Subordinate Theme: Judgements

Amma explained that her culture and faith sometimes interlinked, leading to judgments. "All that they think is you've done something wrong, and you reap what you sow. They they don't have any idea about it, and it is not common. It's not common in our society" (229, p.30) Amma quoted a bible verse to explain that within her Ghanaian community, she felt that people thought she had an autistic child because of something she had done. Amma suggests this stems from a lack of knowledge of autism because it is not "common".

4.6.3.2: Subordinate Theme: Faith and Acceptance

Amma seems to have a multifaceted relationship with her faith which has been a source of comfort but also a barrier to accepting her son's autism. "First off, I said I didn't believe it. Yeah, because of my faith .. I said, ohh God, will change him. I want God to prove to them." (119, 10) From this quote, Amma seems to have found her faith to be a source of hope, but concurrently, the reason she didn't initially believe the differences she was seeing in her son may be associated with autism.

However, despite this, Amma suggests it was her faith that led to her acceptance of her son's diagnosis.

In fact, you have to know that your son is having a problem. So anywhere that the boy will be OK. I mean to me, anywhere that they can support him. I will take him. I will take him because God knows why. I know how my people, my culture, would think about that. I know within me I've done nothing wrong; I know, and even those people who mark me, that you done something I don't believe. It's only in God... I know that when I go to Ghana, people will say a lot of things. Even my own family (402-406, p.30)

Amma's faith helped her accept her son's needs and want them to be supported. She states, "God knows why", which suggests she may hold the view that there is a reason for why she is the mother of an autistic child. Due to this fact, she appears empowered to disregard the negative opinions from within her culture, including her own family.

4.6.4: Superordinate Theme: Difficulties Accessing Support

Amma also shared that accessing support for her son was challenging.

4.6.4.1: Subordinate Theme: Race

Amma wondered whether the difficulties she faced were due to her race. "Sometimes I'm having something ... that because I am a Black, the way they take care of my son is not enough." (735, p.52) Amma shares that she sometimes feels the support her son receives is "not enough", implying she thinks more may be able to be done. She questions whether this may be due to her race as a Black person.

4.6.4.2: Subordinate Theme: Parental Support

Amma shared that she found speaking with other parents going through similar experiences and shared similar racial identity helpful. “We have one lady at our church. She’s also having a boy that special boy like us.. so, she also talked to us a lot.. she also advise us a lot” (385-390 p.29) Amma seems to find the advice from a parent useful, and perhaps she found it easier to relate to her and trust her advice.

Amma expressed her desire for a “community” or groups to support Black parents with autistic children. “If we can create a certain community...especially for the blacks.” (795, p.62) Amma felt that having a specific space for Black parents would be helpful as it could be used to spread awareness of autism and reduce negative perspectives.

4.7 Mother Five: Sanyu

Sanyu is a Ugandan married mother of 3. Her first child, a son aged 7, received an autism diagnosis at age 4.

Table 4.5

Sanyu’s Superordinate and Subordinate Themes

Superordinate Themes	Subordinate Themes
Ugandan culture’s role	Limited awareness Negative views
Working with professionals	Negative encounters Understanding staff
Positive and supportive factors	Believing in God Support groups Feeling empowered

4.7.1: Superordinate Theme: Ugandan Culture’s Role

Exploration of Sanyu’s transcripts revealed that her Ugandan culture significantly influenced her experiences as a mother of an autistic child.

4.7.1.1: Subordinate Theme: Limited Awareness

Sanyu expressed that within her culture, there is no word for autism, and many believe it does not exist. Sanyu shared that child development stages and expectations differ from Western society.

I kind of didn't realise because back home kids can talk at any time.. then you have this kind of thing that boys take longer to do everything.... So, they do say the boys are lazy, so we kind of had that in our mind. (4 -7 p.1)

Sanyu suggests that because of the differing views on development coupled with the reduced awareness, she initially did not notice any concerns in her son.

4.7.1.2: Subordinate Theme: Negative Views

Sanyu explained that as people within her society often did not believe autism existed, it often led to her parenting being questioned.

he's just a spoiled child. You've spoiled him... that used to upset me so much because you would think I wish they would understand what he's going through, what his mind is going through...For them, it felt like it was something I made up as an excuse for his behaviour (413-427, p.42-43)

Sanyu shared that people from her community would say she had “spoiled” her child, and she was making “excuses” for his behaviour, suggesting that she felt her parenting was being judged by implying she did not discipline him.

4.7.2: Superordinate Theme: Working with Professionals

Sanyu’s transcripts showed that she found working with professionals challenging, which she linked to her cultural background.

4.7.2.1: Subordinate Theme: Negative Encounters

Sanyu describes having experienced negative meetings with professionals when autism was first raised. She recalled that this was an upsetting and scary experience.

She was the most rude person that I have ever met I remember the look on her face... she looked at me, and she went, umm, I think I need to refer you because your son is autistic... you will receive a letter in the post as she stood up and left... I remember when she got to the door, she turned around and said to me, good luck... when she left, it was the shock. ... first of all, I do not even know what autism is (86- 101, p.10)

Sanyu explained that reduced knowledge of autism left her feeling shocked. She stated that the health visitor’s initial approach to the possibility of her son being autistic was unhelpful and led her to disengage with services.

Sanyu adds that she felt that this was a missed opportunity for early intervention for her son and had a different approach which, considered her lack of autism awareness, she may have coped better.

If that Lady that I talked to the very first time if she had explained it to me in a way that I know it now. He would have gotten help a year, a year earlier...It would have been good for me as well because then I would have been having that support that I needed so that I would know that it's not me that's doing something wrong. There's something that needs to be done for my child to be better, but I didn't get that, so it was straight away, you block it before you even understand it. (912-917 p. 91)

Moreover, Sanyu explains that once she was over the shock she had difficulties gaining her son's support at nursery.

They tried their best, I guess, but not the very best because they give up so easily, and they realise that every time they would call me, I would come running... they had access to get help to refer him, which they didn't for a long time. So, they kept telling me ohh. He's not settling. You need to come and pick him up... I was very frustrated with them, so I just pulled him out (123-145, p.13-16)

Sanyu describes feelings of frustration caused by her believing more support could have been given to her son to access nursery. She seems to suggest that she felt the staff knew that if they called her, she would come and pick him up and use that option rather than accessing further support.

The difficulties with working with professionals seemed to continue into her son's transition to school. Sanyu described the lack of communication and conflicting views.

"They knew he was smart, but for some reason. They kept telling us that he was not on the same standard as his classmates. So, they left him in reception for a while before moving him into Year one, and that really upset us, but because you're trying to work with the school. You're thinking, right?"

We're just gonna be patient...we didn't know about it until when he had been in reception for about two months” (241-249, p.27)

Although Sanyu was upset at the lack of communication from the school and had differing views, she still attempted to maintain a collaborative relationship with staff. It could suggest that Sanyu did not feel able to voice her concerns at this point, feeling the school held more power.

Sanyu also expressed feeling patronised when attempting to work in partnership with school staff. “We felt patronised at some point because ... you said I know best, but then you're giving me this option, and it's like if I refuse to take it... I'm going to be a bad parent. (671-672, p.68) Sanyu may have felt she would be judged as a “bad parent” if she disagreed with the suggestions of school staff. She seems to wonder if this experience may be because of her race. “I don't want to assume that it had anything to do with my race or the race of my child, but you can't help it” (674, p. 68) Sanyu shared that the school was predominately White, and she worried about systemic racism. Nonetheless, she shared that she has become increasingly confident to “fight” for support.

“We still have systemic racism. We still have all these types of racism going around, very subtle, but they are around. So, you'll think if that happens to a (hand quotations) ‘normal person’. How about my child who has their limitations as well, so I find that I need to make these decisions based on fighting and pushing that they get what they deserve” (705, p.72)

Sanyu associated her race with having to “fight and push” to gain the help she felt was right for her son. The term ‘deserve’ suggests that Sanyu may have worried about unfair access to support due to their race. She highlights her son’s additional needs as a key factor in her motivation to gain him support.

4.7.2.2: Subordinate Theme: Understanding Staff

Sanyu also highlighted times when working with professionals was useful. She recognised this was when they were responsive to her son’s needs. “That was lovely of them because he wasn't forced to stay in the classroom... I appreciated that.” (231, p.25) Sanyu seemed to welcome when the support was individualised to her son, and this seemed to have a positive impact on her interactions with school staff. “We found a lady... she had that calm demeanour.. he gets very attached to

somebody that is calm.” (207, p.22) Sanyu shared that she found the relationship between her son and the TA contained her anxieties as she felt her “calm demeanour” was something her son gravitated towards.

4.7.3: Superordinate Theme: Positives and Supportive Factors

Looking at Sanyu’s transcripts, she identified factors that have supported her.

4.7.3.1: Subordinate Theme: Believing in God

Religion seemed to play a vital role in Sanyu’s life.

We believe in God. So, I think that has also been a very big factor.

That's raising our children, especially Mukisa, because we believe, we always believe that it's not what people are saying about him, it's what God has said about him, and that has really helped us through ... it was a very challenging time (377-379, p.39-40).

Sanyu finds her faith supportive during what she describes as a “challenging time”. She stated it is “not what people are saying,” which refers to the negative views held about autism within her community and finding solace in her faith to ignore them.

4.7.3.2: Subordinate Theme: Support Groups

Sanyu shared that having access to support groups was also helpful.

The support groups that I'm seeing now, I'm like if I had, if I had met these people years ago, what relief that would have been, because then you feel less alone... I used to think for many years...I thought I was doing something wrong. (825-827, p.84)

Sanyu implies that she found support groups to be a place of belonging and helped her overcome self-blame. Sanyu further expressed a desire to deepen this belonging through having culturally specific groups.

I think we need more of that because we are the ones that did not have ... the education .. about autism... So, if you came together, especially because of our culture... we would be more understanding of each other. (842 -848, p.85-86)

She links this to the lack of autism awareness and the need for further education to improve understanding through sharing lived experiences.

4.7.3.3: Subordinate Theme: Feeling Empowered

Sanyu also expressed that seeing her son's strengths and resilience has increased her resilience. "We become more resilient ...I'm more willing to educate and sensitise people. Culturally, People are blinded of what it is, you know, and now it makes you want to teach them even more" (634-638 p.65) Sanyu shares that this increased resilience has helped her be more proactive in spreading autism awareness, especially to community members.

4.7 Mother Six: Afia

Afia shared that she is a Black African Ghanaian. She is married with three children. Her second-born child was diagnosed as autistic at three and a half.

Table 4.6

Afia's Superordinate and Subordinate Themes

Superordinate themes	Subordinate themes
Christian faith	Christianity
Culture	Religion for a cure
	Autism is unheard of
	Judgemental views
Impact on family life	Divided attention
	Impact on siblings
	The role of race
Positives	Increased knowledge
	Inclusive school

4.7.1 Superordinate Theme: Christian Faith

Afia identified as a Christian and expressed that her faith was a significant aspect of her life.

4.7.1.1 Subordinate theme: Christianity

Afia shared that her church members supported her. "They do visit us sometimes, and they have, like, childcare When we go to church ... they have set a place that ...another girl...has an autistic.... both of them go inside play with toys" (12-13 p.1-2) Afia shares that her church members have made accommodations for autistic children, which has enabled her to continue attending church. She also added that members visit her at home, providing adult interaction.

4.7.1.2 Subordinate Theme: Religion for a ‘Cure’

However, Afia also noted that religion is can sometimes be interpreted in a way that hinders acceptance of autism within her culture.

She's from Ghana, and when his firstborn... two years, he hasn't talked. he said when you send a pastor who prays on...anointing oil, then post it from Ghana to here.... she pays the amount of money, and when she used the cream and oil on the boy, he will still be the same. (636-638, p.62-63)

Afia provided an example illustrating the lack of autism awareness and its negative connotations. She explained that people often believed autism could be cured through spiritual or religious means, such as using “anointing oil” and creams, implying that there was something wrong or evil with the child.

4.7.2 Superordinate Theme: Culture

4.7.2.1 Subordinate Theme: Autism is Unheard of

Afia explained that within her society, there is a reluctance to accept autism, as often people believe it does not exist.

Because they don't want to accept it... like back home you don't have that thing there, so they don't want to accept it. Me, if I did not give birth to (son's name), I would not even look for it. (611, p. 60)

Afia shares that it is hard for her community to accept or understand autism because “you don't have that thing there.” She suggests “back home” in reference to Ghana; autism is not seen. Afia quantifies this by adding that she only accepts autism exists because she has an autistic son.

Afia had not heard of autism before her son's diagnosis and shared that there are differing expectations on milestones specific to a child's sex. “People are even telling me boys don't talk early. Boys are quiet... I was following them until he started the nursery, and they told me maybe they something wrong, so I have to seek for an advice.” (69-71, p.7-8) Afia explained that within her community, there are views regarding male children that provided reassurance that her son's development, specifically speech and language, was as expected. However, she sought professional input only when the nursery staff raised concerns.

Afia shared that her reduced awareness of autism made the diagnostic process confusing and upsetting.

The day that they wanted to tell us that he has been diagnosed, I thought maybe they were going to give him medicine so that everything would go. The lady just told me we have gone through everything, but I think sorry to say.... It seems your son has. (pause- tilts head) I didn't want to hear, so I was just quiet, and my eyes, you can see I wanted to cry...I was not comfortable. I was very sad (127-133, p. 15)

Afia's seemed to have conceptualised autism as a medical condition that could be treated with medication. She seems to find the idea of autism uncomfortable, perhaps because of her reduced awareness of what this may mean for her child. Interestingly Afia does not use the term autism here, which could indicate the emotional impact it had on her.

Afia further expanded on the lack of awareness linked to the invisible nature of autism.

Not most of the children have those kind of autism in Africa, so people don't know; the only thing they know is like Down Syndrome. Those people that they face them. because if you see Kofi, they are perfect, there's nothing wrong. (104-108, p.12)

Afia references that autism is perceived as rare or non-existent within some parts of Ghanaian society. She seemingly links disability to visible or physical features, referring to Down Syndrome as the known and seen condition. Afia uses the phrase "those kind of autism, " which further suggests that the term may be used differently within her community to describe other conditions.

Moreover, Afia expressed that this lack of awareness led to judgemental views within her community.

African people, when you go to such places...I quite remember I was going with them, and I had to hold (son's name) hand. And the little boy (younger brother) was going, and someone said. How can you hold the big boy and

then leave the small little one? I just do my own thing because they don't know what is going on here. (194-198, p.21-22)

Afia may have felt that her parenting was being questioned but suggests it stems from the community not understanding her son's needs. Afia further shares that the judgements may also fall on the child themselves.

They may think he is bad boy. He doesn't understand his antisocial because he won't go with people here. And he doesn't like playing with others, so they may think my son is...pompous or like his of himself. (9-10, p.89-91)

Afia explains that her son's autistic presentation may be misunderstood within her community and lead to him being viewed negatively. She specifies the lack of social behaviour as the area likely to arouse the most disapproval, which suggests a strong value of togetherness is present within her culture.

4.7.2.2 Subordinate Theme: Judgemental Views

Afia shared that additional needs and disabilities were viewed negatively in Ghanaian society. "People with autism...they say...Evil something happening to him" (91, p.10) The term "evil" shows an interconnect of religious and cultural beliefs. Afia expresses that autism is often associated with a mother's wrongdoings that result in a negative outcome. "They may say maybe you have done something bad, then you have gotten the result by giving birth that child, or there's an evil thing did that to you. So you normally I don't share." (345, p.36) Furthermore, Afia also highlights a belief that autism results from an "evil thing" having occurred to the child. Afia seems to be referring to a spiritual element within the child. Afia seems to worry about the judgements and negative feedback she may receive from communicating her experiences within her community and, consequently, does not share this part of her life.

4.7.3. Superordinate Theme: Impact on Family Life

4.7.3.1 Subordinate Theme: Divided Attention

Afia spoke about the impact of having an autistic son on her other children.

He has most of the time, and my other kids always complain. I have to be with Kofi, pushing him on the swing and Yao (youngest son) will get angry. 'Why you always with Kofi? I have to play football, so I'll push him one. Then I'll go

and play. (laughs)...I said you know, Kofi has a problem. So, you have to understand. (244-258, p. 27-28)

Afia identifies that her other children “complain” about the amount of time she gives to her autistic son and the feelings of anger and upset it causes in them. She seems to attempt to remedy this by trying to equalise time. However, ultimately, she recognises that she will need to spend more time with her autistic child but caveats this to the other children by explaining his difficulties associated with autism. Afia seems to accept the lifelong nature of autism and acknowledges that her other children will need to understand. Interestingly she uses the word “problem”, which may imply she has constructed autism as an issue that causes her to be unable to share her attention equally.

4.7.3.2 Subordinate Theme: Impact on Siblings

Furthermore, Afia has found that, at times that having an autistic child impacts her other children’s ability to access leisure activities. “They told me to take him out, so I just took him ... When the sister finish, I'll be waiting outside ... So because of that, I can't take both ... to the swimming. I was really, really down.” (420, p. 43) Afia explains that her other children are sometimes unable to attend leisure activities when there are not inclusive, which impacts her mental health well-being, making her feel “down”.

However, she has found that her other children often want to help their brother, sometimes creating conflicting feelings in Afia.

