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An intersectional approach to Black parents' experiences of autism in the UK

Eli Gemegah

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Table of Contents

Dedication

To all the parents who are living with autism

I dedicate this research to Anita, Gabriel and Josiah. Anita, your strength in the face of adversity inspires me daily, birthed the idea for this project and kept me going.

To Gabriel (Gabsy), my bright and shining star, you have taught me that situations change but love remains constant. Your laugh gives me so much joy and hope and I live for it. I am truly grateful to God for your life. You are our miracle.

To my Josiah (Jose), your innocence, unceasing and heart-warming smile and joy revives me! You always lift my spirits during the days when I felt low and disheartened. You are a wonder and I'm privileged to be part of your life.

To my beloved Ma, in your Loving Memory.

My grace is sufficient for you, for My power is made perfect in weakness'' (Holy Bible, 2 Cor. 12:9).

Acknowledgements

Declarations and inclusion of published work

This thesis has not been submitted for an award or degree at any other university or institution. Material derived from other sources have been referenced with full bibliographical information provided. This work submitted is the result of my own investigations fully supervised by Dr Dimitra Hartas.

I have collaborated with Dr Tromans on a narrative review of autism and ethnicity and has been published prior to submission: Tromans, S., Chester, V., Gemegah, E., Roberts, K., Morgan, Z., Yao, G.L. and Brugha, T., 2020. Autism identification across ethnic groups: a narrative review. Advances in Autism.

I worked closely with Dr Dimitra Hartas and Dr Vaso Totsika on my Masters dissertation on a survey examining public attitudes to autism. The findings were published prior to submission: Gemegah, E., Hartas, D. and Totsika, V., 2020. Public attitudes to people with ASD: contact, knowledge and ethnicity. *Advances in Autism*.

I am working with Dr Naomi Ekas to recruit participants on a project with the working title: AfricanAmerican experiences of autism in the US.

Abstract

This study investigates the lived experiences of Black parents caring for a child with autism. Their experiences were examined alongside familial, contextual and systemic contexts that intersect to influence parents' psychological wellbeing. The study expanded upon Corbett and Perepa (2007) who investigated cultural influences in autism and Heer, Rose and Larkin's study (2012) on contextual factors that influence Black and minority ethnic parents of children with learning disability. Since then, there has been minimal research on the role of culture on Black parents' experiences of autism, so this study aimed to begin to address this gap in research. A qualitative approach was adopted using in-depth interviews with participants across England and a hermeneutic phenomenological method provided breadth and depth of findings on experiences from an often-marginalised group of people at the intersection of race, gender and disability. Following an ecological framework, the research findings identified factors at individual (i.e., mothers as primary caregivers, isolation), community (cultural beliefs and cognitive dissonance, lack of autism knowledge, stigma) and structural levels (institutional racism in education, housing; lack of cultural sensitivity during and after diagnosis) that negatively influenced parents' experiences of autism and their wellbeing.

An intersectional lens provided insight of how multiple identities converge in various contexts. The findings revealed that in addition to challenges associated with autism, Black parents experienced distinct and nuanced difficulties associated with race, culture, gender and socio-economic status. Parents' multiple and intersecting identities shaped their experiences of autism and their psychological wellbeing in the face of racism, unequal division of labour and oppressions from structural barriers in the home, community and organisations in wider society.

The findings of the study showed that mothers' primary caregiving role negatively affect their quality of life (isolation, financial hardship) and psychological wellbeing. Culture influenced gender roles and perception of autism, which impacted the family structure and subsystems. However, mothers recounted the valuable nature of their coping strategies including spiritual beliefs, cognitive appraisal and resilience. This study revealed the multi-level intersection of race, culture, gender and disability and provides relevant information for mental health and social practice, policy, and research.

List of tables

List of Figures

CHAPTER ONE

Introduction

This study examines Black parents' lived experience of the autism spectrum disorder (hereafter autism) in the UK, to address the intersectional factors that influence their psychological wellbeing. Unlike predominant research on autism, the focus is exclusively on Black parents' experiences because of the dearth of research on this topic. It posits that a multifaceted lens is necessary to understand minoritized groups, value their experiences and provide relevant support at individual through to systemic levels. This study employs a hermeneutic phenomenology through a narrative approach to examine individual experiences of autism in familial, contextual and systemic frameworks.

Experience is 'something that happens to us', not necessarily something that 'we undergo' (Henriksson and Friesen, 2012: 2), which indicates a continual interaction between individuals and their contexts (Henriksson and Friesen, ibid). Experience is a continuous process, not to be truncated, sectioned or categorised, but rather such continuity grants for links and relationships with different contexts, which allows for the study of intersectionality in various contexts.

Hermeneutic phenomenology is employed to study parents' meaning of their lived experiences by considering their subjective accounts of feelings and perceptions (ibid). Hermeneutic phenomenology, as a mode of inquiry, supports the search for meaning and interpretation parents' associate with their experiences.

This study recognises that parents' experiences are not fixed but rather 'something that is continuously open to new insight and interpretation' in contexts. This mode of inquiry allows for rich descriptions of a phenomenon as it is concretely lived and

offers interpretations to 'contextually grasp parts within larger wholes' in descriptively grounded research (Wertz, 2005: 175). This study recognises and highlights the connection between hermeneutic phenomenology and the intersectionality paradigm. The study of experience opportune insights to the complex ways that identities mesh, blur and overlap, discover ways that human identities are integral to capture the multi-faceted and multi-dimensional nature of experiences because of race, gender, disability and financial status. Intersectionality becomes an open-ended hermeneutic lens through which interconnected systems of oppression (racism, sexism, classism/disablism) can come into focus for social justice (Ruíz, 2017: 335). An intersectional and hermeneutic lens take a significant, systematic approach to combating oppressions based on critical examinations of lived experience – not only as parents, but as socially situated black women at the intersections of multiple social forces and asymmetrical power relations (ibid: 336).

To my knowledge this is the first study to explore an intersectional approach of Black parents' experiences of autism in the UK, with the aim to begin to fill the gap on an under-researched population in the autism field. White parents' experiences, though widely available in literature, lack representativeness and generalizability to Black parents, particularly on the important influence of contextual and systemic factors on parents' psychological wellbeing (Corbett and Perepa, 2007). This study is important because it presents Black experiences of autism to bring marginalised voices into autism discourses and convey how autism shape parents and families' lives. For a holistic understanding and for transformative purposes, this study presents the intersectional factors that influence Black experiences in general, and autism.

Black experience is approached not as a fixed construct or a category but as something in the making within human relationships that is shaped by cultural, religious expressions and systemic oppression. So Black parents' experiences are embodied in cultural traditions, value systems, ideas and institutional forms and thus the importance of looking at both personal and structural/ systemic factors. Individual and familial factors are interrelated as parents' cultural and religious beliefs become the foundation that their family experiences are built upon; their socio-economic position, race and cultural identity in White spaces form the prism through which they understand their individual and familial experiences. Therefore, individual and familial terms are used interchangeably in this study to convey the message that factors that affect parents as individuals directly and indirectly impact the children and the family.

This study adopts Bronfenbrenner's (1979) ecological framework to delineate parents' experiences in familial, social, community and institutional contexts. Ecological theory recognises the complex system of relationships that affect a child's life, from the familial setting to the school context and broadly, culture and law. This study posits that parents' experiences directly and indirectly shape child development, thus, examining parents' experiences of autism using an ecological framework shed light on factors that influenced their psychological wellbeing and indirectly shape children's lives. Parents close caregiving role for children with autism suggests that they interact with the same contexts that their children encounter daily; ecological contexts shed light on existing practices and policies that influence parents' experiences of autism and impact their psychological wellbeing.

Extant research on minoritized groups prompted my interest in Black parents' experiences of children with autism, particularly as there is currently a paucity of research interest in this area. Similar to Heer et al. (2012), Munroe et al. (2016) and Fox et al. (2017), this study aims to explore Black parents' experiences of familial, contextual factors with an additional focus on systemic forces, from an intersectional lens. This research investigates whether African/cultural beliefs and attitudes regarding disability are prevalent despite living in a Western setting. The role of culture in shaping disability perspectives is paramount to this research; examines perceptions and attitudes of autism in the Black community through a cultural lens and their impact on parents' wellbeing.

Systemic factors were included because institutional racism and discrimination are prevalent factors that affect the physical and emotional health of Black people (Stevenson and Rao, 2014); Black experiences in institutional contexts highlight structural barriers in autism related services.

Subsequently, this research aims to present Black parents' experiences in the wider UK context and within their ethnic communities, identify ecological factors that shape Black parents' psychological wellbeing for recommendations in policy, education and public engagement within local communities, healthcare professionals, practitioners and religious organizations.

This study's aim is to demonstrate the gaps in support services in familial, contextual and systemic contexts that if considered and implemented, would benefit parents' psychological wellbeing and aid the child's holistic development. The data from this study will begin to address current gaps while building on current scholarly literature to understand Black parents' experiences from an intersectional lens.

Background on autism and individual, contextual and systemic factors

Autism is a neurodevelopmental disorder characterized by impairments in social communication and restricted, repetitive patterns of behaviour, interests, or activities (American Psychiatric Association [APA], 2013). As a neurological condition, autism can have overlapping comorbidities that manifest as developmental disabilities, sleep disorders, attention deficit hyperactivity disorder (ADHD), and behavioural challenges. The unknown scientific cause of autism does not curtail familial, contextual and systemic factors' impact on individuals living with autism.

The term 'autism spectrum disorder', though medically appropriate, tailors to the medical model lens which focuses on the deficits associated with the condition and has negative connotations of irregularity, malady and dysfunction. This research employs the term 'autism' to reflect the neurological condition that appreciates autism as a mode of being, therefore recognises the uniqueness of children and adults diagnosed despite the challenges they experience. The research records parents' perceptions and experiences of autism, therefore as they endeavour to separate autism characteristics from their child's identity and personality, using the terms 'autism' and 'child with autism' is a form of collaboration and agreement with parents' approach to the condition. It is important for the study and the language employed to reflect a person focused, not disability centred approach.

The focus on autism is critical due to the rise in its prevalence among Black communities and its impact on Black children's educational outcomes. This study recognises three different identities work in parallel: parent gender roles, race and living with autism, and will draw on existing literature that focus on each of these identities to further understand Black parents' experiences.

Recent research report alarming statistics that found that Black pupils have the highest rate of autism in the UK, yet there is little research on the existences of autism in ethnic minority groups (Roman-Urrestarazu, 2021). This research found that one in 57 children are on the autism spectrum, which is 1.76% of the country; Black pupils are 26% more likely than White pupils to have autism, meaning that prevalence was highest at 2.1% in pupils of Black ethnicity out of the seven million pupils in the UK. The study also revealed the effect of race/ethnicity on ASD status was mediated mostly through social disadvantage, with Black pupils having the largest effect, which gives further insight to the intersection of race and ethnicity, health and wellbeing and poverty in Black households. This study recognises that the intersection of culture, race, ethnicity, migration, religion, gender, and poverty influence parents' distinct autism experiences. Black parents' multiple and intersecting identities, their experiences of autism offer a multi-dimensional lens that gives insight to how contexts and systemic factors in the UK, Caribbean and Africa influence autism related experiences.

The autism diagnosis is the beginning of parents' personal journey with the condition; for Black parents, it may be their first-time hearing of the medical term for autism symptomology they have observed (Munroe, Hammond and Cole, 2016: 19-20). The diagnosis is a significant event in parents' lives as they experience

6

emotional and psychological effects of guilt, self-blame, shock, confusion and

devastation (ibid). Consequently, parents make sense of their child's diagnosis by

information from professionals, the internet, religion and their indigenous culture

(ibid). Agreement with the diagnosis offer parents a framework to understand their

child so parents know 'what [their child] has and [they] can see how to help [their

child]' (ibid).

Caring for a child with autism has been associated with negative psychological and

physical health outcomes due to the challenging nature of the condition, and its

varying symptomology across the spectrum (Broady et al., 2017). Parents and

caregivers

> take on additional caring responsibilities beyond those of a typical parent,
> including, but not limited to, the need to maintain a structured environment for
> their child, finding time for their own self-care, having to attend multiple
> therapeutic appointments and sourcing other structures of support (ibid).

The practical and emotional pressures that arise from autism are further accentuated

by the behavioural challenges and social and communication deficits, which affects

parents' psychological and physical health outcomes (Griffith et al., 2012, Gill and

Liamputtong, 2013). A comparison with parents of other developmental disabilities or

typically developing children indicated that parents living with autism experience

more emotional and psychological distress such as anxiety, stress and depression

(Olsson and Hwang 2001; Green, 2007).

There is an under-representation of research, policy and practice for racially

minoritized families, specifically Black families, in autism discourses. One way to

begin to bridge this gap is to examine the lived experiences of racially marginalised

groups living with autism. Notably, two studies (Munroe et al., 2016; Fox et al., 2017)

have examined Black parents' experiences of autism in the UK and emphasised on

the role of culture on parents' beliefs and attitudes to autism, stigma within ethnic minority communities, acculturation and limited knowledge and access to autism related services. Heer, Rose and Larkin (2012) recognise that the experiences of parents of children with learning disabilities from minority background, such as South Asian, are distinctly different from White parents due to conflicting values and beliefs, acculturation, the nature of the migration, language and social status. These factors significantly impact South Asian parents' experiences and perceptions of disability, the way in which disability is labelled, understood and experienced within a family, which can influence service uptake, diagnosis and interventions accessed (Skinner and Weisner 2007). Due to these factors, Heer et al. (ibid) proposed an experiential-contextual framework to understand South Asian families' experiences of learning disability in the UK.

Heer et al. (2012) recognised governmental attempts to provide culturally sensitive support services for ethnic minority groups in the UK. For instance, documents such as the National Carers Strategy (Department of Health, 1999), Learning Difficulties and Ethnicity: A Framework for Action (Department of Health, 2004) and Valuing People Now (Department of Health, 2009) recommend strategies to improve services for minority ethnic groups. However, despite these initiatives, 'mainstream services tend to be ill-equipped to provide appropriate services to ethnic families who define and address disability differently from the majority population' (Heer et al., 2012: 952). For example, the second national survey of learning disability partnership board (Hatton, 2003) revealed that services fail to consider Black and ethnic minority communities when planning and implementing disability services. Crenshaw (1995) suggests that although race and gender are socially constructed, such categories have significance in the world, therefore, it is important to think

about the way in which power is clustered around certain categories and exercised against each other and to further marginalise individuals located at the 'intersections of race, class, gender, and disability' (Erevelles and Minear, 2010). Thus, the study focuses on ways that parents' experiences in various contexts demonstrate the effects of systemic oppression.

*The focus of 'Black parents' in the title and further references throughout the research is contestable. This research predominantly presented mothers' experiences of autism. Two fathers contributed to the interviews, but to avoid marginalising father's voices, particularly with the dearth of literature on Black fathers' experiences of autism, I employ 'Black parents' for inclusivity.

Rationale

Professional and personal reflections on parenting and children with autism:

My first experience with autism was during my teacher training (PGCE) year. I spent some time spent in an inclusion hub for children with special educational needs (SEN) at the school, where I met students diagnosed with autism. The wide spectrum of autism symptomology puzzled me. This late awareness of the condition led me to question why I have not, previously, had any contact with individuals on the autism spectrum. I began to notice the shameful silence associated with disability, whether physical or hidden, in the Black community. A couple of years later, my nephew was diagnosed with autism at the age of two. This diagnosis was a surprise to us all, especially because when my sister had mentioned developmental delays or something 'not right', and to comfort her, I would say, "oh there's nothing wrong, he'll grow out of it. He's not speaking as much as he did because he's an

only child and he doesn't have any peers to communicate with". I clearly remember the day my sister called me to tell me my nephew's diagnosis. She simply failed to get the words out through her tears and sobs. I calmed her down to hear her mumbles. The word 'autism' felt like a sharp pain in my chest because I knew there was no cure, yet.

This diagnosis was not conferred within our family/community, but rather felt like a topic to be discussed in secret. I did not know what autism would 'look like' for him, I feared a future where he would not be able to navigate the world, and I questioned how we as a family can be supportive for him. Since we did not talk about the diagnosis, I accepted my nephew the way he was. I believe my acceptance was influenced by teaching profession and training to accept differences and find ways to support students to achieve their educational outcomes. However, I don't think I have ever heard anyone in my family discuss this condition other than as a nuisance or with shame and trepidation.

I have walked closely with my sister to navigate the world of autism. My sister often asks me to be present for my nephew's Child in Need planning and review meetings, and since Covid 19 and the increased use of Zoom/Teams, I have been able to attend more consistently to support my sister and share any autism knowledge/experience that would benefit him at school and home. Undoubtedly, navigating service provision for my nephew is challenging, and I imagine my sister feels the double/triple disadvantage of low social/ economic capital – she has not worked in 10years and any experience she may have had of the working environment is now dated – and the judgement that professionals make about working class, Black single mothers can make her interaction with them more challenging.

It took my sister years to share the autism diagnosis with her very close friends. I encouraged her to share her experience, and, in the beginning, she shied away from it, the fear of rejection and stigma was constantly on her mind. Now, she advocates for people with autism, participates in walkathons to raise funds, and has gained more confidence in her knowledge and advocacy against disablist attitudes in the community. To say that I am proud of her is an understatement.

Taking this unexpected and unpredictable journey for the last eight years, and counting, has been challenging and rewarding but we have developed some understanding of autism with much more knowledge to be gained.

During my teaching career, I observed Black children in secondary schools with behaviours symptomatic of autism; they were often marginalised in social and education settings, with some generalised support but without the diagnosis and potential funding that followed, there was limited/ targeted special needs assistance. Within my specialist role as a teacher with learning responsibilities for students with SEN, I observed the SENCO's liaison with parents. I observed some Black parents' refusal to acquire a diagnosis for their child, which led to experienced difficulties in navigating their child's challenging behaviours in schools, whilst other parents had received an autism diagnosis for their child but rejected the diagnosis, which created some tension between the parents and professionals, and led to diminished communication and strategies on how to support children in school and home. My social and professional interactions with Black parents gave insight to the cultural dissonance African parents experience with seeking for a diagnosis, accepting the diagnosis and parents' ability to cope with their child's challenging behaviours. These experiences highlighted the importance of liaising with parents through autism

education and showed that without practitioner and parent collaboration, the child is partially and ineffectively supported. My cultural background undeniably played an important role in identifying the role of culture as a dominant lens that influenced parents' experiences of autism, whereas to White professionals, parents may have appeared difficult, 'hard to reach' and unresponsive.

Upon past reflection and through my readings of research, I realised that there is a disparity between Western and African communities' approach to physical and hidden disability. It was apparent that Black parents, particularly Africans, of which forms my cultural heritage, perceived disability negatively and thus, individuals with disability and their families were stigmatised and marginalised.

Recent studies have shown that racialised stereotypes and discrimination from services and structures affect individual's psychological wellbeing (Owuor and Nake, 2015). This research is interested in the intersection of individual, contextual and systemic factors that influence parents' psychological wellbeing (Figure 1 and 3) and takes a top-down approach (Figure 2) to examine the impact of systemic factors on an already marginalised group of people because of stigmatising markers such as race, culture and association with autism.

Figure 1 demonstrates the study's findings on key factors in familial, contextual and systemic contexts that intersect to influence Black parents' psychological wellbeing, whether positively, negatively, or both, following their experiences with autism within ecological contexts.

Familial factors are identified as key aspects within the family that notably shape the family dynamics and have an effect of parents' psychological wellbeing. Mothers' experiences are highlighted due to their primary caregiving role of the child with

autism. This study examined the wider socio-cultural factors that influence Black parents' lived experiences and wellbeing in relation to autism. Culture, religion and community attitudes constitute the wider context that influence parents' experiences. These factors are organisms that largely influence individuals on a personal level and in their communities. Systemic factors acknowledge the various institutions and services that directly and indirectly shape parents' experiences of autism. Structural racism is identified across all support services and this research delineates the various ways that parents are impacted by institutional services.

Figure one depicts bi-directional relationships between familial, contextual and systemic factors to illustrate the intersectional nature of ecological contexts on parents' racial, gender and social class identities and their psychological wellbeing. This study identifies the person-environment interaction (culture, religion and resilience) as contextual factors that interact with the individual and influence their daily experiences. Culture and religion are organisms that exist outside of the individual before one's awareness and conformity to its functions and influences. A person's resilience is framed by consistent encounters with risk factors such as poverty, racial discrimination, labelling and marginalization. Person-environment interactions reveal the different factors that influence Black parents' experiences of autism.

Systemic factors are identified as institutions that parents are likely to interact with due to their individual and childcare needs (healthcare, education, housing agencies, stigma), which influence the ways parents navigate established systems in the UK and the autism condition.

Figure 1: Intersectional factors and psychological wellbeing

Parent/ Family
- Self-stigma
- Fears and worries about victimisation and the future
- Acceptance of autism
- Mother as caregiver
- Single mothers
- Siblings

Psychological wellbeing

Contextual factors
- Culture and Religion
- Lack of awareness on autism in religious organisations
- Cultural beliefs, traditions/perceptions on disability
- Community stigma
- Lack of knowledge/awareness on autism
- Resilience

Systemic factors
- Institutional racism: public and racial stigma
- Double/triple disadvantage and discrimination
- Culturally inappropriate services in health services
- Stereotypes and judgemental attitudes in Education, housing, Local Authorities services
- Financial implications of autism/ material disadvantage
- Respite and external agencies

Research Questions

Overall Research Question: What are the lived experiences of Black parents who have a child with autism?

Subsidiary questions

Research Question 1:

How do familial factors shape Black parents' lived experiences of autism and influence their psychological wellbeing?

Research Question 2:

How do contextual factors shape Black parents' lived experiences of autism and influence their psychological wellbeing?

Research Question 3:

How do systemic factors shape Black parents' experiences in general and of autism specifically, and impact their psychological wellbeing?

Definition of key terms

Autism – impairment in reciprocal social interactions, impairments in verbal and non-verbal communication skills, and repetitive behaviors and interests (APA, 2013).

Black – people of African ancestry and dark skin pigmentation or who self-identify as Black due to their history.

Black African – Black individuals from Angola, Congo, Ghana, Nigeria, Sierra Leone, Somalia, and Sudan. The latter would also include Sudanese of Egyptian origin.

Black Caribbean – those who originate from the Caribbean islands of Antigua and Barbuda, Bahamas, Barbados, Dominica, Grenada, Guyana, Jamaica, St Kitts and Nevis, St Lucia, St Vincent and Grenadines, Trinidad and Tobago.

Black Backgrounds (other) – Black Europeans, Black North Americans (including those from Canada), and those from any other Black backgrounds not included in the preceding categories.

Child with autism – a young individual diagnosed anywhere along the autistic spectrum by a licensed professional, including social communication disorder and autism spectrum disorder (APA, 2014; Autism Speaks, 2014).

Collectivist cultures – place priority on community interdependence and shared group norms and values.

Courtesy stigma – individual/group experiences of stigma from the community because of their association with disqualifying attributes.

Culture – aspects of lifestyles and learned traditions that are shared by members of a particular group, defined by language, habitual ways of thinking and behaving and include thoughts, communication styles, ways of interacting, views of roles and relationships, values, practices, and customs (Berry, Poortinga, Breugelmans, Chasiotis, and Sam, 2011).

Contextual factors – the relationship between the individual and existing social factors such as cultural and religious beliefs and expression, and community stigma.

Discrimination – when a person is singled-out and targeted for negative or less favourable treatment because he has a particular characteristic (Hatzis, 2011).

Emotional wellbeing – an overall positive state of emotions, self-esteem, and resilience that leads to self-actualization, self-efficacy, and health-promoting behaviors (Courtwright et al., 2020).

Experience – a person's insight because of their involvement with the topic/phenomena, for instance, autism.

Individualist cultures – place priority on personal independence, goals and values.

Internalised/self-stigma – occurs when stigmatised individuals accept the prejudice directed towards them as true and is characterised by subjective perceptions of devaluation, marginalisation, shame and isolation (Larkan, 2004; Overstreet et al., 2013).

Intersectionality – relationships among multiple dimensions and modalities of social relations and subject formations (McCall, 2005).

Institutionalised racism – the policies and activities of public or private organisations result in systematic racial inequalities or oppression.

Isolation – physical separation and/or emotional detachment from people and certain spaces.

Marginalization – relegating to an unimportant or powerless position within a society or group and is viewed as a negative experience in both immigrant and host cultures (Berry, 1980).

Minority experience – conflicting values and beliefs (between host and individual), acculturation, the nature of the migration, language and social status (Sue and Sue 1999).

Positive coping – a feeling of closeness and harmony with God/ sacred being.

Positive outlook – continual assessment of the child's development and behaviours to focus on improved areas; the ability to perceive a difficult situation from a positive lens.

Protective factors – promote resilience by reducing the effects of risk and individuals' reaction to difficult situations, e.g. financial stability social and familial support (Zauszniewski et al., 2010).

Psychological wellbeing – a breath of wellness that includes positive evaluations of oneself and one's life, a sense of continued growth and development as a person, the belief that life is purposeful and meaningful, the possession of good relationships with other people, the capacity to manage one's life and the surrounding world effectively, and a sense of self determination (Ryff, 1995).

Quality of life (QoL) – the general perception of an individual of their position in the life (i) considering the culture and value systems and (ii) in relation to expectations, goals, standards, and concerns. QoL considers a broad-ranging concept influenced in a complex and interconnected manner by psychological state, physical health, personal beliefs, social relationships, and relationship to prominent features of the environment (World Health Organisation; Melo-Oliveira et al., 2021).

Racism – system of structuring opportunity and assigning value based on race, that unfairly disadvantages some individuals and communities (Dodgson, 2018).

Religion – a search for significance in ways related to the sacred and a quest to understand earthly experiences through the lens of the sacred (Pargament, 1998).

Resilience – ability to prevail in difficult and /or negative situations (Zauszniewski et al., 2010). The 'process of coping with adversity, change, or opportunity in a manner that result in the identification, fortification, and enrichment of resilient qualities or protective factors' (Richardson, 2002: 308).

Respite – the opportunity for temporary relief from the distressing and anxiety inducing situation.

Risk factors – issues and elements that predispose people to physical and mental health problems such as poverty, racial discrimination, labelling and marginalization for marginalized groups (Bekhet et al., 2012; Owuor and Nake, 2018; Link and Phelan, 2001; Goffman, 1963; Stevenson and Rao, 2014).

SENCO – Special Educational Needs Coordinator.

Stereotype – the separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination (Link and Phelan, 2001).

Stigma – a rejection of individuals' identity or attributes such as family history, gender, sexuality, religion, ethnicity, social class, etc (Owuor and Nake, 2015:2). The

co-occurrence of its components – labelling, stereotyping, separation, status loss, and discrimination (Link and Phelan, 2001).

Systemic factors – the relationship between the individual and existing systemic factors such as poverty, discrimination and access to services, legislations, health and education systems/ professionals and support services.

In this chapter, I have:

- provided background information about autism and the rationale for a primary focus on Black parents and families;
- outlined the development of my interest in the topic of intersectionality of Black experiences in relation to autism and the relevance of the intersectional approach to illustrate factors that contribute to parents' experiences and psychological wellbeing;
- indicated what I set out to achieve in this study, and how.

Structure of the Thesis

This thesis is divided into six chapters. Chapter one has articulated the phenomena that underpins the research focus and provided a rationale for carrying out this study, which included a synopsis of my personal and professional experience of Black parents of children with autism, key concepts, and definitions. Chapter two contextualises the study in the relevant literature following the structure of the order of the research questions. It identifies the themes that emerge from the literature of research in similar areas, which guides the process, topics and themes for data collection.

Chapter three outlines the epistemological paradigms that influence and shape the research methods. It presents the research design and methods used to collect and analyse the data, including the ethical considerations. Chapter four illustrates the research findings with appropriate quotes and themes ranging from parents' [limited] knowledge of autism prior to their child's diagnosis to interactions with professional services and how these factors influence their mental wellbeing. In Chapter five, an analysis of the study's findings grounded in extant research are reviewed following an ecological structure to highlight recommendations for policy and practice. The study's limitation are considered. Chapter six concludes the research by summarising key findings and main contributions that respond to research questions and address the study's aims.

CHAPTER TWO

Literature Review

Introduction

This review takes a broad scope at scholarly works on ethnic minority groups and Black families in Western and African countries to examine wider socio-cultural factors that influence Black parents' lived experiences and wellbeing. Following Bronfenbrenner's (1979) ecological framework, this research explores the various factors at the different micro- , exo-, meso - and macro – systems: culture, community contexts and religion constitute the familial and wider environmental factors that have a bi-directional influence Black parents' general experiences and of autism in particular. Within this broader context, this review examines systemic factors such as institutional racism, structural racism and inequalities result in their interplay with autism.

The study is grounded in the theory of intersectionality (Crenshaw, 1989; McCall, 2005), progresses with a general discussion of intersectionality theory, its relevance to this research along a delineation of contextual and systemic factors that shape parents' experiences of autism and their psychological wellbeing.

Intersectionality: Theoretical framework

Feminist theorists introduced the concept of intersectionality and show ways that people, particularly Black women are affected by multiple oppressions that interact to shape their unique experience (McCall, 2005). This research employs the intersectionality as a useful concept to begin to address the multiple factors that simultaneously shape Black parents' experience:

Intersectionality investigates how intersecting power relations influence social relations across diverse societies as well as individual experiences in everyday life. Intersectionality views categories of race, class, gender, sexuality, nation, ability, ethnicity and age – among others – as interrelated and mutually shaping one another. A way of understanding and explaining complexity in the world, in people, and in human experiences (Collins and Bilge, 2020: 2).

The notion and concept that underlies the intersectional approach recognises the power imbalances in society: the acquisition of power for one group signifies the loss of power, privilege and influence, and delineates disadvantages minoritized groups experience.

Intersectionality is a concept that enables us to recognize the fact that because we are simultaneously members of many groups, our complex identities can shape the specific way we each experience that bias so individual experiences are a result of multiple influences (Gillborn, 2015). These complex identities are shaped by individual (gender, age, ability, disability) environmental factors (family support social networks) the exo-system (race, culture, ideology, etc), health, housing and education in the macro-system (Fig. 2). The ecological structure depicts the confluence of power and the intersectional factors that influence parents' experiences of autism in various contexts. This approach provides empirical basis that delineates social inequalities and the process that create and sustain them (Gillborn, 2015). The concept of intersectionality addresses the question of how multiple forms of inequality and identity inter-relate in different contexts and over time, for example the interconnectedness of race, class, gender, disability, sexuality, ethnicity, etc., (McCall, 2005; Gillborn, 2015) to 'generate coalitions between different groups with the aim of resisting and changing the status quo' (Gillborn, 2015; Crenshaw, 1995).

Central to Crenshaw's (1989) and Collins' (2000) articulations of intersectionality was their critique of single identity politics and call for coalition politics to challenge structures/systems of oppression and privilege.

For this study, demonstrating how structural racism engender social inequalities in various contexts and the processes that create and sustain them will show ways that an intersectional approach can generate 'coalitions between different groups' (Gillborn, 2015). The 'different groups' for this research focus on the various groups that parents interact with in different community contexts: religious groups, community services and families. In structural contexts, coalitions between parents and professionals in education, health, social care institutions are important to address structural inequalities in a meaningful and sustainable way. Like Crenshaw (1991), this study uses the concept of intersectionality to depict the various ways in which race, gender and disability interact to shape the multiple dimensions of Black parents' experiences. This study takes Crenshaw's position to illustrate that

> Black experiences are not subsumed within the traditional boundaries of race or [gender] discrimination as these boundaries are currently understood, and that the intersection of racism, [disability] and gender factors into Black […] lives in ways that cannot be captured wholly by looking at the dimensions of those experiences separately.

As such, Black parents' experiences cannot be perceived exclusively through a disability/autism lens, as a Black parent, a male or female lens. The intersectional approach gives further insight to understand the ways that multiple factors converge within various contexts to shape Black parents' experiences. Services liaising with Black parents of children with autism should not take a narrow approach but rather consider the intersectional factors that shape their experiences, prior to, during and after the autism diagnosis, in their practice. This research, therefore, takes a multi-

layered lens to identify the familial, cultural, community and structural factors that influence Black parents' experiences of autism in the UK.

Crenshaw (1991) recognises that

> Where systems of race, gender, and class domination converge […] intervention strategies based solely on the experiences of women who do not share the same class or race backgrounds will be of limited help to women who because of race and class face different obstacles (1246).

Similarly, the stereotypical representation of 'autism parents', as white, female and middle class (Cascio, 2015) fail to adequately represent the experiences of Black parents of children with autism. This study recognises the challenges associated with parenting a child with autism, however, takes the position that the missing dialogue and delineation of the systems of race, gender, class convergence marginalises Black parents' experiences of autism further in community and wider structural contexts. These factors merge and marry in ways that highlight their intersectionality, and therefore, this research conveys the complexity of parents' experiences.

Intersectionality's focus on the interconnectedness of categories of race, class, gender, sexuality, ethnicity […] shed new light on how social inequalities articulate with global social phenomena (Collins and Bilge, 2016: 88-113). Collins (2000) elucidated the systemic aspects of intersectionality by describing it as a 'structural matrix of domination in which multiple forces of oppression and privilege are mutually dependent and situated within cultural and historical matrices of domination' (3). Systemic policies and practices established to support individuals can also marginalise minority groups. Crenshaw (1991) recognised the ways that institutional structures fostered social inequalities by marginalising groups and individuals that did not fit into the 'race only' and 'gender only' categorical frameworks. Thus, the

importance of reflecting and depicting how Black women's life chances are unfairly and systemically limited in the economy, law, and throughout society; in antiracist, feminist, and other forms of single-axis politics (Crenshaw, 1991; Collins, 2000). In this study, mothers' association with disability highlights a marginalisation trifecta. Collins and Bilge, (2016) recognise that:

> From its inception, the idea of intersectionality worked in multiple registers of recognising the significance of social structural arrangements of power, how individual and group experiences reflect those structural intersections and how political marginality might engender new subjectivities and agency (71-77)

The concept of intersectionality not only recognises the relationship between contexts and individuals; it highlights the structural powers and their effects of individuals who are marginalised. In the case of this research, Black mothers' experiences of children with autism are highlighted to evidence the structural powers in various contexts that further marginalise Black mothers and fail to identify the interconnectedness of identities. This research employs intersectionality to examine the breadth of experiences of social inequalities.

This study foregrounds the social contexts and structural conditions within which categories of race, gender, religion and disability intersect, recognising that systemic factors influence experiences and functions within other contexts. Neville and Mobley (2001) acknowledge that

> most models operate from the assumption that human behavior is multiply determined by a series of dynamic interactions between social systems. Individuals' psychological adjustment is thus dependent on who or what he or she interacts with on a daily basis as well as those systems that structure individuals' day-to-day realities (472).

Therefore, Black parents intersect with individual, contextual and systemic factors that influence their experiences of and approach to autism. For this research, like

Neville and Mobley (ibid), I have broadened the macrosystem to include the social

structures of financial status, race, gender, stigma, double/ triple disadvantages,

professional practices in health care, educational, housing contexts (Fig. 2). The

assumption underlying this decision is that

> we live in a society that is stratified across a variety of social locations or
> identities: hierarchical social system in which dominant groups (e.g., wealthy,
> White, men on average are afforded more social, economic, and political
> advantages compared to nondominant groups (e.g., poor or working class,
> persons of color, women, [dis]abled) (ibid, 2001: 473).

The concept of a stratified society infers that society is engineered to favour some

people who belong to certain socially constructed categories, which explains

inequality in education, health and housing. Furthermore, this study identifies the

person-environment interaction (culture and religion) as contextual factors that

interact with the individual and impact their daily experiences. Thus, this research

observes these concepts to produce an intersectional inverted pyramid model (Fig.

2) with the systemic factors at the top to signify its powerful and governing influence,

followed by contextual factors and then the individual's experiences and

psychological wellbeing because of their daily interaction with autism.

It is worth noting that the ecological model does not lend itself to linear articulations,

rather the arrows show a visual interaction between subsystems to capture the

'complexity and interconnectedness of the ecosystem' (ibid: 473).

Figure 2:
Model of the intersectionality of systemic, contextual factors that influence and shape individual daily experiences in the wider context and of autism (Neville and Mobley, 2001).
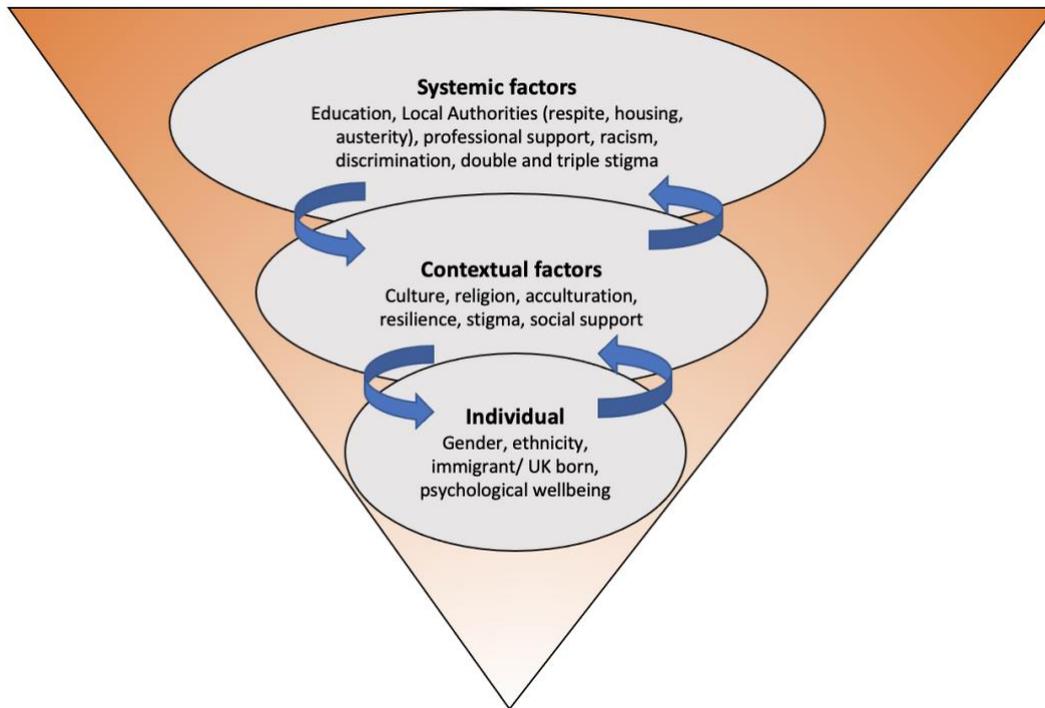
Figure two recognises and represents individuals as simultaneous members of many groups; these ecological contexts shape the specific way individuals each experience complex identities in relation to racism, sexism and disablism (Gillborn, 2015). Complex identities are shaped by individual factors (gender, age, ability/disability) and also factors in the immediate environments (family and social support, community attitudes), the exo-system (race, ideology) and macro system (education, health and local authority organisations). This figure highlights the power that institutions and support services have in influencing parents' experiences in contextual and individual settings; shows the intersectionality and interconnectedness of each context and their impact on parents' psychological

wellbeing. This paradigm interrogates 'the ways that states constitute regulatory regimes of identity, reproduction [of racial and courtesy stigma] and family formation' in autism research (Cho, Crenshaw, McCall, 2013: 785).

Blackness/ Black culture

The 'Black or Black-British' category

> includes individuals from Black Caribbean, Black African or any other Black background. 'Black British' refers specifically to those born in Britain and are second generation (or later) Black Caribbean, Black African, or other Black background (Lindsay, Strand and Pather, 2006).

The remarkable diversity within the Black community on areas such as diet, religion, migration experience, language, education and health behaviours and histories (Agyemang, Bhopal and Bruijnzeels, 2005) indicate dissimilar yet shared experiences because of cultures that amalgamate under the term 'Black'. Thus, the 'Black experience' like Heer et al.'s (2012) coined term 'minority experience' was examined to note African and Afro-Caribbean collective experiences and forms the prism to parents' experiences. This study employs the 'Black experience' as a combination of individual and contextual and systemic factors (Fig. 2).

Race is significant, intersects with Black history and experiences to provide insight to Black culture. Historically, race was seen as a biological difference, a socially constructed term to categorise individuals according to physical features into hierarchical groups that reaffirmed White superiority and Black inferiority. DuBois (1897) contests against this excuse for oppression, questions, 'what then is race?' and responds that it is

> a vast family of human beings, generally of common blood and language, always of common history, traditions and impulses, who are both voluntarily and involuntarily striving together for the accomplishment of certain more or less vividly conceived ideals of life (75-76).

DuBois' definition of race identifies uniformity of past and present experiences and ambition in the life journey. This concept of race moves away from the 'scientific' – biological and anthropological notion to a sociohistorical perspective, identifying the intersectionality of history, culture, language, tradition, etc. The sociohistorical notion of race suggests implications of systemic factors that culminate from 'common history', and contextual factors that reflect 'language…traditions and impulses'. DuBois' definition of race is an example of how individuals' experiences are a result of the contextual and systemic factors that intersect to shape lives; resonates with Hall's (1990: 225) position that cultural identities come from somewhere, have histories and are subject to the 'continuous 'play' of history, culture and power. However, it is important to note the tension between 'common blood…history, traditions' (Du Bois, ibid) and differences in Black history that also shape their present experiences. Appiah (1985) recognises that the history of Africa is part of the common history of Afro-Americans [Afro-Caribbean] not simply because Afro-Americans descended from various peoples who played a part in African history but rather because African history is the history of people of the same race (27). However, concurrently, Appiah's (ibid) view that 'sharing a common group history cannot be a criterion for being members of the same group' conveys the relevance of varied historical structures and colonial experiences that have existing impact on individuals' present lives. Ethnic differences as a result of history, culture, language and experience support the notion that blackness, is not something that is once and for all—'it has always been a process of becoming' (Gabriel 1998, p. 49), thus, resonates with Hall's (2017) definition of cultural identity, which is

> not a set of fixed attributes […] but a constantly shifting process of positioning […] in fact, identity is always a never completed process of becoming – a

process of shifting identifications, rather than a singular, complete, finished state of being (16).

Cultural identities are ways that people from the diaspora make sense of their lives as a product of the historical colonial experience both in the past and its persistent presence identified in structural racism and inequalities. Today, Black people are 'constantly shifting process of positioning' to understand their experiences through the powerful White lens of policy and legal frameworks that 'have the power to make [Black people] see and experience [themselves] as 'Other' (Hall, 1990: 225). As such Gilroy's (1993) characterisation of the Black culture as 'temporary experiences of exile, relocation and displacement' (18) is fitting, so much so that, the 'politics of identity get inscribed in analyses of black culture'. The diasporic nature of Black lives from colonisation to slave history and immigration evidence the conceptualisation of Black culture as 'relocation' and 'displacement'. The search for the exotic, financial freedom, adventure, betterment for oneself and their family are not mutually exclusive reasons for the increase of Africans and Afro Caribbean in Britain today. Rather than offering a unifying notion of black identity, like Gilroy, this research is keen to emphasize the ways in which ''black expressive culture'' is renegotiated in different socio-political contexts (79). Gilroy moves the "discussion of black political culture beyond the binary opposition between national and diasporic perspectives", not to replace one with the other but to set them in dialogue; national identities are placed within a wider ''webbed network'' of interactions ''between the local and the global." (Evans, 2009: 256). Similarly, this research brings 'together the national and diasporic perspectives' of autism to show the connection between and influence of local cultures and national experiences in the Western and African/ Afro Caribbean settings. The main thread connecting the various settings is the cultural

lens that shapes parents' understanding, experiences and attitudes to disability in general, and autism specifically; the racial lens that determines the quality of Black lives in Western contexts. In this study, the African and Afro-Caribbean perceptions and experiences of autism reflect the diversity of cultures traced back to various African and Caribbean countries and reflect the Black experience in the UK. Parents' perceptions of autism could take them 'back to their roots, the part of them which remains essentially the same across time' as parents travel to the West with a cultural lens about disability (Hall, 2017: 16). As such, though their cultural identities and self-perceptions undergo continual transformation, parents' cultural lens, ideas, beliefs and attitudes to disability and autism can be fixed initially, and overtime undergo a process of renewal in different ecological contexts. The intersectional paradigm enables this research to attend to a variety of context-specific inquiries, including, analyzing the multiple ways that race, disability and gender interact in familial, community and structural contexts.

Black people and autism

Research on Black parents' experiences of autism is limited in the UK except for studies by Munroe et al. (2016); Fox et al. (2017). Most studies focus on the experiences of disabled people (Oliver, 1992; Satsangi et al., 2018; Read et al., 2018; Liddiard et al., 2019) and public attitudes towards autism (Dillenburger et al, 2016; Gemegah et al., 2020). Although research has examined how families adapt (Moody et al., 2018; Timmons and Ekas, 2018; Clow, 2016; Ridding and Williams, 2019), the role of culture (Corbett and Perepa, 2007, Perepa, 2019) and the minority experience in Asian communities (Heer et al, 2012), no research exists on Black

parents' experiences of autism from an intersectional lens with a particular attention to culture. Autism research has been criticised for excluding participants of colour and participants who are otherwise marginalised (Cascio, Weiss and Racine, 2020).

Broder-Fingert et al. (2020) recognises that the causes of delays from first parental concern to ASD diagnosis are complex, they can result from several issues including racial bias and discrimination. Existing research on autism in the Black community focus on prevalence rates in comparison to the dominant culture (Tromans et al., 2020), racial inequalities due to structural barriers and challenges Black children experience with outcomes in delayed diagnosis, difficulty accessing treatment services and inevitably worse health outcomes (Broder-Fingert, ibid).

Autism disparities are defined as the unequal access to diagnosis, treatment, and services due to economic status, racial bias, or other forms of discrimination (Mandell et al, 2009). Autism disparities have been known to result from existing structural discrimination within racial and socio-economic areas (Begeer et al., 2009; Mandell, Listerud, Levy, & Pinto-Martin, 2002), limited access and support from health services, professionals' misdiagnosing autism as behavioural/ conduct related disabilities and lack of support from a 'fragmented' health insurance system in the U.S. (Singh and Bunyak, 2019).

