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The Multiple and Intersecting Layers of Experiences of Black-African Immigrant Families Living with an Autistic Child in the UK.

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Dedication

I dedicate this thesis to the black-African families of children with autism who shared their autism experiences with me. Hopefully, their story would empower and motivate other African families of children with autism or other types of disabilities in the UK.

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Firstly, I would like to thank God Almighty for the grace He gave me to complete this thesis. I would like to express my sincere appreciation and gratitude to the people who made it possible for this thesis to be completed. First, a special thanks to my supervisory team-Dr. Joanne Warner, Dr. Michelle McCarthy and Dr. Thomas Akoensi-for their tireless support. The constructive comments and feedbacks they gave me were invaluable.

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Abstract

The specific experiences and challenges faced by immigrant families of children with autism are not fully understood. The purpose of this study is to investigate the experiences of black-African immigrant families who live in the UK and have an autistic child in the family.

This qualitative study uses interpretative phenomenological analysis to explore the lived experiences of participants. 37 individuals in 20 families, including fathers, mothers, and neurotypical siblings were interviewed, and the data analysed. The findings suggest that, as well as the common experiences and challenges faced by all families of autistic children in the UK, families who participated in this study also faced additional challenges. The combination of the common problems and their varied and specific issues which converged to produce multiple layers of autism experiences arise from their multiple identities. Drawing on the intersectionality theory, the study shows how these identities interact to amplify their experiences of racism and racialisation, discriminations, oppression, rejection, stigmatisation, the subjugation of mothers/women, threats to African masculinity and ideal, and the threat to kinship and lineage continuation. Religion and spirituality are deployed as important sources for coping and resilience.

This study answers the questions regarding the specific experiences and challenges faced by this research group. Additionally, it makes recommendations for further studies in this area, and for changes to professional practices and policy developments.

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Chapter One

Introduction

1.1 Why Study Autism Experiences in Black-African Immigrant Families?

The subject of autism has been extensively researched (for example, Waterson 2011; Cassidy et al. 2008; Nealy et al. 2012; Neely-Barnes et al. 2011). However, the experiences of black-African immigrant families living in the UK remain largely unexplored (Perepa 2014; Slade 2014). Expanding knowledge and understanding of culturally-situated autism is a compelling justification for exploring the experiences of black-African parents and siblings of children diagnosed with autism. Investigating the experiences of autism reported by the participants in this study will help professionals and scholars to appreciate the deeper meanings that this group may have derived. Therefore, I have taken an interpretative approach based upon philosophical hermeneutics, and conducted an interpretative phenomenological analysis to illuminate these participants' lived experiences of autism.

Sub-Saharan Africa—where the participants of this study originate—is a region comprising countries on the African continent, which are geographically located south of the equator, and south of the Sahara Desert. Sub-Saharan African countries account for most of the African continent, numbering fifty-four independent nations, predominantly occupied by black people. The region is endowed with rich human and natural resources, but it also has some of the poorest countries in the world (World Bank, no date). Countries in sub-Saharan Africa comprise diverse ethnic, cultural, religious, and multi-lingual groups of people (Kiyaga and Moores 2003). As a multicultural and multi-lingual region, there are a wide range of values, customs, traditions, cultural practices, and attitudes toward disability, both within the region and its diaspora. However, as will be explained in chapter three, many black-African countries possess similar ideological paradigms of disability. Therefore, my reference literature was selected using the techniques described above in order to present a brief overview of disability culture in Africa within the context of my study. My intention is not to give a comprehensive narrative of disability-related discourses in sub-Saharan Africa.

1.2 The Inspiration for this Study

In my social work career in England, I have worked with families from diverse ethnic groups. I was able to observe how the black-African families in my caseload, residing in the same London borough, attempted to cope with multiple challenges at home, and how they navigated the paths to educational support and social care services. The assessments and interventions I carried out with black-African families provided insight into these experiences. Four of those families particularly stood out, and their experiences have inspired this study. In one of these cases, we took a brother and a sister from a Congolese family, each with severe autism, into Local Authority care due to evidence of child abuse. In the second case, I had to challenge the school of an autistic boy to prevent them excluding him from school when his single mother felt helpless to do so. In the third family, the father was based both in Nigeria and the UK. In order to protect his neurotypical children from his autistic son’s violent behaviour, he took his son with him to and from Nigeria on each visit. In the fourth family, a single mother insisted on keeping her son—a teenager with autism—at home, despite the frequent injuries he caused her. My hope is to contribute to practice and policy changes that will improve outcomes for families such as these. I have remained in practice throughout the duration of this study, and my role includes managing social workers, and making decisions about resources and operational issues that impact on disabled children and their families, amongst other responsibilities.

1.3 The African Participant Samples in the UK

Since the 2011 census, the population of black-African-born residents in the UK has increased significantly, currently numbering over 1 million people (Office for National Statistics 2017). Similarly, the population of people with autism in the UK is estimated to be about 700,000, or 1.1 percent of the UK population (National Autistic Society 2018; NHS Digital 2012; Baron-Cohen 2008). Therefore, in the UK, approximately 2.8 million individuals in families with autistic children are indirectly experiencing autism by association, according to the National Autistic Society (2018).

In January 2015, for example, the number of black-African pupils in English schools with autism as their primary need was 3,585, according to the National Statistics (2015). In January 2018, 119,909 pupils in English schools had autism (National Statistics 2018; Ministry for Education 2018). In the same period, there were 308,082 black-African pupils of compulsory school age in English schools, of which 43,341, or 14.1%, were in the special educational needs (SEN) category (National Statistics 2018). Among the 43,341 black-African pupils with SEN, 5,715 of them (about 17.4%) had autism as their primary type of need (National Statistics 2018). The 2018 figure is higher by approximately 37.3% when compared with the 2015 figure. In 2018, however, the number of black-African pupils with autism is disproportionally higher than some other ethnic groups. For example, in January 2018, there were 6,297,000 white British pupils in English schools, of which 819,620 had SEN. Of these, 84,639 (10.3%) of them had autism as their primary need; meanwhile, among Indian pupils with SEN, 10.4% had autism as their primary need (National Statistics 2018; Ministry for Education 2018).

Several factors could explain the rise in the number of school-age black-African children with autism: (a) increased migration from Africa to the UK; (b) an increase in the birth rate among black-African parents already living in the UK; (c) an increase in diagnosis of autism in black-African children, or (d) a combination of these factors. Nevertheless, data shows that there are a significant number of black-African families with autistic children in the UK.

1.4 The Multiple and Intersecting Layers of Autism Experiences

It has been widely reported in the literature that autism affects children from all socio-cultural and geographical backgrounds (Dyches et al. 2004; Bakare and Munir 2011; Doig 2012; Desai et al. 2012; Anthony 2009). Generally, the arrival of an autistic child in a family means changes and challenges (Goldworthy 2005; Copp 1998; Stroebe and Schut, 1999). I will focus on the specific challenges faced by black-African families, living with their autistic children in the UK. I will argue that due to their multiple and intersecting identities, the participants in this study are likely to have multiple layers of autism-related experiences in the UK and in Africa, in addition to the common experiences of autism.

Whilst this is not a comparative study, I compare the experiences of my participants with existing evidence about those of other groups. The experiences of first-generation African immigrants with an autistic child may differ slightly from their peers in Africa, and also from UK-based families with autistic children. Many of their African counterparts might not have experienced life in the UK with an autistic child; similarly, many of their UK peers might not have experienced life in Africa with an autistic child. There may also be slight differences in each group's experiences and perspectives of autism, due to political, socio-cultural, and geographical factors. As a result, the findings from this study are multi-layered and complex.

Additionally, race, ethnicity, migration, culture, religiosity, gender and disability by association, all simultaneously intersect to produce nuanced autism experiences. I am not suggesting that participants in this study have a direct 'autism identity'. Rather, I make the point that family members have an indirect 'autism identity' via their relationship to their autistic family member. Literature suggest that the identity of neurotypical family members of a person with an atypical behaviours/traits is often affected by their association with the atypical individual (Goffman 1963; Scambler and Hopkins 1986; Link and Phelan 2013; Gray 1994). This process is also known as 'courtesy stigma' according to Goffman (1963, p. 43).

A few research studies have identified the experiences and challenges faced by BME families of children with autism (Baba 2014; Slade 2014; Perepa 2014). However, to my knowledge, no research has used the concept of intersectionality to consider the distinctive sets of additional challenges faced by black-African families which include an autistic child, and the meaning they make from their challenging experiences. Although my findings are analysed through the lens of intersectionality, I have also employed other theories and concepts, due to the multidimensional focus of my research questions. For example, I used lineage/kinship theories and the concept of 'Africanness' to explore the African cultural dimension, spoiled identity theory to explore stigma and rejection, immigration and acculturation theories to discuss issues around immigration and nationality, and religious theories for spirituality and religiosity. The experiences of my study participants have been framed by these theories, and their thoughts and feelings explored through intersectional analysis in order to make sense of their multi-layered nature.

My approach has been informed by the work of Frueler (2013), Teater (2014) and Coady and Lehmann (2016). For instance, in her study of American military families raising autistic children in multiple and transient locations, Frueler applied three theoretical perspectives: 'family stress theory', 'ecocultural theory', and 'theories of transaction' (2013, p vii). I have applied multiple theories in my study, enabling a broad and holistic view of my participants' lived experiences.

1.5 A Brief Overview of Autism Spectrum Disorder

The word 'autism' comes from the Greek language *autos*, or 'self' (Frith 2003, p. 5). The direct translation of autism in the English language is 'self-ism' (Feinberg and Keenan 2005, p. 166; Frith 2003, p. 5), and was first used by Eugene Blueler in the early 20th century to describe individuals with schizophrenia who withdrew into themselves most of the time (Frith 2003; Feinberg and Keenan 2005). The term was later adopted by Leo Kanner to describe children he observed in his clinic who did not show interest in others (Kanner 1943; Frith 2003; Feinberg and Keenan 2005).

It is currently believed that autism is caused by a complex combination of genetic, neurological, psychological and environmental factors (Boucher 2011; Baron-Cohen 2008; Betancur 2011; Geschwind 2011; Powell and Monteggia 2013). Historically, causal theories were more simplistic. For example, Bleuler (1911) claimed that autism was a form of schizophrenia, caused by mental illness. Kanner (1943) linked autism to the occupations and educational attainments of parents of children with autism, while Bettleheim (1967) suggested that autism was due to a mother's unloving attitude towards her child (Happe 1994). Tinbergen and Tinbergen (1983) suggested various factors, such as lack of maternal attachment to the child from an early age, rubella viral infection in mothers, domestic violence and oxygen starvation during childbirth (Boucher 2011; Frith 2003). Such theories were challenged and disproved by support groups formed by mothers of autistic children in the USA and the UK (Frith 2003; Boucher 2011), and contemporary researchers have rejected such lines of thinking.

Autism affects a child's perception of the world, and how to live within it. Autistic children often require lifelong care and support (Baron-Cohen 2008; Wing 2002; Frith 2003), whilst appearing no different, physically, to a neurotypical child (Portway and Johnson 2005). This partly explains why many parents, including black-African parents, struggle to accept that their child has any impairment at first (Bakare and Munir 2011; Dyches et al. 2004; Mandell and Novak 2005).

Autism starts in early childhood and lasts a lifetime (Baron-Cohen and Bolton 1993; Geschwind 2011). It is often characterised by problems with forming relationships, communicating, or interacting with others (Wing 2002; Boucher 2011; Wing and Gould 1979). Other symptoms include social imagination problems, obsessive and repetitive behaviour, and a frequent preference for solitude (Kanner 1943; Feinberg and Keenan 2005; Wing and Gould 1979).

Kanner (1943) situated autism research in Euro-America, creating the impression that autism did not exist in other parts of the world (Sanua 1984; Lotter 1978). This is partly because the earliest recorded discovery of autism was based on Euro-American children (Dyches et al. 2004). Therefore, children from the west have been the main focus of research, but autism is now known to affect all children, regardless of race, ethnicity or culture. However, the link between race, cultural beliefs and experiences of BME groups within a dominant western culture requires further investigation (Dyches et al. 2004; Slade 2014). Most research on autism has paid little attention to the combined impact of race, ethnicity, religion, gender, culture, and immigration (Gibson 2014; Ravindran and Myers 2013; Neely-Barnes et al.2011; Waltz2005).

1.5.1 Classification of Autism

Wing and Gould (1979) recognise that autism varies in symptoms and severity, and that it often manifests both with associated concurrent conditions and a wide continuum of diagnosis of atypical presentations. The concept of autism spectrum disorder (ASD) attempts to capture the wide varieties of features associated with autism (Wing and Gould 1979).

For example, difficulties with verbal communication experienced by individuals with autism can include a complete loss of speech and language, selective-mutism (choosing when to talk), echolalia (repeating memorised words), inaudible or impaired speech. Yet other individuals with autism may possess both fully-developed language skills and underdeveloped social communication skills. Such difficulties can manifest as poor or overly literal understanding of words and non-verbal cues, inability to appreciate jokes or comprehend figures of speech such as metaphors. Individuals within this group may also display other traits such as a tendency to disengage socially from other people, difficulties in taking turns during social interaction, self-centredness, poor understanding of social rules, failure to recognise other people's emotions, and other awkward and embarrassing behaviours (Boucher 2011; Baron-Cohen and Bolton 1993; Gray 2006; Wing 2002).

In terms of impaired social imagination, people with autism are often unable to pre-empt the actions of others, or to have an abstract imagination of what is not concrete. They are also known to exhibit repetitive behaviour within minimal ranges of interests. Some of the common types of repetitive behaviour include, but are not limited to, 'stimming' (hand flapping, rocking, spinning), repeating words/phrases/sounds, prolonged obsession and preoccupation with objects/interest/activities, restricted diets, and an interest in mechanical or automotive objects. Other common areas of interest include dates, history, particular genres of music and film (Baron-Cohen 2008; Frith 2008; National Autistic Society 2014; Eyal 2010; Eyal et al. 2010). Therefore, autism might be defined as a combination of significantly impaired development and functioning in social interaction, coupled with social communication disorder, poor social imagination, and a restricted range of activities and interests. This combination can vary according to the individual (Dyches et al. 2004; Weru 2005; Happe 1994; Ravindran and Myers 2013).

1.5.2 The Diagnosis and Operationalisation of Autism Spectrum Disorder

There is a variety of criteria and tools for diagnosing autism, which create confusion and controversy in the field (Sponheim 1996; Eyal 2010; Levin 2013). Clinicians use various assessment tools to diagnose autism, including 'Autistic Behaviour Checklist' (ABC), 'Diagnostic Statistic Manuals' (DSM), 'International Classification of Diseases'

(ICD), ‘Childhood Autism Rating Scale’ (CARS), (Sponheim 1996, p. 513). I will focus on the DSM manual tool, which is commonly used in the UK.

The DSM manual is used to standardise, classify, and diagnose mental illness (Samuel et al. 2013). The word ‘autism’ did not feature in earlier versions of the manual, and it was not until the 1980s that DSM-3 and DSM-3-R applied the terms, ‘infantile autism’, ‘atypical autism’, ‘autistic disorder’ and ‘Pervasive Developmental Disorder Not Otherwise Known (PDD-NOS)’ to describe children with autistic traits (Kaufmann 2013, p. 6). But DSM-4 and DSM-4-TR expanded the list of autistic traits to include ‘Asperger Syndrome’, ‘childhood disintegrative disorder’, ‘Rett’s syndrome’ (Kaufmann 2013, p. 6), and ‘classic/Kanner’s autism‘ (Eyal et al. 2010, p.10). These disorders share similar features, often making differentiation between them difficult (Eyal et al. 2010). Further changes were introduced in the DSM-5 manual in May 2013 (Samuel et al. 2013; Buxbaum and Baron-Cohen 2013; Kaufmann 2013). ‘Asperger syndrome’, ‘Rett’s syndrome’, ‘PDD-NOS’, Classic/Kanner’s autism, and others were merged to form a single diagnosis: ‘Autism Spectrum Disorder’ (Samuel et al. 2013, p. 7), whilst new conditions were added to the manual (Samuel et al. 2013; Kaufmann 2013; Buxbaum and Baron-Cohen 2013).

Some parents, professionals and scholars argue that the multiple changes to the diagnostic criteria in the DSM manuals is confusing and frustrating (Samuel et al. 2013). Others are concerned that the changes could mean that people with Asperger Syndrome would lose their identity and not qualify for social care (Samuel et al. 2013; Buxbaum and Baron-Cohen 2013). However, Kaufmann (2013, p. 18) believes that the changes were necessary to prevent an, ‘autism epidemic’.

When I selected my samples, I applied the criteria described in the DSM-4 and DSM-4-TR manuals, as it encompasses the complete range of autism spectrum disorders, including Asperger Syndrome and classic autism among others. This is because all the black-African children whose family participated in my study were either diagnosed with classic/Kanner's autism, or with Asperger's Syndrome. I have therefore defined autism as a combination of impaired development, functioning in social interaction, social communication disorder, poor or lack of social imagination, and a restricted range of activities and interests, all of which vary according to the individual and their level of development and age (Eyal et al. 2010). This definition suits the autistic children in the families who participated in my study because many of them were non-verbal, had fixated and narrow interests, poor social interactions, and were at different stages of their development. Many of my participants, including parents and siblings, consistently reported that they found their autistic child or sibling's behaviours in the public arena, and in places of worship to be stigmatising and embarrassing. This indicated impaired social interaction, and poor understanding of social rules. Lack of speech and language skills was a major concern for parents and was an early sign that their child had a problem, prompting them to seek help.

Some parents tried unconventional approaches, using traditional remedies or home training. Others made an assessment based upon cultural norms and concluded that delayed speech, was normal for boys, whilst hoping that the child would grow out of it with age. Another group of parents kept the problem to themselves, and one of them explained why:

> It is difficult! It is not easy to make the decision. But [for] me, I did not have a choice, because I have 3 [autistic] kids, I do not have a choice. But this is African people for you because where we come from we don't talk about your dirty things in public, so how are you going start exposing [your private life to others]… (Mrs Dibango, Cameroonian).

Most of the parents were urged to seek a formal diagnosis when the child reached school age and his/her behaviour became unmanageable. But many did not want the diagnosis or, more specifically, the label of 'autism', because the latter made public the 'dirty things' to which Mrs Dibango refers above. They fear that the child would be stigmatised, whilst recognising that, in order to access support, their child must be formally diagnosed as autistic.

Securing the diagnosis was a challenge for parents, some of whom experienced delays of up to two years, whilst others found that professionals linked their child's problems to the cultural environment in which he or she was raised. See section 5.4.1 for details about the problems that families faced in the course of seeking diagnosis.

1.5.3 Diagnosis and Assessment of Autism

There is no definite organic, clinical diagnostic test for autism, as is the case for Down syndrome or Fragile X syndrome, for example (Eyal et al. 2010). Rather, an autism diagnosis is often made by observing the behaviour of an individual in a controlled or uncontrolled environment, considering developmental patterns, and relying on the account of parents and teachers (Happe 1994; Frith 2008; Boucher 2011). Current methods of diagnosis often rely on the interpretation of professionals, with the use of behavioural pattern checklists, which are often inconsistent (Wing and Potter 2002;

Eyal et al. 2010; Baron-Cohen et al. 2000). At the same time, the scope of diagnosis and language used to describe autism have widened significantly, due to the emergence of autism spectrum disorder (ASD) as a concept (Wing and Gould 1979), and changes in diagnostic criteria, explored earlier in section 1.6.2 of this thesis (see, Buxbaum and Baron-Cohen 2013).

With the expansion of diagnostic tools, the ease with which autism is currently recognisable, and increased public awareness of autism (Mandell and Novak 2005), autism diagnosis among BME children in the UK in gradually picking up (National Statistics 2018; National Autistic Society 2018). For example, in 2015 there were 3,585 black African school age children who were diagnosed with autism, but in 2018, the number increased to 5,715 children. However, some BME parents of disabled children believe that institutional racism and sexism is engrained in the process of autism diagnosis and treatment (Angell and Solomon 2017; Bywaters et al. 2003; Mandell and Novak 2005). Prior to diagnosis, most parents in my study observed that there was something wrong with their son/daughter when compared with their peers or their older siblings. The deficit in social behaviour of autistic children is not universally understood across all cultures, and the differences in diagnostic criteria do not help matters according to Weru (2005).

1.5.4 Common Examples of Comorbidity amongst Individuals with Autism

Comorbidity is when two or more medical conditions coexist simultaneously in one individual, but neither condition is necessarily part of, or a consequence of the other (Boucher 2011). Individuals with autism tend to suffer from comorbidity at a higher-than-normal rate (Boucher 2011). Some of the illnesses and conditions that tend to coexist with autism include learning disabilities, dyspraxia, epilepsy, Phenylketonuria (PKU), hyper/hypo-sensory sensitivity, mental health problems, and social behavioural problems (Boucher 2011; Wing 2002; Baron-Cohen and Bolton 1993; Gates 2003). People with autism also suffer from other medical problems present in the general population (Wing 2002). Some of the children in my study have some form of comorbidity, and learning disabilities were common occurrences amongst the group.

1.5.5 The Neurodiversity Concept

According to Armstrong (2010), neurodiversity is a concept used to describe the variations in the human brain that determines sociability, learning, attention, mood and other mental functions without pathologizing it.

The needs of neurodiverse people should, therefore, be treated in the same way as other social diversities such as gender, race, ethnicity, and sexuality. Neurodiverse people, including those with autism, must be accepted and not viewed as individuals who have an infirmity or require treatment and/or cure. (Ortega 2009; Jaarsma and Welin 2012).

The medical model of disability classifies autism as a disease, requiring a cure. The social model argues that society should adjust to the various differences that autistic people have, as they would for other diverse group in a society (Norbury and Sparks 2013; Ortega 2009). The emergence of the ‘neurodiversity movement’ (Ortega 2009, p. 46), an advocacy group for people with various atypical neurological traits such as people with high or low functioning autism, was credited to Judy Singer (1999). The former refers to those with normal or above ‘normal’ IQ score, and the latter are those who are generally below the ‘normal’ IQ score (Jaarsma and Welin 2012). The neurodiversity movement is however dominated by high-functioning autistic people (Armstrong 2010).

The neurodiversity movement favours the social model of disability, and argues that ‘ASD is a natural human variation and should be viewed as a separate minority culture [in its own right, rather than] a disorder’ (Norbury and Sparks 2013 p.46). Therefore, autistic children have a natural variation in language, communication and social interaction, rather than a deficit or a developmental disorder. The neurodiversity movement argues that autism does not require a cure, but a different human identity variation, as with gender and race, and must be accepted. Advocates of neurodiversity believe that the brain of an autistic person, whilst different, is naturally wired, and not diseased (Ortega 2009).

In general, the neurodiversity movement rejects the use of terms such as ‘a person with autism’. They argue that this suggests that ‘there is a normal person trapped behind autism’, preferring the term ‘autistic person’ or ‘autists’ (Jaarsma and Welin 2012 p.3). Nonetheless, the neurodiversity community disagrees about the use of either term. Temple Grandin views autism as part and parcel of whom she is and would not exchange it for a non-autistic personality. Donna Williams, an author with autism, believes that being autistic is akin to being in an invisible prison, from which the person cannot escape (Jaarsma and Welin 2012).

Given that autism is viewed from a diversity standpoint, and not an illness, campaigners oppose any attempt by parents or professionals to find a cure for it, because that would discredit the definition of autism as a human difference (Ortega

2009; Armstrong 2010). There are two sides to the debate on the autism/neurodiversity discourse: pro-cure and anti-cure. The latter is mainly comprised of members of the neurodiversity movement who claims that autism is not an illness. Therefore, an attempt to rid someone of autism is a violation of his or her human rights. Some anti-cure group members believe that attempts to find a cure for autism is reminiscent of promoting 'eugenics' and ‘genocidal policies' against autistic people (Ortega 2009, p. 429). The pro-cure group is comprised mainly of parents of autistic children, some autistic adults, and medical professionals. This group believes that the anti-cure and neurodiversity groups deny the suffering experienced by parents raising an autistic child. Judy Singer and Temple Grandin, both neurodiversity advocates, welcome treatments that help to relieve suffering, but not one that would aim to eradicate autism completely.

Ortega (2009) reports that whilst not all parents of autistic children oppose the views of the neurodiversity movement, not all autistic adults accept their views either. Equally, not everyone in the movement opposes efforts to find a cure. ‘Those who are within the movement and support the idea of finding a cure seem to be silent about their views’, claims Ortega. Whilst most high-functioning autistic people oppose the possibility of finding a cure, some low-functioning autistic people support it.

The black-African parents of autistic children in my study indicated that they are pro-cure, due to resentment of how autism has changed their children’s identity, and that they had actively sought a cure for the condition. Whilst some were in denial before and after the diagnosis, and had attempted to keep their child’s condition a secret, those who migrated to the UK in search of autism services had already accepted it prior to migration. All participants had to accept both the diagnosis and the label because they realised it was the only way to access autism support services. Otherwise, some might not seek a diagnosis, as this would confirm that their child had a neurological condition, whilst appearing to be physically ‘normal’. According to Ortega (2009) the label of autism or Asperger given to individuals affects them and their family, and they often change their behaviour to match the label.

1.5.6 Autism Presence in sub-Saharan Africa and its Prevalence among Black-African Children in Europe

The existing body of literature on autism is vast. However, very little is known about the condition in non-western countries, particularly in sub-Saharan Africa, where the rate of basic knowledge and awareness is low (Igwe et al. 2010; Audu and Egbochukwu 2010; Bakare et al, 2008; Eseigbe et al. 2015; Egbochuku and Imoitseme 2012; Thomas at al. 2015; Lagunju et al. 2014; Okandeji-Barry et al. 2015). Earlier studies emanating from sub-Saharan Africa reported a low prevalence rate for autism (Longe and Asuni 1972; Lotter 1978; Sanua 1984), yet recent Africa-focused research revealed a lack of data on the prevalence rate (Eseigbe et al. 2014). The rate of autism in sub-Saharan Africa is presumed to be similar to that of the west (Weru 2005; Mohammadi 2011). Due to the absence of epidemiological studies of autism in sub-Saharan Africa, the prevalence rate remains unclear (Newton and Chugani 2013; Mankoski et al. 2006; Bakare and Munir 2011).

Recently, research to assess awareness of autism in Africa has been undertaken by several scholars. For example, studies undertaken in collaboration with education and healthcare professionals (Audu and Egbochukwu 2010; Igwe et al, 2010) and (Bakare et al. 2008 and 2009; Igwe et al. 2010 and 2011; Bakare and Munir 2011; Eseigbe et al. 2014), have consistently demonstrated poor knowledge and awareness within both sectors. Studies in Nigeria have reported a significantly low level of autism awareness among final year medical, psychology, and nursing students (Igwe et al. 2010 and 2011).

Although research about autism began to emerge from Africa over four decades ago (Lotter 1980 and 1978; Longe and Asuni 1972; Sanua 1984), output has increased during the last decade (Mohammadi 2011; Igwe at al. 2010). However, according to Bakare and Munir (2011), whilst the body of autism research in Africa is still growing, the issue remains under-reported.

Wider awareness of autism in Africa is growing, due to campaigns by non-governmental organisations, charities, and parent groups. These bodies obtain financial support from international organisations such as the United States African Development Foundation (USADF), the World Health Organisation (WHO), the World Bank, the UK Department for International Development (DFID), and the United Nations Education and Scientific and Cultural Organisations (UNESCO n. d; BBC 2011). The presence and activities of these international organisations, alongside grassroots African community projects, and the promotion of disability awareness, is vitally important. In many countries, these organizations also fund grassroots projects - such as Community Based Rehabilitation services (CBR) - which African governments often fail to do (Otte et al. 2013; Hartley et al. 2005).

Some studies report a higher prevalence of autism amongst children from black-African immigrant populations in Europe (Barnevik–Olsson et al., 2008; Bolton et al.

2013; Gillberg and Gillberg 1996). Others report lower diagnosis rates among BME groups, in comparison to their white counterparts. (Dyches et al. 2004; Jegatheesan et al. 2010). Marchant et al. (2010) attribute the dichotomy between high prevalence and low diagnosis to language barriers, and the possibility that professionals often misdiagnose autism symptoms as language difficulties arising from the children speaking a second language at home (Jegatheesan et al. 2010). This study is focused on the specific experiences of black-African immigrant families of autistic children in the UK, as set out in the research questions below.

1.6 Research Questions

The overarching goal of this study is to explore the experiences of black-African families who have a child with autism, and to reveal the layers within the contextualised, intersecting experiences that might distinguish this group from the wider autism population. To this end, the research questions posed by the study are:

- What are the beliefs of black African immigrant families about their child's autism?
- What are the experiences of black-African immigrant families with an autistic child in the UK, and how do they cope?
- How does black-African culture and tradition influence parents' perceptions of their autistic child?
- What are the barriers or challenges that black-African families experience when attempting to access formal services in the UK?

1.6.1 How my Research Questions are Derived from the IPA Framework

Wagstaff et al. (2014) affirms that researchers do not have to constrain themselves to the standard method of doing IPA research. They can be creative and flexible. Pietkiewicz and Smith (2014) support the application of flexibility and creativity to any part of the IPA framework, including the formulation of research questions or topics. It is the adaptability of IPA that enables its use in investigating a diverse range of research problems and disciplines, rather than solely health psychology, from which it originated (Wagstaff et al 2014; Pietkiewicz and Smith 2014; Spiers et al. 2016). According to Pietkiewicz and Smith (2014), when using a qualitative methodology, it is important that the research questions define the parameters of what can be found and is reflexive. This means that the research questions should delimit or define the scope of the research, and consider the role of the researcher in the research processes.

Although the research questions were not strictly articulated within the IPA framework of this study, they established the boundaries. The questions were informed by the extant literature investigating families of black and minority ethnic background with an autistic child (e.g. Mandel and Novak 2005; Doig 2012; Gray 1993 and 1995). Methodologically, it was important to generate interview questions that would illuminate the ‘Africanness’ worldview and perception of my study particiants. Secondly, the research questions were framed in such a way that the findings reflect the cultural views of my participants as much as possible, and ensured that ‘rich data’ was gathered, which is an important requirement of an IPA study (Smith et al. 2012 p.56).

Therefore, the contribution of this qualitative phenomenological study to the existing body of research is threefold. Firstly, it examines the experiences of African families living in the UK with their autistic children. Secondly, the study expands the current literature about autism-related challenges faced by BME groups in the UK. Finally, it will contribute to the understanding of African cultural diversity, so that professionals could more easily recognise the intersecting needs of this group and the challenges they face.

1.7 Chapter Layout

This thesis is divided into 9 chapters. In chapter one, I had discussed the inspiration for this study, its scope and limitations, and some of the challenges associated with living with and caring for an autistic child. I briefly outlined the cultural characteristics of the study participants, the reason for their presence in the UK, and the intersection of these experiences. I also provided a brief account of autism, and of the geopolitical space of sub-Saharan Africa, the rationale for my focus on black-African immigrants, and the aims and significance of my study.

Chapter two focuses upon the conceptual framework of this study, including the concept of ethnicity and how it applies to my research, and it offers some theoretical insights into the complex task of categorising black and minority ethnic (BME) group. I also examine culture, racialisation, and unpick kinship/lineage theories in the context of ‘Africanness’, and explore other theoretical frameworks, such as religion and spirituality, spoiled identity, and immigration. Finally, I introduce the concept of intersectionality as my analytical tool for understanding the multiple layers of the participants’ experiences.

In chapter three, I present my literature review. Here, I explore a range of empirical research papers on autism, and grey reports about, for example, UK policy developments that have had a direct impact on my participants. The experiences of families with autistic children from diverse groups in the UK and internationally are presented. I also explore literature from sub-Saharan Africa, focusing on disabled people/children, their families, societal attitudes, the availability of services, and the contribution of international organisations. I conclude that, despite the growing research into the experiences of BME families with autistic children in the UK, knowledge gaps remain.

Chapter four describes the research design and methodology, in particular, my use of interpretative phenomenological analysis (IPA), participant recruitment, the ethical implications and their mitigations, and my analysis and coding procedures. I also account for my own reflexivity.

Chapters five to eight present my findings. In chapter five, I give an account of the challenges faced by the study participants when attempting to access autism services, in their home countries and in the UK. I also outline the reasons for migration to the UK, and the challenges they have experienced. To gain more insight into the implications of immigration policies on these individuals, I have created three categories: ‘undocumented’, ‘temporary residents’, and ‘settled residents’. Overall, the undocumented subgroup had the worst experience when accessing support in the UK.

Chapter six outlines the stigma and rejection that participants perceived or experienced both in Africa and the UK, and within their families. I explain that any stigma or rejection that they experienced in Africa is mediated by culture and tradition, while the same experience in the UK is mediated by race and ethnicity. I further categorise my study participants into two subgroups: ‘single mothers’ and ‘married couples’, and infer that among the married couples, some mothers faced uncertainty, whilst others felt rejected by their husbands. The ‘single mothers’ subgroup had experienced the reality of rejection. I infer that, due to polygamy being culturally acceptable in most African societies, fathers in my study could potentially have multiple wives, in Africa and Europe, in response to having an autistic child. I also report on the experiences of neurotypical siblings.

In chapter seven, I explore the implications of ‘Africanness’, and the challenges of attempting to raise an autistic African child in the UK. The chapter consists of six themes: (a) African kinship practices; (b) threats to the continuation of lineage, (c) African cultural expectations; (d) preparing an autistic child to be respectful and obedient; (e) being an African father to an autistic child; and (f) African spiritual and cultural worldviews about autism. These themes help me to unpick some of the African cultural worldviews around autism, and the implications of such attitudes for the participants.

Chapter eight concerns the religious and spiritual beliefs of the study participants, and how such beliefs help them to cope. For analytical purposes, I grouped the spirituality and religiosity of the participants into three qualitative subgroups: ‘strong’, ‘stronger’ and ‘strongest’. These participants often ‘spiritualise’ autism through God by attributing most positive outcomes to him, including believing that he could cure autism. I infer that, due to their religion and spirituality, these participants were resilient and had coped well with their challenges. I conclude that members of the ‘strongest’ religious subgroup are more likely to have better coping outcomes than members of the other subgroups.

In chapter nine, I list some distinctive autism experiences of my participants, discuss my findings and their limitations, make recommendations for future policy and practice, identify potential areas for further research, and conclude by summarising the findings.

In the next chapter, I will discuss some of the conceptual and theoretical frameworks I have used to address my research questions.

Chapter Two

Theoretical and Conceptual Perspectives Informing this Study

2.1 Introduction

In this chapter, I discuss some of the pertinent concepts that I have used in this thesis. I begin by addressing how the term ‘black-Africans’ is operationalised not as an umbrella identity for all people from sub-Saharan Africa, but as a terminology used for differentiation purposes. I will further discuss culture in the context of philosophies of ‘Africanness’, concomitant to kinship/lineage theories. Other theories—such as immigration theories, religious and spiritual theories, and the theory of spoiled identity—are also examined. Finally, I explore intersectionality theory and its applications in this thesis as an analytical tool to help understand the experiences of my study participants in the intersecting contexts of autism and the other identities they simultaneously occupy.

2.2 The Concept of Ethnicity

Black-African residents in the UK are often grouped as part of the wider BME group, but their specific classification in official statistics is ‘black-Africans’ (Office for National Statistics, 2017). The purpose of this section is to clarify how and why I have used the term ‘black-Africans’ in this thesis.

Ethnic minority is officially defined as all the sub-groups in the UK population who are not white, and who also hold some cultural and traditional values originating partly or wholly from their countries of origin (Aspinall 1997). Generically, ‘black’ is used to define ‘those members of ethnic minority groups who are differentiated by their skin colour and/or physical appearances, and may therefore feel some solidarity with one another by reason of past or current experience, but who may have many different cultural traditions and values', including Africans, Caribbeans, Chinese, Indians, and Pakistanis (Aspinall 2002, p. 805). According to Aspinall (2002), the use of word 'black' as an umbrella term for wide ranges of people who do not have physical or cultural similarities can be misleading.

Even more confusing is when similar terms are used interchangeably in the literature and in official documents, For example, 'BME' or 'black and ethnic minority' or 'Asian, BME' (Parekh 2000, cited in Aspinall 2002, p. 805). 'Minority' can be misinterpreted as meaning 'less important or marginal' (Aspinall 2002, p. 804). In settings where non-white ethnic groups are in the majority, 'minority' can be misleading or inaccurate; and the phrase 'BME group' could be misinterpreted to mean that black people are not part of the minority ethnic groups (Aspinall 2002; Emibayer 1997).

The term 'black' was introduced in the 1960s by groups of people who were perceived to be different by skin colour and other physical features from the majority white population (Aspinal 2002; Fatimilehin 1999). It was used as a campaign symbol against racism, discrimination, disadvantages, and oppression in the UK (Fatimilehin 1999). Since then, the term has been continually used for the section of population deemed different from the white population, even though some members of that group (Chinese, Indians) are not black. Therefore, the term 'black' [and minority ethnic] is generally used to describe people living in the UK who are ethnically (self) described as non-white.

2.3 Models of Ethnicity Theories

Ethnicity is generally conceived in sociological literature as a socio-political construct, originating from human interactions (Brubaker 2002; Bradby 1995; Ghosh 2015).

Ghosh (2015) identifies four types of ethnicity theory: ‘primordialist’, ‘modernist’, ‘instrumentalist’ or ‘mobilisationist’, and ‘constructionist’ models (pp. 54-60). The primordialist model views ethnicity as emanating from long-standing, historic traits shared by a group of people (Brubaker 2002; Ghosh 2015). The modernist model is the negotiated relational and adaptive nature of ethnicity. In this model, ethnicity, as a result of pervasive social tension, is used as a means of differentiation between ‘us’ and ‘them’. The mobilisationist model suggests that ethnicity is used as a tool to contest for resources. From the constructionist perspective, however, ethnicity emanates from interactions between groups, including what people believe ethnicity to be (Ghosh 2015). Arguably, the black-African participants in my study could occupy any one of these models, or a combination of them, in a given time and space. In the following section, I will briefly discuss the primordialist model for practical reasons.

2.3.1 The Primordialist Model of Ethnicity

In line with the primordialist perspective, Bradby (1995, p. 406) defines ethnicity as ‘the real, or probable, or in some cases mythical, common origins of a people who may also have visions of a shared destiny…which are manifested in terms of the ideal or actual language, religion, work, diet, or family patterns of those people’.

Bradby’s definition of ethnicity implies that people from specific ethnic groups share common values and practices. Supporting that line of thinking, Smith (1996) sees ethnicity as a form of cultural identity, defined by the following characteristics: a common collective name, shared myth of common descent, shared historical memories, one or more elements of common culture, an association with a specific territory, and a sense of solidarity.

In Smith's (1996) view, mythology is essential in linking past and present so that collective loyalty to the common ancestors establishes a firm set of moral obligations that direct group action in the present and future. In other words, for Smith, ethnicity is rooted in its enduring, normative, connecting ancestral history. The participants of this study are a group of people who originate from various countries in the sub-Saharan Africa with over 50 independent nation states. They have some similarities and differences in terms of race, language, migration trends, colonial history, religion, culture, and other shared values (Kiyaga and Moores 2003; Curran and Runswick-Cole 2013); which fits in well with the idea of primodialist model of ethnicity. However, Ghosh (2015) views the primordialist model as obsolete because it suggests that ethnicity is fixed, whereas most sociologists view ethnicity as an active, transient, and dynamic process (Maleševic 2011; Brubaker 2002). Nonetheless, Gosh's four models of ethnicity are important in offering insight into some of the subtle ethnic spaces these participants mentally occupy in various contexts.

2.4 Operationalising Ethnicity

The relationship between individuals and groups come into play when exploring ethnicity operationally. If we accept that ethnic identity exists, we must then examine its formation in groups and individuals. According to Jenkins (2008), groups and categories are often implicated in each other's formation. Thus, identifying similarities with others through social interaction requires labelling the 'other'. In Jenkins' view, ethnicity does not need to come from groups. Other writers argue that ethnic groups do not exist in and of themselves; instead, it is what people do and the choices they make that produce outcomes identified as ethnic relations (Brubaker 2002; Emibayer 1997; Maleševic 2011; Ghosh 2015).

In sociology, and other disciplines where ethnicity, race and culture are concerned, 'group' is a common and indispensable concept. It is also a concept taken for granted; one which seems unproblematic, and is hardly ever analysed on its own (Brubaker 2002; Maleševic 2011). Researchers treat the group as a basic component of social life, a unit of social analysis, which leads to the reification of the concept. The tendency to view the world in terms of social groups, or to divide ethnicity into groups, make it appear as though these groups are 'internally homogenous, externally bounded… with common purpose' (Brubaker 2002, p. 164). Brubaker (2002, p. 164) challenges this treatment of 'groups as real, substantial things-in-the-world, [rather than]… as constructed, contingent, and fluctuating… emphasising the fragmentary, the ephemeral, and the erosion of fixed forms and clear boundaries'.

Brubaker (2002) argues that ethnicity should be conceptualised as a way of understanding and interpreting experience; a dynamic, eventful process, rather than as a thing or an entity. In other words, we should think of ethnicity as an operational category or a discursive framework, a cognitive code, not as a substantial, tangible thing (Brubaker 2002 and 2006; Brubaker et al. 2004). To view ethnicity in this way, is not to dispute its reality or minimise its importance, but to reconstruct its reality and importance in new ways.

The tendency to view ethnic groups as common-sense, established entities dominates discussion of ethnicity (Maleševic 2011; Bradby 2003; McKenzie 2012). This common-sense view suggests that, when we talk about ethnicity, we are automatically talking about ethnic groups, and thus reifies both concepts (Brubaker 2002; Mason 2000). By reifying groups, we treat them as social beings, we 'crystallise' them, evoke them, and call them to life. Reification is not only a social process, it is also an ‘intellectual bad habit’ (Brubaker 2002, p. 166). We should avoid unintentionally reinforcing the reification of ethnic groups in ethnicity related practices, and in social research analysis. Maleševic (2011, p. 78) accepts that ‘ethnicity is clearly not a thing’, but also argues that ethnicity is much more than a cognitive way of understanding and interpreting social world: it is also a useful way to make ‘individual and collective experiences meaningful’ in terms of ‘collective discrimination…with collective humiliation, fear or threats.’

In this study, the term ‘black-African’ is used specifically as a political connotation, which acknowledges that black people from sub-Saharan African countries are part of a wider BME group, who experience racism and discrimination due to their skin colour. In this context, it is important to note that ‘black-Africa’ is not used here as an identity marker for all people from sub-Saharan Africa. Within that understanding, ‘it is important to be aware that identity does not possess a fixed, permanent or essential quality and that an individual may occupy a range of identities at any given time’ (Fatimilehin 1999, p. 305). Hence, people from sub-Saharan Africa living in the UK could be grouped both geo-territorially, and as part of the wider BME subgroup. In this study, I have chosen to use the term ‘black-Africans’ to denote people who share similar political experiences to other members of the wider BME group in the UK, rather than as a geo-territorial identity of a group of people from the sub-Saharan region. Therefore, the term ‘black-African’ is used in this research for functional and operational purposes, and not as a cultural identity.

2.5 Cultural Implications

Broadly speaking, sociology scholars seem to agree that culture is central to the analysis of ethnicity (Gunaratnam 2003; Nagel 1994). In my research, I employ culture as another analytic strand connecting the contexts of ‘black-African’ and ‘autism’. This is because the concept of culture leads to connected questions about how people of different ethnicities conceptualise autism, how people in different cultures relate to individuals so classified, and how culture impacts on experiences and understanding about autism (Jenkins 1994; Jenkins 1998).

Defining culture is difficult. Wuthnow et. al. (1984, p. 3) define culture as ‘the symbolic-expressive aspect of human behaviour.’ This definition is broad enough to take into account ‘verbal utterances, gestures, ceremonial behaviour, ideologies, religions, and philosophical systems generally associated with the term culture’ (Wuthnow et al. 1984, p. 3). Some writers suggest that we are living in a world where culture, with its attention to meaning-making, is now analytically central to all social science research (Alexander 1996).

In his analysis of the conceptual relevance of culture to ethnicity, Maleševic (2011) argues that ‘ethnicity can never be reduced to culture, neither can it be explained without extensive reference to culture…. Although ethnicity is not culture there is no ethnicity without culture’ (p. 77). Maleševic’s exposition is helpful because he locates culture within the political, suggesting that individuals call on their cultural markers when they experience socio-economic and structural change. In this sense culture is a social construction. Groups can create markers to delineate themselves during structural changes, or powerful actors can make claims on behalf of a group to the state, which in turn can accept or resist these requests (Nagel 1994).

Contributing to the discussion on culture, Dewalt et al. (1998) argue that culture has explicit and implicit elements. The explicit part of culture are those visible activities such as dress styles, food, traditions, social norms, lifestyles, and artefacts. The implicit parts are those aspects of culture which are not obvious and are generally outside our consciousness. Dewalt et al. (1998) make the point that culture consciously and/or unconsciously stimulates human activities, and that aspects of culture reflect the daily routine of individuals. Implicitly, people draw on their internalised social habits—which may be based on kinships, customs, or ideas passed down through generations—in their decision-making process, or when making sense of a phenomenon. Similarly, the notion of culture also implies shared values which guide the actions of a group. In context of this study, black-Africans who conceptualise autism as a supernatural phenomenon, for example, could be tapping into their internalised way of viewing unexplainable conditions based on ancestral traditions. Thus, culture stimulates recurring patterns of behaviour within clans and families, or in organisations, which leads to taken-for-granted knowledge and localised re-interpretations of social customs (Kunda 2002). In the following section, I will examine African cultural worldviews using the philosophy of 'Africanness' (Uduma 2014).

2.6 The Implications of the Concept of 'Africanness'

Some sub-Saharan African cultural values, principles, and practices define, shape, and mediate the experiences of African parents of children with autism (Baba 2014, Slade 2014; Bakare and Munir 2008). I do not suggest that African culture is homogenous, but there are sufficient commonalities and patterns to enable me to reconstruct a common worldview about autism that resonates with my study participants, and indeed many African societies (Ritcher and Morrell 2006; Uduma 2014; Holmes 2000; Horton 1967).

Black-Africans who came to the UK in the mid-twentieth century are likely to be somewhat acculturated to UK society (Van Hear 2010; Kimberlin 2009; Kim 2009). It is also assumed that some black-Africans often continue to maintain ties with their respective countries of origin, a practice known as transnationalism (Kim 2009; Kimberlin 2009). I also acknowledge that culture evolves, including African cultures (Scambler 2008). However, as Holmes (2000, p. 2) says, the 'Kenyan past is also informed by experiences of a Kenyan present.' This means that the present-day experiences of Kenyan people are also influenced by their past experiences, according to Holmes. Also, other writers insist that traditional African cultural practices, values, and belief systems have not vanished (Uduma 2014; Kuper 1982; Haviser 2007). This would suggest that my study participants remain influenced by their experiences of growing up in sub-Saharan Africa, and that cultural values and beliefs persist both in Africa and in the diaspora (Bjork 2007; Haviser 2007). This African cultural worldview is referred to in modern African literature as 'Africanness' (Chimakonam 2015, p. 33).

2.6.1 The 'Africanness' Philosophy

According to Spronk (2009):

> Africanness means testifying to an African or black community that [Africans] are proud of; it is about a kind of sociality which they celebrate by cracking jokes about each other's tribes, claiming entitlement to certain ethnic customs as part of a larger African universe, or dressing in elaborate...African dress[es]. They see themselves as Africans because they have more in common with people from other African countries, than they do with people of other continents (p. 509).

‘Africanness’ is a philosophical discourse concerning the worldviews and processes of interpretation and meaning-making expressed by sub-Saharan Africans in oral and written texts. Any literature concerning African philosophy must emanate from an African identity, culture and worldviews. It relates to the basic beliefs, practices and worldviews underpinning the existence of people in social environments (Chimakonam 2015; Uduma 2014; Somjee 2000; Gluckman 1949). This thesis utilises African philosophical views in the context of autism experiences because the participants are Africans, who were born and grew up in Africa before they migrated to Europe. Any interpretation of African parents’ experiences of having children with autism, and the sense they make of them, would be incomplete without taking account of relevant ‘Africanness’ ideas. Chimakonam (2015) opines that, to gain insight into an African’s worldview, the writer must collect, interpret and retell the African cultural proverbs, maxims, conceptions, folktales, idioms, and practices that are fundamental to their understanding of existence. However, that is beyond the scope of this thesis. Suffice to say that ‘communitarian ontology is the bastion of African thoughts’ (Chimakonam 2015, p. 42). An African discourse and philosophy are obtainable from the cultural, historical and existential experiences of Africa in the context of a given phenomenon or problems (in this case having an autistic child) examined through the lens of African cultures. It is on this premise that I will extrapolate and synthesise the intersecting experiences of African parents of autistic children, and examine what it means to them from an African philosophical standpoint (Sahlins 2011; Chimakonam 2015; Uduma 2014).

Despite some of the variations in clan and kinship systems in sub-Saharan Africa (Oheneba-Sakyi and Baffour 2006); broadly speaking, familial and kinship practices are quite similar (Evans-Pritchard 1929; Evans-Pritchard 1951; Bjork 2007; Khunou 2012). These similarities allow for the application of lineage or kinship theory as a complementary conceptual framework, within which the experiences of this participants can be examined. This thesis is thus located within the context of African cultural knowledge (Bjork 2007; Owor 2012; Noon 1942).

The sub-Saharan social system is mostly influenced by tribalism, customs and tradition, colonialism, religions, socio-politics, and economics (Thurnwald 1929; Brown 1951; Noon 1942; Holmes 2000; Ritcher and Morrell 2006). Some of the similarities between cultures can be attributed to concepts such as ancestry, duty and responsibility, respect and loyalty, lineage continuation, reciprocity, communism, spirituality, patriarchy, and land tenure. (Khunou 2012; Kuper 1982; Evans-Pritchard 1951). Whilst not an exhaustive list, these are some of the concepts, which constitute some of the fundamental values and principles through which most black-Africans view the world. Understanding these values will help to illuminate some of the ideal African cultural familial and kinship practices, which are discussed below.

2.6.2 Kinship/Lineage Systems and Theories

In this section, I will discuss African family and kinship systems, with reference to kinship or lineage theories (Evans-Pritchard 1951; Bjork 2007). Sahlin (2011a) defines kinship as ‘mutuality of being… where relatives live each other’s lives and die each other’s deaths’ (p. 2). The ties of kinship are established through mutually shared lands, responsibilities, bloodline, and ancestors who also lived as mutual beings in their own lifetime (Sahlins 2011a, and 2011b).

Evans-Pritchard (1929) is generally credited with first theorising lineage during his anthropological study of Africa in the colonial period. Prior to this, though, other anthropologists such as Morgan (1887) and Rivers (1924) had studied sub-Saharan African familial systems and described them as people who value kinship and lineage practices. Evans-Pritchard and contemporaneous European and American anthropologists expanded this by studying many social groups or tribes across different regions of sub-Saharan Africa (Donohugh 1935; Baumann 1928; Noon 1942; Thurnwald 1929). They concluded that lineage systems played a central role in the operationalisation and organisation of social and political relationships in African societies. Contemporary literature suggests that the lineage and kinship values persist in modern day sub-Saharan Africa, and in the diaspora (Holmes 2000; Kuper 1982; Mokgoro 1998; Haviser 2007; Owor 2012).

Anthropologists generally refer to larger kinship groupings as ‘lineages’ and ‘clans’ (Holmes 2000, p. 3). Most African societies are segmented into kinship groups (Evans-Pritchard 1951; Sahlins 2011). Each kinship group is made up of a number of clan segments; each clan has a number of lineage segments; and each lineage comprises an elementary or nuclear family, and an extended family. Members of a clan often share a common language and idioms through which their values and principles are expressed and transmitted for generational continuity (Kuper 1982; Khunou 2012; Owor 2012). According to Edwards and Strathern (2000), ‘persons in [the west] may have a sense of common belonging through what belongs to them [as individuals],’ but ‘families [in Africa] consider themselves as people who belong to one another…[and] kinsmen are members of one another’ (p. 150). In contrast, Sahlins (2011) claims that in African kinship systems, members ‘lead common lives, they partake of each other’s sufferings and joys, sharing one another’s experiences even as they take responsibility for and feel the effects of each other’s acts’ (p. 14). The kinship, clan, and lineage systems survive as a basic form of social relationship and identity, even among Africans in the diaspora (Bjork 2007; Haviser 2007).

The idea of family or household in Africa is not the same as the western nuclear family system (Bjork 2007; Khunou 2012; Sahlins 2011). A family or household, often described as a compound, is in most African societies much wider and deeper than the nuclear family (Bjork 2007; Gluckman 1949; Ritcher and Morrell 2006). It usually includes father and mother, aunts, siblings, uncles, cousins, grandparents, and other extended relatives, including dead ancestors all sharing the same genealogical ties (Bjork 2007; Ferrara 2003; Kuper 1982). Therefore, it is important to understand that, for most Africans, including the participants of this study, when they talk about a unit of family, they refer to a wider network of people who share collateral kinship relationships (Bascom 1942; Bjork 2007; Sahlins 2011). These kinship systems persist through time, surviving because of continuation in lineage. Old members are lost through death, but new members are absorbed by birth or adoption to sustain the cognate kinship and affinity of interlinking individuals in a complicated web of relationships (Gluckman 1949; Bascom 1942; Kuper 1982).

Although the traditional kinship system in Africa has been affected by globalisation to some extent (Annor 2014), some authors argue that African social structures, beliefs, and practices have not changed significantly (Owor 2012; Bjork 2007; Sahlins 2011). A classic example is the Somali kinship system which is practised by diasporic Somali communities in the UK and Europe (Bjork 2007). According to Bjork (2007, p. 10), 'clan is ubiquitous in daily life outside Somalia', just as it is for Somalis in their home country. The families within these clan segments comprise unitary/elementary and/or polygamous family units, often headed by men (Holmes 2000; Kandiyoti 1988; Brown 1951).

The senior male is usually referred to as father, who, as the head of the extended family, holds overarching parental and other rights and responsibilities. His seniority in age places him at the top of the hierarchy, above other males of his generation in the extended family (Brown 1951; Kuper 1982; Ferrara 2003; Owor 2012).

Each lineage segment would usually set up a home, known as a 'compound' or 'household' (Horton 1967, p. 264). Wives, unmarried women, and other cognate relations and dependent people are part of the extended family lineage. There are other types of extended family systems, such as the matrilineal system practised in Ghana and Congo, but this model of family relations is also headed by the eldest male in the segment (Gluckman 1949; Ferrara 2003). However, the patrilineal system is the most common, and is the system considered in this thesis. Members of a co-resident group or compound usually extend their financial, emotional, and other support and assistance to each other, and disputes are settled by common consent and arbitration within the family segment, with sanctions imposed on the individual found to be at fault (Brown 1951). Even after the death of their joint father, a set of brothers usually continues to share the same compound, and to share agricultural production (Spronk 2009). Wives, children, and other dependents, continuing for another generation or two, are known as ‘a lineage or lineage segment’ (Brown 1951, p. 264).

Brown (1951) makes the point that the lineage and clan system survives even when descendants establish homes elsewhere when the main compound becomes over crowded. These offshoots continue to associate with the lineage or clan for generations, including sharing the same surname and returning to the ancestral home for activities or during ceremonies/celebrations. Members of the offshoot lineage do not take wives from their originary clan (Brown 1951; Holmes 2000; Owor 2012). This practice and value system extend to most sub-Saharan Africans living in the diaspora (Bjork 2007).

