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Experiences of Black fathers of autistic children in the United Kingdom

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Autism Centre for Education and Research (ACER) focuses on developing evidence based practice and provision in autism across the lifespan, covering the range of ability levels and using methodologies based on knowledge co-construction with autistic people, practitioners and families.

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Executive summary

Autism research on parental experiences have largely focused on White middle class mothers' experiences as primary caregivers. While there is a gradual increase in research examining ethnic minority groups and Black mothers' lived experiences of their autistic children in the United Kingdom (UK) (Ashong and Perepa, 2023; Munroe et al., 2016; Fox et al., 2017), it is still starkly evident that the voices of Black fathers living in the UK is missing. A few studies have highlighted Black fathers' participation and involvement in family life (Reynolds, 2001; Guishard-Pine, 2003; Williams et al., 2012), but did not focus on how they see their role in relation to their autistic children. Hence, this study is the first to examine the experiences of Black fathers with a child on the autism spectrum and living in the UK that begins to bridge this research gap. We conducted a small-scale study to examine resident and non-resident Black fathers' experiences.

This research interviewed eleven Black fathers and outlines their role as a father and illustrates their involvement and engagement with their autistic child[ren] and in domestic life. The primary goals of this research are to:

- 1) address existing power imbalance in research by ensuring that marginalised groups are reached,
- 2) humanise Black men's experiences as fathers and give Black fathers an opportunity to narrate their own experiences, their attentiveness, participation and involvement in their child's life and to name the joys and challenges that accompany fatherhood.

The findings identify that Black fathers find themselves marginalised in different sectors of their life. This then has an impact on their ability to support their families and to play their role as fathers for their children.

The key recommendations of this report are:

- To develop support that addresses the needs of Black fathers. Such support will need to be flexible and culturally sensitive.
- To develop training for professionals working in education, health and other public facing sectors on the experiences of Black fathers of children on the autism spectrum.
- There is a need to review organisational policies to eradicate conscious and unconscious bias and racism in the policies.
- There is a need for specific support with employment to facilitate these fathers to continue working while also meeting the expectations in their role as fathers.

Background

Fatherhood is a life changing experience. The notions of fatherhood are dynamic and fluid individual experiences, a constantly evolving concept and has undergone a shift due to a host of social, cultural and economic factors such as migration, social and economic 'decrystallization' (Nye, 1976) of gender roles, most recently, social pandemic of Corona virus (Covid-19). Shifts in social expectations, the changing definition and presentation of fatherhood in response to social and cultural values has led to a gradual change in gender role stereotypes, which mean that fathers are now more involved in various aspects of family life, including childcare (Williams et al., 2012). However, there are still distinct gender roles in some aspects, particularly fathers' role that aligns and exceeds social expectations of fatherhood, particularly when fathering autistic individuals.

The most recent event that contributed to fathers' increasing involvement in the home is the Coronavirus pandemic. During the Covid-19 lockdown in 2020, more fathers worked from home, which contributed to fathers' multifaceted roles and its implications for the family structure and wellbeing. The Office for National Statistics (2020) showed that the first Covid lockdown in the UK led to a 58% increase in men's responsibility for childcare, and although women still took more childcare responsibilities, the gender role and care gap narrowed, compared to 39% of men involved in looking after their children in 2015. Burgess and Goldman's (2021) Fatherhood Institute's report 'Lockdown Fathers' demonstrates more father involvement and stronger bonds/relationships with their children as fathers in all socio-economic groups were involved in domestic life: 78% of fathers spent more time with their children, 68% more time on home schooling and helping with homework and 59% were more involved in housework. Similarly, fathers of colour 'were more likely (29%) than White fathers (19%) to report a positive impact of lockdown on their mental wellbeing and to report closeness with their children (79% vs 61%)' (5). The lockdown underscored the benefits of their presence in the home, as fathers were 'more confident as parents, understanding [their children] better, and feeling closer to them', which resulted in better mental wellbeing (Burgess and Goldman, 2021: 2).