Angell et al. (2018) discussed the disparities in health care diagnosis and intervention among children with autism. They reported evidence of racial and ethnic autism disparities even when socioeconomic status is controlled. Their study generates a need for more research that focuses on addressing and reducing the cultural and linguistic barriers that people from minority communities face. Angell et al. (ibid) utilized health care disparities research to highlight the crucial need for

34

intersectional factors in the provision of autism specific health services to individuals and families.

Singh and Bunyak (2019) conducted a systematic review of qualitative literature that investigated disparities in autism diagnosis and access to care, focusing on the experiences of racial and ethnic minority families with autistic children. They found that these families experienced barriers to access rested at the intersection of ideological, economic, and political domains, and that these barriers were experienced differently based on race, language, and culture. Therefore, Singh and Bunyak (ibid) suggest that the integration of intersectional frameworks to tackle familial, cultural, and structural barriers would improve diagnosis, assessment, and treatment. Reported structural factors demonstrate the multiple intersecting factors that influence the autism diagnosis process and parents' experiences after diagnosis. Mallippedi and VanDaalen (2021) note that

> For many autistic people of color or those who have minimal access to quality medical care, health inequities often arise from the relationship between the social determinants of health, such as class, language, or geographical barriers, with disability identification.

The continued theme arising from the relationship between institutional racism and Black people's experiences in health sectors is marginalisation, under-representation in policy and practice that leads to unmet needs and health deterioration. The intersectional framework provides valuable lenses for understanding social oppression and its consequences through the integration of multiple contextual factors (Mallippedi and VanDaalen, 2021). Structural racism is one component that impacts the family and the child with autism but does not offer a holistic presentation of the complex factors that shape parents and children's experiences of autism. Whilst this study recognises the multiple structural factors that may contribute to delay in diagnosis and treatment, its main emphasis is on the importance of culture

and the cultural lens that limits parents' awareness and understanding, which ultimately shapes their attitude to autism and marginal experiences in their community.

Hence, this research employs an intersectional approach to begin to highlight the various familial, community and institutional factors that contribute to delayed diagnosis, among other experiences, which result in the parent and child's poor health outcomes.

Despite the growth of research on autism over the last few decades (Zainal and Magiati, 2016) there is a dearth of quality works on the relationship between culture and autism (Dyches et al., 2004: 211). The government-funded project entitled '*It's not as simple as you think: Cultural viewpoints around disability'* (DfES, 2006) examined the relationship between culture and disability. This document went on to consider disability as a concept that is understood differently in different cultures and gave the example of the Western term 'learning difficulty' having no direct translation into South Asian languages. Shaw and Hughes (ibid) noted an overall lack of research that considers the intersection of culture and disability and individuals with disability are often regarded as 'culturally neutral' (ibid: 3). The project recognised the complex situation that people from ethnic minority groups experience: 'they may be part of a culture that has a different concept or no concept of [disability]' (ibid: 6). Limited research in this area shows that government policies and initiatives for people with a disability cannot be generalised to Black and ethnic minority parents/ caregivers. Thus, this research responds to Corbett and Perepa's (2007) assertion that the neglect of Black families by researchers, professionals and service providers is 'unacceptable and must be addressed with urgency' (4).

This study acknowledges culture as the primary determining factor and dominant lens that initially shape Black parents' experiences. Adopting a cultural lens gives space for the Black man's customs and the sources on which they were based to exist in autism research (Fanon, 1967: 83), offers another meaning and framework that allow professionals to understand and value how Black parents' perception and experience of autism. The cultural lens invites the social model of disability to demonstrate the importance of social attitudes to disability and autism in Black communities and more widely in UK society.

Contextual factors

Culture and Disability

Culture is often the lens people perceive and understand the society they live in. It subconsciously influences people's thoughts and actions so can be the invisible, yet the powerful driving force behind their beliefs, choices and perceptions.

Various cultures exist within the classification of Black in the UK and there is considerable diversity within Black Caribbean and African cultures. Each culture is an amalgamation of histories, collective beliefs, norms, and values which shape their behaviours and attitudes, especially towards disability.

Diller and Moule (2005) referred to culture as aspects of lifestyles and learned traditions that are shared by members of a particular group, defined by language, habitual ways of thinking and behaving. This definition presents culture as the fabric that weaves people together through shared ideologies and values concerning various aspects of society. Coles and Scior, (2012) recognise that 'the way a cultural group understands […] disability is likely to affect responses to individuals with […] disabilities' (178).

Disability studies is a critical response to two cultural perspectives (Goodley, 2017):

> A moral stance perceives disability as a sin (a punishment from God forgiven through divine intervention) while a medical position understands disability as pathology (a diminished physical, sensory or cognitive state that 'handicaps' those 'afflicted' and requires the divine intervention of medicine and its para-professions) (6).

Moral positions have included disability as a reflection of God's dismay (Ancient Greece), as evidence of an intimacy with God (medieval Europe) and a divine response to parental wrongdoing (Renaissance period) (ibid). Negative social reaction to different sensory, cognitive, psychological impairments are still prevalent in society and the Social Model of Disability offers an alternative framework to positively shape society's attitudes (UPAIS, 1975)

Culture influences family decisions, behaviours and psychologies when caring for a child with a developmental disability: from noticing and making sense of differences, to selecting treatment approaches, interactions with healthcare systems and future expectations (Ennis-Cole, Durodoye and Harris, 2013; Ravindran and Myers, 2012a; Norbury and Sparks, 2013; Mandel and Novak, 2005).

Danseco (1997: 44) notes that culture constructs people's beliefs. Danseco's interviews (ibid) reported that parents from different cultural groups (Mexican American and Chinese American) held biomedical, physical and sociocultural beliefs (supernatural, magical, metaphysical or religious) about their child's disability. Cultural beliefs that bad parenting and supernatural factors cause autism are dominant beliefs, values and attitudes in Eastern and Southern Asian and Hispanic communities (Lin et al., 2011; Reyes et al.'s, 2018; Ratto et al., 2015; Gulyn and Diaz-Asper, 2018). These beliefs are shared in Black communities (African and Afro-Caribbean) and influence how Black and ethnic minority parents understand and

approach disability. For instance, Indian parents living in the USA and elsewhere drew on a combination of biomedical, traditional Asian and religious beliefs such as Karma (Ravindran and Myers, 2012b).

Ethnic minority groups are also influenced by their community contexts and the way in which their own community recognises and responds to learning disabilities (Skinner and Weisner, 2007). Members of 'ethnic groups traverse between two sets of cultural beliefs and norms' support the belief that attitudes to disability, particularly autism stem from cultural settings (Danseco, 1997: 44). Slade (2014) observes that Black 'families can be exposed to messages from their [indigenous] culture, which can carry a strong influence and counteract the knowledge that families might have developed about autism in the UK' (11). Cultural stigma attached to disability covertly shape Black parents' lives in the UK. Black parents have identified common perceptions of disability in their community; autism has been seen as spiritual attacks, thus resulting in labelling children as 'mad', 'possessed', 'demonic' or 'naughty' (Munroe et al., 2016:23-24; Bankole, 2016) or 'a generational curse' (Corbett and Perepa, 2007: 9).

Other contextual factors that influence parents' experiences of autism and delineate the Black experience, include: poor knowledge/awareness about autism; negative cultural beliefs and practices (Bakare et al., 2009; Bakare and Munir, 2011; Igwe et al., 2011), language difficulties for non-English speaking parents when explaining their child's behaviours prior to diagnosis (Corbett and Perepa, 2007), late access and take up of services due to cultural differences, religious beliefs and family traditions (Lindsay, Pather and Strand, 2006; Heer et al., 2012; Papadopoulos, 2016a).

Extant literature on the differences in attitudes to disability concur with the view that culture is one of the influencing factors. This research adopts a cultural lens to demonstrate the role of culture on parents' experiences of autism in ecological contexts, primarily, forms of oppression that exist and intersect at familial and community settings. This research's primary focus on culture offers further insight to the various factors that intersect to offer a nuanced and complex understanding of parents' diasporic experiences in the UK. The cultural lens emphasises the underlying presence of traditional beliefs and attitudes to disability and autism, among marginalised social groups, which leads to low levels of autism information/education and high levels of poor mental health and disability stigma in the Black community.

Religion's general and specific influence

Religion is recognised as a 'potent coping strategy' that facilitates adjustment to life stresses and religious service attendance has been associated with lower psychological distress (Williams et al., 1991: 1261). Furthermore, internalising religious principles which entail having a relationship with the sacred or 'God' is associated with healthier psychological well-being (Butler-Barnes et al., 2018: 1989). Therefore, having a close relationship with God/ the sacred can act as a protective factor against social and systemic oppression (Williams et al., 1991; Butler-Barnes et al., 2018).

Li et al.'s (2016) twenty-year study found that women who attended religious services more frequently tended to have 'fewer depressive symptoms, had lower mortality, specifically, from cerebrovascular disease and other cardiovascular diseases, lower risk of breast cancer mortality and colorectal cancer mortality' (780-

782). VanderWeele (ibid) believes that 'part of the benefit seems to be that attending religious services increases social support, discourages smoking, decreases depression, and helps people develop a more optimistic or hopeful outlook on life' (Pickles, 2016). The physical health benefits of religious service attendance are evident: women who attended religious services more than once per week had a 33 per cent lower risk of death compared with women who never attended religious services (Li, 2016: 782; Pickels, 2016). Although these studies evidence the impact religion has on the public's physical and psychological health, one main limitation with Barnes et al.'s (2018) research is that the study did not ask participants how they use religion to cope with life's stresses, so a qualitative approach is required for participants to explain how they use religion as a coping strategy. Participants' self-identified as Christian therefore findings may not be generalisable to other religious faiths, although there may be similar coping styles and methods. Li et al.'s (2016) study consisted of White Christian US nurses with similar socioeconomic status who tend to be more health conscious; albeit findings cannot be generalised to Black women, the impact of religion is worth noting. Sunak and Rajeshwaran (2014) mention that 'in contrast to White participants, Black residents are more likely to have a religion, practice that religion, and feel that religion is an important part of their life'.

This could be because

> […] main ethnic groups largely follow the predominant religion of their origin country – Indians are split between Hinduism, Islam and Sikhism; Pakistanis and Bangladeshis are overwhelmingly Muslim; and Black Africans and Black Caribbean are mainly Christian with a sizeable amount of Muslim Black Africans […] (Sunak and Rajeshwaran, ibid: 38).

Culture and religion appear to be inherently linked within Black groups and the myriad of cultures mirror the various religious beliefs that inform their understanding

of children, disability and childrearing. Thus, religion is likely to have more significance amongst Black groups who face double discrimination due to their ethnicity and association with disability in a dominantly White society.

Tarakeshwar and Pargament (2001) explored the relationship between positive and negative religious coping, stress and depression among families of children with autism. They defined positive coping as seeking a positive relationship with God (sacred being): experiencing intimacy and harmony with God, whereas negative coping involved blaming God or the belief that God had abandoned or punished them. Findings indicate that positive coping was associated with positive perception of 'challenging experiences, better religious outcomes and greater stress-related growth' (254); in contrast, negative coping was associated with increase in depressive affect and anxiety. Since the negative psychological effects of parenting a child with autism are well documented, (Dunn et al., 2001; Olsson and Hwang 2001) recent research focus on factors that directly reduce the psychological effects associated with parenting (Timmons and Ekas, 2018; Hastings et al., 2005; Roffeei et al., 2015; Vitak et al., 2011).

Ekas, Whitman and Shivers (2009) report that religious beliefs and spirituality were associated with less negative and greater positive maternal socioemotional outcomes. Therefore, mothers who reported 'higher levels of religious beliefs and spirituality, also reported lower levels of depression, negative affect, and parenting affect' (712) and mothers with 'higher levels of spirituality also reported higher self-esteem, life satisfaction, positive affect, wellbeing, and control of internal states' (ibid). Studies convey the positive effects of religion on individuals in society, particularly for parents and mothers.

Following the autism diagnosis, religious parents may draw upon their faith to construct meanings as a 'punishment from God', a 'blessing' or an 'experience/ test' to increase their compassion (Skinner et al., 2001; Jegatheesan et al., 2010: 98). A mother says "this is God's challenge for me. I believe He only gives how much He knows you can handle", yet some parents who experience negative religious coping feel anger towards God and feel they are being punished (Tarakeshwar and Pargament, 2001: 255, 257). Jacob (2004) described how South Asian parents, both Hindus and Muslims, turn to prayers, pilgrimages, and religious adornments such as amulets and saffron threads to ensure their children's wellbeing. Ethnic minority parents perceived their child with disability as having high spiritual status or appointed to carry out a religious mission (Shaked, 2005). In keeping with Hindu beliefs about reincarnation and Karma, parents believed that disability was a gift from God or given to them because of sins committed in their previous life (Gabel, 2004; Jegatheesan et al., 2010: 98), was a way to release them from the cycle of death and rebirth (Jegatheesan et al., 2010: 98).

Jegatheesan et al.'s (2010) study reported South Asian Muslim parents felt blessed to be a family chosen by Allah to raise "His special child." The belief that the child comes from (or belongs to) Allah gave parents a sense of responsibility or high calling and encouraged parents to hold positive attitudes. Moreover, parents believe that Allah chose them specially to take care of their child by considering factors such as their moral character, loving nature, and resilience; their ability to protect the child; and their fate or Karmic connection to the child' (ibid: 101); a parent states: 'I think Allah found that we have the capability to handle it. We have the strength to deal with it. Not to be rude to him… not to blame the child but love the child very much'

(ibid). Parents draw strength, comfort and resilience from such religious beliefs when they experience autism related challenges.

Jegatheesan et al.'s (2010) explored religion as the main framework that parents understood their experiences resonate findings from other religious faiths (ibid: 102; Gabel, 2004; Skinner et al., 2001). Parents perceived their child's disability through a religious lens to gain meaning and understand a condition that, as yet, has no identifiable cause showed that religion can be a resource to cope (Tarakeshwar and Pargament, 2001: 256). Religious coping styles are associated with psychological adjustment and can affect childrearing practices whether positively or negatively (ibid: 257). Parents can traverse between positive and negative coping styles due to the various challenges parents experience; coping styles are not constant, and neither are they default methods parents opt to cope.

Despite the strong reliance on positive religious beliefs and spirituality to understand and accept autism, parents complain that religious organisations perceive disability, particularly autism negatively and displayed insensitive attitudes towards the challenges of raising a child (Tarakeshwar and Pargament, 2001). Religious activities were associated with more negative and less positive outcomes: mothers who reported a 'greater frequency of involvement in religious activities reported higher levels of parenting stress' and 'lower self-esteem, psychological well-being, positive affect, and control of internal states (Ekas et al., 2009: 713; Tarakeshwar and Pargament, 2001).

Subsequently, Tarakeshwar and Pargament, (2001) recommend 'sensitizing religious congregations to the challenges and demands of a child with autism

through brief informative discussions' about the disorder and its implications. They believe that

> Such knowledge may help leaders and members better understand the behaviors that are characteristic of autism and the resulting accommodations that these parents are forced to make in the practice of their religion (257).

The main emphasis is understanding, practical support and accessible services in religious settings. Similarly, Black parents of other faiths have also reported judgemental attitudes and a lack of support from faith groups at places of worship (Slade, 2014: 9). These negative attitudes stem from lack of understanding, low awareness of and intolerance towards disability, at churches, Gurdwaras and mosques (ibid).

Cultural and religious notions that disabilities stem from spiritual attacks mean that people from religious organisations are 'reluctant to interact with people with disabilities in practical ways' (Slade, 2014: 10) and show limited understanding of the autism condition, its implications for the child and the impact of the diagnosis on the family, which increased parents' stress levels. Slade (2014) reports that one mother in particular 'has learnt not to expect any direct help or support from most of the local community', which can accentuate the feeling of loneliness and isolation from their ethnic minority community and Western society. A Christian autism activist stated that churches must be more willing to understand and learn about autism to include families in religious services (Tooley, 2016).

Research found that groups with higher levels of religious faith are more likely to stigmatise disability (Wisneski et al., 2009; Tzouvara and Papadopoulos 2014). Papadopoulos (2016a) explains that may be because greater levels of religious faith are found in communities where services are less available, inaccessible and/or distrusted (sometimes due to poor cultural awareness). These communities are more

likely to be disadvantaged and most likely inhabited by marginalised groups. A Black parent notes that

> …Black communities face more challenges than other communities when trying to access services and gain information. One of the reasons is [people from Black and minority ethnic communities are] more likely to live in deprived, disadvantaged boroughs and as there have been many budget cuts (but even before cuts), the services that we (the BAME community) have access to are not of the same high standard as in, for example, the more affluent areas (Slade, 2014: 17).

This parent's comments show the effects of structural racism and inequalities that negatively affect the quality of care and treatment in areas largely populated by Black and ethnic minority groups.

Systemic stigma, social inequality, and poverty influence the quality of autism services and has overlapping socio-psychological effects on marginalised communities. Limited professional support and autism awareness in ethnic minority communities has led Black groups and ethnic minority groups to perceive autism through the lens of religion and culture to offer explanations, comfort and strength (Jegatheesan et al., 2010); marginalisation from the dominant society perpetuates cultural and religious beliefs about autism.

Systemic factors and contexts that govern and perpetuate inequality

This study explored systemic factors as organisations and contexts parents are most likely to encounter and interact with where evidence of stigma, poverty, double/triple discrimination/ disadvantage are present and contribute to the Black experience. This research identifies systemic factors as the culture within institutions, organizations and social structures that reflect its beliefs and values through policy and behaviours towards people. Similar to culture and religion as contextual factors

that shape Black experiences in the UK, stigma is identified as the common thread that influences other systemic factors such as structural racism but also accentuates Black people's marginal experiences and wellbeing.

Stafford and Scott (1986) defined stigma as an individual's characteristics that contradict a social groups' norms and shared beliefs; such definitions of stigma reflect the power exertion and relational conflict between individual and societal values. Similarly, Owuor and Nake (2015: 2) defined stigma as a rejection of individuals' identity or attributes such as family history, gender, sexuality, religion, ethnicity and social class. Goffman's definition of stigma as an 'attribute that is deeply discrediting' and that reduces the bearer 'from a whole and usual person to a tainted, discounted one' (Goffman 1963: 3) resonates with Link and Phelan's (2001) conceptualisation of stigma as 'the co-occurrence of its components–labeling, stereotyping, separation, status loss, and discrimination–and further indicate that for stigmatization to occur, power must be exercised' (363).

Stigma research focuses on stigma as an attribute, for instance, the stigma or mark is seen as something in the person rather than a designation or tag that the majority affix to the minority (Link and Phelan, 2001: 366). According to Oliver (1992) research examining the sources and consequences of exclusion from social and economic life are far less common, which Fiske (1998) echoes that more attention needs to be focused on structural issues. Therefore, it is essential to identify the systemic factors that enable the stigmatisation of individuals. This study focuses its attention on the producers of rejection and exclusion—those who do the discriminating and its impact on the people who are the recipients (Sayce, 1998) to illustrate the connection between systemic factors, individual experiences and their

psychological wellbeing. Similar to Link and Phelan (2001), this research proposes that there is a relationship between the structural stigma that manifest as stereotypes and labels inflicted on individual attributes (366). Stigma is formed when elements of labeling, stereotyping, separation, status loss, and discrimination co-occur in a power situation:

> First, people distinguish and label human differences […secondly] dominant cultural beliefs link labeled persons to undesirable characteristics—to negative stereotypes. In the third, labeled persons are placed in distinct categories so as to accomplish some degree of separation of "us" from "them." In the fourth, labeled persons experience status loss and discrimination that lead to unequal outcomes. Finally, stigmatization is entirely contingent on access to social, economic, and political power that allows the identification of differentness, the construction of stereotypes, the separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination (ibid: 367).

Link and Phelan (ibid) identify the systematic approach powerful persons and institutions employ to marginalise and gatekeep their access to certain spaces. Systemic structures can become the socially and culturally embedded process through which individuals experience stigma: stereotyping, devaluation and discrimination, poverty, violence, double and triple disadvantage all evidence the conflict between the dominant and minority groups (ethnicity, sexual orientation, sex, gender, religious identities, visible disabilities, body size or invisible disabilities) that can discredit the individual (Owuor and Nake, 2015). The dominant group determines undesirable characteristics, and discernible attributes such as religious and racial characteristics show ethnic and cultural difference (Kern, 2013; Owuor and Nake, 2015). Scrambler (2009) noted that social groups will discriminate between labels such as 'normal' and 'abnormal' and 'insiders' versus 'outsiders.' Such distinctive labelling enforces power and status, which can impact minority groups' quality of life.

These factors reflect the interactivity between institutional racism, stigma and poor health, welfare, wealth and educational outcomes on individual and collective experiences (Fernando, 2017). Systemic barriers lead to worse health outcomes, higher poverty than the general population, with variation between and within different ethnic groups; less represented in politics, limited awareness and participation in policy processes (Fernando, 2017; Wood and Cracknell, 2014) and are significantly more likely to be socio-economically deprived compared to White British people (Burns et al., 2007; Bécares et al., 2009). The effects of Coronavirus on the Black community, predominantly, clearly indicate the devastating impact of structural inequalities:

> […] people from a Black ethnic background are at a greater risk of death involving COVID-19 than all other ethnic groups. The risk for black males has been more than three times higher than white males and nearly two and a half times higher for black females than white.
>
> The mortality rate for deaths involving COVID-19 was highest among males of Black ethnic background at 255.7 deaths per 100,000 population and lowest among males of White ethnic background at 87.0 deaths per 100,000 (Nick Stripe, Office of National Statistics, 2020).

Similarly, Black Americans had 1.4 times higher infection rates, 3.7 times higher hospitalization rates, and 2.8 times higher death rates from COVID-19 than White Americans (US Centre for Disease Control and Prevention, 2020; Dickinson et al, 2021). Such alarming statistics reveal structural inequalities that show 'peculiar indifference' of the nation towards Black people in Western contexts as the root cause of health inequities (Du Bois, 1899, 2003). Differences in health outcomes confirm Du Bois' arguments that racial differences in health reflected unsanitary housing, poor air quality due to the housing locations, irregular food and other social conditions representing poverty and marginalisation that result from structural racial stigma (WHO, 2021).

Segal (2014) and Link and Phelan's (2001) reported that it takes power to stigmatise mirror the 'imbalances of economic, political and social power between the stigmatised and those doing the stigmatising' is evident in the UK (Owuor and Nake, 2015: 3). Stevenson and Rao (2014) evidence ethnic inequalities across multiple dimensions of life:

> Black applicants had to send 16 applications for a successful outcome compared with 9 for White applicants. National data showed little evidence of occupational progress among ethnic minorities between 1991 and 2001 when other factors such as education had been adjusted for. Within occupations, the largest earning gaps were seen in managerial and professional groups confirming that Black people find it difficult to obtain high-ranking executive positions […] In terms of educational attainment, ethnic minorities in England have become increasingly better qualified than their White British counterparts but continue to experience inequalities in education and the labour market (7).

These statistics exemplify Gary's (2005) definition of discrimination, a product of stigma, as 'decision-making and behaviors that are observable, measurable, and reportable' (981) and reflect the inter-related elements of stigma and structural inequalities. Similarly, Fernando (2017) records examples of institutional racism where finances allocated to Black patients in psychiatry was redirected into a service that disadvantaged Black people; good practice and good outcomes in support services towards Black people have failed to be evidenced in Health reports nullifying the progress made that could have been disseminated for good practice. Fernando (ibid) observed that

> What had happened, by means of institutional processes, seemed to be that the white establishment of the statutory service had successfully prevented a service for black people from developing—a reflection of institutional racism.

The suppression of knowledge and financial support towards Black patients further marginalises their experiences and highlights the pervasiveness of institutional racism from those with power. The structures and procedures related to housing,

whether government supported housing, privately acquired through rent or mortgage, are complex and is an area that perpetuate racial stigmas in local authority institutions and services. As a necessary and basic requirement to meet people's physiological and safety needs, housing – the quality and neighbourhood – is a contributing factor to individuals' wellbeing.

Housing is an area that perpetuates racial stigmas and inequalities. Black parents' experience of social and economic disadvantage lead to social deprivation that manifests as poor social housing in impoverished neighbourhoods affiliated with council housing and limited opportunities for home ownership. Longstanding research studies consistently record the presence of institutional racism in council housing inadequacies and inequalities, whereby Black applicants for council housing wait longer than Whites, and when rehoused receive inferior accommodation to Whites (Simpson, 1981; CRE, 1986). These 20-year-old findings are not dissimilar to recent official statistics which note that the household with the highest rates of overcrowding were inhabited by ethnic minority groups: Bangladeshi (24%), Pakistani (18%), Black African (16%), Arab (15%) and Mixed White and Black African (14%) ethnic groups. Whereas 'White British households were less likely to be overcrowded than households from all other ethnic groups combined – this was across all socio-economic groups and age groups, most regions and income bands, and regardless of whether they owned or rented their home' (English Housing Survey, 2020). Black (15.2%) and Asian (15.7%) people are living in the most deprived 10% of neighbourhoods so Black Caribbean (20%), African (16%) and Mixed White and Black African (33%) live in non-decent homes that do not meet the basic legal health and safety standards for housing, in an unreasonable state of repair, not have reasonable modern facilities and ineffective insulation. For majority

of Black and minority ethnic groups, basic physiological needs are not achieved and likely to affect the wellbeing of parents and children. Under the Children and Families and Care Act (2014), Local Authorities are responsible for promoting individual wellbeing through the suitability of living accommodation (Section 1.2.h). This example of an unfulfilled duty of care for the carers and individuals with disability highlights the gap between legislations and practice.

The New Economics Foundation (NEF) analysed the data from the Annual Population Survey and summarised their findings on ethnicity that:

> Black, Arab, Bangladeshi, Pakistani and Indian people experience significantly lower wellbeing than White people in the UK. The differences are large in size, apply across multiple measures of wellbeing, and persist even after taking into account a number of factors known to affect wellbeing such as relationship status, labour market status, and home ownership (NEF, 2012).

Extant literature paints a dire picture of the quality of life Black and ethnic minority groups experience. The NEF did not control for income or financial status; therefore, it is necessary for this study to examine the effects of hardship and subjective poverty on Black parents' wellbeing and experiences of autism.

Bonding and bridging capital

The relationship between parents, their familial networks and the wider society resonates with Bourdieu's (1985) concept of social capital. This study examines parents' social support and socio-economic status (evidenced in limited resources) and its implications through the concept of social class to reveal cultural and classist attitudes in community and professional contexts.

There are differing definitions of social capital, however the central theme from each definition focuses on social capital as a property of the individual's set of relationships with others (Bourdieu, 1985; Coleman, 1990). It can command scarce

resources by virtue of membership in networks or broader social structures (Portes, 1995). Social capital is embedded in social structures, which determine the resources available to the network as well as the rules of behaviour governing participation (Lin, 2001a, b). These definitions show social capital as the invisible currency that provides (or restricts) access to resources, social networks and private settings.

Following the ecological system, familial, social and professional support show social capital as a system that commands support and resources from parents' set of relationships with others' (Bourdieu, 1985; Coleman, 1990). Putnam argued further that it is bridging capital, which links different networks and resources that is more advantageous than bonding capital, which inheres in densely knit social groups (Putnam, 2000). Social capital can function to reproduce inequality and exclusion if parents lack access to relationships with people in positions of authority and power. Hall (2002) links these social networks to social class in an analysis of Great Britain. He posits that the middle class have more extensive and diverse social networks because of their social, cultural and economic investments; whereas, the working class are more likely to have bonding relationships with people at familial and community levels. However, education particularly higher education mediates this polarised view of social capital to aid social mobility.

Two operational levels underpin and frame this study's concept of social capital: sociocultural milieu (bonding capital) and institutional infrastructure (bridging capital) (Tempkin and Rohe, 1998; Putnam, 2000).

Hastings et al., (2005) identified social support as a coping strategy parents employ to alleviate experiences of stress and difficulties. Common sources of informal

support are partner/spouse, family, and friends, and formal support networks are typically defined as clinicians, health professionals and community organisations. Social support includes information, encouragement, motivation, feedback, emotional support, tangible support, and network support exchanged among peers to ease parental stress (Oh et al., 2013; Moh and Magiati, 2012; Santoso et al., 2015; Ha et al., 2014). Ekas et al. (2010) found that family support was associated with lower levels of maternal depression, stress, and negative affect in 119 American mothers. Similarly, Sharpley et al.'s (2015) study found that social support protected parents' well-being against stress if those providing the social support were perceived as competent. In recent years, and since the Coronavirus pandemic, online social support has become a popular form of interaction because distance between people can be shortened through computer-mediation. In the autism field, such social support for information (i.e. professionals) and emotional support (family, friends, etc) on social network sites (SNS, i.e. Facebook, FB) offer parents a platform to share experiences, ask questions, provide advice and a specific network that may not be readily available in their daily lives.

Institutional infrastructure (bridging capital) refers primarily to the presence of neighbourhood organizations (community-based organizations, CBOs) and the actual ability of those CBOs to act on behalf of the residents. These organisations form alliances with professionals in health, education and political spaces to primarily "influence decisions that positively affect the community's [parents'] character over time" (Tempkin and Rohe, 1998:70), for instance, autism support groups within parents' neighbourhood exemplify bridging capital.

There are existing structural barriers that perpetuate health care and/or educational

systems and policies (economic and political domains), as well as racial

discrimination. Jones (2020) focused on the high cost of ASD services, limitations in

the U.S. health care system, the lack of competence and training in ASD diagnosis

and interventions among health care and educational professionals, as well as

various forms of personal mediated and institutional levels of racism. The

intersection of race, low socio-economic status and institutional barriers to ASD

service and treatment programs are evidenced in the high costs of ASD services and

the restrictions of public and private health insurance coverage (Elder et al., 2016, p.

417). Parents' desire to provide their child expensive, necessary and quality

therapies and private interventions; unfortunately, these are not covered by private

or public health insurance in the U.S. or by the National Health Service in the UK.

Furthermore, studies highlight the lack of professional competence in understanding

autism within health care and educational systems. Physicians, as well as educators,

were dismissive of parent concerns, made negative and/or incorrect assumptions

about the parents, and hesitated to provide an early diagnosis and/or special

educational services (Singh and Bunyak, 2019; Elder et al., 2016). Zuckerman,

Sinche, Cervantes, et al. (2014) described how physicians dismissed parents'

concerns and were told, "don't worry" (p. 305). A few parents viewed these

interactions as bias or racism: English-speaking parents felt their education and

understanding of autism was underestimated; and Spanish-speaking parents felt that

they were unable to optimally express their concerns. Physician bias or racism was

also evident among qualitative research with African American parents of a child with

ASD. In a case study of one family, Gourdine, Baffour, and Teasley (2011) reported

how the parents were assumed to be uneducated by the physician and that they

should not put much hope into their child. Similarly, interviews with urban African American mothers of a child with autism and participant observation during the clinical setting found that children and families were marginalized and treated unequally by institutions authorizing autism-related services (Solomon and Lawlor, 2013).

Within the educational setting, interactional tensions also exist between parents, educators, and school administrators. Iadarola et al. (2015) investigated the strengths and limitations of existing services in underserved urban school districts and found that parents, teachers, and teaching assistants all reported a lack of adequate training for educators related to supporting students with autism. Furthermore, inadequate training and resources result in conflicts and tensions arising among various stakeholders including parents, teachers, paraprofessionals, and administrators in their combined efforts to serve students (Singh and Bunyak, 2019).

These studies demonstrate how racial, ethnic, and other underserved communities persistently experience structural barriers especially for those who have limited resources, live in socially disadvantaged communities, or experience different forms of racial and disability discrimination. Singh and Bunyak (2019) observe that

> These intersecting forms of oppression exist at the ideological, economic, and political domains and when they interlink with familial and cultural barriers offer a nuanced and complex understanding of autism disparities (803).

Singh and Bunyak (ibid) recognise the connection between the exo- and meso-systems and familial autism related experiences: social and systemic ideologies, political and economic domains directly impact autism services and quality of care for families and children.

56

Effects of systemic inequalities

Oppression in varied contexts could explain the significant lower levels of subjective wellbeing in comparison to White ethnic groups in the UK (Stevenson and Rao, 2014: 7; Knies, Nandi and Platt, 2014). As such, constant mental distress from anticipating discrimination, experiences of exclusion, racism and discrimination can lead to internalised beliefs of inadequacy and a sense of failure, lack of belonging and 'lowered self-esteem' (Boyd et al., 2010; Dinos, 2014; Swim, Cohen and Hyers, 1998). White ethnic group, which reported an average of 7.4 out of 10 for life satisfaction, compared to 6.7 in the Black ethnic group (Office of National Statistics, ONS, 2013). Reported differences in Black people's life satisfaction can be explained by their awareness of systemic inequalities that act as a filter/lens for feelings and self-perception of inferiority in White spaces and lead to lower subjective wellbeing (Knies, Nandi and Platt, 2014). Interrelated experiences of devaluation, marginalisation, mental distress, racism, shame and isolation amalgamate to form unanimous low levels of subjective wellbeing across Black groups (Owuor and Nake, 2015: 6; Contrada et al., 2000). The persistence of lower levels of wellbeing, across different Black groups and across the social gradient, suggests a correlation between belonging to a Black group and experiencing lower levels of wellbeing (Stevenson and Rao, 2014). This research suggests that internalised beliefs can result from the double consciousness Black and ethnic minorities experience, whether cognizant or covertly in a Western society. Du Bois (1903/ 1989) described double consciousness as:

> this sense of always looking at one's self through the eyes of others […] One ever feels his twoness,—an American, a Negro; two souls, two thoughts, two unreconciled strivings; two warring ideals in one dark body… to merge his double self into a better and truer self. In this merging he wishes neither of the older selves to be lost (3).

In this description of the Black experience following the slave diaspora to America, Du Bois clearly 'captured how alienation and disenfranchisement blended one identity that seemed inescapable with another that appeared unattainable' (Lyubansky and Eidelson, 2005: 4). Hence, ethnic and cultural difference between the dominant and immigrant culture also creates a double consciousness. The history of immigrant Black and ethnic minority groups is one of 'strife' within their internal consciousness but also outwardly in the dominantly 'White' space. Therefore, Black and ethnic minority groups are constantly aware of their 'twoness' – an ethnic minority immigrant or Black British – and always strive to marry the two and reflects the continued process of 'becoming' (Hall, 1990). Therefore, this twoness of consciousness and external conflict between minority ethnic groups and the dominant culture 'can lead to harmful internalised beliefs or actions by those stigmatised and may cause negative health outcomes' (Owuor and Nake, 2015: 2); particularly when immigrants determinedly maintain their traditional and cultural beliefs in the hope that 'his older selves are not lost' (DuBois, 1903/ 1989:3; Welterlin and LaRue, 2007). This 'twoness' is also present in Black parents' experience of disability/autism because 'they [are] part of a culture that has a different concept of (disability) however, at the same time, they are living in a society where [a different] concept [of disability] is firmly embedded' (DfES, 2006: 6). As such, parents strive to merge their cultural beliefs along with the 'firmly embedded' beliefs about disability. This study posits that parents' beliefs, approaches and experiences of autism undergoes a similar transformation to the 'becoming' process of Black identity in varied histories and contexts.

Intersectionality in structural contexts: race, disability and gender

The school context is situated in Bronfenbrenner's meso-system of ecological contexts. This educational setting is far from neutral with respect to race/ethnicity, gender and class, but are in fact disproportionally harmful to communities of colour, to boys and persons diagnosed with intellectual disability in those communities. Disability research supports the concept of 'double discrimination' or 'double stigma', particularly for ethnic minorities with disability as they experience institutional racism and disablism (Vernon, 1999; Begum, 1992; Gary, 2005). Racism in schools within a predominantly White teaching workforce, school policies and curricula perpetuate White supremacy and keep Black and minority ethnic children's educational experiences on the fringes of the school context. At the heart of the intersectionality paradigm is the concept of double/triple discrimination based on individuals' racial identity, gender, disability and class; reveals the school context as a microcosmic reflection of society's ideas on power, stigma and structural inequalities.

From a racial lens, experiences of interpersonal racism and bullying in school resulted in the death of Shukri Yahya Abdi – a 12-year-old Black Muslim girl who came to the UK as a refugee from Somalia; there are concerns that the school failed to respond adequately despite being made aware of the issues (Townsend, 2019). A few months later, the story of Caleb Hills – a nine-year-old Black mixed-race boy made the news cycle (Chantler- Hicks, 2019). Caleb's attempted suicide after being subjected to persistent and explicit racist bullying by his peers highlight the adverse and detrimental effects of racism. These examples of lived trauma Black children encounter at school shape their psyches from an early age - as inferior, insignificant and 'experience [themselves] as the other' - within a school context where they feel they do not belong, particularly when teachers and the school policies [or lack of] fail

to protect them (Hall, 1990: 225). These examples demonstrate the outcomes of the continuous play and intersection of race, gender, nationality and social class status in various school contexts that suggest that children experience the effects of power and the trauma of the colonial experience from their peers and teachers. Within the social contexts, children, like their parents in the wider society, continue to frame and reframe their identity to understand and perform Black identity in White spaces where they are subject to structural inequalities from the continuous intersection of white power, culture and history. These examples draw attention to the 'primacy of race' (Gillborn, 2015) and the structural inequalities that ethnic minority groups experience.

According to the Department for Education (DfE), in 2018, nearly 92% of teachers in England's state-funded schools were White (DfE, 2018) showing wider disparities between teacher and child demographics, with NASUWT and the Runnymede Trust (2017: 9) reporting 'a chronic shortage of BME teachers in relation to the BME pupil population as 27% of pupils in state-funded schools are 'from a BME background' and only 13% of teachers are (Rhodes, 2017). Such disproportionate figures highlight the disadvantage Black and minority ethnic students encounter, where they are exposed to educational professionals who may not understand the 'Black or minority experience' or be racially literate. Teachers may not see covert racialised experiences children may contest; particularly where children may lack the language to detect and identify racist encounters and yet feel its emotional and psychological effects. Teachers may also lack the training and support of school policies to intervene effectively. As a minority ethnic teacher stated:

> most teachers see acts of racism as individual acts of prejudice and they don't
> understand the structural racism and what it means or the history behind it –

they don't know that, because they are just not equipped to deal with racism, both with members of staff and with the students as well (Joseph-Salisbury, 2020: 8).

This discrepancy between teachers' authority in the school context and the [in]ability to intervene in racial tensions among pupils illustrate the disadvantaged stance minoritized children operate in at school.

Conversely, teachers hold multiple identities as professionals and members of society and are likely to hold unconscious biases because of structural racism interwoven into the fabric of society and school policies that disadvantage Black and minority ethnic children. Racial discrimination in relation to disciplinary procedures such as higher rates of school exclusion and expulsion are outcomes of race and structural inequalities (Gillborn, 2008). Racialised teacher expectations can impact upon the sets that pupils are put in, disciplinary procedures and teacher assessments (the latter being a particularly pertinent issue: teachers gave students their GCSE grades from class teachers following the coronavirus pandemic (Gillborn, 2014; Millard et al., 2018; Joseph-Salisbury, 2020).

 In a school context where racism is implicitly discouraged, not discussed or considered as a driving force to the inequalities Black and minority ethnic children experience at school, racial literacy and anti-racist training are worth introducing for teacher's continual professional development at all levels across the school context. Joseph-Salisbury notes that:

> racial literacy can enable teachers to reflect on the racist views they themselves might hold, and to understand their own complicity in (re)producing racism. This is particularly important given the ways in which teacher stereotypes and low expectations are known to impact upon student experiences (9).

Teachers' unconscious biases translate into practice and limits their understanding of structural racism, the visible and invisible barriers that disadvantage Black and ethnic minority children in a school context.

The education context is a primary and necessary space for Black children with autism and parents. The concerning over-presentation of Black (Afro-Caribbean) children with special educational needs and EHC plans (4.4%, DfE, 2019) needs further investigation, though not within the scope of this research. Research shows that socio-economic disadvantage (poverty) and gender have stronger associations, than ethnicity, with overall prevalence of SEN and of certain categories of SEN (Strand, Lindsay, and Pather 2006; Strand and Lindsay, 2009; Strand and Lindorff, 2018). However, poverty is an outcome of structural racism and by default, indicates that students with SEN are structurally produced since minoritized groups are socially, culturally and economically disadvantaged. Although ethnicity may not be a contributing factor that determines SEN, large population of ethnically minoritized groups are labelled with SEN. Black Caribbean and Mixed White and Black Caribbean pupils are around one and a half times more likely to be identified as having Behavioural, Emotional and Social Difficulties (BESD) than White British pupils. The literature suggests teacher and school factors including racist attitudes (societal stereotypes, negative perceptions about the behaviour of Black pupils and underestimation of ability) and differential treatment of Black pupils are reasons for their over-representation in the BESD category (Weinstein, Gregory and Strambler, 2004; Gillborn, 1990). It is easy to imagine the double disadvantage Black children with autism may experience in schools with few teachers equipped to deal with cultural diversity and autism related needs. The school context illustrates how Black

children experience the convergence of structural, cultural and disciplinary power and shapes their experiences at the intersection of race, gender, class etc.

Discrimination in public and Black community contexts

Black and minority ethnic experiences of racism and disablism depict double discrimination within the wider social context. Azmi et al. (1997) interviewed 21 South Asian adolescents and adults with learning disabilities and found that 63% felt they had been treated unfairly due to their ethnicity and 57% due to their disability. Similarly, Black people with hidden disabilities and their families are likely to be doubly stigmatized by people within their ethnic minority communities and the wider social community (Slade, 2014). The National Autism Society notes that nearly a quarter of Black and minority ethnic children have been excluded and face double discrimination in education (Batten et al., 2006: 43).

Corbett and Corbett (2007) cite a parent's belief about the double discrimination their child faces:

> ethnicity has a significant impact on the level and type of education given to my child. There appeared to be more of a belief that my child was bad as opposed to having special needs…I think that Black children are more than doubly penalised within the education system because their special educational needs cause them to have difficulty accessing appropriate education, because they are Black, and because they are boys. This hinders them in achieving what they should in today's educational system (6).

Children with autism from Black families experience disproportionately high levels of discrimination and disadvantage compared to children and parents from the dominant culture. The additional mention of gender also indicates triple stigma and discrimination that Black boys with disability face in a dominantly White society:

intersecting identities of Black, male and displaying autism symptomology are hyper-visible and on constant display.

Black mothers explain the importance of providing protection in a White dominated society. Onaiwu (2017) acknowledges the tension between society and ethnic minorities, which is demonstrated in the widespread police violence against Black people in the UK and USA. She mentions having the 'how to stay alive because you're Black and therefore a threat' talk with her child:

> Don't wear that grey hoodie you love […] make eye contact with authorities […] do it anyway, even if it hurts. Speak in a soft, gentle tone. Keep your hands where they can see them at all times. No sudden or unexpected movements and ABSOLUTELY no stimming or fidgeting or flapping as it might be seen as attempting to strike someone. No echolalia, as it might be perceived as trying to "mock" an officer (145-146).

This list of 'don'ts' begin with manageable ways to avoid being regarded as dangerous: clothing and attempts to make eye-contact. However, instinctive and reflexive autism symptomology are less attainable in stressful situations; that is if the individual with autism can assess the situation to understand its seriousness. Black people/children are instructed and expected to change marked traits that form their identity to prevent/ lessen conflict between them and authorities from the dominant context. Society places the onus of responsibility on children with little understanding of social cues and covert racism; yet Black children's lives are dependent on complying with surreptitious rules.

Similarly, a mother explains the importance of teaching her child with autism independence because "[my child] has three strikes against her. She's Black, she's a girl and she has a disability […] I already know what the world is going to do to her […] people will prey on that" (Burkett et al., 2015: 3427).

These conversations highlight and emphasize the double, even triple disadvantage of race, gender and disability that Black people encounter in a White society.

Unsettlingly, the belief that disabled people from Black communities are 'worthy […] valuable and […] have a right to exist as [they] are without fear of violence' is abated quickly from a young age, carefully, gently but seriously to communicate the triple disadvantage Black families anticipate, witness and experience. Despite race and disability being social constructs, their presence and effects create a detrimental and indelible mark on Black people's lives and disabled people (Brown, Ashkenazy and Onaiwu, 2017: 5, Goffman, 1963).

Negative experiences are further compounded by stigma associated with disability within Black communities. Collectivism and individualism mark a key distinction between Black and Western culture. Stigma research found that collectivist cultures are generally more likely than individualist cultures to stigmatise people who deviate from the norm (Papadopoulos et al., 2013).

Families of a disabled individual are identified as deviating from the norm and are 'vulnerable to being devalued, rejected and stigmatised; families fear such stigmatisation and consequently hide their child's disability from their community' (ibid). For instance, Bayswater et al.'s (2003) study reported that parents' experience stigma from the Pakistani and Bangladeshi community and extended family and are often on the receiving end of 'negative disablist attitudes' such as avoidance, name-calling, and negative comments (506). Fox et al., (2017) also acknowledge that disablist attitudes within the Somalian community meant that many families experienced stigma and social exclusion (309), what Goffman (1963) termed as 'courtesy stigma'.

Selman et al. (2017) provided an in-depth exploration of autism-related stigma within a Somali community. Parents are 'labelled and stereotyped by their child's disability',

and subsequently, the parents are seen as 'different' (Selman et al., 2017: 6) or 'to be blamed' (Munroe et al., 2016). Participants described 'rejection from family, church, the local African community, and [most] mothers […] described feeling unwelcome in public places' (ibid: 16; Slade, 2014: 9). As a result, some participants mentioned hiding their children with autism and were unwilling to talk about them to people in the community for fear of social exclusion and to avoid feelings of shame (Fox et al., 2017; Slade, 2014; Munroe et al., 2016).

Fox et al.'s (2017) study identified autism as a new word that had no linguistic roots and cannot be translated to Somali, which added to their confusion and inability to describe the condition to others (Fox et al., 2017). Participants' assertion that autism is not found in Africa support the cultural belief that autism is a foreign condition and reinforces the community's social distance and negative response (ibid; Munroe et al., 2016).

Selman (2017: 7) recognised that within the Somali and other ethnic minority communities, disability was a highly sensitive subject, and that people with mental/ learning disabilities were described using derogatory language, such as 'doqon' (Somali for 'retarded'). Extended families also 'distanced themselves from the household, or families have felt ashamed and therefore avoided their extended families', which further reduced the support available to them (Slade, 2014: 14). Subsequently, along with parents, specifically mothers, children with autism were labelled and stereotyped as 'sick', 'naughty', 'different' (ibid: 8) leading to social rejection and isolation of both parent and child.