The clan system requires continuity, stability, and a sense of purpose to function effectively (Kuper 1982). Therefore, in order to meet these needs, the clan requires cooporation from its members in the form of territorial or kinship ties which transcend the interest of individuals in the group. According to Kuper (1982, p. 77), in most African kinship and lineage systems ‘the real bond is belief in common descent rather than habitation of a common territory’. Most African kinship-based systems are unilineal groups of people from the same genealogy; as a result, there is motivation to continue with the relationship. It is Kuper's (1982, p. 76) view that 'the family is omnipresent at every stage of [clan] culture', so the bond generally tends to be strong.

2.6.3 Kinship Care and Education of Children

The care and education of children starts within the kinship system, at the elementary and extended family level and in the wider community (Ritcher and Morrell 2006; McWilliam 1974; Ardayfio-Schandorf 1995). Parents are primarily responsible for educating and disciplining their child, but other adult family and community members assist in this. The authority that parents exert is mainly moral values, which rests on obedience, respect, dependence, and love. Usually, parental authority does not end when a child becomes an adult, especially with adult males. In a predominantly patrilineal society, parents often make demands on their sons' time and labour, and often arrange or prevent their son's marriages; and withhold lands from disobedient sons (Brown 1951; McWilliam 1974).

Understanding the cultural significance of the lineage/kinship systems will in turn help us to understand how having a child with autism interferes with certain traditional African values and principles (Chimakonam 2015; Holmes 2000).

2.7 Religious and Spiritual Theories

Religion and spirituality are complex concepts. Diverse and multidimensional, they are difficult to operationalise (Rippentrop et al. 2005; Hill et al. 2000; Mellor and Shilling 2014). This thesis will, therefore, make reference to religion, spirituality and the existence of God only within the context of its importance to my study participants. Philosophical debates about religion and spirituality are outside the scope of this thesis. I am not concerned with questions around the existence of God, but rather, about what it means to my study participants to have strong religious and spiritual beliefs.

The word ‘religion’ derives from the Latin *religio*, meaning ‘a bond between humanity and some greater-than-human power’ (Hill et al. 2000, p. 56). The word ‘spirituality’ is also derived from the Latin: *spiritus*, which means ‘breath of life’, and *spiritulis*, denoting ‘a person of spirit’ (Hill et al. 2000, p. 57). Spirituality can be defined as a relationship with a Higher Power which affects how an individual function on earth; whereas religion can be defined as the practices undertaken by people of faith in order to connect with a Higher Power (Zinnbauer et al. 1999; Zinnbauer et al. 1997). The term ‘spirituality has been frequently mentioned…[and] referenced in the context of religion and is still both experienced and expressed by many through conventional religious understanding’ (Hill et al. 2000, p. 57). In other words, spirituality and religion are often used interchangeably to mean the same thing, despite their distinct origins. In this thesis, the terms are used interchangeably to attempt to describe the religious identities and affiliations with God and religious organisations by my study participants. The categories of ‘strong’, ‘stronger’ and ‘strongest’ religiosity and spirituality are used in the findings section to differentiate between the three levels of religiosity/spirituality I observed in my study participants. For a more complex and in-depth discussion of the sociology of religion and spirituality, see Mellor and Shilling (2014).

2.7.1 The Social Construction of Religion and Spirituality

Social construction is the worldviews and behavioural patterns of a social group about an issue in their society (Crotty 2012; Elder-Vass 2012). Social construction theory can be used to explain how a society's worldviews are created and reified. For example, those people that view their world from a spiritual standpoint are more likely to be influenced by their spirituality when faced with a serious situation like autism (Elder-Vass 2012; Ravindran and Myers 2013; Tarakeshwar and Pargament 2001; Marchant et al. 2006; Dyches et al. 2004). McNair and Sanchez (2008) argue that, subject to one's denomination, Christians' social construction of disability is often based on Biblical principles. That said, religious faiths have contradictory positive and negative constructions of disability (McNair and Sanchez 2008; Rippentrop et al. 2005; Ismail et al. 2005). For example, Christianity and Islam teach that humans are created in the image of God, which affirms to disabled people that they are as valuable as their non-disabled counterparts (Ismail et al. 2005; Tarakeshwar and Pargament 2001). But they also teach that disability can be a result of sin, and that disabled people can be healed, if their faith is strong enough (Ismail et al. 2005; McNair and Sanchez 2008; Rippentrop et al. 2005). Other positive religious and spiritual constructs that are often applied to disability include disabled people 'being angel unaware, or God's special children, or that their parents are somehow selected by God to have a child with a disability' (McNair and Sanchez 2008, p. 37).

Ismail et al. (2005) carried out a study of South Asian adults in England who were diagnosed with and were receiving treatment for epilepsy. Their respondents included people of Muslim, Sikh, and Hindu faith. They found that the majority of respondents believed that their epilepsy was God's wish. Some believed that their epilepsy was punishment for sins committed in a previous life, or by their ancestors. Some, particularly those who were born in the Indian subcontinent, believed that their epilepsy was linked to spiritual possession. Others, including ‘educated’ respondents such as medical doctors, mentioned ‘black magic’; some doctors also shared the belief that epilepsy resulted from past sins, or from spiritual possession (Ismail et al. 2005, p. 30).

2.7.2 Religion and Spirituality as a Source of Coping

Coping can be defined as an active process— which could involve belief systems and actions—through which an individual might try to make sense of and deal with a challenging phenomenon in their life (Haworth et al. 1996). Religion and spirituality have been shown to be an effective coping strategy for people experiencing various types of acute life events, such as having an autistic child (Gray 1993 and 2002; Jegatheesan et al. 2010). Religion and spirituality are often used by people undergoing difficult life events to interpret and to make meaning of their problems and as a source of coping with their daily difficulties (Haworth et al. 1996; Ismail et al. 2005; Poston and Turnbull 2004). For most of the parents in Haworth et al.’s (1996) study, religion and spirituality were a way of life, and part of their identity. They used religion and spirituality to make sense of their situation, such as having a child with a disability being a curse, or a reward, or a lesson, or duty which God expected them to carry out (Carter et al. 2015; Tarakeshwar and Pargament 2001; Rippentrop et al. 2005). Some parents adopted a passive approach, praying for God to intervene in their problems without engaging in practical processes to help themselves. Literature shows that belonging to an organised religion provides various types of support, enabling families to cope with the daily experiences of raising an autistic child (Haworth et al. 1996).

Religion help parents to make meaning of autism, a complex phenomenon which is yet to be linked to any specific causal agent. The parents in Tarakeshwar and Pargament's (2001) study sought spiritual, practical and emotional support from their churches to help with managing their children's challenges. According to Tarakeshwar and Pargament, 'the church and its beliefs can be regarded as a resource for the parents' emotion-focused coping efforts, because they help to minimise stress by providing parents with alternative ways of interpreting the challenges of parenting an autistic child' (2001, p. 256).

Tarakeshwar and Pargament further point out that people who reframe disability, acute illness, or other major stressful events as a blessing from God tend to draw strength from their faith and their community, and are thus more likely to experience positive coping outcomes. Conversely, people who appraise disability as punishment from God often expressed dissatisfaction with both God and congregation, and are likely to experience negative coping outcomes (Zinnbauer et al. 1997; Tarakeshwar and Pargament 2001; Zinnbauer et al.1999).

In her research on white British parents of children with autism in the UK, Waterson (2011) found that 'the overwhelming view was that religion played no part in their [parents] lives at all and was not part of any coping strategy' (p. 205). This finding contradicts findings from other researchers in countries such as Australia (Gray 2006). In Asia, Africa and the Americas, families of children with autism mentioned that core religious values, such as prayers, hope, and faith, played an important part in their coping. It has been widely reported that most black-African (Baba 2014; Audu and Egbochukwu 2010; Anthony 2009; Chukwueloka 2016); and Asian (Desai et al.

2012; Doig 2012; Xue et al. 2014) parents with autistic children often turn to religion and spirituality for solace. Waterson (2011) concluded, though, that the situation in the UK may be different due to the shift from religiosity to secularism in the latter part of the 20th century.

Other scholars concur with Waterson (2011) that secularism is on the rise in the west, as people continue to lose faith in organised religion (Zinnbauer et al. 1997; Mellor and Shilling 2014; Hill et al. 2000). Other research also suggests a parallel increase in focus on individual spirituality and personal relationships with God, as distinct from organised religion (Hill et al. 2000; Zinnbauer et al. 1997).

2.7.3 Can God Protect and Cure Acute Conditions?

Most religious individuals believe that they are working collaboratively with God for the prevention and cure of illnesses or misfortunes by way of prayer, meditation, reading religious texts, and other practices (Rippentrop et al. 2005; Haworth et al. 1996; Hill et al. 2000). In a survey conducted in the USA by Sloan et al. (1999), the majority of their respondents agreed that spirituality can help with recovery from illness. Sloan et al. report that ‘of the 296 physicians they surveyed during a meeting of the American Academy of Family Physicians, 99% of them were convinced that religious beliefs can heal, and 75% believed that prayers or other [religious and spiritual activities] could promote a patient’s recovery…that faith in God has a health promoting effect’ (p. 664).

Religion and spirituality have also been reported to play significant roles in patients’ recovery (McNair 2008; Saroglou et al. 2008). For example, Sloan et al. (1999) found that elderly women who were religious had recovered faster from major surgery for a broken hip than their non-religious peers. Another example cited by Sloan et al. is a randomised clinical trial where born-again Christians performed ‘daily intercessory prayers’ with a group of patients in a coronary care unit, with the outcome that the patients in ‘the prayer group had fewer cases of newly diagnosed heart failure and of newly prescribed diuretics’ (p. 666). They conclude that ‘religious comfort and strength was significantly associated with lower mortality after cardiac surgery in the elderly, even after control for relevant confounders’ (p. 666).

Powell et al. (2003) argue that religion and spirituality can minimise the risk of disease and death, and improve health. They further claim that religion and spirituality can help to minimise death from cardiovascular diseases because spirituality encourages individuals to live healthier lifestyles. They suggest that attending weekly church services could prevent an individual from developing cardiovascular disease and cancer. They assert that ‘deeply religious people are protected from death’ and that they ‘live longer’ (Powell et al. 2003, p. 43). It is outside the remit of this study to debate the rights or wrongs of this assertion. However, Benedetti et al. (2005) report that a randomised control trial of placebo analgesia and antidepressants triggered complex chemical reactions in the patients’ brains, producing a healing outcome. Some of these participants share the belief that God can cure and protect. Religion and spirituality are further explored in chapter seven of this thesis. In the next section, I will discuss immigration theories, another one of this study's conceptual dimensions.

2.8 Immigration Theories

The participants in this research study are first-generation African immigrants to the UK and are therefore considered part of the UK immigrant community. Being immigrants, the concept of immigration becomes analytically relevant. There is a broad acknowledgment that immigration is a significant phenomenon for contemporary social work practice (Kimberlin 2009; Sirojudin 2009). Having previously discussed ethnicity and culture, lineage/kinship, and religious theories, in this section, I will present some immigration-related theories that might help to illuminate the challenges that these participants might have encountered prior to emigrating to, and while living in the UK. I will also highlight some of the immigration policies developed to discourage 'health tourism' by migrants. Finally, I will demonstrate how immigration-related experiences form one of the intersecting multiple-layers of autism experiences for my study participants.

International migration is the movement of people across national borders for a variety of reasons and purposes (Massey et al. 1993). Immigration straddles various social science disciplines and it provides an opportunity to adopt various social science theories that can inform social work practice with immigrant communities (Kimberlin 2009). Despite the important role social workers play in the lives of immigrants, immigration as a topic is inadequately addressed in social work education/discourse (Kimberlin 2009; Lee and Hernandez 2009).

According to Massey et al. (1993, p. 423), 'currently, there is no single comprehensive theory for international migration, rather there are fragmented set of theories often segmented by disciplines. None of these units of theories in isolation is capable of explaining modern international migration. Modern migration is complex and sophisticated in nature'. Some of the theories Massey et al. refer to include economic, psychological, neoclassical, political, political economy, social sciences, sociological, internationalization, acculturation, anthropological and feminist (Massey et al. 1993; Van Hear 2010; Lee and Hernandez 2009; Richmond 1988). However, in this thesis, for the purpose of space, I will limit the discussion to economic, psychological, and feminist perspectives. Economic theory will help explain potential push and pull factors that, along with the quest for better autism services, inform the process of deciding to immigrate. Psychological theory will help to extrapolate the experiences of immigrants in their destination country, and feminist theory will illuminate the role of women as immigrants and primary carers.

2.8.1 Economic Theories of Migration

Economic theories of immigration include a variety of related concepts, such as rational choice theory, supply and demand theory, world ecosystem theory, and push and pull factors (Sirojudin 2009; Van Hear 2010; De Haas 2010).

Kimberlin (2009) argues that poor standards of living, lack of economic opportunities, or strife in the country of origin can become push factors for immigrants. So too, one imagines, a lack of access to autism services might push families to migrate. Pull factors towards the destination country might be the promise of job opportunities, comparatively better wages, and relatively good living standards (as well as better autism services). Supporting a similar, but slightly different line of thinking, Kim (2009) and others have argued that immigration can be examined through a personal or microsystemic lens. Kim posits that immigrants are individuals who make rational choices by weighing the costs and benefits of emigration before doing so. However, Richmond (1988) disagrees that migration is an individual’s choice, taking the view that the decision to emigrate is often taken ‘in consultation with family members or others in a close-knit community or religious group' (p. 7). For Sirojudin (2009) however, immigration can also be explained through supply and demand economics. The high demand for labour in the industrialised countries attract migrants from countries where employment opportunities are scarce. However, using the neo-Marxist world-system theory, Kimberlin (2009) sees immigration as a form of economic exploitation, influenced by global corporations and rich capitalist economies. This view argues that global corporations control the supply of jobs, deliberately seek workers from poorer countries, and pay them low wages in order to maximise profits. It is possible, therefore, that some of my study participants who came to the UK prior to having an autistic child were motivated by economic factors, before autism intercepted their motive. Participants who gave birth to a child with autism in their home country before migrating to the UK were likely to be motivated by the search for better autism services. They will also have been likely to have the financial means and educational qualifications to enable travel abroad.

Issues relating to labour and employment have also helped to inform debates on gender and immigration analysis (see, Henry 2009; Horevitz 2009). Gendered issues around immigration are explored in the following section.

2.8.2 Feminist Theory of Migration

According to Henry (2009), international migration studies was traditionally focused on the movement of men across borders. However, recent studies show that the rates of international migration by men and women is the same (Henry 2009).

Feminist theorists such as Young (1996) viewed immigration from a gendered perspective, positing that the functionality of public enterprise depends on domestic work taking place in the private home environment. Horevitz (2009, p. 752) notes that ‘women are often the mediators between the individuals in the household and the outside world through their dual roles in reproduction and production’. Therefore, the ‘private’ domestic sphere and the public sphere are interconnected. In line with that idea, Henry argues that many women from developing countries migrate to developed countries in order to fill employment gaps in the care and hospitality industries. Previously, these jobs have been taken by women in the receiving countries, who are now more inclined to pursue higher-status careers. This movement of women from developing to developed economies leads to a ‘care drain’ in developing countries, as fewer women remain to fill care and hospitality vacancies (Henry 2009, p. 694). Ehrenreich and Hochschild (2004) also cite push (unstable political and economic climate) and pull (work opportunities) factors that explain this pattern of women’s migration.

Advancing this line of thought, Horevitz (2009) highlights shifts in gender roles, arguing that, by participating in the labour market and working outside the home, immigrant women transcend the traditional gendered division of labour.

However, Henry (2009) notes that female immigrants are more vulnerable to abuse and exploitation than their male counterparts. Immigrant women, particularly undocumented immigrants, might be compared to female victims of domestic violence who are often vulnerable due to their isolation (Anitha 2008). Similarly, immigrant women employed in domestic roles such as housemaids and nannies often live with their employers; making them more susceptible to abuse, as their living situation isolates them from the public (Ehrenreich and Hochschild 2004; Henry 2009). Henry

(2009) believes that immigrant women-carers are even more vulnerable than women experiencing domestic abuse, because they face more barriers, such as fear of approaching the authorities for help, lack of knowledge of their legal rights, language barriers, and precarious employment. Therefore, immigration policy makers in receiving countries need to be sensitive to gender inequality.

2.8.3 Psychological Theories of Migration

Lee and Hernandez (2009) examine immigration from psychological perspectives. They use psychological theories to explain the motivational, cognitive and behavioural processes of migration, including the processes of acculturation, which refers to the ways in which immigrants mentally adjust to living in a new country. According to Lee and Hernandez, acculturation can take four forms:

- assimilation—where immigrants completely abandon their old culture and embrace the culture and values of their destination country
- integration--whereby immigrants retain some of their old culture and adopt some new practices
- separation—completely retaining the culture of origin and not adopting the new culture at all
- marginalisation—abandoning/refusing both the old and new cultures.

Kimberlin (2009) notes the obvious relevance of acculturation, but adds that psychological theories can also be used to explain how immigrants develop new ethnic identities, and how they navigate the social identities imposed on them by the host country.

Psychologists are also concerned with acculturative stress, which is caused by a variety of immigration-related issues. Acculturative stress often leads to mental health problems and sociocultural adaptation problems for immigrants (Kimberlin 2009; Kim 2009). But Lee and Hernandez (2009) believe that a long term-stay in the host country, with support from social networks and relevant institutions, can help to alleviate the cumulative effects of acculturative stress and promote social integration.

2.8.4 The Rate of Social Integration for Black African Migrants into the UK Society

Integration was one of the key policies of the New Labour government, according to Mitton and Aspinall (2011). This was demonstrated by the formation of a commission to focus on cohesion and integration in society (Mitton and Aspinall 2011). In 2007, the number of black Africans in England and Wales was estimated to be about 736,000. More than half of them emigrated to the UK as first-generation migrants. But when they arrived in the UK many of them encountered issues such as language barriers, financial problems, inadequate living conditions, and cultural changes in terms of gender roles, particularly around power dynamics in the west between husbands/males and wives/female (Phillips 1997; Daley 1998; Mitton and Aspinall 2011). These factors partly influence the overall level of integration for this group (Phillips 1997; Mitton and Aspinall 2011).

According to Mitton and Aspinall (2011), country of birth could be used as an internal differentiation category within the black African group, in terms of integration into UK society. Integration takes place over a long period of time. So, some of the factors attributable to integration are English language proficiency, purpose of migration, age at migration, length of stay in the UK, and level of educational attainment (Dustmann and Theodoropoulos 2010; Mitton and Aspinall 2011). For example, migrants from Anglophone countries such as Ghana or Kenya are more likely to have a better command of English language compared to migrants from Francophone countries such as Congo or Mozambique. Migrants from Somalia, Congo or Rwanda were more likely to migrate to the UK to seek asylum on the basis of conflicts in these countries, while migrants from Zimbabwe were more likely to come for both asylum and economic reasons, but a high proportion of Nigerians came to study (ONS 2013). Second generation African migrants and those who came to the UK as a child are more likely to have a better command of English language compared to their parents or those who arrived as adults.

A good command of English is essential for social integration, so too is the place where an African migrant acquired their educational qualification (Dex and Lindley 2007). Being educated in the UK, having a job and getting a mortgage are other factors associated with good level of integration. Nigerians and Zimbabweans are more educated, more in employment, have a good command of English, hence they are more socially included and socially integrated in the UK society than migrants from other African countries. Somalis and Congolese are the least integrated and more socially isolated (Mitton and Aspinall 2011).

The black African migrant groups with the highest education qualifications or attainments are Nigerians, and fewer of them are unemployed compared to other African migrants and they are often over-qualified for their occupation and a high number are in business or in self-employment category (Dustmann and Theodoropoulos 2010; Nwankwo 2005; Mitton and Aspinall 2011).

There is also a low unemployment rates among Zimbabweans whose main career is in Health and social care. But the Somalis have the highest unemployment rate, and their women are less likely to engage in economic activities. This is attributable to various factors such as language barrier, religion and marriage. In addition, the salary of Somalis in general is far less when compared to a white British's salary (Mitton and Aspinall 2011).

The number of Nigerians on income support or whose children receive free school meal is similar to the white British and less compared to other African migrants, and Nigerians are doing better economically compared to their peers. Similarly, the Zimbabweans are also less deprived, are more likely to live in a less deprived area and their children are less likely to receive free school meals (Mitton and Aspinall 2011). But the African migrants from Somalia, Congo or other French speaking countries live in the most deprived areas and have a higher number of their children who receive free school meals (Mitton and Aspinall 2011). Being in sustained employment is a strong indicator of integration because employment presents an opportunity for a migrant to socialise with people from host country and other social groups. The income earned from employment can also provide a good opportunity for social mobility which further enhances integration opportunity.

Somalis and Congolese are the most disadvantaged and most deprived sub-groups of African migrants in the UK. Therefore, their rate of integration into the UK society is lower when compared to their peers (Mitton and Aspinall 2011).

2.8.5 Immigration Policies Developed to Discourage ‘Health Tourism’ to the UK

Alvarez et al. (2011) describe health tourism as ‘the movement of patients across an international border for the purposes of obtaining healthcare’ (p. 2). Such group of patients are often referred to as irregular migrants. Irregular immigrants are described as the nationals of non-EEA countries who do not have the right to live in the UK, or those whose rights have been withdrawn for various reasons and are therefore removable from the UK once they were located (Duvell et al. 2018).

In 2012, Theresa May, then Home Secretary promised to make ‘Britain a really hostile environment for illegal migration’ (Duvell et al. 2018 p. 11). In 2014, this policy informed the Immigration Act 2014 and the subsequent amendments made to the legislation. The 2014 Act created an instrument which deny irregular migrants access to NHS care, a bank account, renting properties, driving licence, employment and benefits (Duvell et al 2018; Sitkin 2014).

The Home Office (HO) encourages other government departments and private organisations to inform them about any suspected irregular migrant on their records. As part of implementing the hostile environment policy some hospitals often screen the identity of a suspected irregular migrant, to prevent them from using the services (Duvell et al 2018).

Prior to the 2014 hostile environment policy, in 2004, the government had introduced the ‘Charging Regulations’ in order to crack down on ‘health tourism’ (Yates et al. 2007 p. 299) and to give the NHS the power to charge overseas visitors for using the health services in the UK. Since the charging regulation, known as ‘immigration health surcharge' was introduced it has generated millions of pounds from overseas visitors using the NHS services and 'non-EEA nationals coming to the UK to live, work or study for six months or more' (Department of Health 2017, p. 2). For example, in 2015/16 alone the scheme had generated £290 million. The regulation also mandates all NHS Trusts to place a 'unique identifier'/number on the NHS numbers of every oversea visitor to make it easier to identify a foreign patient from outside of the EEA who is liable for charges (Department of Health 2017, p. 3).

All these schemes are designed to make it more difficult for an irregular migrant to settle in the UK, and to force them to leave the country (Duvell et al. 2018). However, despite the hostile environment policies of the 2014 Act and other similar measures introduced by the government, irregular migrants, landlords and some employers have found a covert ways to avoid detection (Sitkin 2014; Yates et al. 2007; Duvell et al 2018). According to Duval et al. (2018) detecting those who are illegal immigrants in the UK is often a challenge to the authorities because such people have a way of avoiding detection. Therefore, the undocumented immigrant African parents in my study were somehow able to access services in the UK without being detected.

2.8.6 Immigration Identity and Behaviour

When a black-African immigrant arrives in the UK, they navigate many aspects of migration, such as acculturation experiences and immigration policies (Kimberlin 2009). In terms of behaviour and identity, the black-African parents in my study have to deal with not only acculturative stress, but also, manifold additional stressful experiences arising from caring for a disabled child, navigating immigration policies, dealing with unfulfilled dreams, managing expectations from back home, role changes, and other factors. In addition to these, they also try to adjust to the norms and values of the UK society, while simultaneously maintaining a relationship with their country of origin (Lee and Hernandez 2009).

The relationship my study participants have with their countries of origin, based on kinship practices, is also an important factor to consider when conceptualising their immigrant identity and behaviour. These relationships range from complete severance—where a participant severs all ties with their country of origin—to transnationalism, where they maintain close ties with their origin country. An immigrant's identity and behaviours are shaped by both the level of acculturation and his or her relationship with their country of origin; and all of these paradigms are linked to psychological, economic, social science, political, and sociological immigration theories.

2.8.7 The Aspirations of Black African Parents for the Children in the UK

The immigrant parents in my study who came from Africa (including those who migrated from other developing countries) believe that living in the west provides an opportunity for social mobility for themselves and for their children (Salami et al. 2016). They are more likely, therefore, than their host parents to encourage their children to aspire for higher education (Roubeni et al. 2015; Salami et al. 2016). Immigrant parents are four times more likely to push their children towards university education and are more likely to sustain that aspiration until it is achieved according to Roubeni et al. (2015). Equally, research considers that immigrant children tend to be more aspirational to achieve their academic goals than their host counterparts (Roubeni et al 2015). In spite of the disadvantaged beginning for immigrant parents in the west, their children are often assessed as having better score in their physical, emotional and psychological wellbeing; have better self-efficacy and perform better in education compared to children of host parents (Salami et al. 2016; Roubeni 2015).

Salami et al. (2016), however, consider that the second generation children of African immigrants feel overwhelmed with the expectations from their parents to observe their cultural values, excel in education, adjust the social expectations of destination society, be resilient to social and peer pressure or discrimination all at the same time. The African parents in my study also have similar expectations for their children. They also understand the role of education as a status symbol and also as means to financial security which would also enable the children to assist their parents in old age financially, but the presence of autism poses a serious threat to the realization of these aspirations.

An African immigrant parent often sees educational success as a means of recovering the social and material loss they suffered as a result of migration (Salami et al. 2016). It is perceived as a pathway out of poverty and for upwards social mobility, but the participants of my study are frustrated that their autistic children are not likely to achieve these objectives. In general, African parents place high value on formal (education acquired at an institution) and informal education (education offered through parenting at home) for their children. They see both as integral to success and moral uprightness in the society (Sow and Bledsoe 2011; Salami et al 2016; Roubeni 2015). However, the parents in my study discover that autism is a serious impediment to any meaningful formal or informal educational success for their autistic children.

According to Roubeni et al. (2015), African parents value the need (or see it as their inalienable duty) to train their children on moral values, while also investing in their formal educational and professional successes, with the view to mitigate the losses they suffered as a result of migration. Their children's success is linked to their quest to recover those losses and as a hope for an improved future for the family. Dryden-Peterson (2011) suggests that black African immigrant parents perceive academic success as ‘the number one key for success’ (p. 17) in the United States, ‘in which over 96% of parents held expectations that their children would complete college’ (Roubeni et al. 2015 p. 295). In the UK, most of the parents in my study have lowered their expectations for their children as a result of the impact of autism on them.

The African parents in my study had experienced trauma, sudden loss of their material possessions, social status, and culture due to war, persecution or voluntary migration. As a result, they are likely to have a stronger coping mechanism and are likely take greater risk in order to attempt to recover their losses (Roubeni et al. 2015). Therefore, they feel the need to push their children harder for educational success, because the success of their children would invariably help them to regain their losses and reduce the impact of the loss on the family (Sow and Bledsoe 2011). Black African parents, including the ones in my study, believe that their children must succeed in formal education offered in institutions, and on informal education offered at home. The former is required for upward social mobility, while the latter is to guarantee the transfer of cultural, religious and moral values for continuation into the future generations (Roubeni et al. 2015; Sow and Bledsoe 2011). However, these hopes, dreams and aspirations are gradually fading away for the parents in my study because they are realizing that, despite pushing their autistic children harder, they are unlikely reach their potentials.

Whilst black African parents are keen for their children to succeed in their host country, they are also worried about the impact of the exposure to the values of the West such as autonomy, freedom, 'indulgence' and 'permissiveness' on their children's moral development (Roubeni et al. 2015 p.297). Hence, in order to give their children the maximum chance of a good development and to fulfill their familial obligation some parents send their children back to Africa in the care of relatives (Roubeni et al 2015; Salami et al 2016; Sow and Bledsoe 2011). According to Sow and Bledsoe (2011), West African parents send their older children back to Africa for a number of reasons, including to experience some hardship there in order to build more resilience for their future, the need for the younger generation to know their ancestral home, to have a ‘secure footing’, for ‘low cost of living and abundant child care’ and for discipline (p. 747). Discipline is deemed an integral part of a child's intellectual development, hence children are sent to Africa because parents believe that the western society 'cuddle and spoil' children and prevent parents from accessing the discipline they believe children need to develop into a rounded citizen in the west (Sow and Bledsoe 2011 p. 748). Also, parents fear that their undisciplined children are more likely to be attracted to gangs, crime and to a violent lifestyle.

These parents are also concerned that their children are losing their African identities and ideals because of exposure to western culture (Salami et al 2016; Sow and Bledsoe 2011). Hence, when some African parents realise that due to the interference of the authority, they are unable to discipline their unruly children, they opt to send them back home to either live with relatives or to a boarding school (Salami et al 2016; Sow and Bledsoe 2011). The gender of a child also plays a role in an African parent's decision to send their child home, and it can influence their parenting styles in the West. For example, females are sent home for the purpose of circumcision as the practice is unlawful in the West and they are encouraged to engage more in domestic roles and discouraged from socializing outside the home. The boys are sent back because they believe that their behavioural problems would be better managed in Africa. They also have more freedom of association and socialisation outside of the family environment than girls (Salami et al. 2016; Sow and Bledsoe 2011). No parent in my study, though, had sent their child back to Africa, and this is partly due to fear of stigma, social rejection and a lack of, or the scarcity of autism services there.

Salami et al. (2016) suggest that African parents believe strongly in the use of physical chastisement and corporal punishment as means of disciplining and controlling children, but the child protection and welfare law makes such practices illegal in the west. Without the freedom to use physical punishment, African parents feel that they have lost control of their children and the children have been empowered to challenge them and to call the police on them. In contrast, some of the parents in my study reverted to educating their family members about autism related behaviours they can expect from their autistic child. So, instead of trying the model the child to fit into their African cultural expectations, family members were taught to adjust and to accommodate the autistic children’s atypical behaviours.

To conclude this section, immigration is an important part of the UK’s political, economic, and social landscape. The black-African parents in this study, who are living in the UK with their autistic children, are part of the UK immigrant population. Their decisions to emigrate are all unique and complex but can be explained by the aforementioned theories/concepts. When migrants arrive in this country, they must navigate the social, economic, and political environment and acculturate to the UK, in addition to redefining their identities. Some maintain strong relationships with their countries of origin and their families back home, while others have a weak one. Another distinctive factor is that often an African parent of an autistic child who arrived in the UK prior to the birth the child would have often made a rational economic decision, being pushed out by adverse social and economic conditions in their countries of origin, and often pulled into the UK by promises of better job opportunities and a more comfortable lifestyle. They are likely to have high hopes of creating a better quality of life for their family members, both in the UK and in Africa. Subsequently, having a child with autism could have caused significant disruption to their aspirations. The African parents of autistic children in this study who migrated to the UK after the birth of their autistic children had done so mainly to seek better autism services for their children, among other benefits. Both groups undoubtedly benefit from the higher quality of autism support in the UK relative to Africa. For some parents, this is possibly the single potent pull factor that influenced their decision to move to the UK.

In the next section, I will discuss the theory of spoiled identity, and show how these participants can experience stigma in the UK and in their home country simultaneously.

2.9 The Theories of Spoiled Identity

Over fifty years ago, Goffman (1963) published his book on stigma and the theory of spoiled identity. According to Goffman, the term stigma originates from Ancient Greece, where it was used to refer to a physical malfunction of the body, social outcasts, and a person of immoral character or physical infirmity. People with tarnished characters, such as slaves, criminals and traitors, usually carried a symbol or mark burnt or carved onto their skin to differentiate them from others. These signs, designed to expose them to the public, were a form of social identity and categorisation, so that anyone who encountered their bearers could identify and avoid them. In modern times, though, the term is used more to describe the shame and disgrace experienced by a person who differs in some way from the norm in their society (Link and Phelan 2001; Scheff 1974). Goffman defines stigma as an 'attribute that is deeply discrediting [that reduces the bearer] from a whole and usual person to a tainted, discounted one' (Goffman 1963, p.14). Where differences between a person's perceived and real identity exists, and the difference is conspicuous, the different attribute effectively spoils their social identity. Goffman describes two main sources of stigma: the 'discredited' and the 'discreditable' (Goffman 1963, p. 14). The former refers to an individual whose difference is obvious, and therefore unconcealable; whereas the latter refers to individuals whose difference is not immediately obvious, and therefore concealable. Most people with autism fall into the ‘discreditable’ or concealable stigma category (Portway and Johnson 2005; Gray 2002; Smart and Wegner 1999).

Since Goffman, the literature on stigma has expanded, creating a variety of definitions (Scambler and Hopkins 1986; Corrigan and Miller 2006; Link and Phelan 2001; Smart and Wegner 1999). For example, Stafford and Scott (1986) define stigma as a ‘characteristic of persons that is contrary to a norm of a social unit,’ where a ‘norm’ is defined as a ‘shared belief that a person ought to behave in a certain way at a certain time’ (Stafford and Scott 1986, pp. 80-81). For Link and Phelan (2001), ‘stigma [is] the convergence of interrelated components. Thus, stigma exists when elements of labelling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them’ (p. 377). Crocker et al. (1998, p. 505) indicate that ‘stigmatised individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context’.

With Crocker et al’s definition of stigma in mind, I want to argue that being a parent of a child with autism or another disability conveys a social identity that is devalued in an African context (Hollos and Larsen 2008; Ibisomi and Mudege 2013; Baba 2014). The attribute or characteristics of a parent of a child with a devalued social identity is perhaps linked to that parent's inability to have a child who is not devalued to replace them after death (Ibisomi and Mudege 2014; Baba 2014; Hollos and Larsen 2008). Therefore, the label of autism links the child and their family to stereotypical traits that can lead to stigma. For example, in some African societies, children with autism characteristics are often described as being ‘crazy’ or ‘mad’, which is also a common stigmatising word used to describe people with mental illnesses (Baffoe 2013; Link et al. 2004; Yang et al. 2013). Therefore, people who conflate autism with mental illness are likely to be conceptually deploying what Yang et al. (2013, p. 3) have defined as ‘tangible threat’ and ‘symbolic threat’. ‘Tangible threat’ is the perception that mentally ill patients are dangerous or hazardous, which in turn leads people to establish social distance from those patients. 'Symbolic threat’ is when an individual is seen to have failed to stop himself from acquiring mental illness, a failure which then threatens the fabric of society. This perceived inability to prevent their own mental illness makes patients a target for blame, engendering anger and punishment towards the individual for posing a threat to the social order.

The definition of stigma offered by Crocker et al. (1998) implies that experiences of stigma can be situational (Gray 2002). In order words, the effect of stigma is a continuum mediated by various factors and attributes, such as culture, race, gender, society, and individual perceptions. Therefore, some individuals might be more deeply stigmatised while others might be less so, even if both groups are faced with similar public reactions. Taken a step further, I would argue that the participants in my study are likely to experience multiple-layers of stigma, both in the UK, due to their race and ethnicity, and in Africa, due to certain African beliefs and traditions. It is reasonable, therefore, to infer that the combination of these multiple intersecting factors leads to African parents experiencing multiple-layers of stigma on the basis of their association with their autistic child. This is known as ‘courtesy’ (Goffman 1963, p. 43) or ‘affiliational’ stigma (Scambler and Hopkins, 1986, p. 34).

2.9.1 Courtesy Stigma

Courtesy stigma is a type of stigma experienced by an individual who is socially related to a stigmatised individual. As a result of this social relationship, society tends to treat both the stigmatised and their relations in the same way (Goffman 1963). This means the parents and siblings of children with autism often experience similar stigmas to their child/sibling (Gray 2002). An individual with courtesy stigma could pass as normal if their relationship with a stigmatised person is invisible to or concealed from the outside world (Portway and Johnson, 2005). For example, if a parent or sibling of a child with autism does not accompany them in public, or if the child does not present with atypical behaviour in public, the parent/sibling would not experience stigmatising behaviour from others. However, in rural Africa, for example, with its kinship systems and communal social structures, it is difficult for someone related to a stigmatised child to avoid being discredited, whether or not the child is with them. Another way for a relation to avoid courtesy stigma is by attempting to change or eradicate the stigmatising symbols. For example, one of the obvious stigma symbols for most children with autism is a lack of speech. In response, parents might make concerted efforts to eliminate this stigmatising symbol by spending time teaching the child how to speak. In this way, the child might ‘pass’ as ‘normal’.

Another strategy often employed by people who practice ‘passing’, (the act of concealing a stigmatising treat to prevent others finding out) including the discredited, the discreditable, and those with courtesy stigma, is voluntary distancing (Gofman 1963, p. 65). By avoiding getting close to their relations, the stigmatised individual can avoid the obligation to disclose stigmatising information (Goffman 1963; Scambler and Hopkins 1986; Corrigan and Miller 2006). By keeping a distant relationship, the stigmatised individual ensures their stigma remains concealed. By restricting physical closeness, individual resists the possibility of others finding out about their stimatising identity (Corrigan and Miller 2006). By living far away from their immediate close family and friends in Africa, not attending family functions, and not making or receiving contact from ‘home’, migrant parents of an autistic child can safely and successfully practice un/intentional distancing.

Conversely, the stigmatised person might decide to forego the act of ‘passing’. By voluntarily disclosing themselves to others, the individual removes themselves from the category of a stigmatised person with a secret to conceal, becoming instead, someone with a situation to manage (Scambler and Hopkins 1986; Goffman 1963). But from the moment a stigmatised person divulges this personal information, they have to recalibrate their interactions with the people to whom they have disclosed. For example, families in my study who disclosed their child’s autism to their African kin, or those who travelled home to Africa with their child, had to adapt their interactions with African relations.

Since Goffman’s (1963) conceptualisation of the theory of spoiled identity and stigma, many sociology writers have refined and elaborated the concept, demonstrating that stigma has a negative impact on the lives of the stigmatised. For example, Scambler and Hopkins (1986) applied the theory to people with epilepsy, perceived as a discreditable condition. They reported that people with epilepsy experience negative attitudes from the public, structural discrimination, and rejection due to stigma associated with epilepsy (Scambler and Hopkins 1986; Caveness and Gallup 1980). Scrambler and Hopkins (1986) suggest that there are two types of stigma: enacted and felt stigma. Enacted stigma refers to discrimination and other negative attitudes directed towards people with epilepsy due to their perceived inferiority and public rejection. Felt stigma refers, broadly, to the fear of enacted stigma, and the feelings of shame and embarrassment associated with being stigmatised. Scambler and Hopkins argue that felt stigma emanates from the worldview about epilepsy based on them witnessing a seizure episode, which can mean that people with epilepsy try to hide their condition. Whenever possible, they tend to ‘pass’ as ‘normal'. The notions of enacted and felt stigma have been applied to people with autism and their families (Gray 2006; Gray 1993) to show how they are often able to hide their condition, ‘passing’ as neurotypical people until they display a stigmatising behaviour in public (Portway and Johnson 2005).

2.9.2 How Stigma Varies by Family Role

According to Corrigan and Miller (2006), stigma affects both the individual with a discrediting condition and their family members. The prejudice and discrimination directed against these individuals are extended to their family, because they are linked to the stigmatised person (Corrigan and Miller 2006; Gray 1993; Link and Phelan 2001). Corrigan and Miller refer to stigma experienced by family members as ‘family stigma’, which is the same as ‘courtesy stigma’.

Experiences of family stigma vary according to gender and family role. In a family with a stigmatised child, mothers are said to experience more stigma than fathers or other family members and are more likely to be blamed and discriminated against (Corrigan and Miller 2006; Gray 2002). This is because mothers are usually primary caregivers, are more closely associated with, and are more likely to be seen with the stigmatised child (Gray 1994; Gray 2006). According to Gray (1993), public responses to an autistic individual's perceived violation of social norms depends on the age of the individual. The public are likely to be more sympathetic towards younger children than older people with autism, especially given that many autistic people do not have an obvious physical disability marker (Portway and Johnson 2005; Gray 1993).

Human beings have an innate need to belong and be accepted, but social rejection is an inevitable part of social life (Kurzban and Leary 2001; Goffman 1963). One of the ways that rejection can occur is through the process of stigmatisation, whereby some individuals are excluded from certain social interactions due to their differences. Some members of diverse and minority groups, such as people with autism, are susceptible to the risk of social rejection. The end result of stigma, according to Kurzban and Leary, is the 'spoiling' of an individual's social identity, meaning they are assumed to be incapable of fulfilling the requirements of social interaction. An African parent who is living with an autistic child in the UK and maintaining ties with their country of origin is likely to experience stigma both in the UK and in Africa.

In the next section, I will explore the concept of racialisation, in order to demonstrate that an individual can experience racism without necessarily being racially stereotyped.

2.10 The Concept of Racialisation

Racialisation is a way of describing an individual as being racially conscious. It can also be an act of making sense of an interaction between people of different races in a racial context, even when the act of racism was not intended (Ahmed 2002 and

2007; Garner 2010 and 2017). Racialisation is also a product of domination in a power relationship whereby the racialised group slowly start to identify with the attributes ascribed to them (Ahmed 2007; Garner 2010 and 2017). Racialisation is ‘one of the key ways that academics make sense of the meaning of race’ or how race becomes meaningful in a given context (Garner 2010, p. 19).

A number of writers have traced racialisation to the history of black slavery and the colonisation of African countries by Europeans (e.g. Ahmed 2002; Garner 2010; Fanon 1967 and 2008). For Fanon (2008), race and racialisation are European ideologies whereby blackness is seen as bad and whiteness as good. This ideological process created binaries: dominated and dominator, ‘colonised’ and ‘coloniser’ (p. 61), ‘black and white’ (p.58). Fanon argues that ‘blackness represents the diametrical opposite [of whiteness]: in the collective unconsciousness. It stands for ‘ugliness’, ‘sin’, ‘darkness’ ‘immorality’ [while] white means ‘clean’ and ‘pure’ (p. xiii). To consolidate their oppressive position, ‘European[s] created the ‘Negro as a category of degraded humanity: a weak, irrational barbarian, incapable of self-government’ (Fanon 1967, cited in Garner 2010 p. 20). Racialisation was used by Europeans as the justification for colonial expansion, and for the continuation of slavery and other forms of oppression of black people in the nineteenth century (Ahmed 2002; Garner 2010; Fanon 2008). Fanon (2008) concludes that when a group experiences colonisation, oppression, and dehumanisation over a long period of time, they are likely to develop an, ‘inferiority complex’-(p. x), as well as the ‘idea of the inherent superiority of the colonising [oppressing] culture’ (Fanon 2008, p. ix).

Ahmed (2002) supports Fanon’s colonial contextualising of racialisation, adding that colonialism caused the black body to be racialised by constructing the black body as dangerous and primitive, an object for investigation and oppression. Ahmed notes that the scientific community in the late eighteenth and nineteenth centuries debated whether the different human races were the same species. The bodies of humans in colonised countries were examined and compared to white bodies. The white race was considered superior to others, with white men seen as the ideal humans, at the top of the hierarchy. Although white women were stigmatised and oppressed at the time, they were second in the pecking order. The black race was considered the ‘lower race' (p. 51), and ‘closer to apes…, [and] blackness as more primitive, or less evolved' (p. 50). Humans thus 'become grouped together and apart from other humans through the invention of race itself' (p. 50).

Although Fanon’s and Ahmed’s work is useful in putting racism and racialisation into its historic context, Ahmed and other writers make the point that racialisation as a process is not only in the past. Racialisation is contemporary and multidimensional, an ongoing phenomenon that is present in modern western society (see Garner 2010; Ahmed 2002; Skinner 2006). Garner (2005; 2010; 2017) suggests that racialisation is a way of viewing race relationships, and how racism has quietly crept into the labour market, international migration, politics and the distribution of resources in the west. Garner concludes that ‘racialisation represents an essential sociological tool because it draws attention to the process of making ‘race’ relevant to a particular situation or context” (2010, p. 21).

While Garner takes a broader perspective of racialisation, Ahmed’s (2002) work focuses more on the racialisation of black ‘bodies’ (p. 53). For Ahmed, racialisation is a process of giving skin colour a meaning, so black skin and white skin is no longer considered as just skin, but as a racial identity. A racialised body, according to Ahmed,

...suggests that that we cannot understand the production of race without embodiment…these processes involve the marking out of bodies as the site of racialisation itself (2002, p. 46).

It is Ahmed’s view that bodies become racialised through everyday encounters in public space, or during direct or indirect interactions between bodies that are different. In this context, the black body, for example, already 'knows' about the white body and the knowledge is played out through the response/reaction of the white body to the black body (p. 56). This response could be verbal or visual, transmitted through body languages or mannerisms. In other words, the white body does not have to say anything to the black body, or even if something is said, it does not have to be explicitly racist in order for the black body to feel racialised. A visual interaction, for instance, creates the impression that the black body is 'being dissected under white eyes, the only real eyes' (Ahmed 2002, p. 56).

Ahmed allows us to understand how racial stereotypes impact, and are impacted by the daily encounters between people of different races, and how racialisation can be an inter and intra-psychic processes whereby an individual can feel racialised by an encounter without any obvious stereotypical transaction between the two. This idea can be constructed as 'felt stigma’ (Scambler and Hopkins 1986, p. 38); or a 'psychoanalytical projection' (Ahmed 2002, p. 57). Nettleton (2001) shares this psychological view of racialisation. She points out that the process of interaction between a black body and a white body is socially and cognitively mediated. During an interaction, there is an ongoing meaning created between the two types of bodies, to the extent that each body accentuates the position of itself and the other body. This serves to confirm society’s normative ideas about each body. The information transmitted during an interaction between a black and a white body, for instance, consolidate the internalisation of that meaning.

Ahmed (2007) widens the debate by suggesting that racialisation is an emotional process. She points out that the impression that an encounter between a white person and a black person is a racial encounter, even where no words are spoken, is an impression shaped by emotions. For instance, when a black person feels racism, it is because they have the impression that all black bodies are racialised, and all white bodies are 'racist' (Hayes 2013; Gillborn 2015). In other words, any black/white encounter moves the subject away from the object. Emotion makes this 'awayness' possible (Ahmed 2007, p. 8). An internalised racial emotion is a subjective feeling, which, if expressed, would give others an impression that racism is felt/has occurred.

2.11 Intersectionality Theory

So far, I have discussed a number of relevant theories and concepts, including spoiled identity (Goffman 1963); kinship theories (Evans-Pritchard 1929); ethnicity and cultural theories (Brubaker 2006; Maleševic 2011); immigration and acculturation (Lee and Hernandez 2009; Brady 1995); and racialisation (Fanon 1967; Garner 2010). This is because of the multi-dimensional aspect of my topic. However, none of them could provide all the conceptual tools I needed for answering my research questions. Other theories such as double jeopardy (Westen and Drubel 1978) or ecological models (Bronfenbrenner 1994) were insufficient in illuminating the complexity of my study participants' identities. Viruell-Fuentes et al. (2012) assert that it is time to move away from using culture or acculturation to explain inequalities in health and social care for immigrants. Rather, they argue, researchers should turn to intersectionality, which considers the 'simultaneous and mutually constitutive effects of multiple social categories of identity, differences, and disadvantages that individuals inhabit' (Viruell-Fuentes et. al. 2012, p. 2099). In this section, I will discuss intersectionality as it applies to people from BME group. I employ Crenshaw's (1989 and 1991) theory of intersectionality as an analytical tool to gain a better insight into my study participants' experiences. For example, how would having a combination of multiple identities and social locations in terms of gender, 'ethnicity and race', immigration status and nationality, religion/spirituality, association with autism, and being located in the UK and in an African country affect their overall experiences of raising an autistic child?

This thesis is located within both social identity theories and feminist/critical race theories. The social identity approach touches on the features that make up my participants' identities, such as black race, sex/gender, immigration status, ethnicity, culture, and disability. The feminist/critical race approach broaches the intersectional issues of multiple identities, and how these identities can cause an already disadvantaged group to experience multiple, intersecting disadvantages, including the values, thoughts, feelings, behaviours, and attitudes encountered as they attempt to make sense of their autism-related experiences (Rogers et al. 2014; Best et al. 2011; Erevelles and Minear 2010).

Intersectionality, rooted in black feminist and critical race theory, has been widely used as an analytical tool in research with people from minority and multiple identity social groups. Kimberlé Crenshaw introduced the theory in her 1989 essay ’Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics’, (Crenshaw 1989). In this paper, Crenshaw highlighted the legal, political, and economic marginalisation of African-American women in American society. Two years later, she elaborated further in ’Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color’ (Crenshaw 1991), which shows how the umbrella women's liberation movements had failed to account for the specific disadvantages faced by black women, especially those from immigrant and impoverished communities (see Carbado et. al. 2013).

Literature suggests that the concept of intersectionality originated from the struggles of black-American feminists in the nineteenth century. The theory has been traced back to an 1851 speech made by the antislavery campaigner Sojourner Truth entitled ’…And ain’t I a woman…’ (see Hooks 1981; Brah and Phoenix 2004, p. 77). Brah and Phoenix (2004) state that Truth argued that, whilst white women where campaigning for suffrage and equality with white men, African-American women were fighting for liberation from white oppression, and against multiple-layers of disadvantages arising from the combination of their racial and sex identities. The latter idea was echoed by other black feminist activists after Truth and prior to Crenshaw (Brah and Phoenix 2004); such as Hooks (1981 and 1984).

Various authors have defined intersectionality in different ways, and according to the context of their social research (Shields 2008). But all available definitions state that multiple identities on a personal level combine to determine social interactions (Shields 2008; Gillborn 2015). Bowleg (2012) defines intersectionality as

> a theoretical framework that posits that multiple social categories (e.g., race, ethnicity, gender, sexual orientation, socioeconomic status) intersect at the micro level of individual experience to reflect multiple interlocking systems of privilege and oppression at the macro, social-structural level (e.g.,racism, sexism, heterosexism) (p. 1267).

Bowleg's definition is useful because it captures the essence of the concept whilst broadening its scope out from black women alone, who were the sole focus of many other intersectionality theorists (Ross-Sheriff 2008; Brah and Phoenix 2004; Inuzuka 1991). Bowleg's definition shows that intersectionality theory can be adapted to encompass any group of people, marginalised or not (Carbado et al. 2013). Black immigrant African families with autistic children who are living in the UK is one example of a marginalised social group.

Since Crenshaw, intersectionality has been widely used by scholars to conceptualise a wide range of social issues. For example, Viruell-Fuentes et. al. (2012) used it to explore health outcomes for immigrants in the USA; Bowleg (2012) applied it to an investigation of public health outcomes for women of colour in the USA; Gillborn (2015) investigated the experiences of black-African middle-class parents educating their children in England; and Roland and Burlew (2017) used intersectionality theory to examine the experiences of lesbians, gay, bisexual and transgender people across racial identities. Carbado et. al. submit that there is ’always another set of concerns to which the theory can be directed, other places to which the theory might be moved, and other structures of power it can be deployed to examine’ (2013, p. 2). This thesis takes up this challenge and applies intersectionality to the experiences of black-African families of autistic children living in the UK—an area which, to my knowledge, is yet to be explored.

In nearly all the literature on culturally diverse autism experiences that I reviewed, the nuanced, multiple, intersecting identities of ethnic minority groups played little role in the research. Most researchers of the autism experiences of ethnic minority groups approach issues from broader cultural perspectives (Freeth et. al. 2013; Samadi et. al. 2012; Tek and Landa 2012). Others tend to analyse issues separately: autism, immigration and national identity (Keen et. al. 2010; Tincani et al. 2009), or autism with religion and faith (Slade 2014). But they rarely explore within-autism differences (Shields 2008), and how the intersections of these differences are constitutive of multiple-layers of disadvantages. For example, immigration statuses can create classes of migrant identities (undocumented/illegal, settled legal, and unsettled legal/illegal). To understand the experiences of an individual or a group with multiple intersecting identities, we can compare individual identities to each other and we can consider the intersections of those identities, as well as their outcomes. Intersectionality at an individual level impacts on interpersonal and structural levels.

In other words, the multiple identities attached to an individual or a group influences their social and political relations (Shields 2008; Inuzuka 1991).

Intersectionality theory asks us to recognise that the multiple features that create and delimit social identities—race, gender, age, disability, sexuality, to name the most obvious—could also be individual sources of discrimination. But the combination of any number of these descriptors, for example, gender or disability and race, leads to additional layers of discrimination and other types of experiences (Shields 2008). All the parents who took part in this study had emigrated from Africa and are generally underprivileged and marginalised in the UK. Living in the UK has not addressed some of the autism-related issues they experienced, and has also contributed to their multi-layered experiences, often preventing them from taking full advantage of the autism services and promised lifestyle that brought them to the UK in the first place. Participants find themselves shouldering additional burdens such as racial discrimination, racialisation, immigration restrictions, restricted access to social care support, housing issues, threat of homelessness, and extreme poverty. Where features of race, gender, disability, and nationality converge as they do in the experiences of immigrant black-African parents with an autistic child, viewing their experiences from the lens of a wider autism group who do not share similar multiple identities would obscure the particular experiences of this group (Crenshaw 1991; Best et. al. 2011).

Black immigrant families of autistic children in the UK are marginally situated in the political, social, and economic world (Hooks 1984; Crenshaw 1991; Viruell-Fuentes et al. 2012). Black-African families ‘occupy positions both physically and culturally marginalised within dominant [white UK] society, and so information [and research] must be targeted directly to them in order to reach them' (Crenshaw 1991, p. 1250).

Intersectionality helps us understand that, although all families of autistic children face challenges, not all families experience autism in the same way. Black-African families, for example, face multiple challenges and experiences. Carbado et al. (2013) point out that certain

> dynamics…specifically one's demeanour and other characteristics such as name, accent, hair, political identity, social identity, marital status, residence, and religious affiliation—caused [their research participants] to be a victim of discrimination (p. 8).

All the parents in my study are ostensibly in the same intersectional group—immigrant African parents of autistic children—but because some of them might have stronger accents or different immigration statuses, or occupy different gender roles than those defined by their cultural norm, they are likely to experience what Carbado et al. (2013) call 'intra-intersectional discrimination' or oppression (p. 9). To view the discriminatory experiences of black women from the prism of race or sex without considering the intersectionality of both categories is a failure to appreciate the effect of gender, race and sex discrimination combined on black women (Crenshaw 1989).

Intersectionality theory posits that any stigma or discrimination against a white British family of an autistic child, for example, is clearly recognisable as disability-based stigma and discrimination. But one against a black-African family of an autistic child is much more than disability-based discrimination or stigma. It is due to their association with disability, and their ascribed identity of being black and an immigrant. So, to assume that any stigma or discrimination against a white British parent of an autistic child represents discrimination or stigma against all families with an autistic child, including black-African families, is to be ‘colour blind’. It assumes the non-existence of multiple-disadvantaged groups in the UK, and the homogeneity of their experiences, which is not the case. It assumes that there is no ‘disparate impact theory of discrimination’ on black-Africans and other minority groups in the UK (Crenshaw, 1989, p. 146). It is to erase black-African families’ distinct experiences, and to construct their diversity as irrelevant. The racial, ethnic, and cultural dichotomies between black-African and white-British families of autistic children is such that research into the experiences of white-British families could not adequately represent the experiences of their black-African counterparts (Crenshaw 1989; Hook 1984). Relying on such research would constitute a failure to recognise the existence of compound discrimination and stigma and rejection against black-African families in the UK and in their home country. It would obscure the distinct experiences of black-African migrants living in the UK with an autistic child, and maintaining their kinship links in Africa. To do this would be to wrongly assume that black-African immigrant families’ experiences would resemble those of white-British families and/or black-African families who have remained in Africa in totality (Crenshaw 1991; Crenshaw 1989). In this research, I differentiate black-African migrants from both of these groups, and recognise their experiences as worthy of study in their own right.