Autism is a lifelong, neurodevelopmental condition that affects social communication, interaction, flexible thinking and sensory perception (APA, 2013) which affects how a person communicates with and relates to other people, and how they experience the world around them. Research on autism within minoritised groups in the UK identify the various cultural, racial, gendered socio-economic factors that shape marginalised groups experiences of their autistic children (Ashong and Perepa, 2023; Munroe et al., 2016). The concept of intersectionality, first coined by Crenshaw (1991) describes how interlocking systems of power affect those who are most marginalised in society, hence focused largely on women of colour, poor women, and immigrant women. Mahalingam (2007) characterised intersectionality in terms of the "interplay between person and social location, with particular emphasis on power relations among various social locations" (p.45). As far as we know, to date, there have been no research that examines the intersectionality framework on Black men who are also fathers of children on the autism spectrum in general and living in the UK specifically. This research aligns with Chepp and Collins' (2013) view that systems of power should be studied and analysed in relation to each other, not in isolation, to

understand how they correspond with each other to produce social, economic realities (such as patriarchal rule, capitalism, racial hierarchies) that lead to distinct and unequal experiences for marginalised individuals.

This study identifies central tenets of intersectionality (Chepp and Collins, 2013) as a lens to closely examine the research findings:

- analysis of power and inequality in different contexts - social practices that construct race and gender involve hierarchy and inequality; individuals and groups can simultaneously experience privilege and disadvantage within different domains of social organisation, i.e., structural, cultural, disciplinary, and interpersonal, (Collins 1998), that reflect hierarchies of privilege and power that structure social and material life;
- analysis of how social categories and positions depend on one another for meaning (occupied by actors, systems, and political and economic structural arrangements) and lead to a more nuanced understanding of how social categories of identity, difference, and disadvantage shape experience;
- standpoints—and not just social relations – thus acknowledging the presence of alternative truths in intersocial locations.

Multiple and intersecting factors influence Black parents' experiences of their autistic child, which although similar to the White dominant group, highlights nuances to Black parents' experiences and specific support (Ashong and Perepa, 2023). Alongside the dominant theme of lack of knowledge and awareness of autism in the Black community in the UK, cultural beliefs about autism further isolate parents who experience double stigma because of their proximity to autism and their race/ethnicity (ibid; Selman et al., 2018; Slade, 2014). The diverse presentations of autism and the various health, education and social support and intervention required suggest financial provision can be a significant need. Black men's experiences in their family and more widely highlights socio-cultural and economic factors that influence and undergird family durability, strength and resilience that can inform, enhance and challenge Black fathers' experiences (Gemegah, 2022; McLaughlin et al., 2008) of having a child on the autism spectrum.

There has been gradual increase of research on fathers' experiences of their autistic children. Extant literature documents fathers' general experiences after diagnosis (Burrell et al., 2017), their psychological distress (Seymour et al., 2017), expectations and difficulties coming to terms with the autism diagnosis (Cheuk and Lashewicz, 2015; Potter, 2016), experiences of courtesy stigma in community, professional, educational and public spaces (Alareeki et al., 2022). Whilst aspects of fathers' experiences in general may be applicable to Black fathers' experiences, a main limitation is a lack of ethnic representativeness in autism research, ethnicity was mentioned only in one study (Alareeki et al., 2022); so far, autism research tends to ignore how the intersectionality of race/ethnicity, gender, class/socio-economic status can have a nuanced and different impact on fathering experiences. The following section focuses on Black fathers of autistic children; a primary focus on Black men's experiences to show the ways that having a child on the autism spectrum can exacerbate life pressures in the family and domestic context.

Black men have often been perceived from a one-dimensional, stereotyped, and limited lens as hyper-masculine, hyper-aggressive, and threatening, thereby evoke fear, disdain, and scorn in the public (Reynolds et al., 2015; Reynolds, 2009; Bright and Williams, 1996). These views are extended to their fathering role, and often negatively stereotyped as absent, distant, unengaged, and uninvolved in their child's care. Extant research on Black fathers' experiences, largely within Western contexts, are mainly from an American lens and landscape, with a focus on African-American fathers' experiences (Hannon, 2017; Hannon and Hannon, 2017; Hannon et al., 2017; Hannon et al., 2018; Hannon et al., 2019). Hannon's studies recognise the relevance of social and cultural capital to African-American fathers' measure of fatherhood and father duty/responsibilities, which supports Cazenave's (1979) study that economic resource and availability acted a 'springboard' for Black fathers to be more involved psychologically and presently for their children. Non-resident Black fathers in the UK relied on social resources (extended family, friendship and community groups) to facilitate and inform their fathering roles, identity and practices (Reynolds, 2009). Hannon's study (2017) delineates how different forms of capital are important for Black American fathers as they assume multiple roles in their families, e.g., provider, protector, shared decision-maker, child socialiser, and supporter of his partner/spouse (McAdoo & McAdoo, 1997), which illustrate a more balanced and multi-faceted view of fathers' roles. Research on fathers demonstrate financial status as an effective means to carry out father roles, which highlights the importance of an intersectional lens to understand and examine the role of gender, race, culture, socio-economic status/class in Black fathers' experiences of their autistic child in the UK.