Ohh, she's the caring one... Last time she said something, and I was very sad, she said. So, when Kofi grows up and I will grow up. I will still stay with Kofi if you are not around, and I was very sad...I feel very happy that even if I'm not there, they can take care of Kofi (283-293, p31-32)

Afia seems to express happiness and sadness at the thought of her daughter saying she would continue caring for her brother if she is “not around”. Although Afia reports feeling happy that her son would be taken care of, I wondered if the sadness stemmed from the thought of placing that responsibility on her daughter and, more crucially, the fear that her son may not be fully independent. “All of my children are

independent, but he is not independent... I don't know whether he'll work or not.” (456- 475, p.46-48) Afia clearly worries about what the future will look like for her son and how he will manage.

4.7.3.3 Subordinate Theme: The Role of Race

Afia adds that she has times wondered whether some negative experiences may be related to her race.

Sometimes when they see you and, I don't know. Maybe being a Black person and your child have... Because they have White people who are the same thing, but when they come close to them. 'Ohh hello' the way they will behave to them. You Black person, when your child go, then they give him a look. (369-401, p.38-41)

Afia seems to feel there may be different experiences between the Black and White racial groups for autistic children and parents. She questioned whether she has experienced negative attitudes and her child has been treated less favourably because they are racialised as Black.

4.7.4. Superordinate Theme: Positives

Afia acknowledges some positive experiences she has had as a mother of an autistic child.

4.7.4.1 Subordinate Theme: Increased Knowledge

Afia explained that she found the input from professionals beneficial to developing her understanding of her son and enhancing her ability to support him. “Speech and language ... they were educating me on how to play with him in the house. And even I have...portage in my house.” (155 p.17) Afia seems to suggest that she had access to early support that she found useful in helping her support her son. It seems to have increased her confidence and enhanced her skills to play and engage with her son within the home.

4.7.4.1 Subordinate Theme: Inclusive School

Afia also spoke about her children's school helping to raise their awareness of special needs. “So sometimes he will be teaching him. ... The school is helping a lot. Yeah, there are teaching them people with special needs.” (274, p.30) Afia expressed that the school have been able to explain differences, and she feels that

this has led to her children understanding their brother better and wanting to help him. I wondered whether this increased understanding helped Afia ease some of the guilt she may have felt about the level of attention her autistic child receives.

4.8 Patterns Across Participants

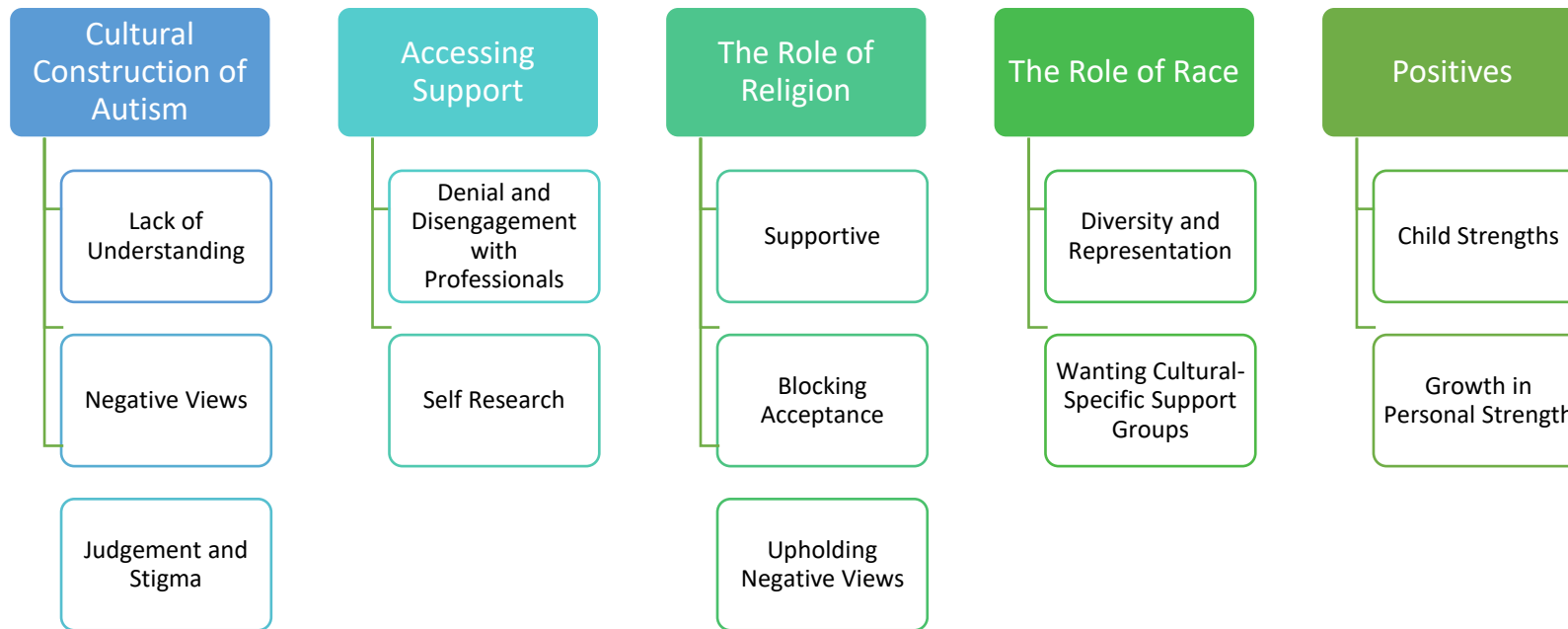
Patterns across cases were explored. Individual participants' subordinate themes were analysed at the group level and categorised into themes. Superordinate names were then produced that labelled these themes. To increase trustworthiness, identified themes were included if there were present in more than 50% (3 or more) of the participants' transcripts. Interpretations made by the researcher were also shared with participants.

4.9 Analysis and Interpretation of Superordinate Group Themes

Five superordinate Group themes were developed from the analysis (see table 4.1). Each group superordinate and the subordinate theme is discussed in relation to the research question, highlighting the lived experiences of Black African mothers of autistic children. Tables display the subordinate themes and displays which participants provided experiences related to that theme.

Figure 4.1

Superordinate Group Themes



4.9.1: Superordinate Group Themes: Cultural Construction of Autism

A strong narrative among participants was the negative perceptions of autism within their communities.

Table 4.7

Subordinate Themes Relating to Superordinate Theme: Construction of Autism

Construction of Autism						
Subordinate Theme	Aisha	Keza	Tiwa	Amma	Sanyu	Afia
Lack of understanding	✓	✓	✓	✓	✓	✓
Negative Views	✓	✓	✓	✓	✓	✓
Judgement and Stigma	✓	✓	✓	✓	✓	✓

4.9.1.1 Subordinate Theme One: Lack of Understanding

Participants were asked during the interview about their awareness of autism before their children’s diagnosis and whether there was a word in their various languages for it. “I don't have any name for autism. They will classify them as mental... Mental health.” (Amma 210, p.17) All participants shared that no word for autism existed, and often, the words used to describe disability held deeply negative and discriminatory connotations such as ‘evil’, ‘stupid’ and ‘mental’.

Within their communities, the mothers shared that A was viewed as either non-existent or uncommon. “I think it doesn't exist... They don't see, you don't even mention it.” (Sanyu 422, p.43) The majority of the mothers only had limited awareness of autism, and some of their knowledge contained misinformation such as links to MMR vaccinations or something that was rare or did not affect their community. The lack of awareness seemed to lead to confusion, upset and shock during the diagnosis process. “he's like, yeah, your son is on the spectrum. And that for me was a blow. It was too much to deal with.” (Keza 28, p.4)

All mothers expressed experiencing great sadness that was rooted in the negative connotations that autism is given within their culture. Some mothers felt overwhelmed and unable to manage as an initial response. They often worried about what autism would mean for their children’s future and how they would be treated as a community member.

It affected; it wasn't just me. It affected the whole family... How it was gonna be viewed in society. They worried about him as well. Umm, you know, how he was going to cope in a society like going to school, how he was going to be viewed or treated (Aisha, 78-80 p.13)

Most mothers explained that the diagnosis affected the wider family and felt they had to manage their feelings on top of their own. Most mothers shared wanting to increase their family's knowledge so that they could accept their autistic child.

4.9.1.2 Subordinate Theme Two: Negative Views

All participants shared that autism was viewed negatively within their specific cultures.

In my country, for you to be a proper person..., you have to be able to communicate. You have to be able to... do things like your peers...once you can't do that... then they regard you as someone who's not complete. (Tiwa 85-87, p.10)

Differences in development and perceived lack of ability to succeed in life seemed to underpin some negatively held perceptions of autism. However, the most significant narrative was the perceived causes of autism, often linked to spirituality. Mothers gave examples such as "evil eye", "mami wata", and being "bewitched". Autism was also often viewed as the result of mothers being punished for wrongdoings.

because some parents think...they've bewitched my child...something that I did wrong, and my child is paying for it all... in people's minds is like we can fix it. So, take you to... like a medicine man⁴ or whatever and have it fixed. (Sanyu 431-337, p.44)

Disabilities, including autism, were often seen as a disease or something that could be cured. Again, here it suggests that the conceptualisation of autism within some African societies is that something is wrong that needs to be fixed often through traditional means such as "medicine men".

4.9.1.3 Subordinate Theme Three: Judgement and Stigma

The lack of understanding and negative view of autism often meant mothers felt judged by their communities. They shared that their parenting was often questioned,

⁴ medicine man, also called a medicine healer or witch doctor, is a person believed to be knowledgeable about the magical and chemical potencies of various substances (medicines) and skilled in the rituals through which they are administered

and they were blamed for not disciplining or placing boundaries on their child's behaviour. Mothers shared that people tended to view autistic traits as 'misbehaviour' or being 'spoiled.'

It's very difficult... Sometimes you can't even do the things you want to do... he doesn't understand. Sometimes he will, he will just wake up and if you don't be fast, he would just wee on the floor, something that I never like in my life to smell wee in your house and also sometimes the way people see you. I mean it's like your happiness has been taken away from you.... (pause) I mean (deep sign) ... it tough, it is in fact, it was where you want to go, because of him, you cannot go... so I'm always in house (Amma 619-644 p.45-47)

Mothers were clear that the negative views caused them to often alienate or distance themselves from their communities to avoid judgements. Some mothers highlighted receiving "looks" as a main concern, suggesting they felt they were failing to meet the expectations within their communities.

4.9.2 Superordinate Group Theme: Accessing Support

Support was another superordinate theme found across participants. Having support was significant for the mothers and their children.

Table 4.8

Subordinate Themes Relating to Superordinate Theme: Accessing Support

Accessing Support						
Subordinate Theme	Aisha	Keza	Tiwa	Amma	Sanyu	Afia
Denial and Disengagement with Professionals	✓	✓	✓	✓	✓	
Self-Research	✓	✓			✓	

4.9.2.1: Subordinate Theme: Denial and Disengagement with Professionals

Another common narrative was the difficulties mothers experienced in accepting their child's diagnosis of autism. Many parents spoke about going into a "denial phase" and had feelings of "depression" or low mood. This often led to disengagement from services and was often cited as an initial response.

I went into, you know, denial mode straight away. I was like no, it's not happening. There's nothing wrong with him. And even when the letter came through, I just I tore it up... I was like, no, I refused. Because in my head I was like they it can't be...what kind of childhood is he going to have, you know? Is he going to be happy? Is he going to be picked on? Is, Especially the fact that where we live down here. I refuse to take him. (Sanyu 106, p.8)

Many mothers expressed that the disengagement resulted from disbelief and upset at the suggestion of possible autism. Mothers appeared to find it difficult to comprehend as often they had not linked their children's needs, often delayed speech with possible autism. Furthermore, some mothers worried that an autism diagnosis would mean for their children. Mothers were concerned about the possible negative treatment of their children within society, including prejudice and discrimination from their own communities but also wider society in the form of racism. Many mothers linked their disengagement with professionals directly to their cultural background.

100% I think that if I came from a culture where mental health wasn't stigmatised, it would have been an easier journey for me because the denial was both on my end but also on the on like the the larger family unit, right? ...

I think it played a big part in how long the denial phase went on for. (Keza, 111-115 p.16)

Intriguingly, the mother seemed to be highly motivated to educate members of their communities about autism to raise awareness and, in turn, increase acceptance and normalise it. This seems to suggest that mothers want their children to belong and be welcomed by their communities but also to recognise that there are differences because of their autism. “I’m trying to explain things to them. So, I’m thinking by the time we will go... there will understand. Yeah because when they know how he is behaving, they will adapt.” (Afia 351-355, p.37) Here Afia suggests that sharing knowledge about autism would make her son’s and her experiences easier as her friends will be able to adapt, knowing what to expect.

4.9.2.2: Subordinate Theme: Self-Research and Difficulties Accessing Support

Some mothers raised the lack of readily available information post-diagnosis as an important issue and often felt there had to engage in finding out information for themselves. “I feel like once the diagnosis comes into place, there should be (pause), you know, the information should just be coming at you. You shouldn’t have to struggle to find what you need.” (Aisha 113, p22) Many mothers expressed that this left them feeling unsupported and frustrated at professionals not offering information about the type of support available.

Some mothers shared that attempting to gain support was challenging. “The developments that he's gotten at the moment is also because of the help that we had to fight so hard for, to get.” (Sanyu 320, p.34-35) The mothers described this challenge as a “fight” to get support for their children. Mothers explained that they

often encountered barriers to accessing support. They felt they had to be well-informed and ready to speak up against professionals to gain the support they felt their children needed.

4.9.3: Superordinate Group Theme: Role of Religion

Religion seemed to play a significant and often conflicting role in most participants’ lives.

Table 4.9

Subordinate Themes Relating to Superordinate Theme: Role of Religion

Role of Religion						
Subordinate Theme	Aisha	Keza	Tiwa	Amma	Sanyu	Afia
Supportive	✓			✓	✓	
Blocking acceptance	✓		✓	✓		
Upholding Negative Views		✓	✓	✓		✓

4.9.3.1 Subordinate Theme: Supportive

Mother’s faith seemed to provide support and comfort. Many found it to give them the strength to accept their child’s diagnosis and engage with support.

Participants shared that their faith helped them to believe their children could make progress. Mothers shared that they felt there were as deeper purpose or meaning as to why their children were autistic. Some parents felt they were “chosen” to parent an autistic child.

4.9.3.2 Subordinate Theme: Blocking Acceptance

Some mothers’ faith seemed to block their full acceptance of their children’s autism. Many shared praying for the autism to “go away”. “As an African woman, I still pray that one day everything just disappears. Through prayers, you know what I mean. Yeah, and I still, I still believe I still believe, yeah.” (Tiwa 135, p.35) Many mothers seemed to believe that through prayer, it is possible for autism to “disappear”.

However, mothers often also recognised that prayer was helpful and believed more social support was necessary for their children’s development.

4.9.3.3 Subordinate Theme: Upholding Negative Views

Some mothers shared feelings of judgement that stemmed from religious interpretations often intertwined with cultural beliefs. “Maybe you have done something, and someone has cursed you” (Afia 628, p.62) Mothers reported that autism was viewed as evil, a form of punishment for “sins” or wrongdoings of the mother. These interpretations led to beliefs that prayer was needed for mainstream faith leaders. However, often there was also a belief that support needed to be sought from traditional spirituality. “Faith has nothing to do with it; it’s just society.” (Tiwa 97, p.12) All the mothers seemed to at least partially reject the negative religious connection and identified that it was more a cultural belief stemming from spirituality.

4.9.4: Superordinate Group Theme: The Role of Race

Many mothers often wondered whether their race as a Black person played a role in their experiences.

Table 4.10

Subordinate Themes Relating to Superordinate Theme: The Role of Race

The Role of Race						
Subordinate Theme	Aisha	Keza	Tiwa	Amma	Sanyu	Afia
Diversity and Representation	✓	✓		✓	✓	✓
Cultural-Specific Support Groups	✓	✓		✓	✓	✓

4.9.4.1 Subordinate Theme: Diversity and Representation

Most mothers expressed concern about the lack of diversity among healthcare professionals and school staff. There feared that it may disadvantage them and the type of support there received. “He's the only, you know, Black kid in the school that as well spooked us.” (Sanyu 298, p.32) Mothers expressed not wanting to believe that there may be systemic racism due to their race.

I don't think it's it's enough. They are doing enough to support him. I don't know how they handle the other, but maybe...I don't want to say it is this thing but to me. That means sometimes. It's not good to me. (Amma 747-789, p.53)

However, some mothers described negative experiences that made them think that their minoritised race group was an underlining reason for it. Due to this, the majority of mothers hoped that greater representation would occur among professionals. “Probably have like diverse. Like people of different backgrounds that can relate to, you know, to the parents and the culture.” (Aisha 108, p.21) Many parents wanted greater diversity as they felt this would help professionals understand their experiences more deeply, including their cultural identity and its impact on their lives.

People need to educate themselves about small things, especially with different cultures. They will come up to you with an open mind and try to understand you from that perspective ...because it's it's part of you... My culture is part of me. (Sanyu, 778-781, p.81)

Mothers highlighted wanting professionals to take an approach that considered the lack of awareness and the negative perception autism held within their cultures. There felt that this additional cultural layer was often missed, and they were not fully supported.

4.9.4.2: Subordinate Theme: Cultural-Specific Support Groups

Mothers who had accessed parental support groups highlighted wanting specific groups for African mothers of autistic children.