The aim of intersectionality is not only to understand the interrelations between identities and disadvantages, but also to interrogate the issues that emerge, and identify hidden or assumed dynamics, in order to facilitate social change. In general, this is what critical race theories attempt to achieve (Carbado et al. 2013). However, intersectionality has been criticised by some scholars as a theory that serves the interests of black women, and it is underdeveloped as an all-inclusive theory (Best et al. 2011). Others argue that intersectionality is applicable to any section of society, privileged or underprivileged (Best et al. 2011; Gillborn 2015). Gillborn states that some scholars portray critical race theorists as anti-whites who view ’all white people as universally and irredeemably racist (Gillborn 2015, p. 277). To support this view, Hayes (2013) asserts that critical race theory ’is not really a ‘theory’ at all, but rather a ‘perspective’ or a set of beliefs about racism…, it is a political position pretending to be a theory… [adding that] critical race theory boils down to one simple claim: ‘If you are white you are racist!’, [and that] ’whites [are] depicted as racist, and blacks as permanently oppressed’ (Hayes 2013, no page number).

Hooks (1984), makes the point that, as a black woman she is often asked whether her ‘black’ identity is more important than her ‘female’ identity, and whether fighting against sexist oppression is more important than fighting racist oppression, or vice versa. She responds that, as a black woman, her fight for liberation is two dimensional—addressing racism and sexism—whereas for a white woman, liberation is singular. While white women give primacy to one oppression, women from ethnically oppressed groups recognise and fight two or more oppressions.

Crenshaw (1989; 1991), an African American feminist theorist, challenges the idea that there is one universal female experience, pointing out that black women's experience of sexism is also informed by gender, race and social class. So, instead of treating race, gender, and class as separate and independent identity categories, Crenshaw argues that these identities simultaneously combine to produce inequalities for women of colour.

2.11.1 The Intersectionality of Gender Identities

Gender is an important dimension in theories that stress intersectionality. Therefore, viewing intersectional identities from the prism of gender enables us to look at how people's social identities influence what people believe about gender and how they experience it. For example, Shields, (2008, p 301) argues that 'gender must be understood in the context of power relations embedded in social identities…[and that identity is the] awareness of self, self-image, self-reflection, and self-esteem…[which serves] as a quality that enables the expression of the individual's authentic sense of self'. Therefore, a gendered lens can be employed to explore how power relations manifest itself for women in a context. Crenshaw (1989 and 1991), argues that the power relations between males and females is such that a black woman for example is more disadvantaged compared to a black man. In an African context, for instance, the meaning and the value of male compared to female is such that the female gender is profoundly disadvantaged in that society (Dyer 2007; Ibisomi and Mudege 2014]. Hence, intersectionality helps us to understand that gender does not only operate as a social identity, but also as a source of oppression. Goff et al. (2008) suggest that there is often a positive perception about black males in terms of associating them with a higher rating of 'masculinity' and racially, all 'blacks are men and all women are white' (p. 394); while black women are often negatively perceived as 'welfare queens… [who are] content to take the hard-earned money of tax pay[ers]… and remain married to the state' (Collins 2000, p. 80). In Rogers et al.'s (2014) study of male students in an all-black boys school in the USA, they found that majority of the black students in their sample saw themselves as males first and blacks second, but white people might see them as black first and men second (Collins 2000); but the perception underscores the importance of gender in a social research.

Scholars often combine the terms ‘black woman’ together as one unit of social identity in literature rather than conceptualizing the terms as two separate units: racial, ‘black’ and gender, ‘woman’ identities (Crenshaw 1989; Inuzuka 1991). For example, Inuzuka (1991) reports that when the US congress were passing the piece of legislation called “Women’s Business Act” (p.1229) and other antidiscrimination laws on grounds of race and gender; the legislators assumed that black women were part of wider female gender, and are of black race. Therefore, black women’s concerns would be addressed within any law that deals with gender and race simultaneously. However, the legislation did not recognise specific situations whereby the needs of black women could be different from the needs of white women or from the needs of black men. Inuzuka asserts that ‘women of colour [should be analysed] as separate and distinctive group’ (p.1234).

Gender has been described as a power relationship dynamic associated with the marriage institution or as part of organised family structure (Goff et al. 2008; Ferree 2010). Ferree (2010, p.242) defines ‘gender as a social relation characterized by power inequalities that hierarchically produce, organize, and evaluate masculinities and femininities through the contested but controlling practices of individuals, organizations, and societies’.

The changes in family dynamics in the West includes power shifts between genders (husbands and wives), and parenting (children and parents), which challenges the norms of an African family institution in the west. According to Salami et al. (2016) '[m]igration also affect[s] the [male/female] gender relationship…due to post-migration economic pressure, where a second income is required to support the family, the father's traditional role as head of the family is often undermined'.

In this thesis, to conceptualise the experience of black African parents living in the UK with an autistic child without investigating the nuances between fathers and mothers from a gender perspective would be insufficient. Hence, gender identity is addressed in this thesis as part of wider analysis of intersectionality. This is not to suggest that gender is more important than other social categories in this thesis; but when linked with the roles that the black African parents in this study played in raising their children with autism in the UK, the patriarchal social system that exist in an African culture, it highlights an additional social inequality which the mothers face compared to fathers (Bowleg, 2008), and the higher value placed on male children compared to females (Dyer 2007; Salami et al 2016; Sow and Bledsoe 2011).

Although Viruell-Fuentes et. al. (2012) state that intersectionality is making an impact on feminist theory, critical race theory and other social discourses, they argue that its use in the exploration of disability is limited. I propose that its application in the study of how African immigrant families of autistic children are simultaneously shaped by intersecting identities will contribute to filling this gap in the literature.

Intersectionality supports the idea that disadvantage is pervasive, situational, and dependent on context. It highlights the effects, experiences, and outcomes in every social setting or social situation, and a single ascription category (race or disability for example) could dominate others in different social situation or geographical location according to Best et. al. (2011). Therefore, my study participants' negative autism-related experiences in the UK and in Africa are mediated by the slightly different intersecting identity ascriptions in the UK, and in Africa. But the sum total of these experiences constitutes the multi-layered experience of my study participants. For example, whilst racism and racialisation are among the evidential and nuanced intersecting issues for black-African families of autistic children in the UK, racism is not an intersecting issue for them in their 'home' countries. African culture, however, becomes an issue. For instance, while the cultural identity of motherhood for the women participants (and fatherhood for men) is spoiled and devalued by being the parent of an autistic child, this does not have the same impact in the UK. These shifting, intersecting oppressions demonstrate that my participant's experiences and outcomes are multi-layered and trans-national. Applying intersectionality in this study will respond to the call made by intersectionality theorists such as Best et. al. (2011); and Carbado et. al. (2013) to treat the theory 'as a social movement' (p. 19) and to broaden its reach 'within and across disciplines' (p. 5), and across scholarly and 'national boundaries' (p. 6).

In this chapter, I have interrogated the concepts of ethnicity to introduce 'black-Africans' as a subgroup of wider BME groups in the UK, explored African culture, Africanness philosophy, and religion and spirituality as a means of contextualising the values and principles that inform my study participants' actions and decisions. I then examined the concepts of immigration, stigma, and racialisation, and their implications. Finally, intersectionality theory was introduced to demonstrate that black and ethnic minority groups in the UK and other western countries are disadvantaged and experience discrimination due to their multiple identities. I conclude that intersectionality is the most suitable conceptual framework for this study.

In the next chapter, I will review relevant literature from the UK, Africa, and other parts of the world, showing how my study will fill gaps and contribute to existing knowledge.

Chapter Three

Literature Review

In the previous two chapters, I explored literature relating to autism spectrum disorder (ASD), and the relevant policies, theories and concepts that I employed in this thesis which provided the backdrop for answering my research questions. The aim of this chapter is to provide an in-depth interrogation of some more relevant literature.

3.1 Introduction

This literature review explores the ideas and themes central to addressing my research questions. It focuses upon black-African immigrant families living with an autistic child in the UK and their understanding of their experiences within that context. Firstly, I set out my literature search strategies, and demonstrate gaps in existing relevant literature. Due to the relative scarcity of papers that used recent immigrant black-Africans in the UK for research, I established that little is known about their demographic composition in empirical research studies. Therefore, I briefly report on their demography in the UK to provide some context.

Secondly, I address literature that explores specific challenges faced by members of BME families of children with autism (and other disabilities) when attempting to access (autism) services in the UK. As the participants of my study migrated from countries in sub-Saharan Africa, I will also explore some literature that reports on autism services in some African countries. The impact of immigration status and other specific identity categories on access to autism support services, both in the UK and in African countries is also examined.

Thirdly, due to my study participants' association with autism and its intersection with other identity categories (gender, sex, race, ethnicity, culture and marriage), stigma and rejection becomes relevant to them. Having investigated literature on the concept of stigma and spoiled identity in chapter two, I will explore literature on the stigma and discrimination experiences of participants from BME groups in the UK, and the attitudes of some societies in Africa towards people with a disability.

In the fourth section of this chapter, I will examine literature relevant to the experiences of black-Africans and other BME families regarding some African attitudes to disabilities. I will investigate how they seek to understand their child's disability from their cultural perspectives.

Finally, I will interrogate literature concerning religious and spiritual beliefs among BME parents of children with autism and other disabilities, both in the west and specific African societies.

3.2 Literature Search Strategies

Hart (2018) indicates that the purpose of a literature search is to find out what was previously done, and what has not been done, in order to cover any gaps in knowledge, highlight strengths and limitations, and to avoid making similar mistakes made by previous researchers. The search process I used include two major approaches: computer-based searching which included an online search, and offline searches including visiting three universities' libraries for textbooks and offline journals. All searching and reviewing of literature was carried out logically, using the seven stages of literature search framework, developed by Hek, et al. (2000). It includes the following:

- Main Computerized databases search
- Narrow and more focused selection

- Supplementary searching
- Management and acquisition of relevant literature
- Quality appraisal of the literature
- Literature review saturation
- Thematic review of the literature

For more details about this framework, see Hek, et al. (2000) ‘stages of review process’, adapted by Alexis and Vydelingum (2005, p. 45).

Different research questions for this thesis were considered, refined and modified before arriving at the final questions. I used the following key words and phrases in my searches: ‘autism’, ‘families with a child with autism’, ‘African families’, ‘disability in African’, ‘African cultural beliefs and disability’, ‘autism in Africa’, ‘black African cultural practices’, ‘autism and African children’, and a combination of some of these phrases. Each phrase and key word yielded multiple results of peer-reviewed papers. Keywords relating to other minority groups were also used to locate literature about parents from the Asian continent, the USA, Australia, the global Jewish community and others. At the first stage, a total of 8,727 papers were found (see appendix 9). These were eventually narrowed down to the most relevant papers, numbering 59, by applying the seven stages of literature search process by Hek et al. (2000). But a lot more papers were added to this number in the course of writing the thesis.

The University of Kent’s online library services host a great deal of electronic resources, including databases (such as SCOPUS and EBSCO); electronic books (such as Dawsonera and Myilibrary) and many others, which were searched to retrieve relevant material for this thesis.

Search engines, such as Internet Explorer and Google were also used extensively, along with Google Advance Search, Google Scholar for accessing material from specialized categories, e.g. ‘grey literature’.

A combination of specialist search techniques was also used to collate material. For example, ‘snowball sampling’ was employed to trace citations and bibliography cited in existing literature, and Boolean search operators such as ‘and’, ‘or’ as well as ‘wildcard’ symbols (-, +, *) to define, limit/narrow or widen the searches (Ridley 2008, p. 41).

Following the initial application of the seven stages of the literature search strategies, I commenced writing the literature review chapter, but in the process, I discovered that literature review was an ongoing activity. I stored all retrieved literature, along with drafts of my thesis, in folders on my home computer hard drive, and on several ‘cloud storage’ applications, including Microsoft OneDrive, Google Drive, and Dropbox. I also employed Refworks and Microsoft Word References tools to create my citations and bibliography.

3.3 Highlighting Knowledge Gap in this Field of Study

Far too little attention has been paid to the experiences of black-African immigrants living in the UK with an autistic child (Perepa 2014; Slade 2014). To date, research has focused more on autistic white children and their families in the UK, Europe and USA (Waterson 2011; Cassidy et al. 2008; Nealy et al. 2012; Neely-Barnes et al. 2011; Dillon and Underwood 2012; Dowling and Dolan 2010; Gibson 2014; Langan 2011). The few studies undertaken with families of autistic children from BME provide insight into some cultural issues and other challenges (Perepa 2014; Manning et al. 2011; Manning et al. 2011; Ravindran and Myers 2013; Slade 2014; Dyches et al. 2004). However, those studies that did research the experiences of families from BME groups often focused on Asian families that included a child with autism or other types of disabilities (Ravindran and Myers 2013; Jegatheesan et al. 2010; Doig 2012; Heer et al. 2015). The small number of studies that explore the experiences of black families are often concerned with other types of disabilities. Participants are often drawn from second-generation black families, mostly of Caribbean origin (Keen et al. 2010; Cooper 2005; JRF and Rampaul-Chamba 1999; Atkin et al. 1998).

Previous research, focusing on black-African families, often merge them with participants from wider BME communities (JRF and Rampaul-Chamba 1999; Slade 2014; Perepa 2014; Corbettt and Perepa 2007). However, there are some differences within people labelled as BME in the UK (Aspinall 2009). Families with an autistic child are a globally heterogeneous group (Neely-Barnes et al. 2011; Sotgiu et al. 2011; Daley 2002), which presents methodological problems when grouping them together, as they may not share the same ethnicity or culture (see for example, Perepa 2014; Dyches et al. 2004; Ewart 2002). By grouping Africans with other BME participants in a research study, distinctive findings are diluted or under-reported (Perepa 2014; Welterlin and LaRue 2007; Dyches et al. 2004). To my knowledge, there are only a few existing studies of UK-based, first generation black-African families with an autistic child (Slade 2014; Perepa 2014; Bolton et al. 2013) and the USA (Welterlin and LaRue 2007). Some of these studies are about the prevalence, causes and diagnosis of autism (Ven et al. 2013; Barnevik–Olsson, et al. 2008; Gillberg and Gillberg 1996).

Most of the participants in these studies were based in Nigeria (Chukwueloka 2016; Ulofoshio 2017); Kenya (Weru 2005); South Africa (Fiorilli 2014); Ghana (Anthony, 2009). A case study of a Nigerian family living in Ohio, USA, with autistic twins (Baba, 2014) is the only paper I found that explored the experiences of a black-African family in the diaspora, but Baba did not apply intersectionality theory in her research. Hetherington (2012) explored the intersections of race and autism from an educational perspective, but her participants were African-American mothers.

Several studies have reported the increasing awareness of autism and the needs of autistic children, but little is known about the impact of multiple identities on black-African families with autistic children in the UK. A review of literature shows that the experiences of African-born migrant families with autistic children is under-researched in the UK, despite their growing population (Coleman 2010; Office for National Statistics 2017; Corbett and Perepa 2007).

Coleman (2010) reported that between 1991-2001, the BME population grew by 53%, approximately 9% of the total population in England. According to the UK Office for National Statistics (2017), the black-African population rose from 484,783 in 2001 to an estimated one million in 2017 (Statistics.gov). The population of African-born migrants living in the UK was estimated to be over 500,000 people in 2008 (Office for National Statistics 2011). African migrants to the UK come mainly from sub-Saharan Africa (Office for National Statistics 2017). The rise in population of this subgroup would invariably include more African children diagnosed with autism (Slade 2014;

Corbett and Perepa 2007).

The small number of published studies that have considered the experiences of migrant black-African families in the UK, including Slade (2014), Corbett and Perepa (2007), and Perepa (2014), have grouped participating African families with other BME subgroups.

Several scholars have consistently highlighted the dearth of research about the experiences of autism and other types of disabilities by people of BME background (see Perepa 2014; Ravindran and Myers 2012; Doig 2012). Many scholars have advocated for more autism-related research on this population group (Jegatheesan et al. 2010; Dyches et al. 2004; Walterlin and LaRue 2007; Keen et al. 2010; Canary 2008; Xue et al. 2014). Thorburn et al. (2004) argue that 'a research review on BAME children and their families give a clear message that this is a group worthy of study, worthy of being the exclusive focus of research' (p.14). More research on this population group is needed. This thesis, therefore, will primarily focus on black-African families who have recently migrated to the UK. It does not include other BME groups, such as second-generation black British-born families, black Caribbean, African Asians or white Africans, travelling families, or black families from other parts of the world, or other minority white groups belonging to the wider 'BME group'.

3.4 The Demography of Black-Africans in the UK

According to the Office for National Statistics (2018), Nigerians and South Africans account for the greatest proportion of African-born migrants in the UK, each country represented by approximately 191,000 people. However, the South African group comprises a mix of whites, Asians, mixed-race and blacks, which means that, overall, Nigerians are the largest black-African migrant community in the UK (Aspinall and Chinouya 2008). Somalians follow with an estimated 101,000 people (Office for National Statistics 2013; Owen 2008).

3.4.1 Educational and Employment Status of Black-Africans in the UK

British universities usually attract African students, who often remain in the UK after their studies and start a family (Phillips 1998). There is a link between the relatively large African student population, and the significant proportion of highly educated Africans living in the UK (Algan et al. 2010; Nwankwo 2005).

Black-Africans are among the most educated people in Britain, compared to other members of BME groups (Algan et al. 2010; Abubakari et al. 2013; Chiswick 1980). They spend relatively longer time in education (Algan et al. 2010). Daley (1998, p. 1709) report that black-Africans, born in the continent of Africa, tend to be better qualified than those born in the UK, confirming that Nigerians are among the most educated of all African migrants (Nwankwo 2005; Daley 1998). Yet research has indicated that their average wage was over one-third lower than the white host population (Lindley 2009; Lindley and Lenton 2006; Dustmann et al. 2003; Dustmann and Fabbri 2003).

The rate of unemployment and underemployment among Africans is relatively high, according to Prost et al. (2007). Hence, many black-Africans work in jobs for which they are overqualified, such as taxi driving (Nwankwo 2005; Phillips 1998; Prost et al. 2007). A significant number of employable black-Africans own businesses (Nwankwo 2005). Daley concludes that ‘some [Africans in the UK] may opt to adopt [an] underclass position in Britain to secure a higher status lifestyle on their return home' (Daley 1998, p. 1717). Black et al. (2003) report that Africans living in the UK remit a substantial amount of money back home every year, which is invested in properties and businesses, and also to support their wider families. The impact of the mismatch between educational qualifications and employment in the UK makes it difficult to place black-Africans in specific socioeconomic classes (Daley 1998; Nwankwo 2005).

3.4.2 Social Class and Population

Daley (1998) reports that a significant proportion of economically active, black-Africans belong to all socioeconomic classes in the UK. However, Nigerians are overrepresented in the middle social class stratum, compared to other black-African migrants. This is partly due to their relatively higher educational status, and higher population numbers (Daley 1998; Office for the National Statistics 2013). As a result of the confusing and paradoxical social economic statuses of black-African migrants in the UK, social class was not used as an identity category in this thesis.

3.4.3 Religious Demography

According to Aspinall and Chinouya (2008), 68% of black-Africans in England and Wales identified themselves as Christians, 20%, as Muslims, 8.1% 'not declared', and 2.3% as 'no religion'. Aspinall (2000) emphasises the importance of religious categorisation as part of ethnic identity, and its implications for integration and acculturation. Therefore, members of the BME group who strongly identify with their religious and ethnic origin are less likely to integrate into British culture, according to Reininghaus et al. (2010).

3.4.4 Spatial Pattern of Residence

The largest (80%) number of people, self-identifying as black-Africans reside in Greater London (Onwumere et al. 2002; Nwankwo 2005), with a significant number living in the boroughs of Lewisham, Southwark, Haringey, Lambeth, Newham, and Barnet. In London, the pattern of concentration along the ethnic divide makes it possible to link certain areas in London to particular nationalities. This is because migrants tend to live in areas where there are other people from their country of origin to support one another (Phillips 1998).

Bartley (2004) argues that differences in income, education, environmental and social status, apart from ethnic or racial differences, could be used to explain inequalities in health in the UK and the USA. BME groups often live in environmental clusters, and are regarded as deprived (Bartley 2004; Phillips 1998; Scambler 2008). Therefore, areas with a high population of ethnic groups tend to have poor services and housing, and high environmental degradation. This could also suggest that black-African families with autistic children choose to live in areas with a high concentration of people from their own ethnic group, for the purpose of getting kinship support and guidance. They are also likely to experience poor service provision for their autistic child, due to their economic and socio-environmental status. As a result of the high concentration of black-Africans in London, the majority of my interview respondents lived in and around London boroughs.

In summary, the current literature shows that black-African migrants living in the UK are a highly educated group. They are also likely to be underemployed, deprived, living in social housing, based in London, and of the Christian faith. Their acculturation and level of integration into British society is determined by various factors. Data also show that Nigerians form the largest population among black-Africans in the UK.

Invariably, the demographic composition of the participants of this study reflects this: 50% of families are Nigerian, 75% are Christians, 75% of families live in London, and 60% of adults hold higher educational qualifications.

3.5 The Potential Impact of Constrained Public Spending on Autism Services in the UK.

The UK welfare state has been described as, 'a cradle to the grave' system of social support, intended to improve health, education, employment and social security (Beverage 1942, cited in BBC 2014). Following the Great Recession of 2008, the UK government introduced a fiscal policy of austerity (Youdell and McGimsey 2015). This meant a high reduction in spending on public services: between 2010 and 2019 more than £30 billion in spending reductions were made to welfare payments, housing subsidies and social services. Despite this, local government authorities (LGAs) were expected to provide the same or higher level of services with the fewer resources allocated to them (Hills and Orne, 2011). The austerity measures affected service provision in areas such as education, children and young people's services, health, criminal justice, and local governance (Gray and Barford 2018; Webb and Bywaters 2018; Youdell and McGimsey 2015).

Although the impact of UK austerity was wide-ranging, the former UK Department for Communities and Local Government had seen a 50% reduction in funding between 2010 and 2015. This meant that LGAs had to restructure and readjust their service provision in order to survive (Gray and Barford 2018). The key factors that differentiate LGAs, in terms of resource availability are the level of need within communities, the proportion of grant revenue received from central government, and the capacity to generate tax revenue locally. In the period between 2009-2010, LGAs in the most deprived areas of the UK received 82% of their funding from the central government, whilst well-resourced LGAs received up to 36% of their annual budget. Although the resource allocation formula favours more deprived areas, these same areas were amongst those worst affected by the cuts, whilst their populations have a greater need for services and reduced capacity to generate revenue locally (Gray and Barford 2018).

Webb and Bywaters (2018) argue that the resource allocation formula, which favours poorer councils, is a form of rationing: a process of allocating finite resources to meet infinite demand for resources. The aim of rationing (distributing limited resources to meet an unlimited demand) is not to ensure that resources are shared equally, but to distribute resources proportionate to need.

Webb and Bywaters (2018) also contend that the capping of Council Tax increases to a maximum of 2% have contributed to a reduction in the resources allocated to LGAs. The ‘trickledown effect’ is that children’s services have had to change their eligibility criteria for funding. Webb and Bywaters argue that the number of children eligible for children services in England, as well as the demand for children's services in general, have increased, and the poorer local authorities have seen a higher increase in demand for services. Local authority spending on each child has declined from 2010/2011 and 2014/2015 levels according to Webb and Bywaters (2018). However, the National Audit Office (NAO 2016) and Hastings et al. (2015) disagree. For example, the NAO points out that ‘in 2014-15, local authorities reported spending £1.8 billion on children’s social work, 11% more in real terms than in 2012-13’ (NAO 2016, p.7). To support this claim, Hastings et al. (2015, p.14) state that, ‘particularly striking is the situation for social care spending (combining children and adult services)… This has actually risen in real terms in the least deprived categories (by £28 per head or 8%)'. They conclude that funding for children's social care has generally been protected or enhanced, while the adult social care budget has been substantially cut. In other words, Hastings et al. (2015) imply that the spending cuts introduced during the period of austerity should not constrain the resources that local governments allocate to children's services in general. Nonetheless, participants in my study who migrated to the UK specifically in search of autism services might be oblivious to any austerity measures. This is because the services they received were regarded as superior to those available in their home country, where there was little to no autism service provision. Indeed, some of them were grateful for any services they received here in the UK. For example, these two parents, Mrs Diya and Mrs Kromah, (pseudonym) expressed their gratitude respectively:

> The school are doing well. He has a one-to-one help. The Local Authority is trying. They are very good… they gave us this place…[do you mean the no recourse team?]. Yes. Thank you no recourse team, yes… bearing in mind, I believe in one thing, even the paper [immigration rights /visa]… I believe having paper is not a right, it is a privilege. A lot of people are out in the street. They don't have help. (Mrs Diya, Nigerian).

> We are also grateful that we are in this country, because if it was in Africa, I don't know how we will manage (Mrs Kromah, Liberian).

Slade (2014) and others recommend that, whilst every autistic child, and his or her family, should have equality of access to statutory support services, they often face challenges in the process. Some scholars suggest that some individuals from the

BME population often face additional challenges (Montes and Halterman 2011; Ahmed and Jones 2008). These are often due to their multiple identities; ethnicity, culture, race, immigration, language and communication issues; and indifference from professionals.

3.5.1 Criteria for Social Work Support to Families of Autistic Children in England

The majority of autistic children are also simultaneously diagnosed with a learning disability (Wing 2002; Boucher 2011). According to Gates (2003), a learning disability is an impairment of the mind, which has an impact on learning, comprehension, retention of new and complex information, and the overall skills set required to function and to live an independent life. This often starts at birth/childhood, or is caused by an accident, and lasts for a lifetime. It is diagnosed by a clinician, using the intelligent quotient (IQ) test, and other assessment tools. However, children with Asperger syndrome are often diagnosed with average to high intellectual ability, (Wing 2002; Baron-Cohen 2008).

Individuals with an IQ test result of 70 and below are considered as having a learning disability or 'mental handicap' (Baron-Cohen and Bolton 1996, p. 52). Their learning capability is usually slower than average; therefore, they generally need additional help when compared to people with an IQ of 70-130, (Baron-Cohen and Bolton 1993; Gates 2003). Along with risk and wellbeing factors, IQ is also an important criterion used by local authorities to assess the type of support children with autism and/or a learning disability, and their families, are eligible to receive from their local authority in the UK. For example, a child or adult with an IQ score of 70 or below is likely to be eligible for additional educational and/or social care support from their local authority.

A child with autism with an IQ score above 70 may be deemed ineligible for some or all forms of local authority support.

3.5.2 The Equality and Antidiscrimination Legislation in the UK

The Race Relations Act (RRA) 1965, based on ‘formal equality’, was the first legislation in the UK to deal with racial discrimination against black and Asian immigrants who migrated to the UK from Commonwealth countries. It also functioned as a trade-off to the Commonwealth Immigrants Act 1962, which restricted opportunities for black and Asian immigrants to come to the UK (Hepple 2010:12; Dickens 2007). The RRA 1965 was followed by the Race Relations Act 1968, and other anti-discrimination and equality legislation has followed since. This raft of legislation included the Disability Discrimination Act (DDA) 1995, which gave legal definition to disability as a physical or mental impairment which also has a substantial and long term adverse effect on a person’s ability to carry out normal day-to-day activities (Byrane and Carr 2005; Dickens 2007; The National Archives, 1995; Hepple 2010; Woodham and Corby 2003).

The DDA 1995 made it unlawful for any employer to discriminate against anyone with a disability during the job application process and in defining the level of remuneration for the successful applicant (Dickens 2007). Employers were also required to ensure that reasonable adjustments were made in the workplace to accommodate disabled employees (Dickens 2007). The Disability Discrimination Act 2005, which amended the DDA 1995, created equal opportunities for disabled people in the UK, and mandated that every public building and infrastructure be made accessible to disabled people in wheelchairs (Bryan and Carr 2005; Roulstone and Warren 2006). However, the Equality Act (EA) 2010 (Hepple 2010; Legislation.gov) consolidates the provisions of both the 1995 and 2005 Disability Discrimination Acts, along with seven previous major pieces of discrimination-related legislation (Hepple 2010). The EA 2010 seeks to reduce socio-economic inequalities, relating to disability, age, gender, race, religion and others; protects people against direct and indirect discrimination, and defines harassment and victimisation. Although it is illegal for anyone to discriminate against a person on the grounds of disability, race and other identity categories, the EA 2010 does not address racial consciousness.

3.5.3 The Implications of the Autism, Children and Family Legislation(s)

The Children and Families Act 2014 is one of the latest legal and policy instruments used by the UK government to improve services for vulnerable children and families in the UK (The National Archive 2014; The Department for Education 2013; UK Parliament Online 2014). The government used the Act to reform children's services, including special education needs (Department for Education 2013; UK Parliament online 2014). The 2014 Act introduced a 'New Birth-to-25 Education, Health and Care Plan', and a Personal Budget to provide families with more choice and control over the types of support their child received. It also encouraged more joined-up working among professionals and a greater involvement of children, young people and families in the provision of local services. The 2014 Act made provision for children with autism and special education needs in the UK to remain in education until aged 25 years old. The implication for families without the right to live in the UK, however, is that their children might be prevented from benefiting from parts of this legislation. A child with autism is considered a 'child in need' in accordance with part 3, section 17, subsection 10 of the Children Act 1989. The Act defines 'child in need' as any child whose health or development is likely to be significantly impaired, or who is disabled (The National Archive 1989; Turnstill and Algate 1995). The local authority has a legal duty and responsibility to support the child in need and its parents. Section 17 mandates local authorities to ensure the welfare and safety of a child in need by offering them the services and support they need, including cash or material assistance (Turnstill and Aldgate 1995). In addition, the Autism Act 2009, which is applicable in England only, requires the Secretary of State for Health to publish an autism strategy to provide guidance to the local authorities on meeting the needs of people with autism, and improving service delivery and outcomes for autistic people (The National Archive 2009).

A black-African child who is diagnosed with autism and is living in the UK with his or her family should be protected by the Autism Act 2009 and the ‘Every Child Matters’ policy of the Children Act 2004, no matter the immigration status of their parents (Brayne Carr 2005, p. 247). Other legislation that should support a black-African family under immigration control includes the Human Rights Act 1998; the Carers and Disabled Children Act 2000; the Care Act 2014 (Legislation.gov.uk). Therefore, any black-African child with autism who is living in the UK qualifies as a child in need, and should benefit from local authority support and assistance. Families of such children should also receive support from their local authority for bringing up their autistic child. But parents of autistic children under immigration control or the threat of deportation would be ineligible for benefits.

3.5.4 Immigration and Asylum Legislation in the UK

The Nationality, Immigration and Asylum Act (NIAA) 2002, which succeeded the Immigration and Asylum Act (IAA) 1999, defined the conditions for obtaining nationality and citizenship in the UK (The National Archives 1999; The National

Archives 2002). Section 22 removes the duty incumbent on local authorities to assist families with dependent children who are receiving support from the Secretary of State, under Section 17 of the Children Act 1989 (The National Archives 1989). Section 4 of the Immigration, Asylum and Nationality Act (IANA) 2006, amended both the NIAA (2002), and the IAA (1999) in order to empower local authorities to offer accommodation and support to individuals or families under immigration control (The National Archives 2006). The IANA 2006 also gave local authorities power to evict families under immigration control from their accommodation without a court order (Clayton 2012; Audit Commission for Local Authorities and the National Health Service in England and Wales 2000; The Stationery Office Staff 2002). An African family with an autistic child under immigration control, and without recourse to public funds, could obtain support from the Secretary of State, and be offered accommodation by their local authority. Under section 17 of the Children Act 1989, the autistic child would receive state support as a child in need, due to their disability. However, if the family's application to legally remain in the UK failed, the council could, in principle, evict them from their home and end any further support to the family.

3.5.5 Implications of UK Immigration Policies for African Migrants

Slavery and colonialism are the two biggest factors that created ethnic and racial divisions in Western society (Littlewood and Lipsedge 1997; Ahmed 2002; Luongo 2011). Spencer (2003) claims that the colonial practices of Britain and other European countries fueled the mass migration of people from their countries of origin to different parts of the world for economic purposes. However, Cornelius et al. (2004) point out that colonial practices alone did not cause mass migration, noting that the British government invited people from the Caribbean, Pakistan, India and Bangladesh into the UK to help rebuild post-war Britain (Earle and Letherby 2008; Bottomley and Sinclair 1970; Bartley 2004). Likewise, Indians and Pakistanis who were persecuted in Uganda and Kenya were also accepted by Britain (Cornelius et al. 2004; Spencer 2003). Migration from sub-Saharan Africa is also a significant contributory factor. For example, from the 1980s onwards, Britain experienced mass immigration from countries such as Sierra Leone, Somalia, Rwanda, Ethiopia, Zimbabwe, Nigeria, Liberia and others, due to war, famine or oppressive regimes and for economic purposes (Cornelius et al. 2004; Spencer 2003; Bottomley and Sinclair 1970; Zontini 2010).

Littlewood and Lipsedge (1997) have focused upon the role of immigration in creating racial and ethnic dichotomy, both in the UK and other parts of Euro-America. Inequalities based on race and ethnic differences have existed at different periods of British history, and are linked with marginalisation, discrimination, prejudice, and political and structural barriers (Bartley 2004; Littlewood and Lipsedge, 1997).

Ethnic differences and negative social attitudes are not the only barriers facing black-African migrants in the UK. They also encounter ‘social and economic hardship’ (Ibrahim et al. 2008, p. 621), including poverty, unemployment, low income, and housing problems (Ibrahim et al. 2008; Anitha 2010; Taylor 2009).

One of the most pressing issues faced by immigrants from sub-Saharan African countries is that of immigration control, prior to obtaining the right to live and work in the UK (Ibrahim et al. 2008; Taylor 2009; Cornelius 2004; Crawley 2001). Therefore, sub-Saharan African migrant families who do not have the appropriate documents or those with immigration restrictions are likely to experience additional barriers (Ridge et al. 2008; Ibrahim et al. 2008; Fakoya et al. 2008). Black-African immigrant families with an autistic child are also affected when attempting to access support, due to the No Recourse to Public Funds (NRPF) policy (Anitha 2010; Ibrahim et al. 2008); meaning that they are not entitled to state welfare benefits in the UK. See section 5.3.1 of this thesis for more details about this policy.

According to some writers, the average minimum length of stay in the UK for a black-African immigrant before gaining permanent residency status is 7 years (Ibrahim et al. 2008; Fakoya et al. 2008). Half of the black-African participants in Ibrahim et al. who reported residency status, are likely to have had temporary residency, which meant that they were under immigration control. In addition, about 5% of the 704 black-African participants in the same study 'said that they had no papers to be in the UK' (Ibrahim et al. 2008, p. 620). However, Ibrahim et al. believed that the number of participants in their study without papers could be significantly higher.

In my interviews, I explored whether participants had issues with sensitivity, because immigration is often a sensitive subject for people who do not have the legal right to live in the UK (Ibrahim et al. 2008). Initially, I thought that these participants would not share their immigration circumstances with me, but they did. In fact, for some of them, the impact of their immigration experiences was an integral part of their reported daily stressor.

3.6 Access to Services Experiences for Black and Minority Ethnic Families in the UK

In this section, I will critically evaluate literature that has a direct bearing on my own study, in the context of access to services. These are specific research studies, involving UK-based black-African families with an autistic child. I will also draw on research focusing on a broader group of BME families in the UK and their experiences of accessing autism services. Papers from the USA are also explored for a broader western perspective.

Current knowledge of the experiences of black-African families with autistic children in the UK specifically is mainly based on the research conducted by Slade (2014); Perepa (2014), and Corbett and Perepa (2007). In these studies, black-African families were part of a wider group of BME participants. Also, the studies by Perepa (2014) and Corbett and Perepa (2007) were conducted within the context of education, while Slade (2014) focuses upon the wider service provision for BME autistic children and their families.

Previous findings on the experiences of BME families with autistic children when accessing services have been consistent about the challenges facing this wider group (Perepa 2014; Slade 2014; Doig 2012; Corbett and Perepa 2007). Slade (2014) found that the BME group faced the same problem as white families when accessing services, such as delay. However, he also argues that, in addition to common experiences, BME families also experience other specific difficulties not shared by the white community.

Slade (2014) used a focus group interview method with 130 participants from BME communities and whites in his qualitative research. The participants included parents, carers, siblings of autistic children, and autistic adults from across England. The ethnic origins of participants were as follows: 71 Asians, 56 blacks, 2 white, an Arabian, and two adults with autism. The gender composition of this group is 106 women and 24 men. The ‘blacks’ were black-African, Caribbean and UK-born. The aim of the study was to identify the problems BME communities encounter when attempting to access services in the UK.

According to Slade, the parents in his study reported challenges and barriers, not only during their child’s diagnosis, but also post-diagnosis, when communicating with professionals or accessing support and services for their child and family. Slade concluded that the barriers and challenges these families faced were due to the double jeopardy of being black or Asian and having a child with autism. A combination of a lack of knowledge and awareness about autism in the BME community, problems communicating with professionals, accusations by professionals of aggression and volatility from black parents, the impact of negative attitudes and perceptions of their family members, the wider BME community, and their cultural practices and beliefs all served to worsen their experiences, according to Slade (2014). Slade’s explanation is unsatisfactory because he appears to put the blame on BME communities, whilst disregarding external factors influencing the challenges they face. For example, Slade cited ‘communication with professionals’, and that ‘first-generation migrants felt nervous…lacked confidence [and]…language barriers…’ as major issues for some of his participants (Slade 2014, p. 18). However, most studies in this area focused on how the attitudes of professionals made black participants feel, thereby externalising the problem. The externalisation of any problem associated with the conduct of professionals, alongside other factors, e.g. racism, discrimination, oppression and stereotyping, played a pivotal role in creating a barrier to services for BME families with disabled children in the UK and the USA (see for example, Bywaters et al. 2003; Gourdine 2011; Ali et al. 2001, JRF and Rampaul-Chamba 1999; Xue et al. 2014).

For example, Ali et al. (2001) conducted a series of literature reviews to establish the perceptions of disabled and non-disabled children, and young people from black and Asian families on disability and impairment issues. The study found that the attitude of professionals toward BME disabled children and their families differed from their attitude towards white disabled children. In addition, Ali et al. (2001) reported that disabled BME children felt that 'when you are black or Asian [and disabled] you are a third class' and that they were often treated differently due to their race and ethnicity (p. 960).

Another example of the negative attitudes of professionals towards BME families with autistic children and those with other disabilities, was reported by Bywaters et al. (2003) and Woodgate et al. (2008). In a qualitative study of 19 Bangladeshi and Pakistani families with a disabled child, Bywaters et al. found that negative attitudes held by professionals and care providers about the attitudes of Asian families in regard to care of their disabled children was unjustifiable. For example, Bywaters et al. found no evidence to suggest that religious beliefs, attitudes and practices of the Bangladeshi and Pakistani families in their research were responsible for the low uptake of services. Rather, professionals and service providers' racist attitudes were blamed for the low service uptake.

In the USA, Gourdine et al. (2011) found that many African-American families experienced negative attitudes from healthcare service providers, such as racism, stereotyping, discrimination, and feeling devalued by white health professionals. Gourdine et al. also reported that even well-educated, middle-class black parents had experienced negative attitudes from professionals because of their race (Angell and Solomon 2017). Hence, black families who were not well educated often feel intimidated by health professionals.

Nonetheless, several authors seem to have reached a consensus about some of the experiences of BME families in the UK and USA. One such area is the discrimination experienced by BME families in the course of seeking diagnosis for their autistic child (Slade 2014; Jegatheesan et al. 2010; Gourdine et al. 2011; Montes and Halterman 2007). Despite the obvious benefits of early diagnosis of autism, these authors noted that diagnosing BME children takes a long time, and their parents often experience misdiagnosis, delays and other problems before their child could eventually receive correct diagnosis and support (Atkin et al. 1998). For example, Jegatheesan et al. (2010) reported that immigrant Asian families with autistic children waited for 24 months, after several consultation sessions with a wide range of professionals before their children were diagnosed. The parents described their experiences as long and traumatic. On the contrary, Waterson (2011) reported that the white parents in her study had received an easy and early diagnosis for their autistic children. Montes and Halterman (2011) found a marked difference between the diagnosis and treatment of autism in children from African-Americans and those from white-Americans in the USA (see also, Angell and Solomon 2017). African-American children with a low IQ were less likely to be diagnosed with autism; even if or when they were diagnosed, it was more likely to occur at an older age than their white counterparts, according to Montes and Halterman (2011).

Similarly, the parents in the study by Gourdine et al. (2011) reported a negative diagnosis experience where staff at the diagnostic clinic were predominantly white, and assumed that the black parents of autistic children were uneducated. The white professionals also showed a lack of cultural awareness or sensitivity towards them. Jegatheesen et al. (2010) argue that more BME health professionals should be employed to care for patients from a similar ethnic background. Although supported by authors such as Atkin et al. (1998), others such as Canary (2008) do not believe that employing BME health professionals solely to care for people from a similar background is a realistic solution.

To support her argument, Canary (2008) locates the problem squarely on the level of assertiveness, self-advocacy, level of acculturation and integration, and length of stay in a new country by parents of a disabled child as being firmly associated with the ability to advocate for one’s own rights. Canary concludes that BME families experience additional problems when accessing formal health or social care support, no matter their country of residence. Employing more professionals with a BME background may not solve all the problems BME families experience when communicating with professionals or accessing autism services.

For Slade (2014), however, the most pressing concerns for BME families include the lack of clear and accessible information about autism diagnosis processes, a reasonable timescale for diagnosis and limited access to help and support, post-diagnosis. Slade makes the point that BME parents feel confused as a result. Migrant families from countries where the first language is not English often encounter barriers due to limited access to interpreters. He adds that even some families who migrate from English-speaking countries find it difficult to interact with UK professionals about their child's disability due to difficulties in understanding their accent and a lack of confidence to challenge the *status quo*.

Corbett and Perepa (2007) advance the argument by suggesting that the provision of support for families with autistic children in the UK does not adequately address the needs of the BME population. They claim that families within the BME community experience 'disproportionate discrimination and disadvantage' (Corbett and Perepa 2007, p. 4). In other words, there are inequalities in the distribution of these services, which favour the interests of the white population. Likewise, Montes and Halterman (2011) found that in the USA, BME families do not always receive care that is culturally sensitive, nor do they perceive that professionals listen to their concerns. The result of Montes and Halterman's research strongly suggest that the level and quality of access to family-centred care for BME families with an autistic child, leaves much to be desired.

One important gap in these papers (Slade 2014; Perepa 2014; Corbett and Perepa 2007), along with other relevant literature, is that the barriers created by immigration requirements for migrant families in the UK have not been fully addressed. For example, Slade (2014) mentions the word 'migrants' three times in his paper, each within the context of parents attempting to communicate and interact with professionals. Perepa (2014) and Corbett and Perepa (2007) made no reference to immigration. By not addressing immigration challenges for BME families of disabled children, these papers have over-simplified this very important issue.

These studies did not also consider the intensity of the ‘fighting’ within which some black-African parents have to engage to access services. For example, although Perepa and Corbett (2007) found that some BME parents participating in their study had fought hard, this was solely in the context of their child’s education. Whilst Perepa (2014) never referred to ‘fighting’, Slade (2014) used the word ‘fight’ once to illustrate how a parent from ‘Jamaican heritage’ fought for services (p. 20). Earlier in this section, I mentioned that Slade had stated that people from the BME group are accused of ‘volatility and aggression’ (p.18), a view also supported by authors such as Atkin et al. (1998). However, Atkin et al. clarifies that this is usually due to the cultural tendency for some members of the BME group to raise their voices when expressing frustration. Again, Slade’s (2014) paper has not only identified a Jamaican parent as being linked to the fighting for service, but also as being aggressive, volatile, ‘overbearing and difficult’ (p. 18). This suggests that only Jamaican parents in his study had fought for services, inferring that parents from other BME origins did/could not fight. However, Angell and Solomon (2017), for example, disagree that parents from other BME groups could not advocate for better autism services for their children, citing the achievements of Latino parents (a USA-based ethnic minority group) in this regard.

Neither Corbett and Perepa’s (2007) nor Slade’s (2014) papers offer any explanation for the distinction between BME parents who have the capacity to fight for services and those who do not. For example, despite stating that some of his participants were, 'first-generation migrants [who] felt nervous and lacked confidence…and [were] reluctant to assert themselves due to their own differential attitude to figures of authority' (Slade 2014, p. 18), the paper does not distinguish between any internal differences within the broader BME group in his study. This also applies to Corbett and Perepa's (2007) paper.

A more focused study on the specific experiences of black-African immigrant families with an autistic child could explore the effect of immigration-related challenges on families and any distinctions that exist within the group itself. My study aims to identify internal differences by looking at how the various identities of an immigrant black-African intersect with autism in an attempt to address the gap in this specific knowledge area.

In the next section, I will explore the literature about autism and other disability services in some sub-Saharan African countries, to provide insight into any problems that exist there. As the participants in this study were originally from that geographical location, it is important to examine what life would have been like for them there instead of the UK.

3.6.1 The Situation of Autism and other Disability Services in some African Countries

In recent years, non-governmental organizations, such as *Autism South Africa*, may have increased awareness of autism, but services remain scarce there (Malcolm-Smith et al. 2013; Fewster and Gurayah 2015; Ulofosio 2017; Chukwueloka 2016). Where they are available, they are often difficult to access according to Malcolm-Smith et al. (2013). Therapeutic interventions and education for autistic children and families both require further improvement in Africa (Anthony 2009).

Historically, governments of most sub-Saharan African countries have given low priority to psychiatry, child psychiatry and paediatric social services in general (Longe and Asuni 1972; Lotter 1978; Sanua 1984). That trend continues into 21st century Africa (Bakare et al. 2011; Eseigbe et al. 2014; Ulofosio 2017). The scarcity of government-funded specialist and structured healthcare and social services in sub-Saharan African countries results in negative and stressful experiences for autism sufferers and their families in those countries (Lagunju et al. 2014; Bakare and Munir 2011; Bakare and Ikegwuonu 2008). For example, Audu and Egbochukwu (2010), and Chukwueloka (2016) report that autism support services are scarce in Nigeria. Mankoski et al. (2006) report that there are only two schools for autistic children in Tanzania. Reports of poor services for autism and other disabilities are consistent across other sub-Saharan African countries: Sudan (Mohammed and Babikir 2013); Cote d'Ivoire (Bayat 2014); Kenya (Frantz et al. 2011); Zimbabwe (Munsaka and Charnley 2013); Botswana (Chataika et al. 2012). Yet South Africa (Klientjes et al. 2013); Ghana (Anthony 2011) and Uganda (Minde 1977) seem to have improved on their autism and disability services in general.

Scholars such as Bakare et al. (2009) report minimal availability of facilities to meet the needs of children with autism and other neuro-developmental disorders in Africa. They report that these facilities are inadequate or not fit for purpose. Bakare et al. (2014) confirm that most of the available facilities are government psychiatric units, which are not equipped to meet the needs of children with autism. There is a lack of multidisciplinary management of autism care, a limited number of special education facilities, inadequate provision of communication or social skills training for autistic children, their families and professionals in most sub-Saharan African countries (Fiorili 2014; Chukwueloka 2016; Eseigbie et al. 2014). Bakare et al. (2014) conclude that, ‘there is scarcity of intervention programs for children with autism and other neuro-developmental disorders in Africa. The available services are unaffordable to most of the parents of affected children’ (2014, p. 4). Most African governments prioritise the reduction of childhood communicable diseases, such as malaria or HIV/AIDS, with the aim of reducing childhood mortality rates in Africa (Mankoski et al. 2006; Bakare et al. 2011).

Autism services are one of several sectors where increased support is required to meet the needs of disabled people in sub-Saharan Africa (Klientjies et al. 2013; Frantz et al. 2011; Bakare and Munir 2011). Historically, disability issues have not been prioritised by governments in most sub-Saharan African countries (Kotzé and Open Society Initiative for Southern Africa 2012). In order to protect their basic human rights, disabled people in some African countries formed self-advocacy groups to lobby governments to implement policies and legislation, and to provide adequate services for disabled people (Eleweke 2013 and 1999; Chataika et al. 2012; Frantz, et al. 2011; Klientjie et al. 2013). Despite the activities of self-advocacy movements in sub-Saharan African countries, however, improvement in the experiences of disabled people in that region are probably minimal at best (Frantz et al. 2011; Eleweke 2013).

There are only a few countries in sub-Saharan Africa that provide financial support to their disabled citizens (Wazakili et al. 2006; Sandy et al 2013). Many of them do not. For example, South Africa and Zimbabwe are among very few countries that offer disability welfare benefits (Wazakili et al. 2006; Sandy et al. 2013). The South African government provides the Disability Social Grant, a monthly state benefit to help disabled people with their cost of living (Sandy et al. 2013 and 2006). However, despite state benefits paid to children with a learning disability in South Africa, families feel that the money was not enough to meet their daily needs, and disabled people who receive social grants are targeted by robbers (Sandy et al. 2013). Zimbabwe was reported to offer financial support to disabled people in Africa (Munsaka and Charnley 2013), but the government's disability benefit system does not function well due to economic problems in the country. Hence, disabled people are not getting the money they were promised, and some were withdrawn altogether from the system.

In general, disabled children and their families live in abject poverty (Mji et al. 2011; Zidan 2011; Singal 2011). Unemployment prevalence rates for disabled people of working age are estimated to be 90% in sub-Saharan African countries; in developed countries, the equivalent rate is approximately 60% (United Nations 2002). In addition, the social security system in sub-Saharan African countries is based mainly on employee contributions, so people with disabilities are excluded (Frantz et al. 2011).

The burden of caring for a disabled child, and the additional cost of basic needs (treatments, equipment, adaptations, transport), for raising a child with a disability reduces the financial capacity of a family (Kotzé and Open Society Initiative for Southern Africa 2012; Mji et al. 2011). Parents of disabled children often spend most of their time caring for their offspring throughout their lives, rather than earning income for the family (Singal 2011). As a result, no social or economic capital is available for transfer to the subsequent generation. This results in inter-generational poverty **(**Singal 2011; Zidan 2011; Wazakili et al. 2006). Consequently, disabled children and families in sub-Saharan Africa often rely on handouts from both the wider family network and immediate community for food, clothing, shelter and medicines (Singal 2011; Zidan 2011). It is possible that, as a result of the scarcity of autism services and support for families in most sub-Saharan African countries, some parents of autistic children are likely to migrate to the West, where better resources are available.

Aside from the lack of financial and welfare benefits, several authors are concerned about the scarce educational provisions for children with autism, and those with other disabilities (Moswela and Mukhopadhyay 2011; Chataika et al. 2012; Bayat 2014; Botts and Awusu 2013; Mji et al. 2011; Anthony 2011). Most African countries ratified the United Nations Education and Scientific and Cultural Organisation's (UNESCO) Salamanca Statement for Education For All (EFA) in 1994, and again in the Dakar Framework for Action (Anthony 2011; Chataika et al. 2012; Munsaka and Charney 2013). Whilst these agreements legally challenged discriminatory attitudes against the disabled, and promoted equal educational opportunities for disabled children (UNESCO 1994), they do not appear to have implemented necessary strategies for this course of action (Anthony 2011; Munsaka and Charnley 2013; Bornman and Donohue 2013).

Most African countries have not taken these responsibilities seriously, while those who have implemented them have taken a passive approach. For example, in Botswana, which has an inclusive education policy, primary education is not compulsory, and teachers are not trained to deliver education to children with special needs (Moswela and Mukhopadhyay 2011 Chataika et al. 2012). The number of disabled students who enrolled into higher education in Botswana increased from 5 to 54 in 10 years (Chataika, et al., 2012). A similar picture emerges from Lesotho, Namibia, Cote d'Ivoire, Tanzania, Malawi, Uganda, Nigeria, Senegal, Ghana, Zimbabwe, South Africa, Kenya and Ethiopia, where teacher training in special needs education is inadequate. In addition, negative attitudes from teachers and students, along with structural problems and the implementation of pro-inclusive education policies is problematic (Anthony 2011; Chataika et al. 2012; Moswela and Mukhopadhyay 2010; Bayat 2014; Botts and Awusu 2013; Mji et al. 2011).

Some authors took different views on these issues. For example, Frantz et al. (2011), report that the Kenyan government committed to achieving Education for All (EFA), and inclusive education, gender equality and support for children in special needs schools. Similarly, the governments of South Africa and Zimbabwe also promoted disability rights and equal access to education for all learners, backed by legislation and policies (Engelbrecht et al. 2005; Bornman and Donohue 2013; Chataika et al. 2012). Botts and Owusu (2013) stated that the Ghanaian government provides free, mandatory, universal primary and inclusive education, supported by Ghana's constitution.

Despite inclusive education and social inclusion initiatives, parents in Ghana, Zimbabwe and South Africa, have reported strong resistance from teachers, lack of access to building and negative attitudes from teachers and children who are not disabled (Engelbrecht et al. 2005; Bornman and Donohue 2013; Botts and Owusu 2013). As a result, many parents were sceptical about sending their children to mainstream education (Sandy et al. 2013; Chataika et al. 2012).

According to Eleweke (2013 and 1999), the government of Nigeria views funding for disability services as a waste of resources. Nigeria has no legislative framework that protects the interests and rights of disabled people (Eleweke (2013). Structural and cultural barriers remain a major problem for disabled people in that country. Even in countries where policies and legislation for inclusive education and social inclusion exist, it does not translate into reality for disabled children, students, or disabled adults and their families. Without government support, special needs education remains elusive in some sub-Saharan African countries (Singal 2011). However, some sub-Saharan African countries support the implementation of the World Health Organisation Community Based Rehabilitation (CBR) services, aimed at supporting disabled people, creating community cohesion, and promoting disability awareness within communities (Crabb et al. 2012; Otte et al. 2013).

In the next section, I will explore literature on the stigma and discrimination experienced by BME families in the UK and black-African families in sub-Saharan Africa.

3.7 Stigma and Discrimination Experiences for Ethnic Minority Groups in the UK

This section explores literature on the stigma and discrimination experiences of BME groups in the UK, and for black-African families in sub-Saharan Africa. As previously stated, the research papers investigated here are those most closely related to my study (Slade 2014; Perepa 2014 and Corbett and Perepa 2007), as well as Doig (2012) and others.

In recent years, there has been an increasing interest in the experiences of stigma and discrimination by families of children with a disability, and those with autism (see for example Gray 2002, 2006 and 1993; Link and Phelan 2001 and 2013; Doig 2012; Slade 2014; Baffoe 2013; Potter 2016). It is becoming increasingly difficult to ignore evidence of stigma and discrimination in BME-focused research (Doig 2012; Slade 2014).

Despite evidence provided by ethnically-diverse research studies which suggest that stigma is an important concept and experience, Perepa (2014) has not addressed it in her paper; while Corbett and Perepa's (2007) paper did not fully address it. There is only one mention of 'stigma' in the Corbett and Perepa's paper, in the context of its implications for access to educational services. They said: 'stigma around disability can be particularly acute in certain minority ethnic groups and this may result in the reluctance of families to seek a diagnosis for their child' (p. 9). While this claim is supported in other papers with an ethnically-diverse focus (for example, Jegatheesan et al 2008; Xue et al 2014t; Atkin et al 1998), Corbett and Perepa's paper did not show how stigma and discrimination could affect their participants in other contexts such as social care, nor examine implications for their participants' wider family and among their communities in Africa and the UK.