Internalised stigma and autism

Researchers associate stigma with a poor understanding of autism, a lack of vocabulary related to autism, and prejudice against mental illness and learning disability within the Black community (Selman et al., 2017:10; Slade, 2014). Parents struggle to accept the autism diagnosis because of the cultural beliefs and disassociation from the condition, the 'invisibility of the condition' (ibid: 7), conspicuous maladaptive behaviours such as tantrums and self-destructive acts; navigating the impact of this new weighted condition on the child, family and their identity within their community.

Munroe et al. (2016) explain cultural African beliefs about disability, especially hidden disabilities like autism. One participant explains that 'someone in a wheelchair, that's disability, you cannot convince them that this person is able, this person can work [but] if they don't see [a physical disability] this person [with a hidden disability] is mad' (23). This explanation exemplifies Link and Phelan's (2001) conceptualization of stigma through labelling human differences: physical disability 'that's disability' and hidden disability as 'mad' – cultural beliefs consider both as undesirable characteristics but placed in separate categories. Hence, labelled persons experience status loss and discrimination that lead to unequal physical and psychological outcomes: cultural beliefs lead to the devaluation of disabled people and result to social marginalization. The intersection of cultural beliefs and stigmatization lead to barriers that disable individuals with physical and hidden disabilities in Black communities. Thus, resonates with the Social Model of Disability which recognizes that people are disabled by physical or attitudinal barriers in society, not by their impairment or difference.

Munroe et al.'s (2016) participants believed that 'their sons were viewed by the African community as either 'mad', 'possessed' or 'naughty'. These perceptions

appeared equally painful, as they could not bear to internalize such labels towards

their child, however, the alternative was to label themselves as 'bad' mothers (ibid:

23). Limited awareness and knowledge of developmental disability lead to beliefs

that behaviour which deviates from the norm is a result of irresponsible parenting or

the child's inherent nature as senseless, spiritually possessed, disobedient or

mischievous.

Munroe et al. (2016) observe that

> holding these sets of conflicting beliefs appeared to create a sense of cultural
> dissonance for the mothers, leading them to re-evaluate their previous beliefs
> and assumptions and to find ways of integrating these sets of apparently
> conflicting information (23-24).

Subsequently, mothers embrace a new explanation: autism, which enables them to

maintain their identity and their child's humanity. Acceptance of a medical

understanding offered a framework of meaning, absolving the self and community

blame they experienced and protecting their maternal identities (ibid: 30). Thus,

supports Croot et al.'s (2008) suggestion that while parents may initially adopt

theological, traditional and cultural explanations, they may also adopt biomedical

explanations when faced with negative ideas from other people within their ethnic

minority communities.

Papadopoulos (2016b) relates the concept of internalised or self-stigma to the field

of autism and among autism caregivers as

> the phenomenon by which the public's negative stereotypes towards both
> individuals with autism and, crucially, their caregivers, subsequently become
> accepted by caregivers and incorporated within their own psychological
> identity (1).

Internalised stigma suggests caregivers are more likely to hold negative perceptions

of self, their experiences and perhaps even towards their child, particularly when

their child displays maladaptive behaviours. The cultural understanding of autism in the Black community often blamed parents, who in turn felt guilt, shame and internalised these feelings resulting in inadequacy and low self-esteem (Slade, 2014). Parents, most likely the mother, felt shame 'when a child's autism was thought to reflect badly on [the] family' and parents felt judged by for not 'being normal'. Fathers blamed the mother for having done something wrong in pregnancy, such as having an affair or not living and eating healthily to explain this 'foreign' condition (ibid; Munroe et al., 2016; Fox et al., 2017). Despite the outdated approach that blamed cold 'refrigerated' mothers for causing their children's autism, research indicated that Black communities often targeted mothers as scapegoats to explain the presence of the autism condition. The burden of practical care and emotional engagement with autism often fell more heavily on mothers; as well as coping with their children, many witnessed their partners/husbands' denial, frustration and blame from extended families and the Black community (Slade, 2014: 12).

Mothers of children with autism are generally considered to be at risk of lower well-being: exhibit clinical levels of parenting stress, depression and anxiety (Davis and Carter 2008; Ekas et al., 2009); mothers who felt more stress have lower wellbeing and felt less competent as a mother (Kuhn and Carter, 2006). Experiences of race and ethnicity-related discrimination was the factor most frequently identified through the research as driving and influencing wellbeing in Black communities (Stevenson and Rao, 2014: 28). Stevenson and Rao (ibid) acknowledge that

> In terms of variations in wellbeing *within* Black communities, there is a paucity of published literature on gender differences, or on those with dual-minority status such as individuals who are from a Black background and have a disability […]. It is possible that such groups face even greater marginalisation and discrimination than Black counterparts without the additional characteristics (48).

Internalised stigma occurs when stigmatised individuals accept the prejudice directed towards them as true and is characterised by subjective perceptions of devaluation, marginalisation, shame and isolation (Larkan, 2004; Hasan et al., 2012; Overstreet et al., 2013; Boyd et al., 2014). The power the dominant culture exercises over minority groups in society has strong psychogenic influences, particularly when the minority group are considered an outgroup (Allport, 1954), which accentuates Black and ethnic minorities feeling of alienation from the dominant group and culture.

Papadopoulos (2016b) asserts that new caregivers of children with autism are most vulnerable to public and internalised/self-stigma. Studies explored so far also indicate that ethnic minority mothers are also susceptible to double self-stigma because of disablist attitudes that perpetuate within Black communities and racialised stigma within a White dominant culture (ibid: 3; Selman et al., 2017:10; Slade, 2014). Cultural stigma impacted maternal identities and mothers internalised the belief that they were 'bad parents' with accompanied guilt, stress and shame (Munroe et al., 2016: 18). Mothers' decisions to either have second a child or not, to alleviate the stigma and self-blame, were underpinned by internalised stigma (ibid) and highlight the high sense of blame and responsibility mothers felt for their child's condition. Education and exposure on the autism condition could alleviate the effects of self-stigma if mothers were exposed to the multifactorial aetiology of autism, varying from adverse perinatal events such as growth restriction and new-born hypoxia (Hultman, Sparen and Cattingius, 2002; Glasson et al., 2004). Papadopoulos (2016b) notes a few of the significant consequences of self-stigma: increased feelings of self-blame; reduced self-efficacy, self-esteem, empowerment; and importantly, poorer psychological well-being (Ali et al., 2012; Werner and

Shulman, 2013; Kinnear et al., 2015). I suggest that Black parents of disabled children in general and autism in particular encounter double stigma and higher chances of significant low self-esteem. Black mothers are more likely to internalize the shame and blame associated with disability within the Black community, and subsequently experience marginalization and devaluation, and self-isolation as a form of self-protection (Munroe et al., 2012; Byswater et al., 2003; Fox et al. 2016).

However, some mothers respond to stigma by creating a positive identity of a strong, supportive, loyal and dedicated mother to their children. One mother explains that 'I have to be very strong, if not for me, for him'; another states: 'if you accept what the family are saying about your child, then your child is going to have nobody…so you sort of stand with your child and stay by yourself…' (Munroe et al., 2016: 19). Mothers perceive and portray themselves as defensive shields to hostilities from their immediate/ extended family and the public, which demonstrates resilience. African American mothers state: '"We just deal with it", […] "not pretending that nothing was wrong'' and another expressed ''You do what you got to do, not what you want to do. That is the motto.'' (Burkett, 2015: 3249). Mothers build resilience to the challenges of racial stigma and their child's disability through similar approaches. Such evidence of resiliency reflects the coping strategies some parents employ to endure the challenges associated with double stigma and disadvantage.

Internalised stigma in public and professional services

Parents interact with health, housing and education professionals to meet their families' needs. Primarily, autism diagnostic clinicians usher parents into the world of autism: refer parents to health service providers and autism organisations/support

71

groups to confront the host of challenges associated with the autism condition. Despite the inherent role of cultural dominance in parents' perceptions and experiences of autism, Munroe et al. (2013) notes that 'a family's […] minority community, difficulties and diagnosis, […] may conflict with the dominant medical model of the host healthcare system attempts to support them' (3-4). This tension in perspectives on autism characteristics could lead to conflict between parents and health professionals. The belief that the White culture 'host[s]' ethnic minorities could be exhibited behaviourally, such as treating ethnic minorities differently in professional dealings, suggests one reason for Black groups lack of confidence and sense of belonging within the wider culture, and can explain poor access to healthcare (Stevenson and Rao, 2014; Slade, 2014). Black service users may perceive health services to be discriminatory and as representing a source of formal authority and social control. In such cases, individuals were more likely to avoid contact with formal services (McLean, Campbell and Cornish, 2003; Keating and Robertson, 2004). Service users can be acutely aware of the 'Whiteness' of institutions and perceive health services to 'reinforce a White Euro-centric model of healthcare with little consideration or understanding of ethnicity' (Weich, Griffith and Commander, 2012).

The minority experience shows the effect of systemic factors, social and cultural dissonance between minority and majority groups, which can amalgamate to internalised stigma. For instance, participants believed or felt that 'professionals had assumed they lacked intellectual capacity because they have a strong accent or language difficulties' (Slade, 2014:18). Thus, support Slade's (2014) observation that Black families, particularly those who are first generation immigrants 'felt nervous and lacked confidence' and experienced 'low self-esteem or had expected

discrimination if they were unfamiliar with or felt excluded from mainstream culture'

(18). This is an example of how power exerted in professional contexts 'had the

power to make [them] see and experience [themselves] as Other' (Hall, 1990: 225);

power that the dominant culture utilizes to discriminate against minority groups to

enforce stigmatized binary opposites: superior/ inferior, ingroup/outgroup and

belonging/marginalized (Goffman, 1963). These dichotomies are problematic and

harmful because they perpetuate negative stereotypes and devalue people by

focusing on their differences; such subjective perceptions of devaluation and

marginalisation results in low confidence which they assimilate from the dominant

culture.

Mandell (2002) and Knopf (2020) reported that Black children were diagnosed later

and were more likely to be misdiagnosed with conduct disorder or adjustment

disorder than White children (Mandell et al., 2007, Mandell et al., 2009).

Professionals' focus on Black children's 'conduct' is indicative of stereotypes

associated with the Black ethnic group (Slade, 2014). Furthermore, it resonates with

a mother's view that onlookers do not associate public meltdowns with autism

because 'people will see the behaviour and then the colour of my child's skin', which

reinforces negative behavioural stereotypes about Black groups (Carpenter and

Engerton, 2017).

Whereas 'adjustment disorder' suggests that Black children 'misbehave' because

they feel displaced and experience a limited sense of belonging in Western culture

(Mandell et al., 2007, Mandell et al., 2009). That 'communicative problems that

characterize autism could be unduly interpreted as language problems related to

minority groups' (Begeer et al., 2009: 142) implies some of the difficulties associated

with diagnosing minorities. This indicates that healthcare providers inappropriately

stereotype Black children due to their ethnic identity; subsequently, mistaken autism symptoms as limited language skills to communicate effectively. On the other hand, the language barrier between ethnic minority parents and healthcare providers could also contribute to the misdiagnosis or delayed diagnosis of autism. Corbett and Perepa (2007) and Lindsay, Pather and Strang (2006) acknowledge that 'the lower numbers of children with autism in certain ethnic groups may be because of difficulties disentangling learning difficulties from issues associated with English as an Additional Language (EAL) and/or because professionals fail to appreciate the need to make a distinction.

Papadopoulos (2016a) identifies the cultural barriers immigrants face, especially when beginning to understand the autism condition (i.e., aetiology and autism prognosis) and misunderstandings between service providers and immigrant parents may result in compounding tension instead of raising autism awareness. Papadopoulos (ibid) supports a working relationship between professionals and families of a minority ethnic background by stating that 'if minority groups access services but experience poor cultural awareness from service providers, they may reject these services' (3). Similarly, Bankole (2016) recommends for professionals to 'familiarise themselves with different African cultures before meeting parents, to encourage better understanding' between the health care service and families (2). Heer et al., (2012) calls for personalised health care as they acknowledge the need for services to consider the role of culture in shaping the experiences of minority communities. They observe that despite higher prevalence of learning disability within the South Asian community, 'service uptake and utilization amongst this community in the United Kingdom remains low' (949) and acknowledge the large

interplay between the minority experience and the medical model for South Asian parents. Thereby, report that 'families adopting non-medical explanations for learning disabilities are less likely to engage with medical services, instead preferring treatment options that are in keeping with their own cultural beliefs' (954). Professionals may perceive parents' failure to engage with treatment plans as non-compliance, instead of based on different understanding and approach to autism. In response, parents may feel judged and unable to identify with professionals' views, which can lead to poor service uptake (Bywaters et al., 2003; O'Hara and Martin 2003; Jeergathesan, 2010). Heer et al., (2012) emphasise 'the need for services to consider the cultural orientation of ethnic communities in order to implement and deliver culturally appropriate interventions' (949). They provide detailed examples of ways healthcare services could utilize an experiential–contextual framework in service delivery by incorporating a multi-dimensional approach encompassing both the medical model and minority experiences. They note that:

> Service providers would need to adopt flexible approaches that encourage the exploration and sharing of cultural views of learning disabilities in a non-judgemental manner, so that families feel understood by services. Services could draw on the therapeutic qualities of religious explanations in allowing parents to better cope and deal with the challenges of care-giving (954).

As minority ethnic groups see evidence of their cultural religious beliefs incorporated in medical services, Black parents are likely to feel heard and evoke a sense of belonging within the dominant culture and 'create more collaborative relationships between service providers and users' (ibid). Williams et al. (2019) recommends that:

> when working with [Black] families, clinicians should specifically ask about the role religion and spiritually may play for these families. Clinicians should be mindful of how religious coping could be maladaptive and add additional stress as opposed to only be viewed as a positive source of coping… By asking about the role of religion in families' lives, clinicians can assess for potential negative religious coping and address it in therapy.

These preliminary assessments could enable the platform to increase professionals'

understanding and awareness of internalised stigma and risk factors are ways we

can commence to bridge the gap between the network of health, educational

professionals and parents. Williams et al. (2019) suggest that 'broaching difficult

topics such as the family's experiences with structural racism or prejudice in medical

care may enhance the therapeutic alliance and reveal stressors that are not typically

covered in a basic clinical interview' (1031) and suggests that professionals can be

trained to identify 'when there is a real risk of self-stigma developing, and when it has

already occurred' to mitigate against its harms to parents' subjective wellbeing

(Papadopoulos, 2016b).

Resilience: Risk factors and coping methods in general and specific autism contexts

This research examines resilience as a form of coping, or result of coping, in

response to the call to apply a balanced approach (negative and positive

perspectives) when conducting research on families raising child with autism

(Hastings, 2016) and illustrate the interactivity of contextual and systemic factors that

influence Black groups and parents.

Resilience is the ability to prevail in difficult and /or negative situations (Zauszniewski

et al., 2010); 'a dynamic process encompassing positive adaptation within the

context of significant adversity' (Luthar et al., 2000: 545); the 'process of coping with

adversity, change, or opportunity in a manner that result in the identification,

fortification, and enrichment of resilient qualities or protective factors' (Richardson,

2002: 308). Resilient characteristics are improved over time by experiencing various

adversities, such as structural racism and inequalities, that develop protective factors

and coping mechanisms. It also suggests a self-awareness of identifying the problem and planning ways to manage risk and protective factors that build resilient characteristics overtime. Choice phrases 'process', 'positive adaptation' and coping with adversity 'in a manner' implies that resilience is a process, an ongoing relationship between the individual and selective aspects of their environment (i.e. religion, social support and culture) that stimulate or enhance resilient outcomes (Ekas, Whitman and Shivers, 2009). If resilience is a process as opposed to a trait, then it would follow that individuals would/can not be resilient all the time, under all circumstances (Sixbey, 2005). It is important to note that the presence of resilience does not eliminate parents' suffering; the notion of the coexistence of resilient traits and psychological ill health indicate that resilient traits develop out of necessity. The resilience theory identifies risk factors, protective factors and indicators of resilience. Resilience outcomes are examined in Black parents of a child with autism. Bekhet et al. (2012) define risk factors as factors that predispose people to physical and mental health problems such as poverty, racial discrimination, labelling and marginalization for Black groups (Owuor and Nake, 2018; Link and Phelan, 2001; Goffman, 1963; Stevenson and Rao, 2014).

Ekas and Whitman (2010) found that having more than one child with autism lowered parents' life satisfaction, and sense of wellbeing; greater severity of symptoms was associated with poorer psychological wellbeing, life-satisfaction and high prevalence of depression. Whereas, protective factors promote resilience by reducing the effects of risk and individuals' reaction to difficult situations (Zauszniewski et al., 2010); this includes social support […] locus of control, cognitive appraisal, and religious beliefs and spirituality (Bekher et al., 2012). Autism support groups develop protective factors and are considered powerful and

complementary resource services for instrumental, informational and emotional support critical to parents' wellbeing. Parents of children with developmental disabilities are highly satisfied with the sense of agency and belonging they obtain from participating in groups (Solomon et al., 2001), have a sense of solidarity as they improve their parenting skills, and concurrently reduced sense of isolation, obtain important information about services, and feel a greater sense of emotional support (Kerr and McIntosh, 2000; Law et al., 2001).

Parents benefit from social support, whether online and at autism support groups as they experience interpersonal relationships at both individual and collective levels due to the reciprocating nature of the messages in which an individual would post questions and/or thoughts and other members would comment, validate, or respond to in group settings. Such findings support the benefit of maintaining relationships and promoting strong ties among members as a result of shared experiences that build a sense of belonging and acceptance. The online platform encourages communications even when face-to-face interactions are either not possible or regarded as being too complex (Namkoong et al., 2013).

Autism support networks widen members social circle, knowledge, beliefs and influence as other members may be of different social demographics. Existing research shows that parents perceive the informal social support received from other parents, both off- and online as highly beneficial (Huws et al., 2001; Mackintosh et al., 2012; Mandell and Salzer, 2007; Wynter et al., 2015) and increase parents, specifically mothers' resilience as they are often the primary caregivers.

An additional coping method is a change in cognitive appraisals, which involves changing the way one views or makes sense of a situation by using positive

reinterpretation, and finding meaning, acceptance, and humor (Terry and Hynes, 1998). Research have shown that families can perceive (or cognitively appraise) the impact of their child with a disability as both negative and positive (Trute et al., 2007). For example, a family can think that their child has led to limitations in social contacts outside their family home – a cognitive appraisal that is negative; simultaneously, yet independently, they can also think that their child makes life more meaningful for them − a positive cognitive appraisal (Schlebusch and Dada, 2017). Similarly, the main purpose of Black groups' migration to the UK is for 'a better quality of life' compared to what they believe their countries of origin can provide them. As such, though they may experience systemic factors that threaten their wellbeing, positive cognitive appraisals and comparison of their lives in the UK and their home countries may build and encourage resilience.

A study conducted by Tunali and Power (2002) found that in a sample of 58 mothers of children with or without autism, those who used positive cognitive appraisal showed the greatest life satisfaction. Positive appraisals have been associated with better relationship quality (Paynter et al., 2013; Stuart and McGrew, 2009), and better family adjustment (Neely-Barnes and Dia, 2008). Schelbusch and Dada (2018) found that the experience of parenting stress is not the sole experience; families can and do experience and appreciate the positive effects of autism. Interestingly,

> seven out of the 10 highest-ranked items were related to the benefits of their child with autism; for example: a greater appreciation of differences between people, a greater awareness of the needs of others, and a greater clarity about what matters (90).

Parents considered their child to have a substantial positive impact on their family, showing positive cognitive appraisal. Schielbusch and Dada (2018) acknowledge that context is particularly important for cognitive appraisal: how families define the

impact of their child with disability reflects to some degree the larger context of

societal attitudes and historical realities within which that interpretation emerges

(Ravindran and Myers, 2012a; Silverman, 2008). Schielbusch and Dada's (2018)

research of South African parents recognize that:

> Researchers have to conduct a great deal more research in low- and middle-income countries to establish the measurement of universal family concepts such as positive and negative appraisal; to test the generalisability of existing family research findings; and to investigate how multicultural families in different contexts adapt to raising a child with autism (90).

As such, this research on Black families who are likely to appraise their income as

low and middle income in the UK, responds to the call to investigate how

multicultural families in different contexts adapt to raising a child. Findings that South

African parents experienced both positive and negative appraisals of the impact of

their child's disability align with Larson's (1998) concept of 'paradox of disability':

> loving the child as he or she was and wanting to erase the disability, between dealing with the incurability while pursuing solutions, and maintaining hopefulness for the child's future while being given negative information and battling their own fears (865).

These findings support the universal properties of positive and negative appraisal

when raising a child with a disability (Schielbusch and Dada, 2018). However,

parents in the study (ibid) did not experience isolation from their family and social

group: the least substantial impact was that families felt hesitant to phone friends

and acquaintances, indicating the importance of parental support within a collectivist

culture. Schielbusch and Dada's (ibid) study contrasts with current UK findings that

Black communities stigmatise families with disability in general and autism in

particular; as this study was conducted in a non-Western context, parents may not

be exposed to the double stigma – racial and disability – associated with Black

parents in Western countries. Additionally, resilient attributes of coping: social

support, positive and negative appraisals of the impact of autism on Black parents

and their families, family belief systems, family organisational patterns, communication/problem solving are yet to be explored.

Conclusion

The experiences of Black families living with autism in the UK are under researched, thus contributes to the dialogue and ongoing debate on how best to support parents, particularly in the Black community. This literature review contributes to extant studies on the Black experience and Black parents: the 'Black experience' in a White dominant society are largely negative, underscoring the dominant and pervasive role of stigma within systemic structures and its effects on parents' quality of life (Stevenson and Rao, 2013; Sunak and Rajeswaran, 2014). Research on Black experiences specifically, notes the double or triple discrimination Black mothers and children experience from their ethnic minority community groups (Onaiwu et al., 2017; Williams, 2016; Sue and Sue, 2013; Stevenson and Rao, 2014; Slade, 2014; Papadopoulos 2016b). This study gives insight to challenges associated with autism symptomology and additional stressors associated with the minority experience and coping strategies (Heer et al., 2012; Ekas et al., 2009; Timmons and Ekas, 2018; Hastings et al., 2016).

This review delineates the intersectionality approach within familial, contextual and systemic contexts - shape Black parents' experiences of autism and their wellbeing. The intersectionality paradigm reveals how race, gender, class and disability leads to additional disproportionally small power relations and devaluation of minority groups in various contexts.

Black and ethnic minorities will inevitably be influenced by their own communities and the cultural beliefs associated with autism as well as new information and beliefs they encounter in a Western setting so autism support services should target these

communities. This research shows the relevance of identifying parents' cultural beliefs as part of their child's autism assessment, diagnosis and treatment. This research highlights the way Black families experience disability and autism in this research: how disability is labelled, understood, and experienced within Black families and community to influence parents' access to health services and their service uptake that impacts diagnosis and interventions accessed (Skinner and Weisner 2007).

CHAPTER THREE

Research methodology

This chapter delineates the study's purpose, its epistemological foundation that influenced and directed the methodology used for the research study. Participant demographics are illustrated along with a description of the research context and design. This section presents the study's protocols and a description of the procedures employed to ensure research quality and transferability.

Aims of the Study and Methodology

This research examines Black parents' experiences of autism in familial, contextual and systemic UK contexts from an intersectional lens, employs a hermeneutic phenomenological approach to study Black parents' lived experiences of autism and examines how personal narratives shape and are shaped (Heidegger, 1962) within specific contexts and structures (Smith, 1987) and their impact on parents' psychological wellbeing. The study examines power dynamics and systems that privilege certain groups over others to purport how minoritized groups are

disproportionately impacted through discrimination and marginalization based on intersectional factors such as race, culture/ethnicity, religion, gender, socioeconomic status, and disability. Hence, the study examines the intersectionality of race, gender, culture, and double disadvantage and stigma, religious coping on parents' experiences and psychological wellbeing to promote social justice.

This research brings marginalised voices to autism research in a way that highlights the Black Lives Matter movement and principles:

> When we say Black Lives Matter, we are broadening the conversation around state violence to include all of the ways in which Black people are intentionally left powerless at the hands of the state. We are talking about the ways in which Black lives are deprived of our basic human rights and dignity . . . How Black women bearing the burden of a relentless assault on our children and our families is state violence (BLM website).

This movement is a result of the history of social, racial and structural inequalities and injustices in the US context. The worldwide adoption of this movement is significant in an age where racism thrives in systemic structures. The mention of 'state violence' relates to the oppression Black lives experience from institutions and systems in existence; supports the study's intent to bring marginalised voices to the forefront, identifying and highlighting intersectional factors that perpetuate the coexistence of power and oppression, in the autism field. Black attitudes, perceptions and experiences of autism have been mildly captured in autism research, this study identifies the root of these attitudes to inform further research, policy and practice.

Central to the Black Lives Matter Movement is the influence of the intersectionality framework which recognises the coexistence of race, gender, sexuality, etc. This study highlights Black voices living in the UK to show the social and cultural intersection of African, Afro-Caribbean and UK culture and gain perspectives of how

their immigration and colonial history and cultural lens of disability shapes their present experiences.

Hermeneutic phenomenology gives insight to Black parents' experiences of autism in familial, contextual and systemic contexts and offers an interpretative process to analyse intersectional factors (Fig. 3) and their influence on parents' lives. Interpretivist and transformative paradigm provide a lens to intersectional factors that frame and shape individual experiences/Black lives in a Western context. Phenomenology as an epistemological method grants access to identify and analyse the multiple identities that intersect in various constructed contexts and realities since '[participants] realities are wholes that cannot be understood in isolation from their contexts (Lincoln and Guba, 1985:39). Central to hermeneutic phenomenology is the relationship between the participants and their context, it recognises that each person has their own point of view, and enables an analysis of the meaning parents associate with experiences in each ecological context. Orlikowski and Baroudi (1991: 5) recognise that "people create and associate their own subjective and intersubjective meanings as they interact with the world around them" and thus interpretive research and hermeneutic phenomenology "attempt[s] to understand phenomena through accessing the meanings participants assign to them" (ibid). These methodological paradigms connect through their fundamental framework that centres on individual experiences of history, culture and beliefs that form collective identities and experiences, and give cause for this research phenomena. Hermeneutic phenomenology shapes the study's epistemological position as researcher-participant dialogue is the only meaning method for generating data

about parents' experiences. The rich detailed description of parents' experiences are depicted verbatim as accurately as possible.

Heidegger (1927/1962) considered human consciousness as a creation of historically lived experiences. A person's history or background include cultural beliefs and values that are shared and passed down to understand the world (Laverty, 2003). Munhall (1989) described Heidegger as having a view of people and the world as indissolubly related in cultural, social and historical contexts, and recognised the intersectionality between ecological contexts on individual experiences. This study posits that these various contexts are not linear or hierarchical, rather they intertwine and intersect to form individual experiences. As such, the intersectional framework allows a breadth and depth of understanding parents' experiences in familial settings, various community and structural contexts. Intersectionality as a theoretical model and paradigm links to Heidegger's (1927/1962) pre-understanding structure – meaning is found as we are constructed by the world while at the same time, we are constructing this world from our own background and experiences. There is a transaction between the individual and the world as they constitute and are constituted by each other (Munhall, 1989). Heidegger (1927/1962) stressed that every encounter involves an interpretation influenced by an individual's background or history. Polkinghorne (1983) described this interpretive process as concentrating on historical meanings of experience and their development and cumulative effects on individual and social levels. This interpretive process is achieved through a hermeneutic circle (Fig. 3), which moves from the parts of experience to the whole of experience and back and forth again and again to increase the depth of engagement and the understanding of texts

(Annells, 1996; Polkinghorne, 1983). For this study, the 'texts' are equivalent to the individual experiences being studied through historical, social and structural lenses to understand their experiences in its entirety.

Figure 3:
The link between hermeneutic phenomenology and Intersectionality as theoretical models

Collective experience

Intersectionality

Race
Culture
Gender
Class
Family status
Geographic location
Disability
Education
Religion
Nationality
Generation status
Immigration status

Background

Hermeneutic phenomenology

Pre-understanding
Understanding
Sub-interpretation
Interpretation

Individual experience
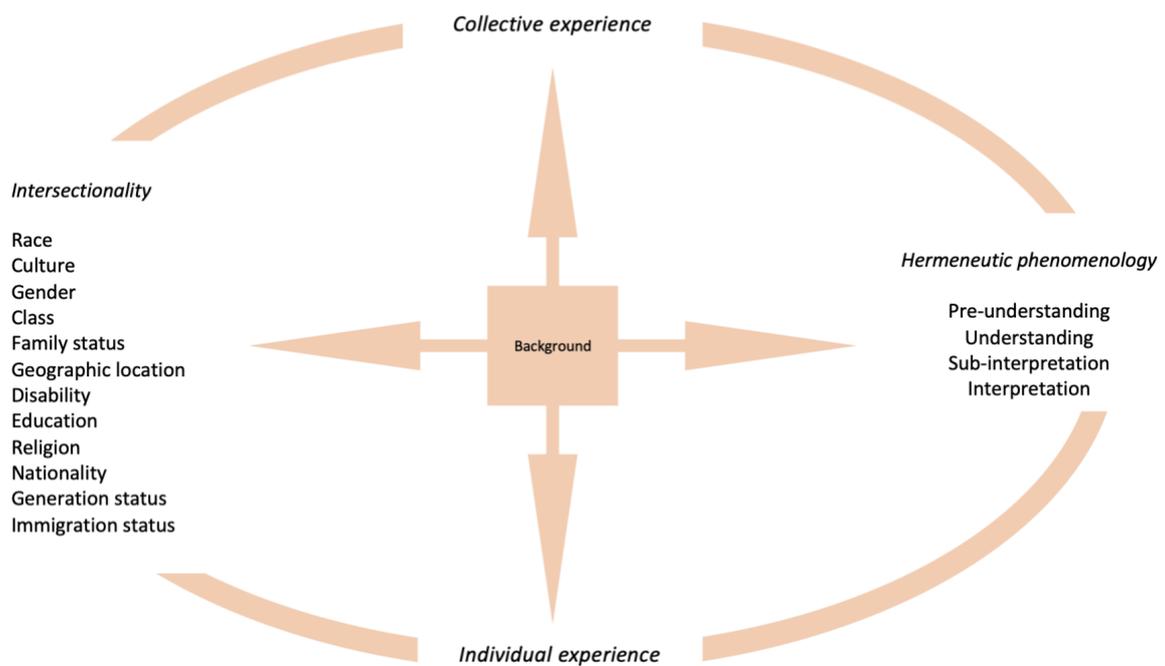
For instance, individual experiences of racism, cultural stigma, gender stereotypes from a patriarchal society become part of Black mothers' collective experiences, which are demonstrated through the intersectional paradigm and hermeneutic phenomenology.

Transformative paradigm

Social research is concerned with environmental, cognitive, social and behavioural experiences, or a blend of any or all these factors to explore and examine the social phenomena (Creswell and Plano Clarke, 2011). Brannen (2006) asserts the

importance of considering paradigms, philosophical assumptions, and worldviews during the process of selecting an appropriate methodology (2006: 9).

The transformative paradigm views knowledge as a social construction shaped by the knower's individual experiences, personal characteristics, and community affiliations. This paradigm aims to understand the lived experiences of marginalized groups with the understanding that marginalized groups have their own individual and community strengths and legitimate knowledge systems. To gain further insight and understanding of doubly marginalised groups, this research learns from community members and view participants as essential partners (Jewiss, 2018), moving away from marginalized groups traditionally excluded from research and evaluation efforts. This study investigates and analyses social inequalities within contextual and systemic factors to address issues by bringing about and recommending social action or change.

Within the transformative paradigm there is no assumption of homogeneity – that all ethnic minority parents share the same characteristics within the research sample, but that the research framework take cognisance of within-group diversity in terms of autism spectrum, functional limitations, daily experiences, and accesses to support (Doyle et al., 2013: 95). Identifying and investigating these differences add to the focus of the study to examine Black parents multi-faceted experiences of autism (ibid). Mertens (2003) states that such a perspective informs the work of researchers by providing increased knowledge and understanding of 'diversity within communities and implications for social justice and equity for diverse groups' (69).

Research Design

This research documents participants experience of socio-cultural phenomena of cultural beliefs, race and autism related experiences; the focus on experience requires a qualitative approach (Denzin and Lincoln, 2011). The qualitative tradition supports purposive sampling of small populations, researcher and participant reflexivity, and respect for multiple realities (O'Leary, 2010). Qualitative approaches allow the researcher to gain an intimate understanding of the 'lived experiences of service users, carers and practitioners, [and in] depth understanding of how policies and practices are played out in situated contexts' (Sharland, 2013: 14).

The study follows a narrative approach grounded in social constructionism epistemology to describe individuals' lives by collecting and retelling their experiences in familial, contextual and systemic contexts. The narrative approach encourage parents' accounts of past events and foregrounds significant and complex socio-cultural factors that frame their present experiences. This approach shows parents' informed perceptions, interpretation and meaning of encounters that highlight the ubiquitous presence of intersectional factors (Giaxoglou, 2021:46). This approach has been used in many disciplines to learn more about the culture, historical experiences, identity, and lifestyle of the narrator (Lieblich et al., 1998) to gather in-depth data through detailed descriptions.

Research Context: Why this study?

Research has explored the experiences of parents of autism (Ekas, 2012; Hastings, 2005; Ekas et al., 2009; Ekas and Whitman 2010; 2012) and some studies on Black and minority ethnic parents' experiences of autism (Fox et al., 2017; Slade, 2014;

Munroe, et al., 2016; Jegatheesen, 2017; Heer et al., 2012). The purpose of the qualitative method of the study is to bring marginalized voices into the conversation for transformative purposes, present Black parents' experiences of autism in the wider UK context and within their minority ethnic communities to highlight intersectional factors that shape Black parents' experiences and psychological wellbeing. Examining individual, contextual and systemic factors will give insight to the various contexts that contribute to Black parents' experiences of autism. The research findings will provide a transformative-based framework to advance the needs of underrepresented and/marginalised populations in ecological contexts (Cresswell and Plano Clark, 2011).

Research Sample

Participants

The target population for this study were Black parents of a child diagnosed with autism living in the UK. Research participants were selected if they met the study's inclusion criteria: parents of a child with autism and identified as Black (British, African, and Caribbean). All respondents met this criterion. The study recruited participants from a diverse socio demographic: economic status, gender, ethnic and religious group (Table 1). The researcher identified key themes/variables from the literature review and specific to the research study, which contributed to semi-structured interview questions on parents' experiences of autism in the UK (Appendix C). The study reached data saturation after 15 interviews and provided insight into parents' experiences.

Demographic Questionnaire

Participants' data description are provided in detail of for validity (Table 1). All participants received and completed a face sheet with demographic questionnaire (Appendix A) on their generation status, the number of years in the UK, gender, age range, ethnic origin, gender, highest level of education, religious/spiritual affiliation, household income and subjective poverty/ financial hardship status (Table 1).

In line with UK data protection regulations and guidelines, each participant was listed by his or her assigned initials. No identifying information of any of the participants such as place of employment, where the child attends school, or location of residence were included or required for the research or analysis for participants' data protection.

Table 1: Parents' social demographics

	SA	VB	HO	CO	MK	HP	YV	FP	AK	UO	UB	GE	VA	FA	JO
Aware of autism	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Yes	Yes	No	No
Generation status	1st	2nd	1st	1st	1st	1st	2nd	1st	1st	1st	1st	1st	2nd	1st	1st
*Years in the UK	11-15	UK Born	21 >	6-10	16 - 20	21 >	UK Born	21 >	1-5	11-15	16-20	11-15	UK Born	16-20	-
*Gender	F	F	F	F	F	M	F	F	F	F	M	F	F	F	F
Age	40-49	50 - 59	50 - 59	18 - 29	30 - 39	Over 60	40 - 49	Over 60	40-49	40-49	40-49	30-39	40-49	30-39	30-39
*Ethnic origin	BA	BC	BA	BA	BA	BA	BC	BA	BA	BA	BA	BA	BA	BA	BA
*Religion	C	C	C	C	C	C	C	C	C	C	C	C	C	M	C
*Level of education	D	VQ	PG	AL	D	D	AL	FQ	VQ	D	PG	UG	VQ	NQ	AL
*Household income	3	2	1	-	1	1	1	1	1	2	2	1	1	-	-
*Hardship	3	2	1	4	3	2	3	2	2	4	4	2	1	4	-
Length of time since	4	14	18	5	4	18	8	18	14	5	5	3	7	3	10

diagnosis (years)														
Child's present age	8	18	21	11	6	21	12	22		11	11	5	12	5	13
Marital status	M	S	M	L	S	M	S	M	L	M	M	C	M	M	L

Years in the UK:
*Gender: Female (F); Male (M)
*Ethnic origin: Black or Black British- African (BA); Black or Black British - Caribbean (BC)
*Education: Degree (D); Vocational (VQ); Post-graduate (PG); A-level (AL); Foreign qualifications (FQ); Undergraduate education (UG); No Qualifications (NQ)
*Religion: Christian (C); Muslim (M)
*Household income before taxes: less than £25,000 (1); £25,000 – £34,999 (2); £35,000 - 49,999 (3)
*Hardship: Finding it **very** difficult (1); Finding it **quite** difficult (2); Just about getting by (3); Doing alright (4); living comfortably (4)
*Marital status: Married (M); Cohabiting (C); Lone parent (L); Single (S, never married)

Sampling method

The study's purposive sampling method identified Black parents of a child with autism. Convenience and snowball sampling methods were employed to reach the specific target population through networking to ensure validity and research saturation. Convenience sampling describes the process in which respondents are selected due to their availability and access by the researcher (Tolmie, Muijs and McAteer, 2011:23) and participants were asked to assist the researcher in identifying potential subjects (snowball method). For this study, the two major examples of convenience sampling are volunteers and the use of existing parent autism support groups (Gay and Airasian, 2003). It was necessary to use a convenience sample, which resulted in recruiting 15 parents, because the study could not be completed any other way due to interviewees' awareness of their double marginalised status (Gall, Borg, and Gall, 1996). The practical constraints of the convenience sampling method is that it offers little protection against sampling bias and leads to generalizability issues (Tolmie, Muijs and McAteer, 2011: 23; 288). Participants were

carefully selected based on their self-identification as Black and parents of a child with autism.

The study's participants were solicited through a variety of methods. One main method was through contact with autism support groups across the UK. These groups were identified through professional network connections from Ambitious about Autism, A2ndVoice, Resources for Autism, as well as through posting a request for participants on various groups on Facebook, Twitter and other bulletin boards. Additionally, agencies with an interest in the subject of autism were contacted and asked if their clients would like to participate. A recruitment poster (Appendix B) was posted on various social media sites (Facebook, Twitter, Whatsapp) and parent support groups.

Research method: Interviews

The interview method offered a flexible approach to generate knowledge between people on complex and deep issues, as a form of collecting data (Cohen, Manion and Morrison, 2011). Interviews enabled participants to discuss their interpretations of the worlds in which they live and express how they regard situations from their own point of view (ibid). The nature of the interview as a mutually constructed and developed interaction between interviewer and interviewee stresses the importance of establishing relationships and lends the data to an interpretivist and constructionist approach (Esterberg, 2002). The interviews purposed to get as close to the interviewees' reality of their experiences.

This study employed a semi-structured interview (Appendix C) for a rich (broader and deeper) and more reliable understanding of a phenomenon than a quantitative

approach would yield and to examine the intersectional link between individual, contextual, and systemic factors on parents' psychological wellbeing. I conducted 15 parent interviews, a large enough sample to acquire depth and heterogeneity, for rich data on their experiences of autism. The interview questions were prompts developed from the literature to offer a holistic representation of intersectional factors that influence parents' lived experiences in general and with autism (Padgett, 2017). The interview guide was divided into seven sections. The first part was concerned with parents' knowledge of autism prior to their child's diagnosis, the age their child was diagnosed and what their experience of autism has been so far. The second section focused on parents' culture and cultural perspectives of autism/disability. Next, the interview questions explored whether parents were religious and how their religion influenced their outlook. Following this, the questions sought parents' acculturation to autism and the UK as first and second-generation immigrants. Next, parents' experiences of being treated differently and their financial status were solicited and finally, parents' perception of their ability to cope with autism. Although the interview guide followed this structure, the interview questions were formulated to facilitate free-flowing discussions with the participants, thus encouraging a narrative approach.

Interviews were conducted in locations participants felt most comfortable, varying from their homes, coffee shops and restaurants local to them; accordingly, the face-sheet included place of interview.

The interview guide was pretested, first on two of the researcher's peers. Following this, the interview was piloted with two parents, male and female to make necessary adjustments on the structure, carefully worded questions, clarity and length (Appendix C for final interview guide). Questions on culture, systemic factors and

acculturation were all refined and simplified to ensure all participants understood the questions. The researcher was aware that through conversation, the interviewer may still need to question participants to explore their answers further and paid attention to topics that required further expansion. All interviews were in person and participants gave their consent (Appendix F); their experiences as Black (British, African and Caribbean) parents living with autism. The interviewer constructed a face sheet that included demographic information about the interviewee and the name (initials) and code number of the interviewee, the place and time of the interview (Padgett, 2017; Appendix A). In addition to this, interviewees were presented with participation information sheet prior to the interview for participants to familiarise themselves with the research and give consent (Appendix D and F).

Themes on individual, contextual, systemic, and psychological factors shaped the researcher's interview guide and framed the open questions to ensure that key questions are included. The interviewer followed participants' lead to facilitate their 'voice' and gain insight to their true experiences and reality as Black parents living with autism in the UK. To obtain rich data, the researcher ensured to avoid dichotomies and leading questions, but to ask both general and specific questions (their Black experiences and as parents, in particular), and encouraged participants to develop or explain their responses further on topics, using phrases such as 'tell me more about…', 'elaborate on…' and 'explain further on…' (Esterberg, 2002: 98). Facilitator notes allowed the reader to prompt the participant on certain topics for more detail.

At the beginning of the interview process, the interviewer reminded interviewees that the conversation will be recorded to allow insight and analysis of inflections and

nuances to responses. Tape recording also enabled an informal, conversational style interview: the interviewer concentrated and listened attentively to the interviewee's responses to build trust and establish rapport, as a practiced form of 'transformative-emancipatory' (Tashakkori and Teddlie, 2003) instead of frantically taking notes, which prevents eye contact with the interviewee or give participants full attention (Esterberg, 2002: 106). As guided by Silverman (2008), extensive field notes were made to support the audio recordings and capture my immediate thinking during data collection. Recording the conversation also facilitated repeated listening of the interview, transcription, multiple readings, and analysis of the interview (Appendix E for audit trail). All interviews lasted between 30 – 80 minutes to obtain rich data and were transcribed verbatim. To achieve research rigour, the researcher participated in multiple readings of each transcribed interview at different stages: data collection and analysis, both of which were done consecutively to ensure accuracy. The researcher gathered, transcribed, and analysed the interview data manually to expound knowledge and understanding of Black parents' experience. These validity checks ensured that the data elicited are reliable and analyses are trustworthy (Bryman, 2017; Marczyk et al., 2005).

Data analysis

Qualitative data analysis is predominantly inductive by nature and establishes the credibility of findings by generating themes, sub-themes and conclusions from particular facts or data (Teddlie and Tashakkori, 2009: 251). Therefore, themes are 'grounded in data and not given a priori' (Lincoln and Guba, 1985:344) and dependent on the iterative nature of qualitative data analysis, where the researcher repeatedly combs through various data during and after data collection to eventually

yield themes. Following this qualitative process, this research employed both

deductive and inductive approaches to data analysis: researcher framed interview

questions based on 'a priori themes based on theory and extensive research

findings' (Miles and Huberman, 1994) to observe whether participants' experiences

are similar and/or different. This research also employed an inductive approach to

allow for generation of new themes that the research did not identify a priori but

reflected the verisimilitude of parents' experiences. The themes were organised to

reflect the narrative approach and ecological framework to understand parents'

experiences in familial, contextual and systemic contexts.

Table 2:
Data analysis process (Creswell, 2011)

Transcription	Typing participant responses verbatim
Text	One-to-one interviews
Rereading all textual data	to identify codes
Codes	E.g., Challenging behaviour, depression, isolation, finances, stigma, racism, resilience
Master themes	E.g., The impact of ASD on parents and families Contextual factors and parent wellbeing Systemic factors
Organising themes	E.g. the impact of autism on the family structure
Theorising	Intersectionality and Hermeneutic phenomenology; transformative paradigm Writing/discussion

To verify themes, this research employed the similarity and contrast principle

(Spradley, 1979). Categories were determined by looking for information with similar

content to guide the thematic process and facilitating the search for commonalities in

data (Teddlie and Tashakkori, 2009). Whereas the contrast principle allowed for

comparison between findings and categories to examine the differences that exist between cases (ibid; Yin, 2003).

This study addresses standards of rigor. To ensure validity checks in data analysis and interpretation of research, the research adopts Tashakkori and Teddlie's (2003) Inference quality and Inference transferability. They defined Inference quality as the degree to which the interpretations and conclusions made based on the results meet the professional standards of rigor, trustworthiness, and acceptability as well as the degree to which alternative plausible explanations for the obtained results can be ruled out (Tashakkori and Teddlie, 2003:709).

This definition of Inference quality is dependent on the design quality and this study employs several techniques and design quality to ensure quality and transferability (ibid): purposive, convenience and snowball sample, maximum variation sample, reflexive journaling, audit trail, triangulation and peer debriefing were utilized to ensure the inferential quality of the study.

To ensure credibility, this study employed audit trails for the interview transcription and analysis for accurate representation of parents' experiences (Appendix E). For this research, field experience included interviewing 15 parents over a period of three months (September 2019 – December 2019). Inference transferability was strengthened through the following techniques: selecting a relatively large sample size for the qualitative methods (Tashakkori and Teddlie, 2003: 710). This study employed the use of interview protocols, rich and detailed description of context and observations, selection of audit trail, and reflexive journaling to ascertain confirmability.

To establish transferability, a detailed description of the sample is provided (Table 1). The researcher wrote reflexive entries after interviews to note her own perception and experience of the interview and interviewee, recognise how her biases, values and experiences with the researched phenomenon might shape the interpretation of the findings and how to avert any misinterpretation and misrepresentation to encourage objective analysis and prevent researcher bias (Appendix G). In this research, triangulation is achieved using Intersectionality theory in conjunction with the research paradigms (hermeneutic phenomenology, transformative paradigm) to validate the accuracy of the findings. This research engaged in a form of 'briefing' through discussions of observations of participants and primary data findings with the researcher's supervisor.