But it's almost a level of comfort or just knowing that, hey, you have a community of people who are going through this, and you're not the first person to go through it, right? But that that having that added layer of having like someone with a similar culture who understands those little things, that that, to me, was the most important. Yeah.... So just things you don't have to explain, or you can just say that the person says, oh my God, that's I get it. (Keza 150-152, p.21)

They seemed to reason that it would help spread awareness but, more importantly, foster a sense of belonging with other parents going through similar life experiences, including their cultural aspects.

4.9.5: Superordinate Group Theme: Positives

All mothers identified positives attributed to their experiences as a mother of an autistic child.

Table 4.11

Subordinate Themes Relating to Superordinate Theme: Positives

Positives						
Subordinate Theme	Aisha	Keza	Tiwa	Amma	Sanyu	Afia
Child’s Strengths	✓	✓	✓	✓	✓	✓
Growth in Personal Strengths	✓	✓	✓	✓	✓	✓

4.9.5.1: Subordinate Themes: Child’s Strengths

All mothers often spoke about the strengths they found linked to their children’s autism. Characteristics included memory abilities, academic achievements, resilience and loving. “I’ve never seen anyone that’s been through so much, and they’re so resilient, you know what I mean? Like, you’re so strong” (Keza 166 p.23) Mothers seemed to admire their sons’ strengths, which was a source of great pride for them. Moreover, the mothers seemed to find motivation and drive from witnessing their children’s achievements to continue advocating for greater awareness and acceptance.

4.9.5.2: Subordinate Theme: Growth in Personal Strengths

Most mothers also explained that they felt they had gained skills through raising their autistic children. Skills included being more knowledgeable, tolerant, social, and resilient. “So, what I will say is if you think your child is different from other children, just accept it. Then seek help yeah. And he and he’s not any evil thing that has come to” (Afia 623-624, p.62) Whilst speaking about strengths and positives, Afia expressed that she had gain an understanding that her son was not evil and this helped her understand and motivated her to seek A key message mothers took

away was the knowledge that their children could progress with the right support, and they felt empowered to be the providers or advocate for their children to ensure their needs were met.

4.10 Chapter Summary

This chapter outlined the researcher's interpretative analysis of the superordinate themes of the participants both at the individual and group level. The findings illustrated varying experiences of Black African mothers raising autistic children. Such experiences appeared to be underpinned by their cultural and racial identity. The following chapter will present how the findings relate to the research questions, previous research, and psychological theory.

Chapter 5: Discussion

5.1 Introduction

The final chapter will outline the themes in relation to the research question. Although the researcher will primarily use the identified group themes, individual participant themes will also be discussed to incorporate IPA's idiographic principles. The link between previous literature and psychological theory will be presented. A discussion of the strengths and limitations of the current study will be provided. The chapter will conclude with the researcher's reflections and plan for disseminating findings.

5.2 Research Question

This study aimed to explore the lived experiences of Black African mothers of autistic children within the UK. Research looking into the experiences of the global majority is minimal, particularly within the UK. This research used a participatory approach to capture Black African mothers' voices and provide new insights and knowledge.

5.3 What are the Lived Experiences of Black African Mothers Raising Autistic Children within the UK?

The current study outlined a range of experiences of Black African Mothers of autistic children that appear closely linked to their cultural and racial backgrounds. The themes that arose from the study often interlinked due to the underlining cultural influence on the mothers' experiences.

5.3.1 Cultural Construction of Autism

This research found a close link between how autism is understood and the mother's cultural background. The findings suggested a general lack of knowledge of autism within African communities to which they belong. Bronfenbrenner's (1994) ecological model is a helpful framework to examine different systems and their influence on the understanding and view of autism.

At the macro or community level, participants in the present study reported an absence of language about autism, sharing that there were no terms or words for autism within their various languages. Mothers also explained that there were widely

held views that autism was non-existent or rare within their communities. This aligns with previous research (F. Fox et al., 2017; Hussein et al., 2019), who also found a lack of vocabulary about autism in Somali society, and many community members believed it did not exist.

This study also revealed that there were some differing views on child development expectations between Western and African cultures. Afia and Sanyu explained that boys were often reported to develop more slowly, particularly around speech development. These differing views of child milestones seemed to have mitigated early concerns around development for the mothers and often meant worries were first raised by professionals. This mirrors existing literature findings that reported Pakistani (Habib et al., 2017) and Latina (Gordillo et al., 2020) mothers described broader developmental milestones for children within their culture, which often meant that parents initially had no concerns when their children displayed some traits associated with autism.

Furthermore, at the individual level, mothers in the present study had limited or no awareness of autism before their children's diagnosis. This echoes previous research findings that found global majority parents often only heard of autism following their child's diagnosis leading to deep confusion and difficulties in understanding what professionals meant by the term (Gordillo et al., 2020; Hussain et al., 2019; Ijalba, 2016; Munroe et al., 2016).

At the macro level, participants in the current study shared that autism was viewed negatively within their communities. Most mothers within this research explained that words used to describe disability or differences from typical development were negative or derogatory. For example, terms such as evil (Afia), stupid, or mental illness (Keza) were commonly used within their communities. This is similar to the findings by F. Fox et al., (2017), where Somali families often labelled atypical development as mental illness. Likewise, parents from this current study also expressed that people within their communities believed autism resulted from

spiritual involvement. Examples of such spiritualities included the “evil eye” (Aisha), “mami wata” (Amma), “curses” (Afia) or being “bewitched” (Sanyu).

Furthermore, autism was also conceptualised as a type of disease or illness. The mothers explained that this often meant that within their society, there were views that it could be cured or fixed, usually through traditional methods. Moreover, autism appeared to be perceived as a barrier to a “successful” life, often linked to high expectations such as academic achievement. This mirrors the findings of Theara and Abbott (2015), who found that ethnic minority parents from South Asia also viewed autism negatively as they believed it posed a threat to achieving ‘success’ within their society.

Such negative views and lack of understanding within the different cultures often led to stigma and judgements for the mothers in the present study. Many felt their children’s autistic behaviours were seen as naughty, and their parenting skills were questioned or blamed. Mothers shared that their wider families and communities often held disapproving views and perceived the behaviour as due to a lack of boundaries for their children. This is similar to the findings in the study by Lovelace et al., (2018), who found that African American mothers also reported that family and community members blamed their parenting for their children’s autistic behaviours. Likewise, many of the participants in the current research felt alienated from their communities and often distanced themselves from others due to fears of judgements and blame. This finding fits in with previous studies, which also found that global majority parents often felt alienated and socially isolated due to the negative perception of autism within their societies (Ijalba, 2016; Khanlou, 2017; Selman et al., 2018; Slade, 2014).

Stigma is often defined as characteristics that deviate from social norms (Link et al., 2014). Previous studies (Obeid et al., 2015; Someki et al., 2018) have suggested that stigma around autism is greater in collectivist societies such as the countries of heritage of the mothers in this study (Ghana, Uganda, Nigeria and Rwanda). This

has been linked to societal values around cultural tightness, which refers to clearly defined and strict social norms and the punishment or rejection of behaviours that go against or violate the norms (Triandis, 1989). In such societies, people tend to desire sameness and social harmony. Such communities also tend to view uniqueness or individual differences as a threat to this harmony and consequently perceive it negatively (Someki et al., 2018).

Additionally, increased levels of cultural tightness has been found to predict prejudice against individuals viewed as not aligning with social norms, including those with disabilities (Jackson et al., 2019). This could explain the heightened stigma the mothers in this present study reported as a result of the culture to which they belong. For example, Afia shared that she worried about her son's autistic trait of reduced social interaction being misunderstood as antisocial and how he would be treated as a result. Furthermore, Keza shared that those children considered to not "fit the mould" were "dismissed" in her community. Amma also shared a similar belief, who explained that being different from peers was viewed negatively, and such children were perceived as "incomplete" and often experienced prejudice and discrimination.

Nevertheless, considering a social constructionist viewpoint, multiple truths exist that are influenced by a person's culture, beliefs, and background. Therefore, it could be interpreted that the negative perceptions that appear to exist within African communities could be due to the differing beliefs about autism. The Western standpoint often takes a positivist stance: an individual must meet diagnostic criteria (the dyad of impairment- please see chapter one for further details) to receive an autism diagnosis, which implies a universal truth exists. However, the present study's findings suggest that this directly clashes with the viewpoint of the mother's cultures, who do not have a name for autism and, in some cases, believe it does not exist.

5.3.2 Accessing Support

This study highlighted a close link between culturally negative views about autism and mothers' engagement and experiences with professionals. Most parents reported experiencing difficulties accepting their child's diagnosis, often describing going through a denial phase that initially led them to disengage from professional

services. This response seemed to be associated with the stigma of autism and what this would mean for them and their children within their communities. Moreover, Sanyu and Amma shared that family members advised them not to accept an autism diagnosis due to their belief that it either did not exist or the stigma associated with the label. Similar findings were also found in past research where family members also urged parents to reject the diagnosis (Gordillo et al., 2020; Lovelace et al., 2018; Selman et al., 2018)

Most of the mothers in this study associated the lack of knowledge and understanding of autism as a key factor in the negative views and stigma within their cultural group. As a result of the negative views, many mothers in the present study explained that they attempted to raise awareness of autism amongst their family and friends to increase their child's acceptance within their communities and consequently enhance their wellbeing. Maslow's (1987) Hierarchy of Needs could explain this objective from the mothers. The theory outlines that the third human need is love, belongingness, and acceptance after physiological and safety needs. The theory suggests that in order to achieve "self-esteem" and "self-actualisation," the previous layers need to be fulfilled. Mothers within the present study could therefore be said to be attempting to meet a basic need for belonging.

There is some evidence from previous research to suggest that increasing autism awareness can be effective in reducing stigma. Gillespie-Lynch et al., (2015) found that college students in the USA showed decreased stigma towards autistic peers after partaking in training to increase their knowledge about autism. Likewise, raising autism knowledge in members of collectivist societies with heightened autism stigma also effectively reduced negative perceptions. Someki et al., (2018) compared the US (individualist) and Japanese (collectivist) students' stigma levels following engagement in autism awareness training. They found that Japanese students showed a greater decrease in stigma after finishing the autism training than their US counterparts. However, research into cultural factors in autism stigma is minimal, and most previous research has used university students.

Mothers seemed to have to break away from traditionally held views to accept their children's diagnoses and reengage with professionals. However, another narrative raised by this research was the lack of readily available information and difficulties accessing support for their children. This mirrors existing research that found parents often had a limited understanding of available services, and information was not readily provided following their child's diagnosis. (Khanlou, 2017; Lovelace et al., 2018; Theara & Abbott, 2015). Mothers in the present study often felt they had to engage in self-led research to find information and fight for support.

5.3.3 The Role of Religion

Parents reported having a varied experience of religion, which was seen as a source of support but also as upholding negative views and blocking full acceptance of their children's autism. Mothers shared that their faith helped them accept their children's diagnosis, and parents often felt a deeper purpose or felt chosen by God to parent an autistic child. This aligns with past studies that found religion supported parents by providing hope and acceptance (F. Fox et al., 2017; Habib et al., 2017; Hussein et al., 2019; Lewis et al., 2022; Munroe et al., 2016; Selman et al., 2018). However, like some previous studies (F. Fox et al., 2017; Ijalba, 2016), there was some indication in this study that a mother's faith also acted as a barrier to full acceptance. As with F. Fox et al., (2017) and Ijalba, (2016), some parents engaged in prayer in the hope to "cure" their children's autism. The present research also found that the wider family often advised prayer as the main form of intervention and reason for not accepting the diagnosis of autism. Nonetheless, in line with the findings of Hussein et al., (2019) and Lovelace et al., (2018), most mothers in this research study also seemed to accept the need to access healthcare services and professional advice to support their children's development.

Religion was also reported to uphold negative views in this research study. Mothers shared that often their communities viewed autism as the result of wrongdoing, past sins, or a form of punishment. The current study added to mainstream religious beliefs links around autism within their communities to include more culturally spiritual ones. Mothers explained that religious beliefs seemed to become interlinked with cultural beliefs. Some mothers reported as autism was thought to be caused by

spiritual forces; there were beliefs within their communities that support needed to arise from traditional spirituality, such as medicine men. Existing research echoes these findings. Ndlovu (2016) described that some indigenous African beliefs about physical and psychological illness or difficulties/disabilities are linked to punishment from ancestors, curses, or witchcraft. As such, Ndlovu (2016) reported that some African communities, therefore, believe that to counterbalance these ailments, help is needed from traditional methods through “diviners or medium” (p.32) “to restore the health and well-being of the patient spiritually, morally and socially” (p.33). A similar was also found by Sarkar et al., (2021), who explored pathways (traditional or biomedical care) to care for mental, neurological and substance use disorders. They found that care choice stemmed from what was believed to be the cause of the disorders. Traditional care choices were therefore linked to beliefs that the illness or disorder was due to bewitchment.

5.3.4 The Role of Race

A novel and significant finding from this present was study was the concerns about systemic racism due to a lack of diversity within the healthcare and school system as well as being a global majority member in predominately White areas. They worried that being racialised as Black might impact accessing support and community experiences.

Afia, for example, shared that she sometimes felt that her son being Black and autistic led to him being treated less favourably within the community. She explained that she felt that White autistic children were often given more acceptance and understanding in society. This could be understood through the concept of White privilege (Leonardo, 2002), where whiteness is seen as the norm and often, White people receive more compassion (Collins, 2018). Furthermore, Sanyu shared that she felt patronised by school staff and worried about systemic racism when discussing what support may suit her son and explained that she had to fight to ensure he gets the support she felt he deserved. Research suggests that systemic racism exists within the UK education system that continues to create significant ethnic inequalities at all stages of schooling (Alexander & Shankley, 2020).

Institutional racism was also found to lead to discrimination and prejudice within school practices and teachers' attitudes towards Black pupils (Timpson, 2019).

Crenshaw's (1991) Intersectionality framework can also help understand the mothers' experiences. The framework proposes that social identifiers such as race, gender and disability overlap to produce societal privileges or discrimination. In this study, therefore, being Black and the proximity to disability could create disadvantages and power imbalances for the mothers. Likewise, Purdie-Vaughns and Eibach's (2008) notion of Intersectional Invisibility states that individuals with multiple marginalised social identifiers can become 'invisible' compared to people with one marginalised identity. It is argued that such individuals experience unique social privileges and disadvantages.

Moreover, CRT also explores race-based oppression and argues that both overt and, importantly, covert racism should be identified and actively addressed to remove inequalities and injustice (Treviño et al., 2008). CRT aims to produce social justice by removing barriers and equalising processes and institutions for marginalised groups (Treviño et al., 2008). This research study used a participatory approach by recruiting a Black African mother of an autistic child as a co-researcher to plan and explore the lived experiences of this marginalised population. The study aimed to promote social justice by providing the opportunity for Black African mothers of autistic children to voice their experiences that recognised the impact of their ethnic, racial, and cultural identity.

Mothers shared wanting access to culturally specific support groups where they could access families from similar cultural and ethnic backgrounds and those with shared life experiences. They explained wanting a space where their cultural experiences were readily understood and acknowledged, having often found that racial and cultural factors were often absent. White privilege (Leonardo, 2002) may also explain the mother's hopes for such a space. Many autism parent support groups exist within the UK. However, they may be argued to predominantly stem

from White Western experiences of autism and, therefore, may exclude global majority cultural experiences. Having such support for global majorities that considers their specific cultural experiences may enhance their wellbeing. Sanyu shared that belonging to such a group has been a “relief”, and she felt “less alone” (p.84), whilst Keza explained she found “comfort” (p.21) in attending such support groups. The notion of belonging has been suggested to be a basic psychological need, and when it is absent can cause people to experience negative mental health wellbeing, stress, and loneliness. This suggests that people are highly motivated to create secure and meaningful relationships with others. A lack of belonging can therefore have a detrimental effect on wellbeing (Baumeister & Leary, 1995).

5.3.5 Positives

All the mothers in this study identified strengths within their children that they attributed to them being autistic. These included academic achievement, resilience, and enhanced memory abilities. Mothers also expressed gaining personal skills from their experiences of raising an autistic child. Many mothers reported improved resilience and increased autism awareness. Mothers described feeling empowered to share their knowledge as well as advocate for their children to ensure they receive support to allow them to progress. This mirrors previous studies (F. Fox et al., 2017; Habib et al., 2017; Lewis et al., 2022; Munroe et al., 2016; Theara & Abbott, 2015), which also found that parents had increased appreciation of their child’s strengths, feelings of positivity for the future as well as personal growth (Lovelace et al., 2018).

The mothers’ personal growth can be understood through the notion of post-traumatic growth, which theorises that people can develop positive attributes, new perspectives or coping strategies following adverse psychological experiences. Some studies have explored post-traumatic growth in parents of autistic children (Feng et al., 2022; Tedeschi & Calhoun, 2004; Qin et al., 2021; Wayment et al., 2019; Zhang et al., 2013). Zhang et al., (2013), in particular, highlighted that mothers of autistic children reported viewing new possibilities and gaining personal strengths after overcoming the initial upset and shock of their child’s diagnosis. Furthermore, the personal strengths reported in this study could also be understood through the theory of internal locus of control (Rotter, 1966). After a period of coming to terms

with the diagnosis, mothers appeared to take responsibility and engaged in self-research about autism and sought to find the right support for their children, suggesting they developed a belief that they had the power to be able to help in their children's progress and development.