Slade (2014) had explored the implications of stigma in great depth, showing that there is an unambiguous relationship between being an ethnically diverse family with an autistic child and a negative stereotypical response from others. Slade viewed stigma from a cultural lens, or 'cultural stigma' (p. 11), from an educational perspective, within BME communities, and the internalisation of stigma by parents through 'self-blame' (p. 16) and 'feeling of isolation, and shame…' (p. 21). Cultural stigma is an attitude informed by cultural belief systems and practices arising from the intersection of disability with culture (Scior et al. 2013; Mshana et al. 2011), rather than with race. Slade reports that some of his participants insist on their child attending mainstream school to avoid stigma, and 'hope that the child will acclimatise to being 'normal'…[as] they attach stigma to special schools and specialist services' (p. 12). Some BME parents are, therefore, inclined to keep the condition of their child a secret (Kim 2012; Bywaters et al. 2003; Ismail et al. 2005).

While Slade's account provides insight into the stigma experiences among BME families of an autistic child, there are also notable gaps. The paper does not recognise or differentiate between the types of stigma and rejection experienced within and outside a family. The paper does not also consider 'racialisation' as a process of making sense about an interaction between whites and blacks (see Ahmed 2002; Garner 2010).

Several papers agree with Slade that societies' poor understanding of the challenges associated with raising a child with autism, ignorance, and a lack of empathy was responsible for the negative attitudes that parents and their children with autism experience (see for example, Sotgui et al. 2011; Neely-Barnes et al. 2011; Woodgate et al. 2008; Hornby 2007). The combination of the child's behaviour and the negative attitudes of the public, make parents reluctant to go shopping with their autistic child, for instane (Hornby 2007; Gibson 2014). Due to fear of stigma from within the BME community, family members either give parenting advice or reject the child as a member of the family (Bywaters et al. 2003; Fazil et al. 2002). Therefore, to avoid stigma and 'save face', some parents of a disabled child, living in the diaspora often avoid informing distant family members about the child or their condition (see, Bolton et al. 2013; and Canary 2008).

Other authors examined stigma from a slightly different perspective, pointing out the differential stigma experience associated with the age of an autistic child (Woodgate et al. 2008; Gray 2002). They make the point that people's stereotypical and stigmatising attitudes get worse as a child with autism grows older, due to the social behaviour expected from an older child, especially as autism is 'invisible' (Woodgate et al. 2008, p. 1078). Another form of differentiation generally reported in the literature is that mothers are often blamed and stigmatised for having a disabled child (Nealy et al. 2012; Dowling and Dolan 2010). It is, therefore, conceivable that negative societal attitudes towards families with an autistic child are not reserved for BME families alone (Waterson 2010). It is, however, evident that racism worsens the experience of the BME group, when compared to their white counterparts (Ali et al. 2001; Fazil et al 2002; Slade 2014).

Nonetheless, there are gaps in Slade's (2014) paper in terms of exploring the stigma experiences of his BME participants in their countries of origin and the attitudes in that part of the world. In the next section, I will explore the stigmatising attitude towards disabled people in sub-Saharan Africa as an example.

3.7.1 Stigmatising Attitudes toward Disabled People in sub-Saharan Africa

Although Slade (2014) cited one of his participants as saying that ‘people with disabilities are stigmatised in Gambia’ (p. 14), studies by Perepa (2014) and Corbett and Perepa (2007) did not investigate autism from the perspectives of the society from where their BME participants originated. Looking at stigma and rejection from that perspective gives a broader and deeper insight into what stigma and rejection meant for this group, how they experience stigma if they travel home, and/or how their peers in Africa or Asia, for example, experience stigma and rejection.

Several authors have demonstrated that there is a high level of stigmatising attitudes against disabled people and their families in parts of Africa (Hartley et al. 2005; Gona et al. 2010; Bayat 2015; Mshana et al. 2011). These and other studies claim that due to prejudice, ideological beliefs, stereotypes and misconceptions about disability, cultural stigma is present in sub-Saharan Africa (Otte et al. 2013; Kiyaga and Moores 2003; Wazakili et al. 2006). The existence of negative attitudes toward disabled people is supported by Mshana et al. (2011) and Otte et al. (2013) who state that stigma leads to discrimination, deprivation, oppression and marginalisation for disabled people in their own communities. Crabb et al. (2012) and Wazakili et al. (2006) remind us that stigmatising experiences often mean that disabled people are being isolated and excluded from social, economic, political and religious participation.

Wazakili et al. (2006) go on to consider that the adverse impact of stigma and rejection on families is such that some parents find it hard to come to terms with having a disabled child, while other parents also treat their disabled children with a negative attitude. They further argue that, over time, victims of stigma tend to internalise the negative attitudes against them by believing that they deserve to be discriminated against, and that their perpetrators were right to do so.

Taking the idea of cultural stigma and rejection in parts of Africa further, Zidan (2012), and Scior et al. (2013), claim that disability related stigma and rejection is often demonstrated through oppression and discrimination (Shibre et al. 2001). Several studies from Ghana, however, take a pragmatic view about the impact of cultural stigma on disabled people in terms of their experience of avoidance and social distancing, verbal and physical abuse, ostracisation, destitution, exclusion, and extreme poverty (see for example, Ghanean et al. 2013; Lewin 2009). Other authors examine an implication of cultural stigma, namely, that fear of such stigma is one reason why suitors often avoid marrying into a family with a disabled individual (Zidan 2012; Scior et al 2013; Munsaka and Charnley 2013; Rule and Modipa 2012; Lewin 2009). Although such implications are common in that part of the world, some authors refocused the discussion of the common cultural stigma issues by putting the blame squarely on various nation state governments in Africa (Hartley et al. 2005; Gona et al. 2010; Bayat 2015; Mshana et al. 2011). They make the point that the lack of government support for initiatives that promote disability rights, health, economic or social services, social inclusion or inclusive education, and support for disabled people have meant that the situation has been slow to improve.

For example, Kleintjes et al. (2013) looks at stigmatising attitudes from the viewpoint of government officials and policy makers in South Africa. They found that due to entrenched negative cultural beliefs and attitudes about disability, government officials discriminate against, and marginalise, disabled people. As a result, budget allocations to support services for disabled people are often insufficient, and there is a low level of general interest in issues relating to mental health and disability (Kotzé and Open Society Initiative for Southern Africa 2012; Kleintjes et al. 2013; Kleintjes et al. 2010).

In order to draw the attention of non-disabled people to the impact of stigma and discrimination on disabled people, Amosun et al. (2005) carried out a social experiment study with some medical students in South Africa. They made the non-disabled students use a wheelchair around the university campus for five days, with the aim of improving the attitudes of healthcare professionals towards disabled people. The physical barriers, stigma and rejection, including other emotional and psychological impacts reported by the participants, demonstrate the detrimental effect of living with a disability. In the next section, I will look at the stigma experiences of members of BME families with an autistic child, but not including the child itself.

3.7.2 Stigma Experiences of Fathers, Mothers and Neurotypical Siblings

This section reviews the findings from three studies, focusing on the stigma experiences of fathers, mothers and neurotypical siblings: Slade (2014), Perepa (2014), and Corbett and Perepa (2007),.

Slade's (2014) paper did not state how many BME 'fathers' took part in his study, but it reported that a total of 24 men had participated. So, we assume that some are BME fathers. Although Corbett and Perepa (2007) did not include fathers in their study, Perepa (2014) did include them. The demography of participants in Perepa (2014) included '29 white British, 16 'Afro-Caribbean', 12 South Asians and 6 Somalis' (p. 4). Among these were 9 white fathers, 20 white mothers, 3 fathers and 13 mothers of 'Afro-Caribbean' background, 5 fathers and 7 mothers from South Asian background, and 6 mothers of Somali background. The method used by Perepa (2014) to group participants, however, limits the scope for proper differentiation of participants in her study. For example, in her 'Afro-Caribbean' group, she listed participants from 'countries such as Nigeria, Ghana, Guyana, Congo and Sierra-Leone' together, but listed 'Somali' separately (p. 3). All the countries in the 'Afro-Caribbean subgroup, (except Guyana which is a Caribbean country) are sub-Saharan African countries, including Somalia. Her grouping appears to suggest that the participants in the 'Afro-Caribbean' subgroup are all from the Caribbean, or perhaps her use of hyphenation is causing the confusion. Therefore, we do not know the specific background of her BME participants.

The single specific experience mentioned in Perepa's paper, in relation to fathers, concerned their keenness to teach their autistic children to respect the personal space of others. Therefore, the significance of the gender role of fathers was not fully acknowledged. Although Slade did not report that fathers experienced stigma or rejection either, he offers more insight than Perepa into the roles of gender, and the experiences of fathers in particular, than Perepa. For example, Slade found that fathers in his study blamed mothers ‘for having done something wrong in pregnancy, such as having an affair or not living and eating healthily’ (p. 12). In other words, fathers stigmatise their wives/mothers of their autistic children, but no evidence is presented that fathers themselves experienced stigma, suggesting that there is a gender bias against mothers. There are two possible inferences which may be drawn: either the fathers in Slade and Perepa’s studies did not experience stigma, or the authors have not considered the implications of stigma for fathers.

Slade (2014) also considers that, apart from being blamed, mothers also carry ‘the burden of practical care and engagement with autism’ (p. 12) and are therefore more likely than fathers to express themselves, seek help and ‘encounter other mothers or carers’ (p. 12). Put differently, a BME woman/mother of an autistic child is a primary care giver, is more open and willing to accept help, and more likely to be seen with her autistic child; hence, she is also more likely to experience stigma and thereby more likely to participate in a research study than their male/father counterpart (Nealy et al. 2012; Dowling and Dolan 2010). According to Corrigan and Miller (2006), stigma experiences of family members vary, depending on roles in the family: parents, siblings, father, mother; or gender: male or female; while mothers are often reported to experience the most stigma (Gray 2002). Literature on the roles and experiences of mothers has consistently portrayed them as being the dominant respondents to research in any ethnic group (Rivers and Stoneman 2003; Xue et al. 2014; JRF and Rampaul-Chamba 1999; Ponde and Rousseau 2013; Neely-Barnes 2011; Tincani et al. 2009; Keen et al. 2010). McConkey et al. (2006) carried out a comparative study of mothers of children with intellectual disability from Ireland, Taiwan and Jordan, which established that, globally, mothers of children with a disability share some common experiences of stigma.

However, some studies of the role of women in an African society offer a different view of stigma against women, compared with those outlined above (Ibisomi et al. 2014; Hollos and Larsen 2008). For example, Ibisomi et al. (2014) revealed that, in an African society, the intensity of stigma experienced by a woman who is childless or has a disabled child is such that she may face ‘open ridicule and isolation, and is likely to experience economic deprivation, physical violence, taunts, threats, rejection and abandonment by her husband and his family, or divorce by the husband which may result into distress, depression and lowered self-esteem for the woman’ (p. 62).

Both Perepa’s (2014) and Corbettt and Perepa’s (2007) papers did not investigate the role or experience of siblings in a family of an autistic child. However, Slade’s (2014) paper examine some siblings’ experiences: feeling neglected/ignored, reprimanded more frequently than the autistic sibling, picking up some of the habits of the autistic sibling, being child carers, taking on additional responsibilities, feeling under pressure, confused about their identity, ‘embarrassed about or resentful towards the child with autism’ and socially isolated (p. 13). While Slade’s findings were helpful to our understanding of siblings' experiences, it only considers negative experiences. There is, however, a growing body of research on neurotypical siblings of autistic children, and the findings reflect both positive and negative experiences by this group of participants (Waterson 2011; Dyson 1998; Petalas et al. 2009; Canary 2008; Seltzer et al. 2009; Joseph, et al., 2009).

The considerable amount of research published to date on the experiences of neurotypical siblings of autistic children were about white families. The majority of the papers originate from the USA, only a few were from the UK, and only Slade (2014) focused on black-African siblings. The experiences of black-African neurotypical siblings of an autistic child living in the UK are, therefore, under-researched.

To conclude this section, I have attempted to review Slade's (2014); Perepa's (2014) and Corbett and Perepa's (2007) papers, being the papers most closely related to my study. I have also interrogated the wider literature in regard to other types of disabilities, family roles and genders, along with papers from outside of the UK. In particular, I looked at papers from Africa, the USA and Europe. The aim was not only to establish what has been documented in terms of stigma and rejection experiences for families of disabled children, but also to highlight any differentiation between the experiences of UK-based Africa families, for example, and their African-based counterparts. I also wanted to establish whether differences exist between the experiences of individual BME research participants. So far, however, there has been little or no substantive discussion about any such differences in the literature I reviewed. For example, Slade (2014), Perepa (2014), Corbett and Perepa (2007) did not differentiate between courtesy stigma (stigma by association) and direct stigma (faced by people living with a disability themselves). They have not differentiated between enacted stigma and felt stigma, the stigma and rejection associated with family roles, gender, stigma arising from UK attitudes to race and disability, and stigma that relates to culture and disability in Africa. Importantly, I have not come across a paper that explored the simultaneous stigma experiences of BME research participants in the UK and in sub-Saharan African families with an autistic child. I will, therefore, attempt to address some of these gaps in my research.

In the next section, I will explore papers relating to specific African or BME groups of families with autistic children and other disabilities. The aim is to identify any references to nuanced or distinctive cultural experiences in the current literature.

3.8 Some Black and Ethnic Minority Cultural Values and Belief Systems

This section explores research relating to specific African or BME groups of families with autistic children and other disabilities. It examines the cultural experiences of these groups, whilst resident in the UK, which have a particular bearing on my study (Slade 2014; Perepa 2014; Corbettt and Perepa 2007), along with a wider range of literature.

Given that these three studies were mainly focused on BME families of an autistic child, it is expected that a significant portion of the findings would be strongly linked to their specific cultural worldviews. For example, issues discussed by Corbett and Perepa (2007) refer to the additional cultural barriers that prevent families from accessing educational services, and the need to offer culturally orientated educational services and support. Perepa (2014) focused more on cultural differences between whites and the BME participants in her study, including the variations in cultural meanings given to a specific autism characteristic such as eye contact. She explored how the education of BME autistic children could be enhanced by the existence of a culturally sensitive educational system. For Slade (2014), however, cultural experiences were central to his research. For example, he identifies several cultural themes that he used to expose some cultural experiences of his BME participants. He proposes that they: (a) assume that the developmental delay and naughty behaviour of their autistic son was culturally normal for boys, (b) ‘place a strong emphasis on continuing the family line, including marriages…’ (p. 12), (c) mothers speculating that fathers feel that having a disabled child is a threat to their masculinity, their gender, their identity and status, hence they found it hard to accept, (d) the avoidance of eye contact by a child/younger person when speaking with an older person as a cultural norm, (e) parents being accused by kin in their home country of becoming ‘westernised’ and of being influenced by prevailing values and beliefs in/from their ‘home’ countries such as autism being ‘unnatural’, caused by ‘someone’ and ‘cure[able]’ (p. 11). Slade’s findings are consistent with what is already known about some of the cultural beliefs and values of some BME research participants (Jegatheesan et al. 2010; Doig 2012; Bywaters et al. 2003; Kim 2012; Tedam 2014; Kurzban and Leary 2001); including some black-Africans (Baba 2014; Evans-Pritchard 1940a; Bakare et al. 2008).

Slade (2014) also draws attention to the difficulty in recruiting black-African men/fathers for research purposes, the ‘patriarchal cultur[al]’ role of a father in a black and minority ethnic family (p. 12), suggesting that fathers are often insular and emotionally expressionless. Several authors support Slade's ideas about fathers' lack of emotional expression (Hornby 2007); the challenges of using BME men for research (Fazil et al. 2001; Doig 2012); and fathers in general (Hornby 2007; Neely-Barnes et al. 2011; Waterson 2011). However, Hornby (2007) takes the view that fathers do actually experience, and express emotional and psychological feelings about their autistic child, but he blames researchers for not reporting them.

That said, Slade's exposition of fathers would have been more culturally persuasive if he had analysed patriarchy in greater depth; or considered more cultural dimensions such as witchcraft beliefs, and/or kinship systems for example. Other authors provide a more in-depth analysis of the patriarchal cultural system in an African context, and its contemporary relevance (see for example, Khunou 2012; Holmes 2000; Ritcher and Morrell 2006; Costa et al 2001). Costa et al. (2001, p. 321) argues that in an African society, social/gender roles are 'internalized early in development'. Hence, at an early age, boys are shaped to fit into the traditional role of a patriarch, while fathers are patriarchs and represent their family in wider community (Khunou 2012; Kandiyoti 1988; Silberschmidt 2001). In a patriarchal African culture where sons are highly valued, 'daughters don't matter', claims Holmes (2000, p. 249). The cultural beliefs about witchcraft in Africa are well documented in scholarly literature (see for example, Tedam 2014, Otte et al. 2013; Sandy et al. 2013; Reynolds 2010; Kiyaga and Moores 2003). Other writers make the point that even elite and educated black-Africans living abroad and/or in Africa often believe in witchcraft as a causal agent for death, misfortunes and acute illnesses (Legare and Gelman 2008; Jahoda 1968; Adegbaju et al. 2013; Bakare and Munir 2011; Ramanathan and Makoni 2010). For example, Onyinah (2009) claims that about 90% of Ghanaians believe that witchcraft exists, and use it to explain misfortunes. We do not know if this is true or not, but this and other papers highlight the presence and acceptance of witchcraft beliefs in an African society.

In conclusion, Slade (2014); Perepa (2014) and Corbett and Perepa (2007) have contributed to our understanding of the cultural beliefs and value systems that are characteristic of BME groups in the UK. Most notably, Slade's accounts of the cultural values and belief systems present in BME communities in the UK demonstrate the importance of viewing autism from a sociocultural lens. However, one notable gap in Slade's work in this area is that the implications arising from either the witchcraft narrative or kinship systems which are so important in shaping some of the meanings that BME families in the diaspora often make about their child's autism and other acute conditions is not fully highlighted (see, Tedam 2014; Bjork 2007). Also, Slade's paper does not include the experiences of his participants (or that of other families of autistic children) in their home countries. Consideration was also given to any differences that exist within a family unit from a cultural gender/sex role perspective. My study is designed to address these gaps in relation to the sociocultural experiences of black-African families of autistic children in the UK.

In the next section, I will review papers relating to religious and spiritual beliefs and practices within African or BME groups of families with autistic children and other disabilities. The aim is to gather further information about any religious and spiritual coping strategies from the current literature.

3.9 The Religious and Spiritual Coping Strategies and Meaning-Making about Disabilities

This section begins by appraising the three published UK research papers of most relevance to my study of black-African immigrant families of autistic children in the UK, within the context of spirituality and religiosity of this group. Having explored the theory of religion and spirituality in the second chapter, I focus here on evaluating the available research to establish what is already known about the religious and spiritual coping mechanisms for this group.

Both Perepa (2014) and Corbett and Perepa (2007) have not fully explored the importance of religious and spiritual belief systems in and among members of BME groups in the UK. Pepera (2014) did not consider any religious and spiritual implications in her paper, whilst Corbett and Perepa (2007) paid limited attention to the subject. They focused more on the importance of meeting the religious and spiritual needs of autistic students in schools as a way of increasing religious tolerance and achieving better community integration. But this is insufficient to help us better understand the religious and spiritual meaning that families make about autism. On the other hand, Slade (2014) ‘encouraged [his participants] to consider the possible impact of…faith and religious beliefs…’ (p. 7). However, findings relating to religion and spirituality are sparse in his paper. For example, he reports that a participant claimed that her church members believed that ‘bad experiences are a spiritual attack’ (p. 10); BME group’s religious and cultural needs are ‘not understood’, as a result, their spiritual and religious needs are unmet (p. 17); a lack of tolerance and low awareness about autism is present in ‘churches and mosques’ and among worshipers (p. 9).

The little attention given to religious and spiritual matters by these authors suggest that there is a knowledge gap in this area. It is important, therefore, to explore the role played by religion and spirituality in the lives of black-African families of children with autism specifically, just like other papers that has investigated families with disabled children from other ethnic groups (Hill et al. 2009; McNair and Sanchez 2008; Tarakeshwar and Pargament 2001; Ismail, et al., 2005). Although Slade promised to encourage his participants to share their religious and spiritual experiences, his paper contains limited information on religion and spirituality. The scant attention given to religion and spirituality in these papers (Slade 2014; Perepa 2014; Corbett and Perepa 2007), is a missed opportunity to demonstrate the importance of this concept for most BME families of children with autism and other acute conditions (see, Rippentrop et al. 2005; Tarakeshwar and Pargament 2001; Powell et al. 2003; Haworth et al. 1996).

Researchers have found that religion and spirituality is a strong source of support for BME families of disabled children (Tarakeshwar and Pargament 2001; Ismail, et al., 2005). For instance, Gourdine et al. (2011) claims that parents from BME groups often view their child’s autism through a religious and spiritual lens, and regard their autistic child as a gift from God, and a challenge to be overcome through religious and spiritual practices, capable of improving the child’s condition, (Bywaters et al. 2003; Ravindran and Myers 2011; Jegatheesan et al. 2010). Other authors take a similar view but suggest that support from religious organisations and the clergy could be important resources for families (Canary 2008; Ravindran and Myers 2011).

Dein and Bhui (2013) highlight a potential paradox in that whilst religion and spirituality could be a source of support, it could also undermine the uptake of autism support services by families. But Bywaters et al. (2003) would disagree with Dein and Bhui that religion and spirituality could be an impediment to access to services. Bywaters et al. found no evidence to suggest that the religious beliefs, attitudes and practices of the Bangladeshi and Pakistani families in their research, for example, was the reason for the low uptake of services. Rather, they blame professionals and service providers' racist attitudes instead. A number of scholars seem to agree with the opinion of Bywaters et al. (2003), by insisting that services, such as respite and short breaks, are not usually tailored to meet their cultural and religious needs (see, JRF and Rampaul-Chamba 1999; Doig 2012; Mandell and Novak 2005).

However, Howarth et al. (1996) and Mengesha and Ward (2012) move away from the debate about whether or not religion and spirituality were responsible for low uptake of care services, and focus more on investigating differences and distinction instead. For instance, Howarth et al. (1996) employed a 12-item Likert scale to establish the location of their participants within their religious commitment continuum, and the outcomes they received. They found that those parents whom, 'without prompting… voluntarily describe their own religious experiences…demonstrated that religion is an important part of their everyday lives, a lens through which they look at the world', compared to those who did not volunteer information or spoke negatively about religion (p. 227). Mengesha and Ward (2012) categorised their African-American participants with depression into three religious and spiritual subgroups of high, medium and low religiosity. They used this approach to measure the qualitative values their participants placed on their depression experiences vis-à-vis their religious/spiritual beliefs. They found that severity of depression symptoms decreased for those in the ‘high’ group, compared with those in the ‘low’ group. In other words, the higher a participant’s position on the qualitative religious/spirituality continuum, the more positive their coping outcome, compared to those in the lower part of the continuum.

What Mengesha and Ward, and Howarth et al. brought to the discussion about religious and spiritual coping and understanding is that they show that it is possible to avoid applying a blanket description to all participants’ religious and spiritual experiences. They demonstrated that there is more to glean from some of the nuances that can be found within a group of participants that share religious and spiritual belief systems. This is something that neither Slade (2014), nor Perepa (2014) or Corbett and Perepa (2007) considered.

To summarise this section, I have critically appraised the three papers most directly relevant to my study in the context of religious and spiritual experiences. All of the three papers have not fully accounted for the religious and spiritual experiences of their participants, leaving some gaps about what we know concerning this research group.

3.10 The Conclusion to Chapter Three

To recap, having appraised some of the papers that are closest to my research topic, I found that although some of them acknowledged certain nuanced issues that black-African families of autistic children face in the UK; certain issues were either not fully addressed or not broached at all. This means that gaps in knowledge about the experiences of this research group remain. For example, although Slade's (2014) paper is the only one that mentions immigration related issue and some cultural practices, it has not fully explored these issues. Also, none of the papers differentiated between the various types of stigma experienced by the BME group. Therefore, further research is needed to fully explore some the issues that significantly impact on this research group's autism experiences. These are the implications of immigration requirements for migrant families in the UK, the various nuanced categories of stigma and rejection and its impact, specific cultural belief systems and practices, including religious/spiritual and beliefs in witchcrafts and their impacts. These issues are fully explored in my research.

Chapter Four

Methodology

4.1 Introduction

In this chapter, I reiterate the aims of my research and provide justification for my choice of methodology. I describe the qualitative research paradigm and phenomenological design used to explore the multi-layered experiences of black-African families living in the UK with an autistic child, and I explain the rationale for choosing a qualitative research approach, informed by phenomenology. In addition, I describe the participants, the selection process, the role of the researcher, and the ethical considerations. I also outline the data collection methods, including the coding process and threats to data quality.

My research is underpinned by assumptions about the nature of reality and its characteristics (ontology), the methods used by the researcher to gather knowledge (epistemology), including the methodological processes used to acquire the knowledge (Crotty 2012; Cresswell 2007). I aim to analyse the lived experiences of black-Africans living in the UK with an autistic child, using interpretative phenomenological analysis (Smith 1996; Smith et al. 2009).

There are four fundamental elements to social research: ontology, epistemology, methodology and methods (Crotty 2012). These elements provide the framework for planning, implementing and evaluating research. Generally, qualitative research refers to social research, whereby the researcher uses text data instead of numerical data analysis in his or her research, with a view to understanding the phenomena under study (Carter and Little 2007; Ewart 2002).

4.2 Ontology & Epistemology

The ontological debate is concerned with what we believe to be absolute reality, in terms of whether there is a reality and ‘truth’ or whether there are multiple realities based on social interpretations (Patton 2002; Parker 1998). Ontology, therefore, is a study about the nature of physical and social realities (Creswell 2007; Carter and Little 2007), focusing upon the nature of existence (Crotty 2012). The nature of reality from a positivist ontological perspective assumes that reality or entities exist whether human beings are conscious of them or not. Such research is often naturalistic or empirical, frequently providing a descriptive analysis of the findings (Bogdan and Bilken 1997; Creswell 2007).

Social research undertaken from an ontological positivist standpoint requires the researcher to detach themselves from the process in order to produce ‘factual’ knowledge without the researcher’s own subjective interpretation. (Crotty 2012; Gray 2014; Bryman 2008). Guba and Lincoln (1989) claim that something becomes real in the subjective mind of the person experiencing the phenomena. Creswell (2007) asserts that when we conduct social research it involves exploring different realities, and that a reality could be subjectively experienced by participants.

Philosophically, epistemology is concerned with how we come to know the social world, how we get to know if things are true or not , and what steps we need to take to obtain reliable knowledge about the world (Crotty 2012; Cresswell 2007; Gray 2014; Lewis and Staehler 2014). It focuses upon the difference between everyday beliefs, or common-sense knowledge, and knowledge gained through a logical scientific process. It is ‘the study of the nature of knowledge and justification’ (Schwandt 2001, p. 71; cited in Carter and Little 2007, p. 1317).

According to Crotty (2012), there are three types of epistemologies used in social research. The first of these is objectivism, which holds that absolute reality exists outside human consciousness. The second is constructionism, ‘meaning is not discovered but constructed…by human beings as they engage with the world they are interpreting’ (Crotty 2012, pp. 42-43). Finally, there is subjectivism, which maintains that whilst meaning and reality are subjective to the person experiencing them, it does not come from the interaction between objects and subjects (Cresswell 2007; Bryman 2008).

4.3 Interpretivism

I have employed an interpretivist theoretical framework from the subjectivist epistemological standpoint. Interpretivism is concerned with understanding and interpreting the social world through culture and time, as opposed to positivism, which seeks to explain the natural scientific processes of the world (Crotty 2012; Bryman 2008; Bogdan and Biklen 1997). Interpretivism is generally linked to Max Weber (1864-1926), and the emphasis is on ‘Verstehen’ (the German word for ‘understanding’), and interpreting the world, rather than explaining it (Crotty 2003, p. 67). The interpretivist approach to human and social investigation can be linked to the methodological traditions of symbolic interactionism, phenomenology and hermeneutics (Smith et al. 2009; Bryman 2008). Interpretivist researchers apply their subjective understanding of social phenomena. The aim of this research is to understand the subjective experiences of black-African families as they seek to understand their child’s autism. Therefore, the interpretivist approach, which has already been applied to autism research by other scholars (Anthony 2009; Laird 2012; Doig 2012; Bishop 2012), is suitable for this type of study. According to Bryman (2008), double interpretation takes place within interpretivism. I have interpreted participants' accounts to provide a qualitative insight into their experiences about autism.

4.4 Methodology & Methods

Methodology is the process of analysing the assumptions, principles and procedures of an approach to a research investigation (Crotty 2012; Bryman 2008; Carter and Little 2007). It is 'the study, the description, the explanation, and the justification of methods, and not the methods themselves… ' (Carter and Little 2007, p. 1317). 'Method' is the 'action part' of a research project: the active, practical process, the tools and techniques of gathering evidence for research. The connection between epistemology, methodology and method in social research is that 'methodology justifies method, which produces data and analyses. Knowledge is created from [that] data and [its] analyses. Epistemology modifies methodology and justifies the knowledge produced' (Carter and Little 2007, p. 1317).

The primary purpose of using any research methodology is to provide a framework for answering research questions (Lobiondo-Wood and Haber 2006; Bryman 2012; Silverman 2010; Patton 2002). Given the qualitative nature of this research, it was carried out using qualitative methodology, which is concerned with interpreting text data (Patton 2002; Sarantakos 1994). Lobiondo-Wood and Haber (2006, p. 572) define qualitative studies 'as the study of human experience which is often conducted in natural environment, [using] data from text or words to describe the experiences that are being studied'. Qualitative researchers attempt to capture social realities from their participants; and interpret the meaning that the participants gave to their subjective realities (Sarantakos 1994; Patton 2002). Conversely, quantitative research converts data ‘into numerical symbols and statistical figures [which] results in loss of a perception of the objective nature of human behaviour’ (Sarantakos, 1994, p. 45). Both qualitative and quantitative methodologies have strengths and weaknesses, but each is designed to answer different questions in social research.

Qualitative study allowed my study participants the freedom of expression. They shared their views and experiences of raising a child with autism from the perspective of their subjective worldviews. The use of open-ended questions in my interviews helped me to elicit the feelings and emotions of my participants, which I translated into text. It provided the opportunity to apply social research scientific processes in the course of my data collection, analysis and interpretations.

The function of quantitative methodology is usually to ‘isolate causes and effects, measure and quantify phenomena…[for the purpose of] generalisation of findings…[and to] operationalise theoretical relations’ (Flick 2009, p. 13). Quantitative study by nature is usually deductive, objective and numerical, and researchers usually have little or no contact with participants. Quantitative methodology also has defining features (Sarantakos 1994; Bryman 2012; Patton 2002). Sarantakos (1994) points out that some of the features include generalisability, reliability, objectivity and detachment, and having less direct personal contact with participants. Nonetheless, given that my research questions are about experiences and meanings, it is appropriate to address them using qualitative methodology.

4.5 Justifying an IPA as the Preferred Methodology for this Research

The decision to employ an IPA method in my research was made when it became apparent that, in order to harvest the deeper meanings that my participants made about their autism-related experiences, and for a much deeper level of understanding, a double interpretation was necessary. Firstly, I attempted to understand my participants' experience of autism and what it meant to them. Secondly, I placed this within the contexts of extant literature, existing theories and wider social and cultural issues (Larkin et al. 2006), by providing a critical, conceptual account of a black African parent’s experience of having an autistic child in the UK. The approach allowed me to develop an insider's perspective, using ideographic principles to explore, understand and report the experiences, and meaning each participant attempted to make about the situation. Following the IPA analytical perspective, I developed patterns of meanings from my participants' accounts of their lived experiences and reported these. My research questions were not designed to investigate the nature of autism, but to investigate the autism experiences of my participants, and understand the sense they made about it.

Braun and Clarke (2006) recommend thematic analysis (TA) as a method for qualitative research. Like IPA, it is accessible, flexible and adaptable, offering tools applicable to other qualitative methods. However, the simplistic and flexible nature of TA means that it lacks clear usage guidelines (Braun and Clarke 2006; Larkin et al. 2009; Watts et al. 2009), making it unsuitable for a complex study such as this. Another reason why I did not use TA is that researchers who use the method tend to focus on themes, isolate them from their original source and context, and combine them with similar themes for analytical purposes. The resulting analysis and reporting is often descriptive (Watts et al. 2009; Braun and Clarke 2006). To reinforce this argument, Braun and Clarke (2006) report that with a TA ‘approach, the themes are identified within the explicit or surface meanings of the data, and the analyst is not looking for anything beyond what a participant has said or written (p. 84), [so any analysis done using a TA approach] has limited interpretative power beyond mere description’ (p. 97).

Given the distinctions between the TA and IPA methods, it was hard for me to endorse TA for this study. Also, recent research in this area has demonstrated the suitability of IPA for this type of study (Doig 2012; NAS 2014; Ponde and Rousseau 2012; Ravindran and Myers 2011). Neely-Barnes et al. (2011) and Gourdine et al. (2011) have also used qualitative research and IPA analysis for social work-related autism research. I employed IPA to explore the reasons behind the black-African parents’ thoughts, feelings and behaviours regarding the experience of bringing up an autistic child in the UK. I considered IPA to be the most appropriate method of analysis to illuminate the complex, personal problems that my participants faced, through a more individualised and collective analysis of their experiences. Finally, the IPA method is useful because it could assist efforts to discover a fresh perspective about a set of culturally oriented autism research questions.

4.6 The Background to Interpretative Phenomenological Analysis

According to Watson et al. (2008), the interpretive phenomenological process is implemented via the application of the hermeneutic circle, which entails moving back and forth between both the individual parts of the data, and the data as a whole. The hermeneutic circle is concerned with the active connection between the part and the whole of a discourse. Therefore, one needs to understand the individual parts of a discourse, and to understand the parts, one needs to understand the whole. For example, a word makes sense when considered in the context of a whole sentence, while the meaning of a whole sentence depends on the collective meaning of specific words in the sentence (Smith et al. 2009).

Utilising the hermeneutics circle, I was able to move back and forth through a range of different ways of thinking about my data (Pietkiewcz and Smith 2014; Wojnar and Swanson 2007). In the process, my understanding of the data evolved in accordance with the hermeneutic circle. Thus, my interpretation of the data took place in the context of my previous knowledge of the subject, but that knowledge evolved and modified due to my encounter with new texts (Smith et al 2009; Wojnar and Swanson 2007).

'IPA is concerned with examining how a phenomenon appears, and the analyst is implicated in facilitating and making sense of this appearance' (Smith et al. 2009, p. 28). This means that as an IPA researcher I could not separate myself from any presumptions about my participants' experiences. My knowledge both of autism and some African cultures gave me an insight into the sense-making of my participants, enabling me to understand their individual experiences of having and bringing up an autistic child in the UK.

I analysed my data using the 'IPA framework' (Pietkiewcz and Smith (2014, p. 11), which is time consuming. My main objective was to show how the participants made sense of having an autistic child, by alternating between 'emic and etic perspectives' (Pietkiewcz and Smith (2014, p. 11). An example of an emic perspective occurred when I asked one of the participants in my study, Kakooza (pseudonym), '*What name* *do they give to people with autism or disability in Africa*?' There was a brief moment of silence following the question before Kakooza said '*Malima*, which means lame people…'. The word *malima* was in Kakooza's local dialect (emic). In my analysis, I tried to make sense the meaning Kakooza attached to the word *malima*, or what *malima* culturally meant to her by illuminating understanding of the word through my interpretation (etic). The etic perspective enabled me to analyse the data, by interpreting my participants' feelings and thoughts, using appropriate theories and concepts. Applying the emic perspective, on the other hand, enabled me to evaluate their personal perspectives from an external standpoint.

In my data analysis, I extracted a verbatim quote from a participant to demonstrate his or her views, feelings and interpretation of a specific issue. I used explanatory comments to qualify the verbatim quotes. I then compiled the emergent themes and selected those most closely related to my research questions. I used direct quotes from the interviews to describe each theme, and provided my analysis, citing relevant extant literature.

4.7 Sampling Methods

I used purposive and snowballing sampling procedures for this qualitative study (Sarantakos 1994; Patton 2002; Silverman 2010; Gray 2014). Purposive sampling is a non-probability sampling procedure where respondents are selected because they are knowledgeable in the subject (Gray 2014); in this case having a child with autism, and being a member of a black-African immigrant family in the UK. The snowballing sampling technique is a non-probability sampling procedure where existing participants help with the selection of new recruits, through referral and recommendations (Lobiondo-Wood and Habber 2006; Gerrish et al. 2006). According to Gray (2014, p. 223), the snowballing sampling technique is particularly helpful in recruiting from the 'hidden population' and difficult-to-reach social groups.

The snowballing and purposive non-probability sampling techniques are suitable for this qualitative study for several reasons. For example, they enabled me to access a small number of participants, who are a relatively homogeneous group (in terms of their demography and identity categories) and share similar experiences of autism. These sampling methods are also suitable for research groups who are known to be hard to reach (Doig 2012), like the black-Africans in this study. The low visibility of this study population makes it difficult to recruit participants; therefore, the snowballing technique was particularly useful. However, it was also prone to sampling bias (Patton 2002; Sarantakos 1994). For example, participants are likely to recommend people within their social network and who are likely to share similar experiences.

4.8 Participants Characteristics and Selection Criteria

There were criteria that my study participants had to meet. Firstly, they had to be members of first-generation, black-African families with an autistic child and living in the UK. Secondly, the parent(s) of the autistic child must have been born in sub-Saharan Africa. It is not important that the child was born in the UK or abroad, but the child must have been formally diagnosed with autism in the UK. Ideally, the families should have another neurotypical child or young person, but a family with an only child with autism was not to be excluded. Thirdly, the autistic child must be aged 0-18 years of age and living at home with his or her family. Finally, he or she must be capable of communicating in English.

The purpose of using parents with good English language skills is to avoid the need for an interpreter. Since this qualitative study focuses upon the experiences of individuals, it is reasonable to interview only people who could directly respond verbally or in writing in English, and not via an interpreter. In the event, participants were able to verbally respond directly to my questions, so an interpreter was not required. Whilst recruiting only participants who can communicate in English risks excluding those who are unable to speak English, the aim of the study is to explore the views of those who have relevant experiences to share about autism. However, I did not come across any potential participant who could not speak or write in English.

4.9 The Demography of this participants

A total of 37 individuals took part in this study. They include 19 black-African mothers, 11 black-African fathers and 7 neurotypical siblings of the autistic child. Altogether, there were 20 black-African families, of which there were 7 single-parent families, and 13 married or coupled families. Smith et al. (2009) recommend 'small sample sizes' (p. 55) for an IPA study, but acknowledge that 'there is no right answer to the question of the small size' (p. 56). In other words, 'small sample size' is subjective. Nevertheless, several researchers using the IPA model have pushed boundaries about sample size. For example, Eatough and Smith (2005) used a single participant, while Reynolds and Prior (2003) used 35 participants. I increased the number of my participating families from 15 to 20 to mitigate for the high educational attainments of the original 15. In the process, I ended up with 37. Several previous studies, which used the IPA approach to investigate the experiences of families with autistic children and other groups, had surveyed relatively high numbers of participants. For example, Anthony (2009) used 30 participants, Uhrman (2013) 20 participants, and Peet (2015), who investigated the early onset of dementia, used 20 participants.

Each family had at least one autistic child, but one family within that group had three autistic children, whilst another had twin autistic children. The majority of participants live in South East London, whilst the remainder live in other parts of the UK. In terms of their respective countries of origin, Nigerian families are by far the largest group represented, with ten families. Of the remainder, two families were from Ghana, and one each from Somalia, Congo (People's Democratic Republic of Congo), Zimbabwe, Cameroon, Gambia, Kenya, and Liberia. There are 20 parents with graduate/postgraduate degrees and 10 non-graduate parents in the sample. The high number of graduate/postgraduate participants reflects the pattern of educational attainment for people from sub-Saharan Africa, living in the UK. See Chapter 3, Appendix 1 and Table 1 for more details about my participants' demography.

Table 1: Demographical Composition of Participants

20 Families	**Family Pseudonyms**	**Country of Origin**	**Immigration & Residency Statuses**	**Years in the UK**	**Marital & Habitation Statuses**	**Autistic child's age**	**Educational attainments**	**Religious & Spiritual classification**
1 2	Mr Egal Mrs Egal	Somali Somali	Undocumented Undocumented	5 5	Married Cohabitants	8yrs	Non-graduates	Both Muslims and **Strongest**
3 4	Mr Adisa Mrs Adisa	Nigerians Nigerian	Settled, British Settled, British	29 20	Not married Cohabitants	6yrs Twin	Graduate Graduate	Muslim **strong** Catholic **strong**
5	Mrs Okeke 1 (sibling Okeke)	Nigerian	Temporary residency	13	Married, Husband: Part UK&Nigeria	5yrs	Graduate	Christian, **Stronger**
6	Ms Mulumba 2 (sib. Mulumba)	Congolese	Temporary residency	10	Single mother	15yrs	Non- graduate	Christian, **Stronger**
7	Mrs Okoye	Nigerian	Settled, German	3	Married, cohabitants	12	Graduate	Christian, **Strongest**
8 9	Mrs Matonga Mr Matonga	Zimbabwe Zimbabwe	Temporary Temporary	10 10	Married Cohabitants	16	Non-graduates	Both Christians, and **stronger**
10	Ms Kakooza	Ugandan	Settled, British	18	Single mother	18	Graduate	Christian

20 **Families**	**Family** **Pseudonyms**	**Country of** **Origin**	**Immigration & Residency Statuses**	**Years** **in the UK**	**Marital & Habitation Statuses**	**Autistic child's age**	**Educational attainments**	**Religious & Spiritual classification**
								Strongest
11	Mrs Dibango	Cameroon	Settled, British	18	Divorced	16, 16 14	Post graduate	Christian **Strongest**
12	Ms Kama	Gambian	Settled, British	14	Single mother	7	Graduate	Christian, **strong**
13 14	Mr Yeboah Mrs Yeboah	Ghanaian Ghanaian	Settled, British Settled, British	20 22	Married, cohabitants	13	Graduate Graduate	Christians **Stronger**
15	Ms Dimka 3 (sibling Dimka)	Nigerian	Undocumented	1.5	Divorced	10	Post graduate	Christian, **Stronger**
16 17	Mr Kimani Mrs Kimani	Kenyan Kenyan	Temporary Temporary	5 5	Married, cohabitants	11	Non-graduates	Christians **Stronger**
18 19	Mr Akinloye Mrs Akinloye	Nigerian Nigerian	Undocumented Undocumented	7 9	Married, Husband: UK & Nigeria based	6	Graduate Non-graduate	Both Muslims and both **Stronger**
20	Mr Ibori	Nigerian	Settled, British	27	Married, cohabitants	14	Post graduate	Christians

20 Families	Family Pseudonyms	Country of Origin	Immigration & Residency Statuses	Years in the UK	Marital & Habitation Statuses	Autistic child's age	Educational attainments	Religious & Spiritual classification
	4 (sibling Ibori)							**Strongest**
21	Mr Kromah	Liberian	Temporary	6	Married, cohabitants	12	Non-graduates	Christians
22	Mrs Kromah	Liberian	Temporary	6				**Strong**
	5 (sib. Kromah)							
23	Mrs Bankole	Nigerian	Temporary	9	Married, cohabitants		Graduate	Both Christians
24	Mr Bankole	Nigerian	Temporary	9		7	Graduate	**stronger** (W) **Strongest (H)**
25	Mr Achebe	Nigerian	Settled, British	18	Married,	18	Post graduates	Christians
26	Mrs Achebe	Nigerian			Husband: UK & Nigeria based			**Stronger**
	6 (sib. Achebe)							
27	Mr Aguda	Nigerian	Temporary	12	Married, cohabitants	6	Post graduates	Christians
28	Mrs Aguda	Nigerian	Temporary	10				**Strongest**
29	Ms Mensah	Ghanaian	Settled, Leave to Remain.	10	Single mother	16	Graduate	Christian
	7 (sib. Mensah)							**Strong**

20 Families	Family Pseudonyms	Country of Origin	Immigration & Residency Statuses	Years in the UK	Marital & Habitation Statuses	Autistic child's age	Educational attainments	Religious & Spiritual classification
30	Mrs Diya	Nigerian	Undocumented	11	Married, Husband: UK &Nigeria based	6	Graduate	Christian **Strongest**

4.10 The Participant Recruitment Process for this Research

I started my recruitment drive following ethical approval from the University of Kent social research ethics committee (Appendix 5) and permission from the Association of Directors of Children’s Services (Appendix 6). The cohort was selected from African families, living in the West Midlands, and the cities of London, Manchester, Cardiff and Edinburgh. Using the snowballing and referral techniques, I went where the recruitment drive took me. Since there did not appear to be a single database for black-African families with autistic children, I sought access to them from local authority social services such as Lewisham, Greenwich, Lambeth, Southwark, Bexley, Croydon and Bromley. I also approached special needs schools, and with permission from school heads, and parents at the school gate, I handed out leaflets containing information about my study, and invited them to participate (See Appendix 2). I also contacted relevant organisations for families of children with autism such as the National Autistic Society (NAS), and my former work and student colleagues for referral. I requested referrals from families and friends, and I used social media networks such as Facebook and WhatsApp as part of my recruitment tools, until I found my 20 participant families. It has been widely reported that BME people are hard to recruit for research participation, and I had faced some challenges in my recruitment drive. The most useful strategy was referral by word of mouth from parents who introduced me to other parents of autistic children. Although I gave out many recruitment flyers, only a few people showed interest by either writing their telephone number on the back of the flyer and handing it back or returning it on another day. The first set of participants, 15 families, were recruited between November 2014 and March/April 2015; while an additional set of 5 families were recruited between May/June and August 2015. When a potential participant gave me their telephone number, I called them to book an appointment, sent a letter of introduction (Appendix 3) and enclosed a consent form and information sheets for families (Appendix 4). Following the letter, I contacted interested families by telephone and explained the rationale for the study, its aims and their role in the data gathering process.

The participants who wished to take part agreed for me to meet them at home at a set time and date. All the interviews took place at the homes of the participants. On the day of interview, I gave them further information, and answered any questions they had about the study, and about myself as a researcher. I collected signed consent forms from those who were happy to take part.

Whilst I had considered running a pilot study to test my research tools, this was not possible, due to the time needed for recruitment and selection of participants.

4.11 The Data Collection Methods

I had considered several qualitative data collection methods such as focus group interviews, ‘the people’s story’ (Flick 2009, p. 147), ‘vignette interview’ (Bryman 2008, p. 79), video recording parent-child interactions (Gray 2014), and a ‘joint narrative’ (Flick 2009, p. 147), where a whole family would tell their story about their collective experiences in a group discussion. However, I opted for a family group interview where possible, and a one to one interview with each family member. I usually started with the group interview, where father, mother and sibling were present. There were only three families where all of these individuals were present at the same time, but in all cases, mothers were the main respondents. After the group interview, I interviewed family members separately. In families where a mother, a father and a sibling were available, when interviewing one member of the family, the other was either in another room in the property or had gone out to allow the interviewee the freedom of expression. In some cases, I had to go back on a different date to meet a participant, usually the father. At least one parent was present during interviews with all the siblings.

Authors such as Silverman (2010) argue that the one-to-one interview data collection method takes more time than group discussion, and that in a group discussion, a member gains strength from others in the group. In my study, I found that there were merits in the one to one interview method because of the freedom of expression, and drawbacks associated with the group interview method, because mothers had dominated the discussion. But the combination of approaches compensated for one another, and enabled me to gather some rich data about views, beliefs, attitudes and experiences about living with an autistic child in the UK. An interview with each family had lasted between one to two and half hours, subject to how many people were interviewed and the openness and expressiveness of interviewees.

The children with autism were not interviewed for this study for various reasons, (a) it was not relevant to my research questions, (b) most of the interviews took place during school hours, when parents felt they were free, (c) in some cases, where the children were present, the majority were too young to understand the discussion, or they were nonverbal, (d) there were only two families where the children were verbal, but one of the parents did not wish to give the child the ‘liberty’ (as he put it) to talk to me, and the other child was unable to articulate his views.

4.12 Research Instruments

The problem statement and the purpose of the research, as well as the methods of data collection, guided my choice of design and data collection instruments for this study (Dempsey and Dempsey 2000; Patton 2002). Punch (2000) indicates that the most important ‘instrument’ in any research project is the researcher. Punch points out that the researcher must understand the research process and have an interest in the research topic in order to deliver a successful research project. Therefore, the research instruments that I used for this project included myself, and the interview guide/schedule (Appendix 7). Other instruments were a digital tape recorder and a note pad. The tape recorder was used to record conversations to ensure accuracy. The recorded conversation gave me the chance to play the voice data repeatedly and transcribe audio conversation without missing relevant words (Gray 2014; Bryman 2009). The tape recorder was also useful for ‘repeated listening to recordings which often reveals previously unnoticed reoccurring features’ (Silverman 2000, p. 150).

4.13 Ethical Considerations

As a social work professional, the social work ethical principles of upholding human rights, promoting social justice and observing professional integrity underpins my practice guidance (British Association of Social Workers 2014). It also informs my ethical responsibilities toward my research subjects. This section considers the ethical implications of my research, and explains how I attempted to mitigate some ethical issues that arose during the course of my fieldwork.

4.13.1 The Social Work Research Code of Ethics

This research is embedded in the discipline of social work (Butler 2002). Therefore, I abide by the social work research ethical codes, in particular, and the wider ethical guidelines for research with human subjects (Butler 2002; The Nuremberg Code 1949; Declaration of

Helsinki 1975, cited in Shephard 1976). For example, Butler (2002) proposes 15 ethical codes for social workers to consider when carrying out social work research. The Nuremberg Code (1949) calls for human subjects in research activities to have the legal capacity and free will to give voluntary consent without coercion, force, fraud or deceit. Similarly, the Declaration of Helsinki (1975) emphasised the need for researchers to have respect for human dignity and protect the rights of human subjects (Dempsey and Dempsey 2000; World Medical Association 2000; Shepard 1976). At the centre are the four ethical principles of beneficence, non-maleficence, autonomy and justice (Beauchamp and Childress 1989). Autonomy relates to the researcher's moral duty to respect the self-determination of individual participants. Justice is the moral obligation for equality, equity and honesty. Beneficence and non-maleficence are acts of doing more good than harm, and prioritising the welfare of research participants by ensuring that benefits and rewards outweigh cost and risk (Butler 2002; Beuchamp and Childress 1989; Flick 2009). Some statutory English laws such as the Human Rights Act 1998, and the Data Protection Act 1998 (The National Archives 1998; The National Archives 1998), both reinforce the need to respect the rights of human subjects in a research study.

4.13.2 Consent, Confidentiality and Anonymity

Following the principles outlined in 4.13.1, I obtained written informed consent from participants before embarking on my study. Issues of informed consent raise ethical concerns, especially for people considered to lack capacity, such as children and adults with autism, because they may be unaware of the implications of formal agreement to participate in a research study. Lowe (2006) note that, if a subject is unaware of the true nature of research, but willingly gives his or her consent to participate, it is not necessarily informed consent. This is partly the reason why I did not interview children with autism. The neurotypically developing siblings I interviewed were between 8 years to 18 years of age. The wording of their questions was simplified, and they were able to articulate their views. Their parents were also present when the interview took place. I underwent an Enhanced Disclosure and Barring Check, due to my professional status as a social worker with children and vulnerable adults, and was certified approved. I ensured that all participants' rights were protected in my research. For example, by using parents and children from the same family, any issue about consent was resolved because a parent has the power to make decisions for their children (Gov.UK 2018). However, I remain aware of my moral and ethical responsibilities toward any children involved in my research.

Every participant was informed that their participation was voluntary, but was also advised of their right to withdraw whenever they wished, and that their withdrawal would not affect them, nor compromise any services they were receiving from their respective local authorities or voluntary agencies. (Some of those who had initially expressed interest subsequently withdrew from the process). In addition, they were reassured of their anonymity by concealing their identity (a pseudonym was used to identify each participant) and a guarantee that their personal details would not appear in the final report. All raw data from this research will be stored safely for 15 years and destroyed thereafter (Waterson, 2011). The purpose of storing the data for that length of time is to allow for any academic challenge (Waterson 2011). I received ethical approval from the University of Kent Social Research Ethics Committee, and followed their stipulated guidelines. In addition, I had applied to schools, children's services and voluntary agencies, for permission to contact potential participants, before approaching them directly.

4.13.3 Recognizing Potential Ethical Issues about this Cohort

With reference to Butler's (2002, pp. 245-247) 'code of ethics for social work and social care research', I considered relevant ethical issues throughout the course of this research. I outline here how I attempted to mitigate any impact arising from my data collection activities. For example, due to the potential political issues some of these cohorts may experience, such as racial, cultural and language discrimination and oppression, and immigration issues, I was sensitive when asking questions about these areas. Some ethical issues encountered included the following:

- Some family members were clearly upset and distressed during interview. When some of them reflected on their deeply felt experiences, they became emotional. More than half of the 19 mothers I interviewed wept, and one or two fathers were visibly tearful. To address such emotional upset, I suspended the interview, paused the recorder, and waited for them to regain their composure. I would ask them if they were willing to resume the interview or to stop. They all expressed the wish to continue. Although they became upset, the interview experience was not necessarily negative to them. Overall, they were keen and relieved to share their experiences with me.
- I used a demography questionnaire to collect relevant sensitive information, such as immigration status, that a participant might find hard to disclose directly to me at the interview.
- The neurotypically developing siblings of the child with autism could have held some deep negative feelings about their family dynamic and other experiences

before and during the interview. If such a situation had arisen, I would have suspended the interview, but no such issue arose.

- Some of the children with autism had displayed some challenging behaviours at the time of interview. In at least four families, the autistic children had disrupted the interview, and needed attention or distraction from their parents. For example, some autistic children showed interest in my voice-recording device and wanted to play with it. They became upset when they could not have it. One child had snatched the device from the table and thrown it across the room, and another had damaged his own device in anger. One child started attacking his mother physically, including pulling her hair, hitting and throwing objects at her. His father had to take him out to their local park for a while as a distraction and to calm him down. When they returned the child was calmer, but continued to seek my device, hitting his mother occasionally. One child had locked himself in the bathroom, and I had to assist his mother to get him out safely. On each occasion, I suspended interviewing until the situation was under control. Again, I gave the parents the choice of stopping the interview, but each of them chose to continue on each occasion. I must clarify that my presence had not necessarily caused the children to be distressed. This is part of their daily experience of living with their autistic children.
- I explained my choice of career to each family in order to reassure them that I did not have any hidden intention. The purpose of the research was explained to each family before starting. I always wore my University of Kent identity card during any visit.

- For the avoidance of doubt about my intentions and the outcome of the interview, I reassured them that taking part in my study would not have any bearing on the services they received, or on any other part of their lives.
- For those families who expressed concerns about their anonymity, I reassured them that they would not be identified from the information they provided. To ensure anonymity of the families, I used a pseudonym to identify each family. See Appendix One for demographic details of participants with pseudonyms.
- I offered each family a £20 gift voucher for the child with autism, as a gesture of appreciation for their time. I gave out the gift vouchers at the end of each interview, but at least one family declined the voucher.
- Two parents in two separate families told me that they disliked social workers generally because of past negative experiences, but they were happy to engage with me.

4.14 Data Analysis

A qualitative research data analysis is a process underpinned by subjectivity, because most of the analysis is informed by the participant's experiences and the researcher's description and interpretation of them (Dempsey and Dempsey 2000; Lowe 2006). Therefore, the data for my study were gathered through verbal interviews and was analysed. Data analysis is the systematic processing of raw data to identify and extract common patterns from it in order to understand the responses and to evaluate them for the purpose of answering research questions (Reid 1993; Bell 2005). Combinations of words and phrases were selected from the interview transcripts and coded in order to identify significant relevant themes and categories for analysis. This process enabled me to conceptualise trends for use in answering my research questions. It also helped with understanding the experiences of the black-African families with an autistic child who took part in my study.