Understanding Black fathers' experiences in Western contexts require an acknowledgement of how individual and systemic racism shape their experiences and influence their ability to perform the various roles. Researchers have broadly defined father involvement as engagement (interacting with the child directly), accessibility (being available for the child, but not interacting directly with the child), and responsibility (monitoring and providing for the child) (Pleck, 2010; Coates and Phares, 2013). Following an intersectional lens of race, class and gender, Posey-Maddox (2017) examined Black fathers' engagement and family-school relationships and challenges dominant portrayals of Black fathers as largely absent, uninvolved, detached, and distant fathers. Some schools in the US require parent's active engagement and involvement in their children's school (such as parent and teacher meetings, or volunteering) as a way for the school to gain more federal funding (Title I funds). Fathers' experiences in their child's school illustrates their double consciousness of how White professionals/teachers perceive them: 'big black guy', lead to change in their behaviour, such as speaking in 'non-threatening ways' so his 'careful use of tone and language was meant to assuage white teachers' potential racialized fears' (p.588). This example illustrates Black fathers' awareness of individual and systemic racism in their child's educational context and the minute ways that they modify their behaviours and speech to dispel myths about Black men and uninvolved fathers. It also offers viable insight to how multiple social statuses might be experienced simultaneously (Black and male) in various contexts and demonstrates the importance of analysing the 'meaning and consequences of multiple categories of identity, difference, and disadvantage' (Cole, 2009: 170), which suggests the inextricable link between statuses that produce double stigma and disadvantage.

Hannon et al.'s (2019) study demonstrates Black fathers' unique and nuanced experiences of 'microaggressions influenced by fathering stereotypes related to their ability and agency to care for their children' and 'microaggression influenced by autism stereotypes' (p.202). Fathers' experiences of microaggressions stem from racial stereotypes and prejudice about Black men's capacity to fulfil their fathering duties and responsibilities; microaggressions are also levied against people with disabilities, the intersection of race and disability can perpetuate stereotypes about Black fathers, Black children and reinforce microaggressions. Hannon et al.'s (2019) study illustrate the societal and systemic challenges Black fathers of autistic children experience in the US landscape, which demonstrates the significance of an intersectional lens to recognise the role of gender, race, culture, socio-economic status/class and autism perceptions of fatherhood. This current study is the first to acknowledge and involve Black fathers in dialogue within the autism field in the UK.

Research Methodology

Participants

Eleven fathers living in the UK and raising at least one child, aged 10–24 years and diagnosed with autism were recruited in the study. Most of the participants were the biological fathers to their children on the autism spectrum, except one adoptive father. Racially and ethnically, the fathers identified as African (N=7) and Afro-Caribbean (N=4). Five of the eleven fathers reported to be married to the biological mother of their autistic child. The average age of their children was 13 years. All the children and young people received a formal autism diagnosis, with the earliest age of diagnosis being 2 years old.

Procedure

To recruit participants for one-to-one interviews, the study was advertised through autism organisations and support groups, social media and the authors' professional networks. Interested fathers contacted the first author by email to receive further information. All participants were sent the consent form and then scheduled an interview at a convenient time and location. The study recruited resident and non-resident fathers, biological, adopted, divorced, married and single fathers. The first author conducted the semi-structured interview using an interview guide (see Appendix 1) to structure conversations yet encouraged fathers to narrate their experiences that allowed for a flexible and conversational flow of their experience. Interviews, while lasting an average of 50 min, ranged in duration from just over twenty minutes to more than an hour (21–94 min). Interviews were audio-recorded and later transcribed verbatim. The study received ethical approval from the University of Birmingham's ethics panel. To confirm their interest, participants signed and returned via email an informed consent form before the interviews were conducted.