5.4 Limitations

Although this research has added to the limited literature on the lived experiences of Black African mothers of autistic children, some limitations are recognised.

Firstly, it should be noted that the researcher is working within a Western psychological paradigm. Therefore, most theories used to interpret the experiences of Black African mothers have stemmed from this dominant, predominantly White culture. All participants and their children are based in the UK with some being British citizens. They are therefore living in a Western society, making the use of Western psychological theories appropriate to some degree. Nonetheless, it is acknowledged that some caution should be taken when applying such theories to Black African mothers.

Moreover, the study's small sample size means the generalisability of the findings may not represent this population as a whole. This study recruited 6 participants. However, in line with IPA, a purposeful sample was sought to allow for an in-depth exploration of lived experiences. Participants were recruited as they were able to share experiences of raising an autistic Black African child. All participants identified as Black African mothers who had an official diagnosis of autism obtained in the UK. Their children were all between the ages of 6-12 years old. Participants were also recruited from a similar geographical location. Moreover, all the mothers had sons. This added to the homogeneity of the group; however also further impacted the generalisability of the findings. Nonetheless, the study aimed to gain knowledge and understanding of the mother's lived experiences rather than statistical generalisability.

Another limitation of the inclusion criteria was that mothers needed to be able to speak English at a conversational level (as it was not in the remit of this study to recruit a translator) to participate in the SSIs to express their views and experiences. This excluded mothers who were not fluent in the English language. Therefore, it is

possible that the experiences of such mothers could differ from those within the study, primarily because of the impact of a language barrier.

All the participants were self-selected, which could have influenced the findings as parents were motivated to engage in the study. This again could have impacted the findings as participants were willing to engage with a professional and share their experiences.

The study successfully recruited a co-researcher to work alongside the researcher who hoped to fully take part in the various aspects of the researcher process. However, due to life circumstances this was not possible for her, making the co-researchers participation limited in some areas. Consequently, the sharing of power primarily remained with the researcher. On reflection, it may have been helpful to have multiple co-researchers to allow for participation to continue for a fuller participation for the entirety of the research project. This could increase social justice for Black African mothers of autistic children.

A final consideration is the subjective nature of IPA studies. As discussed earlier, the process of double hermeneutics means that the participants and researchers can view the same phenomena in various ways (J. A. Smith et al., 2012). As such, the interpretations made by the researcher can be impacted by their values, beliefs, and past experiences. Consequently, the participant's original meanings may not be represented. To mitigate the researcher's bias, the researcher engaged in member checking to strengthen the representation of findings. This aided the triangulation and provided additional insights into the views and experiences of the mothers. Of those who responded (4 of 6 parents) reported the finding to be a good representation of their experiences.

5.5 Strengths and Distinct Contribution

A main distinctive contribution of this study is that it adds to the limited research into race, culture, and autism. To the best of the researcher's knowledge, this study is the first in the UK to use PR approaches and IPA to explore the lived experiences of

Black African mothers raising an autistic child in the UK. The study has provided insights and rich data into their values, identity, and views. The research demonstrated the importance and need for professionals to engage in culturally sensitive practice.

Another key strength is that this study promoted the voice of Black African mothers to share their experiences within autism research, an underrepresented group in this area. Moreover, the study took on PR principles and recruited a co-researcher. She worked collaboratively with the researcher in various stages of the research process, including planning and reviewing the final group themes. By engaging in this process, the present study offers in-depth and relevant findings of the experiences of this population. This, therefore, increased the trustworthiness of the study. The study also acted as a form of social justice by providing the space for a marginalised group to share their experiences first-hand. Furthermore, the researcher and co-researcher identify as Black African mothers with an autistic child, which provided an insider perspective. This again enriched the study as a culturally sensitive approach was taken throughout the study (Tillman, 2002).

The current study's findings emphasised that the experiences of Black African Mothers are underpinned by their racial and cultural backgrounds. Although there were many similar themes across participants, there were also several differences. This study highlighted the importance of recognising the need to continue to be mindful that CYP and families hold unique characteristics, and a person-centred approach and cultural responsiveness should be adopted when working with them. This research demonstrated the significance of intersectionality in the participants' life experiences and how having multiple marginalised social identities can impact them. It is hoped that the findings can aid EPs and other professionals working with diverse populations to better understand and tailor the support encompassing their racial and cultural experiences.

5.6 Suggestions for Further Research

The current study highlighted the interlinking nature of cultural and racial backgrounds on the experiences of Black African mothers of autistic children. Autism

research into lived experiences has tended to omit participants' ethnic or cultural backgrounds as essential factors. Following the findings of the present study, it is key for future research to continue emphasising the role culture and race play in lived experiences.

This study looked into the experiences of individuals who identified as Black African mothers. It would be interesting to explore the experiences of Black African fathers of an autistic child, particularly as previous research showed a lack of inclusion of fathers in research. Likewise, this study also only had mothers of autistic boys. Further research could also explore parents' experiences with autistic daughters to examine possible gender differences, particularly as some mothers in this study suggested different beliefs on gender roles and expectations. Moreover, some participants raised the impact of having an autistic sibling on their other children. Further research could, therefore, also seek to gain such siblings' views and lived experiences directly. Equally, gaining direct views from Black African autistic children would also enhance knowledge and insights into their lived experiences.

A key narrative from the findings in this study was the negative views about autism that were linked directly to cultural beliefs. This often led to stigma, judgements, and reduced wellbeing in parents. There is some evidence of targeted intervention aimed at reducing stigma being effective in other collectivist populations (Hofstede et al., 2010). However, there appears to be a lack of research involving African populations. Future research could therefore aim to provide tailored intervention for members of the Black African community to reduce stigma and promote inclusion and acceptance.

5.7 Implications for EPs

The present study raised many recommendations and implications for EPs and other professionals working with Black African families. The findings of this study have illustrated the significance of culture and ethnic background on individuals' lived experiences. As EPs, it is recommended that we demonstrate cultural competence by being actively aware of cultural factors and considering these during our practice and service delivery (BPS, 2017; HCPC, 2015). Moreover, by encompassing the

ecological systems model (Bronfenbrenner, 1994) in practice, EPs are well placed to work within and across the various levels to support CYP and their families.

Subsequently, such a position enables EPs to promote social justice and anti-oppressive practice. EPs can challenge assumptions, raise awareness of inequalities, and advocate for improved experiences to increase marginalised groups' wellbeing and positive outcomes. In line with PR principles and to continue to promote social justice, it will be crucial for such families and their CYP to be actively positioned as the experts in their lives and included in conversations about how best to support and meet their needs.

Furthermore, EPs can promote social justice in their practice by owning and understanding their privilege. Speaking about and acknowledging racial injustice and facilitating conversations around power dynamics during consultations and planning meetings will be essential. The Six Stage Conceptual framework is a valuable resource for such discussion (M'gadzah, 2022). This is a tool that can be used to explore where individuals and organisations are in their journey towards understanding and dealing with racism. It also examines the challenges faced and provides ideas, strategies, and support for dealing with and challenging racism (M'gadzah, 2022). Additionally, the Social Justice Standards (Learning for Justice, 2016) be utilised as a guide for anti-bias practice within educational settings. These standards and learning outcomes encompass four domains (identity, diversity, justice, and action). The four domains can be used to encourage discussions within the classroom around anti-bias, multicultural and social justice issues.

By holding culturally responsive consultations, EPs can also encompass cultural competence by remaining curious about clients' cultures and how they may impact their experiences. Using cultural interview schedules, such as the Cultural Formulation Interview (Lewis-Fernández et al., 2020) or the Jones Intentional Multicultural Schedule (Jones, 2009), may be helpful resources to help guide EPs' questions to ensure that culture is explored and included in the formulation and support of clients. EPs may ask questions such as:

- Why do you think this is happening to you? What do you think are the causes of your issue?

- What do others in your family, friends, or community think is causing your issue?
- What has helped you cope?
- What is the best way I can support you?
- How does religion or spirituality affect your family?

Key guidelines and legislations for EPs also highlight the need to include CYP and families' views in the decision-making process about their lives (Department for Education and Department of Health, 2015). Working at the individual level, EPs can gain the views of parents and include them in the planning and delivery of support for their children. By following person-centred planning approaches, EPs can be responsive to individual family needs. This study has illustrated the value of empowering mothers to share openly about their experiences when positioned as the experts in their lives. EPs can act as advocates and aim to balance power dynamics for global majority parents to ensure their voices are heard and included to foster a holistic understanding of the CYP, including their cultural and ethnic experiences.

Another essential role of the EP is to provide psychoeducation and aim to make a positive change. This study and previous research have found that often global majority families hold negative perceptions of autism, which can impact engagement with services and the wellbeing of the CYP and family. EPs can support school staff by raising awareness of potential negative views and sharing knowledge about developing a sense of belonging, for example, by having culturally specific parent workshops or groups around autism.

This study's findings also highlighted the importance of the wider family and their community as they play a crucial role in providing information and advice to mothers. Often the families and wider community appeared to hold belief systems that differed from Western culture. As EPs, we are skilled in identifying such differences and, by adopting participatory approaches, can work alongside community members to

promote community cohesion (Boyle & Lauchlan, 2013). Mothers in this study stated the importance of positive relationships with those working with their children and identified this as a helpful factor in their lived experiences. Therefore, EPs can provide evidence-based interventions and best practices that support the systems around CYP to develop family, school and community partnerships and help increase engagement with global majority communities (Boyle & Lauchlan, 2013). At the cultural level (macro), for example, EPs could provide culturally sensitive interventions to increase awareness and reduce stigma around autism. Considering the pivotal role religion played in participants' lives, promoting links with religious leaders may also be beneficial.

Finally, all mothers in this study were able to speak about the strengths and positives of raising their autistic child, including personal growth. Taking a positive psychology perspective and solution-focused approach could provide a new way to engage with families and increase and promote coping strategies for them.

5.9 Reflexivity and Reflections

In this section, the researcher will present her reflections on her position during the research and its impact on her practice. As reflections stem from a personal position, this section is written in the first person.

5.9.1 Power Dynamics

Throughout the research process, I held in mind power dynamics, particularly the work of Bourdieu's (1986) Theory of Capital and, more specifically, cultural capital theory. I reflected on the possible power imbalances between the participants, the co-researcher and I. I drew upon attuned interaction principles and consultation to keep a self-awareness of my dual position as a TEP and researcher and the effect this may have on the interactions and relationships with the co-researcher and participants. I was highly aware of the high value that the title of EP (even as a trainee) is likely to hold due to the educational level and how this may lead me to be positioned as an expert in autism. Therefore, I made it explicit to both the co-researcher and participants that only they knew best their lived experiences and were the experts in their life. I aimed to empower the participants by encouraging them to lead conversations in the interviews and for the co-researcher to make decisions in the stages she wanted to be involved in. I took the opportunity to

discuss any power imbalances and how to manage these during my supervision with my university tutor and placement supervisor. This allowed me to be transparent during the research process about the decisions I made. I also engaged in the process of reflection in action and on action (Schön, 1983) to reflect on my role as a practitioner-researcher.

5.9.2 Researcher's Identity and Position

Throughout the research process, I reflected on my motivation to explore autism and culture. As mentioned previously, I am a Black-African female with an autistic son. Furthermore, my background is working in a specialist autism school, where I often came into contact with parents and had discussions about their lived experiences. I wanted to explore Black African mothers' experiences from a social justice standpoint but also because of my own personal experiences. I was consciously aware of the impact this may have on the research process. I felt my experiences enabled me to have an insider perspective that helped me facilitate a culturally sensitive approach and foster rapport with participants and the co-researcher. This helped them to share their experiences openly and to understand the nuances of their ethnic and cultural experiences to some extent, enhancing the trustworthiness of the findings. Coming from the same background as the participants and co-researcher also seemed to help rebalance power dynamics when exploring culture and race. This was especially important as there is an underrepresentation of global majority members within the field of psychology (York, 2019).

Nonetheless, I did worry during the analysis stage whether my personal background would skew some of the themes and whether I may have motivated perception or blind spots and seeing what I wanted to see rather than the accurate representation of the data. By engaging in member checking of the interpretations and having a co-researcher to overlook the group level themes helped me remain objective and remain in a position of neutrality which added a layer of rigour to the research.

5.10 Plans for Dissemination

The principles of PR recommend that community members being researched should be included in disseminating the research findings. This increases the finding's meaningfulness and credibility (Willig, 2013). Therefore, the co-researcher will be given the option to take part in sharing the findings with key stakeholders.

On completion of the research project, the researcher and co-researcher will create a one-page summary of the key findings that will be shared with participants with the option to speak about the research. It is also planned that the findings will be shared with EPS and LA's autism advisory service. In the future, it is also hoped that the research can be published to allow for broader sharing of the findings that will help inform other professionals working with this population.

5.11 Concluding Statement

This study is the first to use a participatory approach to explore the lived experiences of Black African mothers raising an autistic child in the UK. The research study adds to the developing field of autism and culture research, looking into lived experiences. Mothers expressed experiences of negative views about autism in their communities, the impact of race and the role of religion. Mothers also shared their experiences of accessing support and the positive outcomes of being a mother of an autistic child. The present study produced important implications for EPs, schools, and other professionals. In particular, it highlighted the need to demonstrate cultural competence to provide support that integrates racial and cultural identity when working with families of autistic children. The current study emphasised the stigma autism holds within this community, highlighting the crucial need to raise autism awareness to combat this and increase the wellbeing of the CYP and the parents. Moreover, the study demonstrates the need to incorporate the ecological model (Bronfenbrenner, 1994) when planning and implementing support for this population to target the different system levels. Lastly, the co-researcher, participants and researcher hope that this study can help lead to social justice through equalising power by promoting collaborative participation of a marginalised group with a limited voice and presence in autism research.

5.12 Chapter Summary

The final chapter presented the research findings, connecting them to the research questions. The main findings of the present study were embedded into the existing literature and explored through the theoretical and conceptual lens to enhance understanding. The strengths and limitations of the study were identified, and the unique contributions were also highlighted. The researcher's reflections and reflexivity were discussed, including the researcher's positioning. Implications of the

study and ideas for future research were also included. The chapter ends with a concluding statement.

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Appendix A - Critical Appraisal of Studies

Study	Participant s	Research design and epistemology	Analysis	Findings	score	Critical analysis
Fox, Aabe, Turner, Redwood & Rai. (2017) UK	15 Somali parents of children with a diagnosis of autism 3 fathers 12- mothers Children five were girls and 12 were boys. 4 to 13 years	In-depth interviews Community based participatory research approach	Inductive thematic analysis	Lack of autism awareness amongst the community. – no word for ASD. Disability viewed negatively associated with stigma. Difficulties accepting ASD.	9 High quality	community-based participatory research (CBPR) allowing direct work with Somali families Had a pilot study to help refine the interview schedule. Participants can speak in their first language if needed. Obtained insider perspective- one researcher same ethnicity No statement of ontological and epistemological positions. No critically examined of own role, potential bias, and influence (one of the authors founded the organisation where participants were recruited from. No details given whether results were checked by participants not all themes discussed/presented- stated this was due to space.
Gordillo, et al. (2020) USA	Twenty mothers Latina vs. non-Latina diverse mothers of children with ASD. Asian -25%	semi-structured qualitative interviews	thematic analysis	Immigrant mothers-half of who were Latinas thought children from own background couldn't have ASD. Latina mothers struggled to accept ASD. – associated with stigma	8 High quality	Participants had previously been involved in research before- could this miss out on the range of experiences. mentioned of ethical considerations. No statement of ontological and epistemological positions. Participants could choose to be interviewed in English or Spanish. Did not specify the results for each ethnic group – all grouped together.