Following the interviews, the recorded conversations were transcribed verbatim. I had played the tape over and again to ensure that the exact words from conversations were transcribed fully. Silverman (2000) argues that phenomena recorded at interview are better understood in conjunction with a detailed transcription of the participant's account of the events. I found the transcription challenging and time consuming.

4.15 Codes and Coding Activities

Qualitative analysis is a process of optimising research data by applying codes, while preserving the meaning. A code is a word, a phrase or a sentence chosen to define specific parts of a data set (Saldana 2013). In phenomenological research, the coding process involves labelling and sorting the data based on the internal relationships within it, synthesising it by piecing the labels together, categorising the data and establishing themes that help us to understand the phenomenon in question. According to Saldana (2013, p. 14), 'a theme is an outcome of coding, categorisation or analytic reflection'.

4.15.1 The Description of the Process of Coding

After transcribing my audio data into text, I used Microsoft Word (MS Word), using the 'new comments' tool, found in the MS Word 'review' menu, to write my codes. I used the 'macro' tool located within the 'developer' menu to extract the codes and transferred them into separate MS Word documents from the original transcripts. In the separate MS Word documents, I attempted to sort and categorise the codes and to regroup the data to form themes or categories, but it became problematic (Chambers 2017; Peach 2014). I stopped using MS Word and reverted to a manual coding process, which I describe later in this section.

Following the advice of my supervisors, I listened to the audio recordings multiple times, before and after transcription. I also read and re-read the transcripts multiple times before and after the anaylsis. These processes helped me immerse myself in the data, recall some details of the interview and the environment. I also reflected on my interview experiences, and made notes of relevant recollections.

At the earlier stage of reflection, I made some notes as I read the data, which helped with my interpretation, while ensuring that any interpretation was grounded in the original data. An example of this can be found in the quotes relating to Kakooza touching her skin (see page 234 of this thesis). Having annotated the 350-page transcripts, I applied the hermeneutic circle approach of interpreting parts in relation to the whole and interpreting the whole in relation to its parts (Pietkiewicz and Smith 2014). In practice, I created codes from the raw data, discarded many, and combined relevant ones to form categories, and combined some related but relevant categories to form themes, which showed some emerging patterns. The themes helped to succinctly interpret the data, summarised my findings, answered my research questions, and illuminated our understanding of the research topic.

On the first level of my qualitative data analysis, I created over a thousand codes (see appendix 8: Table of Codes), which are words/labels closest in meaning to a section of the data. On the second level, I merged similar codes to form 51 categories which gives a broader sense of the data; and categories with similar characteristics were grouped to form themes, the third level in the process. My coding activities involved me reading the transcripts multiple times, absorbing what I had just read, and devising suitable labels that I felt best described the participants’ account of their experiences as they expressed them. I paid particular attention to the participants' comments, the words and phrases they used, local dialects, metaphors, symbols, body languages, emotional responses/expressions, repetitions, hesitations, pauses, and some observed introspection, in accordance with an ‘emic’ perspective (Pietkiewicz and Smith 2014, p. 11). I also observed how some comments made by some participants could be linked to my reflexivity, my personal characteristics as a black-African male, and how my identity helped to shape the good rapport I had with my participants.

I then used the traditional method of pen/pencil, paper, highlighter and razor to code the transcript manually. I wrote the codes on the righthand margin and the anchor codes or categories on the left-hand side of the transcript documents’ margins. Further, I had cut into strips the direct quotes along with the annotated codes and anchor codes from the transcripts. I then sorted and compiled similar quotes from various respondents in accordance with related themes and categories and slotted each compilation into an envelope I labeled with respective themes and the research questions intended to answer. I created a Microsoft word document table where I recorded all the codes, categories and themes I had generated from the interview transcripts, ready for analysis. I used direct quotes from the interviews to describe and exemplify each theme. This is followed by my analytical comments which are linked to concepts, theories and references to relevant extant literature, in accordance with an ‘etic’ perspective (Pietkiewicz and Smith 2014, p. 11).

Using direct quotes from the interviewees played two roles: it added credibility to the interpretation and retained the voice of the interviewees, validating the emic perspective. The aim was that the findings included the participants’ account of their experiences in their own words (emic) and my commentary and interpretation of their accounts (etic).

For a rigorous and systematic analysis, I was careful to evaluate the findings through the lens of my participants, and refrained from imposing my own preconceived ideas. However, as an inexperienced researcher this was a challenge.

4.16 Design and Methodological Limitations

The designs I used for this study has some inherent limitations. For instance, the use of ‘black’ as a category meant that African families with autistic children from North Africa for example were excluded from this research. But this is a study about the experiences of black-African families of children with autism in the UK, so participants had to match that criteria. (See section 9.6 for more details about limitations). But to mitigate for any inherent limitations, I had often discussed any challenges I encountered with my supervisors for advice and guidance.

4.17 Researcher’s Reflexivity

It is important to acknowledge how my own intersectional identities, and the thoughts and feelings I have had about the topic, have shaped my approach to this study. As a black-African, and as a researcher, I accept that I might not be neutral, because I am a social being with history and experiences. Some of my biases could have informed my decisions about the design and methodology, data collection, coding and analysis, and data interpretation. I do not have a child with autism but, in my various social work roles, I have spent periods working with African families with an autistic child. It was whilst working with some African families with autistic children in London that I developed my interest in researching their experiences. Willig (2008) states that 'reflexivity requires an awareness of the researcher's contribution to the construction of meanings throughout the research process as well as an acknowledgement that one cannot remain 'outside of one's subject matter when conducting the research' (p. 32).

Some writers opine that qualitative research inevitably involves the subjective interpretations of researchers who have their own opinions about the subject matter (Lincoln and Guba 2000; Doig 2012; Willig 2008; Freuler 2013). Lincoln and Guba (2000, p. 183) claim that maintaining reflexivity throughout the research is vital to ensure that the researcher appreciates that he or she has 'multiple identities that represent the fluid self in the research process'.

Therefore, reflexivity allowed me to reflect on my past and present experiences, my personal biases, my strengths and weaknesses as a human being, and my worldview that could potentially affect my perceptions of the experiences shared by my participants.

Whilst I remain aware of my role as a researcher, I found that my cultural background and my profession as a social worker helped me to investigate this group of participants. I believe that I formed a connection with them, which encouraged most participants to share their experiences without reservation.

Being reflexive made me aware of my own assumptions and potential biases, but I ensured that they did not compromise my role in gathering and analysing the knowledge gained during the research process. My reflective activities helped me to avoid being overtly influenced by my personal and professional experiences.

In the next four chapters, I present some findings from the research process.

Findings Chapters

Introduction and Context to Chapters 5 - 8

In this section, I attempt to justify why I analysed the data in the finding chapters, (five to eight) alongside previous literature and show how it aligns with the principles of reporting IPA data. I also justify the inclusion of comparative analysis by drawing on published IPA research to explain how this approach is consistent with IPA. Finally, I will attempt to explain how I selected the quotes I used on chapter five to chapter eight. Chapter five, titled 'the multiple intersecting layers of identities and the struggle for autism services' reports finding about the experiences of the undocumented, the temporary and the permanent resident migrants in my study. In chapter six, 'the multiple, intersecting layers of stigma and rejection for black-African families of autistic children' I discuss the stigma and rejection experienced by parents and siblings both in the UK and in their home countries. Chapter seven, 'the intersectionality of Africanness and autism in raising an autistic child in diaspora' discuses some of the cultural implications of having an autistic child and how the participants made sense of it, from their cultural perspectives. Finally, in chapter eight, 'coping with autism using religion and spirituality', I show how the participants attempt to make sense of their experiences from their religious paradigm and how they drew on their religion and spirituality as a coping mechanism.

i) Justifying the Approach to Reporting Data Alongside Previous Literature in an IPA Research

In their IPA study of couples who went through human fertility treatment, Phillips et al. (2014) had discussed their findings along extant literature within their data analysis and reporting of the four themes that make up their findings. For example, on page (535) of their paper, immediately after the direct quote from one of the participants, referring to existing literature they wrote: ‘existing literature assumes that biological parenthood has overwhelming importance for couples pursuing fertility treatment’. Similar approach is located on pages 537, 538 and 539 of their paper, prior to the discussion section. Smith et al. (1999, p.227), who is credited with the creation of IPA methodology, says ‘sometimes the themes are presented together in one analysis section while a separate section is devoted to exploring their implications in relation to the existing literature. In other case each theme is taken in turns and linked to the existing work at the same time’. In other words, according to Smith et al. (1999) researchers are free to simultaneously analyse their themes with extant literature or choose to analyse them separately. This is also in keeping with the creativity, flexibility and adaptability of IPA research. With this approach, it is easier for readers to appreciate the findings of the research (e.g. whether it converges with or diverges from previous findings) in context of the extant literature.

ii) Justifying the Inclusion of Comparative Analysis in an IPA Research

Consistent with the idea of creativity and flexibility in the application of the IPA methodology, Lamb and Cogan (2016) combined focused group, IPA and comparative analysis in their research investigating work-related stressors and resilience among mental health workers in the NHS and the private/voluntary sectors. They concede that using focus group interviews is ‘still a relatively novel approach’ (p.476) and that adopting a comparative approach in an IPA study is ‘unusual’ but is doable (p.477). They add that IPA studies usually use one-on-one interview method with multiple people from a homogenous group to investigate shared experiences. However, they argue that the idea of comparing data which is gathered from different groups of workers who have similar career but work in different settings is not against the principles of IPA methodology either. To further justify their approach, Lamb and Cogan (2016) state that ‘adding a comparative component to a methodology using IPA provides an additional dimension’ to the processes of attempting to make sense of the experiences of others using ‘interpretative framework’ (p.477). In their analytical process, therefore, Lamb and Cogan (2016) identified variations between the two groups of participants.

Wagstaff et al. (2014) investigated the experiences of using IPA by eight scholars in diverse disciplines from different countries; in order to find out their perspectives about the strengths, weaknesses and gaps of using IPA. They found that some of the common weaknesses include the tension between the adaptation of ideography perspective in IPA and the principles of generating themes to represent the experiences of all; and the use of general themes which obscure the divergence and nuances in data. Taking a critical stance about the usual IPA methodological process, Wagstaff et al. (2014) argue that:

> While IPA allows for variation within a theme, the emphasis on commonality of experience seemed inconsistent with the idiographic thrust of IPA and led Nolan [one of the IPA researchers interviewed for the paper] to believe that fundamental individual differences were being obscured by the focus on common experiences. These stories left behind while pursuing what was deemed by the researcher and supervisor to be a ‘correct’ approach were considered a valuable loss (Wagstaff et al. 2014, p. 6).

In other words, why focus on common findings which generally supports a strict IPA process, and forego relevant experiences which enrich the findings, rather than weakens it, just because it does not strictly conform with the IPA methodological framework. Nolan criticizes the IPA culture of finding common themes. In her view, such practice moves away from the nuances and specifics within the data, which is sacrificed in an attempt to generate common themes. Some of the specific words and phrases used by specific participants is lost in the process of trying to 'herd' these words into broader categories (Wagstaff et al. 2014 p. 6).

Similarly, Phillips et al. (2013 and 2014), moved away slightly from the conventional approach of generating general themes in their IPA study of couples who were undergoing an In Vitro Fertilization (IVF) treatment by introducing ‘divergence and convergence’ (Phillips et al. 2013, p. 534). For example, Phillips et al. report that in addition to interviewing couples together, ‘individual interviews were employed because we wished to obtain independent accounts of each couple’s coping strategy selection’ (Phillips et al. 2014, p. 3). Hence, the interviews generated ‘contradictory extracts…showing variability of experiences’ (Phillips et al 2014, p. 3) from the same phenomenon/problem. In accordance with idiographic process they analyzed each interview separately and in detail. They found out that each spouse's account of the same problem was experienced slightly differently (Phillips et al. 2013 and 2014). If they had insisted on reporting common experiences, the nuances would have been lost (Wagstaff et al. 2014).

Just like Phillips et al. (2013 and 2014), I had interviewed couples together and separately and found some convergence and divergence in the data, hence I reported them separately in order to reflect the variation in experiences. In following with Lamb and Cogan (2016) I have also used comparative analysis in my IPA study, and this approach is line with the flexibility and creative application of IPA methodology which several IPA researchers (Wagstaff et al 2014; Pietkiewicz and Smith 2014; Spiers et al 2016; Lamb and Cogan 2016; Phillips et al. 2013 and 2014) advocate for. By adopting comparative analysis, I have revealed nuanced reflections that would have otherwise been lost should the analysis be limited to a strict IPA framework.

iii) Justifying the Allocation Participants into Subgroups in an IPA Research

Conceivably, applying subgroups is a novelty in an IPA research, as no known extant paper has done so yet, but I made the conscious decision to use it in this study for several reasons. The idea came about during data analysis and interpretation, and while I was applying the hermeneutic circle and attempting to make sense of my participants trying to make sense of their world of autism. According to Tuffour (2017, p.3), ‘hermeneutics…is the art and science of interpretation or meaning. Meaning…is deemed as something fluid that is continuously open to new insight, revision, interpretation, and reinterpretation’. In the context of my study, the ‘new insight’ and ‘reinterpretation’, for example, comes by way of segmentation, because I believe it offers another way of connecting parts (individual’s experiences) to a particular cluster of participants’ experiences (subgroups) and the study group as a whole. In a hermeneutic circle ‘to understand any given part, you look to the whole, to understand the whole, you look to the part’ (Smith et al. 2009, p.28); which could mean looking into the individual, a subgroup and the whole study group’s experiences. For example, I believe the story of an individual participant makes more sense when clustered together with those who have similar distinctive experiences; to form subgroups and to link them to the collective autism experiences of all the participants in the study. Earlier in this thesis, Carbado et al. (2013) allude to the possibility that one homogenous group could have internal social identity differences, which they describe as ‘intra-intersectional[ity]’ (p. 9). In other words, subgroups can exist within a homogenous group.

In chapter two of this thesis, Brubaker (2002) and Maleševic (2011) respectively caution against treating sub/groups as a real or tangible thing, or as a compartmentalised social unit, to avoid creating the impression that it is an entirely homogenous entity with boundaries. Instead, they advise treating sub/groups as a constructed discursive framework for operational and analytical purposes (see chapter 2). I employed subgroup for this purpose and for more in-depth interpretations, whereby some obscured parts of the multiple layers of autism experiences of my participants were exposed.

Although my study participants were all black-African families with an autistic child, it does not mean that they were an entirely homogenous group. This was evident when I dived deeper into the data and realised that clusters of them shared some nuanced experiences due to some distinctive or additional intersectional identities (the undocumented/temporary/settled residency migrants; strong/stronger/strongest religious subgroups, and others). So, as part of telling their stories, it made sense to focus attention on individual experiences, as part of ideographical processes, identify some convergences and divergences, and at the same time dissecting the participants into subgroups as part of underscoring the various layers of their autism experiences.

Therefore, I believe that using subgroups in this IPA study, which appears to be the first, meets some IPA methodological principles, some theoretical and conceptual underpinnings of this study, contributes to answering my research questions and responds to the overarching aims of this study. As a ‘forward-looking research methodology’ (Tuffour 2017, p.4), IPA gave me a new way of analysis, which complies with the guidance provided by several IPA researchers (Wagstaff et al. 2014; Pietkiewicz and Smith 2014; Spiers et al. 2016); who advise IPA researchers not to restrict themselves to the standard processes of doing an IPA study, but to be creative and innovative. Hence, subgrouping is consistent with this advice and it adds to the depth and the richness of the findings of this study, which are supported with direct quotes.

The quotes presented in the thesis were carefully chosen because they provided some of the most powerful, insightful and thought-provoking account of the experiences that resonates with most of the participants in the study.

The selection of quotes was guided by the need to answer the research questions (Brocki and Wearden 2006). To this end, I used the transcription and coding processes to identify the quotes that meet this objective. According to (Brocki and Wearden 2006, p. 95), ‘…In IPA the aim is to select [quotes] in order to illuminate a particular research question, and to develop a full and interesting interpretation of the data’. I meticulously searched through the data for illuminating, value-based and thought-provoking comments and coded them. I grouped all the similar codes to form a category, and similar categories to form a theme. So, once I have decided to use a theme or a category to explain a phenomenon or to answer part of my research questions, I go back to the transcript (which I had already marked) that has the comment, which best illustrates and illuminates the idea or argument I was trying to describe and copy and paste the verbatim comment as a quote on the thesis. It was important that the comment I was quoting was closely linked to the idea I was trying to describe and interpret. Brocki and Wearden (2006) caution that ‘IP researcher should take particular care [when selecting their] lists of themes to ensure that each theme is actually represented in the transcripts’ (p. 97). In some instances, I found that several quotes were relevant for a specific idea/analysis. But when this happened, I weigh up the various comments and choose the one that best tells the story and conveys a meaning of a situation which resonate with other participants and consistent with ideographical principles of IPA.

Chapter Five

The Multiple Intersecting Layers of Identities and the Struggle for Autism Services.

5.1 Introduction

The concept of multiple intersecting layers of identities is reflected by the experiences of participants in my study who simultaneously identified as blacks, Africans, immigrants, having an autism identity by association, and living in the UK. The purpose of this chapter is to explore whether these participants experienced additional challenges in attempting to access autism-related services, as a result of their multiple identities. Central to the concept of the multiple layers of identities in this chapter are race, gender, ethnicity, nationality and immigration. For the purpose of analysis, I will focus on the intersectionality of racial and immigration identities, and their interaction with autism identity by association. This is because the challenges faced by the majority of the participants are linked directly/indirectly to their immigration experience and, to some extent, their perception of discrimination, depending upon their racial or ethnic identity.

20 families participated in this study. 55% (11 families) were subject to immigration control, at the time of interview. This group includes undocumented migrants, temporary residents, those subject to No Recourse to Public Funds (NRPF), and those with settled residency status. NRPF is a visa category which permits the holder to live and work in the UK legally, without entitlement to state funded welfare or economic benefits (Anitha 2010). 45% (9 families) of the participants were not subject to UK immigration control at the time of interview, but the version of the UK

immigration rules in force when they entered the UK would have applied to them as African immigrants. These included those who have settled status or indefinite leave to remain in the UK, either as British or other European citizens, and were therefore not subject to any immigration restrictions or obligations. Furthermore, 50% (10) of the autistic children in the research group were born in Africa before they were brought to the UK by their parents. 45% (9) of them were born in the UK. One child was born in Germany before his family migrated to the UK. This composition does not necessarily mean that all 9 of the UK-born autistic children were from families with settled status, or that all the African-born children were from families with temporary residency status. As the composition of the group is mixed, this cannot be regarded as a consequence of participants' social class. (See chapter three of this thesis for more detail).

The various immigration policies in the UK have inadvertently created categories of immigrants among my participants. For analytical purposes, I have categorised the participants into three subgroups of African migrants: (a) those with settled residency status, (b) those with temporary residency and with restrictions, and (c) those deemed as undocumented migrants, which means that they are living in the UK illegally. I will argue that the participants with settled residency status have a better overall experience compared to their peers in the other two subgroups. They are more likely to report that any challenges they faced in accessing to services was as a result of racial discrimination, and are more likely to be assertive in their demand for such services. But the undocumented and temporary residency participants faced additional challenges (economic hardship, uncertainty, confusion, complicated immigration policies, anxiety, and fear) to those likely to be faced by members of the settled residency subgroup, and are less likely to fight as hard for services for fear of deportation back to Africa.

In order to explore the challenges that these families experienced in the process of attempting to access services, this chapter is divided into four main categories: (a) the experiences of undocumented African migrant families of autistic children in UK, (b) the experiences of African migrant families of autistic children in UK with temporary residency, and (c) the challenges faced by African families of autistic children when accessing autism services in the UK. As the settled residency families did not report any immigration-related challenges, I did not include them in that section of the findings. But members of the three categories faced various challenges in the course of accessing autism services. I will conclude that on the whole, these participants experienced multiple layers of challenges, as a result of the intersection of their multiple identities as immigrants, blacks, Africans and their association with autism, regardless of their location in the immigration subgroup.

5.2 The Experiences of Undocumented African Migrant Families of Autistic Children in the UK.

20% (four families) of the participants in this study reported that they had overstayed their visa. Therefore, they had no legal right to remain in the UK at the time of interview. All of the undocumented migrant participants were likely to have given birth to their autistic children in their home countries before migrating to the UK. But there are slight variations within this sample. For example, some of the autistic children of the settled resident migrants were also born in Africa before they were brought to the UK. It is also acknowledged that the undocumented migrants had chosen to take a major risk in leaving their home countries, and had made a conscious decision to remain living in the UK illegally. Consequently, they faced serious obstacles when attempting to access the services that were their main reason for entering the UK. For them, however, the risk was worth taking, which is why they remained in the UK.

5.2.1 Families of Autistic Children Feeling Excluded in Their own Countries and Emigrating from there.

All the undocumented migrants whose autistic children were born in Africa had many reasons for leaving Africa. These ranged from feeling excluded and unrecognised in their own society, feeling devalued and not being accepted in their own community, and the lack of adequate autism services in their home countries. To illustrate this point, a participant from Nigeria said this about the lack of autism services in her country:

> They don't go to school. They just keep them at home. They don't go to school. And I said look why don't you take them to special school. And the special school they are talking about in Nigeria, they are just school for the deaf, dumb and blind. That's it. That's it. For disabled people, they call cripple, and Down's syndrome. The Down's syndrome is just like a hospital. But the special school they are talking about in Nigeria is either a deaf and dumb, or the blind school, that is it. we don't have any other thing. (Ms Dimka, Nigerian).

Similar experiences were reported by participants who originated from other sub-Saharan countries. e.g. Zimbabwe, Uganda, Somalia, Democratic Republic of Congo, Cameroon and others. For example, a mother from Ghana had said:

> ...because the government and the people, you know, all these [government] Ministers or whatever, they are not doing anything for, not [only about] autism, but disability as a whole. You know. They just push them. They don't have education. In Ghana, there is only blind school that I know. I think there is only blind and deaf school. Deaf and blind. I think in Africa, that is the main thing. I don't know about other African countries, but in Ghana, that is the main thing they see as disability… (Mrs Yeboah, Ghanaian)

Another mother from Uganda suggests that the doctors in her home country were unable to give her daughter an adequate diagnosis. They were ambivalent and ambiguous about her condition:

> Because in Uganda they had told me, if she was Down Syndrome how she would be [should look like]. So, she is not. If she was...they gave me all [sorts of]..condition[s], but the problem is her head and eyes might grow bigger, her teeth would just mangle themselves [said the doctors in Uganda]. You know, they gave me a very, very funny picture, that is why I said no. I won't take your [the doctors in Ugandan's] report. Let me write my own report [by migrating to the UK]. So, when this doctor [a doctor in the UK] told me what has happened [diagnosed her daughter with autism], I was relieved from what I was told [by doctors back in Uganda]. (Ms Kakooza, Uganda).

Another parent gave a similar account, and she was encouraged by a doctor to migrate to the UK in search of a better service. Below is her responses to the following question:

Interviewer: Where was he diagnosed?

> Here in London. As I said, they could not diagnose him in Africa, because the doctors we see [saw] didn't know what…[the condition was called] in French…Yes, he was born in Africa. [It was] a doctor who saw him in one specialist hospital in Kinshasa

> who gave us the idea to take him to the UK. He [the doctor] was trained here [in the UK].

(Ms Mulumba, Congo)

The combination of the stress of caring for an autistic child without any adequate support in Africa, the stigma and shame associated with having an autistic child, and issues of devalued identity, meant that some of the parents became desperate for help. Some participants felt that they were exploited by professionals claiming to be experts on autism. One parent gave an account of how she believed she was financially exploited:

> People exploit you! I was exploited. I won't lie to you, I spent a lot of money. I spent all my income on child Dimka. I neglected his brother. I spent all my income. I paid people who said they are teachers. I paid people who claim to know about child Dimka's background and anything. I am not talking about small money here, but at the end of the day he was getting older and older, and I didn't hear anything. I didn't even hear ma… before we came here, I must have spent up to, because I spent over N400,000.00 in Nigerian currency, a month [equivalent of £1,600 p/m] for school fees, treatment and childcare….his school fees is 250,000 per term. His speech therapy is 150,000 a month. If I estimate….huuuh! (Ms Dimka, Nigerian).

Ms. Dimka believed that people used the lack of specialist autism services in her home country as a means to exploit her. She said elsewhere that she was left financially drained, emotionally stressed and physically exhausted by her experiences. She also reported elsewhere in her interview that her child was permanently excluded from three schools in Nigeria, and he had stayed at home for one year. When she was advised by her consultant to take her son abroad, she resigned from her well-paid job in Nigeria, and used her life savings to fund the trip to the UK, where she expected to get a better standard of autism support. She felt that the risk was worth taking even though she was facing a great deal of hardship in the UK.

Mr Egal and Ms Mensah, who originated from Somalia and Ghana respectively, also reported that they were advised by their respective paediatric doctor to emigrate to the UK or the USA if they wanted access to good autism services for their children. Sandhu et al. (2016) also wrote about Turkish families who migrated to the UK for similar reasons. (Please see chapter 2 for a more detailed discussion of the economic theories regarding migration).

In Africa, autistic children experienced discrimination (Baffoe 2013; Anthony 2009); and felt marginalised and undervalued, as there was no provision of support for them (Okandeji-Barry et al. 2015; Bakare et al. 2009). A similar pattern was reported in parts of the Asian subcontinent (Desai et al. 2012; Xue et al. 2014). For example, Kpobi and Swartz (2018, p. 2) report that, in Ghana, support services for people with an intellectual disability is limited, and that ‘there is also no formalised or established government disability welfare system, thus most families rely on non-govermental organisations’ (NGO). Baffoe (2013) confirms Kpobi and Swartz’s claim, but maintains that the NGOs are grossly under resourced, adding that the NGO workers who participated in his study ‘complained that not much progress has been made [in Ghana since] the Person with Disability Act 2006…was passed’ (Baffoe 2013, p. 195). Anthony (2009) found that parents who hoped for an inclusive education soon found out that such ‘services in Ghana remain elusive’ (p. 207). Bakare et al. (2009)

concludes that ‘child mental health services have not received adequate attention from policy makers in Nigeria and other sub-Saharan African countries’ (p. 2). These papers validate the claims made by Ms. Dimka about limited service provision for autism and other disabilities in Nigeria, and those of Mrs Yeboah about Ghana, and in other sub-Saharan African countries.

While Ms Dimka and others in my study were able to leave Africa in search of better autism services, the vast majority of other families in Africa were unable to leave for various reasons. Yet those who did come to the UK soon began to feel excluded by the UK immigration system.

The undocumented migrants were in a more difficult situation than their temporary and settled migrant peers. One participant, who has since been awarded settled residency status, recalled that, as an undocumented migrant, she was unable to claim benefits for her three autistic children for 7 years after their birth. Another participant who was undocumented at the time of interview described how she and her two children had to live on a stipend of £74 per week:

> I think they are one of the best boroughs in the UK that is looking after people under no recourse. But even at that, I am gonna be 2 years here in January. Nobody has ever come here. They don’t know how am living…. You give me £74.00 every week, is that all? I have a child with challenges. Even if I don’t have a child with challenges, we are just [sounding exasperated] human beings! Just put us in a house, we have that little money to get on with our lives. That is not enough, because they don’t know where I live, they don’t!... I don’t like it! The other day I try complaining, [but] I just kept quiet… My prayer is…, if my papers comes out, I get out under social worker. I move on, that’s it! [getting very angry at this stage]. (Mrs Diya, Nigerian).

Mrs Diya felt that she was stuck in the system, and although she is grateful for the little help she received from her social work team, her situation was frustrating to her. She believes that once she obtains indefinite leave to remain in the UK, the majority of her problems would be resolved.

Some undocumented migrant participants in this research did not get any help from their local government. They had relied on the support of families and friends to survive. For example, one participant who relied on her social network to survive shared her story:

> Yeah! because I came on a visitor's visa, and ummm... It is more like I am not able to collect any benefit to help him. Because I am not able to work. I don't have a home of my own, I am being helped. In the UK, people will tell you, you have overstayed your welcome, come and start going. I am an independent person. I want…my…home, even if I have to pay for it, if I can get a job. I am not disabled. I am a very hard worker. I cannot work, I cannot do any of those things because I don't have the status to do that….(Ms Dimka, Nigerian)

The challenges experienced by undocumented migrants and failed asylum seekers who were prevented from working, accessing welfare benefits and health and social care services, and the hardship they face in the UK has been well documented (Mulvey 2011; Anitha 2008; Hernández-Plaza et al. 2006; Sales 2002). In order to survive, some of them resorted to working illegally and suffering exploitation as a result (Wrench and Modood 2000; Mulvey 2011; Sales 2002). A smaller group rely on support from their settled migrant social/community network in the UK (Hernández-Plaza et al. 2006; Sales 2002). Undocumented migrants with acute health conditions, such as HIV/AIDS, were denied free treatment by the UK National Health Service, (Pollard and Savulescu 2004).

Despite these multiple challenges, the undocumented migrants in my study chose to remain in the UK, albeit under the challenging conditions previously described. I would argue that the combination of their ‘nuanced’ immigration situation, financial hardship, and their children’s autism all converged to create multiple layers of disadvantage, far more onerous than those experienced by their peers in the settled and temporary residency subgroups.

5.3 The Experiences of Temporary Residency African Migrant Families of Autistic Children in the UK.

35% of the participants (7 families) in this study had one form of temporary residency permit or another. They include those with the Highly-Skilled Migrant Visa, asylum seekers, Family Visa and others. Members of this subgroup were legally allowed to live and work in the UK temporarily, but there were restrictions attached to their residency. In this thesis, this subgroup is referred to as those with temporary residency, and participants gave various reasons why they felt the need to migrate from sub-Saharan Africa to the UK. These included education, economic, and political factors, along with the desire for a better quality of life. Members of this subgroup were unlikely to have left Africa to access support for their autistic children. Ogunsiji et al. (2012) reported that there was already a precedent for Africans to migrate to other countries in search of better living conditions.

5.3.1 No Recourse to Welfare Benefits for Black-African Families of Autistic Children

It has already been established that a lack of autism support services in parts of Africa was one of the main ‘push’ factors for outward migration to the UK. However, when these black-Africans arrived in the UK, they soon found out that their expectation of better autism services and an improved quality of life would be more difficult to attain, than expected. The process of acquiring the right to reside in the UK was disrupted by their stressful and frustrating experiences of UK immigration procedures. Such adverse experiences featured quite strongly in interviews, both for participants in the temporary residency and undocumented migrant subgroups. Most of the participants in the latter subgroup talked about the hardship they experienced, such as poverty, the threat of homelessness, housing issues, unemployment and financial problems. They were also subject to the NRPF immigration condition, which meant that they were not entitled to state-funded support, including welfare benefits and some elements of social care provision. But while those in the temporary residence category could earn a living, the undocumented migrants were not allowed to take up employment.

One of the participants, Mrs Bankole, who is in the temporary residency subgroup, shared her experiences of holding a temporary resident permit and what the NRPF status meant to her:

> The truth is, we now have [a] housing issue as I speak. As I stand here, we have been taken to court. The no recourse team in Greenwich was going to rehouse us, and then the paper [work permit visa] came and they say to us go and work as you are no recourse, you know. [Interviewer: ok, so it set everything back]. It sets, in fact it just shattered us. In fact, that is where I am coming from now. I don’t know what to do. I cannot work, I cannot work! because of child Bankole’s [autism]. Not because I am lazy. I do somethings for myself. I sew in the house. That is the most I do. It sustained this family for 9 years, you know… So, giving us no recourse is just like giving us cake

> and asking us not to eat it**.** Just looking at the cake. Just look at it in the glass, you are not allowed to eat it. you know, why show me the cake at all. Although it looks good, it feels good. I am not complaining, I give glory to God, but why give me the cake if I can’t have the icing on it? so the no recourse team are not willing to help us anymore…they say go and work. (Ms Bankole, Nigerian)

Mrs Bankole suggests that if she had been given permanent residency instead of temporary residency, her situation would have been much better. She could have been entitled to state benefits, housing and extra support for her family. She would also have been able to choose whether to work or not, but as a temporary resident, she was denied that choice.

Another parent described his multiple layers of experiences and the frustration of juggling the need to stay in employment, meeting the minimum annual income required in order to stand any chance of their temporary visa being renewed by the Home Office, saving up to pay the high cost of their visa renewal application, attending their child’s appointments and complying with other immigration rules:

> My thing is that if we don’t have recourse to public funds, we are not entitled to anything. I will not necessarily leave my work, because that is the only place where we can sustain the family. So, I mean we have series of meeting now already lined up. Some I am going to go, some I say I might have to push to maybe February/March, when I can get at least one day off in a month. I cannot go to work and start telling them that look, am off tomorrow, am off tomorrow, and start telling them lies. There are things you can’t even tell them at work. You want to take time off to go to your child’s, you can’t tell the full history of your family. I am like look… these people think there is benefits somewhere. If I can’t take care of him, then the council will come for

> us. If I can’t pay my house rent my landlord will throw us out in the street. (Mr Aguda, Nigerian).

Mr and Mrs Aguda came to the UK as students and decided to stay after finishing their studies. Whilst here, Mrs Aguda gave birth to an autistic son, but restrictive immigration conditions created problems for them. Like most parents in the temporary residency subgroup, Mr and Mrs Aguda feel trapped by their immigration status. It is not possible for one of them to be a fulltime carer, if the other becomes unemployed due to frequent absence, unlike other parents of autistic children who are not subject to immigration restrictions.

In addition, the fact that Mr and Mrs Aguda have had to deal with the Home Office, and their lawyers, was stressful and time-consuming. The challenges associated with their immigration experience are such that (a) if they fail to work, they are likely to be asked to leave the UK, (b) if they lose their jobs they will not have the income to survive as they cannot claim welfare benefits, (c) if they take too many absences from work to attend their child’s appointments, they are likely to lose their jobs, (d) if they fail to attend appointments for their child, it could lead to a child protection investigation of possible child neglect. If they are deported back to Africa, the impact of lack of support, adequate resources and stigma they would face there would be extremely stressful. Such are the realities of life for most of the participants in the temporary residency subgroup, yet this would be true for any employed parent of an autistic child. But the fact that these participants are obliged to engage with the Home Office about their immigration issues – a time-consuming and stressful process – creates a multi-layered experience, and one which most other families in the UK with an autistic child might not necessarily experience. One of the participants summarised it as follows:

> It is incredibly stressful. You are not only dealing with the pressure of trying to raise your [autistic] child with limited income, but you are also stressing everyday about your immigration problems. (Mr Kimani, Kenyan).

A number of studies about the immigration experiences of BME groups in the UK, including South Asian women victims of domestic violence (Anitha 2008; Anitha 2010), black-African men and women who are HIV-positive (Fakoya et al. 2011, Fakoya et al. 2008), asylum seekers (Sales 2002, Stewart and Mulvey 2014) consistently describe the challenges they face, including the impact of NRPF. Anitha (2008 and 2010) carried out researches with South Asian women who acquired their temporary residency immigration status via their spouse and subsequently faced domestic violence in the UK. Anitha makes the point that NRPF conditions attached to their residency permits restricted their chances of escaping domestic violence. Similarly, Fakoya et al. (2011) reports that HIV-positive black-African men and women in their study faced serious economic hardship and multiple challenges due to strict immigration conditions. As a result, meeting their immigration obligations took ‘precedence over their health and seeking an HIV test, even when [they] experience ill health’ (Fakoya et al. 2011, p. 6).

In the next section, I will present the experiences shared by some participants in their quest to renew or acquire the right of residency to ensure they were not asked to leave voluntarily or be forced to leave the UK through deportation.

5.3.2 Living with an Autistic Child and the Fear of Deportation from the UK

In recent years, research on the concept of deportation within wider migration theory is receiving a great deal of interest (see Drotbohm 2015; Schuster and Majidi 2015; Drotbohm and Hasselberg 2015; and Coutin 2015). Deportation is the practice of forcefully removing a foreigner from one national territory or country to another (Drotbohm and Hasselberg 2015; Coutin 2015). It is ‘a process that begins long before, and carries on long after, the removal from one country to another takes place’ (Drotbohm and Hasselberg 2015. p, 551). In other words, deportation is a long and arduous experience with significant emotional, social and economic consequences for the deportable, the deported and their families. Members of both the undocumented and the temporary residency subgroups in my study have a shared experience of deportation as they are considered ‘deportables’, in accordance with UK immigration rules (Bloch and Schuster 2005; Coutin 2015).

Therefore, the prospect of deportation not only causes anxiety for the deportable, it also intersects with his/her identity and shapes his/her relationships with the UK and his/her country of origin. As previously established, being an undocumented migrant or one with temporary residency has serious ramifications for these families. The subgroup of undocumented migrants, such as Ms Dimka, whose comments were presented earlier, are likely to avoid engagement with the Home Office for fear of deportation. But both subgroups (the undocumented and temporary residency) reported experiencing serious anxieties about their immigration status. For those in the temporary residency subgroup the level of their anxiety and stress peaked when the time to renew their visa approached.

One participant described his emotions concerning his immigration situation:

> …but we are restricted, because our papers are not complete… it makes you feel angry, powerless and frustrated. We are very scared that they might ask us to return home to our country. They refused us the second time we applied, then we appealed. We are waiting for the appeal now (Mr Kimani, Kenyan).

Mr Kimani implies that the uncertainty as to whether or not his family could remain in the UK must have been very stressful, particularly when combined with the demands of raising an autistic child. He believed that, should his appeal fail, he and his family would either have to leave the UK voluntarily, or be forced to return to Kenya. The thought of returning to Kenya, a country with inadequate support services for autistic children, and the hardship they might face is another source of stress for these people.

Mr and Mrs Aguda also found themselves in a similar situation with the Home Office when they attempted to renew their visa:

> …Well, we felt that… we had to even go through the MP, Theresa Pearce. At a point in time, I had to write to our MP, I said look this is our situation, the Home Office has refused us. We had to pay a lawyer in Covent Garden, Central London, Thousands of Pounds, just for the case. The Home Office said they will give us the paper, but they held on to it…. And later the home office said they have accepted their mistake that they will issue us with all our documents, but they still held it for months. We had to involve the MP who wrote to them [again]…(Mr Aguda, Nigerian).

Mr. and Mrs. Aguda were concerned that when their application to renew their visa was rejected by the Home Office, and delays in the decision-making process meant that they had overstayed their legal right to remain living in the UK. The consequences for ‘overstayers’ (Anitha 2010, p. 467), which is the term often used for people who have stayed longer in the UK than they were legally permitted to do so, is that the Home Office has the power to arrest and remove them from the UK, and deport them back to their home country without warning (Anitha 2008; Anitha 2010; Bloch and Schuster 2005). Retaining an individual's travel documents, therefore, enables the Home Office to accelerate any deportation plan (Coutin 2000; Black et al. 2003; Black and King 2004). Therefore, the Aguda family were worried that the Home Office's decision to retain their passports was an indication that they were about to be deported from the UK.

A number of authors have documented the experiences of immigrants, including the potential implications of being sent back to their home countries. It is documented that the 2000 Ghanaians who were forcefully removed from various countries, including the UK (Black and King 2004; Black et al. 2003) faced an uncertain future once back in their home country. Drotbohm and Hasselberg (2015) report that deportation from Europe and the USA is percieved as a serious failure on the part of the deportees by their community in Africa, and that they and their families 'suffer from high level of stigmatisation' (p, 555). I have yet to find any scholarly article focusing on the experiences of immigrant black-African families of children with autism, when facing the prospect of deportation.

The next section of this thesis will focus on the experiences of the three subgroups of participants in their struggle to access services in the UK. Participants in the settled residency subgroup are more likely to have an overall better experience of autism services, and to self-advocate for access to services, but also more likely to be dissatisfied with the services they receive. On the other hand, the undocumented and temporary residency subgroup are more likely to access very basic or limited autism services, less likely to self-advocate, but more likely to express appreciation and gratitude for any services they received.

5.4 African Families of Autistic Children Struggling for Autism Services in the UK

Whilst facing the challenges of engaging with the Home Office about their immigration status, members of the undocumented and temporary resident subgroups were simultaneously encountering additional challenges in trying to access autism services. Even members in the settled residency subgroup reported experiencing challenges and institutional discrimination for being black-Africans. According to the participants, the struggle to access autism services started when they initially sought diagnosis and continued beyond that stage.

5.4.1 Diagnosis and Statement as Passport to Services?

Although some of the parents reported that they were initially reluctant to seek diagnosis of their child's condition, others were keen for their child to be diagnosed. However, parents in all the subgroups realised that without the autism diagnosis, and the allocation of an Education, Health and Care Plan (EHCP), their child might not receive the funding needed for specialist services, as one parent had commented:

> What I think is that initially before the diagnosis, he used to behave well in school, but there are one or two occasions when he behaved naughty. So, I think they don't understand the reason why he is being naughty. Or they do understand, but they kind of…they make it because he doesn't have his statement that they can't have the responsibility. Like maybe lunch time, because at the time he was being naughty at lunch time, and they said his one-to-one cannot stay there with him at lunch time, because he wasn't, he didn't have a statement, but other children with special needs

> had. So, I think it was more about the funding. That is why they don't really care…(Mrs Aguda, Nigerian).

Mrs. Aguda, a member of the temporary residency subgroup, had described elsewhere in her interview how difficult it was for her child to be diagnosed with autism, and that she was often asked to supervise her child at school during lunchtime. The diagnosis and EHCP were vital to receive adequate support at school, and also meant to Mrs. Aguda that other people would recognise and appreciate that her child had a disability and show more compassion and empathy to him.

It was not only the participants in the temporary residency subgroup that had found it difficult to obtain the diagnosis and EHCP. Some of the participants in the settled residency subgroup, who also requested a diagnosis had struggled to obtain it:

> The girls there was no problem. The son, I remember he went through a lot of speech and language therapy, Occupational Therapy, all those little things they were doing. But for me I requested for him to enter the process of being diagnosed, and they will tell me no, no. You have to wait, you have to wait. until he was at an age of starting school (Mrs Dibango, Cameroonian).

Ms Dibango has two older twin girls who were diagnosed with autism and had access to services, but when her son presented with autism, he was initially refused a diagnosis. She said elsewhere in the interview that she had recognised the early symptoms of autism in her son, but when she asked for him to be diagnosed, she was told to wait. When he was 5 years old, Ms. Dibango said she had prevented him from starting primary school in protest, until he was diagnosed and allocated an EHCP.

Ms Kama was another participant whose son’s diagnosis was delayed, in his case, until he was approximately 7 years old. However, Ms Kama believed that her struggle to obtain a diagnosis was both a consequence of her restricted immigration status at the time, and her ethnicity. Ms Kama was, however, a member of the settled residency group at the time of the interview, but in this comment, she reflected back to her time as an undocumented or temporary residency migrant:

> Obviously, during my struggle there were people who said oh! My son was diagnosed at 2 or at 4 [years of age], and I would say, my child was only just being diagnosed. How is that fair? Is it because, obviously when I first came I worked on a work permit, so we weren’t entitled to anything. So, I assume it had to do with that. I think I got my visa, indefinite when he was 3 [4 years ago] that is when we started getting benefit and stuff…(Ms. Kama, Gambian).

Ms Kama also stated in her interview that she had to take her son to the USA for diagnosis, but the confirmation statement was not recognised by her son’s school, and he was unable to receive funding for one-to-one support at school. As a result, just like many other parents in this study, she was often called to collect her son early from school, as they could not cope with his behaviour. Family doctors and other professionals dismissed her concerns when she tried to convince them that her son was not developing normally. Ms Kama felt that she was not taken seriously because she was a black-African woman and was ‘fobbed off’.

The importance of diagnosis, and of being in possession of documentary evidence of autism, or other acute childhood conditions, as requirements for accessing services in the UK has been widely reported (Strand and Lindsay 2011; Slade 2014; Dowling and Dolan 2010). However, it has also been well documented that delayed diagnosis of autistic children in the UK is a common experience and not restricted to black-African families alone (Perepa 2014; Corbett and Perepa 2007). However, whilst delay can also result from structural and operational issues in the service, some participants in my study felt that it is reinforced by their ethnicity and their immigration status.

Both Ms. Kama and Mrs. Dibango are, however, suggesting that their views and knowledge about their children's atypical presentation were not taken into account, and that the lack of consideration had contributed to the delay in diagnosis. Ms. Kama firmly linked the delay to her being an immigrant of black-African ethnic heritage. Other research has reported that black-African parents had felt that professionals had discounted their views when expressing their concerns about deficits in their children's health and development, leading to delay in diagnosing their children with sickle cell or thalassaemia conditions, for example (Atkin et al. 1998; Ahmad 1995; Ahmad and Atkin 1996). To support the idea that the intersection of race with ethnicity could play a part in the diagnosis of unobvious health conditions for black-African children, Atkin et al. (1998, p.1643) found that 'several parents commented on their ethnicity, feeling that white health professionals were used to fobbing off black people and treating them as though they were thick'. Angell and Solomon (2017) reported that the Latino parents of autistic children in their study in the USA were treated by professionals as though they were 'uninformed', 'inferior' and were spoken to like 'idiot[s]' despite their educational background, career position, and demonstration of autism awareness (p. 11). I would therefore argue that Ms. Kama, Mrs. Dibango and

Mrs. Aguda, quoted above, and other participants in this study, infer that racism is felt through the way services for children with autism operate, much in the same way that immigration systems work. Hence, racism and ethnicity contributed to the delay in diagnosis, and obtaining the EHCP required for access to support services. Without the EHCP, their children might not receive additional educational needs support, in the same way that, without the right immigration documents, the family might not receive statutory benefits. The stress and frustration caused by delayed diagnosis is another layer, much like the uncertainty and stress of the immigration process, in the multiple layers of autism experiences. In the next section, I will discuss the perceived institutional discrimination and inequalities, based on comments made by parents during their interviews.

5.4.2 Feeling Discriminated against for Being a Black-African Parent of an Autistic Child.

I have attempted to establish that participants from all three immigration subgroups are likely to have experienced delay in receiving an autism diagnosis, believing that it was due to their multiple identities. Participants from all the immigration subgroups created for this study believed that, apart from being treated differently as part of the wider disability groups both in the UK and in Africa, they experienced disadvantages and inequality when they compared themselves to other families with autistic children. Some of the participants inferred that they had experienced institutional derogation and racism, structural subordination and marginalization, and institutional discrimination due to their race and ethnic identity as black-Africans. For example, one parent reported that she was often asked to repeat herself many times when she was asking for information or support on the phone, because of her Francophone-African accent:

> And sometime when you are talking to them on the phone, they will keep asking you to repeat yourself, because they cannot understand my English…. Ahhhh!... (Ms Mulumba, PDR of Congo).

Ms Mulumba was originally from the Democratic Republic of Congo, a Francophone African country. She had temporary residency as an asylum seeker. Her spoken English language skill was not proficient, but her understanding of English language was good enough for communication. She felt frustrated in her communications with various professionals. But frustration was not the only emotion she had experienced. Ms. Mulumba is likely to perceive difficulties communicating with professionals in English and their derogatory attitude to her. Stubblefield (2009) argues that when an individual fails to understand another person, or a respondent fails many times to give their questioner the answer to their question, the questioner will often 'conclude from this that the respondent has cognitive deficit' (p. 535). To Fazil et al. (2002) language barriers experienced by BME groups in the UK is much more than a communication problem. It is also a precusor to an 'information breakdown', which affects parents' knowledge of a child's condition and of service availability. But barriers created by communication have been reported by Ali et al. (2001, p. 961) 'as a consequence of institutional racism'. So, the various professionals with whom Ms. Mulumba attempted to communicate were not only stereotyping her as a 'thick' black-African woman (Atkin et al. 1998, p. 1643), she was also inadvertently experiencing institutional racism due to the intersection of her race, ethnicity, accent and nationality.

Another parent had similar experience and reported that:

> This is how I have always felt, because I was brought up here. That I have always had to work harder as a black person… So, we know that is a fact. (Mrs Achebe, Nigerian)

Mrs Achebe said that, whilst she was brought up in the UK, she was not born there. She came to the UK from Nigeria at a very young age and belonged to the settled residency migrant subgroup. It was Mrs. Achebe's view that black-African families with autistic children were more likely to be disadvantaged in society due to their black-African identity.

For Mrs. Achebe, she was convinced that she experienced structural subordination and marginalisation, due to her intersecting and mutually constitutive identities as a black-African woman, and the mother of an autistic child. For example, feminist scholars, such as Inuzuka (1991), use the concept of marginalisation to describe how individual and organisational limitations are imposed on black women, which affect their ability to take full part in the polity of American society. Hooks (1984), who also explored the experiences of black-American women, describes marginalisation as follows: 'to be in the margin is to be part of the whole but oustide the main body; in a dominant white American society (p, ix). It is Erevelles and Minear's (2010) view that white people enjoy 'privileges…linked to the subordination of people of colour' (p. 132). Hooks (1984) emphasises a relationship between subordination and marginalisation, which informs the position of black women. Firstly, the concepts of 'superordination-subordination', which is akin to 'superior-inferior' or powerful-powerless or 'master-slave [relationships] is first learned and accepted as natural' (Hooks 1984, p 36). This relationship then creates the space where the marginalised are located. For Mrs Achebe, to break out of that margin and of the subordinated position to accessing services for her autistic child, she has to work harder than the average person due to the combination of her mutiple idenitities.

Some participants in this study have taken the above issues a step further, complaining of direct discrimination when accessing autism services, owing to their racial and ethnic identity. For example, one parent felt quite strongly about her perception of discrimination:

> I see white people, there is one opposite me who has got disability. There is one near me who has got special needs. You see them, they are comfortable. And I have even shouted out of frustration and stress, that why am I being treated like that. And the old woman came and met me. You know she felt it. What can be done for A, should be for B.…The council [needs] to be sincere with you. Consider African children as important as white children. I am not being racial. But when you have, when you bring your problems, or you want to seek help, I see, from my point of view, help is given to white people more than the African people. Reasons I don't know…So, it makes you feel, oh, or is my child different person from the others…? (Ms Mensah, Ghanaian).

Ms Mensah, who belongs to the settled residency subgroup, was alluding to her perceived experience of institutional discrimination by her Council due to her black-African ethnic and racial background. The black race is historically linked to oppression, marginalisation, and discrimination in the UK, and other parts of the West (Inuzuka 1991; Gillborn 2015; Rogers et al. 2014; Beal 2008). Bowleg (2012) states that ‘multiple social identities such as race, gender, nationality and disability intersects at micro level of individual experiences to reflect interlocking systems of oppression [racism, patriarchy, xenophobia, disablism] at the macro social level; (p. 1267)’. Therefore, the multiple intersecting identities of the black-African families in my study converge to predispose them to institutional discrimination at a macro social-structural level. Other scholars posit that black individuals who are at the intersection of multiple identity descriptors are more likely to experience institutional discrimination, compared to whites (Crenshaw 1991; Crenshaw 1989; Gillborn 2015). When Ms Mensah and others in my study percieve that they experienced discrimination from their Councils in the course of accessing autism services, compared to their white counterparts, it is reasonable to infer that such experiences result from their multiple identities.

Black-African immigrants in my study complained of being disadvantaged. It has been documented that some of the indigenous white British population perceive that some immigrants were prioritised for access to welfare benefits and social housing (Ford 2008; Dennison; and Goodwin 2015). These participants experienced derogation, institutional discrimination, marginalisation, subordination, and racism, due to their multiple intersecting identities. Such challenges converge to exacerbate the multiple layers of autism experienced by these participants. In the next section, I will discuss my participants' experiences of their attempts to overcome these disadvantages, by increased campaigning for increased access to autism services.

5.4.3 African Parents Fighting Harder for Autism Services in the UK.

Most of the parents in this study reported that obtaining funding for services, including social services, was often long and protracted. They found it to be time consuming, complicated, frustrating and stressful. These participants understood that other parents of autistic children have similar experiences and lobbied their Council for better access to services. They also believed that they had to fight harder than members of other autism groups, and some African parents developed a 'siege mentality', due to a perception that institutions treated them differently. One parent described how she redoubled her efforts to obtain funding to educate her son at home, when several schools could not meet his educational needs. She said this about her encounter with her Local Authority:

> [What the Local Authority should ask is] Do you want your child to attend school or do you want him educated at home? But you don't get that. It is as if you are always fighting, fighting, fighting the Local Authority. All we did was to fight the Local Authority (Mrs. Achebe, Nigerian)

In using the word ‘fighting’ several times in this short excerpt, Mrs. Achebe indicated that they had fought harder than they would have done if they had been of white ethnic background. She also wanted me to understand the intensity that she associated with her struggle, by repeated use of the word ‘fighting’.

Mrs Achebe went on to say that she felt:

> Like a gladiator, It didn't damp[en] my spirit....it made me ummm....it didn’t dent my spirit. It was draining, but it didn't knock me back. It made me want to fight even more to get my son the support that I felt that he needed. It didn't move me. I know that there are people who are in tears and stuff like that. The day I cried was when he was diagnosed (Mrs. Achebe, Nigerian).

Mrs Achebe implies that she was resolute and determined to fight for as long as it takes. She was not fazed by the barriers and was not prepared to back down until she received what she wanted for her son. Although she recognised that the experience was incredibly stressful, the feeling intensified her determination.

Mrs Adisa, a member of the settled resident subgroup, shared a similar experience about how she had to fight harder than most, by constantly contacting the authorities and retelling her story from the beginning of her autism journey:

> Health professionals! umm… very, very daunting. You have to fight for everything. …, you have to fight, even extra hard. Ummm, for me, as I said to you, I even fought to get diagnosis. I fought to get statements. It's been fighting all the way. I am constantly emailing, writing and backing up. So, it is always being a struggle. I mean it is always a struggle. I just find that, with everything, if you don't fight for it, you don't get it. and it shouldn't be that way. You are dealing with a lot already. You don't have to fight for these services. Someone should be able to give you the services. You don't have to recap your story every time! … But for every other thing, I found out that you have to fight…And I think at that time the school knew they were gonna be [in] for a for a long run, because here they are with a parent who was gonna be very, very problematic, and kind of proactive…I think at that time everyone sat up and said we need to do what we need to do to get the right support in place, because this is not gonna go down without a fall…(Mrs Adisa, Nigerian).

It has been documented that fighting for autism services is a common experience for white families (Connolly 2015; Harding 2013); Asian families (Doig 2012); black-African families (Slade 2014) in the UK; and minority groups such as black-African Americans (Gourdine et al. 2011; Starr et al. 2014) and Latinos (Angell and Solomon, 2017) in the USA. Nonetheless, Angell and Solomon (2017) reported that '…parents of colour, however, face even greater challenges…to successfully obtain services in the United States…' compared to white groups (p. 6). They reported that government spending and the allocation of funds to children with autism was disproportionate to that of white people. Their findings show that despite the Latino parents learning how to 'fight like a bear' for their children, they were still met with fierce resistance and unequal treatment from the authorities (p. 9). Angel and Solomon (2017) suggest that although Latino parents fought harder than their white counterparts, they still experienced inequality compared to the white people who may not fight as hard but receive a better service. Similarly, Gourdine et al. (2011) reported that ‘many black [African] families struggle to obtain appropriate care and support for a child with autism’ (p. 465), implying that they might have fought for services, but the services they received might be below par. Other writers such as Starr et al. (2014) describe how minority groups regard the fight to access services as a ‘battle’ (p. 6); while an African parent in Corbett and Perepa’s (2007) research with BME parents of autistic children describes their experience of accessing autism education for her child as a ‘big fight’ (p. 12).