Data analysis

Interview data were thematically analysed following Braun and Clarke's (2006) process of familiarisation, initial coding, search for themes, review of identified themes, defining and naming themes. Familiarisation and initial coding entailed repeatedly listening to audio recordings, reading corresponding transcripts, and documenting first impressions. Following an inductive and deductive approach to analyse the data and formulate themes, we followed Berg's (2001) practice of reflecting the main message of the data while retaining the wording of our participants.

Interviews began with fathers providing information pertaining to their family structure, the age and gender of their child(ren) with and without autism diagnoses, their marital status, and their experience of the autism journey so far. All fathers were employed - some fathers explicitly mentioned the nature of their work whilst others inferred it through their financial status/hardship level. Fathers' demographic information is summarised in Table 1.

Table 1: Fathers' demographics

Name	*Heritage	Total no. of children	No. of autistic children	*Child's age	Age of diagnosis	*Fathers resident status	*Relationship to child	Marital status	*Financial hardship level	Religion	Immigrant status
AJ	A	3	1	24	10	R	A	M	1	C	1 st
MF	AC	5	2	18, 6	9, 2	NR	B	S	3	C	2 nd
JF	A	2	1	7	4	NR	B	D	1	C	1 st
BO	A	4	1	12	2	R	B	M	1	C	1 st
FA	A	3	1	10	4	R	B	M	5	C	1 st
MM	AC	2	1	14	2	NR	B	M	5	C	1 st
HP	A	5	1	25	2	R	B	M	-	C	1 st
LLF	AC	4	1	5	2	R	B	C	5	-	2 nd
KM	A	3	1	5	4	R	B	M	3	C	1 st
HD	A	2	1	-	3	NR	B	W	3	-	1 st
JH	AC	2	2	11, 9	10, 3	R	B	C	5	-	1 st

*Heritage: A – African; AC – Afro-Caribbean

*Child's age – at time of interview

*Resident (R) Non-resident (NR)

*Father's relationship to child: A – Adoptive father; B – Biological

*Marital status: Married (M); Cohabiting (C); Divorced (D); Single (S, never married); Widow (W)

*Immigrant status: 1st generation (born outside the UK); 2nd generation (born in the UK)

*Financial hardship level: Finding it very difficult (1); Finding it quite difficult (2); Just about getting by (3); Doing alright (4); living comfortably (5)

*Religion: Christian; empty if not mentioned

*Immigration status- First generation (1st), second generation (2nd)

Adhering to Creswell et al.'s (2011) recommendation in reporting research findings, this study examined fathers' lived experiences and placed them in the position of experts of their own experiences. The following section communicates the data analysis to accurately reflect fathers' narratives of their individual experiences of their autistic children.

Our sample is, in many ways, homogeneous, with most fathers indicating being married (N = 6), biological fathers (N = 10) and employed (N = 11). One father is divorced, and another is an adopted father. Fathers in our sample have a total of 35 children between them, of whom 13 are autistic, all are sons, with two fathers having two autistic sons.

While it is not within the scope of this research to provide cross-cultural analysis of the demographic characteristics of these fathers, it is important to highlight that variances in fathering experiences occur because of social class, heritage/cultural

factors, first- or second-generation immigrant; and these intersect with race/ethnicity and gender to inform and shape their fathering identity.

Results and Discussion

This research study examined Black fathers' experiences of their autistic children in the UK, which begins to address the dearth of knowledge on this topic and provides Black fathers' a voice in the autism landscape. This research draws on an ecological framework to understand fathers' roles and involvement in domestic settings, their responsibilities to their children's lives and the social, cultural and institutional systems that shape and influence their experiences as a Black man in the UK. The research also employs an intersectional lens to demonstrate the ways that multiple statuses and social categories connect to shape fathers' experiences as Black men and Black fathers of autistic children in the UK.

The study yielded eight themes that gives an insight into fathers' understanding and multi-dimensional role and responsibilities to their children and their family: the family structure and the various ways that autism impacts fathers and the family overall. Fathers' culture and their journey to knowledge about autism, their expectations of fatherhood and how autism alters these expectations, and the support fathers would benefit from wider systems and services. The themes (Table 2, Appendix 2) also include fathers' experiences of various systems and their impact on their autistic children and their experiences as Black men in the UK.