The study adhered to Erzberger and Kelle's (2003) guidelines for using triangulation to ensure inference quality through various sources in the research study: interpretive rigor was strengthened by using member checks, reflexive journaling (see appendix G), detailed description, and debriefing.

Ethical considerations

Data collection began once independent reviewers at the Education Studies department granted ethical approval. To ensure privacy and confidentiality, interviewees were informed that the interviews will be anonymized with no space to record personal details such as participants name. All questions were designed to maximize the potential for anonymity (the study included opportunities to collect participants' initials, age bracket (not dates of birth), generation status and how many years they have lived in the UK). Statements for consent were validated as a

prerequisite to complete the interviews (Appendix E). The statements included (1) participants' perception of the information sheet and their ability to ask any questions prior to completing the survey; (2) participants' understanding that their involvement is voluntary and their freedom to withdraw at any time without giving explanation and 'without penalty' (BERA, 2011); (3) participants' anonymized data will be securely stored for a minimum of 10 years, in line with the University of Warwick Research Data Management Policy and (4) participants agreement to take part in the study. All participants were informed that all data formed part of a database stored securely at university drives where only the research team have access.

Researcher's reflexivity and 'insider' researcher

Finlay and Gough (2003) define reflexivity as a 'self-critical lens' through which to develop 'thoughtful, self-aware analysis of the intersubjective dynamics between researcher and the researched' (p. ix). I was aware of my insider status as a Black woman with proximal experiences of autism, which I believed encouraged the participants' trust in me. There was an unspoken mutual understanding and parents were open to share their experiences with me. As a fellow Ghanaian immigrant, participants most likely identified with me because of our shared historical and socio-cultural background as Africans. I was aware that participants may have suffered exclusion and other forms of social injustice, and any similarities between myself and participants encouraged a sense of belonging and understanding for them to share their experiences comfortably and truthfully.

I viewed my history and experiences as an opportunity to get close to a marginalised community who were more likely to trust the research. Patton (2002) urges that it is necessary to fully comprehend the various experiences of the different 'stakeholders'

in order not to exacerbate participants' already existing concerns. However, it was important to remain professional and objective so that familiarity would not compromise transparency and credibility.

Patton (ibid) succinctly states that 'experience affects perspective. Perspective shapes experience' (335). Throughout the research, I was aware of the possibility of my association with autism and my prior experience as a Special Needs learning co-ordinator could mislead or shape and enrich my perceptions and judgment. The insider experience has been instrumental to better develop and broaden my understanding of the social phenomenon being researched (Blaikie, 2007). I felt the weight of responsibility to present my findings truthfully as a form of promoting social justice for these participants (and others with similar experiences) who trusted me with true and credible accounts of how autism, race, gender and class has shaped their lives. The burden to represent participants accurately was also because of my appreciation that parents disclosed hidden aspects of their lives to me, a total stranger, despite the considerable prevalence of stigma associated with autism in the Black community. I noticed that once parents were aware of the research aim and subject, they showed relief and enjoyed talking, giving the impression that they rarely shared their experience and felt like their involvement with autism, its effects on them as individuals, parents and as a family mattered to the research.

Having been in the UK for most of my life, I was unaware of some cultural beliefs about disability and was surprised to note the prevalence of some attitudes towards autism as 'demonic'. This highlighted my acculturation towards the British culture and showed the conflicting cultures at play in my mind. I was aware and worried that including these cultural views in the research would encourage UK readers to hold a

superior attitude to cultural perceptions of hidden disabilities. However, I reminded myself that it is such views that prevent education and perpetuate stigma, therefore it is critical to highlight such innovative research findings. The vantage point of this research is the cultural elements that would offer a deeper understanding and strategies of how Black parents initially frame their child's autism symptomology and allow for culturally sensitive practices.

However, while I do not hold similar views as the participants about the aetiology of autism, I sought to respect theirs so that their voices are brought into autism related discourse to strike a neutral balance that ensures accuracy in reporting findings. My personal and professional interest in autism focuses onevidence that advocate for the benefits of early interventions. I am conscious that my upbringing in the UK has formed my understanding and approach to disability, as the participants commented that the UK has normalised autism/disability, which is not the case in their African and Caribbean communities in the UK and abroad.

Chapter summary

The methodology chapter delineates the methods and procedures the study employed. This chapter began with a description of the methodological frameworks and transformative design, that guided the qualitative study. Following this, sampling and data collection procedures were illustrated for the qualitative methods, issues surrounding quality and accuracy of inferences were addressed to ensure research credibility. Data analysis techniques were explained and followed with a summary of concerns and possible limitations within the study. The next chapter discusses findings from the interviews and thematic analysis.

CHAPTER FOUR

Thematic analyses

This research study examined Black parents' experiences of autism to begin to address the dearth of knowledge on this topic. This paper draws on an ecological framework to understand the social, cultural and systemic factors that impact parents' experiences. The first two themes illustrate parents' experiences of autism from diagnosis to their coping methods. The next theme describes contextual factors and the inextricable link between culture and religion that influence parents' experiences. Resilience is explored as a direct relationship between individual and contextual factors and is structurally placed between these sections to reflect this link. Stigma and racism are explored independently to delineate their pervasive nature across the ecological contexts. Following this, the section on systemic factors presents how individuals' lives are affected by institutions and autism-related organisations.

The current study examined various factors that contribute to Black parents' experience of autism. Participants were asked to broadly summarise their lived experience since their child's diagnosis, which was categorised as the first emerging theme from the participant interview. All participants began with a summary of autistic characteristics their child displayed that caused concern: not responding to their name, delayed physical and speech development (Samadi and McConkey, 2011), watching spinning items and flapping their hands for long periods of time, not meeting developmental milestones typical for their age group, behavioural meltdowns, tantrums such as banging heads and hyperactivity (Crane et al., 2018). Most parents were conscious of these behaviours as previously, their children were

meeting some development milestones such as interacting with them and calling out "mama"/ "mum" and "good morning" after waking up (AK, GE, JO). Parents discussed their labour experience: three children were born premature (MK, VA, JO), two parents experienced hypoxia (FP, GE), one parent (MK) mentioned epilepsy and a few mentioned degenerating behaviours such as limited speech after their child experienced fever and other physical illness (GE, YV, VA) (Lotter, 1980; Mankosi, 2006). Majority of the parents also described their children as almost non-verbal.

Themes derived from research

Parents shared similar experiences with some variations, as a result, six major themes emerged from the participants' reports. The themes created were: 1) Parents' experiences of autism, 2) Family care structure and wellbeing, 3) Resilience, 4) Cultural and religious views of disability/autism, 5) Stigma, and 6) Racism, 7) Systemic factors. This chapter is structured following the ecological framework to present each theme and sub-themes that emerged from the interviews in response to primary research question: 'What are the lived experiences of Black parents who have a child with autism?'

Table 3: Themes from interview

Research Questions	Themes	Sub-themes
R.Q.1. What familial factors shape Black parents' lived experiences of autism and influence their psychological wellbeing?	1. Parents' experiences of autism	a) Journey to acceptance b) Practical problem-solving as a coping exercise c) Parents' emotional coping strategy (child) d) Familial support and lack of social networks: isolation

	2. Family care structure and wellbeing	a) Family structure and wellbeing b) Care: Mothers as primary caregivers c) Parents' fears and worries d) Impact on siblings/family
	3. Resilience	a) A sense of purpose/making meaning b) Inner strength and gratitude c) Parents as advocates
R.Q.2. What contextual factors shape Black parents' lived experiences of autism and influence their psychological wellbeing?	4. Cultural and religious views of disability/autism	a) Lack of knowledge/awareness of autism in the Black community b) Cultural perception of disability: Physical vs hidden (or both) c) Cultural barriers that lead to marginalisation d) Religion's role e) Autism awareness in religious organisations
	5. Stigma	a) Public stigma to autism b) Stigma and autism: parents and children c) Black/African community stigma d) Autism support groups: self-stigma is mediated by education and support groups
	6. Racism	a) Racial stigma in public and autism related contexts
R.Q.3. What systemic factors shape Black parents' experiences in general and of autism specifically, and impact their psychological wellbeing?	7. Systemic factors	b) Professional support for autism related issues (lack of) c) Education, and respite from organisations d) Emotional and financial implications of autism: Mothers lived experiences: Limitations, restrictions and Finances; the need for external services.

Theme 1: Parents' experience of autism

All parents briefly described the emotions they experienced the day their child was

diagnosed, the day "my life changed for the worse" (MK) and the "day I will never

forget" (GE, MK, HO). Four sub-themes emerged from this overarching theme of

parents' experience: Journey to acceptance, Practical problem-solving as a coping

exercise, Parents' emotional coping strategy, Familial support and lack of social networks: isolation.

1a.   Journey to acceptance

All parents expressed the idea that their experience of autism is a continuous journey and identified acceptance of the diagnosis as the beginning of the journey, not the diagnosis itself. As an important stage, parents described the emotional responses that eventually led to acceptance: denial, anger, resentment, pain, depression.

> HO: Acceptance is the key. That's when you start the journey. It starts with the denial state, takes a while to accept it, then sadness comes in and you begin to ask yourself 'why?' after, you accept the responsibility, and you start thinking of how to support your child. After this, you identify the problem, then how you are going to tackle the problem. For instance, I have a special needs person in the family, our lives are not going to be the same as other families, so I should be happy with my life, let's see how we can create, as a family, a supportive, accepting and inclusive environment for our child.

> MK: You have to accept it, if you are in denial, then you are in deep problem, I accept is because I live with it, I deal with it.

> PP: You have to accept the condition and the next step is to be a helper for your child.

> AK: I have accepted the diagnosis. I have a child with autism. I accepted it when he was diagnosed.

FA: Do you really think I want my daughter like this…it's happened. I have to accept it. I've accepted that I have a child with special needs. I have to deal with this.

SA: Accepting the diagnosis took me time. Initially I wouldn't accept it…it was a big struggle. The stages of denial, resentment/anger and then acceptance to face reality. I was very low. Is it my fault? What have I done wrong?

VB: I accepted my child's diagnosis from the moment he got it. I knew that there was something wrong, something different...

FP: I thought it was because he got stuck, I didn't blame anybody, not even myself.

JO: I didn't want to accept it, but I knew it's up to me to make a change. In my mind, he didn't have it but then I see him, and I know he does. I've only just accepted it in the last two years, and he was diagnosed when he was three turning four [he's ten now].

However, one parent, UO, expressed "I have still not accepted the diagnosis 100%. I just can't come to terms with it. We are still in the stage of denial. I think this is because of how my culture back home looks at autism".

1b.   Practical problem-solving as a coping exercise

The second sub-theme from parents' experiences of autism focused on the practical method and approaches they adopted to support their child and understand the autism condition. Parents emphasised pragmatic approaches that aided their child's behaviours and development:

HO: I was more focused on solving the problem than just crying over it and finding ways to tackle all the various needs, communication, behaviour,

sensory, etc. Apart from that, being able to go to a lot of lectures and trainings to understand special needs more. I take my child to those who are more tolerant. I plan where I go, what time I should go, what things to have in place, or maybe I don't take him out to the park or take him early in the morning before people start coming. I went to two workshops every month on what autism (*sic*) is, signing, Makaton, therapies etc.

GE: I started to go to workshops, meetings, reading a lot about autism.

PP: There is always an appointment, hospitals, agencies, charities, always.

CO: You can't just pray and not do anything practically. Everything has to be practical with him…looking into professional help and support available for him.

YV: I go to trainings and workshops, parent support groups

AK: Practically, there's a lot to do, he learns with pictures.

Parents adopted pragmatic methods, through trainings and workshops, and applied the practical activities following their acceptance of autism. On the other hand, parents expressed difficulty in coping with their child's challenging behaviours and identified specific coping tools in the form of medication, diet and beverages recommended by friends and family, not necessarily healthcare professionals, to calm their child's behaviour.

UO: There's nothing we didn't try to calm his behaviour, friends, family and colleagues recommend ways to stop child being hyperactive – we even googled it…we have been using camel milk and there has been significant improvement in his behaviour – he is able to sit down and concentrate more.

GE: When he was three, my son couldn't sleep in the night. I went for a month without sleeping. I got depressed…really depressed. I was struggling. My aunt recommended Melamil Melatonin to help him to sleep and Genius drop supplement for him to calm down and concentrate.

MK: I give him Acilis Silica water. This cleanses his system to help with the autism. Parents are vulnerable to schemers because they are desperate to see a change in their child's behaviour so they'll buy whatever people recommend. E.g. organic, gluten free foods.

1c.   Parents' emotional coping strategy (child)

The third sub-theme is emotional coping, which identifies positive and negative factors that contribute to parents' emotional wellbeing and quality of life. Parents largely derived their inner strength and motivation from their child[ren], and equally identified that their child's challenging behaviours and difficulties in attaining life skills, autism symptomology, mainly influenced many negative thoughts and feelings.

MK: He started banging his head on the wall, tantrums. There were times I had to call the GP to tell them "I can't cope…what if he cracks his skull, he'll scream and lie on the floor." I'll sit and cry and ask myself 'what's going on', 'what's this?' 'Where did I go wrong, where did this come from?'
They keep me motivated. I live for them. I'm doing a damn good job. My [autistic] child has taught me to be strong. I have to cope; I have no choice.

GE: My strength is only because of them. When I was depressed, I was only getting out of my bed because of them. I should take care of them. I live for them. Everything I'm doing is for them. I said I will not give up. I'm a strong mum. I never knew that before. I don't know how I haven't lost my mind yet. They've made me realise a part of me that I didn't know existed. I used to say

I don't know how to take care of a child with autism. Now, I can smile. I used to think my life was finished/over.

YV: I'm trying to fight for him to be toilet trained. He's not a great sleeper. It is hard. There are times when I think how am I going to cope, I don't think I can cope with this, I don't know what to do, I can't seem to get this right, am I a bad mother? I'm beginning to grow a thick skin.

JO: You have to see potential in your son and work with it.

FA: At first it was difficult. I cried a lot, I was depressed but I had to be strong for my children, if I am depressed who will look after them? So now I manage.

HO: I came home one day, and he had flooded the house. Also, the frustration of 'why me', 'why us' 'why are we going through all this' and the stress of dealing with life. It's a whole combination of things. Everyday life is already stressful and then you add the SEN on top of it. Those sleepless nights, they rip your house apart. The emotional stress is a lot. It's not easy. They look up to you and you are the only one that can help them. You brought them into the world. It's a different life that you fall into. I wouldn't brag, I've done my best. I've tried my best. I'm more tolerant, understanding, and more resilient. It has taught me a lot. My husband always says that he wouldn't exchange our son for the world.

VA: My child is a fighter; he fights to get through every day in this society so I have to fight for him too.

1d.   Familial support and lack of social networks: isolation

Parents' narrative of their experience largely involved the family support they have received since their child's diagnosis. Familial support is described as receiving emotional support from extended family and practical support from their immediate

family. Most of the participants reported receiving some type of support from their immediate and extended families. Support is reported as mainly emotional support in the absence of nearby physical and financial support.

Familial support:

> MK: Mum is supportive though she's not here.

> GE: No one supports me, here – physically, I don't have support. Only God supports me. My mum is not here. My mum and sister call me and give me support. They call me every day to encourage me and support me.

> HO: If you work hard to accept it and come together as a family to handle it, then the family can't break down under the pressure.

> PP: The whole family is chipping in so because of that we are coping well. I am coping well because I have support from my family. We recruited everyone in the family to make him comfortable, not to make him feel left out.

> UO: We cope as a family unit. We have been very supportive of each other. This situation has made us closer, fight and face the challenge in front of us

> SA: My sister supports me, especially because she is in the medical sector, so she advises me, just having someone to talk to helps.

> FA: My children and husband have been my source of support.

Lack of social networks: Isolation

Isolation is defined as a physical separation and/or emotional detachment from friends and other networks because of mothers' role as the primary caregiver.

Parents expressed the negative impact of their physical, social and emotional distance from others.

AK: My husband withdrew from everyone after this child was diagnosed.

GE: I don't go out; I don't have a social life. I don't have a childminder. It's only me, me, me, me. I don't have a life. Since my son got his diagnosis, I don't have a life. He was struggling with all the sensory needs. I decided not to go out.

YV: I don't socialise much. I don't know how he will react, getting him ready sometimes takes so long that by the time I get him ready, I'm late. It's not easy. His dad didn't understand, he was in denial and thought I was spoiling [child's name].

MK: I don't get involved in my community. I've even lost friends. It is isolating.

VB: Sometimes it's better to stay on your own in that way you are in your safe space...having a child where no one can see [the disability] makes it a lot harder and it's annoying.

Theme 2: Family care structure and wellbeing

Family care structure and wellbeing was the second theme to emerge from the interviews. This theme shows the role of mothers and fathers as primary caregivers and the impact on the parent/family's wellbeing. This theme reveals how the family structure and function change when living with autism. Under this theme of family care structure and wellbeing, two main sub-themes are identified: Family structure and Emotional implications. Family structure shows the marital implications of

autism, father's role/mothers' pattern of care for their child and the impact of the family. Mothers' feelings of limitation and restriction, fears and worries are explored under the sub-theme of emotional implications.

2a.   Family structure:

Several mothers described the implications of autism on their marriage, their psychological wellbeing and subsequently, the family.

> AK: My marriage broke because of him [child]. My husband didn't believe that there can be something good out of this experience. He fell into depression. He withdrew from everyone after this child was diagnosed. Having a son such as this comes with a big depression.

> GE: When my son was first diagnosed, he [my husband] left me. He said he was depressed. I was depressed too but I never gave up.

> HO: A lot of men run away. We have to make our own community. As a mum, I was the main carer

> SA: It causes a strain on marriage

> JO: I stayed out of marriage because of my son. His dad said, 'look at what you gave birth to' and that brought a lot of problems.

> YV: He was diagnosed at the age of three. His father left a year and a half later. His father was in denial. He thinks I'm spoiling him [the child]. Eventually, his father accepted the diagnosis, but he couldn't handle his child's behaviours.

> FA: At first my husband would say 'don't worry, she'll be okay. There's nothing wrong with her', then he thought that maybe she's possessed. But I told him

that he needs to change the way he thinks, he cannot leave me to deal with this by myself. I told him he needs to help and support me and my daughter no matter her disability. She's non-verbal but she sees and knows things. She'll know if he's involved in her life.

2b.   Care: Mothers as primary caregivers

Mothers are the primary caregivers in all family structures: lone parent, single parent and marital households.

SA: As Africans, it's the mother who will carry the load of childcare etc. I'm the mum. I'm the one that has to stay at home, look after my child, bear the consequences of the…or when I find work, I have to work according to my husband's schedule.

HO: As a mum, I was the main carer. It's what we do.

FP: My husband doesn't know anything about it…about the child. Everything about the children, I do it. I fill in all the forms describing my child's needs, for financial aid and registration for carers. I took it as my challenge to bear and fight to make him better. It was tough but I had to manage. Where we are from, it's the mother who is responsible for the home to make sure the children brought up well.

JO: I look after him and my daughter alone.

Single mothers:

GE: Single mothers have to fight all the time or else you'll just be forgotten. When you don't have anybody to support you, it's exhausting.

VB: I feel the stress of doing everything on my own, cooking, cleaning, washing…if you have autistic children, just be prepared to do all the work..I just smile it off. It's hard. It's hard work.

YV: There are times when I think how am I going to cope, I don't think I can cope with this, I don't know what to do, I can't seem to get this right, am I a bad mother? I am a single mother.

JO: I look after him and my daughter alone. It's hard but you have to go with it.

MK: When the child doesn't behave, they think the mother has done something wrong, start blaming the mother.

2c.   Parents' fears and worries

Parents' fears and worries described how present and/or future incidents contribute to parents' wellbeing. Parents' fears and worries are mentioned in relation to their child's abilities and competency in life skills.

GE: He can't protect himself. The thought that someday someone can hurt my son can make me crazy sometimes. I was concerned about my child because he couldn't explain or say what he needed, if he wanted to use the toilet…if he's hurt himself, if he was in pain. He couldn't say nothing. I started crying, I was very depressed...how will my son live in this world? I think of them, what will happen when I'm not here?

MK: What is his future going to be like? Is he going to be married? I won't take him to residential sleepovers. Especially when he doesn't talk, he's vulnerable to all kinds of abuse. You can't trust anyone because he's non-verbal.

HO: After the diagnosis, my first thought was 'is he going to be able to live an independent life'?

JO: I need to help him to express himself clearly. He needs to learn how to talk.

VA: I am anxious, my child doesn't know how to communicate with me, so how do I know how to support him, how to protect him? Secondary school is what I'm worried about.

2d.   Impact on siblings/family

The fourth sub-theme is the impact of autism on the family system. Parents have acknowledged the positive and negative impact on the family.

HO: It affects the whole family. When you have another child, you can't spend much time with them because all your attention goes on the SEN child. The other children suffer. My daughter wanting to do something in medicine/nursing has been influenced by my son's condition. If you work hard to accept it and come together as a family to handle it, then the family can't break down under the pressure.

FP: We are a united family - I registered all my children [four girls] as young carers, these young carers group helped them, this charity helped the whole family. He used to beat the youngest child a lot. But when [child's name] was in pre-school and the youngest wasn't, [child's name] will hold the youngest child's photo the whole day.
There were so many challenges, especially when we go out as a family. At times, we will be in house and a neighbour will bring [child's name] to the house, we didn't know he had even left the house.
The whole family is chipping in so because of that we are coping well. It's been difficult for my children. They worried whether he would be taken

advantage of and they were very protective over him. When [child] goes on the bus in the morning rush hour, they get very worried.

PP: We recruited everyone in the family to make him comfortable, not to make him feel left out. Everyone has to sacrifice for him, for him to be comfortable and happy. My other children [all girls] have been influenced by their brother's condition – I believe they chose career routes in healthcare: paediatrician, educational psychologist, and a Masters in neurology. I am coping well because I have support from my family.

AK: They are limited. The youngest one doesn't want to have his birthday party in the house because he doesn't want to bring his friends home. My child with autism is a twin and his twin brother is very protective of him.

JO: My daughter tells me I don't spend time with her, only my son. That makes me feel bad.

MK: The younger brother suffers – [child] hitting and smacking, he switches lights on and off randomly – younger brother doesn't get to sleep. When my last son was born, whenever he cried, the oldest boy with autism would grunt, scream and hit the baby. I think he didn't like the cry. The youngest struggled with social interaction growing up. He didn't know how to play and speak to children his age because he was used to [child's name] not talking and hitting him when he tried to interact with him. It took a while to build his confidence. I can even see the effects when it was time for him to go to school.

UO: He beats his youngest sister. But the young ones also look out for him and help him. They are protective of their brother, even at this young age. My eldest daughter looks after her brother like he is her child. She sometimes understands him more than we do.

FA: My older daughter helps me. She chose to study about autism to help me, to explain her sister's behaviours. When my daughter is angry, she is

116

pinching, biting…me and my older daughter know how to calm her down, no one else in the family. She's now doing child nursing because of her [sister]. It used to be me and my eldest daughter who looked after her. It has had a big effect on the family, they can't handle her when she has a meltdown.

VA: Although they fight, his younger sister helps him. I tell her that she will have to help and look him after him when I'm no longer here.

Theme 3: Resilience

The third theme that emerged was resilience. In this study, resilience is defined as a person's ability to adapt to a difficult and stressful situation. The study recognises parenting a child with autism as a difficult situation and parents' ethnic minority status can add its challenges of racism and double discrimination. Parents are also aware that their family, their children and siblings have become resilient as a result of their experiences and encounter with autism. Within this broad theme of resilience, several sub-themes were identified: A sense of purpose/making meaning, Inner strength and gratitude and Parents as advocates.

3a.   A sense of purpose/making meaning

The first sub-theme that emerged from the interview data is a sense of purpose and/or making meaning. In this study, parents searched for their child's purpose in their lives. Making meaning is described as ascribing meaning, whether religious or functional to having a child with autism to understand and manage the daily challenges parents experience.

FA: Everything happens for a reason. I don't know why God gave me this child.

MK: God has a reason for giving me [child's name] to keep me grounded. My child is a blessing, I don't know why he chose me…there are people who don't have children and even want someone to call them "mum".

UO: We believe there is a reason for having our son. I don't know what the reason is but that's what we believe

HO: The family is like a jigsaw puzzle…the child with special needs also has role in the family too. He's really special. He's a blessing

AK: There is a purpose for everything. What am I going to do now? Look for the purpose for this boy coming into my life…try to talk to others about their child's purpose in their lives. He might not be a lawyer and a doctor but he came into my life for a purpose. For example, now I see disability as diverse way of being able...they are able in different ways. I call my son a blessed child. They teach us what we wouldn't have known if we didn't have them.

PP: I believe there is a purpose to my son's condition. I believe that God is using me to help so many families because of my own experience, "tell people that your child's condition is not the end of the world".

VA: I think God's got a purpose for him. I don't know what it is but he's going to be something in the future. He is a blessing.

FA: God knows why he gave me this child. I don't know why He gave me this child. It teaches you to appreciate what you have.

3b.   Inner strength and gratitude

The next sub-theme under the overarching theme of resilience is inner strength and gratitude that stem from a positive outlook. Positive outlook is the ability to perceive a difficult situation from a positive lens. Despite the challenges, parents identified earlier, they were equally able to recognise the positive impact of autism on their role as parents and individuals, while expressing gratitude. Parents expressed gratitude for a myriad of reasons ranging from their child's progress, the facilities, information and opportunities available in the UK, which sheds light on a fundamental aspect of resilience in the face of difficulties.

> MK: My child has taught me to not take anything for granted in this life. He's has taught me to be patient; taught me to strong; taught me to be a mum; he has taught me to look at life in another way. This country is one million times better than where I come from...I am grateful, they are looking after our kids. Where I come from, I don't have all these facilities…you don't bite the hands that feed you...I am grateful. We have to appreciate the amount of help they give our kids.

> HO: This experience has shown me a lot, it's shown me patience…it has taught me a lot. I'm more tolerant, understanding, and more resilient. I've come out a different, better person. If you think negatively, you struggle more, if you think positively, you are able to tackle the problem then to move on. Changing your mindset is key.
> In this country, they even look after special needs kids very well. They have a lot of resources, look after them very well, create a nice environment…we should give them the best because they are special…information is more available here in the UK. There's still a lot of help, choose the best way to get the help. It is better than nothing, better than Africa.

> JO: From this experience, I have learnt a lot, how to be flexible and adaptable to situations because we know anything can change at any time. Nothing can surpass dealing with my child's autism. I've learnt that I am strong.

119

SA: I have made up my mind that I will make the best out of my situation, having that mentality and attitude is what keeps me going. I have to maintain that positive attitude; it keeps motivating me that things will get better. I'm grateful for the progress she has made, because of the progress she has made, time since diagnosis, my professional training, interactions with others, now I'm in a place where I'm more grateful than anything.

CO: I cope by positive believing that some things are going to change. Now, we just deal with things [his behaviour, challenges] as they come. This is now our family's new normal. In this country, there are more opportunities, jobs/ employment. If you want work, you'll be able to find a job.

PP: We don't have to dwell on the challenges – when you think negatively, you act negatively. We have to think positively and be positive. My child and my family have benefitted from the facilities, help, support available the awareness, education.

FP When I look back and see my son's progress, I am so happy.

GE: Everything I'm doing is for them. I said I will not give up. I'm a strong mum. I never knew that before.

FA: I used to think I'm not gonna *[sic]* manage but I know I'm a strong mum. I have to manage but it's not easy. I've made up my mind that I'm gonna be ready for anything that's gonna happen because it is for the rest of her life.

3c.   Parents as advocates

The last sub-theme that developed from the data is parents as advocates for their

child. Parents expressed the constant need to fight for their children's development

through their own efforts but also in various social, educational and healthcare contexts.

> VB: I'm always fighting for them [parents and children with autism], to help them.

> SA: I am just trying to fight for her interest. I was fighting for her to fit in the school, to be accepted but what the school was doing was glaring that they didn't want her. Without the behaviour challenges, you won't know she's autistic…it's not what you want to say about your child. I would only tell someone if it was absolutely necessary...I want to protect my child's information as much as possible.

> YV: I'm trying to fight to get him toilet trained. You want to fight for your children. You've got to be a fighter.

> GE: Everything I saw on the internet that could help my son; I would do it. All I've done is good…he started to read, write and speak but he still has problems with communication…he can say what he needs: "food, water, toilet". He cannot have a conversation yet.

> FA: I speak out for my child. She was kicking the lady and I told her it's because she likes you. I don't like to explain to people every time. I used to tell people about autism, but they don't get it so I don't anymore.

> VA: I fight all the way for him. Our children are fighters, so we have to be as well. You have to stand for your child. But I do know that it's going to be a constant fight for the rest of his life. My child gives me the strength to fight. It's been a fight…a struggle.

> CO: If we have any Black friends around, you talk about it in a very light way because you don't want them to look at you like your child has autism. You don't explain properly what's going on…you just say 'just be careful, he might

121

hit your face'. If it is with a professional, you can talk about disability deeply. But with a normal person, people, you talk about it lightly, you say 'he's aggressive or he plays aggressively', because you are aware of the stigma, especially within our community.

Theme 4: Cultural and religious views of disability/autism

The fourth theme that emerged identified the significance of cultural and religious views of disability/autism. Cultural views of disability are the pre-existing and adopted views of disability within a group of people with common beliefs and values. Similarly, religious views of disability can be described as shared attitudes influenced by religious beliefs and organisations. The sub-themes are: Lack of knowledge/awareness of autism in the Black community, Cultural perceptions of disability: physical vs hidden (or both), Religion's role and autism awareness in religious organisations.

4a.   Lack of knowledge/awareness of autism in the Black community

The first sub-theme that emerged from parents' narrative of their experiences is the lack of knowledge/awareness of autism in the Black community. Most of the parents had some awareness of autism from the media, their profession and friends before their child was diagnosed. Some parents mentioned being vaguely aware of autism; described the difference between knowing about and living with autism. Parents experiences have also been shaped by the limited awareness, education and understanding of autism in the Black community.

> CO: There's more understanding of autism within the White people than amongst us ethnic minority groups. We have less information and less understanding about the condition. We didn't know [my] child's condition as

autism. As a Black family, we attached it [his behaviour] to cultural and religious issues…he's not talking because of … being stubborn…we must pray. I didn't know what autism was until I came to the UK. There is no knowledge/information of autism in Africa, those in Nigeria who may know of autism have travelled outside.

MK: I didn't know about autism. I heard of autism in this country. They are not aware of autism in Africa. There are friends that don't understand, when they come, they say [speak language], translation: [Child's name] doesn't look like a child who has autism… [Child's name] is fine, you [the mother] are looking after him. The mentality [sigh]…even my mum, though she's educated, when I tell her, she doesn't understand it. People don't understand, they don't know. She doesn't understand the level of stress… care… worry… attention.

MK: When the child doesn't behave, they think the mother has done something wrong, start blaming the mother, maybe there's a curse in the family…maybe this is a child from the devil. I'll sit and cry and ask myself 'what's going on', 'what's this?' 'Where did I go wrong, what's this, where did this come from?' Now, I think: 'why should I care how people look at my son? He didn't choose to be born this way. There's more to life than what people have to say about my child'.

HO: I grew up in Ghana, we were never taught about autism. Even though I had been in the UK for a while, I didn't know what autism was.

AK: Autism is not rampant/ known in my country.

YV: No awareness of autism in Dominica.

JO: I wasn't aware of autism, I felt it was a challenge and it'll be fine. But after two to three years of things not changing…

FA: Our people, people from Africa, when you tell them about the autism diagnosis, their response is 'she'll be okay, she'll be fine, don't worry'. The people here, the Africans here (in the UK) and back home do not understand.

4b.   Cultural perception of Disability: physical vs hidden (or both)

The second sub-theme is cultural perceptions of disability. African parents identified the cultural perception of disability as a physical handicap that is noticeable and find hidden disabilities difficult to understand and accept.

Physical disability:

UO: In Nigeria, the people we consider disabled, you'll have to be in wheelchair or physically challenged. My son will not be classed as disabled. Autism cannot be classed as disability because he doesn't look disabled. This impact [sic] how we accept the diagnosed to some extent. With disabilities that people don't see, Africans, specifically Nigerians will say, 'there's nothing wrong with this child, its spiritual, you've just got to pray. It's something that can be healed.

VA: My parents see disability as a physical disability so because my child doesn't fit into that image, they don't see anything wrong with him.

VB: Some churches and religious organisations are choosing to see disability as a physical disability rather than hidden.

JO: He's not disabled, he's only autistic.

Hidden disability:

MK: There are friends that don't understand, when they come, they say [speak language], translation: [Child's name] doesn't look like a child who has autism… Child's name is fine. The mentality [sigh]… Even my mum, though

she's educated, when I tell her, she doesn't understand it. People don't understand, they don't know.

SA: Without the behaviour challenges, you won't know she's autistic [and] because my child doesn't look it [autistic], they [my old church] believe she's spoilt.

VB: If he had Downs' Syndrome, you'll see it, but just because we don't see autism doesn't mean it's not there…when you look at him, you wouldn't know that he's got autism. No one sees the disability I am constantly justifying and explaining why my child behaves in a particular way. Having a child where no one can see makes it a lot harder and its annoying.

VA: When you look at him, you wouldn't know that he's got autism. They think 'oh there he goes with his naughty behaviour'

HO: Because autism is not a physical disability so they [Ghanaians] are more in denial.

JO: When you see him, you wouldn't really know until you try to talk to him, and he doesn't respond...then you'll know there's something wrong somewhere.

4c.   Cultural barriers that lead to marginalisation

The third sub-theme developed from the interview is cultural barriers that lead to marginalisation. This sub-theme explores the impact of cultural barriers and attitudes to autism

MK: I stay away from my community…I don't go out with [child's name] or put him in that environment because of the way my culture sees autism/disability. I don't get involved in my community.

125

VB: I feel lonely because I don't meet a lot of Black parents who will come out to share their experience so I'm on my own.

CO: Stigma comes from the Black community. You are worried about what people are gonna say. They can even take you back to the stage you overcame.
You feel much more comfortable talking about it with someone from a background different ethnic group, say a White person, because they have more understanding…there's more understanding of autism within the White people than amongst us ethnic minority groups.

VB: If you try to fit in with your family and friends who don't understand, then you'll always feel stressed.

GE: When Black people see my child, they treat me like autism can be contaminated, like their kids can also contract autism. So I feel like wow..I will be alone in this world.

4d.   Religion's role

The fifth sub-theme of religion's role reveal how parents' religion and spirituality offer support and resilience in difficult times. Parents expressed strong religious identities and depended on their religious faith as a framework to make sense of their experiences. Parents' relationship with a sacred being/God and religious values and beliefs also helped them to cope with autism related challenges.

MK: I have faith, I pray that's what keeps me going. I believe in God. I see [child's name] as not mine, he's God's and with the help of God…He has seen me through with so many things [epilepsy, lupus] with [child's name]. Prayer

and faith keep me going. My confidence is in God. [child's name] is a blessing. He is a testimony. I don't know why He chose me..I've asked God, 'why me?'

HO: I prayed and cried to God to give me that inner strength was my biggest support. I read the Bible a lot and there are many verses in the scriptures that God will not leave you…[child] is a blessing

VB: I go to church...it has given me the patience, wisdom and understanding to deal with the challenges.

SA: I'm a Christian, I believe in God, my religion helps. I still believe that God is a healer, but I am ready to accept any help – information, disability allowance…

PP: The Bible teaches us to endure with challenges in life. I use the word of God to cope. God knows there is autism, God can and has used autism as a blessing to us.

FP: I put my confidence in God. I know what my God can do.

FA: I'm Muslim, my religion has helped me because we believe whatever God has planned for you is better, so I have to think that way. I don't know why God gave me this child. It's a blessing. It teaches you to appreciate what you have.

UO: Faith in God gives you grace to handle situations and manage. We believe that with prayers, there will be a lot of changes. The prayers we have said in the past are being seen now.

JO: With him, I got to really, really know there's God, especially when he has epilepsy. If he had an attack, those silent attacks, at night, I could have lost him.

CO: It does help to pray. You are not praying for a cure…but you are praying for progress/positive things…we pray for him to grasp what we are doing/telling him.

VA: My child is blessing.

YV: Knowing that God is not going to leave me has helped.

GE: Only God supports me. I ask God every day to give me strength for them.

4e.   Autism awareness in religious organisations

Raising awareness in religious organisations is the final sub-theme under the overarching theme of cultural and religious views of disability. Religious organisations are places of worship that reflect the traditional beliefs, doctrines and principles and the congregation follows (listen and obey) the leaders' teachings. All parents ascribed to religious beliefs and went to places of worship. Although parents identified the positive role of religion in their ability to cope, they reported that lack of autism awareness and education contributed to disablist attitudes in religious contexts.

VB: The congregation do see autism from the demonic side of it. We [the congregation] are told that we've got to pray and fast about autism, they'll listen to the church leader and not listen to other things like the practical side. I've asked my pastor to alter the service because of noise, tambourines, you have to…if you say you'll finish at a certain time, you have to do that. But just because we don't see autism doesn't mean it's not there. It's like someone in a wheelchair. If someone is born without a limb, is the limb going to grow out?

Or a blind person without a socket, [will it] come up? We have to change the environment to accommodate people. We have to alter the way of thinking. You can't say your church is inclusive and you still don't see disability in the church...some churches and religious organisations are choosing to see disability as a physical disability rather than hidden. There needs to be a lot of challenges to change perspectives about autism.

YV: My church family are great. They call me during the week to check how I'm doing. They wanna help you if you wanna start a business so it's not just you…I feel like I'm part of a family. They accept my son. They have activities that my son can be included in. It's really helped my confidence to be part of the praise and worship team.

FA: I don't take her to the mosque. When I go to the worship place, I don't take her because of her sensory issues. I don't say anything to anyone anymore.

Theme 5: Public, racial and community stigma

The fifth theme that emerged from the interviews was the stigma parents experienced in various situations and communities. Stigma is being treated differently due to recognisable but 'unacceptable' trait[s]. The data revealed various kinds of stigma, which are grouped into sub-themes: public stigma to autism, racial stigma, community stigma, and autism support groups: self-stigma is mediated by education and support groups.

5a. Public stigma to autism

The first sub-theme of public stigma revealed public attitudes to parents. Public stigma is defined as people's reactions and attitudes to autism behaviours in public

spaces. Participants gave accounts of negative remarks and behaviours from the public, blaming the parents for their child's behaviours.

> HO: People make comments: "sort your child out", "sort that behaviour out" "you should know better", "you are not disciplining your child properly". But families whose child can talk, they find it more difficult because people see them as 'normal' so they get more labels like "bad parenting", "you don't train your child well" or "the child is behaving like that because of your of own bad parenting". Because my child is non-verbal, they can see the autism more.

> MK: People stare, touch each other for other people to look…when I go out, I deafen my ears and blind my eyes, ignore people's attitudes and responses to my child's behaviour. I don't go out anymore.

> PP: In public places, [like the] train or the bus, people keep away from you, they don't want to be in close contact with me and my child.

> FP: When he goes out, some children thought he would hurt them. My child did not have friends, only other children like him in the school.

> GE: Other parents, whether Indian or White also stop talking to me because of my child.

> FA: When your child starts to cry, people look at you like you are crazy. I don't like to explain to people every time.

5b.   Black/African community stigma

The third sub-theme is community stigma. This study described community stigma as negative treatment within the Black/ African community.

HO: Cultural barriers to disability and autism is still very present among Ghanaians. Also, the stigma attached to a special need in Ghanaian culture is the biggest thing, parents don't want that all. They don't want to be associated with any sort of disability, whether physical and especially hidden disability. People see it as 'having a problem in their family'. Parents don't want their children associated a child with SEN. Parents can even take their child out of the school. Parents believe autism is contagious and would not want their child near others with autism.

CO: Stigma comes from Black community…you are worried about what people are gonna say…you don't tell people my child has autism. The only time we say that word [autism] is unless the child has very extreme behaviours. When people come to the house, we don't let him be around the environment too much…we take him away to his room. We don't tell people exactly what's going on. If we have any Black friends around, you talk about it in a very light way because you don't want them to look at you like your child has autism. You feel much more comfortable talking about it with someone from a different background ethnic group, say a White person, because there's more understanding of autism within the White people than amongst us ethnic minority groups. We have less information and less understanding about the condition. Naturally, it's not a proud thing to say that my child has autism. We Africans, it's very difficult to say my child has this condition, my child is disabled. In this society, Western society has normalised disability, but within the African community it is hard to open up and say my child has disability. You talk about it lightly, you say 'he's aggressive or he plays aggressively', because you are aware that within our community, there's stigma, they'll be talking about you. Because of the stigma, you don't want to talk about it too much. It's upsetting.

GE: Stigma from the Black community is worse than the White community. Africans can't understand autism...they see everything as spiritual. European people understand more. When Black people see my child, they treat me like

autism can be contaminated, like their kids can also contract autism. So I feel like wow, I will be alone in this world.

AK: My husband would not take my children to Africa because of my son's diagnosis. He said they would laugh at him…it's that mentality that my husband has now removed himself from all the African community meetings and networks. He doesn't communicate with anyone from the African community. A person living with us said that I have taken my child for money ritual. That is Africa for you.

VB: I see discrimination as a Black mother, being in a Black community. Then when I am in the White community, it [having a child with autism] is more accepted, there's more support.

5c.   Autism support groups: self-stigma is mediated by education and support groups

The final sub-theme that emerged recognised that autism education and support groups mediated self-stigma. This section focuses on how parents transitioned from the state of depression and self-stigma to a more objective approach. Parents identified autism parent support groups/community and education as instrumental to their progress.

MK: I relate more with people who have a child with autism than other parents.
I don't mind taking him to an autism group where everyone understands what is going on

VB: I get my support from the autistic community – especially parents of a child with autism…that's my community. We have to make our own community, so our children feel safe. That's why I created my parent support

group...to help others and speak for them (parents and children with autism) until they can learn to speak for themselves

HO: I socialise with other parents who have a child with autism. I help a lot of them.
I don't go to places where their children don't have autism. I have had so much information, learn more and go to classes and workshops, therapies, what is autism, Makaton, the signing, different charities, reading materials, shows. I've set up the parent group teaching other parents how to accept the condition, give factual information about what autism is…the child has complex needs…some parents think that schools, therapists, professionals are a magic wand, their kids will change and improve and when you go through all the recommended training etc and the kids don't improve, the frustration that comes is what I help with. The progress comes but it takes time. As much as we are struggling, we still help others.

PP: My experience and knowledge of autism has enlightened me and helped me to support others in a similar situation.

UB: I get encouraged more when I speak to other parents of an autistic child. They give me consolation when they tell me where their child was before and where their child is now. Their experiences encourage me to accept it.

YV: I would prefer to socialise with parents who have SEN children – there's more understanding and mutual compassion. I go to trainings and workshops, parent support groups

SA: Of course, I won't come out to say to people [strangers] that my child is autistic. I feel I'm doing everything that I can do. It's not my fault, it's not her fault. I didn't start like that. At some point, I was very low, is it my fault, what have I done wrong? Especially among Blacks, the expectations we have for

our children and parents can be so rigid and inconsiderate. Now I believe it just happens, it's not about you, it's not what you've done.

AK: Initially it was tough…I didn't expect it. I asked, 'why me?' I searched my life some people said it was something you did when you were young. I searched my life. I didn't see why I should have this as a punishment. Now I know that it's not what I did.

FA: Before, I used to think, 'why? why? why my daughter? what did I do wrong?' Maybe it's something I did, but now I'm calm. I think it's something that happened.
But now it doesn't bother me. I think because I've met other parents who have a child with autism, and I understand about it now so now it doesn't bother me.

Theme 6: Racism

6.   Racial stigma and autism: parents and children

Racial stigma occurs when people from a minority ethnic group are treated differently and often negatively because of their race/ ethnicity. Parents identify places where they have experienced racial stigma: work, education, housing etc. Parents have also noted that race is a significant factor when the public observes their child's behaviours.

Parents:

MK: Health assistants have been rude, she literally pushed us out of the room. But I don't respond because of how Black women have been labelled as "rude" and "aggressive". We are treated differently because of our colour.

VB: When it comes to the White community, they have the same problems as us with autism, but the difference between the White and Black community is

that we face discrimination anyway, so when the public see an [autistic symptom] behaviour, they won't see autism, because of the screening and the diagnostic tools they see a Black child misbehaving, Black and Asian people are known to have a behaviour.

VB: If English is your second language and you've got an accent, already you've got a barrier. If you can speak the language and the British accent, then you can fit in, you are more likely to be accepted in the White community and autism organisations.
When you come from another country and English is not your first language, then you do struggle. You don't understand the English way of living…you deal with the cultural breakdowns, the taboos, the myths, stigmas.

HO: Racism is there…it's in every aspect of life. There's an additional problem...going through the system of employment etc in the UK is difficult…there's also the language barriers where we find it hard to understand what is being communicated, coupled with the fact that people feel that because of their colour or race, they don't get the support as White/British people.

SA: In my place of work, there is a certain level that a Black person doesn't get to…the feeling that they believe you are not capable. Racism is there…very real but there's nothing we can do about it. I feel a sense of isolation when I'm in a group and I am the only Black person, like there's no one for me. You get used to the racist behaviours and attitudes and you no longer see it as a challenge or an issue…you make the best out of the situation. You begin to know your place and you know your level. You adjust to the system – if you are Black you know you won't get far in some things. Black people who have an accent get laughed at.
As a Black person, I feel like they [White people] undermine your intelligence, your value, before saying anything, they've place you. The way they look at you, they behave as if we are coming to waste their time...I think because we are Black, they thought we were poor, we didn't appear to be of the standard

of someone who'll get a mortgage. I think they didn't think we could afford a mortgage.

YV: The man specifically said to me: "the help we are offering you, if you were anywhere else, you'll never get it so just take whatever we are offering you, at least you'll not be on the street with your kids". What he [housing officer] said to me and the way he said it made me realise that if I was a different race, he will never take that approach with me, but because I'm a Black woman, single mother, he just looked down his nose at me.

Children:

VA: They (teachers) think Black boys are naughty. ADHD is naughtiness. Nobody sees this White child misbehaving and say it's down to naughtiness. There is the stereotype that Black kids are naughty. It's in the media a lot, that Black boys are naughty, even children. They think 'oh there he goes with his naughty behaviour, when he grows, he will follow that path'. The teachers are not trained to deal with autism.