In order to understand why a black-African immigrant family of an autistic child could fight harder for an autism service, let us turn to the immigration experiences of the so called ‘Windrush generation’ for a parallel example (BBC News 2018). The ‘Windrush generation’ is the term used to describe black Afro-Caribbean immigrants who arrived in the UK between 1948 and 1973, at the invitation of the then UK government, to assist with rebuilding post-war Britain (BBC News 2018; Munoz-Valdivieso 2010; The Guardian 2018). At the same time, individuals from several Commonwealth countries were invited to migrate to the UK: India, Pakistan and Bangladesh. The story of the Windrush generation has been widely reported in the media (BBC News 2018; Channel 4 News 2018; The Guardian 2018). Some members of this group and their descendants were deported to their home countries after living in the UK for 50 years (Channel 4 News 2018). Others facing deportation have had to fight for the right to remain in the UK. There are no reports that their counterparts from Pakistan, India or Bangladesh had the same experience. Whilst I accept that fighting for services is common for all families of children with autism, I will argue that the black-Africans in my study have had to fight even harder for autism services due to the intersections of their race, ethnicity, nationality and immigration status. This is what Mrs. Achebe meant when she used the metaphoric expression, ‘fighting like a gladiator’; and Mrs. Adisa’s comments, ‘this is not gonna go down without a fall’. It indicates that they knew that they had to fight more forcefully than the norm, just as the Windrush generation were determined to do. Paradoxically, being in a powerless position has given these families the emotional strength that enabled them to fight in a way that other parents may not.

Members of the settled residency subgroup are more likely than the undocumented migrants and the temporary residents to fight harder and to confront agencies if they were met with resistance. In the next section, I will attempt to explain why members of temporary residency and undocumented migrant subgroups are unlikely to challenge authorities.

5.4.4 Lacking in Confidence to Challenge Authorities

Although Mrs Achebe and Mrs Adisa demonstrated how they fought the authorities to gain access to services for their children, despite strong resistance, the same cannot be said of some other participants. It appears that the participants who challenged the authorities were likely to belong to the settled residency subgroup. Conversely, the ones who did not challenge authorities were more likely to belong to the temporary resident and undocumented migrant subgroups.

For example, one parent was reluctant to challenge her child’s school when the child was frequently excluded for bad behaviour. She stated:

> In all honesty, I always thought they are doing me a favour. Yes, so maybe that is why I wouldn’t challenge them (Mrs Bankole, Nigerian).

Mrs. Bankole, of the temporary-resident subgroup, felt that the services she accessed in the UK were much better compared to any autism services available in Africa. It is also possible that she was afraid that if she confronted the school, this might indirectly undermine their immigration status. Mrs. Bankole felt that it was better to acquiesce and show gratitude for any service that her son received, rather than fighting the authorities.

Another participant reported that his son’s child minder had criticised his soft approach to challenging his son’s school. He said:

> I have never challenged the school except once…over the phone. And that was when he was excluded for over one week…. She [child minder] was actually blaming us saying… you don’t even complain (Mr Aguda, Nigerian).

Mr. and Mrs. Aguda belong to the temporary residency subgroup. They had to rely on their child minder to challenge their son’s school, as they were unable to do this, despite the fact that the school was discriminating against them. Their child minder had to advocate and fight for them. The exclusion of their child took place during the period when their passports were retained by the Home Office. They were receiving support from their lawyer and their MP to fight against potential deportation. They were in a perpetual state of liminality (Menjivar 2006). It is therefore possible that they were afraid of jeopardising the outcome of their immigration application, and that they felt drained by the fight with the Home Office, and the school.

Researchers have found that some parents of autistic children from BME groups often lack the confidence to challenge authorities when they encounter discrimination for various reasons (Angell and Solomon 2017; Starr et al. 2014). For example, participants in Angell and Solomon (2017) stated that, 'they feared that professionals would exact retribution on their children', so they managed their fear by acquiescing and using a friendly approach (p. 16). Similarly, participants in Starr et al. (2014) study felt that 'confrontation with school personnel might affect their child's program' (p. 6). However, for the undocumented and temporary residency participants, they are also likely to be afraid of the implications for their immigration status, should the school report them to the Home Office.

My participants' fear of challenging a school or a Local Authority can be attributed to a fear of challenging the immigration conditions. The UK media has reported that the Home Office is covertly collecting details, from various government departments and private sectors, of suspected illegal immigrants (The Guardian 2018). UK banks were passing on details of their customers (Travis 2017), the NHS was handing over patients' records (The Guardian 2017), and schools were sharing children's details (Travis and Gayle 2016) in England and Wales with the Home Office to check the immigration status of those concerned. Participants without settled residence are likely to be under the radar. They risk exposure and deportation, should they challenge the authorities. The fear of schools and Local Authorities combined with the fear of the Home Office is likely to result in multiple layers of stress and anxiety for some of the participants due to the intersection of their immigration identity with other identities.

5.5 Conclusion to Chapter Five

To conclude this chapter, I have attempted to demonstrate that my participants belong to three subgroups, due to their respective immigration status. While some were settled, others were in liminal immigration situations. The experiences of the three subgroups differ significantly in terms of immigration status, but less so in the context of their struggle for services. The settled residency subgroup enjoyed a better overall experience, followed by the temporary residency subgroup, and the undocumented subgroup. The settled residency subgroup was likely to challenge the authority for services, but the temporary residency subgroup was less likely to do so. The undocumented subgroup did not challenge the authorities, probably because it is safer for them to remain invisible to the authorities for fear of deportation. The settled subgroup was less likely to be satisfied with the service provision, and more likely to complain, while the temporary residence subgroup was more likely to show gratitude and satisfaction for any services they received. Despite the different experiences, all of them had multiple layers of autism experiences by virtue of their intersecting identities. For example, in addition to sharing common autism experiences with the wider network families affected by autism, these participants had to endure institutional racism, marginalisation, subordination and institutional discrimination. To overcome these barriers, the settled residency subgroup felt that they had to fight harder for access to services. But the undocumented migrant and temporary residence subgroups did not fight for fear of attracting the attention of the immigration authorities. They would rather stay below the radar, acquiesce to the authorities, and feel grateful for any service received, rather than risk exposure to the possibility of deportation.

While it is generally accepted that all families of children with autism in the UK share common experiences to accessing services, it is also important to recognize that black-African families are likely to have experiences, specific to them. Recognising such differences among families with autistic children does not preclude the possibility of research that reflects on the commonality of families' experiences of challenges to accessing autism services in the UK. This should also recognise the intersections of social inequality, such as race, ethnicity, immigration status, nationality and language, which converge to create a qualitatively different matrix of autism experiences for the black-African families in my study, which I consider to be multi-layered. In the following chapter, I present findings about the stigma and rejection felt by my study participants.

Chapter Six

The Multiple, Intersecting Layers of Stigma and Rejection for Black-African Families of Autistic Children

6.1 Introduction

Nearly all the 37 individual participants who were interviewed for this study, including 19 mothers, 11 fathers and 7 siblings; had reported experiencing stigma and rejection. These findings are consistent with previous research (Bolton et al. 2013; Bywaters et al. 2003; Gray 1993; Gray 2006; Gray 1994), including studies focusing on Asian families with a disabled child (Ali et al. 2010; Doig 2012). However, the participants in my study stated that they felt stigmatised and rejected by members of the public in both the UK and their home countries, and by family members. Stigma experiences emerged from their responses, even though the semi-structured interview schedule did not include questions about stigma experiences. Some of the participants' responses were clear enough to be categorised as stigma. In fact, some of them actually used the word 'stigma' themselves without prompting, indicating how strongly they felt about this issue. The majority of participants in this study either perceived themselves or other members of their family as being stigmatised due to their association with an autistic child/sibling. Over half of the participants reported that they had been stigmatised or rejected by family members and members of the public. The types of stigma these parents had experienced can be classed as courtesy, felt and enacted stigma (Goffman 1963), similar to those reported in other studies (Scambler and Hopkins 1986; Corrigan and Miller 2006; Gray 1993; Gray 1994).

However, I will argue that participants were confronted with multiple intersecting layers of stigma and rejection due mainly to their children having autism, their racial and cultural identities, their marital status and their geographical location. By geographical location, I mean their decision to locate themselves in the UK and in Africa. In order to explore this idea of multiple layers of stigma and rejection from these black-Africans' perspectives, I explore their geographical and conjugal circumstances. From a geographical standpoint, they felt stigmatised and rejected both in Africa, and in the UK, and from a marital viewpoint, their geographical location still played a part in their stigma and rejection experiences.

I will argue further that families of white British identity, for example, are less likely to experience the same level of stigma or rejection in the UK as these African families due to the intersection of race, culture and geographical locations (Dein and Bhui 2013; Gourdine et al. 2011; Tincani et al. 2009).

Ali et al. (2001) reported differences in the experiences of disabled people, and in particular, the double discrimination experienced by BME people with disabilities due to the combination of disability and being black, in the UK, compared to white disabled people. They further argued that a black disabled person experiences both disablism and racism, hence their experience is different from white disabled people, because 'race can have a considerable effect on the individual and collective experiences of disability' (p. 950). In other words, a black person with a disability or a black-African family with a disabled child in the UK is likely to experience the general negative stereotypes about disabled people, in addition to racism, discrimination and stigma due to their race and ethnicity.

I will also argue that parents who were married or those who were living with a partner were likely to experience rejection and stigma to a lesser degree, compared to the single parents in this study.

Twelve participants reported that they were married. Among them, some of the women indicated that their husbands were in Africa at the time of the interview. It was not clear as to whether their husbands were permanently based in the UK or in Africa, if they were visiting, how frequently they visited and how long they usually stayed per trip. The women who reported that their husbands were part-based in Africa and the UK were in a state of perpetual uncertainty, because it was unclear to them if they were married or separated from their partners. It is, however, apparent that they were separated from their husbands by geographical distance. Eight of the participants were single parents either due to divorce, permanent or long-term separation, and one was never married at all. Ten of them had their children in Africa before migrating to the UK, and so had a direct experience of what stigma and rejection felt like whilst living in Africa with their autistic children. Some had reported experiencing stigma whilst on a short visit to Africa with their children, and examples of other families known to them. The majority reported experiencing stigma in the UK at one point or another.

The majority of the neurotypically developing siblings in this study had also reported that they felt stigmatised and embarrassed due to their autistic brother or sister’s behaviour in public. Unlike the parents, the neurotypically developing siblings’ experiences do not contain comments that could be classified as culturally specific to black-Africans. However, it was not apparent that their black racial identity and their association with their autistic brother or sister had intensified their feeling of stigma and embarrassment.

I will draw on Goffman's (1963) 'theory of spoiled identity' to conceptualise the experience of stigma. I will attempt to show how some aspects of the theory helps us to understand the lived experiences of stigma and rejection. The chapter is structured under four major categories: (a) African parents' stigma and rejection experiences in Africa, (b) African parents' experiences of stigma and rejection in the UK, and (c) mothers feeling rejected by their partners. Within these three broad themes, I will highlight any impact of intersecting factors, such as race and racialisation, marital status and geographical location, on the participants' experiences. Finally, I will explore (d) siblings' stigma and embarrassing experiences.

6.2 African Parents' Stigma and Rejection Experiences in Africa

The stigmatisation process often starts with the negative labels attached to people with a disability, including autistic children, by society. One mother commented:

> Imbecilic! Imbecile! It is the first one they say. They regard them to be imbeciles. They regard them to be,,. They are stigmatised…as people with no future. And I…if you look for [the] meaning of imbecile, it is like someone with no brain function at all. Someone who's got… there isn't any knowledge there. Someone who like they say, empty vacuum. But that is the name they call children with autism in Nigeria…(Mrs Adisa, Nigerian).

Similarly, in her response to my interview questions, another participant used a phrase to describe how autism or disability is labelled in her Yoruba language discourse:

> Interviewer: In your home country what name do they call people with autism?
>
> Mrs Diya: aaah! *Dem be ode o*! [a Yoruba dialect]
>
> Interviewer: What does that mean?
>
> Mrs Diya: They call them imbecile. They call them imbecile, yeah!
>
> Inter: How do they describe them?
>
> Mrs Diya: Like nonentity. None-en-tity! [stretching the word for an impact/emphasis]. Back home it is [a] serious disability…. (Mrs Diya, Nigerian)

Mrs Adisa and Mrs Diya suggest that people with autism are stereotyped with negative labels in Nigeria, due to how their condition interferes with cultural expectations there. Mrs Adisa states that individuals with autism are subordinated and perceived as valueless in that society, predisposing them to stigma and rejection. Mrs Diya suggests that people can be ruthless towards those with autism, and other types of a visible disability, and would often use disparaging words to describe them. When asked what name is given to autistic or disabled people in Africa, one mother held back for a moment before responding, using a local Ugandan phrase:

> [Silent and staring blankly...appears to be holding back, clasped her hand around her.....more silence...] Malima!, which means lame people…They don't distinguish between disabilities They just call them the same name, Malima. They call them lame! And sometimes they treat you like you are [a] malima as well. (Ms Kakooza, Ugandan).

From Ms Kakooza’s account, the label used in Uganda is similar to that which is used in Nigeria. I argue that African languages are not equipped to distinguish between different forms of disabilities. Ms Kakooza, a single parent, indicated that disabled people are diminished in that society, and that a mother of a disabled child is also ascribed with the same identity. She implies that, as a parent of an autistic child, her identity can be obscured by her child's condition. The fact that she is associated with a disabled person invites courtesy stigma from the public, to the extent that she can also be treated by society as a 'lame' person. In other words, people might also perceive her as impaired and not useful to society. This attitude of ascribing their autistic child's identity to his or her parents is similar to Gray's (1993) report that parents in his study were treated as though they were imbeciles as well, and their identities were somewhat spoiled because they were parents of an autistic child, an experience shared by my study participants. However, there are two differences between Gray's findings and mine. Firstly, Gray's study took place in Australia in the early nineties, so it is possible that negative perception of autism in Australia has improved, compared to Africa (Bayat 2015). We also know that Gray did not report this type of negative labelling in his follow-up studies. Secondly, Gray did not state the race or ethnicity of his participants. So, they could be diverse, including Australian Aborigines, and other ethnic groups such as Africans and whites.

For my study participants, though, being perceived as a 'lame' person means that in Africa, parents of disabled children have multiple spoiled identities. A cross section of African society may have a misconception that only a 'lame' mother could give birth to a 'lame' child. In some African societies, parents' names are often augmented by the name of their child, especially the first-born child (Ibisomi and Mudege 2014; Hollos and Larsen 2008; Anthony 2009). For example, 'mama-John', means 'Johns' mother. Similarly, a parent of twin children is often called ‘mama/papa twins’, and equally they could be called ‘mama/papa disabled’, or ‘mama-malima’, especially behind their back, if they had a disabled child. A parent’s identity can, therefore, be inadvertently fused with that of their autistic child. In the West, where parents are identified by their own names, and not their child’s name, or by a pejorative word such as ‘malima’, a parent who is unaccompanied by his or her autistic child is unlikely to experience courtesy stigma. A mother of an autistic child who is called ‘mama-malima’ in Africa is likely to experience stigma with or without the autistic child being present. Therefore, by inference, if the mother was referred to as ‘mama malima’, for example, even those with no prior knowledge of her would find out that she was the mother of a disabled child (Dyer 2007). Therefore, the multiple layers of stigma experiences take place because a parent of a disabled child is likely to experience stigma with or without being accompanied by his or her disabled child.

Another participant from Ghana reported experiencing stigma, following remarks made by a member of the public in Ghana:

> But the second time around we didn't have a good experience. He was 11 years old. When we went out one day swimming, and ummm he was very upset, and then one man said this boy is mad, you know all those kinds of beliefs in Africa (Mrs Yeboah, Ghanaian)

Mrs Yeboah, a married mother, is trying to describe an example of the negative attitude of a member of the public in Ghana towards her son due to his public display of autistic behaviours. Negative labelling is an essential component of the stigmatisation process, according to Link and Phelan (2013). When the individual had labeled the child Yeboah as ‘mad’, they were effectively indicating that there is a difference between ‘us and them’ or between the child Yeboah and the wider Ghanaian population. Therefore, by labelling the autistic child as mad, they are likely to link the child to the dangerousness perception about mental health patients, which in turn leads them to reject and socially distance themselves from both child and family. If this stigmatizing belief about autism is as widespread in Africa as Mrs Yeboah seems to imply, I would argue that based on accounts of these participants, stigma and rejection seem to occur at two levels - in the society and within the family. In this study, some parents felt that they had experienced some stigma and rejection from within their own family. Also, due to the communal nature of African society, the belief in accountability and retribution predisposes parents of autistic children to experience stigma and rejection (Anthony 2009).

They reported that some members of their families found it difficult to accept that there was a child in the family who behaved differently from a ‘normal’ African child. They believed that the autistic child’s behaviour had challenged the customs, beliefs and cultural norms of the family. Hence, the presence of an autistic child was a source of tension in the family.

For example, Mrs Okoye said this about the response from family members in Africa:

> And then when we went home [to Africa], the aunts came to us, and when they came to us, they poured their anger, saying to him, why have you come to the world like this? You know and they say….It is me and my husband that say no, he is fine, we are ok with it. They say No! if we don’t tell him, he will bring more [you mean reincarnation], exactly! They say they know what they are doing, and they will be speaking to him. (Mrs Okoye, Nigerian).

Some participants reported that, in order to make children fit in with established norms, their autistic child was admonished in Africa, and others were frequently reprimanded with the aim of re-moulding them into a ‘normal’ child. In Mrs. Okoye’s case, her family had attempted a form of exorcism on child Okoye in an attempt to expel any perceived supernatural cause of his autism. They aimed to re-mould him into a ‘normal’ child, and to prevent other children with a similar condition being born into the family. Such exorcism practices have been well documented, both among Africans in the UK (Tedam 2014), and in Africa (Bayat 2015; Bowman 2005; Weru 2005; Kpobi and Swartz 2018). For example, Kpobi and Swartz (2018) report that in Ghana, various types of exorcism were used on people with an intellectual disability to rid them of the condition.

The presence of a disabled child in a family affects external perceptions of that family (Anthony 2009; Grinker 2008). For example, one participant recalled the perception in the community had about a family who had a child with autism. She said:

> In my country, there are [a] lot of people with a disability. We see it as [a] shame. We see it as a taboo, like a curse in the family, or maybe you have done something wrong to the gods. You know all these kinds of stuff. Like when I was growing up, I know of a family that had a child whom I believe was autistic but the popular belief was their father was an occultic man [he belonged to a clandestine group] and that he used his child's brain for money rituals [to make him rich]. (Mrs Kromah, Liberia).

Therefore, in order to avoid being viewed negatively by society, families actively hid their autistic children from, for example, visitors to their home. Mr and Mrs Akinloye said that they used to hide their autistic child away from strangers:

> But later…we got over it and we don’t keep him in-doors like some people do in Nigeria. They lock such [a] child up. When they have guests, they will keep him away (Mr Akinloye, Nigerian).

Mr and Mrs Akinloye felt the need to keep their autistic son out of sight from strangers in order to avoid feeling ashamed or uncomfortable. Mr Akinloye implies that by hiding the boy, it prevents the occurrence of an embarrassing and stigmatising encounter if the boy misbehaves in the presence of a stranger. Although Mr Akinloye said he has accepted his son’s autism and has stopped the practice of hiding him, he believes that the practice still goes on in Nigeria.

Ms Dimka provided an account from personal experience, which substantiates the claim that families tend to hide their autistic children from guests. Keeping the child’s autism secret was a desperate attempt to prevent stigma and rejection experiences. For example, Ms Dimka had reported that her mother often attempted to make child Dimka invisible to visitors, perhaps to avoid spoiling the family’s identity and social status in the community. Ms Dimka said:

> Well my parents, my mum was like she doesn’t want me to tell anybody what was wrong with him. She doesn’t want anybody to know... She was more like, anytime there was someone, she is trying to make sign for me not tell anybody. I wasn’t living with her then, I was living on my own, but anytime I go to visit, she doesn’t want anyone to know. She prefers him to be inside (Ms Dimka).

Ms Dimka implies that her own mother, the child’s grandmother, was struggling to accept her daughter’s autistic son. Based on Ms Dimka’s account I infer that grandmother Dimka was interested in saving the face of her family.

The concept of ‘saving face’ refers to an individual’s duty and responsibility to be morally upright, by ensuring that their action does not bring shame and guilt to the individual and his or her next of kin (Canary 2008; Owor 2012; Khunou 2013; Curran and Runswick-Cole 2013). Therefore, grandmother Dimka did not want people to know that she was related to a child with autism. In essence, she was rejecting child Dimka as a grandchild. It seems that the presence of child Dimka in her house made the grandmother apprehensive, because his behaviour would cause her to ‘lose face’ if a stranger found out that a child with a disability is in the family. She wished that Ms Dimka would not bring child Dimka with her when visiting. I propose that Ms Dimka could be effectively experiencing enacted stigma and indirect rejection, which could make her feel unwanted at the family home. Ms Dimka felt conflicted by her need to maintain loyalty and respect to her mother, and her responsibilities to her autistic son. The notion that some family members in Africa tend to hide their disabled children has been supported by other scholars (Ingstad 1999; Audu and Egbochuku 2010; Bakare and Munir 2011). For example, Audu and Egbochuku (2010) report that in Nigeria, due to fear of stigmatisation, discrimination and shame, most parents hid their autistic children away from the public. Hartley et al. (2005, p. 174) also found that in Uganda, the ‘main problem encountered by children with disabilities… is negative attitudes, [which] manifest primarily as rejection of the child by family members … [including being] hidden from other people…the result is often isolation and loneliness’. Similar findings have been reported about African families of autistic children in Kenya by Weru (2005), among black-Africans in the UK (Slade 2014; Langan 2011), families in India (Desai et al. 2012), Bangladeshi and other Asian families in the UK (Bywaters et al. 2003; Doig 2012), and black families in Jamaica (Mann 2013).

In the next section, I will argue that the stigma experiences of some African parents in the UK were intersected by their geographical location and their black racial identity.

6.3 African Parents’ Stigma Experiences in the UK

As well as being worried about the stigma and rejection they faced in Africa, these families also faced similar negative attitudes in the UK. Nearly all of the 37 participants interviewed for this study had shared details of their encounters with members of the public here in the UK.

Some participants reported that they were worried about what people might say or how they might react if their child displayed abnormal or embarrassing behaviours in public. Many participants, including the neurotypical siblings, said they would not go out with their autistic child/sibling, unless it was necessary. Others said they had to plan the details of their outing ahead of time to minimise the risk of disruptive behaviours, including offering incentives to the child, which did not often work. Two participants reported that they had carried sweets with them when they went out, in order to ‘bribe’ their children to behave well in public places. But they also reported that their children’s teeth were damaged by sweets after eating them for a long time. Planning, preparation and incentives did not often prevent awkward behaviours in public places. The same can be said about the experiences of other families with an autistic child in the general population. However, when the incentives fail, and the child presents with embarrassing and unmanageable behaviours in a public place, the feelings experienced by these African parents can differ from those of white British parents, for example (Bywaters et al. 2003). Mrs Bankole had alluded to some of the differences in her story:

> There was a day we went to… umm, zoo. And he just chose to lie down on the floor. He didn't get up. He was obstructing people, because it was in a shop like that. I didn't know what to do. I sat down with him there, trying to get him up. Child get up….he just fold[ed] himself. He just laid down there, and then one lady said, a white lady, said: you are disturbing, or you were blocking the way or something. She was so nasty! and it felt so bad to me! I felt so sick ... Personally, I just felt, do I have to explain to everyone now. Child, why are you doing this? you know. At a point I just had to say to the lady, sorry I can't do much. He has his moment! Disability! You know tears welled in my eyes. I started crying. Before then I was strong because he is my son. but when people now start picking on you… get him up! What is he doing there, da da da. You start feeling that there is something really wrong…the emotions and all that starts to evolve and you start crying. You breakdown and the child is even in a more terrible state. Because this is you whom he looks up to, now you are broken. And then I had my daughter there too. She was dragging me, child was on the floor and people were talking at me! It was horrible, but I still had to pull myself from the ground. (Mrs Bankole, Nigerian).

The situation described above left the family feeling confused and overwhelmed. Mrs Bankole felt that up until the moment before the white woman intervened, she believed she could control the situation. The white woman's intervention, however, intensified any feeling of embarrassment she had felt as a result of her child's behaviour. Mrs Bankole expected people to show understanding and empathy, yet she received direct stigma and rejection from a white person. The resilience she had built up over the years, and the skills she thought she had acquired was tested in that moment, and she could not cope due to the additional stress of dealing with the stigma in a public space.

Although Mrs Bankole did not explicitly state that this woman was racist, she was keen to point out that the woman was white. In doing so, Ms Bankole had implicitly introduced the idea that the white woman's attitude towards them was racially motivated. At the very least, it made her feel racialised. In this exchange, Ms Bankole was experiencing the white woman as occupying a public space in a powerful way. Hence, she felt totally disempowered at a much deeper level, due to her own and her children's racialised black bodies encountering a more powerful white body (see Garner 2010; Fanon 1967; Ahmed 2002; Skinner 2006). This idea will be explored later in more detail.

By introducing the idea of racism in her experience at the zoo, Mrs Bankole infers that if her family was white, the public and the white woman in particular, would have responded differently, or if the child did not have a disability, the incident would not have occurred. So, 'to be black and female' is double jeopardy (Beal 2008, p. 166). But the combination of autism, being female, and of black-African race was a typical example of triple jeopardy or multiple intersecting layers of identities. Each of these social markers is a potential source of social stigmatisation and rejection. Other families with autistic children, such as white British for example, are likely to experience stigma and rejection based on perceptions of autism or for being the mother of an autistic child. But they are unlikely to experience stigma and rejection in the UK on account of their race. I argue that, based on Mrs Bankole's account of the incident at the zoo, and on experiences reported by other parents in my study, African families are likely to have multiple intersecting layers of stigmatising autism experiences, as black-African mothers of autistic children living in the UK.

In Mrs Bankole's account, she felt challenged and distressed. But, according to Gray (1993), the public is more likely to react sympathetically to an autistic child and their carer for violating social norms, than to an adult with autism who displays similar behaviours. One participant recounted her own stigmatising experiences, in relation to her 17-year-old daughter:

> This is something which I cannot begin to explain to anybody [I can see pain in her eyes]. …One time, I went with her in Tesco, it was Christmas time. Then they were playing this song. 'I am happy...' that song is being so popular. Heyi! You see her size. She started dancing in Tesco... She was dancing like she was in a party, and people were looking, and I am in the counter, and I am like ooooh my God! Oh my God! I can't call her when she is happy and she is singing, but I can see people looking…. You cannot tell everybody she is disabled, no. And if you stop her she would run and go somewhere I cannot see her. So, can you imagine the attention you are having on you and people are looking at you, and you are like as if the ground should swallow you. You know all those stuff, you cannot explain it (Ms Kakooza, Ugandan).

When I asked Ms Kakooza, a single mother of seven children, how the experience made her feel, she responded:

> Silence, {sniffled. Tears welling in her eyes]. I don't know how to explain it. Embarrassing, they look at her strangely, her size, the colour of her skin… (Ms Kakooza, Ugandan).

Ms Kakooza was initially silent, which implies that she was struggling to put into words how her daughter's behaviour in the public made her feel. The image of a big, black girl/woman, who does not have any obvious problem or physical disability, singing and dancing in a supermarket is unusual. It was embarrassing to her mother, and perhaps to other black people there at the time, because of their shared racial identity. It fits into the misconceived stereotypical narrative that to be black and African is to be foolish/stupid or dangerous, according to Beal (2008). Her behaviour was embarrassing and stigmatising, but the combination of her daughter being a disabled-big-black-African-female and the way '*they looked at her strangely*' felt deeply hurtful to Ms Kakooza. The pain was so raw, deep and intense that several months after the event, she was still very much upset about it. Ms Kakooza was trying to imply that there is a subliminal conceptual demarcation between 'us' and 'them'. If this scenario occurred in Uganda for example, a geographical location where blacks are the dominant race, the embarrassment Ms Kakooza felt would not be as intense. This does not necessarily mean that in Uganda, Ms Kakooza would not be stigmatised, embarrassed or offended. But the difference is that, in Uganda, the feeling of stigma would not necessarily be intersected by race. To buttress her point about experiencing a deeper level of stigma and embarrassment for being black, she related an incident, which happened when her daughter saw her teacher on board a flight:

> We were on the flight one time…she started calling me, mummy, mummmmy. like there was a teacher sitting, everyone was just looking at her. How can you call your mummy , and you are a big girl, pleeeeze. She doesn't care, she continued to shout, teacher, teacher...oooooh! Then you start looking down like, and you feel embarrassed, and this thing, the colour [touching her skin] gives you [away], would

> say pleeees, but you cannot do anything... I said are you ok? [She said], no, no, the teacher,…The good thing is that he is a white teacher. He said it is ok, she is my student. You feel embarrassed. And you cannot say you can get used to it, you cannot (Ms Kakooza, Ugandan).

The fact that child Kakooza, a big black girl, was presenting with childlike mannerisms in the presence of other passengers on board a flight was embarrassing and shameful to Ms Kakooza. She indicated that her daughter's behaviours in public made her feel as though she was living in perpetual embarrassment, accentuated by their racialised black bodies.

Interestingly, Ms Kakooza felt that, because this interaction had involved a white person, the impact of the stigma, shame and embarrassment on her was minimal. This is because the white teacher showed understanding and openly accepted child Kakooza's behaviour, making Ms. Kakooza believe that the other passengers had accepted her daughter, which also made her feel better. She implied that by sharing the stigmatising situation with a white person, he had protected her from feeling deeply stigmatised and ashamed of the combination of her child's disability and her black race. This situation is similar to the one which occurred at the supermarket where child Kakooza was singing and dancing. However, there is a slight difference between the two embarrassing scenes in terms of how Ms Kakooza felt. At the supermarket, there was no white person present to intervene and shield her from being deeply embarrassed. In other words, being a black mother of an autistic child engenders the feeling of multiple layers of stigma and shame.

In order to understand the role that racial identity played in the perception of Mrs Bankole’s and MS Kakooza’s respective experiences, we need to turn briefly to the concept of racialisation (Fanon 1967 and 2008; Garner 2010; Ahmed 2002). Historically, the UK is a country where people who are non-whites, especially blacks, are perceived by others as strange due to the impact of slavery and colonialism (Fanon 2008; Ahmed 2007 and 2002).

Racialisation is an emotional process (Ahmed 2007). The impression that an encounter between a white body and a black body is racial, even when there are no spoken words, is shaped by the historic perception held by the West that the black race was a ‘lower race’, ‘more primitive’ and ‘less evolved’ (Ahmed 2002, pp. 50-51). It is the contact between Mrs Bankole and her autistic son's black body with the white woman's white body at the zoo, Ms Kakooza and her autistic daughter's big black body with white shoppers at the supermarket, and on the airplane, that helped to create the perception of conflict between black bodies and white bodies. The response of the white body/woman to Mrs Bankole's stressful experience 'create[d] an impression' of racism, much the same way the supermarket experience left Ms Kakooza 'under the impression' of being racialised, due to their black bodies. This left 'its mark or trace' on these mothers’ minds and bodies (Ahmed 2007, p. 6). This idea allows for an analytical conclusion that these encounters did not only have an impression on these two mothers, they were also left with a racist impression in their psyche (Ahmed 2007 and 2002).

For a deeper insight, Ahmed (2007, p. 10) introduces the ‘outside in’ model of social emotion. This model helps to explain how an emotion that comes from ‘outside’ or from other persons during an encounter is taken ‘in’ by and ignites some emotions in the receiver (Ahmed 2007, p. 10). For instance, in Ms Kakooza’s and Mrs Bankole’s cases, that emotion was a feeling of racism and racialisation. The passengers on the plane might have felt threatened by the ‘primitive’ or uncivilised attitude of a big-black-body jumping up and down in excitement. They do not know what to make of a big-black-body from which they were supposed to ‘distance’ themselves (Ahmed 2007, p. 10). The intervention of a white male body, historically considered as superior to other bodies (Ahmed 2002), is a form of emotional reassurance to the passengers, as well to Ms Kakooza.

The reason why these mothers have the impression of racism is because they have the history of white colonialism and oppression of black people. Therefore, they must have already believed that to be white is to be racist. This belief was reinforced by the way these families came into contact with these white people, which created an 'image that is shaped by colonial histories and memories’ (Ahmed 2007, p. 7). So, when they encountered the white bodies, they already had, 'an impression that is felt on the surface of [their black] skin' (Ahmed 2007, p. 7). To make sure that I understood the racist impressions they were given, Ms Kakooza felt the need to symbolically touch her own black body/skin, whilst Mrs Bankole referred to a ‘white’ woman.

The intersectional identities (black females, mothers of disabled children, a big-black teenage-female, and immigrants) are sources of multi-layered experiences (Shields 2008; Samuels and Ross-Sheriff 2008). Roger et al. (2014) report that, in a race study undertaken in the USA, black youths scored higher on racial identity scales than white majority youths. Thus, Roger et al. (2014) argue that black youths ‘may experience race as more central to their identity than gender and evaluate race more positively’ (p. 2). These mothers may have attached more importance to their black race in their courtesy stigma and embarrassment experiences, which enabled them to evaluate the role that their skin colour played in their conceptualization of their experiences. Rogers et al. warns that writers are in danger of filtering race-related feelings and experiences through the gender lens. In Ms Kakooza’s and Mrs Bankole’s encounters, failure to consider their racial identity in their reactions to these situations is to risk viewing their experience through the narrow lens of autism disability alone. Filtering racial experiences through the disability lens could lead to the social identity of disability overshadowing the presence of race and other identities, and the feeling of racialisation that these women experienced (Carbado et al. 2013; Samuels and Ross-Sheriff 2008).

6.4 African Mothers of Autistic Children Feeling Rejected by their Partners.

As indicated earlier, 12 married couples, and 8 single mothers of black-African origin took part in this study. Among the 8 single mothers, two of them reported that they were married, but their husbands were permanently based in Africa. I categorised them as single parents in the UK, due to their separation from their husbands over a long period of time and distance. Of the remaining six single mothers, five said their marriage broke down or they were divorced from their husbands, either whilst they were in Africa, before they migrated to the UK, or whilst in the UK. One mother was never married. Among the 12 married couples, at least two of the husbands in that subgroup said they were part-based in Africa, and in the UK. However, because they were present at the time of the interview by coincidence, they were included in the married couple subgroup. Within the married couple subgroup, 11 fathers were interviewed, which implies that all of the husbands, except one, were present. In this section, I will explore the perception and reality of some of the single mothers who felt that their husbands left them because of their autistic children. The pattern that emerged from the comments about this theme was that the single mothers who were already divorced had experienced the reality of rejection. Mothers in both the married couple subgroup and the single-mothers subgroup who reported that their husbands were part-based in Africa faced uncertainty, due to their liminal marriage situation. Some of the mothers in the married couple subgroup, living permanently in the UK with their husbands, perceived that they experienced deeper levels of rejection and vulnerability.

One mother was wondering whether her husband was keeping another family in Nigeria where he spent a considerable amount of his time:

> He came back from Nigeria where he is doing politics. I know his family, even those who are close to me, I won't be surprised, if they encourage him to have more children, because as far as they are concerned, this is, my husband is the only son, so it is not as if there are other boys (Mrs Achebe, Nigerian).

When Mrs Achebe was responding to this question, she lowered her voice so that Mr Achebe, who was upstairs at the time, would not hear her. Mrs Achebe was feeling insecure in her marriage and suspected that her husband had fathered a child with another woman in Nigeria. The fact that her husband spent a significant amount of time in Nigeria makes her feel vulnerable. Mrs Achebe thinks that her husband had desired a normal son as a cultural expectation and may have yielded to pressure from his family. I found that the uncertainty surrounding Mrs Achebe and other mothers in this study who were in similar marriage situations, and the emotional instability brought about by the possibility that their husband could be married in Africa, adds another layer of stress that other mothers, such as white British mothers of autistic children, are unlikely to experience (see chapter seven for a detailed exploration of the value placed on a male child and other cultural discourses).

Another mother commented about the attitudes of her then husband and father of her autistic son while they were married and living together in Nigeria:

> …I have had a lot of experiences with my son, … his father, because his father and I have divorced. I have been single handedly raising him up by myself. It has been tough… You see the issue we had…we had a lot of issues, …the communication was not there. And I noticed he was not interested….He has never asked what can I do about my son... He refused to go to the computer to read about autism. He won't even budge.…[overcome by emotions. paused] …He has never sat down one day to talk to his son. If you ask him what is wrong with your son, he can't even tell you. He doesn't even know the word, or the symptoms, as much as I have asked him to read up, but he couldn't be bothered. Even up till now he could not be bothered, so (Ms Dimka, Nigerian).

Ms Dimka, who is in the single-parents subgroup, was divorced from her husband in Nigeria prior to her coming to the UK. Ms Dimka said elsewhere in her interview that her ex-husband had mentally left the marriage before physically leaving it, due to her having an autistic son. She said there that her ex-husband had no interest in their son, had refused to accept responsibility for him, refused to face reality, and had a nonchalant attitude towards his son and his autism condition. I infer that his indifference and attitude of not taking responsibility implies that he was blaming Mrs Dimka, as though it was her fault. His attitudes culminated in him abandoning his family, making Ms Dimka feel stigmatised and rejected. Ms Dimka also described earlier how she felt rejected by her own mother. In another part of the interview, she said that she had sent evidence of her son's progress at home to prove to her family that her son's identity was not completely spoiled by autism as they had believed. In doing so, I would argue that she was attempting to make her family accept her son; if they do, it would make her feel less guilty, less rejected and less stigmatised by her own family.

Mrs Bankole, who lives together with her husband in the UK describe the strain in her marriage:

> Ahhh! [sighs heavily] Well, in Christ alone I stand! You have dejection, you have rejection everywhere staring in your face. Even in the house you are not, you have logger-head because some things are not going right and all that…You just keep strong for yourself and for the child so that you are not breaking into pieces. But, I won't lie to you. it is not a bed of roses! …(Mrs. Bankole, Nigerian)

Mrs Bankole implies that there is instability, frustration and conflict within her marriage, and with wider family members because of her autistic son. She suggests that there is significant pressure, stress, and a lack of cohesion in the marriage, which makes her feel unhappy. Based on the excerpt above, I infer that Mrs Bankole felt that she was not getting the cooperation, support and recognition she needed from her husband. Instead, she found solace in her spirituality.

Another participant was very direct in her response when I asked how her son’s autism had affected her relationship with her ex-husband. She commented that:

> It affected our relationship because he left us because of him, and he asked my family to return my bride price … because you know in Africa a man pays money to a woman’s family to marry her, before the woman can become his wife (Ms Mulumba, Congolese).

Ms Mulumba suggests that her previous husband was unable to cope with the stigma of having an autistic child in Congo. She felt rejected by her husband for leaving her to cope with the multiple challenges of having an autistic child. The feeling of abandonment and him severing their marriage, culminating in him demanding a refund of the bride price he paid to marry her, is another layer of rejection and stigmatising episode to her and her family.

Bride price payment is an African cultural practice, whereby a man pays money to his wife's parents/family to seal the right for him to marry the woman (Mugambe 2006; Ferrara 2003; Kandiyoti 1988; Noon 1942). The demand for the return of a bride price is a profoundly serious issue in African communities. It is an indication that the woman is at fault and is a demand for divorce. Given the collectivist nature of African families, and the huge number of people witnessing marriage unions, any demand to return a bride price is a serious embarrassment, bringing shame and stigma to a family. It is also an indication of male privilege or patriarchy that allows African males to be more available to other women and less committed to marriages and relationships when there is a problem, in this case, the presence of a disabled child. To illustrate the seriousness of this point Mugambe (2006, p. 76) states that ’the husband's payment [of bride price] entitles him to full ownership-rights over his acquisition, his property, his wife...women often fear the threat of being returned to their parents' home and the bride price being returned'. I am not suggesting that all African societies do this, but for those that do, it is considered a serious embarrassment to the family when a woman is returned home. Therefore, Ms Mulumba and her family found themselves in a vulnerable position because she had given birth to a disabled male child.

Ms Mulumba went on to say that:

> Their father [her ex-husband] blamed me for giving him a disabled child, and I think his people also think it is my fault, so that is why they don't even ask of us…. His father has married another woman, but I don't know if he has another son or not. It is because of this problem that he abandoned us for another woman...(Ms. Mulumba, Congolese)

In addition to the stigma of marriage breakdown and being abandoned, Ms Mulumba indicates that she felt slandered and ostracised by her ex-husband and his family. She implies that she was losing face in the family, as she was viewed as the cause of her son's disability. She feels that whilst her ex-husband has a second chance to have another child with another woman, her chances of having another husband is limited because she is the parent of an autistic child.

These feelings were shared by a single mother who had not married or lived with her son's father. She said:

> No! we were not married when I met him. I met him 5 years before we got together, and then I knew he was married. When he met me again, after 5years he told me he

> was divorced. I was living in Selhurst. And obviously, all I did was work, because that is what I came here for (Ms Kama, Gambian).

Ms Kama implies that she was blaming herself for not doing her due diligence and verifying the true marital status of the man she had a child with. She trusted him, but she also felt that he deceived her, took advantage of her and then abandoned her for another woman. In another part of the interview Ms Kama stated that she felt guilty for dating a married man and regretted having a child with him.

Another single parent, a mother of three autistic children, reported that her husband had left her and their children because he could not cope with the cultural stigma of being the father of three autistic children. She said:

> Yeah. So, when I had my son, and the son was diagnosed, because I think for the twins, he was just thinking that the reason for their autism is because they were born premature. And then, we had the son, and when the son was diagnosed, I think that is when, and you know, being African, you have the pressure of the in laws, saying oh, no you need to get another wife to give you child without eehh, to give you a normal child. And you begin to believe it until it happens. Yeah [somber voice, lower tone]. (Ms Dibango, Cameroonian).

Ms Dibango suggests that, being an African man, her ex-husband was under pressure from his kin to leave his wife and children and have a ‘normal’ son with someone else. She indicates that it is culturally acceptable for men to leave marriages but not women. She implies that her ex-husband abandoned her and the children because he could not face being the father of a son who was not, in his eyes and those of his family, ‘normal’. It was too hard for him to cope with the reality. Ms Dibango implies that her ex-husband was able to cope with having two girls with autism initially, especially because he believed that the girls' autism was due to them being born premature. The reasons why Mr Dibango abandoned his family are more complex than outlined, but, ultimately, Ms Dibango felt that Mr Dibango had rejected her because both he and his family blamed her for having three autistic children. Elsewhere in the interview, Ms Dibango reported that she was so desperate to prove that she was not incapable of having a 'normal' child. She said that she had to defy the advice from family and friends not to have another child for fear that it would be her fourth autistic child. Ms Dibango said she had her last child, a girl, many years later, and she is not autistic. She concluded that having that child made her feel somewhat relieved and it exonerated her from her guilt and self-blame.

In their paper on the intersectionality of *identity, oppression and power*, Samuels and Ross-Sheriff (2008) 'suggest that individually, women experience their womanhood and various other interlocking oppressions differently in different context. Likewise, what is oppression in one context may be a privilege in another' (p, 6). In this context, I am not suggesting that the pattern of matrimonial experiences of the African mothers in my study is either a privilege or a form of oppression. But in order to gain some insight into how these matrimonial patterns are sustained we need to consider the patriarchal cultural systems which are common in Africa.

According to Crenshaw (1989, p.163) 'patriarchy clearly operates within the black community, presenting yet another source of domination to which black women are vulnerable'. The intersectional issue of patriarchy, race, and disability further subordinates black-African women to black-African men (Crenshaw 1991), black women to white women (Best et al. 2011) and black mothers of a child with a disability to both groups. These multiple layers of disadvantages reinforce the feeling of rejection and stigma felt by the mothers in my study. For example, fatherhood as a patriarch is a respectable gender role in an African society (Ritcher and Morrell 2006). Conversely, the connective role of women in some patrilineal lineage systems in African society is not often recognised, because 'daughters don't matter' (Holmes 2000, p. 249). The cultural expectation of a man/father in an African society is that of a provider, who is also the protector and a custodian of ancestral and family values. Thus, in a typical African family where hierarchy and patriarchy is practiced, men/fathers are at the top of the pecking order (Kuper 1982; Holmes 2000; Ritcher and Morrell 2006). In the context of this study, these mothers are aware of the patriarchical cultural system and, although they live in the West, their capacity to resist patriarchy and subordination is limited.

Due to parental rejection and stigma, their marital statuses and geographical locations, I argue that the parents in this study had experienced multiple intersecting layers of stigma and rejection, beyond the norm for the wider community of parents with autistic children living in the UK. For example, these parents faced stigma and rejection in their home countries from their own extended family, their partners and the general public. Once in the UK, the feeling of stigma and rejection continues. However, their experiences of stigma and rejection were more intense because of the intersection of racial identity and stigma. When the experiences were examined further to explore the concept of marriage in some African cultures, I found that there were three subgroups of parents. Each of these subgroups also reported different experiences of rejection and stigma. For example, mothers with husbands who are part-based in Africa were more likely to feel anxious and uncertain about their marriages compared to those living with their husbands in the UK. The participants in the single-mother subgroup are likely to come to terms with their status, but are living with the reality of rejection. Participants in the married mothers' subgroup perceive tension and strain in their marriages, but any feeling of rejection is not as obvious as the other two subgroups. Overall, the fathers of the children within the single-parent and part-based in the UK and Africa subgroups have effectively freed themselves from the stress and stigma associated with having an autistic child. In essence, men have more choices than women in the context of African marriages because of the long-established marital practice of polygamy, whereby a man can marry as many wives as he wishes. (Thurnwald 1929; Brown 1951; Ardayfio-Schandorf 1995; Ritcher and Morrell 2006). Mugambe (2006) makes the point that, if a man can afford the bride prices, polygamy is still an acceptable practice in many African societies. Clearly, due to the social and cultural acceptance of polygamy by African society, it is possible for fathers in any of the three subgroups, especially fathers in the part-based in the UK and Africa subgroup, to maintain two or more families across the two continents. Effectively, these fathers could move on and start a new family, or even maintain two families simultaneously in their quest for a 'normal' child. In contrast, these mothers are highly unlikely to do the same, because it is not culturally acceptable in most African countries/societies. Hence, these mothers have deeper multiple layers of stigma and rejection.

6.5 The Neurotypical African Siblings of Autistic Children's Experiences of Autism

I had interviewed 7 neurotypical brothers and sisters who were related to the autistic children in this study, as part of the family groups. However, only one of them had unequivocally declared their unconditional positive affection for their autistic sibling. Some had both positive and negative feelings, and others only negative feelings about their association with their autistic sibling. There were, however, two experiences that stood out: (a) their role as young carers for their brother or sister with autism; and (b) the feeling of courtesy stigma and embarrassment in public due to some idiosyncratic behaviours by their autistic sibling.

For example, sibling Dimka had described the level of care and support he provided for his older brother. He said:

> …when my mum goes to work, sometimes I look after him in the house, I just take care of child Dimka. Sometime I bath for him….I help him wear his clothes. I also help him tie his towel…everyday. (sibling Dimka).

Their mother, Ms Dimka, confirmed that sibling Dimka helps with caring for his brother, and added that:

> He has really done well. He taught him how to brush his teeth, taught him how to use the shower. Child Dimka used to be afraid of the shower, but he taught him how to use it. (Ms Dimka, Nigerian).

The neurotypical sibling Dimka was 8 years old, and his brother with autism was 10 years old. But, despite being the younger brother, he provided a substantial level of care to his brother, which made him a young carer (O'Dell et al. 2010). He had said elsewhere in the interview that his caring role somewhat affected his study time, but he still manages to do his homework. He also confirmed that he was committed to caring for his brother as an adult. Other researchers found that siblings of autistic children assist their parents with care and supervision for their brother or sister with autism (Waterson 2011; Dyches et al. 2004; Kapp and Brown 2014). For example, Kapp and Brown (2014) state that as siblings grow older, they take over some responsibilities such as supervising their autistic sibling, doing house chores to relieve the burden on parents. Similarly, Becker (2007) found that siblings often carry out significant caring tasks and assume a level of responsibility usually associated with an adult. So, having an autistic sibling compels the neurotypical child to mature sooner, exhibiting caring behaviour above that expected for their age when compared to their peers without a disabled sibling.

All but one of the siblings of the autistic children had told their own stories about their stigmatising and embarrassing experiences in public places due to their relationship with their autistic brother or sister.

Several of the neurotypical siblings reported being worried by what people said about their autistic sibling, or the looks they got in public. One sibling described how she felt when people stared at her family in public:

> …No, it is just [the] faces. They look at you. It is just the look…umm, sometimes I get really angry, sometime I don't want him to follow us because he doesn't want to listen. It is the fact that people just look at you. I don't want people looking at me. It is the fact that they don't know your story. Some people just judge you. They just look at you like can't you control your child. What is your child doing? Look at what your child is doing…(Sibling Okoye).

Yet another sibling described how she felt when she heard people in her church talking about her autistic brother derogatively using stigmatising language:

> I feel worried, because sometimes when we go out, there are people talking, sometime when we are at church or going to church, I hear people in the church say child Ibori is very weird. He has bushy hair, bushy eyebrows, and crocodile teeth (Sibling Ibori).

It is apparent that both sibling Okoye and sibling Ibori felt awkward in public places due to their brothers' idiosyncratic behaviours and/or physical appearance and the way people reacted to them. Other authors such as Waterson (2011), whose study was about the experiences of white families with autistic twins, found that negative comments surrounding the idiosyncratic habits of the autistic children, both in school and in public places, left the neurotypical siblings feeling embarrassed.

Due to fear of stigma and embarrassment, some of the siblings who participated in this study, such as siblings Ibori and Okoye, claim that, given the choice, they would not go out in public with their autistic brothers or sisters. They reported that their autistic brother/sister's behaviour outside the home is such that it would attract attention to their family group. This finding is similar to those made by Dowling and Dolan (2010). They suggest that siblings of autistic children miss out on experiences taken for granted by children from a family without a disabled child. For example, they reported that a sibling in their research group had not visited a cinema or a restaurant for many years as his parents could not take him and his disabled brother out in public, due to the latter's disruptive behaviour and the disapproval that this would incur.

Therefore, despite the presence of the behaviours associated with autism, and the perception of church members that child Ibori has an odd physical appearance, and their black racial identities, these siblings did not report that such experiences were influenced by their ethnicity. Therefore, it is unclear as to whether the combination of these multiple identity categories had made a great deal of difference to the level of stigma and embarrassment felt by the neurotypical siblings in this study. My findings are similar to those of other studies exploring the experiences of siblings from families with autistic children from other ethnic groups (Waterson 2011). However, there is a need for further research to explore whether occupying multiple identity categories, results in different outcomes for black-African neurotypical siblings of autistic children in the UK.

6.7 Conclusion to Chapter Six

In this chapter, I have presented findings in relation to the stigmatisation, rejection and embarrassing experiences reported by participants in this study. In the process, I attempted to show that, although the black-African families in my study had similar negative experiences to those of non-black-African families with autistic children, they had also experienced multiple intersecting layers of stigma, rejection and embarrassment. To support my argument, I showed that where participants had simultaneous ties to two geographical locations (Africa and the UK), they experienced rejection and stigmatising behaviours from family members in both Africa and the UK, as well as from the general public in both locations. However, I also attempted to show that while the experiences in Africa were due to a combination of disability, culture and personhood, in the UK, the mixture of race, disability and immigration intensified those experiences. From the perspective of the mothers in this study, I endeavoured to show that, in addition to other negative experiences, they had all been subordinate to their ex/husband/partners, some of whom had eventually rejected them. Therefore, I argued that, due to the presence of polygamous and patriarchal cultural practices in some African societies, the high value placed on male gender, being an African mother of a disabled child, living in the UK and maintaining links with Africa, the mothers in this study have deeper multiple and intersecting layers of stigma and rejection than the norm.

This chapter aimed to tease out some of the nuanced and specific experiences of these participants, with particular reference to: (a) feeling rejected and stigmatised in Africa as a result of negative attitudes to autism, (b) feeling stigmatised and discriminated against in the UK due to differences in ethnicity and race, and the perception of autism as ‘different’ or ‘odd’, (c) mothers in matrimonial relationships and their experiences of being rejected by present, part-present, or absent husbands/partners, (d) fathers having a second chance to marry or have a relationship, and to father a non-autistic son, due to the acceptance of polygamy in most African societies. These experiences are present for these participants, in addition to the common stigmatisation experienced by the wider groups of families with autistic children in the UK. I am not aware of any published research on the stigma experienced by families of children with autism or other disabilities that reported similar issues. Therefore, these ideas form part of my contribution to knowledge in this area. In the next chapter, I will present my findings in the context of African cultural values and belief systems. I will attempt to demonstrate how these beliefs inform their understanding of autism.

Chapter Seven

The Intersectionality of *Africanness* and Autism in Raising an Autistic Child in the Diaspora.

7.1 Introduction

The concept of ‘Africanness’ is the African philosophical discourse comprising a set of worldviews, interpretations and understanding as expressed by sub-Saharan Africans in oral and written texts (Chimakonam 2015, p. 33). Some autism experiences expressed by participants are influenced by the Africanness perception of disability. Thus, the intersection of African identity, cultural worldviews, and autism effectively combine to create multiple layers of autism experiences for these participants (Hetherington 2012). In order to make holistic sense of these experiences, it is vital to understand the intersecting roles of Africanness in raising an autistic child in the UK. The concept of Africanness does not assume homogeneity of African culture and societies, which are extremely diverse. Rather, its value is to identify patterns and nuances that exist within the context of autism and other disabilities. (For more details about the concept of Africanness, see section 2.6.1).

In this chapter, I explore some African philosophical viewpoints as they relate to and intersect with autism identity. This is because the participants are African-born, and have their roots there, whilst living in the UK. In order to unpick the intersection of Africanness philosophy and autism for the purpose of this thesis, and to show how the intersection between autism and African cultural worldview combine to form multiple layers of autism experiences for these participants. I will focus on the following themes in this chapter: (a) African kinship practices; (b) threats to lineage continuation; (c) African cultural expectations; (d) encouraging an autistic child to be respectful and obedient; (e) being an African father to an autistic child; and (f) African spiritual and cultural worldviews about autism. In addition to the common experiences of families with autistic children in the UK, participants' experiences have also been intersected by African worldviews as explored in the six themes set out above.

7.2 African Kinship Systems: 'I've got a big family…I've got lots of family, but they're all over the place'.

In this section, I describe how participants attempt to maintain their African cultural identity by committing to their kinship practices. I will also attempt to show how kinship practice adds another layer to the participants' experiences as parents of an autistic child living in the UK.

Often, when an African, (and specifically the participants of this study) talk about 'family', they refer to members of a wider network who share lineal, affinal, consanguine, and collateral clan and kinship relationships (Bascom 1942; Gluckman 1949; Sahlins 2011a; Sahlins 2011b; Bjork 2007). For example, to illustrate the breadth of her kinship familial network, Ms Kama said:

> I got a big family here in the UK. I got family here, in Northampton, and in Cricklewood. I got lots of family, but they're all over the place. I am the only one here (Ms Kama, Gambian).

Another parent indicated that she has a large family, including some distant family members who live in France. She said:

> It was very difficult, but my husband was working. He never had any problem. He was working but it was very difficult to meet the needs of the children. And obviously it was, like the time when...that is why *the family*, *my family* had to come from France.