	<p>Black/African American – 8.3%</p> <p>Latina/Hispanic – 50%</p> <p>White/Caucasian – 16.7%</p> <p>3–11 years old</p> <p>Reference to daughter and sons- no specific names given</p>					
<p>Habib, Predeville, Abdussabur & Kinsella. (2017) Ireland</p>	<p>7 Pakistani mothers</p> <p>4-18 years</p> <p>6 boys</p> <p>1 girl</p>	<p>Semi-structured interviews</p> <p>Constructivist interpretive</p>	<p>Thematic analysis</p>	<p>Positive experiences- satisfied and content with raising ASD child, positive experiences of education. <i>Positive impact of parenting a child with ASD</i> e.g. makes you strong, tolerate, sensitivity to others' feelings. Strengths of children.</p> <p>Challenges – delays in getting support/ diagnosis, challenges in educations- lack of resources. the immigrant experience- life in the wider community. life within the family</p>	<p>8</p> <p>High quality</p>	<p>Stated epistemological position. Obtained insider perspective – one researcher of the same ethnicity and parent of ASD.</p> <p>No critically examined of own role, potential bias, and influence (one of the authors founded the organisation where participants were recruited from).</p>
<p>Hussein, et al. (2019) UK</p>	<p>32 Somali parents (to an autistic or non-autistic child)</p>	<p>interviews</p>	<p>Thematic analysis</p>	<p>Lack of knowledge and understanding of autism. – prejudice and discrimination- lots of stigma. Atypical behaviour viewed very negatively- usually labelled as mental illness- has negative connotations.</p>	<p>9</p> <p>High quality</p>	<p>Obtained insider perspective – one researcher of the same ethnicity. Ethical approval was mentioned.</p> <p>Essentialist framework was used (to report the experiences, meaning and</p>

	<p>16 parents of autistic children and 16 parents of non-autistic children. 2 fathers 15mothers each group</p> <p>15 boys, 1 girl</p> <p>6 – 15 years</p>			<p>Some believe ASD doesn't exist in Somalia. Believes may be due to MMR and lack of vit D and sunshine exposure.</p> <p>Some hide child's ASD diagnosis as a result.</p> <p>No word for ASD- no provision for autistic children in Somalia</p> <p>Strong reliance on faith Helps parents accept diagnosis Some believes ASD caused by Jinn. Some use faith as intervention – seek support from faith leaders. But also, acceptance of other interventions alongside</p>		<p>reality of participants without attempting to fit the data to pre-existing coding schemes or assumptions of the researchers)</p> <p>Parents were recruited via convenience sampling from just one - region in the UK and were interviewed in English and not in Somali- Somali parents that do not speak an adequate level of spoken English may have different views and beliefs about atypical development.</p>
ljalba. (2016) USA	<p>22 Hispanic immigrant mothers of preschool children with ASD. The mothers were from Mexico (n = 10), the Dominican Republic (n = 10), Ecuador (n</p>	3-part phenomenological interviews	thematic analysis	<p>stigmatization and social isolation, specific features of immigration adding to challenges. , the risk of family separation and conditions of poverty influencing their social context.</p> <p>Unauthorized immigrant status placed parents at risk for deportation and family separation. 3 fathers had been deported. – emotional trauma caused. Losing the primary earner also brought economic hardship</p> <p>Limited awareness of ASD within the community-</p>	7 Medium quality	<p>Phenomenological interviews used- Had three interviews with each participant. Open-ended questions allow participants to tell experiences in a narrative format. No ethical considerations mentioned.</p>

	<p>= 1), and Peru (n = 1).</p> <p>eight girls and 14 boys ranging in age from 37 to 45 months</p>			<p>Economic hardships meant had to be in shared accommodation- overcrowding/ lack of privacy – stressful situations for parents.</p> <p>Some believes children will outgrow ASD.</p> <p>Different expectations of milestones- Family members often supported these notions and advised mothers to wait in obtaining services.</p> <p>mothers' reluctance to speak Spanish with their children. – thought it would lead to more language learning difficulties</p>		
<p>Khanlou. (2017) Canada</p>	<p>21 immigrant mothers of children with Autism, from a diverse ethno cultural background</p> <p>Asia (China, Philippines, Taiwan, Japan, India, Pakistan, Sri Lanka)</p> <p>14</p>	<p>semi-structured interview</p>	<p>House's (1981) four domains of social support to analyze findings</p>	<p>Structural Support: Migration and Settlement Challenges</p> <p>Immigrant mothers found it difficult to navigate the health and social systems in Canada.</p> <p>Language barriers- lack of understanding of service delivery systems</p> <p>Mothers often one who left job to care full time for children whilst fathers worked. – creating further isolation as well as economic hardship. Frustration at lack of employment or limited employment conditions that allow them to work part time and have flexible schedules to care and advocate for their children.</p> <p>Quality and Access to Services</p>	<p>6 Medium quality</p>	<p>Questions designed to explore the four domains of House's classification of social support- concentrated on social support may limit what participants could talk about.</p> <p>Mentions ethical approval received</p> <p>Group results together- hard to know which ethnic group being discussed.</p> <p>Had a team to analyse data- although not much details given on the process.</p>

	<p>Europe (Ukraine, Poland, Belgium, Romania, Albania) 5 Latin America (Costa Rica, Trinidad, and Tobago) and Tobago)2</p> <p>16 boys 11 girls</p> <p>2- 31 years</p>			<p>Key finding- immigrant mothers rarely asked about their needs and about what services are best for them. particularly important in the immigrant family context- diverse values and belief systems</p> <p>social isolation and little leisure time</p> <p>infrequent contact with friends and family.</p>		
<p>Lewis et al. (2022) USA</p>	<p>Twenty-two parents All participants were women, - primary care givers 20 Black African Black or African American White 1</p>	<p><i>Coping Questionnaire</i> and participated in semi-structured interviews</p>	<p>grounded theory</p>	<p>Used different coping strategies – sometimes in combination</p> <p>Parents want more social support – that are more inclusive – to included intersectionality of race, gender, and disability.</p> <p>Social support – family, church-protective factor. Informal support also helpful- emotional support, financial support, babysitting. However, still feelings of social isolation – discrimination</p>	<p>7 Medium quality</p>	<p>Ethical approval obtained Insider perspective – one author- Black mother of a young adult with autism Considered coping strategies- didn't explore broader experiences.</p>

	<p>Latinx 1</p> <p>Children ranged in age from 3 to 17, with a mean age of 10.2 years, and the majority were males (88%).</p>			<p>Positive self-talk – reframe challenges.</p> <p>planful problem- solving parents reported needing to use an emotion focused method, self-control- mindful of how they communicate. female caregivers of autistic Black children use “professional persistence” to counter perceptions of “Black Mamas.” with professionals to avoid sounding “Angry.” Before being able to gain benefits – Black females must overcome the impacts of sexism, racism, and ableism.</p>		
<p>Lovelace et al. (2018) USA</p>	<p>3 mothers (African American)</p> <p>Boys 7-16</p>	<p>Narrative inquiry – interviews</p>	<p>Grounded Theory</p>	<p>Racial discrimination: Covert and overt acts. When work with professionals. far more covert acts -mothers hesitant to state due to race.</p> <p>Complex collaboration: Felt had to fight harder to access services, difficult decisions- between inequitable treatment of their sons, or being placed in uncomfortable situations by educators or service providers.</p> <p>subthemes of resilient advocacy- difficult interactions- mainly negative experiences related to advocating for their sons, they did note that when they met service providers that met their needs, their interactions changed.</p> <p>Family dynamics- <i>Single parenthood</i> - mitigated any positive effects they may have gained from other families’ experiences. impact on well-being,</p>	<p>7 Medium quality</p>	<p>No ethical approval mentioned directly but spoke about getting participants’ permission to record interviews. Insider perspective- African American interviewer. Selection bias in that they represent a group that responded to recruitment materials and volunteered</p>

				<p>commitment to interventions and support</p> <p><i>Familial interpretations.</i> families did not believe in the diagnosis or the cause of ASD in their family member.</p> <p>Community dynamics: the African American community, the Autism community, and in some instances, the intersection of each.</p> <p><i>Community interpretations- negative</i> interpretation of ASD within African American community.</p> <p><i>Lack of resources-</i> The lack of resources was not simply in reaction to physical places to access services. The absence of educational information</p> <p><i>Lack of connection.</i> A consequence of the absence of resources is distance from ASD advocacy communities.</p> <p>Effective sources of support for each woman were their extended families.</p>		
Munroe, Kathryn, Hammond & Cole. (2016) UK	6 African immigrant mothers of a son diagnosed with autism Sierra Leone (n=1), Ethiopia (n=1), Nigeria (n=2) and	Qualitative methodology - interviews	Interpretive Phenomenological Analysis	<p>Most had not heard of ASD prior to the diagnosis, suggesting low awareness among the African immigrant community.</p> <p>Mothers experienced stigma, blame and social isolation.</p> <p>Embarrassment and shame appeared to stem from negative attitudes and stigmatising beliefs held by others in the African community, which blamed the mothers. This led them to feel rejected by, and disconnected from, their potential support networks, and</p>	9 High quality	White British author-possibility of power imbalances, the researcher reported being reflexive through supervision, keeping a reflective diary and speaking with colleagues about positioning and motivation to mitigate this. a social constructionist positions ethical considerations mentioned

	Uganda (n=2). 7-13 years			perhaps led to feeling under pressure to fit into British society. However, religious faith was identified to be a protective factor traditional African beliefs were incompatible with the medical information the mothers learnt. resulted in a feeling of significant cultural and emotional dissonance for the mothers, for whom traditional African beliefs were unbearable when applied to their child. Acceptance of a medical understanding offered a framework of meaning, absolving the blame they experienced and protecting their maternal identities. However, this led to a painful conflict within their cultural identities. It appears the mothers had all, at some point, felt marginalised from both cultures, resulting in feelings of shame and alienation		
Selman, Fox, Aabe, Turner, Raman and Redwood (2018) UK	15 participants, 12 were mothers, 3 fathers-Somali parents)	community-based participatory research approach In-depth interviews	thematic analysis	Two main themes with sub-themes were identified: the nature of stigma (labelling and stereotyping; separation; emotional reactions, discrimination and power) and coping and resistance (the power of language; faith as a resource; learning, peer support and community relationships). Children with autism were labelled and stereotyped (e.g., as 'sick', 'naughty', different') and parents blamed for not controlling them, leading to social rejection and isolation. Stigma was	7 Medium quality	community-based participatory research (CBPR) allowing direct work with Somali families ethical considerations discussed. Insider perspective- The co-researcher, NA, has a child with autism and is the chief officer of AI and a facilitator of education sessions for parents. Therefore, she was known, but not close, to most potential participants. Participants able to speak Somali. Same sample as fox et al. - sample bias

				associated with a poor understanding of autism, a lack of vocabulary related to autism in the Somali community, and prejudice against mental illness and disability. There was evidence of enacted and felt stigma and examples of discrimination. Finding their own language to describe their child's condition and drawing on faith, learning and peer support were important resources in resisting stigma.		
Slade. (2014) UK Diverse perspectives: The challenges for families affected by autism from Black, Asian, and Minority Ethnic communities	130- 71 Asian ; 56 Black; 2 White; 1 Middle Eastern. Almost all participants were parents, siblings, and carers of children with autism. Two were adults with autism. 106 participants were female and 24 were male	Structured focus group discussions	Thematic analysis	Lack of understanding of ASD in BAME community. Impacts access to services. ASD viewed negatively	3 Low quality	analysed data as a whole, making it difficult to ascertain specific characteristics or factors impacting their experiences no mention of ethical considerations no mention of how data was analysed didn't say how participants were recruited

Theara & Abbott. (2015) UK	9 South Asian parents mother and father Pakistan, India and Sri Lanka	In depth interviews Social constructivist lens	Grounded Theory Model	Parents' construction of autism privileged 'medical model' perspectives' and this was largely underpinned by cultural values	8 High quality	a social constructionist position Insider perspective- good for rapport- however, possible bias.
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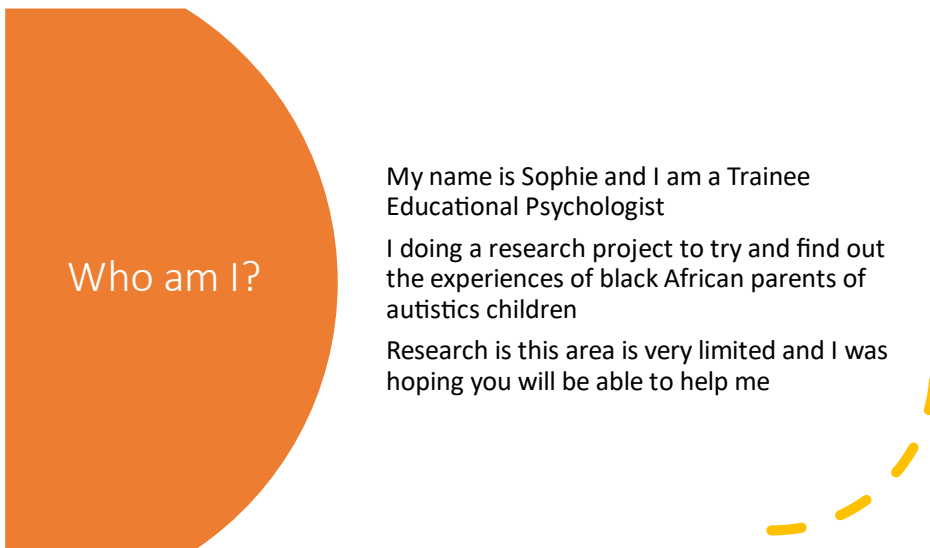
Appendix B - Co-Researcher Presentation Slides



Participatory
research project

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Sophie Lemboye (Trainee Educational
Psychologist)

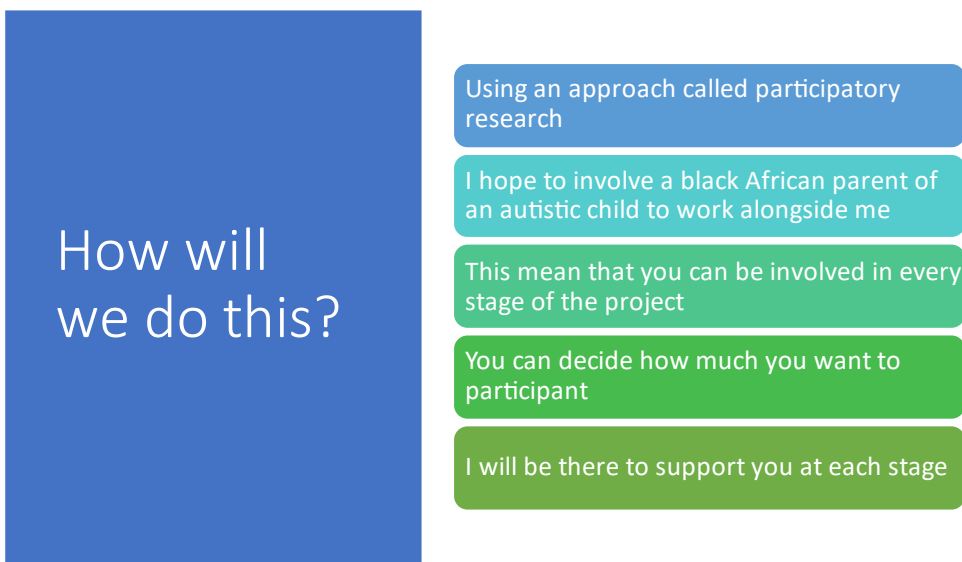


Who am I?

My name is Sophie and I am a Trainee Educational Psychologist

I doing a research project to try and find out the experiences of black African parents of autistics children

Research in this area is very limited and I was hoping you will be able to help me



How will we do this?

Using an approach called participatory research

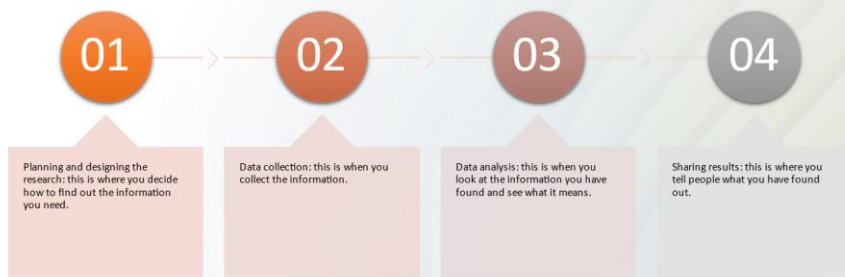
I hope to involve a black African parent of an autistic child to work alongside me

This mean that you can be involved in every stage of the project

You can decide how much you want to participant

I will be there to support you at each stage

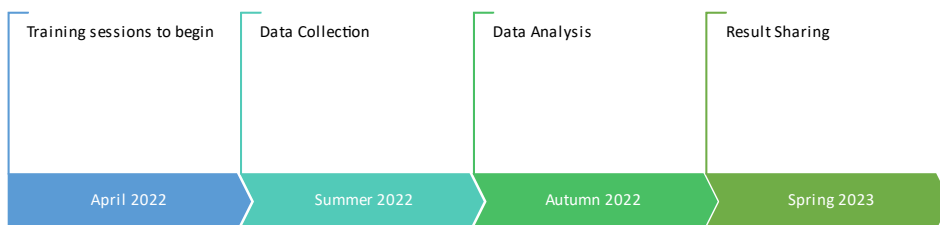
Stages of the research project



What will the commitment be?

-  The level of involvement is up to you
-  You can decide which parts of the research process you want to be part of
-  If chose to be part of each stage, it is likely to involve a weekly commitment
-  This should be no more than 1 hour a week

TIMELINE



Benefits of being a co-researcher

- Learn new skills in carrying out research.
- What an Educational psychologist does and how we work and support children and young people
- I hope you will find it interesting

Key information



If you choose to be involved in the project you can decide to leave at any point.



You can ask us any questions about the project before you make a decision without any commitment.



As a co-researcher it will not be possible for your participation to be anonymous, e.g. you may be in contact with participants during the interview stage.



All the data from these 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 you or others in harms way, then I have an ethical duty to report this

Interested? What do you need to do?



Tell me at the end of this session if you think you might be interested in being a 'co-researcher'.



I will then give you an information sheet that contains all the information we have told you and more.



If you are still interested, then you will need to sign a form that confirms your agreement to become a co-researcher.



Appendix C - Information Sheet for Co-researcher



Information sheet for Co-researcher

Become a co-researcher on a project exploring the lived experiences of Black African mothers of an autistic Child in the UK.

Who am I?

My name is Sophie and I am a Trainee Educational Psychologist

Why am I contacting you?

I am doing research exploring the lived experiences of Black African mothers of an autistic child aged between 7-11 years old.

Can I be the co-researcher?

Yes, if you are:

- Black African
- Have an autistic child between the ages of 7-11 years old
- Your child was diagnosed in the UK
- Your child has had their diagnosis for at least 2 years

What would I have to do?

As a co-researcher it will be your choice as to how much you are involved in the research. Once you agreed to becoming my co-researcher, 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 in. The risks of taking part in this study are low. 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 does and how we work and support Children and Young people as well as their families.