HO: When I used to take him to the park at normal times, people started taking their children away from the sand pit, from my son. They saw a Black boy throwing the sand in his shoes, so parents take them out, even the kids start moving away.

SA: There was a time my daughter was banned from the school…she was in reception [mainstream school]…the headteacher didn't know my child's name…they just focused on getting her out…they don't have the child's interest. They said the school has zero tolerance policy on violence when they know she's autistic.
If I was White, I think I would have been treated with more empathy and respect. At the school gates, the headteacher would be greeting everyone, once it's my turn, she would avoid me, when she sees me, she'll turn her back or move from the place. Sometimes I see myself as a nuisance.

Theme 7: Systemic factors

The sixth theme show various structural agencies that parents had positive and negative encounters. In the current study, systemic factors focused on autism related professional support established to support families. The sub-themes were: Professional support for autism related issues (lack of), Education and respite from organisations and Emotional and financial implications of autism.

7a.   Professional support for autism related issues (lack of)

The first sub-theme explored parents' experiences of professional support available for autism related issues and focused on parents encounters with key workers who embody beliefs, values and procedures of various structural agencies.

> VB: I thought that when the child got the diagnosis, everything will change for the child, their behaviours, communication but the diagnosis is just saying what the behaviour is. Once your child has been diagnosed, there is zero support / tolerance outside the professional assessor.

> FP: Dr [name] was very good, very supportive. He referred us to charities, support groups that can help us with [child's name]. He introduced me to psychologists for them to help me and my child. I had a lot of help. He helped me a lot. This man would come and sit down and watch [child's name] and write. This support was available 20 years ago. I'm aware that it is not the same now.

> VA: There's no support after your child is diagnosed. They send you to CAMHS to do an autism training and then that's it. He received speech and language therapy in schools and occupational therapy for six weeks. You do the rest yourself.

FA: How can Health visitor miss something like this at two-year review? On the list, I tick no, no, no, no. The health visitor said, 'your daughter is not doing any of this'? [sic] I said 'no', she still didn't refer me. I spoke to my GP who referred me. Since she was diagnosed, she hasn't had any official help, no occupational therapy...this borough… the school is giving little help but she needs a psychologist, speech and language therapy, occupational therapy. As a mum, I don't know anything about occupational therapy, I try to do what I can to help my child but it doesn't make a big impact.

GE: The doctor told me that my child would never talk, learn and will be like a vegetable forever.

JO: When he was diagnosed, they said 'he'll not be able to do a lot of things, like use the toilet, to learn, to understand anything, that it's a life-long disorder'. How can someone say something like this about your child? They started supplying diapers in large quantities. How can a normal child suddenly have autism? There should be an explanation somewhere. There hasn't been a lot of support or direction on how to help him, especially to talk. He hasn't received any speech and language therapy.

AK: The paediatricians told me that I 'carried the pregnancy with anxiety'. A psychologist said that 'all the pressure I had during the pregnancy, affected one of the babies in the womb'.

CO: Health professionals need to understand where the Black community are coming from then they can support us, with cultural differences. If they don't understand then they can just see it as the Black community not accepting support.

7b.   Education and respite from organisations

The second sub-theme identified structural factors that impact parents' psychological wellbeing. These intersectional factors were identified as: education, housing and respite from organisations/agencies.

Education

> MK: Getting an EHCP is so difficult. Parents have to pay for the EHCP plan. The council doesn't give the plans so they source the plans privately.

> HO: They have the system in place here in the UK – it's one of the best systems. The child's diagnosis is much quicker, have a SEN setting, therapies and EHC plan. If you don't have special needs nurseries or special needs after school club, you can't leave your child with family members because they'll [child] will be destroying their stuff.

> YV: Getting an EHC plan has also been a struggle. The richer the borough, the easier it is to get an EHC plan...different boroughs work differently. Parents are paying to get their child's EHC plan, sometimes for £1,500. I can't afford to pay that.

> VA: I just got his EHC plan, I got it last year. I did it myself. The company Barnados helped me. It took over a year for the council for me [sic] to get it done. Some people don't even know about the EHC plan, if you don't have a good school, you'll be left. If you are from an ethnic minority and if English is not their first language will find it very difficult to express themselves, wouldn't know where to go, where to get help so it will be difficult, they will be isolated. He's supposed to get supervision at lunch time, but he doesn't get it. It's very frustrating. Not all teachers have the training/understanding on how to deal with children with autism. It's potluck. All the teachers should get the training.

> FP: There was a lot of help 20 years ago but not now. Now, EHC plans are very difficult to get, but my time, it was very smooth. There was a lot of help.

GE: The therapy is once a month and they put all the children in one room and have 5minutes per person, it's not one to one which my son needs. Interventions are not enough at school. They put my child in the sensory room all day. When I visited the sensory room, no window, just somethings for the children to play with, no learning. I told them I don't want my child in the sensory room.

JO: The teachers told me that he can't write, and it'll be like this forever. When he's with me, I help him to write, we write together..so they should do the same. But they don't seem to have the training.

Respite needed from outside organisations and agencies:

FP: I got respite care. There was a lot of help 20 years ago…not now.

HO: Respite care for my child would be great, sometimes you don't have the time to do the mundane everyday tasks of cleaning, washing, etc when I have to look after my child.

MK: I need respite. Just five hours a week so spend time alone and with my other child.

YV: I can't get respite. I go to trainings and workshops, parent support groups, complete house chores, there's not a lot of me time. They said I don't qualify for respite because I'm not working…can you believe this?

GE: I don't have a childminder. Its only me, me, me, me. When you don't have anybody to support you, it's exhausting.

7c.   Emotional and financial implications:

Mothers' Limitations, restrictions and housing

This sub-theme described mothers' social limitations and restrictions, particularly in their careers and their ability to work, which inevitably affects household income.

SA: I feel so limited in what I can do. I can't just go to certain social spaces. I have to think if she's going to fit in, is she going to cope? Also, with childcare, I can't take her to anybody, these are all limitations and it's really difficult. Someone can just say I want to go to the shop and dress up their child, it's so easy like that. For some of us, it's not, it's a whole different ball game. The frustrating thing is you know there is work, you are qualified for the jobs available, but you can't do it because of your child's care needs.

MK: I studied ACCA. It's just circumstances. but I just can't go to work because I have a son with special needs to look after.

CO: We were not able to go on holiday for a long time because we were always thinking if he will cope with the changes...what will happen at the hotel? Will he sit on the plane? When going to family gatherings, one family member has to stay at home to look after him.

GE: I was feeling really bad, and I ask 'why me'? Why am I so creative and I can't use it but I'm stuck here looking after an autistic child? I decided to stop going to university to support my son. I decided to take my life out and help my son to live. When I was depressed, I was only getting out of my bed because of them. I should take care of them. I live for them. Everything I'm doing is for them.

JO: I put everything aside to help him – work, education and my own things. Those are the sacrifices you have to make.

YV: I just feel restricted. I feel stuck. I can't do much because of this. I can't move forward.

HO: Everyday life is already stressful and then you add the SEN on top of it. Those sleepless nights, they rip your house apart. The emotional stress is a lot. It's not easy.

Need for external agencies

MK: I don't drive so sometimes we have to take cabs to appointments – getting on the train and bus can get too much for him and then there's the meltdowns.

YV: Parents are paying their child's EHC plan, sometimes for £1,500. It makes me feel inadequate when others are paying to receive this plan and I don't have the money. If I was working, I could do a lot more.

GE: Now I'm looking for private therapy for my son but it's very expensive. Its £450 for one child for an assessment.

FA: I try to do what I can to help my child but it doesn't make a big impact. There is no other way. The other way is private, which I can't afford, it's too expensive.

HO: Autism condition is expensive – buying additional things for your child to support them, e.g. sensory toys, replacing damage costs

PP: It shoots up the family budget, for example paying for petrol or pubic transport to go to appointments

7d. Financial implications of autism

The main subtheme that developed from parents' experiences is the strain on the family's finances. Parents were aware with how finances have been impacted, often negatively, in connection with their experience with autism. Parents focused on two

specific areas that their finances are impacted: reduced work hours/ no work and resources for the child.

Work:

MK: Autism has impacted on my finances a lot. I studied ACCA. It's just circumstances. I have to look after my son so everything else is just in the back seat. I'm not stupid. I have my qualifications, but I just can't go to work because I have a son with special needs to look after.

HO: Affects your finances too...as parents we are not able to work full time because we have a full-time job as a parent with of an SEN child… So, it affects your work, when they [child] go on holidays you are stuck, you have to care for your child, you become a carer.

VA: I used to work full time, but I've stopped working because of him…so I can be there for him but it has impacted on my finances. Now, it's difficult. Going from £2000 to £400 a month. It's not easy.

FP: I stopped working fulltime – got carers and disability allowance, I was introduced to charities that helped me a lot [financially].

SA: The major thing was this stress all the time thinking about money…when money is finishing, you don't have the security when there's no money. The frustrating thing is you know there is work but you can't do it because of your child's care needs. I was managing different things, my university, placements, and jobs to suit my childcare schedule. My husband is not going to be stopped, you know, professionally. He won't let anything get in his way.

Housing:

YV: I'm sharing a room with my 11year old autistic son, if this was a father and their autistic daughter, that will never happen, they will be given housing. The man specifically said to me: "the help we are offering you, if you were anywhere else, you'll never get it so just take whatever we are offering you, at

143

least you'll not be on the street with your kids". I said, "but the house you are offering me is not safe for my child with additional needs, it's right next to the main road, next to the motorway, [child's name] has no awareness of danger, if he was to let himself out of the property...God forbid".

GE: The house is small, it's not easy but we have to manage.

HO: You can't leave your child with family members because they'll [child] will be destroying their stuff.

FP: [Child's name] put tissue in the bathroom sink and left the water running. The whole bathroom and part of the upstairs was flooded. It's not been easy but we have to manage.

FA: Now, there's no space here. When she's stressed, maybe she needs to relax, we have to leave the room for her. I tried to get enough space, but they don't have enough houses for us to move. So, we have to manage as it is, but it is really difficult.

Table 4: Summary of themes, sub-themes, key findings and illustrating quotes

Sections	Main themes	Sub-themes		Key findings	Illustrating quotes
I. The impact of autism on parents and families	1. Emotional and psychological impact of autism on parents	1.1)	Co-existence of self-stigma and emotional coping	Parents described internalised stigma that are evoked by their child's challenging behaviours.	*"Why me? Is it my fault? What have I done wrong?"* (MK).
		1.2)	Parents' fears and worries about potential for victimization and wellbeing	Parents are largely afraid of physical, psycho-emotional, and sexual predators due to their child's communication deficits.	*"I won't take him to residential sleepovers. Especially when he doesn't talk, he's vulnerable to all kinds of abuse. You can't trust anyone because he's non-verbal"* (MK).
		1.3)	Journey to acceptance	Most parents discussed the importance of accepting the diagnosis and described the emotional grief and psychological journey that accompany their acceptance.	*"Acceptance is key"* (HO). *"You have to accept it, if you are in denial, then you are in deep problem"* (MK).
	2. The impact of autism on family system, dynamics and structures	2.1)	The politics of care: mothers as primary caregivers and subsequent	Mothers are the dominant caregivers in the family and though mothers accepted this role, they experienced social and financial constraints on	*"As Africans, it's the mother who will carry the load of childcare"* (SA).

			low quality of life	their lives, careers and psychological wellbeing.	*"The frustrating thing is you know there is work, you are qualified for the jobs available, but you can't do it because of your child's care needs" (SA).*
		2.2)	Family support and structure: single mothers and autism	Single mothers described the shift in their family structure because of their husband/partners leaving due to their child's diagnosis, autism symptomology and the cultural significance of having a child with a disability.	*"Why am I so creative and I can't use it but I'm stuck here looking after an autistic child?" (GE).* *"It [autism] causes a strain on marriage" (SA); "I stayed out of marriage because of my son. His dad said, "look at what you gave birth to" and that brought a lot of problems" (JO).*
		2.3)	Impact of autism on siblings/family	Siblings living with autism are impacted by physical beatings that are directly targeted at them. Birth order and gender significantly shape sibling experiences: older siblings become surrogate mothers/caregivers and younger siblings can become 'embarrassed' to have friends over.	*"He used to beat the youngest child a lot" (FP)* *"The younger brother suffers – [autistic] child hits and smacks him a lot, he switches lights on and off randomly - he doesn't get to sleep" (MK).* *"The youngest one doesn't want to have his birthday party in the house because he doesn't want to bring his friends home" (AK).*
	3. The impact of autism on social networks and sense of belonging.	3.1)	Bonding social capital	Parents identified social support from friends, family, and spouse as an important contributor to positive psychological wellbeing. However, single parent households required more support from their community.	*"We cope as a family unit. We have been very supportive of each other" (UO).*
		3.2)	Bridging social capital	Autism support groups offered parents the bridging capital to connect with other parents for informational and emotional support.	*"I get my support from the autism community – especially parents of a child with autism…that's my community. We have to make our own community, so our children feel safe" (VB)*
	4. Parent psychological coping strategies	4.1)	Resilience	Parents expressed high levels of resilience, reflected on their personal growth and developed a sense of purpose from their child's diagnosis.	*"I said I will not give up. I'm a strong mum. I never knew that before. I don't know how I haven't lost my mind yet. They've made me realise a part of me that I didn't know existed" (GE).*
				Gratitude was a dominant trait parents expressed to show	*"They have a lot of resources, create a nice*

Sections	Main themes	Sub-themes	Key findings	Illustrating quotes
		4.2) Cognitive appraisal/ Gratitude	their resilience. One key factor that influenced parents' gratitude was the structural scaffolds available in the UK in comparison to their home countries.	*environment … information is more available here in the UK. It is better than nothing, better than Africa" (HO).*
		4.3) Religion as a coping strategy	Parents' religious parents identified with was Christianity, and their religious beliefs and activities offered psychological resilience in the face of challenges, particularly those associated with autism.	*"I have faith, I pray that's what keeps me going. I believe in God" (MK).* *"I know what my God can do'" (FP)*
		4.4) Pragmatic/ problem solving strategies	Parents recognised the essential role of autism education and training to understand and practically manage the autism diagnosis and characteristics.	*"Go to lectures and trainings to understand special needs more" (HO).* *"I go to trainings and workshops, parent support groups" (YV).*
		4.5) Parents advocate for children's rights.	Advocacy is an integral part of being a parent. Parents become a second voice to advocate for their child's need and raise awareness of autism within the Black community.	*"I speak out for my child. She was kicking the lady and I told her it's because she likes you." (FA).* *"That's why I created my parent support group...to help others and speak for them until they can learn to speak for themselves (parents and children with autism)" (VB).*
Sections	**Main themes**	**Sub-themes**	**Key findings**	**Illustrating quotes**

II. Contextual factors and parent wellbeing	1. Perceptions of autism in Black communities of autism	1.1) Community stigma	Disablist attitudes and stigma prevalent among the Black community enforce negative attitudes towards people with disability and their family.	*"Stigma often comes from the Black community […] if we have any Black friends around, you talk about it [autism characteristics] in a very light way because you don't want them to look at you like your child has autism […]" (CO).*
		1.2) Lack of knowledge and awareness about autism.	Limited knowledge and awareness of autism among the Black community and parents, prior to their child's autism diagnosis, highlights the paucity of information and exposure of autism despite being in the UK.	*"I didn't know about autism. I heard of autism in this country. They are not aware of autism in Africa. There are friends that don't understand […] even my mum, though she's educated, when I tell her, she doesn't understand it. People don't understand, they don't know" (MK).* *"Africans can't understand autism […] they see everything as spiritual" (GE).*
	2. Cultural and religious perspectives	2.1) Physical / hidden disability	The presence of mental/neurological disabilities that are hidden but manifest behaviourally produce a mental dissonance in the Black community. Parents' attempt to explain autism symptomology show the influence of culture, religion, traditional and historical practices towards people with disabilities.	*"Without the behaviour challenges, you won't know she's autistic [and] because my child doesn't look it [autistic]" (SA).* *"If he had Downs' Syndrome, you'll see it, but just because we don't see autism doesn't mean it's not there…" (VB).*
	3. Culture and religious contexts	3.1) Lack of awareness on autism in religious organisations	Religion positively influences parents' experiences. Parents employ a religious lens to understand the daily challenges associated with autism. However, parents' identified lack of knowledge and understanding of autism in religious organisations negatively impacted their experiences.	*"The congregation do see autism from the demonic side of it. They'll listen to the church leader and not listen to other things like the practical side it [of autism…]. I've asked my pastor to alter the service because of noise, tambourines" (VB).*
	Racial stigma	Racial stigma and parents' wellbeing	Black parents experience a double or triple advantage due to their race, gender and their association with disability. Young children with autism are also stereotyped. These marked characteristics cause double marginalisation within their ethnic community and the wider UK setting, which	*"Racism is there…it's in every aspect of life. There's an additional problem" (HO).* *"In my place of work [nurse], there is a certain level that a Black person doesn't get to…the feeling that they believe you are not capable (SA).*

			negatively impacts parents' mental health.	*"They [teachers] think Black boys are naughty. ADHD is naughtiness. Nobody sees this White child misbehaving and say it's down to naughtiness" (VA).*
Sections	**Main themes**	**Sub-themes**	**Key findings**	**Illustrating quotes**
III. Systemic factors	1. Public and racial stigma and wellbeing	1.1) Public stigma and its impact on parents' psychological wellbeing	Mothers were often blamed for their child's autism symptomology and describes the stigma parents encountered in public settings.	*"Sort your child out", "sort that behaviour out", "you should know better", "you are not disciplining your child properly" (HO).*
	2. Structural support and wellbeing	2.1) Experiences with professional services	Parents' frustration by the lack of support from various institutions become an additional challenge that impact their psychological wellbeing. Parents expressed disappointment with the lack of autism training for professionals and practitioners within health and educational services and the Local Authority (LA).	*"There's no support after your child is diagnosed" (VA).* *"Getting an EHCP is so difficult. Parents have to pay for the EHCP plan. The council doesn't give the plans so they [parents] source the plans privately (MK)"* *"We've bought like 10 iPads, and he has smashed them" (VA).*
		2.2) Financial implication and housing	The family's financial budgets are extended and stretched by the unconventional needs the child with autism require. Mothers sacrifice to stop full-time work also puts a strain on the family's budget and their psychological wellbeing. Majority of parents' living conditions were small and unsupportive of the needs and general wellbeing of the family, particularly the child with autism.	*"I used to work full time, but I've stopped working because of him…But it has impacted on my finances. Now, it's difficult. Going from £2000 to £400 a month. It's not easy" (VA).* *"I'm sharing a room with my 11-year-old autistic son" (YV).* *"The house is small, it's not easy but we have to manage" (GE).* *"There's no space here" (FA).*
		2.3) Respite and external agencies	Respite was largely mentioned as a necessary coping strategy and yet parents were not afforded this privilege because they were not eligible.	*"I can't get respite. I go to trainings and workshops, parent support groups, complete house chores, there's not a lot of 'me' time. They said I don't qualify for respite because I'm not working…can you believe this?" (YV).*

Conclusion

The themes highlight individual, contextual and systemic factors that impact parents'
lives and autism experiences. This chapter demonstrates how intersectional factors:
race, gender, disability etc., have emotional, psychological, marital, financial
implications for Black parents. The next chapter discusses these contextual and
systemic factors in conjunction with extant research to illustrate how this research
adds to the autism discourse and sheds light on new areas that have not yet been
examined in research.

CHAPTER FIVE
Discussion

Introduction

The recent remonstrations following the murder of George Floyd in the US (March
2020) led to worldwide protests advocating that #BlackLivesMatter. This study
subscribed to this movement, particularly in the field of autism by revealing parent
experiences through an intersectional lens and in ecological contexts.

Following the intersectional paradigm, this study adopted a multifaceted lens to acknowledge Black lives and experiences considering systematic racism, sexism and classism. Specific to autism research, this study captured the confluence of power and dominance in ecological contexts, to demonstrate the visible and invisible harms that result from social constructs of race, gender and disability.

This research inquired: 'What are the experiences of Black parents who have a child with autism'? To gain a holistic understanding of Black parents' experiences, the study revealed parents' experiences at various ecological contexts, using the intersectional paradigm to highlight the connection between identity, social contexts and policy. This approach aimed to demonstrate gaps in support services in familial, contextual and systemic contexts that negatively influenced parents' psychological wellbeing.

This study adopted Bronfenbrenner's (1979) ecological systems framework to shed light on the various factors: familial, contextual and systemic factors that shape parents' lives. This study's epistemological stance along with hermeneutic phenomenology recognised the relationship between parents' experiences of autism and the different contexts: microsystem: (primary caregiver role, single mother), mesosystem: (culture, religion and racism) and macrosystems (services and systemic stigma). This chapter followed this ecological structure to highlight various factors that influence parents' experiences at the intersection of autism, race and gender.

Using intersectionality as an analytic tool fosters more expansive understandings of collective identities and political action (Collins & Bilge, 2020:166). Confluence of social identity markers has been an important dimension of 'intersectionality's emergence as a form of critical inquiry and praxis' (ibid). For this research, the case

of Black women in male dominated families or single mothers (a result of fathers deliberate absence) highlight the politics of race and gender identity praxis that devalue Black women within a micro-system. Black mothers, as primary caregivers, have more interaction with health services, education and local authority institutions and experienced the disadvantages of minority identities at the intersection of race, gender and disability in various ecological contexts and institutions. Their experiences highlighted the need for legal frameworks to offer protection for multiple minoritized groups.

This study highlighted the intersection of culture, gender and disablist attitudes that permeated in the Black community – the meso system. The role of culture is becoming an increasing focus in autism research because of the Black community's dominant influence on parents' experiences (Slade, 2014; Perepa, 2019). These findings supported existing research and recommendations to raise awareness of autism in Black and ethnic minority communities with an added focus of recognising cultural and religious beliefs along with medical research (ibid). This research shows the importance of autism knowledge and education to mediate against disablist attitudes (Gemegah et al., 2020) and highlights the increasing efforts required to curtail harmful beliefs about disability and autism in marginalised communities. Intersectionality paradigm recognises the role of identity performance in social contexts. Power relations were also evident in macro-systems – triple disadvantage of race, gender and social class identities limit the access of quality health care services and legal protection. Conversely, professionals' intersectional identities (White, male, expert status) demonstrate socially constructed privileges that professionals use to maintain their power within macro-systems. This study

evidenced anti-populist culture in health and education contexts that sustain

disproportionate power relations employed to advance public policies against

minority groups (Black people, women, persons with physical/intellectual disability,

etc.). These findings demonstrated Black mothers' position of disadvantage in

health, education and social support services and emphasised the relevance of

streamlined systematic services that responds to mothers' needs at various

ecological contexts.

The following sections expand on the study's conceptual framework and synthesized

the data analysis to highlight the study's contribution to autism and race related

research.

I.   Familial context

1.   Black parent experiences and wellbeing: family dynamics and structure

This section explored family dynamics and structures constructed along the Politics

of care: mothers as primary caregivers and low quality of life, and Family

relationships and siblings.

Biological and cultural factors influence mothers lived experiences of autism in the

familial context. Mothers in two parent and lone parent households described their

role as the primary caregiver, which limited their career opportunities and social

interaction, and contributed to a decline in psychological wellbeing. Single mothers'

role as the primary caregiver expanded to include the breadwinner role and paints a

complex picture of the demands on single parenthood. The disintegration of the

nuclear family to lone parent households show the severe effects of cultural

perceptions and attitudes to autism and its impact on all subsystems. Pile up

demands on mothers put them at significant risk of clinical levels of depression and mental illness; the impact of poverty on parents, particularly on mothers' psychological wellbeing is telling.

1.1.   Politics of care: mothers as primary caregivers

In Bronfenbrenner's (1979) ecological system's theory, the most imminent ecological level is the microsystem - settings that individuals directly interact. Familial context represents one microsystem, encompassing different types of role and functions, family structures and activities that occur within this setting. Among the family context, certain roles and patterns of activities are associated with more negative outcomes than others. Mothers highlighted the negative social, emotional and psychological outcomes of being the sole/ primary caregiver of a child with autism. Parents' experiences shed light on how the family functions are implicitly influenced by societal and cultural views of gender roles.

This study disclosed the existence of power and domination in families and revealed the family structure as a microcosm of patriarchal influences. The family structure delineated traditional, cultural and gender expectations and stereotype apparent in mothers' role as primary caregivers and conveyed the 'synthesis of these oppressions create the conditions' of Black women's lives (Combahee River Collective, 1978: 363).

Families of children with autism, particularly among minority ethnic groups adhered to this traditional caregiving role (Furrukh and Anjum, 2020). In this study's population, there is strong loyalty to traditional beliefs of gender role expectations and stereotypes: "as Africans, it's the mother who will carry the load of childcare... I'm the mum...I'm the one that has to stay at home, look after my child …" (SA).

Another parent commented: "my husband doesn't know anything about it...about the child. Everything about the children, I do it" (FP). These comments reflected stereotypical division of labour in the home.

Within the traditional African/Black family structure, women are considered the 'backbone', an enduring influence on the moral character of the traditional society; they produce and sustain life but also to help instil socio-religious values and morals in the family (Afisi, 2010). Such beliefs have been engrained in the socio-cultural fabric of the African/Black community and supports the study's finding that mothers accepted their role as the main caregivers due to cultural beliefs and biological attribute that 'it is [their] responsibility'. Mothers' perceptions showed culture's direct influence on parents' roles and its prominent effect in a Western context. Phrases such as "carry the load...bear the consequence" (SA) and "my challenge to bear" (FP) indicated that mothers accepted and adhered to stereotyped roles, concurrently recognised the stress and challenges they experience as married, lone and single mothers.

Gender and cultural identities intersect in Black women's roles as mothers. These examples illustrated how patterns of subordination intersect in women's experience of motherhood and how 'intersectional subordination' (Crenshaw, 1991: 1249) are reproduced. The "imposition of one burden [gender inequality] that interacts with pre-existing vulnerabilities" [disability] create yet another dimension of disempowerment. Mothers' experiences revealed the family context as a system where race, gender and culture converge. However, the added element of cultural, traditional and societal views on the role of women within the Black family and community becomes an additional form of stress and disempowerment.

The unequal division of labour in mothers and fathers' roles in the home impacted mothers' career, social and financial options, which has affected their quality of life (QoL). In this study, mothers identified their child's behaviours as the cause of their frustration: "I feel so limited in what I can do...I can't just go to certain social spaces... I have to think if she's going to fit in, is she going to cope? Also, childcare, I can't take her to anybody. These are all limitations and it's really difficult" (SA). Another parent expressed similar difficulties with childcare "I am limited. It's difficult having someone stay at your house, to babysit etc., because they can't manage him" (UO). Due to limited childcare options, mothers of children with a disability engaged in childcare activities on average 13.1 hours more per week than mothers of children without a disability (Crowe and Florez, 2006). Whereas parents of children with autism were found to spend on average 43 hours per week in caring for their children (Järbrink, Fombonne, and Knapp, 2003). Such increase in childcare hours reduce parents' free time for other daily activities, including personal leisure, work, and personal care. In this study, mothers expressed their frustration of limited career opportunities due to being the main caregiver of their child: "the frustrating thing is you know there is work, you are qualified for the jobs available, but you can't do it because of your child's care needs" (SA). Mothers shared various emotions, from frustration to anger, with the common theme being how their child's needs negatively impact their quality of life and subsequently their psychological wellbeing.

This study conveyed the relationship between the micro and exo system in Bronfenbrenner's (1979) ecological systems. The family system required social support from the wider community. Familial support and varied forms of social networks are integral to parents' coping abilities (Bishop et al., 2007; Furrukh and

Anjum, 2020). Studies found social support to be a coping mechanism that is highly beneficial to parents (Miranda et al., 2019) and documented the critical role in aiding parents to successfully cope with higher levels of stress (Tehee et al., 2009; Ekas et al., 2010; Lovell et al., 2012; Weiss et al., 2013). Although the nature of support, whether emotional and/or practical, varied in each family structure, parents clearly valued the support they received and considered it beneficial to their wellbeing. Married parents felt their spouse was their main and highest source of support, because they are physical close or easily accessible through technology (e.g., phones) and have an obligation to assist, particularly in their parental roles (Goedeke et al., 2019).

Social bonding capital among family members were considerably high, as parents gained support from these social networks. Family members/systems often encountered similar challenges and rewards from their lived experiences of autism, therefore required support from various people (neighbours, parents' workplaces, friends) in the eco-system.

Lack of social support has been shown to have a direct relationship with stress, anxiety, and depression among the mothers of children with autism (Boyd, 2002) as single mothers mainly depended on their own mothers or other family members (Burkett et al., 2017: 500). Burkett et al.'s (2017) study reported that single mothers reached out for community and social supports more often than two-parent families, as evidenced in this study. Although all parents sought out support from the community in diverse and disproportionate measures, single mother families required more support. Single parent households required emotional, financial and informational support from their community and professionals, whereas two-parent households required more professional support and guidance following their child's

diagnosis. Single mothers expressed higher levels of depression, distress, and lower adjustment than mothers living with their spouse (Nagib and Williams, 2017; Bromley, Hare and Emerson, 2004). For example, Bassuk, Browne, and Buckner (1996) reported that poor single mothers are more socially isolated, received less emotional and parental support, and have more unstable social networks than married mothers. These findings highlighted the importance and connection of the exo-system (family friends) and microsystem in supporting parents' experiences and development.

Black mothers are directly and indirectly influenced by the micro-, exo- and macro-systems according to Bronfenbrenner's (1979) ecological systems theory, which demonstrates the intersectionality between different contexts and its influence on their experiences. Black women are socially and financially oppressed by patriarchy, their role as primary caregiver limits their social interaction and their career options. This study shows the blind spots in existing autism research that do not consider the existence of multidimensionality of experience and the prevalence of multiple, systematic and intersecting oppressive structures.

 Therefore, intervention strategies for Black women ought to consider the different experiences that women encounter, who because of race, culture and disability face different restrictions. An unfortunate reality is that many women of colour are burdened by poverty, child-care responsibilities and the lack of job skills (Crenshaw, 1991). The Equality Act (2010) recognizes the importance of protecting the characteristics that disadvantage those associated with certain identities, for example, age, disability, race, religion, etc. However, one critique with this legislation is the failure to recognise that for some, these identities are not mutually exclusive;

rather experience multiple minoritized status: a black boy with autism now has three protected identities (age, race, disability), which is unaccounted for in the legislation. This study posits that failure to consider the multiple disadvantaged identities a person can have, or to produce policy/legislation that protects the characteristics of carers/parents of persons identified as disabled exacerbates the disempowerment of those already subordinated by other structures of domination [racism, patriarchy, classism, ableism, etc] (Crenshaw, 1989). McLaughlin et al. (2008: 55) identified the intersectional effects of disability:

> families are often reliant on benefits and those who could claim benefits often find it difficult to do so; benefits that families receive do not meet the additional outgoings associated with having a disabled child; families of children often live in poverty due to reduced work hours and household incomes; families often lack access to accessible leisure pursuits, housing and responsive respite care.

These findings resonate with this study's aim to highlight the intersections of social, economic and cultural poverty compounded with structural racism.

Research has identified various factors associated with low quality of life for parents: challenging behaviours of a child with autism (Dardas and Ahmad, 2014; McStay et al., 2014; Tung et al., 2014); lower household income and parental distress (Dardas and Ahmad, 2014). Mothers are often required to readjust aspects of their life, including their family interactions, family lifestyles, marital relationships, work arrangement, coping styles, and their perspective of life (Ooi, Ong, Jacob and Khan, 2016). The complex interplay between these factors vastly contributed to parents' low QoL and psychological wellbeing.

1.2.   Family relationships and siblings.

The immediate family is the system most directly impacted by autism. Early research recognised that negative effects are not limited to interactions directly involving the child with autism but extend to other family interactions such as the relationship between the parents and to the relationship between the parents and other children in the family (Morgan, 1988: 266). Findings from this study showed that these effects and relationships are reciprocal - the child with autism not only has effects on the family, but the family has effects on the behaviour and adjustment of the child (ibid) and demonstrates the bi-directional relationship between family systems (Bronfenbrenner, 1979).

Parents comments indicated that autism impacted the whole family: the child with autism, the parents and siblings (Romney et al., 2020) and suggests that positive coping and wellbeing required family effort and contribution. The study's findings demonstrated resilience levels in the different family systems – some parents become closer to their spouses and the family as a whole and find meaning from their situation (UO, UB) (Romney et al., 2020: 11).

Parents were highly cognisant of the complex effects of autism, however, highlighted unity as the apex of the positive impact (Burkett et al., 2017: 500).

Ludlow et al. (2011) explored the challenges faced by parents and reported two main themes, which parallel this study's finding that challenging behaviour and the emotional impact of autism on the family contributed to the family's negative psychological wellbeing (ibid). Parents' emotional states were characterised using words such as "suffer" (HO), "many challenges", "difficult" (FP) and "not easy" (FA), which gave an insight to the emotional impact on their lived experiences with autism.

The family's positive and negative experiences showed the complex and interconnective nature of autism on the family systems; highlighting that such experiences are far from linear, rather a continuum and spectrum of experiences that can be unique to each family member and family system depending on familial and other socio-cultural factors. Though families shared common experiences, the impact of autism on each family was different.

Autism behavioural characteristics are repetitive, restrictive behaviours and limited social and communication interaction (APA, 2013) that impact the family system (Sivberg, 2002a; 2002b). All parents shared anecdotes of their child's limited social interaction and communication that resulted in physical and maladaptive behaviours that the family, especially siblings, found challenging to manage. In this study, birth order and gender significantly impacted siblings' experiences and coincidentally, within families of children with autism, having older neurotypical sisters was common. However, in younger parents, the child with autism was the first child and had a younger neurotypical sibling.

An intersectional lens is key to understand sibling relationship and the role different genders play in supporting their parents with their sibling with autism.

Mothers identified the parental role their older daughters embraced, supporting Cridland et al. (2016) report that older female siblings often played 'roles including "big sister," "mother-hen," "maternal," "protector," and "body-guard"' (199). This finding supports Saxena (2015) and Jegatheesan and Witz's (2013) study which showed that older siblings are more involved in care, which may be in response to parental expectations. In this study, parents recognised the important role their daughters played at home when caring for their sibling with autism. Parents' reliance

on their daughters suggested that older female siblings share some of the challenges associated with autism, who become like second mothers/ parents for their brothers with autism and alleviated the emotional and physical challenges of parenting. Siblings are required to support their parent due to limited economic and social capital to provide professional care for their child. Identitiy categories such as sex, race and class are significant and hold underlying influence on parents/sibling experiences of autism. These multiple social vectors are necessary to capture siblings' autism experience in the home: Black girls are exposed to systems of oppression in the home, taking on more domestic and parental responsibilities based on their gender, subsequent of their parents' financial limitations to acquire suitable support.

Mandleco and Webb (2015) indicated that siblings developed additional empathy, which improved their understandings of autism and increased compassion. Findings relative to older siblings support preliminary research that siblings showed more prosocial behaviours (Hastings, 2003; Kaminsky and Dewey, 2002) and positive outcomes for siblings (Hastings, 2016; Kovshoff et al., 2017; Pelatas et al., 2012).

Parents also focused on the positive impact that autism has had on their neurotypically developing children, yet cognisant of the physical/emotional challenges and sacrifices each family member experiences. Parents reported older female siblings of children with autism as more adjusted and their choice of careers (medicine, paediatrician, educational psychologist, a Masters in neurology (FP); nursing (HO); child nursing (UO), etc.) were either directly or indirectly linked to autism. The connection between siblings and their career interests/choices demonstrated the impact of autism on their lives and created a desire and curiosity

to learn about the condition. This finding supports and demonstrates a bidirectional impact of autism in the family system – the child impacts their siblings and in turn, the sibling's interest in autism is increased which promotes understanding, whether emotionally and/or intellectually (Cridland et al., 2016; Morgan, 1988; Jegatheesan and Witz, 2013: 13). This study's findings support Kovshoff et al.'s (2017) study which showed that siblings, rather than being passively influenced by these micro-system factors, may actively shape their own wider environment, for example by contributing, even in a small way, to cultural attitudes towards disability, which can play a significant culminative effect overtime within the Black community.

Parents largely reported negative effects on younger siblings and recogised the complex effects of having an older sibling with autism on the younger sibling. Challenging behaviours like 'hitting' the younger sibling is commonly mentioned and had negative effects on parents' emotional and psychological wellbeing. For instance, the younger siblings exhibited lack of social skills for successful social interaction; the social interaction and communication deficits associated with autism are inadvertently learnt which impact the neurotypical child's confidence in social settings (Benderix and Sivberg, 2007). Mothers, particularly, reported feeling helpless about the impact of aggressive behaviours on siblings. One parent mentioned that: "[Child] was beating [sibling] a lot, because she's the youngest. He hurt her a lot. He can kick you, slap you" (FP). Parents described how younger siblings were often subjected to violent and challenging behaviours evoked anxiety in intense and upsetting situations (Angell, 2012), unpredictability of how the situation would progress, self-blame and stress (Gorjy et al., 2017) which negatively impact their psychological wellbeing.

162

Benderix and Sivberg (2007) and Mascha and Boucher (2006) reported on the unprovoked and unpredictable aggression or violence on siblings, noting that it was very difficult for siblings to cope with, some experiencing these behaviours as frightening and physically hurtful especially when they were the target. Siblings' suggest that social skills, communication and interactions can be impaired because of limited social interactions. Another parent said "he don't want to do birthday parties in the house [sic]. Socially, they are yet to overcome the fact that they have a brother with autism" (AK). Benderix and Sivberg's (2007) research supports this study's finding as some siblings felt they missed out on opportunities for social connection, while others felt embarrassment and trepidation about inviting friends to their home (Dansby et al., 2017).

Sibling research has often focused on older siblings' experiences of 'living with autism' (Cridland et al., 2016) but with limited focus on the impact on younger siblings (Pelatas et al., 2012). The findings from this study show the importance of making the distinction between younger and older siblings experiences to provide specific support and interventions, while providing appropriate coping strategies for their social, educational and psychological wellbeing.

Sonik et al.'s (2016: 336) research that sibling caregivers were more likely to be Black highlights the added support Black families of children with ID require and shows that race/ethnicity is an additional factor that require attention in policy. Their finding that siblings of people with ID were more likely to live in household of food insecurity (23%), have income below the federal poverty level (63%) and much more likely to live in households receiving government benefits throws a caution light to specific social demographic characteristics (women, Black, less well educated and older) for imperative financial, emotional and psychological intervention.

163

The intersection of race, gender and social class is highlighted in sibling care. Social class and culture are important macrosystems with implications of family and sibling experiences (Sonik, 2016). This study recognises the importance of recognising research that highlights positive effects of the carer role, to avoid a deterministic view and conclusion of Black sibling caregivers. However, race, gender, age (birth order) and association with autism all conveyed intersectional factors that shape sibling identity and experiences. Racial identity is a significant influencer – caregivers are more likely to be Black – which suggests limited economic capital to access private care for their siblings' autistic needs.

As mentioned earlier, the Equality Act (2010) further marginalises the caregivers of people with disability who may hold multiple minoritized statuses and yet are not protected by legislation.

II.   Contextual factors and parent wellbeing

This section discusses contextual factors and parents' wellbeing through an examination of Perceptions of autism in Black communities, Cultural and religious perspectives of autism and Cultural and religious barriers that cause parents' marginalisation from the community.

Contextual factors depicted social and cultural values associated with autism in the Black community. This section showed the intersection of Black culture and attitudes to disability in various social contexts that influence parents' experiences and psychological wellbeing.

Black communities, in this research, continue to uphold cultural and traditional beliefs about disability. These traditional and religious beliefs that disability is a result

of spiritual attacks, witchcraft and possession have led to parents' experiences of courtesy stigma, subsequently marginalisation and (self) isolation. This research study highlighted the inextricable link between culture, religion and disablist attitudes towards hidden disabilities, with a dominant perception of disability as purely physical. This research showed a lack of awareness/understanding of autism within religious organisations, with some religious leaders drawing from cultural beliefs of disability and religious practices such "fasting and prayer" to heal/ cure autism. This study contributed to knowledge by delineating to disability organisations how cultural beliefs influenced and shaped parents' experiences of autism in their familial and community contexts. As such, inform disability organisations' policy and practice by raising autism awareness in Black communities that can eventually change perceptions and attitudes.

Perceptions of autism in Black communities

Perceptions were examined along Community stigma, Lack of knowledge and awareness about autism.

2.1. Community stigma

This study captured homogenous beliefs about disability within the Black community. Extant research has shown the evolution of cultural attitudes to disability where persons with disabilities were initially rejected in Black/African cultures, considered outcasts by the public, treated as economic liabilities and grudgingly kept alive by their families (Munyi, 2012). In this study, parents identified intersections of traditional, religious and cultural beliefs about disability as barriers to autism education that merge to shape parents' experiences of autism in the community.

Community stigma against persons with disability is framed around the occurrence of labelling, discrimination, isolation based on physical/intellectual impairments and differences. This study conveyed the power and dominance, through disablist attitudes, that non-disabled persons exercise over individuals and families living with autism. Evidently, existing power dynamics is based on their non-disabled identity, which purports disablist attitudes because of cultural, traditional beliefs and limited education, awareness and contact with disability.

While throughout the world many changes have taken place in status and treatment of persons with disabilities, the remnants of tradition and past belief influence present-day practices and affect such groups (Wright 1973). Kassah (1998) describes how disabled people on the streets of Accra were carried out of the city and hidden prior to the International Conference of Non-Alliance Countries held in Ghana in 1991. This exercise was executed against the will of people with disabilities, yet city dwellers saw disability as shameful to the country (Manu, 2012). Children with varying mental conditions were abandoned on riverbanks or near the sea so that such "animal-like children" could return to what was believed to be their own kind (Munyi, 2012). Such actions purport a common consensus of shame associated with disability.

These examples convey the existence of compound structural oppressions: disablist attitudes appear to pervade across all ecological contexts, subsequently, demonstrate how simple everyday encounters could yield discrimination. The precarious nature of disablist attitudes perpetuate harm against people with disability, highlighting the cultural, familial, structural inequalities that acquiesce inhumane actions and attitudes towards disabled persons and those associated with

them. Disablist attitudes and actions fail to consider human rights; as such, sustain

and perpetuate exclusionary social policies and lack legal protection for people with

disabilities. Bakare et al., (2009) reported that in sub-Sahara Africa, child mental

health has received inadequate attention from policy makers. Evidence of prevalent

disablist attitudes and stigma are ubiquitous in historical events: in 2006 when

Ghana passed its ACT 715 for disabled people, the National Council of Persons with

Disability (NCPD) did not consider autism to be a disability (AllAfrica, 06/04/2009).

This shows one reason for the vast vacuum between policy and practice, which

perpetuates social stigma towards people with autism and courtesy stigma towards

their families. These findings revealed the confluence of cultural, social, structural

ideologies about autism that translate to disablist behaviours in structural settings

and impact systemic and social policies.

The examples of the poor treatment people with disabilities experienced support the

consensus in this study that

> stigma often comes from the Black community […] if we have any Black
> friends around, you talk about it [autism characteristics] in a very light way
> because you don't want them to look at you like your child has autism […] we
> take him to his room to protect him against stigmatised attitudes from the
> Black community (CO).

This parent's comment indicated fear of stigma and rejection from the Black

community while protecting themselves and their child from the community's disablist

attitudes. History shows that ignorance, neglect, superstition, and fear are social

factors that have exacerbated isolation of persons with disabilities (Munyi, 2012;

Anthony, 2009).

Parents' experiences of courtesy stigma demonstrate the prevalence of moral

positions of disability (Goodley, 2017). The Black community "don't want to be

167

associated with any sort of disability, whether physical and especially hidden disability' (HO).The belief that disability is contagious is reflected in the community's disablist attitudes: "people act like autism can be contracted and they stop talking to me" (GE); "my child did not have any friends" (FP) so mothers and children are stigmatized and marginalised, thus support similar findings (Munroe et al., 2016; Fox et al., 2017; Selman et al., 2017; Slade, 2014). These attitudes and perceptions about disability are deeply engrained in the culture that it becomes accepted and unquestioned.

Parents compared attitudes towards families of children with disabilities in White and ethnic communities: "I see discrimination as a Black mother, being in a Black community [sic]. Then when I am in the White community, it [having a child with autism] is more accepted, there's more support" (VB). Another parent expressed similar views with the statement that

> stigma comes from the Black community. You are worried about what people are gonna say[…]. You feel much more comfortable talking about it with someone from a background different ethnic group, say a White person, because they have more understanding…there's more understanding of autism within the White people than amongst us ethnic minority groups (CO).

Mothers' marginalised status suggests that their interactions with the dominant culture were with autism trained professionals; autism is more likely to be understood. Comparing attitudes to disability between White and Black groups highlight the small disproportional levels of autism awareness and education in Black communities.

In this study, the role of culture is apparent in parents' experiences of autism (Mshengu, 2019; Shaia et al., 2019; Akbar and Woods, 2020). Black parents and

caregivers carried the cultural views of shame and guilt associated with disability and/or autism in the UK (Papadoulous, 2016a). Cultural perceptions of disability restrict casual, formal communication and education on the topic of disability and autism. A parent stated: "because of the stigma, you don't want to talk about it too much". (CO); "I don't talk about it to anyone anymore" (FA); "I want to protect my child's information as much as possible" (SA). Lack of communication and representation limits the community's exposure to autism and prevents opportunities for education and evolution of cultural beliefs to support Black/African parents in the UK. Autism education, medical information, cultural beliefs and practices in various ecological contexts will raise awareness in Black communities in the UK and abroad. Entrenched traditional and cultural beliefs of disability highlighted the weight of (self) stigma Black parents experience. Educating professionals, practitioners and clinicians of these cultural attitudes towards disability could provide parents with personalised support where they can share their real concerns and experiences to obtain the appropriate support. A parent stated: "health professionals need to understand where the Black community are coming from then they can support us, cultural differences etc." (CO). Limited understanding of cultural differences and influences can create tension and affect the relationship between professionals and parents.