> They were coming all the time, because I could not go anywhere. (Ms Dibango, Cameroonian).

Ms Kama's illustration of her 'family' composition is typical of African familial social organisation, known as clan or kinship relations (Ferrara 2003; Evans-Pritchard 1951; Holmes 2000; Khunou 2012). Ms Dibano also alludes to having a large family who are helpful. It is interesting to note that Ms Dibango uses the phrases *the family* and *my family* in quick succession in one sentence in the extract above. This suggests that she was trying to indicate that *the family* is the wider network of kinship relations, or people who come from the same clan as her; while *my family* is the immediate members of her family, including brothers, sisters, cousins. For example, where kinship is practised, your 'brothers' or 'sisters' are not necessarily your biological siblings, and your 'aunts' or 'uncles' do not have to be your parents' siblings. The clan and kinship relationships persist through time and survive because of the commitment to foster African cultures and ideals in the diaspora (Sahlins 2011; Bjork 2007).

Due to their determination to stay close to their African heritage, most of the participants in this study strove to maintain links with their ancestral homes. They achieved this by frequently returning to Africa to introduce their children to their kin. They also use the opportunity to come together for celebrations and ceremonial activities, and to show that there are offspring who will continue the family lineage into the future. Eleven families in this study had travelled home to Africa, accompanied by their autistic children, at least once. Another set of five families said they were planning to travel, and some had expressed a wish to travel home, once their UK immigration status had been confirmed. For example, Mrs Okoye tried to explain the purpose of her travelling home to Africa:

> We go for holiday. We just returned from a holiday in Africa, and it was a beautiful weather and he was able to know the relatives and know what is going on in the family. He knows his aunts, cousins and uncles, yes (Mrs Okoye, Nigerian).

Mrs Okeke and sibling Okeke also said:

> Yes, I did. We went there last December. [sibling Okeke, I love going there]. I have been with him 3 times to Nigeria. He has a big space in the compound there. He climbs over the goat. Using the goat as a horse. Laughs. Every morning after bathing him, he will come out and start climbing on a goat, running after them. I say they are goats not a horse. [sibling Okeke: they decorated a goat, they put Christmas tinsel]. (Mrs. Okeke and Sibling Okeke, Nigerian).

Barnes-Dean (1986, p. 335) says that 'Africa has the greatest proportion of unilineal societies of any area of the world, and of these, the majority are patrilineal'. The unilineal pattern is the process of tracing an individual's genealogy through their male or female ancestors (Brown 1951; Barnes-Dean 1986). Other scholars of African cultural family systems have written about the importance that some Africans, including those in the diaspora, attached to maintaining their kinship ties (Kuper 1982; Brown 1951; Silveira and Allebeck 2001). For example, Brown (1951) claims that the lineage and clan system is an enduring family system in Africa. She argues that it survives even when 'off-shoot' descendants established homes elsewhere. She added that these off-shoots would continue to associate with the lineage or clan for generations, sharing the same surname, returning to the ancestral home for activities or ceremonies/celebrations. Brown's claim was supported in recent literature. For example, Bjork (2007) points out that Africans in the diaspora are continuing the trend. To further support the claim that the lineage and clan system still exists in Africa, other writers on African social systems show that lineage and kinship ties are still maintained in some contemporary African societies (Ritcher and Morrell 2006; Spronk 2009; Kuper 1982).

For example, Kuper (1982, p. 71) states that the 'stubborn' (omnipresent) lineage or descent social structure is still practiced by Africans, and Holmes (2000, p. 4) describes 'clan and lineage as the structural truth of African society'. However, in his study of a group of 'young professionals' in Nairobi, Spronk (2009) argues that globalisation and urbanisation is slowly having an impact on African lineage and kinship practices. But Spronk goes on to state that 'many of them [young professionals] migrated to Nairobi to work, while maintaining a bond with their rural 'homes' – giving a helping hand, participating in local organisations, or building their own house in the family compound as custom required' (Spronk 2009, p. 503).

For the parents in my study, the combination of maintaining kinship links with the wider network of families in their clan and their ancestral home, the responsibility that they have in sustaining such relationships, and the potential interest of clan members in the affairs of these participants make them important stakeholders. As a result, meeting these expectations add another dimension to the multiple layers of autism experiences, which are unlikely to concern parents from other ethnic groups.

7.3 Threats to Lineage Continuation about Autistic Children: ‘In Africa you expect that your son will take your place after you have gone…’

In some African societies, a male child acquires certain gender roles, duties, obligations and responsibilities from birth, and reciprocity is automatically assumed. These values and others consolidate the idea of continuity, collectivism and communism in those societies, making the concept of individualism unattainable (Ferrara 2003; Mokgoro 1998; Donohugh 1935; Kim 2012). The continuation of social obligations and customs is most valuable if it can be transferred to future generations. Therefore, most black-Africans are likely to have these values entrenched in their subconscious (Brown 1951; Khunou 2012; Kuper 1982). The duty and obligation to give birth to a male child, a credible successor to continue a patrilineal lineage into the future, is an inalienable responsibility (Dyer 2007; Hollos and Larsen 2008; Ibisomi and Mudege 2014; Baba 2014).

Some of the participants in this study were acutely aware of the importance of this. But they also expressed some consternation at the threat posed by autism to the capacity of their male children to succeed them, and to continue kinship duties. To illustrate the importance of the male child in continuing family lineage, Mr Achebe had this to say about his autistic son:

> But [I] also wish he can go home and take up his position. I suppose he has to be independent to be able to do that…. (Mr Achebe, Nigerian).

Mr Achebe implies that, as a male child, his son is expected to assume a specific status in his kinship system, exclusively reserved for the male gender. But he was also worried that his autistic son was unlikely to achieve this objective. For Mr Achebe, his son must be both independent and willing to take that gender specific position.

When asked about his thoughts on the impact of autism on his twin sons' ability to continue his family lineage, Mr Adisa replied:

> That aspect is something that is a bit worrying for me, and I just think that, are they gonna grow up and have a relationship, a wife, and would they be capable of being in a relationship or socialise with other people, or get married and have kids, you know. So that is a big, a bigger worry for me. I don't know how that is gonna happen. (Mr Adisa, Nigerian).

Mr Yeboah also commented:

> Now I understand exactly where you are coming from, but what can you do? It has happened, so. what can you do, but you embrace it. It is a challenge, but... yeah it is something we think of, and I have thought of it. Its not much you can really do about that. [pause] [*disappointment, pain, helplessness detected in the tone of his voice*]. In Africa you expect that your son will take your place after you have gone...[pause] its hard, really is [tears welling in his eyes]. (Mr Yeboah, Ghanaian).

The threat of autism to the continuity of his family lineage was hard for Mr Yeboah to express verbally. He sounded worried, anxious and disappointed because of this problem. He appeared to be giving up any expectation that his only son could continue his family lineage. He seemed to have accepted the situation, but at the same time he appeared to be struggling with the thought that he had let down his ancestors and his kinsmen.

Mr Aguda shared similar sentiments about his autistic son's future in the following verbatim quote:

> And then, my fear is that when this started, initially, I had no fear, because in medical there is something we refer to as history, or gene, family background. …, my kind of

> family, her kind of family, I was saying I didn't have any problem that any of my children would be 'dullard' or will not come out well in school, because I knew my ability when I was in school, I knew her own ability to date. I knew the kind of lineage I came from. I know the kind of lineage she comes from. So automatically, that will transfer…but I can't say that about him now. I doubt if he carry on with the lineage. Because he is way apart from how I was when I was his age. …I mean, Am looking at his future, am like it is not so bright. It doesn't look well at all. Because I expect him…, …it is every parent's desire or wish that if you have a child, you think big of the child. To be honest, when I had him, I was thinking big of him, that this is going to be one of the most brilliant individual, coming from the kind of background me and my wife came from. (Mr Aguda, Nigerian).

Mr Aguda was beside himself with grief at the perception that his son is unlikley to continue with the family's human pedigree. Unlike Mr Yeboah who sounded as though he has come to terms with his disappointments, Mr Aguda remains deeply upset and incredulous about what he thinks is a dismal future for his son and his family. Mr Aguda is thinking that his son is unlikley to achieve educational success and unlikely to step into the cultural male gender role, threfore the chances of him continuing his family's lineage into the future is slim.

Dyer (2007) argues that in Western countries, men and women are motivated to have children mainly for personal reasons, including personal fulfillment, and for conjugal security and self actualisation. However, in accordance with African worldviews, the purpose of having children goes beyond personal reasons. In most African cultures, men and women are motivated to have children because of the duty to continue family lineage and ensure inheritance, for assistance in domestic and business tasks, for security in old age, for obeying religious doctrine to reproduce, and for other reasons such as joy, happiness, companionship, respect, recognition and social status (Okonofua et, al. 1997; Ibisomi and Mudege 2014).

I am not suggesting that the importance of lineage continuation or the consciousness of the same is peculiar to these participants or to Africans alone. Other ethnic groups, such as Jews (Egorova 2009) and the Japanese (Kumagai 1995), for example, also practice and value lineage continuity. For example, Kleiman (2004) reports that the descendants of the Jewish ethnic group have an inalienable duty to perpetuate their family lineage.

7.4 African Cultural Expectations

All the parents who took part in this study had migrated from sub-Saharan African countries to the UK at various points. Parents who gave birth to autistic children in Africa came to the UK in search of better services for their offspring, whereas parents whose autistic children were born in the UK, post-migration, came to the UK in the hope of improving the quality of their lives. However, achievement of this aim was threatened by having children with autism. Also, in keeping with the Africanness philosophy and kinship systems, these parents have personal and cultural expectations, which may not be realised due to the challenges imposed on them by having an autistic child and living in the UK. As a result, it is likely that these parents have learnt to adjust and adapt to changes imposed by autism (Renzaho and Burns 2006). But they are also continuing to hold on to some of their cultural values. For example, Mr Ibori, who was among the group who gave birth to their autistic child in the UK after migration, said:

> So, money was not the issue. We are not into..,we do not think of income support, DLA [disability living allowance], all those things. Am against it, people going for benefits. I worked hard as an immigrant…. I take care of 14 people back in Nigeria…(Mr Ibori, Nigerian).

In this section, I will show how the combination of autism and other identities interfered with the cultural obligations to care for aging parents and to assist other relatives, and the cultural expectations regarding parenting autistic children.

7.4.1 The Threat to the African Duties and Obligations to Care for Aging Parents and Kin.

In accordance with Africanness philosophy, assisting members of one's kin is part of a collective duty and responsibility, because reciprocity can transcend generations. In other words, everyone is expected to offer help, tangible or otherwise, and to care for one another in times of need. For example, where a huge favour was offered and the original benefactor was unable to pay it back, their offspring could reciprocate (Ferrara 2003; Cobbah 1987). For example, Mr Ibori shared how he was committed to assisting members of his kinship group who live in his home country:

> …I am saying this from my own point of view, but heaven knows my heart...Just the other day, I was explaining to my wife how much we have spent so far for the month… I do it. Normally, I have poor people in my family, poor people at home. That is my calling in life…(Mr Ibori, Nigerian).

Mr Ibori believed that he was duty bound to give financial assistance to some members of his kin who were in need. He felt that his altruism gave him personal satisfaction. Mr Ibori had created an expectation for himself, implying that the people back home relied upon him to survive, and expected him to continue assisting them indefinitely. At the same time, he was thinking about how to raise his autistic child.

Another participant fulfilling the cultural obligation of assisting other members of her kinship group was Ms. Kama:

> …I am the oldest [among my sisters]. I am going to be 37 next month. They've all got children before I did. They are always calling me every time for school fees, and this, and that. But that is not good. They are not working and I am looking after their children. Where is my legacy? That is why I put myself under pressure to have my own child. Am like, if only I had waited. If only I had waited, but if only doesn't matter in this case isn't it. It already happened. (Ms. Kama, Gambian).

In addition to the pressures of working hard to earn a living and caring for her autistic son, sending money to her kin in Africa placed another layer of demand on Ms. Kama. Initially, Ms. Kama felt she had the kinship duty to support her sisters in Africa financially, but she doubted that it would be reciprocated. She resented the fact that her younger siblings had children while she did not. There may be other reasons why Ms. Kama subjected herself to the pressure of having her own child, but she states that she wanted to have her own child in order to have a reason to stop assisting her kin. Ms. Kama seems to regret that she stopped fulfilling that cultural duty and rushed into having her own child who was autistic. Whilst she did not express this, it is reasonable to infer that she felt that if she had continued her altruism for a little longer, she could then have met a different partner and had a 'normal' child with him. In other words, she is implying that having an autistic child is somehow linked to her withdrawal from her kinship obligations. Failing to fulfil a kinship obligation such as this could be regarded as 'infractions relating to the ancestors' (Brown 1951, p. 270), leading potentially to the imposition of sanctions or an ancestral curse (Khunou 2012;

Barnes-Dean 1986; Noon 1942). For example, Brown (1951) reports that, in some parts of Africa, people believe that ‘those who failed in kinship obligations or committed offences against their kinsmen could be punished with moral…sanctions’ (p. 267). Similarly, Sahlins (2011) writes that in parts of Africa and in New Guinea, ‘ancestral punishments’ await anyone who fails in their ‘lineage or kinship’ duties such as this (p, 232).

Some participants reported that they had a cultural duty to look after their aging parents in Africa. Therefore, they expected that their own children would do the same for them in the future. However, some also expressed concern that their autistic children would be less likely to continue fulfilling this duty, which is passed down through generations (Annor 2014; Ardayfio-Schandorf 1996; Khunou 2012). Traditionally, the general expectation is that a parent cares for and raises a child, who is then expected to reciprocate by caring for the parent in old age. Mr Aguda, who had hoped that his children would care for him in old age, doubts this:

> Well… that is part of our prayers. That is partly what we hope for. That is why we have faith, in the grace of God, that things cannot go on like this with him. I mean the more he develops, he will get more understanding of what life is, appreciate life, appreciate parents, friends, people around him. … he can at least be able to understand that, at least these are my parents, these are people that cared for me. He will be able to say, ok, let me respond to them when they grow older as well… (Mr Aguda, Nigerian).

Mrs Okoye also expressed similar sentiments:

> ummm, wow! It kills the heart isn't it. Because a child is born to look after you. Because you have given to him, so you expect….[child interrupts] . So, yeah, in that, I can’t, I can’t I don't see that coming. But I believe. I believe. (Mrs Okoye, Nigerian)

Both Mr Aguda and Mrs Okoye seem to expect that their children are economic assets, a form of familial social security for old age. Mrs Okoye’s comments also seem to suggest that she strongly believed that it was her inalienable right that her children must look after her in old age. The strength of her conviction also suggests that, if her autistic son was ‘normal’, she would have continually reminded him of this duty, until the son felt almost indebted to his mother. The son would then feel guilty if he was unable to carry out this duty of care, or feel gratified if he did. Other African scholars have confirmed that, in Africa, children have an inalienable duty to care for their parents in old age (see Annor 2014, and Ardayfio-Schandorf 1996). According to Mensa-Bonsu and Dowuona-Hammond (1996, p. 16) ‘a child has first and foremost a moral obligation to care for aged parents…owes an obligation to look after their parents in old age…is under obligation to pay his mother’s [parents’] debts…and is liable for his father’s [parents’] coffin’.

It is within this context that Mr Ibori doubted whether his first son, who is autistic, was capable of carrying out his moral duty to bury Mr Ibori after his death. Mr. Ibori said:

> My fear is what I pray about every day... I want my son standing before my body, leading the back with his siblings behind him. So, when I am closing my eyes to eternity… give me..., even if at that point, at that age, if he is not by himself, pick people that can help [him] outside of my family... (Mr Ibori, Nigerian).

Although Annor (2014) recognises the importance of the moral obligation of adult children to care for their aged parents, he points out that this obligation is vital because of poverty and the lack of a social security system for the elderly in Ghana, and in most sub-Saharan African countries. Annor goes on to state that due to migration, hardship, and the stress of family and work commitments, some grown-ups in Ghana are struggling to meet this cultural and moral duty. But, despite these barriers, the pressure to care for the older generation remains. However, in the UK, social security, pension schemes, funeral plans, and other economic, social and welfare benefits are robust and are available for the elderly. Therefore, if their autistic children are incapable of caring for them in old age, or unable to bury them at death, support is available from the UK welfare system. These participants should be aware of this, but it appears that, perhaps subconsciously, they are still holding on to the cultural beliefs and expectation that their children have a moral duty to care for them in old age. Indeed, they themselves are currently caring for their own elderly family members, so they expect their children to reciprocate. Therefore, the possibility that their autistic children might not meet these moral obligations is hard for them to contemplate.

In African culture, the act of transferring care of an elderly parent to a child is a complex process, which is thoroughly explained by Pavlovian Classical Conditioning and Skinner's Operant Conditioning theories (see Hahn 2013). For example, African parents repeatedly tell their child from an early age that the child was born to help them in old age, until the child becomes conditioned (Renzaho and Burns 2006). When the child grows up and has their own children, they transfer that belief to their offspring, and the cycle continues. As an African myself, I am familiar with this process. But for most African children in this study who were diagnosed with autism, it is highly unlikely that they would absorb or put into practice the cultural expectation of caring for an elderly parent. Mrs Okoye’s expression: ’*wow! It kills the heart’* is a summation of the depth of her feeling about this matter, which other parents in this study also shared. Therefore, they worry for their future because it seems less likely that their autistic children could care for them in old age. This situation constitutes an additional layer of stress, and a source of anxiety to the participants. When combined with the challenges of raising an autistic child, it is obvious that these parents were experiencing multiple layers of expectations, duties and responsibilities due to the combination of autism and the moral obligation of Africans to care for their elderly relatives.

7.4.2 The Influence of Africanness Philosophy on Parenting Autistic Children

The cultural expectation regarding parenting a child in an African context differs slightly from the West (Khunou 2012; McWilliam 1974). For example, from an early age, children are taught kinship values, communalism, discipline, respect for elders, and how ’individual rights are therefore interconnected with a duty to community’ (Owor 2012, p. 216; Ferrara 2003; Ritcher and Morrell 2006). Parenting a child in most sub-Saharan African countries entails training them to integrate into society as a functioning part of the social mechanism (Ritcher and Morrell 2006; Gray 1995; Donohugh 1935). It is part of their education, aimed at preparing the child to participate fully in the activities of their own community and the wider world. Although parents have primary responsibility for raising their children, in most African cultures, it is also a collective responsibility of the kin, the community and the society at large (Ritcher and Morrell 2006; Brown 1951). As well as birth parents and other family members, the wider community may care for, supervise and promote the wellbeing of children, especially if their parents were absent. They can intervene to prevent a child from coming to harm, reprimand or smack them, and report them to their parents if they were mischievous in the community. The collective care system in Africa exposes children to the risk of abuse, but this is beyond the scope of this study. Nonetheless, family members and the community in Africa educate children about cultural signs and symbols and how ’proverbs, songs, narratives and prayers…[idioms and other] visual-oral knowledge’ are used as a form of communicating thoughts, feelings and customs/culture (Somjee 2000, p. 98). These and other principles are what ’collective responsibility’ means in the context of raising a child in an African culture (Khunou 2012, p. 317).

Ms Mensah understands this cultural practice, as she refused to give up her son for fostering by a total stranger:

> Oooh, [blows out some air]. They come with my son is going for fostering because of funding, and I say to them, where I come from we don't go fostering. Even if I am gone, or God forbid, I am dead, or I am not well, I have people whom I can delegate to take care of him. (Ms Mensah, Ghanaian).

Ms Mensah was both a qualified registered nurse and the single mother of an autistic son, and a neurotypical daughter. The threat of autism to her son’s development meant that she needed alternative care arrangements for him but was reluctant to accept foster care services. I infer that Ms Mensah, who was born and raised in Africa, recognises the benefits of having family members, rather than strangers, helping to raise her son. Her reluctance implies that she was not accepting the impact of the combination of autism, child development and life in the diaspora, where the African cultural practice of child rearing has been superseded by the UK social care system of alternative childcare. This is because, in the UK, she had no kinsmen available, a change imposed as a consequence of living in the diaspora.

For Mrs Bankole, the impact of Africanness on parenting her autistic son in the UK was presented by her family members. They had expected Mrs Bankole to use physical punishment, including depriving child Bankole of food, and using physical punishment to force him to speak and respond/obey to instructions. Ms Bankole said:

> Well…, initially people were like beat him, starve him. If you don't give him food he will talk, and all that [family members?], yeah. because we've grown up…We have always grown up to be tough, I mean we grow up from the part of the world where hitting, smacking and starving is not prohibited like it is here in the UK. So, they've always said…that by the time I smack him 2, 3, 4, 5 times he will hear me…. So, …why don't you just call his attention by beating him (Mrs Bankole, Nigerian).

Some writers on African cultural practices report that, in Africa, parents use smacking to force children to behave well (Marck 1997; Ritcher and Morrell 2006). Ritcher and Morrell argue that 'children learn from smacking to respect their elders; that physical punishment is a necessary part of their upbringing' (p. 215). This principle informed the decision by Mrs Bankole's family to recommend the use of physical punishment when trying to manage the challenges of parenting her autistic son in the UK. From this, I would infer that Mrs Bankole was experiencing multiple layers of pressure, emanating from interference by the wider family, cultural expectations, the requirements of the UK socio-cultural and legal system, her own personal beliefs about parenting, the fear of failure, and the reaction of other people.

African cultural scholars have reported that the so-called traditional African cultural way of life, encompassing child-rearing methods, collective responsibility, and smacking, is undergoing gradual change (Addai-Sundiata 1996; Annor 2014; Ritcher and Morrell 2006). Addai-Sundiatta (1996) opines that, in Ghana, due to changes brought about by economic and financial pressure, migration from villages to cities, social mobility, changes in traditional roles and the authority pattern between men and women, the collective responsibility of 'the descent group and the household are losing some of their traditional importance'. But Addai-Sundiatta (1996) states that 'in spite of all the changes, however, the family system and the African concept of the family persist' (p. 64). Similarly, Gallinetti (2006) writes that of the eleven countries, which outlawed all types of physical punishment of children, none of them originated from an African country. However, in her research with some black-African migrant men working in the mining industry in South Africa, Rabe (2006) reports that some of them 'highlight the fact that they do not make use of physical punishment when dealing with their children's misdemeanors…many prefer talking to their children or reprimanding them' (p. 259). Rabe's comments suggest that the practice of smacking children is also changing in Africa, and although Gallinetti (2006) claims that it is not unlawful in most African countries, some African countries are starting to outlaw it (Save the Children 2012). But Galinetti (2006) insists that Physical punishment is widely practised in Africa and, 'it never did us harm' (p. 215). Based upon the accounts of my participants, it is reasonable to infer that they still retain their African beliefs and practices regarding collective responsibility in child care, and the use of smacking as a method of disciplining a child when they misbehave, even after living in the diaspora for several years. But living in the UK has affected their ability to apply these practices, because they cannot fully apply African parenting practices (Goldsworthy 2010), a sacrifice which contributes to their multiple layers of autism experiences.

7.5 The Challenges of Preparing an Autistic African Child to be Respectful and Obedient

Respect and obedience are very important African cultural values, as demonstrated by Khunou (2012). The extent to which a child obeys instruction and shows respect to an elder determines how society rates the quality of their upbringing. A child's compliance with these principles, reflects that their parents were good at parenting, and that the child was/is a source of pride to the parents. Therefore, most parents do their best to inculcate these principles in their child from an early age (Salami et al. 2016). But for parents of autistic children in this study, it was a challenging task. The parents who gave their autistic children some home training on the principles of respect and obedience, described how they persistently taught them how to greet, but the ability of the children to develop these cultural values were undermined by autism. Despite the lack of a positive response from their children, the parents did not give up:

> This was a constant battle, you know. Waking up in the morning and saying good morning, good morning, good morning. It didn't matter that they weren't saying it, but I was spending….it was very consistent…My life was like that of a robot…Every morning for about 5 minutes, it would just be… I kneel down and look into their eyes and say hello! Good morning X4, say good morning. Say good morning mummy, good morning daddy. And it was like that, like that. And I will say it up to 10-15 times to each one of them. I wasn't getting frustrated that they weren't saying anything…Their time

> was so managed that there wasn't a time of not doing anything. If they were playing it was learning, they were eating it was learning (Mrs Adisa, Nigerian).

In the West, greeting others is usually about acknowledgement and recognition. But, in most African cultures, greeting is much more than mere recognition. It is an indication of respect for others, a measure of the quality of a child, and evidence of a good parenting outcome (Mokgoro 1998; Kim 2012; Xue et al. 2014). This is partly why Mrs Adisa had put in a great deal of time and effort to train her children in learning to greet others. On account of the large family structure, it is expected that by absorbing the value of respect, it will further enhance the acceptance of the child in the family, and in the wider African community.

However, when her efforts did not yield the desired outcome, she decided to 'train' her own parents instead, preparing them to meet her twin boys for the first time. To avoid significant culture shock, she played for them a video of Temple Grandin, a famous American woman with autism:

> I wanted them to see the video, before they eventually meet the boys…And I think, eventually, when the boys came and they met them, and all of that, it was good for them, because they learned how to approach them. Because I said to them from the beginning, if you come through the door, don't expect them to run to you and give you a hug, saying grandma, grandpa. It is not gonna happen just yet. They would walk away, or they will just walk pass you. or they would push you to leave or whatever. But it was important for them to see how my children were going to accept them. Rather than thinking that it was because they weren't brought up properly. And I think that prepared them…(Mrs Adisa, Nigerian).

Mrs Adisa had shared elsewhere in the interview how her mother was always calling her on the phone from Nigeria to monitor how the children were developing. Mrs Adisa said she felt overwhelmed by her mother's intrusion, to the extent that she started to avoid her calls, until her father intervened to stop her mother from harassing her.

I infer that Mrs Adisa knew that she could not rely on her children to respect their grandparents, because of their autism, so she had to train her parents instead. However, I believe that the grandparents would have felt disappointed that their grandchildren failed to show them respect and recognition. Mrs Adisa had not been completely open with her parents about her autistic twin boys, prior to their visit. She had been avoiding their calls, and her mother had been critical of her parenting skills. She had given Mrs Adisa advice about using physical punishment to modify the boys' behaviour, encourage them to speak, and to force them to eat a variety of foods by pinching their noses while they were feeding. However, Mrs Adisa did not follow her mother's advice, but confirmed that those practices were how she herself was raised in Africa. It is possible that her parents had perceived that she was unable to parent her children in 'the African way'.

Similarly, Mrs Bankole reported that she spent a lot of time teaching her autistic son at home about greetings and respect, but she soon discovered that her efforts did not quite pay off. Ms Bankole said that she once had a visitor from Nigeria who had a long beard and her son embarrassed the man by pulling on it:

> …With the autistic children what you see is what you get, so he had this funny beard he had, and so when he came, my son was pulling on it. He said

> whiskers, you got whiskers like a cat. He is got whiskers like a cat. We laughed. I was telling [him] no, no, it is just his beards. But because it was long and grey in colour, he associated it with a cat. And for him [the visitor] it was strange. I said to him, …It is how he ees it, and he associated…because your beards are flickered up like whiskers he called it a whisker. That is what he conceives it to be (Mrs Bankole, Nigerian).

It is well documented that autistic children have deficits in social communication, interaction, and imagination (Baron-Cohen 2005; Wing and Potter 2002; Frith 2008). Frith (2008) reports that autistic children have limited ability to apply a learned skill to a similar situation in a different setting, due to poor theory of mind (Baron-Cohen 1997; Frith 2008). Therefore, the expectation imposed by these parents on their autistic children to learn and apply some cultural values and ideals might not be realistic.

In most African societies, respect is an important cultural value, and it can be practised during various social interactions. One example is refraining from making eye contact during conversations with a senior person (Weru 2005; Slade 2014). Ms Kama alluded to this value:

> …because they say oh, your child doesn't make an eye contact.…Because I know in African culture, you are not supposed to look at people in their eyes. That is what I used to do when I started [living in the UK]. I did my interview here, I did my nursing training here…(Ms Kama, Gambian).

It is well documented that autistic children do not usually make eye contact (Weru 2005; Frith 2008). In Western culture, the inability of an autistic child to make eye contact is often perceived as a social deficit; in African culture, the trait is considered a strength. In that culture, when a child does not make eye contact with an older individual during a conversation, it is deemed as a symbol of respect (Slade 2014; Bakare and Munir 2011). Therefore, the impact of autism on the development of an African child in this study means that they are naturally unlikely to make eye contact with an older person. Their lack of eye contact could, therefore, be mistaken as a sign of respect, rather than an autism trait.

The role and contribution of an extended family to training a child about his or her kinship values is not diminished by distance. Kinsmen and women who live in Africa offer suggestions, advice and instruction to parents in the UK about how to raise their children in a culturally acceptable way. A number of parents reported how some extended family members had criticised their parenting styles, or gave them advice about how to discipline their children when disobedient or showing disrespect. Mr Ibori gave an example, using advice that his senior brother, who lives in Africa, gave him over the phone about lessons on how to get respect and obedience from his children:

> My senior brother, he was talking to me on the phone, he is the head of our family. He said you and your children are very close. Are you happy about it? I said yes. He said well I should try and ummm…that they will not respect me. I said well, I see where you are coming from, but in this house, they know who is dad (Mr Ibori, Nigerian).

In the comments above, Mr Ibori is saying that his elder brother was trying to warn him about being too close to his children, because this could lead to boundary erosion issues. Should the boundary between Mr Ibori and his children be eroded, the children may not respect and obey him.

Mr Ibori felt the need to point out that the senior brother who advised him about how to gain respect from his children is the ‘head’ of his family. He implied that he has other brothers, but this specific brother is the most senior, respected, and powerful. In kinship practice, each elementary family forms part of the extended family, and parental authority converges with that of the extended family head, who would usually be the senior male across one generation or more (Barnes-Dean 1986; Ritcher and Morrell 2006; Brown 1951). The senior male is usually referred to as ‘father’, and holds overarching parental responsibility, along with other rights and responsibilities (Khunou 2012; Gluckman 1949; Brown 1951). The head of a family is also the custodian of the moral codes of the family or clan, and he is also a link to the ancestors (Baumann 1928; Brown 1951; Khunou 2012). Mr Ibori recognised and respected that role, acknowledging that it is culturally acceptable for the head of the family to intervene in an issue affecting his family members, or to intercede if he believes that his members are deviating from kinship values. His younger family members have a duty to respect and to obey him.

Obedience and loyalty are also important values in African culture (Brown 1951; Bascom 1942; Khunou 2012; Ferrara 2003). Some of the parents in my study alluded to this principle in their responses. Due to the threat of autism to the development of these African children, it is unlikely that they would comply with certain African social rules (Brown 1951; Khunou 2012); and their non-compliance could be perceived as disobedience (Ferrara 2003). Most parents in this study reported that their child showed disobedience to them in public places. They refused to, or were incapable of complying with general social rules and boundaries, some of which were specific to

African culture. Some parents also perceived their autistic child's disobedience as a serious failure on their part to adequately train the child. Mr Ibori gave an example with his son:

> My pain. Because I was so strict towards him. You know the background we came from…I parked the car and we were walking to the school. He dropped his bag and he did not tell me. Because I was walking by his side, I didn't know that the bag was behind us. It had dropped, I didn't know. I said where is your bag, he said don't know. I looked, and the bag was behind us. God forgive me! I flogged him when we came back home. I still cry when I remember it. Nobody knew what he was going through. In fact, I, when I cry, when I am alone, I cry from the point that if I had cognizance of what he was going though…I was ignorant. I was harsh. I was strict. I would smack him. I would call him a fool. It is emotional for me….silence…[tearful]. (Mr Ibori, Nigerian).

When child Ibori defied his parent, by dropping his bag on the way to school, Mr Ibori decided to use physical chastisement in order to deter his child from repeating this behaviour. However, when he realised that this did not yield the changes he wanted, he perceived it as a serious disappointment, due to his inability to raise his child in a socially and culturally acceptable way. As a black-African myself, Mr Ibori felt that we shared common cultural values, which researchers from a different ethno-cultural background would not share. He expected me to understand the cultural rules of social engagement, which define a strict, disciplinarian parent as a common expectation in many African communities. He felt that I understood what that experience meant to him, and I did. His 'pain', which culminated in him weeping, is much deeper than the expected generic feeling of remorse about his strictness towards his son. His pain encompassed much more than a lack of understanding of his son’s autism. His pain and weeping were a combination of these emotions, but the fact that his first son is unlikely to meet African cultural expectations and to continue the kinship ideal is far more an indication of Mr Ibori’s perception of himself as a failed African father. In essence, his ‘senior’ brother and head of his family was already indicting him for being ‘too soft’ with his children, reminding him of his duty to pass on the family’s cultural values to the next generation.

The failure of these autistic children to learn and apply these values reflect that their ability to maintain and continue some of their parents’ African values, already intersected by autism, is at peril. If an African autistic child is unable to practise one of the most basic values - to respect and obey - they are unlikely to practise other more complex African cultural principles, such as caring for their parents in old age, supporting members of the kin, and passing on their African cultural values to successive generations. Therefore, the continuation of the kinship and lineage system could be under threat from the next generation, due to the intersection with autism. Moreover, the value placed on African cultural practices of respect and obedience to which these parents refer, confers an additional layer of responsibilities and expectations on them. I would argue that these responsibilities add to any stress brought about by the challenges of coping with behaviour associated with autism (Waterson 2011; Neely-Barnes et. al. 2011).

In the next section, I will discuss what it means to be an African father to an autistic child, whilst living in the UK.

7.6 Challenges of Being an African Father to an Autistic Child: Changes in Gender Roles?

Having a son is important to most African men, and being an African father to that son, especially one with autism, (Baba 2014) adds an extra dimension to the complex cultural gender role of fathers in some African cultures (Baba 2014; Lesejane 2006; Hollos and Larsen 2008). Added to these complexities, is the role that kinship practices play in fatherhood. For example, Ritcher and Morrell (2006, p. 13) argue that ‘in many African contexts, being a father has more to do with kinship ties than medically established paternity’. In other words, the role of fatherhood extends beyond the biological link between child and father. Some participants in this study spoke of the roles of an African father, and the challenges of being a father to an autistic child.

For example, Ms Dibango seemed to understand that, in an African culture, fathers have a traditional gender role in the family:

> I was kind of doing it most of it on my own, it was kind of because their dad was not [interested]...it is an African thing (Ms Dibango, Cameroonian).

Ms Dibango’s comments suggest that she was feeling frustrated and overwhelmed by the pressure of caring for her three autistic children alone, without sufficient support from her husband. Although she is unhappy that she was playing the role of primary carer, she appears to recognise that African fathers are not traditionally expected to care for their children (Annor 2014). For example, Prinsloo, (2006, p. 137) argues that

’bread-winning is what fathers do, and this in a public arena’. In other words, fathers usually work outside the home to provide for the family. As a result, they are less likely to have the time to physically nurture their children (Mensa-Bonsu and Dowuona-Hammond 1996). However, it is well documented that gender roles are shifting in Africa (Peacock and Botha 2006; Silberschmidt 2001). For example, Silberschmidt (2001) reports that in Kenya, where the male gender role is culturally defined, some men in her study were unable to fulfill the so-called traditional male gender roles of breadwinner and head of household, due to economic hardship. But ‘the understanding of gender roles are so ingrained’ (Desmond and Cos 2006, p. 230), while gender inequality remains entrenched and continues to devastate women’s lives’ (Peacock and Botha 2006, p. 282) in African culture, to the extent that Ms. Dibango has come to accept the African father’s traditional gender role of being present, but absent in child rearing as a norm. Elsewhere in the interview, Ms. Dibango had reported that her husband was working and providing for the family while she stayed at home to care for the children.

In contrast, Mr. Adisa and Mr Kromah each suggest that they might have broken out from the traditional African father, male gender role. Mr Adisa decided to become a stay-at-home father to care for his twin autistic sons, while Mr Kromah carries out intimate personal care for his 12 years old son. Mr Kromah said:

> As you can see, at his age [12 years old] he still relies on us 100%. Instead of him doing things for himself, we have to do it [for him]. You can’t leave him on his own, you bath for him, clean him up [wipe his bottom], and everything else. His needs come first before anyone else in this house. So, yes it has massively affected me, and it has changed whom I am. (Mr Kromah, Liberian)

Mr Adisa reported that he:

> Like, take them to school every morning. I bath them every morning, I cut their hair because they wouldn't allow anybody to cut their hair, I brush their teeth, they would not allow even their mum to brush it. I go out with them to therapies and all [of] these other places. I am fully involved in their lives 100%...there is nothing, umm.. I am well grounded. I am ready to support them in everything. My mum doesn't know what it is about. She is not educated. If I am telling her she will not understand…(Mr Adisa, Nigerian).

Mr Adisa and Mr Kromah's comments suggest that their mindset about their male gender roles of fatherhood reflects the changing perception of the traditional African male gender role, which increasingly favours a new model based upon liberal and gender equality principles (Peacock and Botha 2006). However, Mr Kromah's lamentation suggests that he is reluctantly accepting the gender role change. But he reported elsewhere in the transcript that, unlike Mr Adisa who is a stay-at-home father, he is still the breadwinner for his family.

The complete change in Mr Adisa's attitude and redefining of his African fatherly, male gender role is likely to be precipitated by the presence of autism, changes in African gender roles and identities, his level of education, and the experience of living in the diaspora. Peacock and Botha (2006) report that in South Africa, for example, a social group called 'South African Men's Forum' is actively promoting social change from the traditional male role in that society to one that 'encourages men to play an active role in their children's lives by presenting positive images of [African] men in nurturing roles in relationship to children' (p. 290). However, Annor (2014, p. 30) reports that, in Ghana, the traditional gender role has not shifted much, as 'women showed greater involvement in house chores and childcare relative to men'. Hence, it can be inferred that gender equality and role liberalism is still not generally accepted in most African societies. It is also reasonable to infer that Mr Adisa freely acknowledged his hands-on caring role to me because he felt that, as an educated African UK resident, I would understand. However, he seems reluctant to disclose his gender role change to his mother because she might not receive it well, and his kin in Africa might feel embarrassed.

Indeed, Mrs Adisa seemed to recognise that Mr Adisa had changed his attitude towards the African male gender role when she said that, at one point in the past, Mr Adisa was not helpful:

> He is very, very involved in their lives. He is very, very involved. I mean there are times in the past where he wasn't up to speed, but now he is (Mrs Adisa, Nigerian).

However, Mrs Adisa herself suggests that having been empowered, she started challenging Mr Adisa's approach to parenting, rather than appreciating and encouraging him. Mrs Adisa had commented:

> You didn't do it right that is why he is upset, you didn't do it the other way, or you didn't communicate very well. And that puts a strain, because, for him, there is a lot of African men, they will say, you know, you think you know too much, you know it too well, they will walk (Mrs Adisa, Nigerian).

While some scholars, (for example, Peacock and Botha 2006; Silberschmidt 2001) report that the African gender role model is changing, others maintain that the hands-on responsibility of nurturing and caring for children remains the traditional responsibility of a woman (Mensa-Bonsu and Dowuona-Hammond 1996; Annor 2014; Ritcher and Morrell 2006). The idea that a man would make the transition from the traditional male gender role to the unconventional gender role is, arguably, alien to the concept of Africanness (Uduma 2014; Chimakonam 2015; Spronk 2009). It is therefore likely that due to the multiple layers of responsibilities involved in caring for twin children with autism, Mrs Adisa had put pressure on Mr Adisa to change his African fatherhood attitude to child care responsibilities (Silberschmidt 2001). But she continued applying pressure on Mr Adisa in an attempt to break down any entrenched views about gender equality that he may hold. Mrs Adisa's approach reflects the gradual renegotiation of the stereotyped notions of the dominant male gender role (Silberschmidt 2001), or at best 'minimiz[ing] gender inequality in the allocation of household labour, and reduce the burden' of childcare for their twin autistic boys (Annor 2014, p. 33). However, Mrs Adisa herself admitted that her behaviour might alienate Mr Adisa to the extent that he may decide to leave the family home.

7.7 African Spiritual and Cultural Worldviews about Causes of Autism

In this section, I discuss the theories offered by some participants as to how and why their children became autistic, from the perspective of a strictly African-specific spiritual belief system. It is important to understand that in African society, there is a difference between beliefs in the spiritual power of God in a Christian and Islamic context, and the traditional beliefs about, for example, witchcraft. The former is seen as a good spirit who intervenes against bad spirits such as evil, witchcraft and others. I have elected to discuss these two spiritual belief systems separately, and I will focus mainly on the beliefs about witchcraft in this section.

African spiritual beliefs about the causes of disability, misfortunes or disasters have been well documented in anthropology and allied disciplines (Middleton 1955; Barnes-Dean 1986; Kiyaga and Moores 2003; Legare and Gelman 2008). In the

West, biological theories are often used to explain most acute conditions (Legare and Gelman 2008; Oliver 1996). However, as well as biological explanations, some Africans also use some traditional spiritual belief systems such as witchcraft, ancestral curse, sorcery and others to understand a situation (Otte et al. 2013; Reynolds 2010; Sandy et al. 2013; Kiyaga and Moores 2003). For example, Legare and Gelman (2008, p. 636) state that the African participants in their study had 'combined biological and bewitchments belief systems' to explain their HIV/AIDS illness in South Africa.

According to some anthropologists, who studied African cultural beliefs and practices, a witch is believed to be someone who moves around at night in the guise of a familiar animal or bird and kills people, makes them ill or causes serious disaster such as disability (Legare and Gelman 2008; Barnes-Dean 1986; Middleton 1955; Noon 1942). Witchcraft or bewitching someone is 'something like bring[ing] sickness [or disability or misfortune] by mystical means. [Whereby the witch] walks at night and enters his victim's [home] silently like a rat creeping over the wall…[They can] take the form of an animal especially …cat, …snake, owl…or indeed any animal seen suspiciously near[by] or seen by the victim in a dream' (Middleton 1955, pp. 254-255). An ancestral curse is the belief that patrilineal ancestors have the spiritual power to send illness or disaster to a living descendant as a punishment for wrongdoing. It is also believed that the oldest male in the kin has the power to invoke ancestors to send a curse to a deviant member of the kin, if it is deemed appropriate (Brown 1951; Barnes-Dean 1986; Stone-MacDonald 2012; Sahlins 2011). Barnes-Dean (1986) describes a sorcerer as someone in the family, 'usually women', who 'poisoned' other members of the family, including a child, with ‘concoctions’…due to jealousy (p. 338). Legare and Gelman (2008) expand on this idea by stating that bewitchment, ancestral curse or sorcery could be discharged from a ‘proximal’ or ‘distal’ location, spiritually or mystically to the target to cause them death, illness, disability or a misfortune (p. 635). I will not go into detail about the proximal/distal explanation in this thesis, but it is important to note that distal discourse helps explain why the parents in this study, who are far away from their ancestral homes in Africa and from their wider kin, still believe that witchcraft agents have the spiritual power to cause their children’s autism, even in the diaspora.

In this section, I will focus on ‘witchcraft’ as one of the African worldviews about the causes of disability. This is because at least eight of the twenty adult participants in this study had mentioned ‘witchcraft’ (as well as other African cultural beliefs, and biological explanations) as one of the causes of their children’s autism.

7.7.1 Can Witchcraft Cause Autism?

Despite living in the UK for periods spanning seven to thirty years, some of the participants in this study, including those educated to postgraduate level, strongly believed that supernatural powers, such as witchcraft spirits, were responsible for their children’s autism. For example, Mrs Diya, a graduate, was resolute in her comments about her belief that witchcraft caused her son’s autism. She said:

> You know, am a typical African woman,...Everything na witch! Na witch. I won’t deceive you, because I now looked at my own background. I said we don’t have such a problem from my background, so where can it be coming from. And my husband, we met a long time. We went to school together…So, where could this be coming from. In fairness, I think say na witch o!. It happened all of a sudden. A boy that was

> calling my name.., all of a sudden, he just went blank. Nobody will not say it is not witch now, when I am not a white woman. Based on the background where we are coming from back home, I thought that was it. [It] just happened all of a sudden (Mrs Diya, Nigerian).

Similarly, Mrs Dibango told me she was studying for her Masters' degree at the time of this interview, and had lived in the UK for 22 years. However, she also affirmed her beliefs in witchcraft attack as one of the causes of autism in her three autistic children by saying:

> I believe it is witchcraft….Ummm. You know. Yeah, I believed it was witchcraft, you know. So, that is one of the answers that I got, that it was witchcraft, and all that, yeah, so...here and in Africa (Mrs Dibango, Cameroonian).

These participants' comments broadly represent those of the wider research community in regard to African cultural beliefs about witchcraft attack on their autistic children. They felt that because their children's problems suddenly emerged without warning, witchcraft attack must be the cause. It is normal for an African to make sense of an acute life event through such cultural and traditional spiritual interpretation. According to Legare and Gelman (2008, p. 610) the West regards African worldviews about witchcraft as 'primitive' and 'irrational', and hopes that educating Africans in Western science and Christian theology will supplant them. But 'it is now recognised that beliefs in witchcraft do not necessarily disappear with modernisation and education'. Legare and Gelman further state that in South Africa for example, there are half a million traditional healers who help millions of South Africans make sense of witchcraft spiritual powers and practices. Research on cultural beliefs about acute illnesses, disability or misfortune in other sub-Saharan African countries and among

Africans in the diaspora found that Africans often link adverse life events to witchcraft, such as Parkinson’s disease and intellectual disability in Tanzania (Mshana et. al. 2011; Stone-MacDonald 2012), Down Syndrome and autism in Ghana (Reynolds 2010), blindness in Ethiopia (Kiyaga and Moores 2003), epilepsy in Guinea-Bissau (Otte et al. 2013), disabled children in Kenya (Gona et al. 2010) and in Zimbabwe (Munsaka and Charnley 2013), and children with poliomyelitis in Nigeria (Ogwumike et al. 2012).

However, Oqwumike et al. (2012) report that there is ‘an obvious change from the traditional beliefs that witchcraft and ancestral spirits’ cause poliomyelitis in Nigeria (p. 6). For example, in Nigeria, 64.6% of their 217 respondents rejected ‘the traditional claim that children with poliomyelitis have spiritual problems from witches’ (p. 4), but 35.4% still believe that witchcraft was linked to poliomyelitis.

Although the literature indicates that African worldviews about witchcraft are changing, it appears to be a slow process in the UK, as studies carried out with black-African HIV/AIDS patients suggest that the participants believed that their condition was caused in part by witchcraft (Fakoya et. al. 2008; Chinouya and O'Keefe 2005; Ridge et. al. 2008). Also, the media reported that at least three black-African children died whilst in the care of their family members or carers in the UK as a result of witchcraft beliefs and other complex issues (Laming 2003; BBC NEWS 2012; BBC NEWS 2010).

I argue that participants in this study are grieving for the loss of an ideal African child due to autism. In order to make sense of any loss and grief experienced by these participants, I have employed the writing of Elizabeth Kubler-Ross (1970) ‘on death and dying’.

Kubler-Ross’ (1970) work was orginally formulated to give some insight into the stages of the dying process, but the idea has been applied more widely in terms of personal and organisational change, bereavement and loss, and emotional experiences for the grieving. Kubler-Ross initially identified five stages in the trajectory: denial, anger, bargaining, depression, acceptance and, later, hope (Goldsworthy 2005; Stroebe and Schut 1999; Elrod II and Tippett 2002). Goldsworthy (2005) argues that not all people experience the stages in the same way as implied by Kubler-Ross, and it is likely that my participants’ experience was unique to them. As well as the common emotions of grief and loss that all parents of autistic children experience, my participants’ grief and loss have been shaped mainly by their Africanness principles and practices. In other words, whilst they feel the loss of an ideal African child (obedient/respectful, worthy/valuable, future economic asset, future kinship custodian, able to ensure continuity of lineage), they also feel that they are losing their ideal African cultural way of life (upholding lineage and kinship practices, patriachism, African role model). They navigate through life, thinking about how to protect their children from what they believe to be an immoral and evil world. A world where witchcraft practitioners and sorcerers operate. They perceive these elements as potential threats to their chidren, and one way both to protect their children, and overcome other challenges, is to turn to God through religious and spiritual beliefs and practices.

7.8 Conclusion to Chapter Seven

In this chapter, I have attempted to discuss and interpret some experiences of autism as expressed by my participants with reference to the Africanness philosophy. In doing so, I explored African cultural patterns, including kinship systems, lineage continuation, cultural expectations and duties, cultural values of respect and obedience, fatherhood and gender roles, and some African beliefs about the causes of autism. The aim of this chapter was to demonstrate that, along with the common experiences of autism, my participants also had specific and nuanced perspectives, attributable to their Africanness principles. I tried to highlight these specific experiences, as follows: (a) the challenge of maintaining a relationship, both with a broad network of kin and the ancestral home, (b) the 'threat' of autism to continuity of the patrilineal family lineage, (c) concerns that their autistic children could not care for them in their old age, (d) their inability to apply the 'African style of parenting', due to constraints present in the UK environment, (e) the 'threat' posed by autism to the development of an ideal African child, (f) the challenges presented by autism to those who aspire to being masculine African fathers to their sons in the diaspora, (g) the belief that witchcraft and other African spiritual powers had caused their children's autism. These findings have the potential to change current thinking about the lived experiences of those affected by autism.

In the next chapter, I will attempt to show how religion and spirituality forms an additional layer of experience, and how participants relied on their faith to enable them to overcome the challenges presented by the multiple layers of autism experiences.

Chapter Eight

Coping with Autism using Religion and Spirituality

8.1 Introduction

Of the 20 families that participated in my study, 18 (or 90%) were practising Christians, while 2 families (or 10%) were practising Muslims. Their faith formed part of their identity, and added another category to their multiple identities (race, gender, immigrants, Africanness), and another layer - religion and spirituality - to their existing layers of experiences. Religion and spirituality play both positive and negative roles, and have different levels of importance among various minority groups (Hendrick and Hammer 2017). For example, some papers reported that religion and spirituality were used as a platform to discriminate and marginalise lesbian, gay, bisexual and transgender people (Roland and Burlew 2017; Toscan 2017; Bidell 2014). However, the participants in this study viewed religion and spirituality from a positive standpoint. They used it as a coping mechanism, rather than to discriminate against others. I am not suggesting that they could not use religion and spirituality as a discriminatory tool, but that they did not directly employ religion and spirituality for that purpose in this study. All the participants made references to their religious and spiritual beliefs.

They expressed a belief and trust in God, and that being a Christian or a Muslim is their way of life, implying that religion and spirituality is an essential component of their daily lives. They reported that religion and spirituality gave them hope, succour, comfort; and helped them to cope with the daily challenges of raising an autistic child. They viewed God as a pacifier and a last resort, and prayer and reading of the scriptures as a stress reliever, among other benefits. However, there were also participants who presented themselves as strongly religious, while others appeared to hold beliefs which were not so strong, compared to the former. Finally, there is a third subgroup that I consider to be ‘in-betweens’, comprising participants who were in a liminal space between being strongly religious and not so strongly religious. Religious and spiritual belief systems could be ’viewed as a continuum that ranges from liberal or non-religious to fundamental or conservatism’ (Bidell 2014, p.170). Bidell suggests that religious continuum is a method created and used by researchers to understand the qualitative values of an individual’s religious and spiritual commitments.

Mengesha and Ward (2012) also classified their African-American participants into three religious and spiritual subgroups: high, medium and low. They found that there were no significant differences in the mean scores when they used the Centre for Epidemiological Scale for Depression (CES-D) to ‘measure participation in personal [spiritual] or group/institutional religious activities, …[by ranking their participants] into three groups of high, medium, and low religiosity’. They reported that ‘a protective trend was apparent in their findings, such that low, medium and high religiosity was associated with decreasing depression symptom scores’ among the Africans-Americans with depression in their study (pp. 24-25). Two significant ideas emerged from Mengesha and Ward’s (2012) study. Religion and spiritual qualitative values are measurable and can be ranked. It is also possible for members of each subcategory to experience positive coping outcomes from their acute condition.

For analytical purposes, I classify the religious and spiritual continuum of my participants into three subgroups: ‘strongest’, ‘stronger’, and ‘strong’. There are 13 parents in ‘strongest’, 12 in ‘stronger’, and 5 in ‘strong’. It is also possible that some of them could move between subgroups, depending on their prevailing circumstances. I do not claim to understand the religiosity and spirituality of participants. The classification I use here is in the context of autism-related experiences, and not about the general qualitative values of their spiritual and religious persuasions.

I argue that members of the three subgroups are likely to have additional layers of experiences. However, their multiple layers of experiences could vary slightly, depending on their perception of the outcome they receive or expected to receive from their religious and spiritual beliefs. But all members of the subgroups are likely to experience positive coping outcomes from their religion and spirituality.

I have used religion and spirituality interchangeably to mean the same. Other papers (see Rippentrop et al. 2005; Carter et al. 2015) have used both religion and spirituality interchangeably in their analyses, although the difference has been established in that there is a difference between the two concepts (Poston and Turnbull 2004; Keller 1999; Zinnbauer et al. 1999). Coulthard and Fitzgerald (1999) further suggest that it is important to distinguish support and coping gained through spiritual beliefs, and coping and support gained from organised religious membership. Religion is defined as the ’institutionalized and organized patterns of beliefs, moral, rituals and social structures that people create to help fulfill their spiritual quest' (Poston and Turnbull 2004, p. 96). Spirituality can be defined as the act of having a relationship with a higher power, which affects how an individual functions on earth (Zinnbauer et al. 1999).

8.2 Being Strongly Religious and Spiritual: Putting God First in Daily Life

Participants in the 'strongest', religious and spiritual subgroup are more likely to make reference to God when sharing their daily life activities, and about their autistic children in particular. They are also likely to give credit to God for most significant outcomes, or to report that they trusted and relied on God explicitly for their problems. The 'stronger' religious subgroup could interpret some of their life courses in a similar way as the 'strongest' subgroup, but the difference could be in the frequency of their references to God in their interview and in what context. Due to the benefits that the 'strongest' subgroup believed that they were getting from their religion and spirituality, they were motivated to prioritise God in their daily lives. One participant stated that she loved God deeply and sought his guidance before making any decision in her life:

> Kakooza [child with autism] is a blessing in my life. Without her, I don't know where I will be by now… We believe, we put God first and we hear his voice. We hear God's voice so much [speaks in whispers]. Right now, God tell me child Kakooza is a blessing to me. But [I] just love God so much. If you tell me you are coming [louder] I would first fast and asked him. If he says no, I will say no, so we go through all that (Ms Kakooza, Ugandan).

Ms. Kakooza was spontaneous in crediting God with most events in her life. She infers that she is so strongly religious that she consults God before making any decisions. Such was her level of conviction and devotion to God, she claimed that she has a special power from God, which enables her to foresee events before they happen. For example, she said that she foresaw the 9/11 terrorist incident in the USA, my visit to interview her for this study, a call from her family member in Uganda (during the course of my interview) asking her for some financial assistance, and that God made it possible for her to bring her seven children to the UK, and be granted discretionary leave to remain.

Many other participants shared similar conviction in the power of God. For example, Mr Kimani described the extent of his devotion in the excerpt below:

> Religion and spiritual beliefs play a very important role in our lives. We believe and trust in God. We follow the teaching of the Bible and try to live our lives in the way that God has asked us to live. We pray for forgiveness of sins. We present our problems to him, and hope that he will give us solution. When we are down, or sorrowful, it is a place where we go for comfort….it helps us to cope with our stress (Mr Kimani, Kenyan).