This study highlights Black fathers' involvement and engagement in their family systems and specifically in their children's lives and development, which challenges social stereotypes about absent, detached and uninvolved Black fathers. This study employs an intersectional theoretical lens to examine and highlight the connection between social phenomena and systems of power (race, gender, class, disability/autism) for a holistic understanding of human, individual and group experiences. In this research on Black fathers of autistic children, the intersectionality framework is a prism to examine the multi-dimensionality of their experience (Dill, 1983) and to analyse how systems and social constructs (race, gender, class and association with autism) work together to oppress, while also allowing privilege in other areas that shape fathers' experiences in the UK.

Fathers' privileged status in the home

Black fathers' experiences of their child's autism in ecological contexts offers an insight to their multi-faceted roles and involvement in domestic life and outside the family context. Fathers' role as the '*leader and provider*' (MM), '*guide/ a dictionary/google, teacher*' (FA), '*disciplinarian and the hierarchy*' (LLF) for their children indicates a position of power based on their gender that structure their children's social and material life. Simultaneously, women '*do a lot of the work*' (JH, MM, FA) as the primary caregiver of their autistic children, which suggests mothers experience gender inequality within the domestic setting (Ashong and Perepa, 2023). Roles are divided according to strengths – mothers are recognised as being good at dealing with autistic child's needs and characteristics. For example, JH states '*my partner looks after the children a lot more than I do...she does a lot of the work and I just support*', MM expands that it's '*her on the ground...visiting the schools, talking to the different teachers...she's actively involved in it*'. These views were similar to those expressed by fathers in the study conducted by Raffety et al.,

(2020). Fathers in this study mentioned that they are more responsible for traditional male roles such as *'DIY and taking the bins out'* (LLF).

Fathers and mothers' gender specific roles reflect social practices that construct gender stereotypes and expectations (Collins, 1998). Mothers' predominant involvement as primary caregivers are seemingly shaped by socio-cultural factors that determine fathers' expectations *'the [African] father goes out, make the money, and then the mum is like at home taking care of the kids'*, (JF), *'that was my upbringing...West Indian parent, first generation'* (JH). However, in situations where mothers are not present, fathers become the primary caregiver for their children. For example, MM mentioned that when his wife was away *'it was my responsibility for the entire year or so, to dress him, feed him, take him to school, pick him up from school'*. This indicates a high level of engagement over a range of care and support activities. The results indicate that while Black fathers fulfil socio-culturally assigned gender roles, and take complementary roles when mothers are present, they can also become primary caregivers when necessary. Indicative findings from this research show that men increasingly provide personal care for their autistic children and are involved in the daily management of the house and make personal, work adjustments to fulfil their fatherhood roles. Similar conclusions were made by Towers and Swift's (2006) research with fathers of disabled children, although they did not focus on ethnicity in their research. The similarity in the findings suggests that even in communities where more traditional gender roles are expected, having a child on the autism spectrum or with disabilities may change these expectations for fathers.

Economic status and parenting role

Fathers' class and socio-economic status show the intersecting sequences of social categories and positions that determine their presence and accessibility in the home, which influences the extent to which mothers are involved, some fathers *'work multiple jobs...we are not that financially okay or financially stable'* (AJ) similar to non-residential fathers who recognise that *'it [autism] more impact the mums, because they're with them 24/7'* (MF). Whereas, fathers with middle class jobs can determine their level of autonomy at work or in their job role with some flexibility to work from home, *'I would take him to school in the morning and my partner would pick him up'* (JH) or request a particular working schedule suitable for the family's needs *'I request at work can I have a working pattern which is condensed which can allow me to help picking up the children, dropping off the children'* (KM). Flexibility and autonomy enable them to be more involved in their children's lives *'I changed nappies. I bath them in the mornings when they're going to school or evenings when I bath them'* (KM) and their contribution to the domestic life *'I do a lot actually. I cook, I clean, I do my own laundry'* (LLF).