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 choose to co-publish the researcher.

Will 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 participants during the interview stage. All the data from this study will be stored in line with the 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's way, then I have an ethical duty to report this

If you would like to be my co-researcher, what should you do?

You can email me on u2064585@uel.ac.uk so we can arrange a time for us to meet. I will explain the research in more detail once we met. I will need to get you to sign a consent form.

Thank you for taking the time to read this information sheet

Appendix D - Consent to Participate in Research Study



UNIVERSITY OF EAST LONDON

Consent to participate in a research study

Addressing intersectional invisibility: Exploring the lived experiences of Black African mothers raising an autistic child in the UK

Contact name: Sophie Lemboye

Email: u2064585@uel.ac.uk

	Please initial
I confirm that I have read the participant information sheet for the above study and that I have been given a copy to keep.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation in the study is voluntary and that I may withdraw at any time, without explanation or disadvantage.	
I understand that if I withdraw during the study, my data will not be used.	
I understand that I have 3 weeks from the date of the interview to withdraw my data from the study.	
I understand that the interview will be recorded using Microsoft Teams in the interview is remote or using a Dictaphone if in person	
I understand that my personal information and data, including audio/video recordings from the research will be securely stored and remain confidential. Only the research team will have access to this information, to which I give my permission.	
It has been explained to me what will happen to the data once the research has been completed.	
I understand that short, anonymised quotes from my interview may be used in material such as conference presentations, reports, articles in academic journals resulting from the study and that these will not personally identify me.	
I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to.	
I agree to take part in the above study.	

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

.....

Date:

Appendix E – Co-Researcher Training – Lesson Plans

Co-Researcher Lesson Plans Session 1: What is Research?

Session 1: What is Research?

Learning aims	Knowledge content	Skills	Interactive elements
Begin to develop an understanding of the nature of research	The nature of research/enquiry The importance of research	Critical thinking Separating fact and opinion	Discussion Video
Begin to have an appreciation of ethical issues in research	Different types of research and their main characteristics	Interpreting research findings	

Discussion:

- Experience of co-researcher

Video:

<https://www.youtube.com/watch?v=wBomUBY62a4>

Formulation of a research question

- A methodological design
- The collection of raw data
- In depth analysis
- Scrutiny of validity
- The generation of *new* knowledge
- What do all of this mean?

Why is research important?

- Increase knowledge and understanding
- Can bring about beneficial change
- Promotes problems solving
- Can call out poor or unethical practice

Research and Ethics

Will cover more in depth later Research **must** be ethical – in the best interests and needs of the participants. It must not cause harm or distress. Researchers must be frank, open, and critical

Core Activity Co-researcher reads the following report (fictional) and considers whether this is valid research'.

Prompts given as needed:

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.

- Is this report research ‘?’
- Would you describe it as systematic, sceptical, and ethical?
- What other information would researchers need before they could draw the same conclusions as this journalist?
- How differently do you think a research report might be constructed?

Guided comments:

This would not be considered valid research because:

- Only select pieces of data are used so it is not systematic
- It is not sceptical as it doesn't look for any data that might disconfirm its claims
- The article is unethical as it makes links between fast food and heavier babies without any evidence to back this up e.g., we don't know what the mothers of the larger babies actually ate
- We need a lot more data to claim these as fact e.g. height and weight of parents and their diets, any medical conditions that may affect birth weight (diabetes etc).
- Comparing babies in Japan and India needs to be done alongside other relevant factors, e.g. average size and weight of adults in those countries.

Session 2: Learning from Other People's Research

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

Discussion:

Learning from Other People's Research

How do we know the difference between good and bad research?

If research has all the aims we described last session, we also need a way to evaluate if it has met these aims and practiced in an ethical way.

Much research is written up into research papers. Being able to find our way around a research paper is a key aspect of judging quality.

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.
- Titles often come in 2 parts e.g., ‘Just teach us the skills please, we’ll do the rest’: empowering ten-year-olds as active researchers.

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.
- A good abstract will have a few sentences covering each section of the overall research paper – the introduction, methodology, findings, and discussion.

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.
- This may be quite extensive as authors will need to justify their study area by reviewing previous research to see how well it addresses their research question. This is usually called a *literature review*.
- 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).

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.

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 e.g. whether the methods were appropriate to address the research question(s).
- For example, if making a comparison between girls and boys there needs to be close to equal representation of each gender. It would not be fair to use 100 boys but only 10 girls.

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.

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.

Conclusion

- This draws together the main findings that have been explored in the discussion.
- It is intended to summarise the main points rather than make new ones.

You can use these strategies to decide how relevant a research paper is to you before you read it.

- Look at the title. Does it contain key words that link to your topic?
- If the literature source is an article, read the abstract as this gives you a short summary of what the research is about.
- What year was it written? If it was a long time ago it may be out-of-date.
- Look at the subheadings. Do they deal with subjects that are relevant to your topic?
- Read the first and last sentences in paragraphs and subsections because sometimes they are mini introductions and summaries of the content.

It is also very important to read papers in a *critical* way. Ask yourself the following questions when reading a paper:

- What is the author trying to get me to accept?
- What evidence is the author providing me to persuade me to accept this?
- How plausible is the reasoning and explanation that is provided?
- How reliable is the evidence on which this reasoning is based?

Core Activity

Read the following research paper.

Fox, F., Aabe, N., Turner, K., Redwood, S., & Rai, D. (2017). 'It was like walking without knowing where I was going': A Qualitative Study of Autism in a UK Somali Migrant Community. *Journal of Autism & Developmental Disorders*, 47(2), 305–315.

Discuss the following questions:

- Is the title a good summary of the paper? If not, can you suggest a better one?
- Does the abstract tell you a little about the introduction, methodology, findings, and conclusions?
- Does the introduction tell you what the study is about and why it is being undertaken? Does it review other people's research in the field?
- Is there sufficient explanation in the methodology for replication? Is the method appropriate for the research question? Can you find anything unsound,
- Are the results clear and presented in a way that is easy to follow and understand?
- Does the discussion section relate the findings of the study to the literature reported in the introduction? are there ways in which it could be improved?

Session 3: Research Ethics

Learning aims	Knowledge content	Skills	Interactive elements
Understand the primary importance of ethics in research	Informed consent	Thinking skills	Discussion
	Human rights	Appreciating perspectives other than one's own	
	Confidentiality		

Appreciate a given situation from another person's perspective	Anonymity	Making balanced judgements	
Develop greater ethical awareness		Exploring moral and social values	

Ethical considerations are an integral part of every stage of a research project. Sometimes, the topic of the research itself can be ethically sensitive e.g. bullying. The very act of exploring this with individuals could cause distress, anxiety, or increase a person's vulnerability to a bullying situation. However, it is also important that issues like bullying are explored so that we can increase our knowledge and understanding, to improve prevention. Researchers must always be conscious about the balance of benefits versus costs of a study. These costs can include:

- Emotional e.g. anxiety, embarrassment, depression, loss of self-esteem.
- Financial e.g., cost of the individual's time, loss of earnings, travel costs.
- Physical e.g., pain or other physical effects (e.g., in medical research).

Can you think of another example where researcher(s) would have to be sensitive about individual reactions/safety?

Some guiding principle to focus on (from Alderson & Morrow, 2004):

- Respect and justice – e.g., respecting participants 'sensitivities and dignities.
- Rights – e.g., participants 'rights to be protected from harm, to be fully informed and listened to.
- Best outcomes – to actively promote best outcomes for participants.

Research usually needs to be approved by at least one ethical body before going ahead.

Informed Consent

- *All* research must have the *consent* of all participants. However, before individuals can give their consent they must understand exactly what they are agreeing to. This is what we call *informed consent*.
- It is ethically questionable to not provide any information regarding a research project to a participant, or to not provide enough information to enable them to make a decision about taking part.
- Participants need to be told:
 - The aims and objectives of the research.
 - How the data collected from them will be used (especially in regard to confidentiality and anonymity).
 - How the findings will be disseminated.
- This information needs to be transparent, with no hidden agendas.
- With children, consent needs to be sought from parents too. This is because there are debates about what age is sufficient to be able to make an informed decision. Sometimes parents and children disagree, and this can even go to court in important cases (e.g., *Gillick v. Norfolk and Wisbech*).
- Even if a child is not able to sign a consent form, every effort needs to be made to explain the research to them in an accessible format and be approached about consent.
- Informed consent also relates to *ongoing* consent; participants should be aware that they can withdraw their consent at any time and for any reason.

Confidentiality and Anonymity

- Participants should be protected within the research process. This includes keeping data confidential and anonymous wherever possible.
- Names should be changed when the study is reported.
- Video, audio, or photographic data may be destroyed at the end of a research project.

Core Activity

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 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

Session 4: Framing a Research Question

Learning aims	Knowledge content	Skills	Interactive elements
Begin to understand what a research question is and how it differs from a hypothesis Begin to understand how a research	The pivotal place of a research question in the research process	Question framing Sorting the essential from the peripheral and/or irrelevant	Discussion

question informs the design and data collection methods of a research study			
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Introduction

Before you can think about how they will go about collecting data, they need to frame a research question. The research question will help guide the rest of the methodological planning, so it is important that we get this right. It will need to be tightly worded so that it leads neatly into the research design. It sets the framework for the whole project, giving it direction and coherence. (NB creating a research question is an important step in allowing a co-researcher to feel ownership over a research project) Ask yourself: what am I trying to find out? Use of a 'think sheet' can be utilised to support in the creation of the research question. This can be found below:

Think Sheet

- What are my hobbies and interests?
- What do I feel strongly about?
- What am I curious about?
- What would I like to change if I could?

Topic area

- What aspect of this topic especially interests me?
- What exactly am I trying to find out?
- Where and how could I find this out?

Draft question

- Are there any age or gender issues?
- What are the timeframes I need to work to?

Research question

Sessions 5 + 6: Data Collection – Interview Techniques, Focus Groups and Open/Closed Questions

Learning aims	Knowledge content	Skills	Interactive elements
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	Open questioning Closed questioning Non-verbal body language Avoiding question bias	Discussion

Introduction

The interview is a primary tool that is used a great deal in qualitative research, like this study. You can base your findings purely on data collected in interviews or you can use additional methods as well. The interview can be used in many different ways and different question styles can be adopted to suit the purpose of the particular investigation. If used properly, they can help us to understand other people's feelings about important issues. We will be covering 4 different types of interviewing techniques, including:

- Structured interviews
- Semi-structured interviews
- Unstructured interviews
- Group interviews

The style of interview must be appropriate to the research question being asked.

Structured interviews

These are used when a researcher is interested in standardised answers. They share some characteristics of a survey, although they are asked verbally rather than as a written questionnaire. Let's suppose that a research project is looking to find out how pupils feel about their school lunches. The study wants to know whether children think the portions are large enough, hot enough, healthy enough, whether there is sufficient choice etc. Ideally, questions will be asked in a way that allows some qualification of response without being too free, otherwise you end up with lots of different answers that are hard to standardise. You also want to avoid bias e.g., influencing the answers the pupils give.

So:

Do you think the portions are big enough?

This question may give a biased response because you are implying that they are big. What do you think about the size of the portions you get?

This question is very open, and it would be hard to control the way in which people answer. For example, they might suggest that they are still hungry, or it is the same as they get at home etc.

This will make it hard to compare answers. A good compromise is to provide a few options for the answer. So, perhaps saying:

Would you say that the portion size is about right, too small, or too large? 'This question allows you to categorise pupils into the different response types. See table below:

Response	Too large	About right	Too small
Number of pupils (of 100)	4	28	68

A researcher using a structured interview could do the same for each question asked and collect data for comparison.

Unstructured Interviews

This type of interview is almost opposite. It is very open ended and designed to elicit individual and richly descriptive responses. It is used when a researcher wants to try and understand opinions and/or behaviour at a more complex level without pre-imposing any categories of response. Typically, these will be in depth interviews that produce lots and lots of data. 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.

An unstructured interview might open with a very general question about the topic matter. So, for example, with the school lunches, the researcher might say 'What are the school lunches like here?' The rest of the interview will be led by the interviewee's responses. Semi-structured interviews This type of interview is mid-way between the other two that have been explored. It is becoming increasingly popular, and it involves the researcher having a small core of predetermined questions or topic areas but the interview being unstructured beyond that. The core questions are not necessarily asked in any particular order and may not even need to be asked directly if the answers come up in general conversation. This interview type is therefore very *flexible*.

Semi-structured interviews allow the researcher to pick up on individual responses and take the questioning in different directions where appropriate. For example, with our school lunch research, the interview might begin as follows:

Researcher: What are the school lunches like here?

Interviewee: They're awful. I wanted to stop having them and bring a packed lunch, but my mum won't let me.

The researcher can then pick a few different lines of enquiry to pursue. For example, depending on the research questions and focus, they could either ask:

Why do you say they're awful?

OR

Why do you think your mum won't let you have packed lunches?'

Of course, this does open up the interview to bias from the researcher. It also takes a level of skill to steer the conversation, so it stays relevant to the research question. If it strays too far from the focus area, it can be hard to analyse the data in a thematic way later on.

Group Interviews/Focus Groups

This is where the researcher works with several people at the same time, rather than interviewing individually. Sometimes called focus groups, these interviews can be structured,

semi-structured or unstructured. The role of the researcher is different in focus groups; it is less like an interviewer and more like a facilitator for steered discussion’.

The researcher will also be interested in the group interaction as well as the statements being made. The researcher will guide the topic of the discussion and, depending on the interview style being used, may ask questions. One advantage of asking a question in a group is because it can sometimes access information which not be as forthcoming in individual interviews. This is because people may respond and reflect on what other people in the group have said.

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. There can also be issues with group interviews: for example, the dynamics may be off where one person is dominating conversation, or it may become heated with differences of opinion. It is down to the skill of the researcher to negotiate these situations.

Practical Issues about Interviewing

- You always need informed consent.
- Think about the location of an interview. Is being in school, with all the rules and constraints of this, likely to affect responses? Ditto for home interviews.
- How will you put the interviewees at ease and gain their trust?
- How will you record the data: audio, video, handwritten notes?
- Estimate how long you think an interview will take and allow plenty of time.
- How many individuals will you interview and on what basis will you choose them (e.g., age, gender)?
- Do you need to practice first or to pilot your questions?
- Be aware that a lot of communication non-verbal e.g., body language.
- Show you are actively listening.
- Avoid interrupting your interviewee(s).
- Always remember to thank the interviewee and indicate that you enjoyed talking to them and value their views.

Core Activity – Open/Closed Questions

Learning Objective: Understand 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 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 friendships (e.g., do you have lots of friends?) Give me an example of one closed question relating to friendships (e.g., how do you feel about friendships?)

GENERATION OF RESEARCH QUESTIONS

Session 7 + 8: Data Analysis

Learning aims	Knowledge content	Skills	Interactive elements
Begin to understand how to code and	Transcription Levels of coding Analysis of interview data	Organising, grouping, and sifting large amounts of data	Discussion

analyse qualitative data		Coding and categorising Memoing Theme abstracting	
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Introduction

During this research project we have collected qualitative data through semi-structured group interviews. The data we have has been recorded via audio and will be transcribed. This means to make an exact written copy of the conversations. There are lots of different types of qualitative data analysis, but we are going to be using one called Thematic Analysis. Thematic analysis is done in the following way:

Phase	Description of the phase
Data familiarisation	Reading the data following transcription. Sharing initial thoughts.
Initial Coding	Creating initial categories in which to divide the data. In this study, 6 initial codes were created as basic ideas for how to divide the data.
Abstraction	Systematic coding of the data into the categories chosen. The process helped define and adapt the themes according to the ease of defining where quotes should lie.
Focused Analysis/Reviewing themes	Reviewing the analysis and identifying subthemes or any stronger themes. Defining and naming the themes.
Producing the report	Writing this thesis. Selection of relevant extracts of text, relating analysis back to research questions. This also represents the final opportunity to adjust themes.
Memoing	Making notes on ideas that occurred to the researcher during the other stages e.g., coding, abstraction.

Data familiarisation

This involves getting familiar with the data before analysis. This would usually include reading and re-reading the transcripts, even when the researcher has been present at the data collection stage. This is a part of the immersion process when you become very involved with the data.

Initial Coding

After the data familiarisation stage, you will start thinking about some initial codes for the data. This will be broad themes that seem to come up in the data, *but* these are not yet formal themes. These codes will be used to divide the data into thematic sections. Points to bear in mind whilst coding include:

- Try not to introduce too many codes 'or categories. This process is meant to make the data easier to handle, and having lots of different codes will make this harder.
- Further subcategories can be introduced at a later time if needed.

- Avoid overlapping codes or having similar categories where lines will be blurred. This will make it difficult to divide up the data.
- Decide on a system for differentiating between the codes e.g., a colour coding system.

Abstraction

This is the process of dividing up the data into the previously chosen codes. This will involve going through the transcription line by line and assigning the relevant code to it. Researchers will try to code every line (aside from researcher questions or steering). It is likely that there will be a few lines which are more difficult to assign a code to. Leave this blank during the initial task; researchers can then come back to these at the end and see if there is any greater clarity. If there is more than one researcher, they can also discuss these sections and see if an agreement can be made.

Focused Analysis/Reviewing Themes

After the abstraction has been completed the researchers can consider the codes and the amounts of data in each section. Have there been any surprises? Does the volume of quotes indicate any stronger or weaker themes? Do we need to combine any codes or create subthemes? In this section the overall themes and subthemes will emerge, the first official recognition of them as such.