Also, when Mrs Akinloye, a Muslim mother was asked what role her religion plays in the life of her family, she said:

> …A lot! A lot! A lot! Definitely, the belief that God can help... at least he can give you the heart to go through it. And there is this emotional satisfaction you feel. Umm… falling back to God as well. And umm…whatever it is you will [want], after praying about something, there is this relief you. There is this relief. You know there is somebody there you can relay yourself [to]. And definitely you don't have a choice. It is not that you don't have a choice, you, if there is nothing else you can fall back on, you can fall back on God. (Mrs Akinloye, Nigerian).

The importance of religion and spirituality to BME parents of disabled children, and other types of acute illnesses have been reported previously (Carter et al. 2015; Poston and Turnbull 2004; Rippentrop et al. 2005; Ismail et al. 2005). For example, Jegatheesan et al. (2010) found that religion and spirituality formed part of the daily lives of the Muslim immigrant parents of children with autism living in the USA, who took part in their study. Similarly, other scholars found that families with disabled children who held stronger religious beliefs, including mothers who spontaneously referred to their religion during interview were more likely to cope better than mothers who did not mention religion or spirituality in their study (Haworth et al. 1996; Tarakeshwar and Pargament 2001). According to Howarth et al. (1996, p. 272), there is a 'relationship between positive adjustment and intensity of religious beliefs and frequency of participation and reliance', on religion and spirituality. In other words, the strongly religious parent of a disabled child was more likely to report positive coping and adjustment strategies in regard to their child's disability. Tarakeshwar and Pargament (2001) report that having positive and stronger religious and spiritual values are associated with a better coping outcome for parents who are caring for an autistic child. I would argue that participants in the 'strongest' religious subgroup are likely to experience better coping outcomes as a result of their perceived religious and spiritual values.

8.3 Acceptability of Autistic Children in Places of Worship

All the participants in the three subgroups said that they attended church or Islamic services to worship God, and affirmed fellowship with their fellow Christians or

Muslims, except one participant in the ‘strong’ religious subgroup. She said that she prays with her family and they believed in God. Others in the strong subgroup are likely to attend places of worship more frequently. No consensus emerged from the three subgroups as to whether they found their congregation to be helpful or not. However, some participants in the ‘strongest’ and the ‘stronger’ subgroups were likely to report that they received help from their congregations, whilst others felt that their congregation was not so supportive. Others reported that African churches were unable to cope, and were less accommodating of their autistic children, due to unpredictable behaviours. However, their children coped better in western style churches, and were accepted there. Participants in the ‘strongest’ and ‘stronger’ subgroups were more likely to belong to ‘African’ Pentecostal churches because of the intensity of their religious and spirituality in that denomination. Participants in the ‘strong’ subgroup were more likely to belong to ‘Western’ church denominations.

In African churches, the autistic children were generally seen as problematic and a nuisance. Participants reported a lack of awareness of autism in African churches. The autistic children were more likely to be hypersensitive, hyperactive and disruptive in an African church, because they are likely to find the environment confusing, noisy/unsettling and lacking in routine. A participant compared her experiences in her previous church in Africa and her African church in England:

> Yes. My church helps. My church provides me with therapy for [autistic] child Dimka every Sunday…2 hours. Back home in Nigeria, we don’t go into the church. We sit outside because of child Dimka. If he talks they say, please take him out. But in this country, they sit him in front of the pastor. He sits in front of the pastor. Pastor knows

> him by name. He said his church is for special need children and adults (Ms Dimka, Nigerian).

Ms Dimka, a member of the 'strongest' religious subgroup, felt rejected and ostracised as her child was not accepted by her fellow churchgoers in Nigeria. She reported a different experience in the UK, where they were well received and supported.

For Mrs Akinloye, a Muslim mother who is a member of the 'strongest' group, the Imam, spiritual leader of her mosque, has shown unconditional love and acceptance to her autistic child. She said:

> Funny enough, our Imam has been very supportive. Even before diagnosis, our imam always say, it is just because you don't know this child, you don't that child. He had similar situation, and look at him now, he is fine. …Our little boy is very close to our Imam. He likes him, he treats him like a grandchild. So, he is been…. It is not like we have gone all out to seek the advice. He comes more out to us. He is more like he is the one that comes out to us. (Mrs Akinloye, Nigerian).

In contrast, Mrs Adisa did not quite find her church in the UK accepting or supportive. She said:

> umm.. I go to church. when I can, I try to, but because I don't take the boys to church all the time. But occasionally I have to take them… And again, church community, they don't often help matter, and I don't always relate to that, because I have seen other children who turn up in church who are autistic there. …They are not very helpful… I go when I just want to go… it's not something that I will say it kind of gives me succour all the time, no. I find succour in my own believe and my faith with God, and how I… I pray with my children in the house. You know I pray with them. They

> know how to pray. They know about Jesus and all of that. But I don’t always see the church as a body of institution as where I will go for succour…. I expect the church to be more caring, more sympathetic and make room for disabled people. But that is not what you get (Mrs Adisa, Nigerian).

Mrs Adisa, from the ‘strong’ religious group, does not often take her children to the church for fear of stigma. She felt that church members lacked empathy towards autistic children and their families. Her reported lack of support from the church could be a contributory factor to the level of her commitment. She got her spiritual succour through prayer and spirituality, rather than the membership of a church. She felt that the church as an institution, was not accepting of, and was not communing with disabled people. As a result, she was losing trust in the institution, but the benefit she received from her personal relationship with God was increasing.

Mrs Bankole also felt that her church membership and leaders were unhelpful, unaccepting and unsympathetic:

> ….The church is not any better because when you are in church, child Bankole is not sitting down. He is running around, pacing, then they are looking at you. Go and get your child. Go and get your child! They will grab the microphone off him. They take the drum off him…Take him out of the alter. ...Nobody cares. It is your trouble. You know. You have to be there, make sure he does not stand on the alter when the pastor stands, you know. It will look as if you have done something very terrible. …when everyone is quiet, it’s at that time he wants to sing holly, holly to God in his own way, and then they will stare at you. Can’t you just keep him quiet?..., and the church is not being helpful. So, who do you turn to really. The society is not there to help you. No government respite. Church is not respite. No family respite. It is just you and your

> children. I am telling you the truth…. It's really not it. The church is not… well we are not enlightened. The black people are not enlightened… (Mrs Bankole, Nigerian).

Although Mrs Bankole is a regular church attendee, and is in the 'stronger' religious subgroup, her husband is in the 'strongest' subgroup. I make this inference based on the comments they each made elsewhere in the interview transcript. Mrs Bankole stated that, although she believes that God could make a positive change in the life of her son, she also knows that she has to take some practical steps to improve the chances of that happening. She went on to say (elsewhere) that her husband was more spiritually committed and was convinced that God will solve all their problems through prayers and following God's principles. Her husband tended to present every problem to God for a solution. In the excerpt above, Mrs. Bankole was expressing a number of concerns, including that her child was disruptive during church services.

Despite categorising Mr. and Mrs. Bankole as belonging to the 'strongest' and 'stronger' subgroups respectively, they share the same religious and spiritual values. The difference between them is the intensity of their religiosity. Tarakeshwar and Pargament (2001) report that partners who share a religious faith seem to support one another to cope with the demand of raising an autistic child and are likely to experience reduced marital stress. Whilst that might be the case, slight differences exist between Ms. Dimka who is in the 'strongest' subgroup, Mrs. Adisa in the 'strong' subgroup, and Mrs. Bankole who is in the 'stronger' subgroup, regarding their respective experiences of church membership and the response they received from members of their congregation.

From Ms. Dimka's comments, it is apparent that she is religiously inclined. I make that inference because, despite that her son was not fully accepted by her church congregation in Nigeria, she continued to attend the same church. In the UK, her son was better accepted, and they gained some support from their church membership. Elsewhere in the interview transcript, Ms. Dimka stated that she believed that the spiritual power of God was helping to improve her son’s autism condition. Therefore, I infer that Ms Dimka is likely to be both religious and spiritual, likely to belong to the ‘strongest’ subgroup, likely to benefit from both religious and spiritual support, and to cope well with the demands of caring for her autistic son and other challenges in her life, including being a member of the undocumented immigration subgroup discussed in chapter five.

On the contrary, Ms. Adisa demonstrates that she is likely to be more spiritually inclined than religious. In her comments she alludes that she prefers to pray to God with her family in their home than attend church. In other words, she believes in having a personal relationship with God, rather than through a religious organisation or church membership. Therefore, while she might gain some support through her spirituality, she is unlikely to get support through religion or, church membership. Deriving support from a single source - spirituality - could imply that her religious and spiritual coping resources are limited compared to Ms. Dimka’s, for example. She is also unlikely to look at aspects of her children’s autism through a spiritual lens, and more likely to criticise religious institutions, and to use religious/spiritual phrases less frequently. Hence, I locate her in the ‘strong’ religious/spiritual subgroup of families in this study.

Mrs. Bankole attends church with her son, but states that her church congregation had not accepted her son due to his atypical behaviours and the disruption he caused in the church. As a result, she felt stigmatised and isolated, despite being a member of the congregation. Mrs. Bankole said she did not get any support from her church, and rather than being a coping resource, the church was contributing to her distress. Despite these attitudes, experiences, and the lack of support, Mrs. Bankole continued to attend church services. However, if Mrs. Bankole continues to experience a negative attitude from her church members, it is likely that she would cease attending services. Conversely, her church members could eventually accept her autistic son. Mrs. Bankole also stated that her spirituality was weaker in comparison with that of her husband, when measured on a spiritual continuum (Bidell 2014). She stated that although she believes in spiritual interventions, she also sought practical solutions for her son's autism, unlike her husband who was more inclined to rely on prayers and his personal relationship with God. I therefore locate Mrs. Bankole in the 'stronger' subgroup. Although Mrs. Bankole felt that her fellow churchgoers was unsupportive, she did not stop attending, she is more likely to use spiritual/religious phrases frequently, and to view aspects of her son's autism from a spiritual/religious standpoint compared to, for example, Ms. Adisa. As a result, the quality of her spiritual/religious coping outcomes and the level of her resilience are likely to be better than those in the 'strong' subgroup, but less so compared to the 'strongest' subgroup.

Findings in the existing literature about both the importance and availability of support from members of religious groups to families with an autistic child or other disabilities, or to members of minority social groups such as lesbian, gay, bisexual and transgender is mixed (Coulthard and Fitzgerald 1999; Haworth et al. 1996; Carter et al. 2015; Tarakeshwar and Pargament 2001; Toscan 2017). However, findings about the benefits of spirituality, and a personal relationship with a higher power, consistently report positive coping outcomes (Coulthard and Fitzgerald 1999; Rippentrop et al. 2005). For example, Coulthard and Fitzgerald (1999) found that the majority of parents of children with autism and Down Syndrome in their study reported getting significantly 'less support from their organised religion [and] the formal church to which they belonged, and [the church] did not help them to cope, and [the membership] were rarely there as a resource' (p. 28). But they also found that spiritual beliefs were 'both resource and coping strategy for carers' (Coulthard and Fitzgerald 1999, p. 29). Some authors such as Tarakeshwar and Pargament (2001), who studied the religious coping of families with autistic children, combined both religion and spirituality in their analysis. Tarakeshwar and Pargament found that the 'church and its community function as a special source of informal support for these parents' of autistic children (p. 256). But they also wrote that about one-third of their participants 'reported discontent with their clergy and church members' (p. 256). Norman and Carter, (2017) found that members of the lesbian, gay, bisexual and transgender social group, reported that their spirituality and faith was a source of support and coping, but religion had a negative impact on their social and emotional wellbeing.

Despite the slight distinctions between religion and spirituality that emerged from the above analysis, overall, members of the three subgroups are likely to identify themselves as both religious and spiritual. Mengesha and Ward (2012) reported that the African women in their study identified themselves ‘as both religious and spiritual, and used these terms interchangeably in their identification’ (p. 22). Hence, these participants are likely to report mixed coping outcomes from being members of religious institutions and a more positive outcome from being spiritual. This is because, if a participant experienced negative attitudes as a member of a religious group, for instance, their spirituality is likely to compensate for this in their coping experiences. It is consistent, therefore, that membership of religious groups and their spirituality intersects with their other identities, enabling them to cope with the challenges from their multiple layers of autism experiences.

8.4 Spiritualising Autism to Find a Meaning

In using the term ‘spirtualising’ autism, I describe the interpretation of autism through a religious/spiritual lens.

All the participants in this study, at some point in the interview, attempted to understand their child’s autism by spiritualising their experiences. They indicated that their spirituality gave them hope and strength and helped them make sense of their children’s autism and other challenges in their lives. Some also reported that their family members had applied a spiritual interpretation of autism, as a way of trying to understand what was wrong with the child. When some of the participants themselves were interpreting autism as a spiritual attack, a curse, charm or demonic attack – or reporting such behaviour in others - they were effectively spiritualising the meaning they make about autism. Some of the parents went as far as to interpret all milestones made by the child through a spiritual lens, whilst others attributed any additional support they received from school, social services, the government, the NHS and other agencies to God. They believed that God was using the agencies to assist the family, another form of spiritualisation. One parent openly said that she did not have a social worker and did not need one, because she believed God was her son's social worker. It is therefore consistent that if these participants had spiritualised autism, they were also likely to seek spiritualised solutions to cope with autism.

> Because we see it as something not normal, so it must be taboo, you know. So, that is where the ignorance is. I don't think it is widely spread enough among Africans, because obviously we are always trying to look for everything to have spiritual meaning, doom and gloom meaning behind it (Ms Kama, Gambian).

Ms Kama, whom I classify as being in the 'strong' subgroup, believes that Africans are ignorant about autism, and that generally, black-Africans always seek a spiritual interpretation of most events in their lives. She implies that Africans do not believe in happenchance, especially acute adverse life events. They believe that every significant life event experienced by an African must be predestined, and that there is always a reason why anything, including autism, happens to an African, and the meaning of the event often has a spiritual connection.

Mrs Bankole also stated:

> mmm, well, my husband is very spiritual, so we have always channeled it through prayers, you know, waiting and hoping, we are still praying and waiting for the change. Well… we didn't think it was…, well at some point we thought it was an attack, but… spiritual attack, I mean. Not so bad, I didn't think it was so bad. …it was not just me who was thinking it was a spiritual attack, it was people around me (Mrs Bankole, Nigerian).

Mrs Bankole suggests that being spiritual about life events such as autism is a way of life for her family. She infers that she and her family members spiritualised autism by believing that it was a spiritual attack. Hence, spiritual problems need spiritual solutions, which can be found through praying to God who has the spiritual power to resolve any problem. Likewise, waiting for an answer helped them to cope, but hope helped them to sustain the motivation to continue waiting.

Mrs Yeboah demonstrates the importance of spiritualising her son's autism:

> I feel like it gives me peace, and calm and hope. Yeah, it does. It does. It does really. Like, you know, when it is difficult, you know, I am very, very low. It gives me sense of belonging and understanding and feeling. You know, it is not always bad, that kind of feeling. It is not always bad. Even if it is bad now, it is gonna get better. There is, even if it doesn't get better, better, better, like the way I want it, it is in God's hand, God knows the best and he is not gonna give me something that is going to be so unbearable for me. So yeah. I think that is one that keeps me going (Mrs Yeboah, Ghanaian).

Following the concept of spiritualisation, Mrs. Yeboah found meaning, peace, and hope for a better future through her belief that God has the answers. Her spiritual attitude is a coping strategy to deal with the challenges and the unknowns about her autistic son's future.

Earlier, Ms Kama alluded that Africans do not often believe in 'happenchance' or a chance occurrence. Rather, they have the tendency to explain a complex event using various narratives in attempt to make sense of it. The notion that their child's autism could be a coincidence was often unacceptable to these participants.

The idea of spiritualising autism, disabilities and mental illnesses by Africans has been documented in previous studies, (for example, Bakare and Munir 2011; Audu and Egbochukwu 2010; Crabb et al. 2012; Mohammed and Babikir 2013; Ridge et al. 2008; Wang and Casillas 2012; Kim 2012; Desai et al. 2012). Bakare and Munir (2011) found that parents and a ‘significant proportion of the healthcare workers’ in their study about autism awareness in Nigeria ‘subscribed to preternatural and supernatural factors…further substantiating inseparable spiritual beliefs of Africans and…explanations of neuro-psychiatry disorders’ (p. 209). In Malawi, Crabb et al. (2012:4) found that the majority of their participants had spiritualised their mental illness, and Reynolds (2010) also reports that belief in God is still widely used as an interpretation model for disabilities in Africa. Similarly, in his study of parents with disabled children from Bangladeshi and Pakistani background, Bywaters et al. (2003) found that participants who spiritualised their children’s disability through beliefs in God reported better coping outcomes. Indeed, as people of faith, these study participants remained spiritually strong, including those in the ‘strong’ group. They were more likely to see almost every aspect of their autism experience through a spiritual lens. Therefore, spiritualising autism was instrumental in helping them to cope with and understand their child’s autism.

8.5 Spiritualising Autism through Prayers to God

Fasting and meditation for their autistic children, praying to God, and reading holy books, are other ways of spritualising autism. Participants in this study, especially those in the ‘strongest’ and ‘stronger’ subgroups, spoke about the importance of using prayer as a way of communicating directly with God to intercede for their autistic children. For example, Mrs Dibango believed that prayer yielded positive outcomes for her three children with autism:

> [Prayer brought] deliverance because, …ummm, not healing. Healing....ok, let me say, healing, they are not sick. So, we have done the prayer of healing, so the thing with autism, because there have been so much prayers regarding healing, they never had even cold, you understand. Even like temperature for like 10 years, they have never had that. You understand. So, for me it is like healing is done. It is not healing, it is deliverance. It is like this thing that the child talks to himself, the child is not sick. He is just talking to himself, he is just making noises, and everything. So, when we pray, my prayer is like, because I believe that prayer, fasting, I believe that there is a supernatural which is greater, which can take them, who can take this thing away from...., the fact that they have started talking… (Mrs Dibango, Cameroonian).

Elsewhere in the interview, Mrs. Dibango who belongs to the 'strongest' subgroup had reported that her twin daughters had eventually joined their church choir due to God's spiritual interventions regarding their speech problems. She was therefore prepared to wait in hope for other deferred outcomes to be accomplished through prayers in the future.

Another participant who believed that prayer to God could yield instant, gradual, or deferred positive changes was Mr Ibori. Mr. Ibori is also in the 'strongest' subgroup, and said he had used fasting and prayers to God, and had requested the same from his pastors to intercede directly and indirectly for his autistic son:

> Prayer and fasting is meant to be part and parcel of your Christian life. I have written prayer requests to ministers. The greatest prayer you pray is the picture in your heart. You pray on that picture every day. Like I have said, healing can be instant, healing can be gradual. If you go to the doctor when you are ill, he gives you paracetamol, or

> you have infection, he gives you amoxicillin, it takes time, few days for the bug affliction to clear. Sometime God can decide to do it instantly, or slowly. But he is the same God. Maybe my own is not instant, maybe it is gonna take some time, but a lot of things have changed. I get him to read in church when I am asked to read. We go for bible class on Tuesdays (Mr Ibori, Nigerian).

Mr Ibori goes on to say:

> The reason am alive today is because of God, "I became prayerful, I lead a team in my church.... [digressed]...So even when they [spiritually] attacked my son, he survived it. [child Ibori] has moved on with his life. I thank God. I give God the grace. I learnt to be quite before him [God] allow him to do whatever he is doing. I believe in my lifetime; I would see a miracle." (Mr Ibori, Nigerian).

From Mr Ibori's perspective, the key thing is to be patient but persistent in prayers. Although the results he expected were not instant, he did not stop praying or fasting. He believed that his son's autistic behaviours started improving eventually due to his prayer and fasting.

Similarly, Ms. Mulumba who is in the 'stronger' subgroup, felt that her prayers were making a difference in her child's autistic life. She measured the improvements by some little changes she had observed from his behaviours:

> The aim of my prayers and fasting is to seek God's favour. For God to touch him and change him. At least to improve his life. I am grateful to God, because there have been some small improvements in his behaviour (Ms Mulumba, PDR of Congo).

The importance of prayer in the lives of religious and spiritual people in general, and individuals and families of disabled children have been widely reported in the literature (e.g. Coulthard and Fitzgerald 1999; Kpobi and Swartz 2018; Hill et al. 2000; Poston and Turnbull 2004). Poston and Turnbull (2004, p. 97) postulate that prayer is a ‘spiritual tool’ and that ‘spirituality has a positive effect on health and healing’, when using religion and spirituality to measure the quality of life of families of children with disabilities. Prayer was reported to be a source of comfort, a coping strategy, and a problem-solving method for mothers of children with Down syndrome and other disabilities, while soldiers use it to enhance their cognitive strength in war zones, (Coulthard and Fitzgerald 1999). Coulthard and Fitzgerald found that the parents of autistic children, ‘who sought comfort in prayer had significantly better health…than those who did not’ (p. 27). The importance of prayer was such that even parents, who challenged God for giving them an autistic child, continued praying to God for their child.

It has been well documented that prayer to God is a source of coping for families of autistic children of white background (Gray 2006); Asian immigrant background (Jegatheesan et al. 2010); and black-African immigrant background (Baba 2014). However, for the participants in my study, praying to God is more than a coping resource. They imply that this is a way of life for them, and that they will become more prayerful, due to their children’s autism, noting improvements in their condition, and attributing any major or minor positive experiences to God as a result of their prayers. I have not come across any existing research that highlights these nuances about prayer to God in existing texts about religious and spiritual experiences of families of autistic children. However, Ridge et al. (2008) conducted a study comparing the role of religion and spirituality in the lives of black-African heterosexual individuals with the HIV infection, living in the UK, with white gay and bisexual individuals, also UK-based. They reported that their black-African participants viewed prayer as a transaction between them and God, where they prayed to God in anticipation of ‘favourable outcomes…[and the black-Africans] tended to attribute considerable credit to prayer for their wellbeing and good fortune’ (p. 420). Ridge et al. point out that compared to the whites, the black-Africans’ life experiences were more pessimistic due to the combinations of other stressful events (immigration matters and others) in their lives. However, their spiritual experiences had enriched their life story, strengthened them and made them resilient because they spiritualised their problems through prayer to God. My study participants shared similar experiences to the group in Ridge et al.’s study. However, my participants experienced multiple layers of stressful events due to the intersection of their multiple identities. By spiritualising their autism and other nuanced issues through prayer, the participants believed that they were sharing their burdens with God, which in turn enabled them to be more resistant to the impact of their multi-layered stressful events, beyond merely coping with their challenges.

8.6 Spiritual and Religious Beliefs that God can Cure Autism

Some of the participants went beyond crediting God with any sign of improvement in their children’s autism-related behaviours. At least ten parents in this study emphatically stated that they unequivocally believed that God would cure their child’s autism. Another ten of them were slightly ambivalent about this belief but hoped that God could eventually cure their child’s autism.

For example, Mrs Okoye was trying to be emphatic with her response by repeating the question, and gave a short answer:

> Do I believe God could cure autism? Yes! Yes! Yes! Yes!’. (Mrs Okoye, Nigerian).

Mrs Okoye, of the ‘stronger’ subgroup, was attempting to express her conviction that God has the power to cure her son’s autism. Mr Aguda had also expressed similar beliefs in his comments:

> We believe He will cure it. We believe [it]. I mean, that is our religion. She does a special work in the church as well. She works in the children church; I work in the usher department. So that is our role, and we believe that prayers can work things, even miracles. We do (Mr Aguda, Nigerian).

In addition to playing an active role in church activities, Mr and Mrs. Aguda also mentioned that they were ’born-again Christians’. ‘Born-again Christian’ is a phrase used within Christian Pentecostal movements to symbolise Christians who believe they are at a deeper level of spiritual relationship with Jesus Christ and the Christian God (Sloan et al. 1999, p.666). As a result, Mr and Mrs Aguda are classified as ‘strongest’ in their qualitative religiosity and spirituality. Mr Aguda seems to be implying that the role they played in church, their commitments, and prayers were transactions between them and God. They were therefore expecting their child to be cured of autism because of their devotion.

Mrs. Diya, a member of the ‘stronger’ subgroup, chose to use a story from the Bible to justify her rationale for her conviction that God can cure autism, when she said:

> It [prayers] can cure autism! If Jesus Christ can wake up Lazarus who was dead, talk less of autism that is alive. Do you get me? If Lazarus could rise up. If he can defeat the great army, who is child Diya? Who [what] is autism? Do you get me? So, there is nothing God cannot do. There is nothing Jesus cannot do, if you believe (Mrs. Diya, Nigerian).

Members of the ‘strongest’ and ‘stronger’ religious and spiritual subgroups are more likely to express the belief that God would cure their child’s autism than those in the ‘strong’ category subgroup. For example, Mrs. Okeke a member of the ‘strong’ subgroup had said:

> It is not really to cure him as a cure per se. It is just to help you deal with it in a way. (Mrs Okeke, Nigerian).

Mr and Mrs Akinloye who are Muslim parents and in the ‘strong’ category subgroup also expressed similar beliefs:

> I don’t believe that there is anything the Lord cannot do. And that is it. Even if he doesn’t cure it, God will guide you through it, give you the strength to carry on (Mrs Akiloye, Nigerian).

Existing literature about the spiritual and religious beliefs of families of children with autism, including (Coulthard and Fitzgerald 1999), (Jegatheesan et al. 2010), (Tarakeshwar and Pargament 2001), and individuals with life-long conditions such as mental illness (Rippentrop et al. 2005), report that religion and spirituality can have various influences on health. They wrote that their participants reported experiencing reduced anxieties, increased hope, improved coping, and wellbeing due to their religious and spiritual beliefs. A significant majority of these participants went a step further, believing unequivocally that God would cure their child’s autism. I have not come across any recent studies where parents had expressed such conviction that God will cure autism. In Kpobi and Swartz’s (2018) study, exploring whether traditional and faith healers believe they could cure intellectual disability, they report that the faith healers accepted that they were unable to cure intellectual disability, but believed that God could cure intellectual disability. Meanwhile, Chinouya and O'Keefe

(2005) found that their black-African participants living in the UK with HIV believed that, with prayer, God could cure their HIV disease without medication.

The message that emerged from the belief that autism is curable by God is that these participants actively construct their own (religious and spiritual) meaning of autism, which might conflict with Western scientific and medical discourse that autism is incurable. To draw from the religious and spiritual belief that God can cure autism, we need to briefly turn to the concept of irrational beliefs, which can be described as a set of values, attitudes and practices held by an individual or group of people, despite objective evidence to the contrary (Sperber 1982). A belief is thought to be irrational if it is not consistent with other parallel beliefs. For instance, participants who believe that God could cure autism, paradoxically, may also worry that their children might never look after themselves in the future (see chapter seven). From the scientific context, therefore, the belief that God could cure autism seems to contradict common sense knowledge, and is, therefore, irrational. Sperber (1982) argues, however, that a belief, ‘can be paradoxical, counter-intuitive or self-contradictory, but, in and by itself, it cannot be irrational’ (p, 164). Members of another culture could be perceived as having an incomprehensible worldview with complex belief systems and experiences (Needham 1972). But the lack of scientific proof is insufficient to disregard it. Some beliefs held by people of cultures other than Western culture might be deemed irrational by Western standards, but Douglas (1975, p. 18) recommends that such beliefs should be seen as ‘subjective truth’. Therefore, if these study participants believe that God could cure their children’s autism, this means that, ‘they hold this as true just as true that there are trees [for example]…they [have] assert[ed] it and assent[ed] [to] it as a matter of course', because it is their subjective truth (Sperber 1982, p. 165). This study is concerned with the beliefs and views of these participants.

There is currently no clinical evidence that autism is curable, and I do not claim that it is. But from the perspectives of the participants in this study, who believe that autism is curable by God, this helps them to cope with their autism experiences. A follow-up study is required to determine if these parents still hold the same beliefs when their autistic children become adults.

8.7 Conclusion to Chapter Eight

In this chapter, I have attempted to show how the black-African families of autistic children in my study have used the intersectionality of their religious and spiritual identities to cope with the varied experiences of living with an autistic child in the UK. To this end, I have reported that, relatively speaking, the group as a whole were religiously and spiritually inclined. In the context of their children's autism, and for analytical purposes, I have categorised them as three permeable subgroups: 'strong', 'stronger' and 'strongest'. I further attempted to explore the religious and spiritual meanings that these participants were trying to make about their children's autism, by using four subthemes: being devoutly religious and spiritual, acceptability of autism in places of worship; spiritualising autism through prayer; and the belief that God can cure autism. I tried to distinguish between how members of each group expressed their religious and spiritual values and principles, and the differences between 'religious' and 'spiritual', and the potential coping outcomes from these, both separately and combined. I contend that the participants who are in the 'strongest' subgroup are likely to have a better coping outcome compared to those in the 'stronger' and 'strong' subgroups. I argue that due to their deep religiosity and spirituality, these participants had not only coped with the multiple layers of challenges they faced, but they also believe that by sharing their burden with God they were likely to become more resistant to the impact of the multiple stressful events in their lives, beyond merely coping with them. Reifying and reliving their religious and spiritual values in moments of pessimism and extreme challenges, and bringing them to life through prayers and meditation to God, gives them a mindset of optimism, and hope for a better future into adulthood for their autistic children. This, in turn, motivates them to hold on to their belief system, and faith in God to help them deal with any situation.

My aim in this chapter was to demonstrate that, as well as some common experiences about autism, including religious and spiritual coping mechanisms, my participants also have some specific and nuanced religious and spiritual experiences. These included (a) all the participants being Christians and Muslims; (b) their location within my classified religious and spiritual continuum, which could determine their religious and spiritual intensity, and coping outcomes; (c) the membership of a supportive religious group and commitment to spiritual beliefs promotes positive coping outcomes; (d) African (Pentecostal) churches being less likely than European (Catholic and Anglican) churches to be accepting of autistic children; (e) participants being more likely to process almost every aspect of their children's autism through their spiritual worldview; (f) their perception that prayer improves things, and God will cure autism, are the major findings in this section. Due to their deep spirituality, the participants are likely to have a stronger level of resilience and coping outcomes compared to other parents of autistic children, whose spirituality is weak.

In the final chapter, I turn to my findings, limitations of this study, my recommendations for future studies, and for professional practice and policies.

Chapter Nine

Discussion and Conclusion

9.1 Introduction

This study was designed to explore the autism-related experiences of black-African immigrant families with autistic children in the UK. This section presents findings that addressed the research questions and demonstrates how it contributes to knowledge. Firstly, I acknowledge that some aspects of my study participants' stories about living with an autistic child in the UK are common to all ethnic groups, but some of the distinctive aspects of their experiences are listed:

1. Due to the cultural practices whereby parents are identified by their child's name in parts of Sub-Saharan Africa, some parents in my study had experienced direct stigma in their community with or without their autistic child being present.
2. Some parents had reported that their family members had attempted to use exorcist practices to rid their child of autism.
3. Some participants in my study believe that autism is caused by witchcraft or an evil spirit.
4. Some of the black African mothers of autistic children in my study experienced gender-related discrimination and oppression from their ex-partners/husbands because polygamy and patriarchy are permissible in their culture.
5. The cultural practice of paying a 'bride price' in order to marry a woman in some African societies meant that some ex-husbands had demanded for their 'bride price' to be refunded because their wives gave birth to an autistic child. As a result, these wives felt humiliated, stigmatised and oppressed because of this.

6. Single parenthood has a different meaning for the participants of my study, compared to what the concept might mean to families of autistic children from other ethnic groups. For example, some of the single mothers were ambiguous about their role as a wife. This means that they were ambivalent about their marriage relationship with their husbands, as some were simultaneously living in the UK and in an African country.
7. To the black-African participants in my study, the concept of a family structure means a wider network of people, compared to the nuclear family model.
8. The continuity of family lineage was seen as sacrosanct, especially by fathers in this study.
9. African parents have the burden of caring for their autistic child in the UK and providing financial support to family members in their home country.
10. The feeling of disappointment that their autistic child is unlikely to fulfil his/her cultural duty to care for them in old age is a significant concern to my study participants.
11. African parenting styles practised by participants included educating their children at home about moral and cultural values, such as respect for elders, but due to the impact of autism, the children were unable to put these values into practice. As a result, these parents were frustrated, amplifying their feeling of failure.
12. The participants in my study tended to credit most events that occurred in their lives to God. When I asked a mother to tell me how much money she had spent on her autistic child, she said: ‘*No[thing]. It is free. I get it for free here. It was from God’*.

13. My participants’ strong believe in God, and that they communicate directly with God through prayers, their conviction that God would cure their child’s autism gave them a sense of optimism and resilience, culminating in a higher level of coping capacity.

14. Some of the parents in this study believe that having an autistic child was a sanction or an ancestral curse for failing to fulfill their kinship obligations, or for contravening a custom. As a result, they hold a deep sense of guilt.

Therefore, the purpose of this qualitative IPA study was to enhance existing knowledge about the experiences of BME groups living with an autistic child. The limitations of this study, recommendations for future research, and implications for policies and professional practices are considered.

Previous researches on this topic were focused on the following groups: (a) participants living in the UK and/or other Western countries, (b) participants living in an African country, and (c) the wider BME network in the UK. It should be borne in mind that black-African participants are often grouped with other ethnic minority participants. To my knowledge, this is the first study to (a) explore the experiences of autism of first-generation immigrants to the UK from various sub-Saharan African countries, (b) 'carve out' participants from their peers in both Africa and the UK, respectively, (c) explore their experiences both in the UK and their African countries of origin, and (d) recognise not only that the participants from this group have multiple layers of autism experiences, but also to identify them. The range of theories and the concept of intersectionality employed in this study have introduced new interpretations and fresh understanding of autism-related experiences for this group of participants. Four research questions examined the following issues: (a) the beliefs held by African immigrant families about their child's autism; (b) their experiences of coping with an autistic child in the UK and how well they coped in practice; (c) how their culture and tradition influenced their perceptions; (d) the barriers or challenges they faced when attempting to access support for autistic children in the UK. This section discusses how these questions were addressed, and is structured in accordance with the main themes presented in chapters five to eight.

9.2 Barriers and Challenges to Access to Autism Services in the UK and in Africa

As stated in the literature review, families with one or more autistic children are likely to encounter challenges when trying to access autism services in the UK. These include delayed diagnosis, and having to fight for services (Slade 2014; Waterson 2011; Harding 2013; Connolly 2015; Doig 2012). Also, in a number of African countries, autism services are either scarce or non-existent (Lagunju et al. 2014; Bakare and Munir 2011; Bakare and Ikegwuonu 2008). The current study found that, whilst participants shared some common experiences with their peers in the UK and Africa, they also faced additional barriers and challenges. For example, this study shows that there are three subgroups of migrants. The challenges faced by each subgroup are determined, in part, by their immigration status, thereby creating a continuum of complexities. On the whole, the undocumented migrant and temporary residency subgroups had the worst experiences, compared to those with settled residency status. Fear of deportation was also a major concern.

Some participants had experienced autism services in certain African countries, or the lack thereof. It was the latter which prompted them to migrate to the UK. Their particular experience of challenges and barriers to autism services, both in the UK and their home countries, is unlikely to have been shared by their peers in Africa or the UK. These participants regard UK services as being of a higher standard, and would rather remain in the UK to maintain access to them. No previous study is known to have highlighted this specific difference and aspiration, and it allows this research group to be ‘carved out’ specifically for further exploration. The combination of their multiple identities - immigrants, blacks, Africans, ‘foreigners’ with an accent, and gender - intersecting with autism, converge to create a matrix of challenges when they attempt to access autism services in the UK. These findings align with the intersectionality theory (Crenshaw 1989 and 1991). The current study also found that these participants have multiple layers of experiences when attempting to access autism services: (a) the undocumented immigrants are more likely to have left their countries of origin due to scarcity of autism services there, and came to the UK in search of better ones; (b) the undocumented migrants experience greater hardship than their peers in the settled and temporary residency subgroups, but are more likely to express appreciation, and less likely to complain; (c) the temporary resident subgroup felt challenged by the immigration application process and their visa restrictions; (d) the temporary and the undocumented subgroups were worried about possible deportation; (e) the settled residency subgroup were more likely to feel unsatisfied, report institutional discrimination, and more likely to have the confidence to fight for services, than parents in the undocumented migrant and temporary residency subgroups. These multiple layers of experiences have not been noted in recent research, such as Slade (2014), Perepa (2014) and Corbett and Perepa (2007), and they form part of the contribution made by this study to body of knowledge.

9.3 Stigma and Rejection Experiences for Black-African Families of Autistic Children

Although the second question in this research pertains to the broad experience of black-African families with an autistic child, the findings concerning stigma and rejection experiences were not only significant but also unexpected because they were unsolicited. Broadly speaking, participants had experienced stigma and rejection both in the UK and in an African country, as a result of them simultaneously belonging to two geographical locations. The stigma and rejection originated from their wider family, their communities, and wider society, both in the UK and in an African country. In addition, stigma and rejection in the UK were also found to be a result of the intersection of black race, ethnicity and immigration with autism. In an African country, it was due to the intersection of African custom/tradition, culture and personhood with autism/disability. This finding did not emerge in previous research and it is, therefore, presented here for the first time.

Stigma and rejection may be further explained by a number of different factors. For example, the majority of participants see themselves as ‘transnationals’, which aligns with the immigration theory of ‘transnationalism’. Transnationalism is used to explain how immigrants simultaneously maintain ties with their countries of origin and countries of abode, thereby holding dual or multiple identities (Kim 2009; Van Hear 2010; Kimberlin 2009). Transnationalism represents a major shift from the historical thinking that immigration is a one-way movement from country of origin to a destination country. It views immigration as a two-way process, which straddles country borders and boundaries, and affects the immigrant’s relationship both with his or her country of origin and the destination country. Some participants had traveled to their home countries with their autistic children, but they were not generally received well. Even those whose autistic children were born in their home countries before coming to the UK, and those who had never travelled home, but maintained contact with their country of origin, experienced some negative reactions. These were often borne out of the quest to have an, ‘ideal’ African child, in accordance with Africanness philosophy (see section 2.7 and chapter 6). In the UK, the power differential between black and white, where whites are the dominant and more powerful race; racism, racialisation, disablism and structural discrimination becomes inevitable for this group.

The above findings – participants feeling rejected and stigmatised in the UK and in their homelands simultaneously - have not been previously reported in published research (such as, Slade 2014; Perepa 2014; Corbette and Perepa 2007; Doig 2012; Anthony 2009). Other findings have, however, emerged. For example, this study found that (a) mothers of autistic children were mostly blamed by family members and members of their wider community; (b) that mothers are more likely to experience courtesy stigma than fathers or siblings for being primary care givers; (c) that members of the public are likely to be more sympathetic to a younger child with autism than an older child if they behaved awkwardly in a public space; (d) that neurotypical siblings experience courtesy stigma and embarrassment, and are also young carers. These findings concur with much previous research in this field. For example, Slade (2014) showed that the BME mothers in his study were blamed for their children’s autism. Gray (2002 and 1993) found that mothers of autistic children experienced courtesy stigma more frequently than other members of a family, and members of the public were less sympathetic to older children with autism than younger children in public spaces. Canary (2008) and (Bishop 2012) indicated that the neurotypical siblings in their respective studies provided substantial care and support to their autistic siblings, but also felt stigmatised due to their awkwardness in public spaces. However, the current study went further and uncovered additional themes on the subject of stigma, rejection and discrimination, which do not appear to have been documented previously. For example, (a) mothers are more likely to be rejected by their husbands/partners, and some mothers felt more rejected than others in the group; (b) fathers had a second chance of fathering a neurotypical child, especially a son, with a different partner; and (c) participants feeling racialised by their encounters with white people in public spaces. These three findings may be explained in part by the links between: (a) mothers feeling deeply rejected and the various matrimonial relationships in which they found themselves; (b) the privilege of African fathers to father another child combined with the African cultural practices of patriarchy and polygamy; and finally, (c) the link between the intersection of autism with the black racialised body and living in a space dominated by white superiority. They further support the ideas propounded by the theories and concepts of transnationalism, lineage/kinship, Africanness philosophy, spoiled identity theories and racialisation (see, for example, Kim 2009; Evans-Pritchard 1951; Uduma 2014; Goffman 1963; Fanon 1967). The first two findings (a) and (b) will be interpreted and explained here. For more discussion of racialisation see sections 2.6 and 6.3 of this thesis.

With reference to mothers feeling rejected by their partners or husbands; and fathers having a second chance to father a non-disabled child, the matrimonial relationships were broken into three subcategories (present, part-present and absent spouses or fathers). This categorisation arose because of the complex relationships in which these mothers were involved. Due to transnationalism, some husbands/fathers/partners who are still married to or in a relationship with their wives/partners and live in the UK and in an African country simultaneously. These fathers are considered to be ‘part-presents’ and were suspected by their wives of keeping two families (one in the UK and another in an African country), permitted by the African culture of polygamy, patriarchy and kinship/lineage continuation. Similarly, the ‘absent’ fathers are those who have already divorced their wives, due to them giving birth to an autistic child, thereby creating a great deal of embarrassment for the wife and her family. Fathers in this group are free to start a new family and hope to have a non-disabled child/son. Finally, the ‘present’ fathers are those who remain in the UK with their families, despite the presence of an autistic child in the family. Although there were tensions and conflict in the family, the mothers in this group experienced overall less stigma and rejection from their partners compared to mothers in the other two groups. Ostensibly, these findings mean that, although each member’s identity in the family is spoiled, due to the presence of an autistic child (Gray 2002; Goffman 1963; Scambler and Hopkins 1986), some members’ identities are more spoiled than others. Some of these fathers have distanced themselves from their family with an autistic child and started a new relationship or kept two families simultaneously. The mothers never distanced themselves from their autistic child or kept two families simultaneously, as it is not culturally acceptable in most African societies. And whilst they could begin a new relationship as single parents, it could be more challenging for them to do so, because they are the primary carers for their autistic children.

These new findings add to the multiple layers of autism experiences for the families in this study, and they also form part of its contribution to existing knowledge of this topic.

9.4 The Africanness Philosophy and Cultural Values and Beliefs about Autism

In regard to the question about how some African cultural and traditional principles influenced the participants' perceptions of their child's autism, whilst some findings in this study are consistent with prior research, other findings are new and, as far as can be ascertained, have not been published previously. Starting with the results that are consistent, this study shows that the continuation of family lineage is an important cultural value for these participants, especially for fathers. The potential for an autistic son, in particular, to grow up as an 'ideal' African man who is expected to get married, have his own family, and contribute to the sustainability and longevity of the kinship system is threatened by his autism. Slade (2014) also found that the African participants in his study strongly feel that the continuation of their family line is important, but autism could prevent their sons from achieving this aspiration.

Another finding that was both convergent with and divergent from an existing result is the value placed on discipline, respect and obedience. Participants in this study were keen to teach their autistic child the value of respect to elders in the family and in the community. But the presence of autism was an obstacle. Consequently, the inability of their autistic child to be disciplined, respectful, and obedient is a reflection of poor parenting, particularly by the child's mother, and a reason to blame them for having a child with autism. Burkett et al. (2017) also found that the African-American parents of autistic children in the USA taught their children the principles of discipline, respect and obedience to elders from home. But while parents in Burkett's study were somewhat successful, parents in the current study were unable to achieve this. Nonetheless, these principles and values are also supported by Evans-Pritchard's (1951) kinship and lineage theories, and Uduma's (2014) concept of Africanness.

There are, however, several interesting findings in the context of African culture and tradition, which have yet to be reported in published literature on this topic. For example, the study found that participants felt the need to maintain a relationship with their kin and their ancestral home, are concerned that their autistic children are unable to be an economic asset to them in their old age, are unable to instill the Africanness principles in their autistic child, perceive threats to the masculinity of an African father/male, male children being highly valued, and blaming of witchcraft and other African spiritual powers for causing their child's autism. The combination of these results add to the multiple layers of traditional and cultural experiences for these participants, and contributes to knowledge made by the current study.

9.5 Religion and Spirituality as Coping Resources

An important finding is the role of religion and spirituality in coping with autism. A strong relationship between coping with autism and other acute and stressful conditions, and religious and spiritual belief systems has been widely reported in the literature (Rippentrop et al. 2005; Tarakeshwar and Pargament 2001; Powell et al. 2003; Haworth et al. 1996). The current study found that religion and spirituality is one of the most important coping mechanisms for these participants, who also believe that African (Pentecostal) churches are less likely than European (Catholic and Anglican) churches to accept autistic children. These findings are echoed by, respectively, Tarakeshwar and Pargament (2001), and Slade (2014). For example, Tarakeshwar and Pargament found that religious and spiritual belief systems played a pivotal role in the emotional and psychological coping strategy of the parents with autistic children in their study. Slade's (2014) findings suggest that members of African churches and mosques have low awareness of autism and are not tolerant of autistic children, due to their atypical behaviours in places of worship.

In terms of the availability of practical support from membership of a religious group, this study found mixed results. While some participants reported that they received support from their African churches or mosques in the UK, others did not get any support. In some instances, they experienced rejection and hostility, both in the UK and in an African country. This corroborates the findings of Dein and Bhui (2013) who found that religion and spirituality could be a source of either hindrance or support for families. There are several possible explanations for the positive and negative findings in regard to practical support from a religious group. A possible explanation for this might be linked to the level of devotion that a participant has in a spiritual/religious space and time.

In this study, participants were categorised into three religious and spiritual subgroups: 'strong', 'stronger', and 'strongest' for a qualitative insight into their religious and spiritual persuasions. This enabled an in-depth understanding about the meaning that members of each category made about the importance of religion in their daily coping, the intensity of their religious belief systems, and how that translated into the meaning they make about their children's autism. It was found that the thirteen participants in the 'strongest' religious and spiritual groups are likely to have positive coping outcomes, and are more resilient and optimistic about the future for their autistic children than those in the ‘stronger’ (twelve participants) and in the ‘strong’ (five participants) subcategories. There is no non-religious participant in this study. This is the first known usage of this method of categorisation in autism-related research. The current study is also the first to highlight differences within a group of research participants, drawn from BME families, about their experiences of autism in a religious and spiritual context in the UK.

Another set of important findings which are not known to have been previously reported include: the tendency to credit every aspect of their autistic child’s development to God; viewing their experiences through a spiritual lens; the perception, and in some instances, conviction that prayers improved things; and that God will cure autism. This was irrespective of whether a participant’s religion was Christian or Muslim. These findings have not been reported in any previous study, which is probably because no study has focused exclusively on black-African families of autistic children living in the UK. The findings are, however, consistent with theories which hold that spirituality affects an individual’s daily functioning, whilst religion is the practice (employed by people of faith) to establish and/or maintain a relationship with a higher power (Hill et al. 2000; Zinnbauer et al. 1999). It is on the basis of these principles that the participants of the current study live their lives and try to make sense of their children’s autism. These new findings reflecting the intersection of autism with religion and spirituality, culminating in multiple layers of autism-related experiences for the participants of the current study, also form part of the contribution made by this research to existing knowledge of this group and topic.

9.6 Limitations for this Study

Having reported these findings, the results should be interpreted with caveats for the reasons outlined below:

Firstly, there are some methodological limitations to this study. For example, (a) the relatively large sample size for an IPA study meant that a vast amount of data was captured, but some were not used; (b) the high educational attainments of the majority of participants meant that their views might not adequately represent the views of the wider community of African parents; (c) the disproportionately high number of participants from Nigeria, compared to other African nationals, could limit its representation of views of the wider community of sub-Saharan African families; (d) the high concentration of participants in the London area might not fully represent the experiences of African parents in other UK cities and towns; (e) the large number of participants of the Abrahamic faith might not represent the views of non-religious African parents; (f) the offer of a £20 voucher as an incentive to participants might have attracted people from a lower economic strata but not provided such a strong incentive to those from a higher economic strata; (g) engaging participants from a wide range of sub-Saharan African countries restricted the scope for more detailed exploration of autism-related issues affecting specific sub-Saharan African countries; and finally, (h) the lack of non-English speaking participants limits the relevance of this study to a wider African community.

Secondly, the thesis explored the intersectionality of autism with other identities, such as race, ethnicity, religion and spirituality, African culture and gender. No findings were gathered about the relationship between autism and social class. The reason lies with the difficulties involved with establishing the social class of African immigrants in the UK, due to their specific lifestyles.

For the above reasons, it may not be possible for the findings to be extrapolated beyond the sample for application to the wider ethnic minority groups in the UK, but some inferences could be drawn.

9.7 Recommendations for Future Studies

Firstly, it is recommended that research be undertaken to explore issues relating to sample distribution. This may be achieved via equal representation of black-African participants with high and low educational attainments, relatively equal numbers of participants from wider African countries, non-religious Africans, and those living in locations with more diverse populations. Future research could also focus on participants from a specific African country. These types of studies would help to produce a more balanced reflection of the lived experiences of this group.

Secondly, there is a need for further comparative studies focusing on the experiences of black-African families and white families with an autistic child, black-African families resident in both the UK and an African country, neurotypical black-African siblings and their white counterparts, and the relationship between black-African fathers and mothers. This would enable comparison of the autism–related experiences of these participant groups. It could also highlight any convergence and divergence.

A study of African families, which include an adult with autism, is also recommended. This could investigate the family's 'autism journey', starting from the birth of the autistic child, continuing through childhood, adolescence, and, eventually, adulthood. It may also help increase understanding of cultural and religious influences on the lived experiences of such families, along with any shift in beliefs due to unmet expectations. In addition, such a study could also identify commonality of views with participants in the current study, regarding access to services, stigma, cultural and religious experiences, marriage and lineage continuity, and other values.

Finally, I recommend a study that investigates the views of healthcare, social care and educational professionals about their experiences of working with a black-African family with an autistic child in the UK. This type of research should also query whether professionals have insight into the specific cultural values of this group, and how these might influence their worldviews about autism.

9.8 Policy and Practice Implications

To conduct research of this nature, it is advantageous to have knowledge of autism, and educational, social and healthcare systems. It can be advantageous to 'know' your research participants through having certain things in common, and being sensitive to their issues and concerns. As mentioned previously in this thesis, I am a social work practitioner who has worked directly and indirectly with families from this and other ethnic groups, been involved in decision-making about resource allocation, worked in multidisciplinary service provision, and collaborated with professionals from emergency services, educational, healthcare and allied services. I also share some cultural values with this group of participants.

I believe that the data obtained in this study has produced in-depth and insightful findings about participants' experiences in relation to their autistic child. As well as contributing to knowledge, and addressing gaps, this study contributes, not only to future social work practice, but also to the evolution of autism-related educational and healthcare services. My professional experience and skills, along with my understanding of the cultural values and structural barriers faced by immigrants in the UK, positions this study to make recommendations for practice and policy change.

9.8.1 Implications for Policy

Involving parents of black-African origin in the development of local autism services can enable this group to contribute to policy development, practical implementation, and resource distribution in their local areas.

Policy development for flexible working arrangements should include a recommendation that social workers and other professionals tailor their visits to the needs of ethnic minority groups who could not risk frequent absences from work due to their specific constraints.

A change to educational curricula is recommended. This might incorporate specific Africanness values, within topics relating to ethnic diversity, or role-play activities in social work, nursing, and psychology education.

9.8.2 Implications for Practice

Social workers and other professionals should be aware that African parents often have cultural expectations of their children, including specific duties and obligations. Some are not immediately obvious, and assessment templates are not usually designed to capture such information. One such expectation is that, for African parents, their child is a future economic asset to them. A disabled child is, therefore, unlikely to meet this obligation. In this instance, social workers should remind parents that the UK welfare benefits system is designed to assist them in their old age, so there should be no need to rely on their disabled child for support. Social work assessment forms should seek to identify the immediate and future concerns of parents. Responses to such questions could provide invaluable insight into worldviews about family, which may create an opportunity to further develop cultural competencies for social work practice.

Professionals should have an insight into the factors influencing parents' attitudes and decision-making. These may include religious and spiritual practices and beliefs, along with customs and traditions that inform their thoughts and actions. But this does not negate their duty to promote the child's welfare and protect them from harm. For example, a parent who expressed the belief that their child's autism was caused by witchcraft, or the hope that their child could be cured of autism in the future, could engage in practices consistent with this belief system. Early discussion with parents to confirm that no evidence exists to suggest that autism is caused by witchcraft, or may be curable, would be useful. With this knowledge, parents could discount any beliefs about the role of witchcraft in causing autism, and develop realistic expectations in regard to the prospects of their child to be free of autism in the future. Specific pre-assessment consultation sessions for parents to explore cultural and religious beliefs about their children's condition are recommended for social workers. This could provide information about what is important to them from a cultural perspective, which could inform the development of person/family-centred assessments. Pre-assessment consultation could also be helpful to temporary residents, and those subject to NRPF restrictions in clarifying their immigration conditions. For example, if professionals know that their clients have a mandatory requirement both to be in employment, earn a minimum income per year, and to have no access to welfare benefits, they could plan meetings and appointments at a suitable time and place.

Creating autism awareness and information sharing among black-African communities in the UK could be achieved by carrying out a short campaign or presentation in places of worship and in community centres. This could make congregations more tolerant and accommodating. Local authorities in the inner city of London could encourage more black-African parents to set up their own self-advocacy or parent-support groups in their respective areas. Such groups would provide African parents with a voice to challenge authority where necessary.

Respect and regard are important values for black-Africans, as this study has found. But parents in this study did not always find that professionals respected their views, their parenting styles, cultural worldviews, or acknowledge their expertise. For example, some parents in this study felt that their child’s diagnosis was delayed because their GP was dismissive of their views. It is important that healthcare, educational, and social care professionals show respect for parents’ knowledge, expertise and skills in raising their autistic child. If parents are treated as equal stakeholders, it might promote the positive partnership-working which is required for early intervention.

I plan to set up autism education and resource centre(s) in Nigeria to help address the scarcity of autism services in that country.

Finally, it is hoped that the implementation of these recommendations could help to reduce some of the additional layers within the common experiences of black-African immigrant families with an autistic child in the UK.

9.10 Conclusion

This thesis has given an account of the stories of black-African immigrants who live with an autistic child in the UK, and explained why they are considered as having multiple layers of autism experiences. For this purpose, this thesis has demonstrated that a significant number of people from black-African ethnic background, with an autistic child living in the UK, applied various theoretical and conceptual frameworks, and employed IPA to assist with investigating their experiences. The three research papers (Slade 2014; Perepa 2014; Corbett and Perepa 2007) most relevant to this topic were critically appraised and I concluded that this area of research has not been fully explored. Altogether, 37 participants shared their stories about reality and perception in the UK about their children's autism. The concept of intersectionality enabled the elucidation of embedded convergent and divergent issues and experiences. Furthermore, four major themes emerged from the data to address the research questions, and supported the existence of multiple layers of autism experiences for this research group. For example, the study found that some of the problems this group faced emanated from their multiple identities (Africans, immigrants, foreigners, race, ethnicity, culture, gender, religion, and autism/disability). These identities converged to expose them to racism, racialisation, discrimination, oppression, rejection, stigmatisation, subjugation of mothers, threats to African male masculinity and ideals, and the threat to continuity of kinship and lineage systems. But the role of religion and spirituality, as a coping strategy, provided much needed hope and support for their attempts to make sense of their problems and related circumstances.

It would be timely, therefore, for academics, researchers, professionals and policy makers to acknowledge the voices of black-African families with children who have autism, and other types of disabilities, living in the UK. It is also important for them to appreciate that, in addition to the common challenges faced by all families of autistic children, this group has multidimensional issues. Invariably, the additional challenges engender unmet needs, e.g. culturally insensitive services, poor awareness of specific diversity issues, inequalities, insufficient recognition of intrinsic Africanness worldviews, and unfairness. This study draws attention to these unmet needs and calls for a collaborative approach by all stakeholders to challenge negative stereotypes, discrimination, and oppressive experiences for ethnic minority groups in the UK.

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Appendices 1-9