Parents self-isolated for self-preservation and sought for their child's protection against negative attitudes (Hussein et al., 2019; Gorlin et al., 2016; Lutz et al., 2012). A parent explained further that:

> "sometimes it's better to stay on your own in that way you are in your safe space...having a child where no one can see it [the disability] makes it a lot harder and it's annoying to keep explaining it [autism]" (VB).

Cultural perceptions of autism which result in stigma and marginalisation impact parents' psychological wellbeing (Hussein et al., 2019). Constant conflict from public systems or stigma in the form of blaming mothers for their child's maladaptive behaviours have resulted in parents' self-isolation (Hussein, 2019). The structural factors that increased an individual's risk of becoming socially isolated are experiencing discrimination and marginalisation (Visser and Fakiri), having economic and social policies that produce and maintain socioeconomic inequalities (Nicholson, 2012). Cotterell et al. (2018) identified groups and factors susceptible to social isolation: belonging to certain minority groups and becoming a caregiver (Victor et al., 2000; 2012), having language barriers (Miyawaki, 2015; Platt, 2007), spending a significant amount of time alone (Victor et al., 2012) and having limited financial resources (Savikko et al., 2005). Umberson and Montez (2000) reported that individuals who have little contact with friends and family, have poor quality personal relationships or those who experience regular conflict or dysfunction were at an increased risk of social isolation.

The findings from this study show that (self) isolation is one of the main drivers of poor wellbeing primarily because of courtesy stigma. The intersectional factors attributed to the Black experience are amplified through systemic factors and increased their isolation from their community and the wider context due to their child's autism symptomology. Single mothers, in particular, with limited/lack of social support and interactions with others in various social or professional contexts are more likely to live in isolation and experience negative physical and/or psychological effects.

The study's findings showed that these risk factors are intersectional and suggests that Black parents are likely to experience double marginalisation and a double impact of social isolation for the various individual and combined factors.

2. Cultural and Religious perspectives on autism

This sectioned revealed the intersectionality of cultural and religious perspective on autism as a physical/hidden disability.

2.2. Physical / hidden disability

The link between culture and religion is clear in the Black community. In this study, African parents often associated disability with a physical impairment. Schatz et al. (2018) defined disability as 'the consequences of disease that impair body functions and structures, limit activity, and restrict participation' based on the International Classification of Functioning, Disability and Health (ICF). This view is supported by research that focused on physical disability as the medical model of disability in African contexts (van der Heijden et al., 2019; Kelly, 2017); often failed to define disability rather with implicit references to physical impairments (Howell et al., 2019; Biritwum et al., 2016). This one-dimensional perception of disability is also reported in this study: "In Nigeria, the people we consider disabled, you'll have to be in wheelchair or physically challenged. My son will not be classed as disabled. Autism cannot be classed as disability because he doesn't look disabled" (UO). As there are no biological or genetic markers of autism, the condition is diagnosed behaviourally. This inherently cultural view of disability has led parents to experience a cognitive

dissonance; particularly when the Black community's knowledge of disability is unapplicable or untranslatable to their experience of autism.

Parents' comments indicated that the hidden nature of autism created confusion, denial, lack of understanding and social challenges in the wider Black community (Munroe et al., 2016; Bobb, 2019), which increased parents' frustration when people expressed disbelief about the autism diagnosis and suggested that the child's behaviour is a result of lack of discipline (Bobb, 2019; Mshengu, 2019: 52; Burkett et al., 2017: 500). Parents said: "my parents see disability as a physical disability so because my child doesn't fit into that image, they don't see anything wrong with him" (VA); "my son looks normal, you wouldn't know there's anything wrong" (UB). Hussein et al. (2019) also captures this contention between the physical and hidden nature of autism:

> 'My son looks normal, so when people see how he behaves, they think it's just bad parenting ... I swear it would be easier to explain autism if the child looked disabled, but when a child looks normal and can speak – automatically it's the parents' fault' (1412).

Similar comments in this study revealed that autism as a 'hidden disability' (Schieve et al., 2012; Neeley-Barned, 2011) is a challenge for parents to explain and convince others of their child's disability and behaviours. A parent said: "without the behaviour challenges, you won't know she's autistic [and] because my child doesn't look it [autistic], they [my old church] believed she's spoilt" (SA). Another parent (VB) stated that:

> if he had Downs' Syndrome, you'll see it, but just because we don't see autism doesn't mean it's not there…when you look at him, you wouldn't know that he's got autism. No one sees the disability I am constantly justifying and explaining why my child behaves in a particular way. Having a child where no one can see makes it a lot harder and its annoying to explain everything (VB).

Disability as a physical and mental impairment is difficult for the Black community to understand and accept (Bobb, 2019; Akbar and Woods, 2020). These findings highlighted the importance of education and awareness of hidden disabilities, particularly autism and other developmental disabilities to negate monolithic and outdated views of disability as purely physical, eradicate the myth that hidden disabilities are 'foreign' or 'Western' conditions only, and subsequently address autism symptomology and the impact on the individual and family in the Black community.

Unchallenged negative attitudes on autism appear to disable any progression for autism knowledge, education and structural influence in Black communities, which inevitably impact children's early diagnosis, early intervention for autism symptomology and parents' wellbeing (Magaña et al., 2013; Pearson and Meadan, 2018; Burkett et al., 2015; Slade, 2014). Parents' perception of autism showed a tension between their cultural, religious views and acceptance of the autism diagnosis: "with disabilities that people don't see, Africans, specifically Nigerians will say, 'there's nothing wrong with this child, its spiritual, you've just got to pray. It's something that can be healed" (UO). Parents' religious background influenced the lens through which they perceived autism (Jegatheesan, 2010; Akbar and Woods, 2020). Autism's hidden nature prevented parents from acknowledging the long lasting and interconnected effects of delayed interventions that can support their child's development over time. However, parents challenge cultural views of autism when they sought medical explanations and aetiology that explained their child's behaviours and developmental delays for necessary support for their child (Munroe et al., 2016; Burkett, 2015). Parents' different approaches to autism symptomology

varied from a purely cultural, religious or medical view as well as an amalgamation of each belief system. The conflict and/or amalgamation of beliefs is apparent from respondents at a special school in Tanzania which drew on the dominant religions of Christianity and Islam to explain disability, whilst also considering the role of traditional healers (Stone-MacDonald, 2012; Kuper et al., 2015). Additionally, lack of knowledge and awareness of autism led to religious explanations to understand autism symptomology. Thus, illustrated the importance of educating people from Black and ethnic minority groups on autism, its aetiology, available support and most importantly, the impact of autism on parents and the family.

Cultural and religious factors

This section explored the cultural and religious barriers along Lack of awareness of autism in religious organisations.

2.3. Lack of awareness on autism in religious organisations

Autism awareness and knowledge in religious organisations conveyed the link between culture and religion – culture is influenced by religion and vice versa. The hidden nature of autism and cultural perception of disability from a strictly physical lens perpetuates disablist attitudes. In cultural and religious contexts, disability is seen as purely physical and spiritual, marginalising the needs of people with hidden disabilities (Waldock and Forrester, 2020: 13). All parents identified with a religion, with majority of the participants identifying as Christian and one as Muslim. Parents described the support they receive from their faith, a few identified acceptance and understanding of autism at their places of worship and the impact it has had on their

psychological wellbeing (Carter et al., 2016; Turner et al., 2004). However, parents' felt that religious organisations did not understand autism, its impact on the child and on the family (Waldock and Forrester-Jones, 2020; Howell and Pierson, 2010). Parents reported the lack of autism awareness among their religious leaders as they encouraged the congregation and parents to apply religious activities such as "fasting and praying" (VB) as a response to the autism related challenges. This study found the religious leaders' discussed disability as physical illnesses, applied a religious lens towards physical disability, which led to a one size fits all approach and negatively influenced the congregations' perception about autism and other developmental disabilities. The onus and blame were placed on parents and reveal the implications of limited awareness in religious organisations on parents' experiences.

Parents explained that the hierarchical structure of leader and members, typical of religious organisations, meant that congregants are often influenced by the leaders' beliefs and approach to disability. A parent noted: "the congregation do see autism from the demonic side of it. They'll listen to the church leader and not listen to other things like the practical side of it" (VB). Congregants often saw 'spirit possession as synonymous with autism' or that 'autism can be prayed away' (Waldock and Forrester's (2020) ibid), which revealed that religious leaders' theological understanding of disability influence attitudes in religious contexts.

Religious leaders and organisations limited knowledge of autism is depicted further: "I've asked my pastor to alter the service because of noise, tambourines, you have to…if you say you'll finish at a certain time, you have to do that. But just because we don't see autism doesn't mean it's not there" (VB). The parent's request for structure

and attention to sensory needs highlight ways religious organisations could adapt their services to accommodate people with autism. A versatile approach in religious services echoes the social model of disability for society to adjust their attitudes, perceptions, and physical spaces to enable people with autism to function at their maximum potential. Structural changes (trained aides and staff, learning strategies and materials geared toward autism) encourage a more socially inclusive atmosphere and communicates an accepting attitude among the congregants (Howell and Pearson, 2010: 164). This study, among others (Waldock and Forrester, 2020; Carter et al., 2016) showed the importance of autism training in all religious organisations particularly target training for the leaders on how to support parents and children with autism.

Racial stigma

2.4. Racial stigma and autism: parents and children

The intersection of race, ethnicity and autism is clear and important to discuss, not only in research but in organisations that cater for Black and ethnic minority groups. This research gave voice to marginalised parents, particularly women, who live at the intersection of systemic racism, sexism, disablism and classism. Parents' experiences influenced by social stratifications are essential discussion generators and revealed how these categories contribute to their experiences.

The Black experience, or 'minority experience' (Heer et al., 2012) in a predominantly White space is unique. Factors that influenced 'the minority experience' included: language, material disadvantage, discrimination, limited social support, minority group pressures, stigma, and aspects of the migration and acculturation process

(ibid: 957). This research highlights the primacy of race (Gillborn, 2015) to reveal how racism is linked to the minority experience. The link between low social, economic and cultural capital and being part of a minority group supports a structure designed to oppress and marginalise minority ethnic groups at various social and institutional levels. Doharty and Gholami (2020) support this view and state: 'our environments are charged with a hostile racial climate where schools, workplaces and public discourses are rooted in white supremacist, Eurocentric hierarchies that frame people of colour through deficit narratives' and perpetuate cycles of self-fulling prophecies. These White spaces consistently reinforce tension and conflict that socially and culturally disadvantage minoritized groups.

Race has no scientific basis; rather, it is a social construct. Yet, despite this, race and skin colour often determine Black people's experiences and opportunities in society. Racism has a structural basis and is embedded in long standing social policy. Systemic racism makes clear that racism is not simply prejudice and discrimination held by individuals, but is also 'produced and reproduced by laws, practices sanctioned and even implemented by various levels of government, and embedded in the economic system as well as in cultural and societal norms' (Bailey et al., 2017; 2021; Rothstein, 2017).

Racism and acts of discrimination have taken various forms in the UK over the years:

> From the racisms that have surfaced in popular and political discourses on Brexit, to the racisms manifested in the government's 'hostile environment' policy and the racially uneven impact of the coronavirus pandemic, it should be increasingly difficult to deny that racism is an enduring and fundamental problem for our times (Joseph-Salisbury, 2020: 3).

The persistence of lower levels of wellbeing, across different Black and minority ethnic groups, and across the social gradient, depict a relationship between belonging to a minority group and poor wellbeing (Stevenson and Rao, 2014). Parents in this study also highlighted the presence of racism in their 'minority experience' with statements such as:

> Racism is there…it's in every aspect of life. There's an additional problem...going through the system of employment etc in the UK is difficult…there's also the language barriers where we find it hard to understand what is being communicated, coupled with the fact that people feel that because of their colour or race, they don't get the support as White/British people (HO).

Black people are typically absent in White spaces, not expected and therefore marginalised when present (Anderson, 2014: 10). In this study, parents identified racism as common place, described racism they experienced in professional, health and housing spaces. Parents acknowledged race, accent and language (lack of) as characteristics that evince their lack of belonging in White spaces.

Parents' lived and witnessed experiences of rejection, marginalisation and discrimination are directly and indirectly linked to racial stigma insidiously woven in every fabric of the social and institutional systems. Power dynamics are clearly implied from this mother's work experience and indicate a race-related contention and access to social and economic capital.

Racism limits career progression and indicates that Black women experienced gender and race-related restrictions – the combined effects of practices which discriminate based on race and on the basis of sex' (Crenshaw 1989: 149). Therefore, Black mothers can be doubly marginalised in public, social and private spaces and purports the effects of the sum of race and sex.

Anderson (2014) notes that 'while White people usually avoid the Black space, Black people are required to navigate the White space as a condition of their existence' (11). This observation supports parents' comments and examples of experienced racial stigma in various, often professional, and institutional settings that highlighted the social and structural inequalities that inevitably impact Black people and Black parents of children with autism. The statement that "you get used to it, you begin to know your place" and "people with an accent get laughed at" (SA) evince the impact of limited social contact between Black and White people; where stereotypes rule perceptions and behaviours "they behaved as if we were coming to waste their time" (SA), create a situation that estranges Black people and delegate them to second-class citizens (Anderson, 2014: 13). Structural inequalities that perpetuate racial disparities and discrimination result in suboptimal, substandard, and second-rate experiences and limit Black parents' progress in social, professional and occupational contexts. If parents are treated as a 'nuisance', 'coming to waste their [professionals'] time' (SA) they may not be as forthcoming to seek the relevant advice and aid necessary to support their child's developmental needs.

The autism field has been described as a 'White space' with autism represented as White and male (Matthew, 2019), concurrently, there is under-representation, continued under-diagnosis and misdiagnosis of Black people with autism in clinical practice and within public and Black communities (West et al., 2016; Brown et al., 2019; Jones et al., 2020; Durkin et al., 2017). Families of people with autism have limited access to services due to a culmination of factors such as low economic and cultural capital, scarce knowledge of services available and limited professional support (Thomas et al., 2007). Additionally, there have been limited dialogue on the

impact of racial and disability stigma of Black and ethnic minority groups (Jones et al., 2020).

This study acknowledged the importance of racialised experiences and the racial lens parents hold because of treatment they have received as Black individuals and/or as parents of a Black child. This finding is supported by Jones et al.'s (2020) roundtable discussion, where Dr Johnson comments that 'all of our experiences, whether we have autism or not, happen through the lens of race and racism' (2). Therefore, racism itself is inherent in all aspects of Western contexts,

> […] and by failing to recognize its impact on our clinical practice, our research, how we build community with autistic adults, and families who have children with autism, we continue to fall short with ameliorating the consequences of those systems of racism" (ibid).

This research identified the impact and intersection of race and autism on families as well as the child in various contexts: clinical practice, autism research, education, policy and housing. In this study, parents described the discrimination they and their child encountered because of their race/ethnicity. A parent (YV) described a housing related racial experience:

> The man specifically said to me: "the help we are offering you, if you were anywhere else, you'll never get it so just take whatever we are offering you, at least you'll not be on the street with your kids". What he [housing officer] said to me and the way he said it made me realise that if I was a different race, he will never take that approach with me, but because I'm a Black woman, single mother, he just looked down his nose at me.

This mother's belief and confidence that 'if I was a different race, he will never take that approach with me' highlighted the perception of differences in treatment and reinforced their treatment as second-class citizens as "he looked down his nose at me", which indicates professionals' position of superiority and parents' inferior status

and supports the view that "racialised humans' […] existence is always problematised and they are not fully afforded acceptance in Eurocentric dominant societies" (Doharty and Gholami, 2020). Mother's low socio-economic status is implied and played a significant role in the interaction with the housing officer. This is a further example of Black women facing triple discrimination and marginalisation based on race, gender, poverty. It captures the confluence of power and domination and shows how structural inequalities perpetuate harm against Black women who are excluded from social policies and experience triple discrimination.

These experiences support Black people's belief that they are treated differently from the majority. Statements such as "sometimes I see myself as a nuisance" (SA) and the African proverb "you cannot bite the hand that feeds you" (MK) showed the impact of internalised racial stigma where Black women believed the dominant culture's view and attributed the labels to themselves, which have negative psychological impact on their wellbeing. Black parents are systemically taught to feel grateful and there is to be no criticism, no "bit[ing] the hand" of the services that provide for and "feed" them. This blind gratitude reinforces their positioned status in society as second-class citizens in the UK. Mothers' interactions with support services in health, education and housing show how social capital is embedded in 'social structures, which determine the resources available to the network as well as the rules of behaviour governing participation' (Lin, 2001a, b).

Another parent described her observations in the school context which evince race as a dominant and central influence on parents' experiences in systemic contexts:

> There was a time my daughter was banned from the school…she was in reception [mainstream school]. They said the school has zero-tolerance policy on violence when they know she's autistic.

> At the school gates, the headteacher would be greeting everyone, once it's my turn, she would avoid me, when she sees me, she'll turn her back or move from the place…If I was White, I would have been treated with more empathy and respect… Sometimes I see myself as a nuisance (SA).

Race is once more highlighted as the defining factor of parents' experiences in White institutional spaces. Parents notice how professionals treat them during exchanges in 'White' spaces such as school and professional contexts; parents adopt a racialised lens to understand and interpret the different treatment they [and their child] receive in comparison to White parents. This parents' experience showed professionals' resistance and disregard to autism symptomology in school policy and placed the onus on a young Black child to control reflexive reactions to unwanted stimuli. Understandably, a zero-tolerance policy is established, however, in relation to the autism condition, this policy reflects the rigid structures that do not consider the social model of disability to tailor the environment to support the person with the disability; instead, the child is punished by exclusion. Similar to Gillborn (2015), this mother's middle-class status did not aid to mobilise their capital to aid the situation and felt marginalised from the school context.

Racial stigma is extremely embedded in society to the extent that Black children, particularly Black boys are stereotyped and vilified. This racialised lens is transferred to Black children with autism, a parent stated that 'they don't see autism…they see a Black child misbehaving' (VA) because 'Black and Asian people are known to have a behaviour' (VB) is further exemplified and supported by Dr Waisman's comment that 'my doctors never even thought to test me for autism because they were not looking for autism in someone like me. They were looking for behavioral issues. I missed out on resources other autistic kids might have received' (Jones et al., 2020; Tomans et

al., 2020; Begeer et al., 2009). The intersection of gender, autism and racism by stereotyping and discrimination is evident in parents' comment on how professionals in service sectors, and within the education contexts, perceived their Black child with autism.

Parents largely focused on racial and gender discrimination that occurred in education services, which is likely to transfer to other systemic institutions where racism is prevalent, such as the police (Aymer, 2016; Chaney and Robertson, 2013; Anderson, 2014). Gillborn (2015) observes the segregation of Black boys labelled with Behavioural, Emotional and Social Difficulties (BESD) from the main school and often left in the lowest ranked groups and segregated from the mainstream classes. The dominance of race over gender is key as Lindsay, Pather, & Strand (2006) revealed that rates of Black over-representation are especially pronounced in the BESD category and where Black students are more than twice as likely to be labelled as their White peers. Such alarming statistics resonate the significance of institutional racism, demonstrating its early impact on Black boys grouped in the 'lowest sets' which leads to de-motivation, disaffection and resignation (ibid). The BESD labelling of Black boys' conduct resonates with the need to diagnose and label as a 'tool for control of people that the [education system] wanted to exclude from society' (Fernando, 2017: 92). Gillborn's (2015) study acknowledged that Black parents—even middle-class ones – who can mobilize considerable class capitals (both social and economic)—have an incredibly difficult time getting their children's needs recognized and acted upon. In contrast, schools appear much more ready to act on more negative dis/ability labels (281). Black [middle-class] parents' experiences indicated that the needs of the Black child go largely unmet within a system that uses dis/ability labels to recreate, sustain and legitimise racist inequities

(ibid). The fields of dis/ability and SEN appear to be contexts where [Black] pupils are excluded from the potential benefits (of legitimate adjustments and dedicated resources) but remain subject to the disadvantages of low expectations, segregation, and exclusion that affect their educational outcomes (ibid).

These scenarios evidence the intersectionality of power, discrimination and diagnosis/labelling that take place within educational institutions that work to disempower and devalue Black children.

The intersection of race, disability, and class is significant as it highlights the power of racism and structural inequalities over parents' social and economic capital. These anecdotes exemplify the institutional dominance, invisible and discursive policies that exclude and marginalise a particular race. Such power dynamics supported by existing policies offer very little flexibility, freedom and opportunity for those impacted by racism, disablism and gender to overcome crippling labels and subsequent behaviours. Confronting racism requires not only changing individual attitudes but also transforming and dismantling the policies and institutions that underpin the social hierarchy in Western countries (Bailey et al., 2021).

Teachers occupy the frontline of schooling and curricula delivery, often act as mediators between the students and the educational system of proximate senior management and senior leadership (Joseph-Salisbury, 2020). In terms of race and racism, a range of studies have shown that the role of the teacher is vital in shaping the experiences and outcomes of Black and ethnic minority students, irrespective of class background (Gillborn et al., 2012; Maylor et al., 2009). Parents commented on their children's experience of racism from teaching staff, and the lack of support they

184

experience, particularly when White children/ parents are perceived to have different

experiences. Such views are highlighted in the statement:

> They [teachers] think Black boys are naughty. ADHD is naughtiness. Nobody sees this White child misbehaving and say it's down to naughtiness. There is the stereotype that Black kids are naughty. It's in the media a lot, that Black boys are naughty, even children. They think 'oh there he goes with his naughty behaviour, when he grows, he will follow that path'. The teachers are not trained to deal with autism (VA).

Parents recognise racial stereotypes their children, particularly boys, experienced.

Racism is highlighted as a dominant factor that shapes teachers' perceptions and

attitudes towards Black boys with autism symptomology. The intersectionality of

race, gender and disability is a triple disadvantage for Black boys with autism; they

are misunderstood, misrepresented and discriminated against in educational settings

(Gillborn, 2015). Autism as a hidden disability adds to the existing tension of racial

stigma and stereotypes: autistic behaviours reinforce the stereotypes that Black boys

are subject to; therefore, Black children face double discrimination – being Black and

showing autism symptomology (Brown et al., 2017; Dababnah et al., 2021). This

study shows that race demarcates ethnic minorities and are initially judged before

disability is considered; thus, both factors become a double disadvantage.

Most parents expressed dissatisfaction with their child's school experience. They

often blamed teachers' lack of autism training and inability to accommodate for the

child's academic needs: "they leave my child in the sensory room all day. My heart

broke when I found out" (GE); "not all teachers have the training/understanding on

how to deal with children with autism. It's potluck. All the teachers should get the

training" (VA) to provide effective educational support (Ludlow et al., 2012; Aylaz et

el., 2012; MacKintosh et al., 2012). Limited or inconsistent structural policies for

teacher training on specific disabilities harm young people with autism, particularly those affected by intersecting factors that enable triple discrimination in educational contexts.

Clearly, autism identification and support through access to services also have a racial component and impact which limit the quality of care, resources and information children with autism receive (Mandell et al., 2002; Dababnah et al., 2018). Thus, supports the view that the Black experience is an interplay of race and racism, contextual and systemic factors that ought to be recognised in autism related research.

Matthews (2019) further evidences the intersection of race and autism: in a clinical-cultural tautology, autism presents as a White condition because it is sought out as a White condition, which, in turn, reinforces it as a White condition and incentivizes it as a White condition within mainstream media. Racial stereotypes contribute to the clinical-cultural tautology – Black children and parents have limited access to early intervention – due to racism/ structural inequalities, cultural factors, limited economic and social capital – all which contribute their limited social and communication development, and reinforces the experience of perpetual disadvantage and deficit.

The topic of police brutality towards Black boys did not arise in this study, perhaps mainly due to the predominant age range (4-9years) of their children. The increasing number of police brutality of Black boys/adolescents, especially, through racial profiling and stop and search highlights the vulnerable position of Black boys and adolescents with autism who may not identify social cues and communicate adequately to express themselves (Brown et al., 2017; Wallace et al., 2021). Anderson (2014: 14) aptly commented that 'for the Black person, particularly young

males, virtually every public encounter result in a degree of scrutiny that a "normal," White person would certainly not need to endure'. Race and disability intersect to become hypervisible stigmatising identities that inhibit their freedom in society. The following section examined available/limited structural support such as professional, educational and external agencies and their effect on parents' wellbeing.

III.   Systemic factors

This final section discussed the systemic factors that impact the psychological wellbeing of Black parents. In doing so, it explored Public stigma, Structural support and wellbeing, Education services and autism, Financial implication and Respite needed from outside organisations and agencies.

This research recognises the connection between structural racism and racialised disparities in health outcomes, and access to support services by considering complex systemic factors that influence Black experience and psychological wellbeing. By analysing multiple strands within systemic contexts, this research depicts how they can mesh, blur, overlap, and interact in various ways to reveal knowledge of structural inequalities (Gillborn, 2012; Annamma et al., 2013).

2.3.   Public stigma and wellbeing

Public stigma towards autism is often directed at the parent/caregiver, particularly mothers. Parents described public attitudes they experienced and reported that

"when the child doesn't behave, they think the mother has done something wrong, start blaming the mother" (MK) (Neeley-Barnes et al., 2011; Myers et al., 2009; Woodgate et al., 2008). This quote implies the confluence of racism and sexist behaviours during everyday life that creates harmful discriminatory experiences. In this study, parents recalled some of the public's comments and attitudes towards parents '"sort your child out", "you are not disciplining your child properly" (HO). These comments showed that the parents/mothers, were often blamed and held responsible for their child's behaviours. In public settings, parents and children with autism were often marginalised due to their child's behaviours, with the underlying role of double or triple discrimination of race, gender and disability (Papadopulous, 2016b; Chang and Leung, 2020). Wolff (2004) considered the idea that autism is because of poor parenting the most malignant of ideas ever held about this condition. Yet, research identified blame as a prevalent response, from fathers blaming mothers (Gray, 2003) to extended families blaming parents (Myers et al., 2009; Kwon, 2015). Mothers are typically blamed across the various ecological contexts: the public, spouse and extended family, therefore more likely to experience heightened levels of poor psychological health (Wing, 1997; Papadoulous, 2016). Neeley-Barnes et al. (2011) noted that parents from across all ethnic groups shared similar experiences of blame and public stigma. This study's intersectional focus (gender/ race/ethnicity/culture) revealed that although Black parents experienced public blame, disablist attitudes were prevalent in their community and racialised stigma are evidenced by discrimination in various institutional contexts.

Parents' report of disablist stigma in public settings suggested that the public often noticed saw autism behaviours but either did not have adequate knowledge of autism or failed to deduce that the child has a disability. This is partly explained by

the contrast between the absence of apparent physical differences of disability in most children with autism and atypical behaviors (Gray, 20002; Lilley, 2013), therefore because children with autism look like neurotypically developing children, the public expected that they behaved in a typical and age-appropriate way. Hence, this disparity between their children's appearance and behaviour triggered negative public attitudes towards the child and parents (Chang and Leung, 2020).

Gemegah, Hartas and Totsika (2020) highlighted the importance of public contact on shifting attitudes towards with people with autism. Their study identified contact to positively influence attitudes to autism across Black, Asian and White ethnic groups, therefore, the more contact the public have with people with disability, the more likely a gradual change to positive attitudes will occur. Actively including people with hidden disabilities in society through direct and indirect contact can challenge stereotypes, reduce the public's negative attitudes against hidden disabilities in general and prejudice about people with autism, in particular (Gemegah, Hartas and Totsika, 2020; Totsika and Jones, 2017).

2.4. Structural support and wellbeing

This section delineated parents' experiences with (lack of) structural support through their interactions with professionals in public services in Education, Financial implications and housing, Respite and external agencies were discussed to illustrate the link between systemic factors and their influence on parents' psychological wellbeing.

2.5.   Experiences with professionals

For parents, the day their child received an autism diagnosis was a life-changing experience and how professionals inform/communicate the diagnosis to parents is significant. Professional support provide parents with a sense of being understood, support with daily schedules (Ludlow et al., 2011; Sawyer et al., 2010; Stuart and McGrew, 2009) and assistance in dealing with difficult behaviours (Plant and Sanders, 2007). Positive communication of the autism diagnosis begins to establish a positive and beneficial relationship between parents and professionals (Abbot et al., 2013).

However, in this study, parents reported professional scrutiny, blame for their child's diagnosis or primarily focused on their child's developmental deficits (Potter, 2017; Jegatheesan, 2010). A significant number of parents highlighted lack of support from professional agencies, with issues and frustrations ranging from professionals insensitivity and negative focus of autism characteristics during and post the diagnostic assessment process (Avdi, Griffin, and Brough, 2000; Potter, 2017) and notably, limited support after the autism diagnosis (Braiden, Bothwell and Duffy, 2010; Griffith et al., 2012; Osborne and Reed, 2008; Potter, 2017). Mothers recalled that "the doctor told me that my child would never talk, learn and will be like a vegetable forever" (GE) and another stated "when he was diagnosed, they said 'he'll not be able to do a lot of things, like use the toilet, to learn, to understand anything, that it's a life-long disorder. They started supplying diapers in large quantities" (JO). These anecdotes exemplify how multiple forms of inequality and identity inter-relate in systemic contexts. Professionals' inadvertent and desensitised conduct towards mothers and their children with autism clearly impacted mothers' psychological wellbeing. Their actions communicated to Black mothers their subordinance with

limited future possibilities, their attitudes also demonstrated acts of oppression, subtle racism in everyday situations/scenarios that deeply impact parents' experiences of autism and their psychological wellbeing. The clear discrepancy in professionals' attitudes and communication towards Black and White parents of children with autism highlights the underlying institutional racism that negatively shape professionals and parents' relationships (Abbot et al., 2013; Mandell, 2002; Slade, 2014).

Clinicians held negative implicit attitudes toward people from minority backgrounds and influenced the quality of their recommendations (Fernando, 2017). Professionals' interactions with Black mothers revealed power relations and disclose the existence of compound structural oppressions in the interconnectedness of race, class, gender, disability, ethnicity, etc. (Gillborn, 2015). Professionals are more likely to be White, male and middle class (Fernando, 2017); these everyday scenarios describe the confluence of racial, sexist, classist and disablist forces and its harmful impact on mothers' outlook and experience of autism. Absence of Black people in higher echelons of the professions or in positions of some prominence is incredibly important for various reasons, 'not least because they may well be in a good position to understand and even counteract the effects of racism in service provision' (Fernando, 2017: 144), but can act as advocates for parents; make attempts to affect policy that would benefit Black and minority ethnic groups.

Disproportionate power relations and dynamics are clearly depicted in the interaction between White professionals and Black parents. Professionals' whiteness, knowledge and expert status all intersect to embody power and dominance in institutions and in the autism field. Black parents 'already had some concept of

Whiteness and […] distinguish themselves' by means of race as the 'Other' (Fernando, 2017: 42); thus, being viewed 'outside the dominant White majority' (ibid) and their initial limited awareness of autism intersect to create feelings of inferiority. Evidently, the interplay of cultural, religious factors limit autism knowledge and awareness within the Black community and professionals' attitudes are more likely to inhibit parents' confidence and autism education. Professionals' interaction with Black parents reflect 'complex issues of race and culture intersecting with those of class, gender, poverty and so on, but there is little doubt that racism plays a major role' (Fernando, 2017: 93). Professionals' approach and attitudes do not show an overt racial prejudice against Black parents, but rather that racist attitudes are embedded in the pre- and post-diagnostic process: ways that 'insights derived from white knowledge' are considered as fact and final, in the way assessments are carried out that ignore the role of culture and how autism is shaped by cultural factors. For instance, eye contact is a classic feature of autism; Perepa (2019) recognises that the quality and quantity of eye contact is culturally determined. Different cultures hold varying beliefs and attitudes about eye contact between children and adults. It is important for professionals to develop and sustain their understanding of such examples of cultural perceptions of features associated with autism. Including cultural beliefs and practices in systemic contexts is the beginning of inclusive and culturally sensitive practices which can influence the way Black and ethnic minority children/adults are formally diagnosed and responded to after diagnosis.

Parents' experiences indicated that professionals and/or clinicians portrayed a deterministic approach towards the child with autism: they focused on the child's

impairments and reinforced the medical model of disability in their practice, which further disabled the child from accessing available support and interventions. Professionals' approach and attitudes are likely to have impacted their practice to signpost and encourage further interventions and therapies for the child's development and support for parents. Professionals' disablist comments and actions enforces barriers against children's growth and development in ways that would otherwise encourage independent living, social interactions and sense of belonging as supported by the social model of disability (UPIAS, 1975). Professionals' attitudes towards Black parents further disabled and marginalised an already marginalised group at the intersection of race, gender, low social and economic capital.

Russel (2003) suggested that focusing on a child's strengths, aspirations and the realistic opportunities required to achieve these create a more inclusive process in which parents are more involved. Furthermore, by taking an approach compliant with the social model of disability, expectations are discussed between the child, parents and professionals, conflicts are resolved, responsibilities are negotiated and subsequently, parents have a deeper understanding of their child's disability and implications (Hornby, 2015; Russel, 2003). However, in this study, parents were often left alone to navigate an unknown and complex world of professionals, interventions, therapies and services (Potter, 2017). Authoritative guidelines and guidance on how professionals can best communicate a diagnosis of autism has been developed over the years. *Autism in children and young people* (National Institute for Health and Clinical Excellence [NICE], 2011) deals with this area of practice in greater detail and remains relevant for this research. The guidelines states that professionals should:

share the conclusions sensitively, in person and without delay; explain what autism means and how it can affect development and function […]; provide a detailed written report of the assessment; arrange a follow up appointment to take place within 6 weeks.

Although parents' experiences differ in the quality and content they received, professionals did not adhere to these standards and guidelines for sensitivity and indicates desensitization to autism as a life changing condition. Parents' ability to recall the information and behaviour of professionals who communicated their child's autism condition indicates the pain and trauma of their experience. Neely-Barnes' (2011) perception that 'today, professionals in the health, mental health, and education fields would never tell a parent that he or she is the cause of a child's autism' is not supported in this study as parents reported the implicit blame they experienced from health professionals. Despite having received the diagnosis years ago, parents expressed some resentment at their recollection of the professionals' insensitivity (Potter, 2017). Additionally, health professionals offer facts and opinions with none/limited understanding of the parents' background knowledge of autism and the role of culture that impacts parents' understanding and responsiveness. This gap in knowledge may have affected the level of support professional workers and agencies provided to Black parents and their to receive support (Jegatheesan et al., 2010). Abbot, Bernard and Forge (2012) suggested that parental responses and recollections may be reflective of their own emotional reactions; as, 'the bearer of bad news is never going to be popular' (Cunningham, Morgan, and McGucken, 1984). However, parents' clear recollection of professionals' words about their child/ pregnancy was anxiety provoking and had significant lasting emotional impact. On the other hand, it is difficult to ascertain whether parental dissatisfaction is related to the process of diagnosis or the diagnosis itself (Abbot, Bernard and Forge, 2012).

Nevertheless, it is necessary to ensure greater attention and support are afforded to parents' experiences throughout the process: pre diagnosis, diagnosis and post-diagnosis.

Limited professional support from a wide range of systemic structures suggest that parents lack the bridging capital that stems from social, economic and cultural capital. A recurring theme from the definition of social capital is one's group membership to obtain resources. In Western contexts, social capital can be associated with the social construct of race, gender, ableism and socio-economic status which can give or deny access to a set of relationships with others (Bourdieu, 1985; Coleman, 1990) or certain structures/ institutions to pursue shared objectives (Putnam, 1996). Therefore, for Black individuals, particularly single mothers, low social capital is imminent because of limited career and social interaction opportunities, which manifests in low/non-existent bridging capital with professionals. They are unable to 'command scarce resources by virtue of membership in networks or broader social structures' (Portes, 1995) and social and systemic structures have left Black mothers feeling marginalised from 'broader social structures expressed by networks' (Fukuyama, 1999) due to social constructs such as race, gender and lack of social capital (Bourdieu, 1985). The combination of these factors reinforces a cyclical nature where parents are denied access to spaces, so they lack information, practical support and quality of care for their child's needs.

Autism support groups offered parents the bridging social capital to network with parents from varying social demographics (financial status, race and religion) and pursued shared objectives of understanding the autism condition, seeking ways to support their child and sharing experiences that alleviated psychological distress.

Education, information and solidarity available at parent support groups, workshops and training provided parents tangible support and practical applications to manage their child's challenges (Ooi et al., 2016). Hence, parents increased their knowledge and skill in dealing with behavioural issues, other day-to-day concerns and felt empowered to support their child with autism (Barnett et al., 2003). Support and information parents receive from autism communities/ support groups mediate existing internalised stigma and increased their resilience; sense of belonging with peers in the group; sense of power in their ability to come together and advocate on behalf of their children, at the community level and within service systems and agencies.

This study identifies the intersection of race and gender in the mediating effect of autism support groups. It is widely established that mothers are the primary caregivers, and the additional cultural, traditional expectations of Black women highlights the intersectionality of gender, race and culture. As such, it is expected that autism support groups are dominated by women. However, the added racial element for Black women, is worth recognising. Black mothers are likely to experience isolation in predominantly White autism support groups, where the role of cultural, traditional beliefs are unknown, not discussed or marginalised. Despite comparable autism experiences, Black and White mothers are likely to encounter different and some similar familial, contextual and systemic factors of varied gradation that shape their experiences of autism. However, sharing experiences of ethnically diverse parent experiences of autism can provide further insight of how autism impacts parents of different racial identities. This study recognises the

importance of Black racial identity and its catalytic ability to shape experiences, offer

solidarity and empowerment with autism related challenges.

2.6.   Education services and autism

Parents identified three main professional and organised services that impacted their

psychological wellbeing: education, housing and respite. Educational issues

stemmed from difficulty getting an EHC plan; lack of understanding, autism

awareness, training and subsequently support from teachers at school. Parents

recognised the importance of the EHC plan and its purpose to support their child's

needs in the educational, health and care systems. This study identified multiple

factors that influence difficulty in parents' acquisition of EHC plans: lack of support

from local authorities, poverty and parents' lack of knowledge of EHC plans - how to

acquire it and its purpose (Boesley and Crane, 2018: 4-5; Kandeh et al., 2020).

Parents identified that Local Authority's funding has significant impact on parents'

experience in obtaining the EHC plan; most parents commented on difficulties in

acquiring an EHC plan through their Local Authorities (LA) and often resulted to

paying considerably to get the EHC plan themselves (MK); "Parents are paying to

get their child's EHC plan, sometimes for £1,500, I don't have that kind of money."

(YV); "I just got his EHC plan, I got it last year [2019]. I did it myself" (VA). It is

reasonable to expect that an autism diagnosis guarantees the provision of EHC

plans (DfE, 2018), yet parents reported a continual 'fight' to receive eligible support.

Parents' experiences indicate financial struggles to obtain this resource for their

child's development.

This research recognised multiple intersectional factors, systemic and cultural

reasons, that contribute and influence parents' difficulty in acquiring EHC plans for

their children. Blair et al. (2010) and Kandeh et al. (2020) advocate for collaboration among stakeholders as essential for enhancing and encouraging inclusion within Black and minority ethnic communities and their families/carers at every level: from diagnosis, getting an EHC plan, and access to relevant services that will enhance their independence into adulthood (165).

The Children and Families Act, 2014 and Code of Practice brought significant changes to Special Educational Needs and Disability (SEND), placing a greater emphasis on local authorities to promote the active participation of children, young people and their families (Department for Education [DfE], 2015). The SEND code of practice stipulates that a local authority must assess education, health and care (EHC) needs when it considers that it may be necessary for special educational provision to be made for the child or young person in accordance with an EHC plan (ibid: 142). The purpose of an EHC plan is to secure the best possible outcomes for them across education, health and social care and, as they get older, prepare them for adulthood and increased parental collaboration (ibid: 142). Any education, health or care provision required to meet a child/young person's needs related to SEN must be included in the plan (ibid 2015: 43).

Disparities in legal standards, professional practice and parents' lived reality highlighted the complexity of acquiring EHC plans. Local Authorities may lack financial capital to ensure all children in need of EHC plans are appropriately provided for and breakdown in communication between local authorities and parents contribute to children's poor educational, physical and psychological outcomes, which ultimately disadvantages ethnically and economically marginalised groups.

Local Authority and educational structures are systemic factors that contribute to the exclusion of children with autism from social contexts.

The Department of Education (ibid) recognised that 'Autistic Spectrum Disorder [autism] remains the most common primary type of need for pupils with a statement or EHC plan'; 29% of pupils with a statement or EHC plan had this primary type of need in January 2019, showing a one percent increase from January 2018. These statistics show an increase in pupils with EHC plan but highlight a disparity in statistical reports, parents, and children's experiences. The increase in pupils with autism requiring an EHC plan and the number of children obtaining the EHC plan, according to parent reports, suggest the government statistics are ethnically and socio-economically unrepresentative. In this study, parents largely reported the difficulty in obtaining an EHC plan with a high number of parents having to pay for it to support their child's educational, health and care needs.

Parental voice and collaboration as a significant principle of the SEN reform is limited or at worst, lacking, if parents cannot secure an EHC plan from their Local Authority. This study contributes to knowledge by identifying the avenues parents employed to obtain their child's EHC plan, through charities, independent payment or other means. This research identified a gap between standards for good practice and parents' lived experiences and revealed the contributing intersectional factors.

The research findings suggest an unequal and disproportionate distribution of finances and budgets to boroughs/ local authorities. These factors indicate the intersectional factors, often systemic and logistic processes that impact parents' experiences of autism in their Local Authorities (Shaia et al., 2020).

Additionally, according to Grinker et al. (2011), larger and more competent service provisions are in general more likely to exist within communities where there is a relatively greater level of understanding and awareness towards autism, compared to contexts where awareness is lower. Parents' experiences support the statement that "the richer the borough, the easier it is to get an EHC plan...different boroughs work differently (YV). Parents recognised the lack of support and service provision in their boroughs and acknowledge the impact of systemic poverty on their individual lives. Referencing public health data, Black/African American families are less likely to be given access to the same treatments and quality services for their disabled children compared with their White peers (Mandell et al., 2009, Magaña et al., 2012, Burkett et al., 2015).

Limited access to EHC plans is not exclusive to Black children; rather depicts a symptom of more systemic issues accompanied by austerity. SENCOs recognised the impact of reduced funding on Local Authorities but explained how diminishing resources were leading to an increase in applications (Boesley and Crane, 2018). However, The Department of Health reported that in the UK, the percentage of children identified as having special educational needs and disability in state-funded primary schools with an Education, Health and Care plan (EHC Plan) increased from 51.4 per cent (2010) to 57.1 per cent (2018), with 4.2 per cent of Black Caribbean pupils and 1.8 per cent of Indian pupils having a Statement or EHC plan of special educational needs compared to 2.9 per cent of pupils nationally' (DOH, 2018). The discrepancy between ethnic groups demonstrates the higher percentage of White children receiving an EHC plan, compared to Black and Indian children. The obvious difference is the presence of race, demonstrating white privilege compared to the triple disadvantage of race, gender and low social/economic capital, which further

compounds the effects of austerity and systemic issues Black parents, and children encounter daily in institutional contexts and support services. These statistics unmistakably dispute the legal requirements for Local Authorities to ensure the relevant EHC plan provision for children with autism irrelevant of race.

2.7.   Financial implications

Financial implications and difficulties were factors that increasingly contributed to parents' stress and psychological wellbeing. Parents' described the various ways that looking after an SEN child becomes a "full-time job" (HO) and suggests that finances were not the only areas that are depleted over time but also their career, energy, attention and wellbeing.

Parents described various ways they spent more money because of their child's autism condition, house repairs, challenging behaviour that results in destruction, specialised diets and beverages such as genius drop supplement and technology. In comparison, parents of neurotypically developing children are not burdened by such concerns and expenses.

A parent described the psychological effect of limited finances, "the major thing was this stress all the time thinking about money…when money is finishing. You don't have the security when there's no money, but you want your children to have the things they want" (SA). Another parent compared the difference in monthly income "I used to work full time, but I've stopped working because of him…But it has impacted on my finances. Now, it's difficult. Going from £2000 to £400 a month. It's not easy" (VA). The impact on mothers' career, self-esteem and psychological wellbeing is evident:

Autism has impacted on my finances a lot. I studied ACCA. It's just circumstances. I have to look after my son so everything else is just in the back seat. I'm not stupid. I have my qualifications, but I just can't go to work because I have a son with special needs to look after (MK).

The study revealed a steady relationship between financial difficulty and parents' poor emotional/ psychological wellbeing. Mothers reported their decision to resign from full-time work or career opportunities to take care of their child and take them to treatment (Mitchell and Holdt, 2014; Fletcher et al., 2012; Hirsh and Paquin, 2019; Dillenburger et al., 2010). Consequently, fathers became the primary breadwinners for the home, whereas in single parent households, mothers faced the financial strain of providing for the house and nurturing their children simultaneously (Kwon, 2015; Fletcher et al., 2012). One distinct area that single mothers are commonly affected is financial hardship due to limited childcare and inflexible work/career opportunities (Broussard, Joseph, and Thompson, 2012). Research found that single parents were four times (24%) more likely to be in debt and seek debt advise compared to 6% UK households (StepChange Debt Charity, 2020). It is reasonable to presume that within these statistics, there are parents who have been impacted by financial insecurity. The alarming statistic that 69% of those in problem debt suffered from a mental health issue, compared to 53% for those not in problem debt indicated the marked difference in parents' psychological health because of financial problems.

Parents reported that reduced working hours and the associated loss in income are the largest contributing factors to the cost of having a child with autism (Horlin et al., 2014). Subsequently, single mothers reported lower household income (< £25,000 before tax and with hardship levels 'finding it quite difficult') and low quality of life that negatively impacted their psychological wellbeing.

Parents' limitations and restrictions showed the nuanced impact of autism on their physical, financial and psychological wellbeing. These restrictions have led to diminished quality of life for mothers and single mothers' feelings of isolation, financial insecurity and low self-esteem which impact their psychological wellbeing.

2.8.   Respite needed from outside organisations and agencies

Respite from the daily behavioural challenges is a necessary coping strategy and a practical support that would benefit parents' psychological wellbeing (Galpin et al., 2018: 11, 12; Slade, 2014: 17). The demands of caring for their child along with completing the everyday mundane tasks in the home, while attending educational workshops about autism are time consuming and leaves little room for physical and psychological rest. Mothers expressed their need for time away from their child to attend to other responsibilities such as looking after another child (MK) and complete domestic tasks and activities (HO). Lack of time, finances and childcare options lead to frustrations, depression and exhaustion; these factors have culminated to negatively impact parents' psychological wellbeing (Broussard, Joseph and Thompson, 2012; Romney et al., 2020). In this study, parents were unable to secure respite from organisations, which adversely contributed to their physical and psychological wellbeing. Parents commented: "I don't have a childminder. Its only me, me, me, me. When you don't have anybody to support you, it's exhausting" (GE). Another stated:

> I can't get respite. I go to trainings and workshops, parent support groups, complete house chores, there's not a lot of me time. They said I don't qualify for respite because I'm not working…can you believe this? (YV).