Producing the report

You won't be part of this process on this occasion. What will happen is I will report the themes and subthemes that we have found and use the most pertinent quotes to display them. This will also be a final chance to review the themes and subthemes and see whether they make sense when trying to explain them. I will keep you updated if I think anything needs to change.

Memoing

This happens alongside the analysis process. If you have a particular thought during any stage you can note this down on a post-it for us to address now or later. They are meant to form written reminders.

DATA ANALYSIS BEGINS

Appendix F - Interview Schedule

Before starting the interview:

- Problem free talk.
- Go through the information sheet and answer any questions the participant may have.
- Background to research interest
- Explain the purpose of the research
- Explain key terms such as autism, race, ethnicity, and Culture.
- Parents will be asked what term they prefer to use to refer to **autism** (Autism, ASD, or ASC) and this term will be used throughout.
-
- Ask participants to choose a pseudonyms name if they wish.

Clarifying and follow up prompts:

- “Could you give me an example of...”
- “What do you mean by...”
- “How did that make you feel?”
- “Can you tell me more about that?”
- Anything else”

Interview

1. How would you describe your ethnic and cultural background?
 - Country of origin/heritage?
 - Do you have any religious beliefs/ Cultural and religious practices?
 - If so, what are they? How do they help your family?
2. How old is your child and when did they receive their autism diagnosis?
Family structure, siblings,
3. When did you first notice any difference in your child's development?
4. Had you heard of autism prior to your child's diagnosis?
 - where from/what context
5. How is autism viewed in your culture/community? Is there a word for autism?
 - What role did values/spirituality/faith have?
6. How did you find the diagnosis process?
 - How was it explained?
 - How did you and your family feel?
7. How did you find the transition to school for your child?
 - Decision making- who helped?
8. Do you feel your culture and/or ethnicity has or is impacting on your experience as a mother of an autistic child?
 - Support systems /Help available (schools, services etc)
 - Other responsibility/ demands e.g., supporting family back home
 - Decision making

- Sharing your thoughts and feelings with extended family
- Extended family feelings about diagnosis

9. What if anything, would you like other people to know about being a Black African mother of an autistic child?

Close interview:

End with a positive question!

10. What is the best part of raising an autistic Black African child or what do you admire most about your child?

Debrief: Is there anything else you would like to add? Do you have any questions?

Thank the parents for sharing their views and taking part in the research.

Appendix G - Participant Invitation Letter



PARTICIPANT INVITATION LETTER

Addressing intersectional invisibility: Exploring the lived experiences of Black African mothers raising an autistic child in the UK

Contact name: Sophie Lemboye

Email: u2064585@uel.ac.uk

You are being invited to participate in a research study. Before you decide whether to take part or not, please carefully read through the following information which outlines what your participation would involve. Feel free to talk with others about the study (e.g., friends, family, etc.) before making your decision. If anything is unclear or you have any questions, please do not hesitate to contact me on the above email.

Who am I?

I am a postgraduate student in the School of Psychology at the University of East London and I'm studying for a Professional Doctorate in Child and Educational Psychology. As part of my studies, I am conducting the research you are being invited to participate in.

What is the purpose of the research?

The purpose of the study is to take an exploratory look into the lived experiences of African mothers raising autistic children in the UK.

The study aims to empower participants to share openly and freely their experiences. It is hoped the findings will provide a deeper understanding of this community that can help inform future professional practice as well as lead to practical benefits such as enhanced support and improve experiences for the community.

Why have I been invited to take part?

You have been invited to participate in my research as someone who fits the criteria of people I am looking for to help me explore my research topic. I am looking to involve Black

African mothers with an autistic child/ren aged between 7-11 years old, diagnosed in the UK. The diagnosis would need to have been received at least 2 years prior to being in the study. Participants will need to be able to communicate in English.

You are free to decide whether or not to participate and should not feel coerced.

What will I be asked to do if I agree to take part?

If you agree to participate you will be asked to take part in a semi structured interview conducted by myself and potentially a co-researcher. We will have a chat about your lived experiences of being a Black African mother raising an autistic child in the UK. You can choose to have this interview in-person (if Covid-19 safe) or remotely via Microsoft Teams. If you choose an in-person interview and it is safe to do so, this will be held at the local community civic centre. If you choose to have it online, you can choose to have your camera on or off. All interviews will be recorded. Interviews will likely be around 45 minutes to 1 hour. I (and potentially a co-researcher) might make notes during the chat. If we do, you can check them to make sure that they are an accurate account of your views if you wish. During the interview you will be able to ask me to stop recording at any time. You can also take breaks at any point and withdraw from the interview if you wish.

I will not be able to pay you for participating in my research, but your participation would be very valuable in helping to develop knowledge and understanding of my research topic

What if I want to withdraw?

You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. Separately, you may also request to withdraw your data even after you have participated, provided that this request is made within 3 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible).

How will the information I provide be kept secure and confidential?

Your privacy and safety will be respected at all times.

- You will not be identified by the data collected, on any written material resulting from the data collected, or in any write-up of the research.
- you do not have to answer all questions asked of you and can stop your participation at any time.
- After transcription audio recordings will be deleted. All identifiable information will be removed during transcribing and participants can choose a pseudonym name that will be used. Any quotes or information used in the thesis write up or future publication will be anonymised.
- confidentiality will only be breached if the researcher has safeguarding concerns.

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the 'public task' condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as 'special category data' in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal data please see www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection

What will happen to the results of the research?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository. The findings will be shared with others including the participants, colleagues and those interested in autism research. The research may also be published with the co-researcher. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally as pseudonyms will be used.

You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Anonymised data will be kept until research completion and 2 years after to allow time for possible publication. Following this all data will be deleted

Who has reviewed the research?

My research has been approved by the School of Psychology Research Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Sophie Lemboye – u2064585@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Dr Helena Bunn. School of Psychology, University of East London, Water Lane, London E15 4LZ,

Email: h.bunn@uel.ac.uk

or

Chair of School Research Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.

(Email: t.patel@uel.ac.uk)

Thank you for taking the time to read this information sheet

Appendix H - Participant Debrief Letter



PARTICIPANT DEBRIEF LETTER

Addressing intersectional invisibility: Exploring the lived experiences of Black African mothers raising an autistic child in the UK

Thank you for participating in my research study on the lived experiences of Black African mothers raising an autistic child in the UK. This letter offers information that may be relevant in light of you having now taken part.

How will my data be managed?

The University of East London is the Data Controller for the personal information processed as part of this research project. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. More detailed information is available in the Participant Information Sheet, which you received when you agreed to take part in the research.

What will happen to the information that you have provided?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository. The findings will be shared with others including the participants, colleagues and those interested in autism research. The research may also be published with the co-researcher. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally as pseudonyms will be used.

You will be given the option to receive a summary of the research findings once the study has been completed for which relevant contact details will need to be provided.

Anonymised data will be kept until research completion and 2 years after to allow time for possible publication. Following this all data will be deleted.

What if you have been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways you may find the following resources/services helpful in relation to obtaining information and support:

- **National Autistic Society**
<http://www.autism.org.uk>
- **Health talk.org**
<https://healthtalk.org/parents-children-autism-spectrum/overview>
- **Bexley voice – parent forum – BAME focus group**
<https://www.bexleyvoice.org.uk/bame-focus-group.html>
- **Bexley Snap- parent support group**
<https://bexleysnap.org.uk/>

You are also very welcome to contact me or my supervisor if you have specific questions or concerns.

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Sophie Lemboye – u2064585@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Dr Helena Bunn. School of Psychology, University of East London, Water Lane, London E15 4LZ,

Email: h.bunn@uel.ac.uk

or

Chair of School Research Ethics Committee: Dr Trishna Patel, School of Psychology,
University of East London, Water Lane, London E15 4LZ.

(Email: t.patel@uel.ac.uk)

Appendix I- Initial Notes on Participant 2 Transcript

referral to the Children's Hospital. I think in London. Yeah. And so then they were able to sedate him and give him, like, a proper examination. And we were able to rule that out. Like, there was no ear like audio, auditory problems. I think the the explanation wasn't as adequate. I was, I would have loved cause to this day, I don't think they explained the EHCP to me. I had to go through a private, you know, person to explain the process for me.

no one explained possible pathway

Researcher:

Yeah.

P2:

And I think that because again they, they still like there's a lot of backlog and the systems overwhelmed, they don't have enough time to walk you through the process. But because we did our research and I attended a lot of there would be like webinars on how to write your ehcp how to strengthen it questions you have on. So I make sure I joined all these groups like all these support groups like (names support groups). There was all these different groups that I've joined because I was like, I am going to make sure.

system problem

self motivation to join groups

Researcher:

Yeah.

P2:

I know what I'm doing and I'm getting on the information, so I think that helped. Now we're in a good place because we have this EHCP in place and we, you know, we're actually in the process of editing it now, like revising it, but yeah.

Researcher:

Yeah, OK. And how did well, I think you kind of touched on it already, but how did you feel like what was your feelings at the time and what was your family's feelings at the time of diagnosing?

P2:

Oh my God, I feel like you go through phases, right. It's like it's it's so interesting. First, you're in denial and then the denial also comes with blaming yourself because you're like, maybe I should have done something different. Was it cuz I had a really intense job when I was pregnant with him and I said maybe I didn't take care of myself during the pregnancy, maybe because I also had foceps. Because I had assistant birthing experience and I was like, maybe that's why.

Or maybe maybe I did something wrong in my past? I don't know. Maybe something you know. You start believing in all those superstitious. You know, thoughts. There's a denial. And then there's the fear of the unknown. Because you're constantly wondering what's gonna happen to your child. You. It's not as as clear cut as it would be if you had in your normative child. And then there's also the fear of judgment from society. Right. Coming from a culture that we're in, where you're constantly like, like, I'd literally say, I don't want to meet with certain people because I just don't want them to see that.

denial
First phase
Partnered with
self blame
trying to
find reason
why

lots of feelings of fear
linked to culture - judgment
as isolation - wanting
to avoid certain people.

Researcher:
Yeah, yeah.

P2:
You know what I mean? Like, as opposed to my husband was like, let them take him as he is. Like, that's our boy. Like let's let that's their problem. Right. But to this day I still get a bit weird when I have new people around us because I'm just like I need to like.

*gender difference -
is it due to
diff views / expectation
on mother's
blamed?*

Researcher:
Yeah, yeah, yeah.

P2:
I don't want to have to explain exactly. Yeah. So then we found we found our families. It's crazy like we have another family whose son has, like, a like a stutter, like a speech delay. And so it's like it's so it's so comforting to be around people where you don't have to explain anything. And so it's finding your village and finding your people that won't judge you and being comfortable enough to leave your child in the in the hands of someone that you trust 100% and you know that they will not judge them or treat them any different.

*support system
important
people who
can understand
through
lived experience*

Researcher:
Yes, yes.

P2:
And so you go through denial, you're going through fear of unknown, trying to find your community. And then the acceptance also comes with trying to make sure you're doing the right thing. Try to make sure that you're taking the right boxes. It's like you're constantly doing research to make sure that your son not left behind.

*Self lead
research
support for*

Researcher:
Yes.

P2:
And and then you always get those those doubts that creep in, right? So you're constantly. You're constantly fighting those fears of cause. They literally this. It's so unknown. You're literally learning as you go. So I think I'm in a better place. Mentally. I had to get counseling because it was a lot to deal with.

*Major impact on
mental health*

Researcher:
Yeah.

P2:
And I finally I think my parents are finally on on board. They have accepted both sides of the family and and so now it's more of a matter of just making sure that he's you're doing the right thing for him.

*Impact on
wider family
Their acceptance
seem key.*

Appendix J - Example of Transcription and Data Analysis

<p>Negative view of autism in Nigerian culture</p>	<p>50. Researcher: Yeah And how would you say autism is viewed in your culture or your community?</p> <p>51. P1: Umm very quite negatively, cause and I wouldn't blame them there isn't much awareness about it, I know, in Nigeria, now there is all these NGOs coming out, you know, you know give this awareness of what autism is, you know, it's not, umm you know, this kids are not ill, they just have a different way of viewing things and life, and you just have to adapt to them and they can learn just like every other child just need to know what works for them, you know.</p> <p>52. Researcher: Exactly</p> <p>53. P1:And it It's great that you know that NGOs are coming out. And then I feel like a lot more people are you know coming to terms and yeah</p> <p>54. Researcher: Accepting it</p> <p>55. P1:Yeah, I'm lucky enough that I have so many people in my family. My mom's side of the family, especially who works in that, you know, some of them are carers, some of them are nurse coming across. My mom is a mental health nurse. She has, you know, siblings as well who work with you know</p>	<p>View on autism negative in Nigerian community The cause being lack of awareness <i>'I wouldn't blame them'</i> - was lack awareness the cause of her possible negative views? Repeats the words 'you know' – could suggest spreading awareness is really key to her.</p> <p>Keen for acceptance and awareness within her community</p>
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	<p>autism. Yeah, they they understand I would say they understand. But when we go out, you know, parties and we get looks. Especially when he starts to stim, because he does verbal stimming a lot, you know, we get that. Umm Can you just shut him up? Umm Like, I can't shut him up it's what you enjoys doing!</p>	<p>Having awareness within the immediate family helpful for acceptance and connectiveness <i>I'm lucky' – suggests others may not be</i> Wider community lack of awareness leading to stigma– <i>we get the looks.</i> External behaviours particularly causing stigma Resilience - <i>I can't shut him up it's what you enjoys doing</i></p>
<p>Lack of awareness in Nigeria- no word for autism in Yoruba</p>	<p>56. Researcher: Yeah. And would you say that there's a word for autism.. Well, I guess you said you're Yoruba. Is there a Yoruba word for autism.</p> <p>57. P1: Umm no, no definitely not, definitely not.</p>	<p>Lack of word for autism Adding to the lack of understanding <i>Repeats words no and definitely - suggests this is a key issue</i></p>
	<p>58. Researcher: Yeah. And do you think that that's, like, what role do you think your values, or your faith have in the way autism is, is viewed?</p> <p>59. P1: Hmmm From what, from what I've read so, they just... what do you mean in terms of how people in the religious try to view autism?</p> <p>60. Researcher: So, I guess, do you think that there's something in your values or something in say, Yoruba values that affect the way autism is viewed? Or do you think</p>	

<p>Negative view of 'autism' Mothers often blamed- self-blame/community blame Stigma Link to culture more than religion</p>	<p>there's something in your faith that affects the way autism is viewed or anything like that</p> <p>61. P1: Umm some people say it's the evil eye. Some people say it's you know sometimes it what you didn't do as a mom because I went through that. Because I went through that guilt phase. Did I do something wrong? Did I hurt someone who put evil eye on me while I was pregnant? You know, I wouldn't say I felt like that's more traditional belief because as Muslims I haven't experienced, I would say it's more of like the Yoruba cultural side of things because we definitely have we have that you know, evil eye believe it. I remember my mom, like when he first got diagnosed and she was going everywhere talking to everyone, you know? We can pray away. you know, it's gonna go away but. I think I went through that phase as well that I can pray it away. I mean, you can pray to a certain extent to have like the right support and not just going to go away, you still have to do your part as a parent, like get the necessary support. You know, that's when God will come to facilitate that roles and bring people into your life and then make it better, I guess.</p>	<p>Spirituality and faith Blame of mothers with community- leading to self blame – <i>guilt phase</i> Second time using the word phase- suggesting this is a process- is there an end to the phrase? What is the end phase? Trying to understand Difference between religion and culture <u>Religion as intervention</u> 'pray it away'- immediate family response- although family aware of can be viewed as 'western understanding'. P1 appears to accept both view as intervention '<i>you can still pray... get the necessary support</i>'</p>
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Appendix K- Clustered themes with extracts

<p>The role of faith:</p> <ul style="list-style-type: none"> • Self-blame • Religion and intervention – prayer • Source of support and hope 	<ul style="list-style-type: none"> • Because I went through that guilt phase. Did I do something wrong? Did I hurt someone who put evil eye on me while I was pregnant? You know, I wouldn't say I felt like that's more traditional belief because as Muslims I haven't experienced, I would say it's more of like the Yoruba cultural side of things because we definitely have we have that you know, evil eye believe it. I remember my mom, like when he first got diagnosed and she was going everywhere talking to everyone, you know? We can pray away. you know, it's gonna go away but. I think I went through that phase as well that I can pray it away. I mean, you can pray to a certain extent to have like the right support and not just going to go away, you still have to do your part as a parent, like get the necessary support. You know, that's when God will come to facilitate that roles and bring people into your life and then make it better, I guess • So yeah, it was it was hard. It was it was hard to accept but. Like I said, when you then add a faith to it and know that, you know, everything's got a plan. You know, all of this isn't just happening. And 	<p>Participant 1:</p> <p>Page 9</p> <p>Page 11</p> <p>Page 23</p> <p>Page 24</p> <p>Page 32</p>
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	<p>umm you know It will get easier. And it has gotten easier.</p> <ul style="list-style-type: none"> • And another thing God really helps me with I will say was I got a job where my manager herself had a child on the spectrum... like I said, it's like that support started to come through and I was like oh wow I'm not by myself. There's people there kids are improving and of course (son's name) it's not it's not going to be the outlier he will improve he can do certain things. • Obviously, faith plays a big part. it did. It does Because that's one of the places I feel like I've got my strength from just succumbing to that. Just praying and then you know, my mom is very big on faith. She just says Everything that happens happens for a reason. Yeah. It could have been anything else. And then she, she told me like, it could have been anything look, this this kids who have this diagnosis are in the wheelchair are can't even do anything by themselves. So you have to look at people worse situation than you are. And just say, you know, for my, my parenting, you just have to thank god and just keep it moving and hope for the best. • I worry about that all the time. But then I just like, I mean, I leave it up to God. I mean, he's done it this far. His not my 	
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	<p>child, he has been given to me to look after. The one who create him will look after him, so, I leave the rest. That's how I view it.</p>	
<p>The role of Yoruba culture</p> <ul style="list-style-type: none"> • Lack of autism awareness • Negative views • Stigma and blame • Family as a supportive factor 	<ul style="list-style-type: none"> • Umm I wouldn't. I wasn't familiar with people. I knew what it was. Because umm his dad uumm umm his dad works with special needs children. So we talked about other kids he would see but I didn't, I hadn't experience It's first hand. Yeah. I'd say. • R: Is there a Yoruba word for autism.? P1: Umm no, no definitely not, definitely not. • And I spoke to his dad at the time and I was like, I think we should go for the diagnosis. And even when for the diagnosis up until today, he will still tell you, well now it is much more obvious, but he is still saying no you know it's not what it is you know he is just different you know. You know that, what do you call it ummm. What's the word I'm looking for? You said it earlier on Researcher: the denial. P1: Yeah. Yeah, the denial it's definitely there. But I, I accepted it for what it was way earlier on that he did. He is still struggling. • Umm very quite negatively, cause and I wouldn't blame them there isn't much awareness about it, I know, in Nigeria, now there is all these NGOs coming out, you know, 	<p>Page 7 Page 5 Page 8 Page 9 Page 11 Page 16</p>

	<p>you know give this awareness of what autism is, you know, it's not, umm you know, this kids are not ill, they just have a different way of viewing things and life, and you just have to adapt to them and they can learn just like every other child just need to know what works for them, you know.</p> <ul style="list-style-type: none">• Umm some people say it's the evil eye. Some people say it's you know sometimes it what you didn't do as a mom because I went through that. Because I went through that guilt phase. Did I do something wrong? Did I hurt someone who put evil eye on me while I was pregnant? You know, I wouldn't say I felt like that's more traditional belief• So ummmm I mean I went through a phase of depression, because I was, you know, at the time of the diagnosis, I was going through divorce as well. So it was like, all of this is coming at me, thank god for family you know.• Yeah, I'm lucky enough that I have so many people in my family. My mom's side of the family, especially who works in that, you know, some of them are carers, some of them are nurse coming across. My mom is a mental health nurse. She has, you know, siblings as well who work with you know autism. Yeah, they they understand I	
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	<p>would say they understand. But when we go out, you know, parties and we get looks. Especially when he starts to stim, because he does verbal stimming a lot, you know, we get that. Umm Can you just shut him up? Umm Like, I can't shut him up it's what you enjoys doing!</p> <ul style="list-style-type: none">• No, I wouldn't say that. Because, I mean, in terms of my family, they've been quite supportive. I forgot to mention I have an uncle who has an autistic child as well.	
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Appendix L - Reflective Diary Extracts

First meeting with co-researcher

I felt excited and nervous about meeting with the co-researcher for the first time. I was glad that we took time for a separate rapport-building meeting as we originally were going to join the rapport-building with the first training session. But on reflection, I wanted to make sure she felt confident in her role and that we could establish a trusting relationship, so I suggested we separate them. Speaking with her came very easily; I wondered if it was due to the similar life experiences. The meeting seemed to be mutually enjoyable, with lots of laughter. She remarked how nice it was to speak with someone that “gets it”. However, I was mindful of maintaining boundaries with her, so I built in time to revisit the consent form and asked for her input on how we should work together. The co-researcher spoke with such passion about wanting the experiences of Black African mothers of autistic children to be known so that it may help improve other mothers and CYP experiences. It really reignited my own motivation to aim to produce research that is not only meaningful for this population but also aims to create a positive difference- to act as a form of social justice.

Training with the co-researcher

The co-researcher informed me that she had a university degree she received in Nigeria but coming into the training, she expressed a lack of confidence. I noticed that at first, the co-researcher simply answered “Yes” or “ok, I get that part”. However, during one session, the co-researcher answered, “It’s ok, I know how busy you are?” exploring this, I wondered if she agreed to understand the teaching material because she was concerned about the time I could spend with her. This made me consider the power dynamics between us, and I felt it was important we revisit her role as a co-researcher, and the purpose of the training was to equalise our positions. I wanted to ensure I was responsive to her learning style and needs, so I increased the number of ‘check-ins’ of understanding during the sessions. I also reassured her that I am happy to work flexibly and revisit material before each stage of the research process to ensure she is comfortable and confident in the area.

The first participant interview

Going into the interview, I was unsure what to expect and felt slightly nervous. It was my first time doing qualitative research and using SIs as a tool. I drew upon my experiences as a TEP from consultation meetings and VERP principles to use skills such as active listening and attunement. As the session went on, I was able to relax more and grow in confidence. This seemed to impact the interview positively, as the mother began to share more openly about her experiences. However, looking back, I felt there were opportunities where I could have asked further follow-up questions to

gain even deeper insights into the experiences. Going forward, I hope to increase my responsiveness by using more prompt questions such as “Anything more?”

Keza's Interview

The experiences she described seemed to mirror my own so closely, and there were moments it took me back to my own early experiences with my autistic son, the journey I went through. However, I was very consciously aware that this was her story, her experiences. I was happy I could make this distinction clear in my mind, and I could then focus on ensuring I was ‘present’ during the interview. I noted that at times she said, “As you know”, in reference to assumptions about experiences she felt we would share because of the fact I was also a Black African mother of an autistic child, but we were also of East African heritage. However, even though I did feel I understood what she was describing, I was happy that I still followed up on her experiences to ensure it was in her own words. The interview seemed to go well, and the mother thanked me for providing her with the space to share her experiences and shared that she looked forward to hearing about the findings from the study. Following the interview, it was beneficial to discuss this with my supervisor, and it had an emotional impact on me. I found sharing this experience very containing and supportive and acknowledge that working with people, there will be emotional triggers. What is important is our response to this. On this occasion, I was pleased with my response and maintaining that space for the participant to tell her story.

Data analysis

I was very anxious during this process, I worried the closeness I shared with the research topic might blind me from what participants were saying, and instead, I would see what I wanted to see, what resonated with me. I was surprised when I began to feel a sense of guilt about what quotes to use, what information to keep in, and what to omit. I wanted the participant’s experience to be represented, and I worried if I could capture this in a way that they would be happy with, in a way that would do justice for them. Even coming up with the name of the themes became a worry. I asked myself, “Does this summarises the experience?”. I felt stuck. Speaking with my supervisor, however, was very reassuring, her reminder to stick with the participant’s language was useful in helping me name the themes. Revisiting the double hermeneutics was also helpful as a reminder that my interpretations may differ from another due to our backgrounds. Engaging in member checking was also highly containing, as I felt it equalised power and provided another opportunity for the participant’s voice to be amplified. Moreover, having the co-researcher review and finalise the group themes across participants was reassuring. I was so glad the co-researcher was confident in sharing her opinions.

Appendix M - Ethical Approval



University of
East London

School of Psychology Ethics Committee

NOTICE OF ETHICS REVIEW DECISION LETTER

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

Reviewer: Please complete sections in **blue** | **Student:** Please complete/read sections in **orange**

Details

Reviewer:	Sonja Falck
Supervisor:	Helena Bunn
Student:	Sophie Lemboye
Course:	Prof Doc Educational and Child Psychology
Title of proposed study:	Please type title of proposed study

Checklist

(Optional)

	YES	NO	N/A
Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Detailed account of participants, including inclusion and exclusion criteria	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns regarding participants/target sample	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Detailed account of recruitment strategy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns regarding recruitment strategy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clear and detailed outline of data collection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Data collection appropriate for target sample	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns regarding data storage (e.g., location, type of data, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns regarding data sharing (e.g., who will have access and how)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If required, General Risk Assessment form attached	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If required, Country-Specific Risk Assessment form attached	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If required, a DBS or equivalent certificate number/information provided	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All relevant information included in the participant information sheet (PIS)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information in the PIS is study specific	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Language used in the PIS is appropriate for the target audience	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All issues specific to the study are covered in the consent form	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Language used in the consent form is appropriate for the target audience	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All necessary information included in the participant debrief sheet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Language used in the debrief sheet is appropriate for the target audience	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Study advertisement included	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Content of study advertisement is appropriate (e.g., researcher's personal contact details are not shared, appropriate language/visual material used, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Decision options

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.
APPROVED - BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES	<p>In this circumstance, 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 at the end of this form once all amendments have been attended to and emailing a copy of this decision notice to the supervisor. The supervisor will then forward the student’s confirmation to the School for its records.</p> <p>Minor amendments guidance: typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials.</p>
NOT APPROVED - MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED	<p>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.</p> <p>Major amendments guidance: typically insufficient information has been provided, insufficient consideration given to several key aspects, there are serious concerns regarding any aspect of the project, and/or serious concerns in the candidate’s ability to ethically, safely and sensitively execute the study.</p>

Decision on the above-named proposed research study

Please indicate the decision:	APPROVED
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Minor amendments

Please clearly detail the amendments the student is required to make
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Major amendments

Please clearly detail the amendments the student is required to make

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Assessment of risk to researcher

Has an adequate risk assessment been offered in the application form?	YES <input checked="" type="checkbox"/>	NO <input type="checkbox"/>
	If no, please request resubmission with an <u>adequate risk assessment</u> .	
If the proposed research could expose the <u>researcher</u> to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:		
HIGH	Please do not approve a high-risk application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not be approved on this basis. If unsure, please refer to the Chair of Ethics.	<input type="checkbox"/>
MEDIUM	Approve but include appropriate recommendations in the below box.	<input type="checkbox"/>
LOW	Approve and if necessary, include any recommendations in the below box.	<input checked="" type="checkbox"/>
Reviewer recommendations in relation to risk (if any):	Please insert any recommendations	

Reviewer's signature

Reviewer: (Typed name to act as signature)	Sonja Falck
Date:	16/02/2022

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 UEL's Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.

Confirmation of minor amendments

(Student to complete)

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

Student name: (Typed name to act as signature)	Please type your full name
Student number:	Please type your student number
Date:	Click or tap to enter a 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

Appendix N - Confirmation from Educational Psychology Service

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Categories: Categorise, Snooze, Undo

ethical approval for thesis research

Lemboye, Sophie
[Redacted]

Hope this email finds you well. I wanted to double check if you knew whether I am required to get ethic approval from [Redacted] to do my thesis research or would the university ethical approval be sufficient? I am not due to submit the ethics form in until December/January but thought I would check now as I would need to include a draft copy in with my research proposal!

Regards,
Sophie

Sophie Lemboye
Trainee Educational Psychologist
Working days: Monday, Tuesday and Wednesday
0203 045 3629

[Redacted]

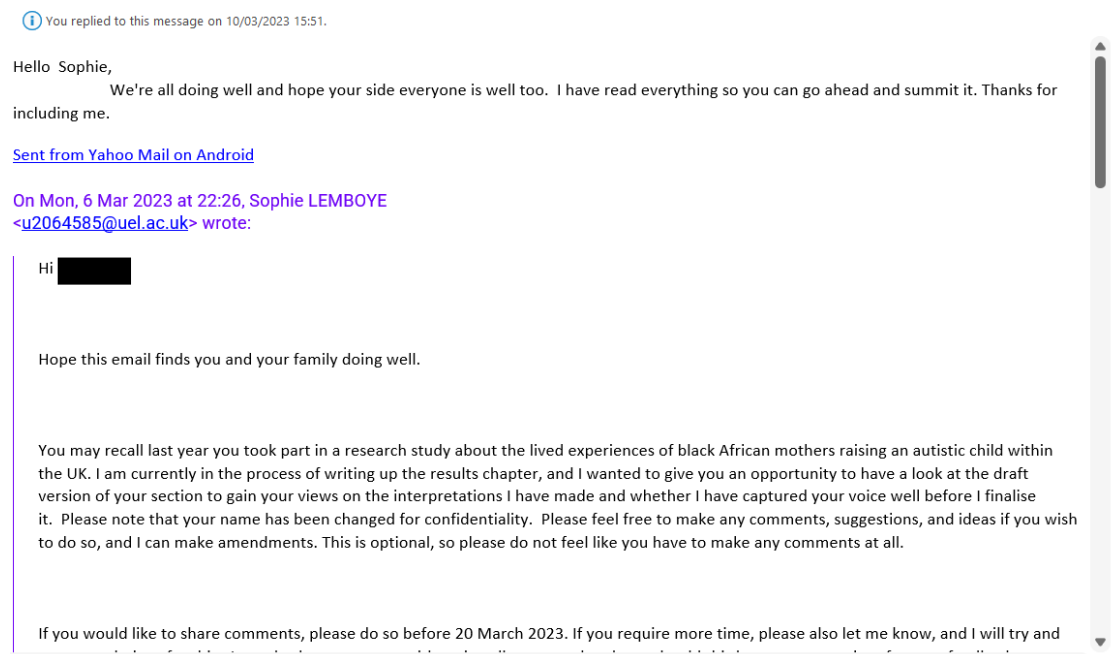
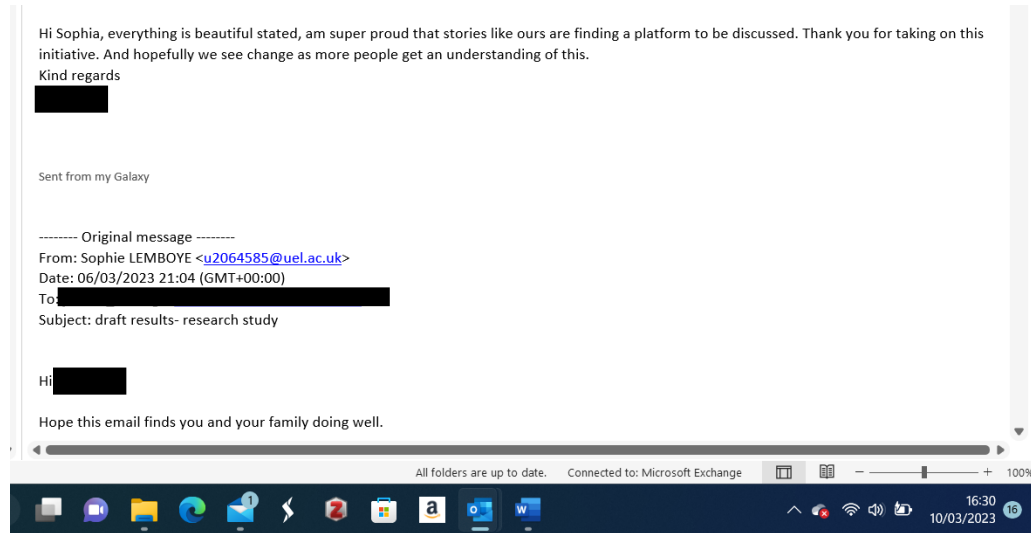
Tue 28/09/2021 13:08
To: Lemboye, Sophie

Hi sophie
As long as your uni is happy then we are happy, so no need for formal ethical approval from [Redacted]. However, it would be great to have a 15 min conversation about your proposal when you are ready to send it in to the uni, just so I am kept in the loop
Regards
[Redacted]

13:25
14/01/2022

Appendix O - Member Checking – Feedback from Participants

Participants were contacted to seek their views on the interpretation made by the researcher and if the write up was an accurately represented of their experiences. Given that member checking is optional, two participants did not respond. The other four participants who engaged in this process feedback is below.



Hello Sophie,

Trust you're keeping well.

Its Perfect, its been drafted to reflect our exact conversation. I am happy for you to proceed. I wish you all the best with it and all your future endeavors.

Kind regards,

Sent from my iPhone

On 6 Mar 2023, at 20:46, Sophie LEMBOYE <u2064585@uel.ac.uk> wrote:

Hello [REDACTED]
Hope this email finds you and your son doing well.

You may recall last year you took part in a research study about the lived experiences of black African mothers raising an autistic child within the UK. I am currently in the process of writing up the results chapter, and I wanted to give you an opportunity to have a look at the draft version of your section to gain your views on the interpretations I have made and whether I have captured your voice well before I finalise it. Please note that your name has been changed for confidentiality. Please feel free to make any comments, suggestions, and

Hi Sophie,

This looks amazing, wishing you the best with the rest of your writing. Let me know how the finalization process goes.

Kind regards,

On Mon, Mar 6, 2023 at 8:51 PM Sophie LEMBOYE <u2064585@uel.ac.uk> wrote:

Hi [REDACTED]
Hope this email finds you and your family well.

You may recall last year you took part in a research study about the lived experiences of black African mothers raising an autistic child within the UK. I am currently in the process of writing up the results chapter, and I wanted to give you an opportunity to have a look at the draft version of your section to gain your views on the interpretations I have made and whether I have captured your voice well before I finalise it. Please note that your name has been changed for confidentiality. Please feel free to make any comments, suggestions, and ideas if you wish to do so, and I can make amendments. This is optional, so please do not feel like you have to make any comments at all.