Respite provides opportunities for parents' self-care, which is currently lacking in their lives. Lorde (1988), a Black feminist asserts perceives self-care as 'self-preservation, and […] an act of political warfare'. Black women are expected to often fulfil social and patriarchal expectations to look after their spouse, children, extended families. The collectivist nature of the ethnic groups and communities expect individuals, particularly women to shoulder the burdens of others with little concern for their own health and happiness. In addition, navigating racist, disablist and classist world is emotionally challenging and psychologically harmful for Black women. Therefore, opposing these social and gender stereotypes through self-care is a political stance that goes against social and familial conditioning. It is an act of preservation and survival, a constant opposition to the stereotype of the strong Black woman that doesn't need rest and support. Similarly, Tongate (2013) advocates for strategies that integrate self-care into broader cultures of community care. In this way, the personal and the political can work together to support the general wellbeing of all within ethnic communities and in wider society. This study reveals how Black women/ mothers' lives are affected by racism, disability/autism and patriarchy and shows that Black women are less likely to have their human rights protected (Henry, Imafidon and McGarry, 2020).

Our perceptions of the world are framed by our positioning in communities and the wider society (Parker and Roberts in Somekh and Lewin, 2011). These findings demonstrate the disadvantage Black parents and children experience in the general public and within their ethnic communities due to disablist and racist attitudes. Parents reported the complex combination of marginalisation, isolation and resilience that underpinned their psychological wellbeing. The systemic factors explored in this

final section purported the intersectional nature of how social structures impact the psychological wellbeing of parents, particularly mothers of children with autism. The disparity between legal requirements for parents' acquisition of EHC plans through the Local Authority evinced how parent experiences do not reflect the standard practice outlined in government guidelines. Parents' limited job/career opportunities due to their child's constant needs impact their socio-economic status, housing and the quality of life, which inevitably affects their psychological wellbeing. These risk factors within their family structures, context and systemic can either amalgamate to build parents' resilience and/or threaten their wellbeing if practical support such as respite, and additional and timely financial assistance are not provided.

Conclusion

This research gives voice to Black parents within the autism field as majority of previous research have focused on the experiences of White parents. This study recognised that it is by the virtue of participants' marginal status that enabled them to offer an alternate experience of autism from the ones that often permeate race-neutral research and scholarly literature.

A particular strength of this study is the examination of the ubiquitous and intersection of race/ethnicity, culture, socio-economic status, gender, stigma and religion, that shape the 'minority experience' (Heer et al., 2012) and Black parents' experiences. This study considers social capital as relationships between individuals and ecological contexts; and was beyond its scope to consider the way social capital operates among other social stratification system because of the study's methodology and small sample size.

Identity markers intersect with other contextual and systemic factors to create individual and collective social realities. Finally, the study identified gaps in service delivery in education, housing and health provisions to ensure stakeholders and service users are adequately supported.

Society often takes for granted the role mothers play as primary caregivers in the home; due to women's biological traits, women often become responsible for their child's care needs. Their child's autism diagnosis becomes an additional challenge as mothers learn about the condition, attend appointments and begin a lifetime of interactions with professionals and support services.

Existing ethnicity and culture research (Perepa, 2019; Tromans et al., 2020) have identified ways that cultural influence is marginalised in autism research and professional services; depict ethnic differences in diagnoses and systemic factors that disproportionally impact Black and minority ethnic groups (Broder-Fingert et al., 2020). This research contributed to knowledge by bringing marginalised voices to conversations on autism and intersectionality in ecological systems. Mothers' experiences of autism highlighted the dominant role of culture in micro- and exo-systems/contexts. Mothers' poor social, emotional and psychological outcomes stem from cultural beliefs and attitudes towards autism, with contributions from other social and systemic factors.

The double and triple labour Black women experience links with their identities at the intersection of race, gender, disability and class. This study highlighted the Black family system as an institution that implicitly enacts intersecting systems of power and puts Black women/girls at risk; depicts oppression through gender inequality in women's everyday lives. Familial contexts highlight factors that contributed to

parents' poor psychological wellbeing, thus LA's opposition to mothers' respite hours is physically and psychologically destructive. Respite hours ought to be a necessity and fundamental to parent support services that accompanying autism diagnoses.

This study demonstrated the significance of contextual factors. The intersection of cultural, religious beliefs within the community, and racial stigma influence mothers' experiences and psychological wellbeing. The intersectional inverted pyramid (Neville and Mobley, 2001, Fig 2) is aligned with the study's findings and demonstrated the powerful influence of varied social contexts on the individuals' experiences of autism. This study, using the intersectionality paradigm, captured the complexity and interconnectedness of identity and ecological contexts.

Cultural and religious beliefs are fundamental to parents' identity, ability to develop coping strategies and sense of belonging. The inextricable link between culture and religion revealed the limited awareness/training on autism among ethnic communities and religious leaders. These findings respond to the research gap and showed the intersection of the cultural and religious factors that influenced parents' experiences of autism and affected their psychological wellbeing. Policy on autism awareness and training within religious and community contexts would foster understanding and develop practical support. Cultural-sensitivity and training for professionals would develop understanding on culture and influence their practice with Black and minority ethnic parents and children.

The study revealed racism and systemic stigma as the main catalyst in education, professional support, public services, housing contexts that shape parents' experiences. This research underlined the importance of systemic factors, limited

structural support and their impact on individual's psychological wellbeing, particularly Black parents' experiences of double/triple disadvantage: disability and racial stigma, gender.

Unconscious racialize thoughts and behaviours permeate professional roles that contributed to tensions and affected the interaction between professionals and parents. These findings support the view that "environments can become hostile for persons racialized as non-white - that is, climates steeped in racial inequality and racism at interpersonal and institutional levels" (Dhoharty and Gholami, 2020). Evidently, one's environment influences their experiences and outcomes, whether directly or indirectly, knowingly, or unknowingly. Parents, particularly single mothers' confined career options due to limited childcare and their child's specific needs deeply impact their economic and cultural capital and housing choices; their children are negatively impacted by these systemic barriers. Gillborn et al. (2021) note:

> Black students, for example, are more likely to live in economically disadvantaged households, they are more likely to be labelled with certain SEND judgements (especially those that carry the most punitive and negative connotations), they are more likely to attend poorly funded and low attaining schools. These are some of the channels through which systemic racist inequity works in society.

Parents' experiences of systemic inequality filter down to affect their children in the UK. Hence, policies, public and professional services would do well to recognize the intersectional nature of these constructs.

This study examined individual and collective experiences to reveal ways that structural supports and services can develop practices, protocols and procedures that offer a more human-centred approach and less as ticking boxes for statistics. This study utilised the ecological framework to understand parents' experiences.

Individual, familial and wider context and systemic factors were discussed and suggested implications about culturally sensitive training for health professionals, clinicians and support staff, structural support services through anti-racist training for Black communities.

2.9.   Strengths and Limitations

There are strengths and limitations to this study. Key strengths are that this research is among very few studies that have examined Black parents' experiences of autism through an examination of the intersectional paradigm of race, culture, gender and disability.

For the interview, research participants were chosen for specific qualities (Black parents of a child with autism) to ensure valid responses to the research question. This method enabled Black parents, specifically mothers, an often-marginalised group in society, to share their individual experiences and provided depth and insight to their experiences. Thus, in-depth interviews enabled this study to be grounded in parents' experiences. The qualitative design yielded a small number of participants with varying marital status, education, socio-economic status and financial hardship levels, which provided a broad, deep and rich insight to individual, contextual, and systematic factors that shape Black parents' experiences. The study sample was relatively homogenous: predominantly mothers, Christian, African immigrants and offers scope into individual and collective experiences.

There are several limitations considered. One limitation of the present study is that parents reported their children's autism diagnoses and were not confirmed using a standardized diagnostic assessment. The underrepresentation of fathers limits a

much needed and beneficial representation of fathers' experiences (Hastings et al., 2005; Potter, 2017). The methods for participant recruitment limited the sample to parents with access to resources such as the Internet and who were more likely to already be part of a network of autism advocacy and support group, parents who are English speaking and literate limited representation on the challenges of non-English speaking parents (Heer et al., 2015; Akbar and Woods, 2020). Conducting the current research with a stratified sample across the United Kingdom would also shed light on Black parents' experiences in urban, and rural areas of the country, across various socio-economic status, gender and including religious faiths to ensure representation of all different groups. Similarly, recruiting parents from healthcare contexts may have produced various participants from different socio-demographic groups. The purposive, convenience and snowball sampling methods this study employed limit the generalisability of findings.

In this specific and sensitive research on autism, it is important to consider a percent of the population group who met this criterion but refused to partake in the research (Groger, Mayberry and Straker, 1999). The cultural and traditional lens through which Black/Africans perceive disability in general, and autism in particular, meant that some parents denied the autism diagnosis, refused to participate in the research to discuss their child's disability due to the shame of having a child with a disability and finally, the fear of being further marginalised by their ethnic community. We may not learn other factors that contribute to the denial of their child's autism diagnosis, their limited experiences of support services and importantly, their child's (limited) development because of delayed diagnosis and early intervention.

CHAPTER SIX

Conclusion

This research examined Black parents' lived experiences of autism following an intersectional paradigm including culture, race and gender to reveal the interconnectedness of individual experiences and the unseen but ever prevalent force of cultural, racist and disablist attitudes within the structures that surround their lives. The study revealed the ways in which individual, contextual and systemic factors intersect in Black families, shape parents' caregiving roles and influence their psychological wellbeing.

The study's key contribution was to engage in broader discussions on intersectionality, particularly, race, gender and autism and how these complex factors contribute to Black parents health and well-being. The study offered insight on challenges in familial, contextual, and systemic contexts to inform protocol and practice in institutions such as disability organisations, education and health contexts. This study has contributed to a holistic understanding of the Black 'minority' experience, current debates about the marginalisation of Black lives and experiences in autism in Black families.

The findings, examined through intersectional lenses, highlighted the challenges of racism in society and patriarchy on Black mothers and female siblings. Family structures are heavily impacted by autism; mothers' role as the primary caregivers limit family income and impact their psychological wellbeing.

Findings illuminated the double/ triple labour Black women experience: the politics of care for their child with autism, attempts to secure careers and when possible, self-care. In this research, Black parents, predominantly mothers' experiences of autism in the familial, community and institutional contexts shed light on the existing inequalities present on a national and global scale, of various layers, shades and hues, that shape parents' experiences. Mothers' experiences highlight the intersectionality of sexist, patriarchal and racist systems of oppression that show the impact of structural convergence in the field of autism.

Care is associated with rosy images of family warmth, utilitarian, and traditional approaches, particularly in the home; the ethics of care are presumed to be peaceful, harmonious, and fair (Held, 2006). Yet, much of navigating domestic, caregiving life is rather chaotic and self-sacrificing for the women in traditionally and culturally influenced patriarchal homes, the unequal division of labour is clear, and the presence of autism exacerbates life pressures. This study revealed the position of violence against women in the home, as caregivers, without appropriate contextual and structural support. Maladaptive behaviours such as tantrums and aggression symptomatic of the autism condition that mothers experience is tangibly evident of physical domestic violence. Moreover, emotional violence is inconspicuously present as mothers described their self-sacrifice in the demise of their goals, ambitions, careers, and financial independence to care for their child with autism but lead to cyclical patterns of subjugation and constraint in a patriarchal family structure and society.

The intersection of cultural and religious beliefs about autism result in community stigma and prevalent disablist attitudes towards parents and children.

Prejudice and discrimination prevalent in the public support the delay, misdiagnoses of Black children with autism and the lack of community support available and accessible for families of children with autism. The study revealed social, cultural and religious influences on parents' experiences; cultural beliefs about disability and autism emerged as an impediment to autism awareness, education, and contact; the important role of religion on parents' framework on autism, but the lack of support and autism knowledge present in religious organisations. Culture is a growing organism that evolves to accommodate the context and thus, cultural beliefs about disability and autism can be changed overtime through autism education interventions and exposure to people with autism.

Religious practices and beliefs proved invaluable to parents and equipped them with an alternate framework for interpreting their situation and finding meaning in seemingly adverse circumstances (Tarakeshwar and Pargament, 2001). However, parents' religious beliefs and practices contrasted against religious formalities and depicted a complex and conflicting picture of religion and religious support. This tension revealed that religious organisations are on the fringe of social and governmental policy and highlighted potential collaborations between religious and health organisations. Black parents' experiences of stigma highlighted the urgency for autism education and awareness, and exposure to people with autism specifically and disabilities in general.

Government provisions and policy (Care Act, 2014) are available to support parents. However, the consensus among parents that everything is a 'fight' suggests difficult access to available support. Parents were often informed by Local Authority professionals that they do not qualify or meet the eligibility criteria for respite and

care allowances despite facing financial challenges and physical and emotional stress as primary carers. This research revealed an information deficit, communication and access issue for parents and this study posits for the government to address these with Local Authorities, health and education gateways. The lack of public funds in services perpetuate and fuel systemic discrimination and racial stigma as scarcity of resources leads to hierarchic distribution of wealth according to race and gender.

Limited structural supports with health, educational and local authority professionals highlighted the existence of racist, sexist, disablist attitudes in parents' interaction with professionals. Parents experiences of systemic inequalities and discrimination in educational contexts, Local Authority and social services negatively influence parents' psychological wellbeing. Austerity and scarce support are clearly seen in parents' housing conditions; no access to respite hours despite clear eligibility and requests, and lack of clear guidelines about EHC plan acquisitions reveal local authority systems that do not meet individual and family needs. This gap in government standards and parents' experiences revealed the impact of ineffective structural practices on the micro-system and parents' wellbeing.

Often, concepts about systemic factors are associated with the power and elevation of one group and equally, the disempowerment of another. These generic views are accepted without a full and thorough understanding about how individuals are impacted by contextual and systemic factors; fleeting awareness of the salience of systemic/ structural racism reinforces a cycle of knowledge and apathy. This research reveals the marginal experiences of minoritized groups subsequent of racial and disablist stereotypes within systemic forces.

Following the intersectionality theory, this study foregrounds serious issues at the intersection of race and disability that have not been given prominence in research and practice. Parents' experiences bring to light how racism unfairly disadvantages some individuals and communities, but advantages others and affects the daily realities in Black communities or 'people of colour' (Dodgson, 2018). The study showed the intersectional factors that impacted Black parents' experiences, recognised the connection between structural racism and racialised disparities in health outcomes, access to support services and psychological wellbeing.

This research highlighted the marginalised experiences of people living at the intersection of race, gender and disability to deconstruct the multifaceted nature of White privilege in social structures as well as in the autism research field.

Social inequalities evinced a contagion effect that negatively impacted children's educational attainment. The study illustrated the school context as a site that reproduces social inequalities, and the education context as a microcosm of intersectional factors that merge within the wider society. Expectations to narrow the achievement/attainment gap within certain ethnic and disability groups should consider the contextual factors that directly and indirectly influence Black children with autism – lone parent, poverty, immigrant groups and the wider social factors such as 'institutional racism, stereotyping and lack of targeted support are important contextual and systemic factors that play a role in a child's life' (Demie, 2003:243).

There are clear implications for education policy that are beyond the scope of this research; this study posits that public health of Black parents and children with autism will continue to fall short of appropriate support services if policy and practitioners ignore the multifaceted ways in which structural racism, as a societal

epidemic, plays a dominant role in the wider community. This study calls for a racialised justice project that seeks to take a holistic perspective to support marginalised individuals vulnerable to double/triple discrimination.

In theory, the existing Equality Act (2010) seeks to provide space and advocate for people living at the fringe of society. The Act prohibits both direct discrimination (s. 13 Equality Act 2010) and indirect discrimination (s. 19 Equality Act 2010) on the grounds of race, gender, disability. The public sector equality duty (s. 149 Equality Act 2010) requires public bodies to identify and eliminate unlawful discrimination, advance equality of opportunity and foster good relations between groups. Whilst these legal acts give the impression of equality and equity, the lived experiences of Black people showed sharply opposing narratives that nullify its presence and intended effect. The onus is on 'public bodies to identify and eliminate discrimination', yet the Act fails to consider the possibility that unlawful discrimination stems from such public bodies and systems through existing policies and legal frameworks. There have been reports of significant barriers to enforcing individual rights under the Equality Act: public sector bodies, including regulator and inspectorates, have shown a lack of knowledge of their duties, discrimination that affect disabled people in housing, transport, and access to the public setting (High Commission, HC, 1470, 2019). Thus, reveals lack of accountability and overseers for public bodies that have delegated power, authority, and control over the lives of marginalised individuals in society, particularly when minorities are under-represented in such positions of power. This study revealed ways that systems and structures within the Local Authority, health and education fail to abide by the Equality Act, and advocates for legal/policy protection for multiply minoritized groups.

216

Tensions that result from prejudice and discrimination between professionals and the Black community are often ignored and further widens the gap between theory, policy and practice.

This study revealed an unsettling disconnect between government standards and implemented practices in structural contexts and institutional policies. The legal requirement for Local Authorities to provide EHC plans for children with special education needs and appropriate housing for parents are unaccommodated. Such incongruity reveals a hostile environment and highlights how parents are neglected, particularly parents who are not familiar with their legal rights to obtain a free EHC plan for their child. The social inequalities that exist for disability and racially marginalised groups impact on parents' psychological wellbeing, and demonstrated the inextricable link between social, economic, and cultural capital and mental health. Consequently, majority of the parents commented on limited systematic support, which indicates a vacuum in service provision, co-ordination of services for families and immediate assistance for parents in need of emotional, psychological and practical support. This study calls for the introduction of services where parents' knowledge and experience of autism are perceived holistically to support their psychological wellbeing, which will enable appropriate and personalised care for their child. Like the integrated education, health and care service provisions for the child with autism, parents, particularly mothers, would benefit from cohesive systematic support for them to experience a seamless, needs-led service.

This study raises the importance of establishing dialogue and partnerships between support services (e.g., Local Authorities, autism support groups, general practitioners, autism parent education and training, religious organisations) to foster trust and a sense of security for parents to share their experiences. Targeted support

for parents on housing, financial issues, and respite hours can positively impact their psychological wellbeing.

The recent Black Lives Matter protests worldwide sparked by the increasing murders of Black men in the US (George Floyd, Michael Brown, Eric Garner, Tamir Rice) and the UK (Anthony Walker, Stephen Lawrence, Christopher Alder, Sean Rigg, Kingsley Burrell, Simeon Francis) to name a few, show the precarious nature of Black lives, particularly Black men in public and under police authority. The Coronavirus pandemic highlighted ways that racialised inequality affect the multiply minoritized groups and resulted in disproportionate mortality rates among Black and ethnic minority groups. This disease has 'laid bare and uncovered those who are particularly vulnerable from zero-hours contracts, low pay, poor housing and inequality in health' (Joint committee of Human Rights, 2020; Haque et al., 2020; Public Health England, 2020). The pandemic has shone light on the harsh circumstances that Black and ethnic minorities live in, particularly in housing conditions and quality of life that belie the civility of a Western context. Such proximate associations of Blackness, mortality and trauma are palpable and tangible within the study. Public and community stigma against Black families of children with autism highlight the double stigma the families and children contend with in public spaces because of stereotypes associated with their race and the notion that autism symptoms affirm 'Blackness'. This study has contributed to National debates about Black lives by bringing forward explicit conversations about public and structural racism in mainstream discourse in public health along with education, local authorities, and policy.

6.1. Implications for future research

Recommendations for further research were based on the need to further examine the experience of Black/African parents. Additional phenomenological studies including more gender-balanced participants should be conducted. The dearth of literature on the experiences of fathers of children with autism highlighted the need for male inclusivity from the diagnosis process to their lived experiences with autism (Potter, 2017). This study made a first step in autism research by including Black father's experience of autism, though a disproportionately small number in comparison to mothers, their voices and experiences are valid and included. Future research would benefit from gleaning from Black fathers and their experiences of their child's autism. This study advocated for the importance and necessity of autism education, specifically for fathers, immediately after their child has been diagnosed and equally, more support for mothers as they are often the main caregiver for their child with autism (Nealy et al., 2012; Pepperell et al., 2016).

Mothers extended their care and attention to their children and their spouses, if married, yet there raises the question of 'who cares for the carer'? This study revealed the significance of self-care and respite on parents' psychological wellbeing as a coping strategy. It is important to examine the role of self-care on parents' psychological wellbeing as previous studies show that primary caregivers neglect their own health and need intervention (Brehaut et al., 2004; Hunt, 2003; Walker et al., 2011). Participants valued their caregiving role as mothers (Held, 2005: 42). The dual purpose and impact of care as evinced in this study show mothers' altruism –

219

their value as caregivers is practically and morally indispensable (Mahowald, 2009). This study attests to this truth but posits that women/mothers' caregiving role ought not be taken for granted. Legal rights and policy for mothers of children with autism should consider the labour imposed on women by the virtue of biology and stereotypes to consciously aim to improve their lives (Michaeli, 2017: 53). The political nature of care was glaring in this study where women are subject to home and child-care responsibilities, with little to no time for self-care. The Care Act (2014) gives Local Authority the responsibility to promote individuals' wellbeing, however, a conspicuous few: 'suitability of living accommodation', 'social and economic wellbeing', 'physical, emotional and psychological wellbeing' are absent in parents' experiences with their local authorities. The dearth of literature following Black lives in the field of autism related to the siblings of Black persons with autism. It is important, therefore, to examine the experiences of Black siblings of persons with autism, with a particular focus on the intersection of race, gender, and socio-economic status.

This study showed the psychological effects of racial and disablist stigma parents have experienced; it is important to examine the impact of counselling for parents focusing on racial stigma and autism; employ personnel from Black and ethnic minority communities who can incorporate their knowledge and personal experience of intersectionality in counselling sessions.

Research on Black people/adults diagnosed with autism and/or who believe they have autism can examine and identify the contextual and systematic barriers that influence their experience for an autism diagnosis and their life experiences.

As faith, religious activities and spirituality contributed to parents' positive psychological wellbeing, there is need for further training on autism among religious organisation for parents to receive the appropriate support and understanding from religious leaders and congregants (Waldock and Forrester-Jones, 2020; Carter et al., 2016; Ekas et al., 2009). It is worthwhile for the government to commission a mixed methods study that examines policies in different institutions and the structural barriers present that inhibit accessibility in education, health, and housing. For instance, examine local authority policies to understand why Black parents and children with autism are living in poor quality government housing. This would begin to address the impact of multifaceted inequalities and evaluate how to target each sinew and strand of disadvantage from a structural lens.

6.2.   Implications of findings for practice and policy

The pervasive presence of structural racism is well embedded in various health, education, police and government institutions that autism, like other disabilities, often has a White face. Social campaigns and research have marginalised Black children and adults who have autism and perpetuates the myth that Black people cannot be on the autism spectrum. To demystify these myths, and offer appropriate support, the Department of Health should:

- Develop evidence base and culturally sensitive training for health professionals, clinicians and support staff to identify autism characteristics for early diagnosis, not to merely look for behavioural issues that delay autism diagnosis (Mandell et al., 2002; Perepa, 2019).

- Increase training on how to communicate the autism diagnosis sensitively, without a dominant focus on its limitations can help build rapport between parents and clinicians (Crane et al., 2018; Jegatheesan, 2012).

- Collaborate with local authorities to raise awareness and understanding of autism among Black/African communities. It is important to specifically target this population because of differing cultural and specific needs. The wide range of cultures that amalgamate under the BAME term makes it difficult to practically 'consult families from BAME backgrounds about their needs' (Slade, 2014). Furthermore, provide appropriate support for contact between persons with autism and the public.

- Establish a training course for parents after diagnosis that highlights the medical explanations for autism while acknowledging biological, environmental causes to alleviate self-stigma. Such training should also include cultural perspectives of autism/disability for parents to feel understood and included in 'White spaces'. For such training to be effective, it is important to 'employ personnel from the Black community – people who can actually relate' to the cultural experience of disability/autism (Jones et al., 2020: 3).

- Establish annual training for professionals and clinicians to identify unconscious racial biases in their practice. The increasing presence of Black people in the UK means that a 'one size fits all approach' is no longer fitting or exemplify best practice, therefore Black parents and children with autism ought to receive personalised care that reflects knowledge of their cultural and ethnic background. Research shows that culturally competent health providers, professionals and clinicians provide better quality of care and make parents feel safe to divulge real concerns (Zuckerman et al., 2014).

Counselling interventions with Black parents can combine knowledge of cultural and traditional factors that can prepare parents for existing public and ethnic community stigma, thus lay the foundations for emotional and psychological resilience.

- Provide guidance for local authorities on how best to commission autism support services that support Black parents' ethnic, cultural and informational needs. Examples are commissioning leaflets on autism that recognise and include cultural perspectives but offer interventions that encourage a practical lens/ aetiology for parents' acceptance.

- Provide further streamlined support services when parents require EHC plans from the local authorities to avoid parent payments.

- Offer training to other institutions such as the police and schools on the behaviours of people with autism, especially under stress: 'may become uncommunicative or nonverbal under stress' (Jones et al., 2020; Brown et al., 2017). Education and training on the intersection of race, gender and disability is also important as Black men with disability/ autistic traits such as Elijah McClain are more likely to be killed by the police (Thompson, 2020; Cramer, 2020)

- Offer guidance and training for parents on how to talk about child sexual abuse (Kenny, Crocco and Long, 2020). To raise awareness and highlight the increasing possibility of abuse on children with autism, consistent, appropriate and relevant messages and resources for children with autism and their parents should be a standard in Educational, health and care sectors.

- Establish a clear criterion to readily support parents who clearly meet the government requirements for respite. Respite hours ought not to be a struggle

to attain for the child and the parent. Clear organisational links to be formed between care agencies and parents so respite is part of the care plan.

- Implement mental health interventions and support services at grassroot and community levels to mediate the mental health of Black people, particularly Black women. It would be an advantage to establish a wellbeing service that can offer more specific and tailored service for parents with autistic children/young people. Counselling may support and maintain Black parents' marriages as they navigate social, contextual and systemic factors that influence their individual experiences and of autism. A whole family therapy/counselling can encourage family effort, understanding and contribution for positive coping techniques and wellbeing.

- Strategically target Black communities to increase autism education and contact. This study supports the recommendation for families of children with autism to be 'supported to access public and social spaces and increase visibility and contact with the public in the hope this may lead to positive social attitudes' (Gemegah et al., 2020). Particularly, within Black and Asian communities as autism knowledge was found to contribute to attitudes within these communities (ibid).

- Evaluate existing race focused initiatives by Government and the NHS including mental health support, especially for Black women, to implement policy change to support Black mothers at the intersection of culture, disability and religion.

- Government and autism research to examine what avenues parents take to acquire an EHC plan, whether through the local authorities, charities or other means. If parents are resorting to other means to obtain an EHC plan, it is

important to determine the factors that prevent/hinder parents and local authorities from fulfilling this legal requirement.

- Government policy for collaboration and partnership between the Department of Health and religious organisations to offer training, autism knowledge and contact among the congregants and religious leaders.

- Promote training in all health, educational, religious and support services informed by current research to continually develop professionals' practice to ensure open access policy that can identify parents who may be having a difficult time with services, depression, anxiety and fear.

- Government initiatives should pay close attention to established organisations that ensure oversight and implement actions following consultations between Clinical Commissioning Groups (CCG's) and All-Party Parliamentary Groups (APPG's) that cater for parents by considering the intersectional factors contributing to their wellbeing through a whole systems partnership approach.

Overall Summary

This study examined Black parents' experiences of their child's autism diagnosis using an intersectional approach in various ecological contexts. This research revealed the prevalence of structural racism within systemic contexts, disablist attitudes against families living with autism and the various factors that negatively impacted parents' psychological wellbeing. These factors showed the complex, dynamic and iterative relationship between individual, contextual and systemic factors. Disability organisations, parent support groups, academics and professionals would benefit from these findings on Black experiences in various ecological

contexts and the key factors that influence their psychological wellbeing. This study's research contributes to literature on Black lives, parents' experiences of children with autism to begin to include the views and experiences of multiply minoritized groups for policy change and professionals' practices.

APPENDICES

Appendix A – Face sheet /Demographics questionnaire

Initials: Date:
Place of interview: Time:
Code:

This conversation will be recorded to allow insight and analysis of inflections, tone and nuances to responses.

Part 1: Questions about your history

A. Before your child was diagnosed with autism (ASD, etc) were you aware of the condition?
  ☐ Yes
  ☐ No

B. Select the generation that best applies to you:
  ☐ 1st generation – you were born in another country
  ☐ 2nd generation – you were born in the UK; either parent born your country of origin
  ☐ 3rd generation – you were born in the UK, both parents born in the UK and all grandparents born in your country of origin
  ☐ 4th generation – you and your parents and one other grandparent born in the UK and at least one grandparent born in your country of origin
  ☐ 5th generation – you, your parents and grandparents born in the UK

B (i) If you are 1st generation, how many years have you lived in the UK?
Please tick the box that applies to you. If you are not 1st generation, please skip to the next question.
  ☐ 1-5 years
  ☐ 6-10 years
  ☐ 11-15years
  ☐ 16-20years
  ☐ 21years or more

Part 2: Questions about you

C. What is your gender?
  ☐ Male
  ☐ Female
  ☐ Other _____
  ☐ Rather not say

D. What is your age group?

- ☐ 18 – 29
- ☐ 30 – 39
- ☐ 40– 49
- ☐ 50 – 59
- ☐ Over 60

E. What is your ethnic origin?

- ☐ Asian or Asian British – Bangladeshi
- ☐ Asian or Asian British – Indian
- ☐ Asian or Asian British – Pakistani
- ☐ Asian or Asian British – Other Asian Background
- ☐ Black or Black British – African
- ☐ Black or Black British – Caribbean
- ☐ Black or Black British – Other Black Background
- ☐ Mixed – White and Asian
- ☐ Mixed – White and Black African
- ☐ Mixed – White and Black Caribbean

F. What is your religion? Please select ONE.

- ☐ None
- ☐ Christian (including Church of England, Catholic, Protestant, and all other Christian denominations)
- ☐ Buddhist
- ☐ Hindu
- ☐ Jewish
- ☐ Muslim
- ☐ Sikh
- ☐ Other (Please specify) _____

G. What is your highest level of educational completion? Please select ONE.

- ☐ GCSE Level education or equivalent (e.g. CSE, GCSE, O-Levels or Entry Level, Foundation Diploma)
- ☐ A-Level education or equivalent (e.g. A, AS, S-Levels, Highers)
- ☐ Undergraduate education (eg University examinations but not completed degree)
- ☐ Degree or Graduate education (eg BSc, BA)
- ☐ Post-graduate education (eg PhD, MSc, MA)
- ☐ Vocational education (eg NVQ, HNC, HND)
- ☐ Foreign qualifications
- ☐ No qualifications

H. What was your total household income before taxes during the past 12 months?

- ☐ Less than £25,000

- ☐ £25,000 to £34,999
- ☐ £35,000 to £49,999
- ☐ £50,000 to £74,999
- ☐ £75,000 to £99,999
- ☐ £100,000 to £149,999
- ☐ £150,000 or more

I. How well would you say you [and your husband/wife/partner] are managing financially these days? Please select ONE. Would you say you are ...
- ☐ Finding it very difficult?
- ☐ Finding it quite difficult?
- ☐ Just about getting by?
- ☐ Doing alright?
- ☐ Living comfortably?

I understand your child has been given a diagnosis of (ASD/autism).

- What age was your child diagnosed?
- Had you heard of autism at the time? If yes, how? If no, why not?
- How many years have you lived in the UK?
- What did you think of your child's diagnosis before your child's diagnosis?
- Briefly describe your experience of autism/your child's diagnosis, so far?

Culture

1. Are you still connected to your cultural background? E.g. do you still speak your mother tongue/ language?

1a. Do these views influence how you see and manage your child?

1b. How do people from where you come from see autism/disability?

Religion

2. Are you religious? If yes, what religion do you identify with?

2a. How does your religious values help you to deal with challenging and stressful situations?

2b. Have you relied on your religious beliefs and values to understand your child's diagnosis? How have you found this approach? What are the positive and negative aspects of this approach, if any?

2c. How have your religious organisations been supportive of you?

Acculturation ASD

3. Do you accept your child's diagnosis (ASD, autism, etc.)?

3a. How did/do your family, extended family and friends respond to the child's diagnosis?

3b. What are the common views of your child's diagnosis within your community?

3c. How do these views influence how you deal/manage with your child's diagnosis?

Acculturation

4.   Do you feel like you belong in the UK? What is the most important and/ or positive (and negative) aspect of living in the UK? Explain.

4a. Has being in the UK changed your views of autism? If so, how has this change influenced your thoughts, behaviour and experiences?

4b. Do you think your experiences will be better or worse in your home country? Why?

Systemic factors - public perceptions and treatment (stigma: UK wider society and BME)

5.   Have you've been treated differently because of your ethnicity/race? Where did this take place?

5b. How do you cope with these challenges? Could you give one example of this?

5a. Now, think of your experiences with your ASD child. What challenges do you experience as a BME parent of a child with autism in the UK and within your ethnic community? Have you or your child been treated differently because of his/her diagnosis/ behaviour? Where did this take place?

5c. Does your economic status affect your parenting especially having a child with additional needs?

5d. Does where you currently are financially affect the way your think and feel?

Internalised stigma and wellbeing.

6.   I'd like you to reflect on your experience since your child's diagnosis, do you think you are coping well with being a BME parent of an ASD child in the UK? If no, what do you think could help you to cope better in your situation?

6a. Describe the emotions you feel when you think of yourself in relation to your ASD child.

6b. How would you describe yourself as a parent of an ASD child?

6c. How would you describe your child's impact on you and your family?

These semi- structured questions were created as a result of consensus in the literature review of BME experiences in the UK and their experiences as an ASD child in the BME community.

PARTICIPANT INFORMATION SHEET
Version 1.0, 15/01/18

Study Title: Intersectional approach to Black parents' experience of autism in the UK

Investigator(s): **Eli Gemegah**

Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

(Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study)

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

PART 1

What is the study about?

The aim of the study is to explore your experiences as a parent of a child with autism. This study is particularly interested in capturing your views as a person from the Black community. We would like to know whether you believe your experiences of your child's autism diagnosis are because of your cultural beliefs, the UK culture, racial stigma and the BME community around you in the UK. For this, we will be asking participants to fill out an online survey that looks at your mental wellbeing, your experiences of racism, if any, whether you are religious, if you use religion to cope and how you have adjusted to life in the different areas of life in the UK. You can also choose to take part in the interview to explore some of their experiences in further detail.

Do I have to take part?

It is entirely up to you to decide. If you choose to participate, we will ask you to tick a consent form to confirm that you have agreed to take part. The study is in two parts: an online survey and face to face or telephone interview, and we will not ask you to sign your name on the consent form. We will not ask you for any personal or identifiable information. If you agree to participate, start the survey and later change your mind you are free to stop at any time. If you agree to participate, complete the survey, and later change your mind, we will not be able to identify your data to remove from the survey. If you choose to no longer take part in the interviews, you can inform the supervisor at the main organisation or inform the researcher/ interviewer.

Isolated situations: people will tell you to sort your child out. I avoid places that he shouldn't go. I plan ahead to not see much of problems. People make comments: 'sort your child out', 'sort that behaviour out' 'you should know better', 'you are not disciplining your child properly'. However, in my case, my child is severely autistic and he doesn't talk so people see the SEN. But families whose child can talk, they find it more difficult because people see them as 'normal' so they get more labels like 'bad parenting', 'you don't train your child well' or the child is behaving like that beavuse of your of own bad parenting', but my child is non-verbal and its easy to see his challenges more than other child who can talk.
I found a way to solve it. I plan where I go, what time I should go, what things to have ie place, or maybe I don't take him out to the parks, or take him early in the morning before people start coming. When I used to take him at normal times, people started taking their children away from the sand pit, from my son. They saw a black boy throwing the sand in his shoes so parents take them out, even the kids start moving away.
Coped well as a black parent?
Hannah: I wouldn't brag, I've done my best, I've tried my best, Ive set the parent group..
Teaching other parents how to accept the condition, give factual information about what autism is..the child has complex needs..some parents think that schools, therapists, professionals are a magic wand, their kids will change and improve and when you go through all the recommended training etc and the kids don't improve, the frustration that comes is what I help with. The progress comes but it takes time.
How has your child impacted your family?
As much as we are struggling, we will help others. We see things in different ways. My child, though still non-verbal, can see that we are trying our best for him. We are ready to plan the future for him. My daughter wanting to do something in medicine/nursing has been influenced by my son's condition.

Hannah
A lot of men run away. We have to make our own community. Always best to think 'how best can we do this'. Im happy that I got myself busy. We will surely come out the other end.

Affects your finances too.. parents are not able to work full time because they have a full time job as a parent with of an ASD child. Autism condition and its impact on the family is expensive – buying additional things for your child to support them, sensory toys..etc.

Venessa
V: I had heard of autism, a family friend was diagnosed with autism. steven wilkshire, rain man – what I thought of autism. My name is Khan.
Before my child's diagnosis, I didn't think of autism because it didn't affect me
V: my experience has been traumatic - before and after. thought that when the child got the diagnosis, everything will change for the child...[include their behaviours etc]. but the diagnosis is just saying what the behaviour is. Once your child has been diagnosed, there is zero support / tolerance outside the professional assessor, etc.

V: I was born here. I've been brought up like an English child... I am black but I don't know what culture means to me because of how my family grew up. I sit on the fence and see from the black perspective the discrimination as a black mother [of an ASD child], being in a black community, then when I am in a white community, it [having a child with autism] is more accepted...more support. In the wider Black community, I get more support from the African community than the Caribbean community. although autism in Africa has been associated with witchcraft 'juju' and demons. Leaders in the church – ministers and evangelists – have been supportive. The congregation do see autism from the demonic side of it. It takes the leaders to change it, so if the people at the top [leaders] say what needs to be said, it'll filter our [to the congregation]. But if we [the congregation] are told that we've got to pray and fast about autism, they'll listen to that and not listen to other things [practical

[handwritten margin: UK public stigma / practical coping / Psyche wellbeing / social / financial / imagination and...]

[handwritten: Support from religious organisations, relevant religion provides support to AIO challenges & parents' wellbeing. However, there is tension between religious organisations vs practical]

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side]. My experience of the African leaders [in the church] is more acceptable but then there are parents who say they'll take their child back to Africa or the Caribbean Islands. There's a lot of ignorance – any culture – but the Jamaican community think the child is 'sick' or they want to 'fix it' [autism]... they are sick, mentally ill, they see it as a mental illness, not a condition. There still needs to be education on what a condition, illness and sickness. Its about the language in our community. anything that don't look right, they will not accept it.
We need more black and autism people to speak about the condition and their experience – so we can start hearing their voices then we realise they exist – but I find that in the Black and Asian community, autistic people are not seen or heard about. Autism people

V: when it comes to the white community, they have the same problems as us with autism, but the difference between the white and black community is that we face discrimination anyway. so when the public see a [autistic symptom] behaviour, they won't see autism, because of the screening and the diagnostic tools they see a black child misbehaving. black and Asian people are known to have a behaviour. A lot of resources are geared more to the white community – publication, conferences, forums is more white-led. There's lack of representation from our community – if English is your second language and you've got an accent, already you've got a barrier – if you can speak the language and the British accent, then you can fit in, you are more likely to be accepted in the White community and autism organisations. When you come from another country and English is not your first language, then you do struggle..you don't understand the English way of living... you deal with the cultural breakdowns, the taboos, the myths, stigmas so when you are in a white led autism group, you won't talk about certain things that affect you at home, in your ethnic community. These things get missed or an not talked about in a White led autism group/organisation. In some African cultures, we eat with our fingers with certain foods, yes they [white people] eat their fish and chips like that too, but how would we identify if the child has sensory needs if we eat with our hands..or a muslim child not wearing the hijab...is it because of the textures...so we need more people from different communities sharing the struggles different people face.

I go to church..it has given me the patience, wisdom and understanding to deal with the challenges..ive asked my pastor to alter the service because of noise, tambourines, if you say you'll finish at a certain time, you have to do that. My pastor tells me that once you are born again, you are a new creature, old things has passed away..the church question why they should change..Its like someone in a wheelchair, you won't tell them to stand up from the wheel chair, you have to adapt the environment for them. we have to alter the way of thinking..its the same with autism. but just because we don't see autism doesn't mean its not there. We have to change the environment to accommodate people. If someone is born without a limb, is the limb going to grow out? Or a blind person without a socket, come up
V: my religious beliefs have kept me calm. Having a relationship with God has helped me to keep calm and grounded. I manage by God's grace. You can't say your church is inclusive and you still don't see disability in the church..some churches and religious organisations are choosing to see disability as a physical disability rather than hidden. There needs to be a lot of challenges to change perspectives about autism. the church encourage parents to pray and fast. my child has learnt how to fit in. he's learned how to deal with it.
I accepted my child's diagnosis from the moment he got it. I knew that there was something wrong, something different. If he had down syndrome, you'll see it. Accept the child's disability and build on your relationship..and the love for your child will come. If you going to church and want to fix everything...
My family doesn't think there's anything wrong with my son. she thinks it's my parenting skills. stigma
I get my support from the autistic community – especially parents of a child with autism...that's my community. people [the public] haven't accepted my children so I have to make sure that the people around them understand them...we have to make our own community so our children feel safe. If you try to fit in with your family and friends who don't

10

[handwritten margin: Systemic racial discrimination within thicker down / Church AND autistic hub]

Hannah
Hannah: I didn't know about autism before my child's diagnosis. I hadn't heard of it before. Even though I had been in the UK for a while, I didn't know what autism was. Also, although I grew up in Ghana, we were never taught about autism. when the paediatrican told us he has autism, its like your whole world comes crashing down in front of you. You start to think 'what is it?' and the added factor that its not curable was another blow ...a lifelong disability. My first question was: 'is he going to be able to live an independent life?' that was 17years ago.
Ghanaian culture views autism, awareness of autism is only just picking up but the cultural barriers to disability and autism is still very present. Because autism is not a physical disability so they [Ghanaians] are more in denial. Also, the stigma attached to a special need is the biggest thing. parents don't want that at all. They don't want to be associated with any sort of disability, whether physical and especially hidden disability. People see it as 'having a problem in their family'. Parents don't want their children associated a child with SEN. Parents can even take their child out of the school. Lack of awareness and understanding influences these decisions, parents believe autism is contagious and would not want their child near others when autism. Also, Ghanaian parents don't want their child to copy/imitate negative behaviour/ bad manners.

Experiences since child's diagnosis
denial state, takes a while to accept it, then sadness comes in and you begin to ask yourself 'why' after, you start thinking of how to support your child. it affects the whole family. My child has severe autism and challenging behaviour. its very difficult. What helped me was I was willing to find out more, learn more and see how to help my child to develop. That willingness helped me to have a lot of training. The denial and stigma wasn't a problem for me. I went over it very quickly. I wasn't shy of my son trying to strip or hold people, taking their food in the street. I tried to go over it very quickly.

How does it impact the family?
Everyday life is already stressful. Go to work, do your house chores and then when you have a child with severe special needs, you do an extra job. You care for them, bath them they might be destroying the house...its an extra work on top of it. The stress is already high. If you don't have special needs nurseries or special needs after school club, you can leave your child with family members because they'll [child] will be destroying their stuff. So it affects your work. when they go on holidays you are stuck, you have to care for your child, you become a carer. It affects your finances. extended families blame each other. When you have another child, you cant spend much time with them because all your attention goes, on the SEN child. The other children suffer if you have other kids. The frustration of why me', why are we going through all this' and the stress of dealing with life. it's a whole' combination of things. If you work hard to attach and come together as a family to handle it, it makes the family can break down under the pressure.

How do you cope?
Hannah: we are Christians. I study from the bible and how God looks after us and protects us in difficult times. In my hard times as a mum, I was the main carer, there are times when we need that inner strength so I prayed and cried to God to give me that inner strength was my biggest support. I read the bible a lot and there are many verses in the scriptures that God will not leave you. Psalm 55. Throw my problems on God. So doing things like that gave me that inner strength. Apart from that, being able to go to a lot of lectures and trainings to understand special needs more for me to be able to open a SEN school in ghana. I was more focused on solving the problem than just crying over it and finding ways to tackle all the various needs, communication, behaviour, sensory etc. I work a lot with research teams. It's not easy. Parents work very hard. It's difficult but we are holding it in. any problems that come, we try to find a solution to it. I have my own parent support group also.

7

[handwritten margin: Parents deal when the nature of autism, community & societal attitudes to autism / Accumulation to ASD / resilience / systemic factors / wellbeing / impact on wellbeing / Resilience – parental effort, family effort / psychology coping / practical coping / waiting, meaning / strong cultural values beliefs / evasion & coping]

Accepted the child's diagnosis.
Hannah: acceptance is the key. Then you are not in denial anymore and you don't mind the stigma you face and say in the community/public. You are ready to take the responsibility to try and help your child and of looking after your child. You are the only one that can help them, they look up to you. You are the parent, you brought them into the world. So acceptance is the key. That's when you start the journey
Accept diagnosis
Hannah: the UK has made a big difference. The UK is one of the leading research on autism. so you are not stigmatised. They even look after special needs kids very well. They have a lot of resources, look after them very well, create a nice environment...we should give them the best because they are special.
This experience has shown me a lot, its shown me patience..it has taught me a lot. My husband says that he will not exchange our son for anything in the world. We have just fallen in love him. It's a different life that you fall into it. I'm more tolerant, understanding, and have resilient. Out of all the problems, we come out a different, better person. But you, the parent, have to make it the better way. If you think negatively, you struggle more. If you think positively you are able to tackle the problem then to move on. Although, everyone has had or gone through depression because of the diagnosis. Changing your mindset is the key. After this, you identify the problem, then how you are going to tackle the problem. For instance, I have a special needs person in the family, our lives are not going to be the same as other families, so I should be happy Birthday, with my life, let see how we can create, as a family, a supportive, accepting and inclusive environment for our child. A parent's love is a parent's love. The family is like a jigsaw puzzle.. the child with special needs also has role in the family too.
Community in the UK
Some of the people have..a number of them don't understand autism and won't tolerate it my child is ripping or destroying their house. I take my child to those who are more tolerable.
Belonging in the UK
if live in the UK but I'm Ghanaian. Although ive lived in the UK for a long time (25years now) so im both. I feel more strongly Ghanaian. I eat our food, I feel so part of my culture.
The most important bit about living in the UK is that there is more awareness and support in schools for the child. The child's diagnosis is much quicker, here a SEN setting, therapies and EHC plan. They have the system in place here in the UK – it's one of the best systems. However, there's not a lot of practical help and support in the home. For instance, back home (Ghana) you can have a house help or extended family to help you with the household chores..here it is difficult. Respite care for my child would be great, sometimes you don't have the time to do the mundane everyday tasks of cleaning, washing, etc when I have to

The UK has helped me to change the way I see autism. if I was in ghana, I would not have had so much information, learn more and go to classes and workshops, therapies. What is autism, macation, the signing, different charities, reading materials, shows . information is more available here in the UK.

ME: Treated differently because of ethnicit?
Racism is there. its every aspect of life. its just how you deal with it. I always had a good relationship with my child's school. I know some people who have been treated differently, not receiving the support because of the ethnic background. There's an additional problem. going through the system of employment etc in the UK is difficult. there's also the language barrier where some people find it hard to understand what is being communicated, coupled with the fact that people feel that because of their colour or race, they don't get the support as White/British people. There are a whole lot of factors contribute to parents' experiences. However, there's still a lot of help, choose the best way to get the help. It is better than nothing. better than Africa.

8

[handwritten: strengthening identity – I feel more strongly Ghanaian / positive thinking / resilience / making meaning / point / system / support / reframing identity / barriers / Gratitude / Do BAME make meaning from autism & their presence in the UK!]

Page 13 (top panel)

to be nice/average. For you to really succeed in high positions, you must also really fit in..be like them socially.

When my daughter was in mainstream school, I really felt like I was treated differently because of my race/ethnicity...my knowledge of autism was very limited and they did not make it easy for me...they made apparent that my daughter was not wanted. There was a time my child was banned from the school...I felt so terrible, as a mother. So many meetings with the school..When I went at uni, I was called many times about her behaviour and I would have to leave uni to go and get her. They made it very difficult. For instance, my headteacher didn't know my child's name...they just focused on getting her out...they don't have the child's interest. They were counting the cost...complaining that it's so expensive to maintain her in the school but the school was spending more than that...costing too much to her if I was white. I would have been treated with more empathy and respect. At the school gates, the headteacher would be greeting everyone, once its my turn, she would avoid me, when she sees me, she'll turn her back or move from the place. Sometimes I see myself as a nuisance. I am just trying to fight for her interest. *[margin: Racism]*

It just happens, its not about you, its how we have done. Whatever the situation, there are worse people. *[margin: No self esteem / worse people]*
Impact of autism on finances etc.
I can't do what I want to do, I can't do it because of your child's care needs. You are qualified for the jobs available but having a child with additional needs means...the consequences of the...or when I find work, I have to work according to my husband's schedule. I wanted to work but because of my child's needs, I didn't want to tell anyone about my child's condition, which limited what help I can get, who I could tell for childminding and of course my finance. The strain was very difficult: financial, socially, emotionally. Managing different things to suit my childcare schedule...working at particular times to suit my schedule. *[margin: Financial & mental wellbeing]*

The major thing was this stress, at the time thinking about money...when money is finishing...you don't have the security when there's no money. The frustrating thing is you know there is work but you can't do it because of your child's care needs. You are qualified for the jobs available but having a child with additional needs experiences.]
Parents/ mothers want to provide children with the positive childhood experiences.]

Parent
Striving – I'll do anything to support her to the best of my ability. Because of the progress she has made, time since diagnosis, my professional training, interactions with others, now I'm in a place where I'm more grateful than anything. Im grateful for the progress she has made, I feel im doing everything that I can do. Its not my fault, its not her fault. I didn't start the progress like that. At some point, I was very low, is it my fault, what have I done wrong. Especially among blacks, the expectations we have for our children and parents can be so rigid and inconsiderate. *[margin: self stigma; coping, invisible progress, gratitude]*

Impact of autism:
Challenging, siblings may not understand
I don't want to go to church sometimes when my child can be distracting.

CO – caregiver   *[margin: Non verbal]*
We didn't know child's condition at autism. as a black family, we attached it [his behaviour] to cultural and religious issues...he's not talking because of possession... being stubborn...we believed that he would get better at some point. we believed that we had to pray really hard for him to get better. When he got diagnosed, we handled it differently. Because im a healthcare assistant so Ive worked with people with autism so it was easier for

me handle the diagnosis. I wont say that I accepted it but I was able to manage the diagnosis practically..this is what is it..lets find find ways to support him. My parents found it really difficult to accept the diagnosis..they are yet to accept. Once you get the diagnosis, you learn new ways to support him, understand him better...before we didn't understand what was going on..looking to professional help and support available for him.

Behaviour is the most challenging part. Extreme behaviour.
Different understanding of autism – more knowledge, more exposed to autism, parents don't have much knowledge – big conflict between parents' knowledge of autism and siblings who is a caregiver. Parents are not as exposed – still hold cultural beliefs of disability.

Education after diagnosis – understand
There's stigma attached to autism/disability. Health professionals diagnosis of autism..we said okay, that's what we were suspecting so we were now able to talk about it openly. Regardless of the report we believe he will get better...
Health professionals to understand where the black community are coming from they can support us, cultural differences etc. if they don't understand then they can just see it as the black community not accepting support. You would think he was a normal kid who was very stubborn, aggressive. There's nothing we didn't do to calm him behaviour, friends, family and colleagues recommend ways to stop child being hyperactive – we even googled it...its not directly from health professionals

Stigma – there's this thing that you want your child to be perfect, you don't want anything to be wrong...you don't want to take your child to family gatherings because they'll be misbehaving. You don't want to tag your child as having a disability..you don't want to mention it, talk about it or you keep it to yourself or within the family.
Stigma comes from Black community...you are worried about what people are gonna say... *[margin: Shame & stigma / self-stigma; parents don't want to cause shame of disability; culture influences]*

Plan every activity to be within his comfort...putting him first in any plan. Give him the life that every child will be...a part of us now, we can't change things. We have been able to manage it...
The hardest part is acceptance. When you accept it, you are more conscious of your child's differences. It reminds you more of what you are dealing with. One condition...it gets real. When you are at home, you are comfortable, everything is fine. In emergencies, Nobody can look after him. *[margin: acceptance, trigger, awareness & realness, coping]*
The major stress is not understanding the non-verbal cues. There are times when you think you know your child, you have everything under control, ive got all the tricks, I know what to do...but there are times when they just cry and you don't know what to do, you don't know why they are crying. frustration when you don't know what to do or how to calm him.
Visitor's response to child – you don't tell people my child has autism, the only time we say that word [autism] is unless the child has very extreme behaviours. When people come to the house, we don't let him be around the environment too much...we take him away to his room. We don't tell people exactly what's going on. Subconsciously, that stigma kicks in ...if we have any black friends is around, you talk about it in a very light way because you don't want them to look at you like your child has autism, you don't explain properly whats going on...you just say 'just be careful, he might hit your face', they just assume everybody is normal. They say, 'hello how are you, say thank you', that pressure is there, that stigma kicks in ...they expect him to be normal...but you feel much more comfortable talking about it with someone from a background different ethnic group, say a white person, because they feel they have more understanding. (There's more understanding of autism within the White people than amongst us ethnic minority groups. We have less information and less exposure. *[margin: stigma in African community, self stigma, shame]*

[handwritten: Systematic? comparisons to royal Black community — Not exposed to hidden disability, Assumption, not understanding]

[page number] 13

Page 11 (middle panel)

understand, then you'll always feel stressed. If my children are around people who don't accept the diagnosis, they'll be fed negative information that they can't filter out. Other parents with an autistic child become your support, I feel the stress of doing everything on my own, cooking, cleaning, washing..if you have autistic children, just be prepared to do all the work..i just smile it off. It's hard. It's hard work. Girls are harder to raise up. *[margin: Psychological wellbeing]*
I have to be very vocal when it comes to autism. There's always going to be a language barrier with black and Asian parents. People think my child's behaviours are because of my parenting skills and that's when I see people treating me differently – *[margin: UK Public stigma]*

Coping:
I feel lonely because I don't meet a lot of Black parents who will come out to share their experience so I'm on my own. Our community are way behind.
I'm a fighter. I'm always fighting for them [parents and children with autism]. I'm always fighting because our community don't want to accept autism. I have to constantly be their voice...until the autistic people in our community start speaking for themselves, I feel the responsibility to fight for them.
I feel drained. I am constantly justifying and explaining why my child behaves in a particular way. sometimes its better to stay on your own than having you are in your safe space, having a child where no one can see makes it a lot harder and its annoying. *[margin: hide disability]*

Sade *[margin: Verbal]*
My experience has been difficult and challenging...mostly because of the child's behaviour. I feel so limited in what I can do. I cant just go to certain social spaces...I have to think if she's going to fit in, is she going to cope? Also childcare, I cant take her to anybody...these are all limitations and its really difficult.
I have made up my mind that I will make the best out of my education, having that mentality and attitude is what keeps me going. With all the condition of things, I won't get anything done. I have to maintain that positive attitude. It keeps motivating me. Persistence is what matters...things will get better *[margin: emotional coping]*
As a mother, you can't give up on your child, you have to believe that things will get better. Being a mother, you know that you have to be responsible for your own child. You have to bear in mind that your child is finding things difficult as well..when you think your child is giving you a having a hard time, she's having a hard time as well. Many people don't know what you go through as a parent of an autistic child..someone can just say I want to go to the shop and dress up their child..its so easy like that..for some of us, it's not..its a whole different ball game. Its not easy like that. Sometimes it gets better. (draw from your own inner strength)
Supportive family - sister – educated (medical field) so she advises me, just having someone to talk to helps.
So many people don't know and understand when they are not in that situation. Without the behaviour challenges...you won't know she's autistic...most of the time, people don't know what's going on behind the scenes. Sometimes, you don't want to bother people what you are going through, its not worth to say about your child. When you don't open about what's going on, people will not help you, people will not know how to help you, I believe that if you are not in the situation, you cannot really know or understand. In our community, they'll think she's a spoilt child they don't discipline her with a firm hand. And because my child doesn't look it [autistic], they believe [my old church] she's a spoilt. Of course, I won't come out to say to people [strangers] that my child is autistic. The first time I told someone was when I needed childcare.. I had to open up and the childminder was surprised. The childminder said 'I thought she's spoilt', now she understands, and may have a change of mind based on that information. I believe it was necessary for me to tell the childminder. I would only tell someone if it was absolutely necessary. I want to protect my child's information as much as possible. I don't want anyone to feel sorry for me, everyone has their own issues. If you are close to me, I don't have to say anything, you will know...

[margin: shame & stigma in the African Black community — African community stigma is due to hidden disability, autism is an invisible disability]

[page number] 11

Page 12 (middle panel, right)

Accepting diagnosis took me time. Initially I wouldn't accept it..she went mainstream school, it was a big struggle...but when the school advised me to send her to a special school when she was going from nursery to reception, I wouldn't accept it. I thought she would get better. It was a big issue/deal between myself and the school. I was doing everything to make sure she was behaving, help her to fit in and academically. I wouldn't accept that my child needed to go to a special school. Finally, it dawned on me that I wasn't getting any support from the school, it was affecting me, every aspect of my life – 2/3 hrs everyday working with my child, going to meetings at school, they would call me to come and pick her up. I couldn't work...you always stress that the school would call you about her behaviour. It was difficult. The mainstream school made it very stressful for me. The treatment I received from the school was not helpful, it dawned on me that they were not willing to help (the child was supposed to get one to one support from the school, she wasn't getting it anymore). It was like they wanted to kick her out... she was not accepted in the school. I was fighting for her to fit in the school, to be accepted but what the school was doing was glaring that they didn't want her...she was not getting the best education. Its her behaviour that's a problem but it's not her ability. I realised she wasn't making progress, I accepted she needed to go to a special school. Now I don't worry that she will be not be accepted or that I will be called. My aim is to get the best out of her – my values, parenting styles *[margin: Systemic]*

Now I see life like whatever life brings your way, don't result to feeling sorry for your self, just make the best out of it. Things happen that you can't help so you have to keep living. Stress from school during nursing degree, child's challenges with school can also bring strain on marriages. As Africans, it's the mother we will carry the load of child care etc. All my life in Nigeria, I've never heard anything about autism, there is no knowledge about it. I didn't believe and accept it when my child was diagnosed. The stages of denial, resentment/anger, acceptance – face reality etc. I still believe that God is a healer but I am ready to accept any help – information, disability allowance *[margin: resilience; UK Acculturation? gratitude]*

Systemic issues –
Bias – as a black person, I feel like they [white people] undermine your intelligence, your value, before saying anything, they place you. For example, when we wanted to get our mortgage, they thought we were playing around, they never took us seriously. The way they look at you, the way they behaved as if we were coming to waste their time. They looked irritated. I think they didn't like we could afford to get a mortgage. My husband and I even asked ourselves whether they didn't dress well...we were even told 'don't waste my time, what questions are you asking me?) *[margin: racial stigma]*
I think because we are black, they thought we were poor, we didn't appear to be of the standard of someone who'll get a mortgage.
During my nursing degree, the race demarcation was more glaring. When you enter a room, you know your place and your place is among your people. Black people who have an accent get laughed at, is what it is. Initially you question whether you can change this situation but eventually you accept that this is the situation. You get used to the racist behaviours and attitudes and you no longer see it as a challenge or an issue...you make the best out of the situation. You begin to know your place and you know what to expect. You adjust to the system - if you are black you know you won't get far in some things. *[margin: racism; racial]*
In my place of work, there is a certain level that a black person doesn't get to...the feeling that they believe you are not capable. Racism is there...very real but there's nothing we can do about it. I feel a sense of isolation when I am in a group and I am the only black person...like there's no one for me.
Retrained from banking to nursing when relocated *[margin: Resilience]*
Coping
I ignore any bias thoughts and attitudes about me and better in everything I do...achieve in life to prove any racist thoughts/attitudes wrong. For us [black] to get to high positions, aspire to a high position, you must be really good, exceptionally but for them, they just need

[page number] 12

Page 15 (bottom panel, left)

understanding about the condition. Blacks – africans predominantly and specifically but also afro-Caribbean's. *[margin: self-stigma]*

Naturally, it's not a proud thing to say that my child has autism, we africans, its very difficult to say my child has this condition, my child is disabled. In this society, western society has normalised disability, but within the African community it is hard to open up and say my child has disability. If it is with in a professional, you can talk about disability deeply, but with a normal person, you talk about it lightly, you say that he's aggressive or he plays aggressively, because you are aware that within our community, there's stigma, they'll be talking about you. Africans link everything to religion, to culture, they'll say you need to take him to church. They can even take you back to the stage you overcame. We are now aware of the support [practical] support the child needs due to the information and education we have received. We still believe that he can get better. But when people don't have the understanding, they can take you back to square one. Take him to Nigeria for prayers to change him...they can see that he's possessed, if your child is not talking its not considered normal. Because of the stigma, you don't want to talk about it too much. It's upsetting. They make comments, they trace it to family hereditary. *[margin: African community]*

Still pray for him: what do you pray for?

Pray for improvement when taking practical strategies such as short stories – pray for him to understand, listen and improve with the strategies being introduced. As Christians, we pray, we cant take it out of us. It's a part of us. It does help to pray. You are not praying for a cure..but you are praying for progress, positive things. These are the sort of things we prayed for: dressing himself, eats well, using the toilet properly. We are not praying for a cure to happen overnight. We pray for progress and the process. Pray for him to grasp what we are doing/ telling him. Positive beliefs that some things are going to change. You can't just pray and not do anything practically. Everything has to be practical with him. *[margin: religious / spiritual; Practical coping & Religious coping]*

We enjoy everyday as it comes. We try not to think of the long term because it's too scary. We enjoy the moment as it is, dealing with the situation now makes it more manageable. We were not able to go on holiday for a while because we were always thinking if he will cope with the changes, what will happen at the hotel? Will he sit in the plane? But now we just deal with things [his behaviour challenges] as they come.
There have been some limitations – for example, when going to family gatherings, one family member has to stay at home – not everyone understands his behaviour, he can run into the street, he wants to explore everything..thinking of that and the stress, sometimes you just rather stay at home. But recently, we've just thought we can't let him stop us from doing what we want to do. Just let him live and it reduces our stress. Recently, he's improved so we are happy. *[margin: resilience / emotional coping]*

Belong in the UK.
Positive aspect of living in the UK: more opportunities, jobs/employment. Actions show that they don't want to be around you or include you. *[margin: UK acculturation gratitude]*

I didn't know what autism was until I came to the UK. There was no knowledge/information of autism in Africa, those in Nigeria who may know of autism have travelled outside. As a healthcare assistant, I gained more knowledge and training about autism. *[margin: racial stigma]*
Here learning difficulties have a name, diagnosis, gain support etc.
Nobody wants to hear that their child has a medical condition. Before my child was diagnosed, we attached it, regarded it, its my belief and I can't take it away. Being exposed to autism information and being educated about it that's when I understand what's going on about autism. education doesn't change my belief but it develops my understanding. *[margin: stigma]*

Coping well.

Page 15 (bottom panel, right)

Siblings are caregivers – they look after him, they play with him, although he can be aggressive.

FP *[margin: Verbal]*
Child is now 21years
I had heard of autism – friends' children and children in my child's school.
Experience has been challenging.
Child was stuck- hypoxia
The child was diagnosed at 2years. Behaviour was extreme, challenging, we didn't understand his behaviour.

I stopped working fulltime – got carers and disability allowance, was introduced to charities that supported us financially. I thought it was because he got stuck. I didn't blame anybody, not even myself. I wasn't sad, I didn't know what can do. I thought it was going to temporary. I didn't think his diagnosis would cause a big school. I got respite care. *[margin: Not self-stigma]*
I went for every appointment. I wanted to get all the help there is. I was not shy to get help. Because I wasn't working full time, I used all my time and attention for my child.

I didn't even want my child to go to special school...went to the tribunal and was advised to go to a special school. *[margin: Special release]*
I wondered that the child was so smart and mentally inclined...drums and cello. They were all [music] – I dimension between speech and what making. He one taught my child how to play drums, he's a special drummer here in the band. He's now leading his life as a DJ, he's also doing performing arts in schools. But he's got learning difficulty. He can do a lot by himself. His disability – I put a lot of effort, I went to meetings, I was a member of a carers group and I registered all my children as young carers, these young carers group helped them, this charity helped the whole family. As a parent, I have to identify what my child needs to help them. When he goes out, some children thought he would hurt them. My child did not have friends, only other children like him. He has no sense of awareness, pushing and kicking people. There were a lot of challenges, but I took it as my challenge to be and fight to make him better for him. It was tough but I had to manage. There was a lot of help 20 years ago, not now. *[margin: Practical coping; Public stigma; resilience, voice to child welfare]*
I included my child in everything we did as a family. We all took part [activities]. naomi a lot, because she's the youngest. He hurt her a lot. He can kick you, slap you etc. The cello calmed him down. Isaac has left the house 3 times.

I socialise with other parents who have a child with autism. I help a lot of them. Now I sort of form myself. When my child was diagnosed, when I look back and see my child's challenges I'm so happy. The government has to know that we know more [about our children] then the psychologists, social workers, teachers. They don't want to listen to parents. Everything I do is for my child to be happy in life. *[margin: Gratitude; making meaning as a mother]*
My husband doesn't know anything about it about Isaac. Everything about the children, I do it. Mothers mould and nurture their children. It takes a mother's eye to take care of her children...for the children to turn out well.
Sometimes I cry when I think about how much he's grown and how far he has come in life. He has grown nicely. Isaac cannot go anywhere else apart from college.

What has helped you to cope?
My faith. I keep on moving and striving to make things better - prayer
Impact.
A united family.
My son is a very wonderful boy.

[handwritten bottom: Diagnosis, understanding, 5 stages of information, financial coping, self...]

Support? Perception of child

Marginalisation from own community
I stay away from my community... I don't go to parties.
I don't get involved in my community. The mentality ... about autism... be even on meds. It is isolating.
I feel lonely because I don't need a lot of black parents ...
will come out to share their experience so I'm on my own.
I'm always judging because our community don't want to accept autism.
Especially among blacks, the expectations we have for our children and ... parents can be so rigid and I'm ...
The stigma comes from [the] Black community... you are worried about what people are going to say.
You feel more comfortable talking about it with someone from ... ethnic group. Stay a white person because you feel they have more understanding... there's more understanding of autism within the white people than parents ...
When black people see their child, they treat ... like autism can be concealed... like their kids can also have autism.

Autism community support
I relate more with people who have a child with autism. I don't mind talking him to an autism group where everyone understands what is going on with my child.
I get my support from the autistic community especially parents of a child with autism... that's my community.
We have to make our own community so our children feel safe.
I socialise with other parents who have a child with autism. Helps a lot of them.
My experience and knowledge of autism has helped me to support others in a similar situation. I have become a counsellor for other people.
I don't go to places where their children don't have autism.
I get encouraged more when I speak to other parents who have an autistic child. They give me ... when they tell me where their child was before and where their child is now. Their experiences encourage me to ...

He's a blessing. My child is a blessing.

Complex perception of autism — Not included in memes – include?

Positive / Negative
I'm doing a damn good job. My life changed per me ...
Good it ... for giving ... I had what taught me not to ...
me this child... to keep me ... anything you ... in their ... grounded
... to be patient, learnt to be ...
I won't replace him for anyone eg. taught me to be a ...
He's my special child. It's been ... before ...
My experience has taught me the diagnosis ...
parent, I'm more tolerant.
Understanding and more resilient. Positive – I have a wonderful ...
We came out a different ... can in his own right. His ...
person.
– My son is a very wonderful boy. Negative – a thorn in my ...
– Coping well. a lifetime problem. It is ...
– I have learnt to be flexible, more Positive – Having him is ...
adaptable and more patient. ...
– I believe there is a purpose to ...

Hope
My son's condition I believe that
God is using me to help so many
families because of my own experience
Tell people that your child's condition
is not the end of the world

Parents' fears: Is he going to be able to live an ...
when I think about his future... who is his future ...
he too late? Is he going to get married?
We try not to think of the long term because it is ...
scary.
– How will my son live in this world? I think of the ...
will happen when I'm not here.
– Child being hurt especially as non-verbal.
I will not allow him to go to residential home ...
ally when he doesn't talk. He's vulnerable to all ...
place. You can't trust anyone because he's not ...

Internalised gratitude – parents are told to be grateful

Opportunity

Genuine gratitude – UK offers good facilities & support for their children
Gratitude: This country is a million times better than where I come from. I am grateful they are working on our kids where I come from, the facilities are not there.
The UK have a lot resources. They even look after special needs kids very well. You are not stigmatised (pe child's sch).
Information is more available here in the UK – what is autism, education, the signing, different charities, reading materials, shows.
Pg 8 Return – It's better than nothing. Back home Africa.
Pg 13 I'm grateful for the progress she has made.
More opportunities, jobs/employment.
When I look back and see my child's progress, I am so ...
My family has benefited from the facilities, help & support available.
The awareness, education.

Impact on siblings/family → Financial impact too
My younger brother ... – child caring & financing it too ...
It affects the whole family. When you have another child, you can't spend much time with them because all your attention goes on the SEN child. The other children suffer.
My daughter wanting to do ... in medicine/nursing has been influenced by my son's condition.
Challenging for siblings, they may not understand.
Siblings become caregivers/carers.
A united family
The whole family is chipping in so because of how we are coping well.
Siblings are influenced by their brother's condition – their career routes – eg. educational psychologist, and ... they could be a result of his condition.
Pg 18 They are united. The other twin is very protective.
eg. The younger one doesn't want any ...

Coping: all

New Findings: Resilience
Example: I studied ACCA. It's just circumstances ...
I have to look after my son to everything else in ... in the back seat. I have my qualifications but I ... can't go to work because I have a child with ... needs to look after. Sacrifice/ ... retention

Marginalisation from own community P 21: I decided ...
I stay away ... it affects ... stop going ... unwilling to support ...
It affects your finances. I decided to take myself ...
A lot of men are away. Help my son to live ...
Parents are not able to work full time because the ...
a full time job as a parent of an ASD child.
Autism condition is expensive – buying additional ...
your child to support them e.g. sensory toys, ...
damage cost.
– Managing different things at work to suit my child...
– I'm the only ... that has to stay home, look after ...
child, bear the consequences when I find work ...
to work according to my husband's schedule.
– The strain was very difficult, financially, social ...
emotionally.
– I could't work... you always stress that the sch...
would call you about her behaviour.
– As a mum, I am the mother who will carry the la...
childcare etc.
– The major thing was his dress all the time ...
about money. When money is ... you don't ...
the security when there's no money. The frustration ...
is you know there is none but you can't do it ...
of your child's care needs. You are gauged ...
job available but having a child with additional ...
– I stopped working full time – got carers and ...
because I wasn't ... working full time, I used all my time ...
my child.

(third image — largely illegible handwritten notes)

237

Culture & Stigma

HO: The stigma attached to a special needs in Ghanaian culture is the biggest thing... parents don't want their child at all. They don't want to be associated with any sort of disability whatsoever, emotional and especially hidden disability. People see it as bringing a problem on their family.

I live here but I'm Ghanaian. Although I've lived here for a long time (23yrs now) so I'm both. I feel more strongly Ghanaian. I feel so part of my culture - both our cultures.

Sab P11: In our community they'll think she's a cursed child. "They don't discipline her with a firm hand."

Eve pt: All my life in Nigeria, I've never heard anything about autism. There's no knowledge about it.

CO P13: We didn't know child's condition as autism. As a black family, we attached it (his behaviour) to cultural and religious issues. He's not talking, or he's being stubborn.

I didn't know what autism was until I came to the UK. There's no knowledge / ignorance of autism in Africa. Here in Nigeria, whoever you know of autism have received outside the country.

Akum pg 18: Called someone told us was our son is in a way that... that's spoke for you. My husband would not take my children to Africa because of my son's diagnosis. He said they would laugh at him.

Autism is not rampant/known in my country. They will say "this is a special child because he's from Europe." In Nigeria, they tell you to go to church.

HO pg 19 19 [Africa] Nigeria: I've never heard or seen anyone with autism... with a disability that people don't see. Nigerians will say "there's nothing wrong with this child. Its opinion, you've just got to pray. Its something that can be healed.

pg 19: In Nigeria, the people we consider disabled, you'll have to be in a wheelchair or physically challenged. My son will not be classed as disabled. Autism cannot be considered a disability because he doesn't look disabled.

pg 22: Africans can't understand autism, they see everything as spiritual.

Religion — my child is a blessing / He's a blessing

pg 4: I have faith, I pray. That's what keeps me going. I believe God. I see my child as not mine, He's God's and was the help of God... He has seen me through when no man helps. **Pg 5** Prayer expensively for going.

MKM pg 3: I fight for my child in prayer. That's the way to go. To battle my confidence is in God. God's grace is sufficient for me. God has a reason giving me my child - to keep me grounded. I don't...

pg 6 why He chose me - I've asked God 'why me'.

pg 9: My faith help me to cope - we are Christians. I study the Bible - and how God took after us, and parents in the Bible - there are many verses in the scriptures that... not leave you. I prayed and cried to God to give me the strength was my biggest support.

√ pg 9 The congregation doesn't criticise. On the democratic side if congregation are what we got to need to pray and fast about it. people will listen and not listen to the practical side.

Culture

MKM pg 4: They are not aware of autism... in Africa, they'll say it's or demon child when the child doesn't behave. The mother has done something wrong. Stare blame the mother, or maybe it's a curse in the family. Maybe its from the devil. **P5** I didn't know about autism...

There are people that don't understand, when they say my child doesn't look like a child who was autistic. Child is fine... + reiterating signs.

pg: My mum is supportive. Although she's not here... doesn't understand autism. She doesn't understand level of stress, care, worry, attention.

HO pg: I grew up in Ghana we were never taught about... Because autism is not a physical disability so... one more in denial - I didn't know about autism before my child's diagnosis.

17interviews: 14 parents and 3 caregivers.

community, it [having a child with autism] is more accepted...more support. anything that don't look right, they will not accept it.
Gen: Stigma from the black community is worse than the white community. Africans can't understand autism...they see everything as spiritual. European people understand more.
Gen: When black people see my child, they treat me like autism can be contaminated, like their kids can also contract autism. so I feel like wow...I will be alone in this world.
AK: My husband would not take my children to Africa because of my son's diagnosis. He said they would laugh at him... its that mentality that my husband has not removed himself from all the African community and networks

Coping: practical
HO: I was more focused on solving the problem than just crying over it and finding ways to tackle all the various needs, communication, behaviour, sensory etc.
I take my child to those who are more tolerant. I plan where I go, what time I should go, what things to have in place, or maybe I don't take him out to the parks, or take him early in the morning before places start coming.
CO: You can't just pray and not do anything practically. Everything has to be practical with him... looking into professional help and support available for him
FP: I put a lot of effort, I went to meetings, I was a member of a carers group
GE: I started to go to workshops, meetings, reading a lot about autism.
Apart from that, being able to go to a lot of lectures and trainings to understand special needs more for me to be able to open a SEN school in ghana
CO: As a healthcare assistant, I gained more knowledge and training about autism.
PP: There is always an appointment, hospitals, agencies, charities, always.
YV: I go to trainings and workshops, parent support groups,
AK: Practically, there's a lot to do, he learns with pictures.
GE: When he was 3, my son couldn't sleep in the night. I went for a month without sleeping. I got depressed...really depressed. I was struggling

There's nothing we didn't try to calm him behaviour, friends, family and colleagues recommend ways to stop child being hyperactive – we even googled it...its not directly from health professionals certain types of food (gluten free diets, special water/milk) , diapers, ipads, camel milk, nappies, melamil to sleep (expensive), genius drop supplement

Coping: emotional (family support)
MKM: They keep me motivated. I live for them. I'm doing a damn good job. My child has taught me to be strong. I have to cope, I have no choice.
MKM: He started banging his head on the wall, tantrums. There were times I had to call the GP to tell them I can't cope...what if he cracks his skull, he'll scream and lie on the floor. I'll sit and cry and ask myself 'what's going on' , 'what's this?' 'Where did I go wrong, what's this, where did this come from?
CO: I wouldn't brag. I've done my best. I've tried my best.
V: I'm trying to fight for him to be toilet trained. He's not a great sleeper. It was hard. There are times when I think how am I going to cope, I don't think I can cope with this, I don't know what to do, I can't seem to get this right, am I a bad mother?

17

17interviews: 14 parents and 3 caregivers.

GE: I am a really strong woman. I never knew I was strong before. I don't know how I haven't lost my mind yet.
YV: im beginning to grow a thick skin.
SA: I have made up my mind that I will make the best out of my situation.
GE: They've made me realise a part of me that I didn't know existed. I used to say I don't know how to take care of an autistic child. Now, I can smile. I used to think my life was finished/over.
GE: My strength is only because of them. When I was depressed, I was only getting out of my bed because of them. I should take care of them. I live for them. Everything I'm doing is for them. I said I will not give up. I'm a strong mum. I never knew that before.
HO: I'm more tolerant, understanding, and more resilient
VA: I'm still learning. He's made me more clued up – going online to educate myself about autism, on top of my mummy duties.
FP: It was tough but I had to manage.
Fa: At first it was difficult I cried a lot but now manage. Its not easy but I manage. Im strong. I'm a strong mum.
HO: The frustration of 'why me', 'why are we going through all this' and the stress of dealing with life. It's a whole combination of things. Everyday life is already stressful.

Family support: immediate and extended family support
MKM: mum is supportive...though she's not here...
HO: If you work hard to accept it and come together as a family to handle it, then the family can't break down under the pressure.
PP: The whole family is chipping in so because of that we are coping well. I am coping well because I have support from my family.
We recruited everyone in the family to make him comfortable, not to make him feel left out.
UO: We cope as a family unit. we have been very supportive of each other. This situation has made us closer, fight and face the challenge in front of us, it has made us to trust in God more..helped us spiritually
GE: No one supports me, here – physically, I don't have support. Only God supports me... mum is not here. My mum and sister call me and give me support. They call me every week, encourage me and support me.
SA: Supportive sister – educated (medical field) so she advises me, just having someone to talk to helps.

Systemic references
MKM: Getting an EHCP plan is so difficult. Parents have to pay for the EHCP plan...they doesn't give the plans so they source the plans privately.
HO: The child's diagnosis is much quicker, have a SEN setting, therapies and EHC plan have the system in place here in the UK – it's one of the best systems.
HO: The UK has helped me to not change the way I see autism. If I was in ghana, I wouldn't have had so much information, learn more and go to classes and workshops, there...

Themes

17interviews: 14 parents and 3 caregivers.

aggressively', because you are aware that within our community, there's stigma, they'll be talking about you. Because of the stigma, you don't want to talk about it too much. It's upsetting
VE: anything that don't look right, they will not accept it. our community don't want to accept autism
FP: When he goes out, some children thought he would hurt them. My child did not have friends, only other children like him in the school
YV: In Dominica, they call my child a mumu because my son babbles
GE: When black people see my child, they treat me like autism can be contaminated, like their kids can also contract autism. so I feel like wow...I will be alone in this world.

Stigma – racial
MKM: Health assistants have been rude, she literally pushed us out of the room. But I don't respond because of how black women have been labelled as rude and aggressive...we are treated differently because of our colour.

VE: when it comes to the white community, they have the same problems as us with autism, but the difference between the white and black community is that we face discrimination anyway, so when the public see a [autistic symptom] behaviour, they won't see autism, because if the screening and the diagnostic tools they see a black child misbehaving..black and Asian people are known to have a behaviour

HO: When I used to take him at normal times, people started taking their children away from the sand pit, from my son. They saw a black boy throwing the sand in his shoes so parents take them out, even the kids start moving away.

SA: there was a time my daughter was banned from the school...she was in nursery [mainstream school]...the headteacher didn't know my child's name...they just focused on getting her out...they don't have the child's interest. At the school If I was White, I would have been treated with more empathy and respect. At the school gates, the headteacher would be greeting everyone, once its my turn, she would avoid me, when she sees me, she'll turn her back or move from the place. Sometimes I see myself as a nuisance.

HO: Racism is there...its every aspect of life. There's an additional problem..going through the system of employment etc in the UK is difficult...there's also the language barriers where some people find it hard to understand what is being communicated, coupled with the fact that people feel that because of their colour or race, they don't get the support as White/British people.

MKM: civilised racism... the racism that they smile at your face but those things don't bother me. Because of your colour the way you are treated, white people are treated differently to Blacks.

15

Themes

17interviews: 14 parents and 3 caregivers.

VE: if English is your second language and you've got an accent, already you've got a barrier... if you can speak the language and the British accent, then you can fit in, you are more likely to be accepted in the White community and autism organisations.
When you come from another country and English is not your first language, then you do struggle...you don't understand the English way of living... you deal with the cultural breakdowns, the taboos, the myths, stigmas.

SA: as a black person, I feel like they [white people] undermine your intelligence, your value, before saying anything, they've place you. The way they look at you, they behave as if we are coming to waste their time.. I think because we are black, they thought we were poor, we didn't appear to be of the standard of someone who'll get a mortgage. I think they didn't think we could afford a mortgage.
SA: In my place of work, there is a certain level that a black person doesn't get to...the feeling that they believe you are not capable. Racism is there...very real But there's nothing we can do about it. I feel a sense of isolation when I'm in a group and I am the only black person...like there's no one for me.
You get used to the racist behaviours and attitudes and you no longer see it as a challenge or an issue...you make the best out of the situation. You begin to know your place and you know your level. You adjust to the system – if you are black you know you won't get far in some things. Some black people have an accent get laughed at.
VE: There is always going to be a language barrier with black and Asian parents.

VA: If you are a black person, with an African accent, they won't take you seriously. So you need to have the British accent to be taken seriously. With an accent, they think you don't know what you are talking about. If you come across like you don't know what you are talking about or don't have facts or confidence, they'll treat you like you are wasting their time.

Marginalisation from own community
MKM: I stay away from my community... I don't go out with [child's name]...put him in that environment because of the way my [judge] sees autism/disability. I don't get involved in my community
Ven: I feel lonely because I don't meet a lot of Black parents who will come out to share their experience so I'm on my own.
SA: Especially among blacks, the expectations we have for our children and parents can be so rigid and inconsiderate.
CO: Stigma comes from Black community...you are worried about what people are gonna say...
you feel much more comfortable talking about it with someone from a background different ethnic group, say a white person, because they feel they have more understanding...there more understanding of autism within the White people than amongst us ethnic minority groups.
Ven: I sit on the fence and see from the black perspective the discrimination as a black mother [of an ASD child], being in a black community. then when I am in a white

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238

Appendix F – Participant consent form

Intersectional approach to Black parents' experience of autism in the UK

CONSENT FORM
Version 1, 15/01/18

[Note this information will be presented as a part of an online survey and as a paper survey]

Title of Project: Intersectional approach to Black parents' experience of autism in the UK

Name of researcher(s): *Eli Gemegah*

Please read the statements below carefully. If you agree with these statements, then tick in the corresponding box. **Unfortunately, if you do not consent to all the statements you will not be able to proceed with the online survey.**

Please tick box

1. I have read and understood the information sheet (*version 1, 15/01/18*) provided for the above study. I have asked any questions I wanted to ask.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

3. I understand that my anonymous data will be securely stored for a minimum of 10 years, in line with the University of Warwick's Research Data Management Policy.

4. I agree to take part in the above study.

Appendix G – Reflexive journal

Note: I started the interviews quite routinely: introduced myself, shared the consent and demographic sheet and thanked participants for their time. I briefly mentioned that my interest in the research stemmed from having a nephew with autism and that I am interested to hear about their experiences so far.
These are excerpts from my reflections

Participant 1 – accessed through snowballing, referred to me.

I met this participant in her home. Aware of the time we have before her son gets home from school, I felt the need to get started quickly.
I noticed that she included me in her community, for instance she said things like "you know where we come from, back home, the way our people are…", which told me that she felt comfortable with me and saw me as part of herself. I felt that this familiarity would encourage honesty and allow me to gain information and access to areas of her life she would otherwise consider private. I noticed that she wanted to showcase her son positively and almost downplayed the negative autism symptomology, though not its effect on her. Her narration of her experiences left me feeling emotional and this sense of urgency to do something.

Participant 2 – accessed through snowballing

I met with this participant in a café. This participant has her own autism parent support group in the UK and in Ghana and was very proud of her ability to support others. She gave me the impression that she knew more about autism than the typical 'average' parent/mother. I saw this in her responses, her objective approach to challenges of autism and her pride towards her son's progress, despite challenges he has experienced.
Once this participant knew I was from Ghana, she attempted to speak in one of the main Ghanaian languages, to which I responded that I was not fluent in that language. To me, this was an attempt to feel sense of familiarity and rapport with me. Although this participant provided many anecdotes of her experiences of autism, I noticed/ got the impression that she was holding back some information, perhaps because she was conscious that the conversation was being recorded.

Participant 3
I contacted her via her website as she has a parent support group, and advocates for parents and children with autism. I participated in one of her meetings where I introduced myself and my research. We exchanged details and scheduled to meet at another time for the interview. I had also gone to the support group meeting hoping to meet more participants.

I met with this participant at a restaurant. This participants' experiences were more reflective as her children were adults and had been diagnosed at different ages, an experience that had caused her a lot of pain and frustration. This participant was eager to share her experiences, particularly the autism stigma her children had faced

growing up in a society that did not want to accommodate autism. I sensed that this participant had been misunderstood by professionals and health care practitioners and wanted the opportunity to be heard. She was very receptive to my questions and answered them as a parent and also an experienced advocate for parents. I was quite inspired by this woman's strength and determination to support her children. I empathised with her and left feeling emotional.

Participant 4 – this participant was a new member of my church.
I was quite hesitant to approach her as I didn't want this to be a reason why she stopped coming to church so I waited a few weeks before approaching her. I noticed her because of her daughters' behaviour. She was receptive to me when I introduced myself and my topic. We exchanged details and I contacted her a few days afterwards for a meeting. We met twice because we were not able to complete the interview questions as she needed to pick up her children after school.
I was very pleased with the rich data the interview produced. She was forthcoming about her challenges with the autism diagnosis and how it has impacted her life. Despite this, I got the impression that there were no go areas: how her marriage has been affected and her determination to protect her child by not saying anything negative about her child. I decided to respect her and accept details she was willing to share. I did not want to invade her privacy or risk her withdrawing from the interview.

Participant 5 – snowballing
This participant's approach to life was very positive. She described her experiences from an objective point of view that made me question how she managed to appear detached from the impact of autism on her life. Her optimism was also directed to her child's future. Again, I noted that she was willing to advertise her son's abilities and didn't want to associate him with negativity.

Participant 6 – accessed through personal networks/snowballing
This participant was optimistic about autism. He downplayed any negative experience and chose to focus on positive aspects of his life with autism. He expressed his pride for his son and showed such warm affection when he talked about him. His approach among others, led me to question why parents highlighted the positive aspects of their child's behaviours? It felt like parents were ashamed to admit that their child can be extremely challenging. Perhaps, they feared I would think badly of them if they expressed the true extent of their struggles?

Participant 7 – accessed through snowballing
This participant provided such detailed descriptions of her child's struggles and how difficult the beginning years was for her. Despite her struggles, she expressed how proud she was of her son, the progress he has made and described ways that she supported him. She was realistic and accepted her son's limitations although she was encouraged her son to experience life. Once again, I left the interview with the weight of how autism impacts the family and the need for the family to come together to support each other. I was extremely aware of how difficult this journey can be without the added support from the family and support services.

Participant 8 – met this participant at a parent support group

We met at a café (noisy). I checked the recording as soon as I got to my car. Thankfully the recording wasn't affected by the noise. This participant was factual about her experiences, offering dates and times of events. Some of her personal experiences in life were given off the record. I redirected her back to the interview questions and I thought she used the interview in a therapeutic way.
 I felt very privileged to be given an insight of difficult life experiences and felt indebted to her for sharing such intimate information with me that when she suggested meeting up the next time I was around the location, I agreed. Due to covid, we were not able to meet up but she has updated me on her progress and I have been happy to hear from her.

Participant 9 – met through snowballing
I met this participant at her home. We both got the meeting times muddled and there wasn't much time to discuss but I felt like this participant gave me so much information! She came across as highly educated, articulate and forthcoming. She was extremely open and thoughtful in her answers. She had a very good memory and could remember minute details and dates from years ago, effortlessly providing examples that responded to the questions. I became quite excited by the interview because I felt the data was rich. She offered details of her experiences in marriage and the community but offered such and objective evaluation of her experiences that I believed she came across as well balanced.

Participant 10 – met through snowballing
I met this participant in her home. She seemed quite reticent in general and had to provide her with more information about myself, the research and what I hope to do with the data. She warmed up towards me a little. I still felt some resistance and asked her what she did in her spare time. She mentioned a company she freelanced for and once I had purchased something from her, she became very talkative and open. I got the impression that she was still withholding some information although she was more willing now. Towards the end of the interview, she chose not to fill in the demographic sheet. I completed the sheet using the information she had mentioned casually in the interview.

Participant 11 and 12 – personal network
I met this married couple in their home and interviewed them together due to time restraints. I also felt that they can share their experiences with their spouse present. The female participant was quite emotional when talking about the diagnosis and we paused a couple of times. I felt uncomfortable when this happened as I didn't know how to comfort her, in different circumstances, I would have comforted her but I was quite aware of my role as a researcher on this occasion and didn't want to shift from this role, especially as this could change the direction of the interview. I was also aware of the time constraints so decided to remain quiet as she calmed down. During this interview, the male participant was mostly agreeing with his wife's experiences and perspectives and only commented when asked specifically. The data I received was quite unbalanced and I was unhappy with this. A few days later, I organised another interview with the male participant to get his experiences. Although he initially stated that his wife's account was accurate, he provided me with different experiences and outlooks that enriched the quality of the data. I was glad I

had that one-to-one interview with him, especially as the female voice dominated the research.

Participant 13 – met at parent support group
What rich data! Although this participant had an accent and sometimes struggled with forming the right word to express her thoughts, she was articulate, passionate and eager to share her experiences. She was keen to describe her experiences at home, with school and professionals and shared her criticisms of the institutions that were established to help parents and children but did not. She was balanced in her responses, giving credit and praise where it was due and showing areas that could be improved, especially in schools. She felt there's limited training on autism for teachers. I felt her descriptions were very personal and painful for her, which made me appreciate her honesty. When she described her schedule, my gratitude increased even more because she took time out to speak to me. This gave me the impression that she valued this research and I felt indebted to her. So that it doesn't seem like I have forgotten about her, I reached out to her a couple of times during the lockdown.

Participant 14 – met at a parent support group
This participant showed me such kindness. When other parents at the support group advised her not to take part in the study, she opted to and provided me with such detailed experiences. I met with her in her home, and she was very transparent about her difficulties with her child's behaviours and how her family are coping. She became sad when she reflected on how she handled the autism diagnosis and how she would have done things differently. This participant also showed a sense of familiarity with sayings such as "back home in Africa", "you know how our people are", and made me feel like she was honest with me because she believes I can truly understand her. She expressed receiving no help from the borough and I wondered whether she knew exactly where to find help, even if there were structures in place and available? Although the time spent interviewing was worthwhile, I noted theme saturation, so I made a note to not feel obligated to include too much of the data from this interview.

Participant 15 – met through snowballing
We met in a noisy café but thankfully the recording was clear. I just checked immediately after the interview. Participant showed me pictures of her child and described him as someone with character. She expressed pride towards her son. She shared descriptions of her son's behaviours in various social settings in a comical and light-hearted manner.
She was convinced that because her son did not look disabled, he was judged more harshly for lacking social skills. She shared examples of her son being bullied and when he retaliates, he gets in to trouble at school. I left the interview being in awe of how parents cope with the various challenges autism presents.

- During the interviews, some parents expressed their views on the cause of autism being the vaccine. I neither encouraged nor discouraged such views – I merely listened. I debated whether to include this controversial view in the findings and decided against it as it didn't fall in the scope of the research.

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256

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