Fathers' class and financial status co-construct their provider and leader roles, which can either reinforce their hierarchy or disadvantage. Fathers with high economic capital are *'in a position to pay for things...private tuition and help'* (JH), *'we also see quite a lot of private doctors... we then go forward with that recommendation, whereas with the NHS you might wait six months'* (FA), and *'having certain legacies - life insurance, home ownership – in place for the boy'* (MM). They are positioned to curtail the uncertainties surrounding their child's future by providing additional

education, health and financial support. Whereas fathers experiencing financial hardship are emotionally burdened by their reduced financial support *'we really didn't have enough money to put him through special education, as it should be, and which really pains my heart a lot'* (AJ), thus, feel limited in their provider role.

The family setting reveals complexities influenced by the nature of fathers' work commitments, which they identified as the main hinderance to their involvement and contribution *'work is the biggest interference... if I could afford to work part time, and spend more time with him, I would love that, but obviously that's not going to happen... you need two incomes to run a household'* (MF), which indicates conflict between work as a means for provision and a barrier to engagement with their autistic child. Domestic settings offer insight of how multiple social categories and positioning because of race/ethnicity, patriarchy and class, shape knowledge and understanding of Black individuals and groups, and identifies inequality within and between groups based on the multiple ways that individuals' identities interact because of how they are differently positioned to experience the family settings, as well as the [unequal] material realities that accompany their positioning (Stoetzler and Yuval-Davis, 2002).

Impact of autism on father's lives

A critical moment for fathers is their child's initial autism diagnosis similar to previous studies which suggest that the diagnostic process is a stressful time for parents (Crane et al., 2016; Gemegah, 2022; Moh and Magiati, 2012; Rafferty et al., 2020). Some fathers reported a range of emotions from denial *'I was like, "No". I was in denial. And we thought it was just a delayed speech'* (KM) and *'I was very stubborn about it because I didn't want to believe it'* (JF). Fathers experience grief when they received the diagnosis *'I was completely devastated'* and *'I'm still grieving'* (JH) for the unmet expectations and loss of the child fathers hoped for, alongside the challenges associated with parenting an autistic child *'it is not always very easy to deal with them'* (HP) which suggests the complexity of fathers' grief. Some fathers described initial depressive feelings *'that was like one of the saddest days of my life and I just walked around the house, I can't even look at him, I look at him... It wasn't so good of a day... I really don't want to think about that moment'* (JF), and later acceptance *'but then I was like, you know what, just have to accept it and find ways how to deal with the situation, find ways how to make his life better and our family life better and try to accept it'* (KM). Some others held alternative perspective *'I've always tried to look at it as it's not a disability it's a different ability or a special ability'* (MF). Research associates the ability to resolve and accept their child's diagnosis with positive outcomes for parents (Oppenheim et al., 2007), the child and the family as a whole as parents develop their knowledge of autism. Fathers in this study were working towards this through *'courses to learn more about autism'* (LLF) and *'researching what does this [diagnosis] actually mean'* (FA) and find ways *'to try and improve his life'* (KM), similar to strategies used by mothers in previous studies (Gemegah, 2022).

Fathers reported the psychological, emotional impact of parenting an autistic child and the practical approaches they employ to support and mediate against their child's challenging needs. Fathers stating that having an autistic child and the support they require is *'something that is always on your mind [...]'*, (MM), and

'...does affect every single thing you do', indicates the ubiquitous nature of the impact of autism on father's decisions, actions and by effect, their psychological wellbeing. Fathers shared that they were '*thinking about how you can improve the life chances of the child or give him a chance to be the best that he would want to be*' (MM), mainly because '*I won't live forever*' (MM). Fathers mentioned that they '*always have to be alert, even when sleeping*' (UO), which suggests a mental strain. These views indicate that Black fathers main concern about their child's future and the impact of fathering a child on the autism spectrum on their mental wellbeing are similar to that of other fathers reported in previous studies (such as Rafferty et al., 2020). Parents endeavour '*to make sure that we're thinking about him in every scenario kind of thing so at least he's comfortable wherever we are*' (LLF) and '*to make our day as predictable as possible [...] and having a routine works*' (FA) and ensure their autistic child is included in the family activities and in social settings. A father details the thought processes and planning involved to ensure their autistic child is comfortable and content and the adjustments him and his spouse had to make to their parenting style:

when we are going to different places, we make sure that we have certain things for him, like earmuffs or his headphones. We have to make sure that his certain types of foods are always there. We have to make sure that his, because he likes his tablet and he listens to music on it, we try to make sure that overnight it's charged. So, it's things, it's little things which you have to think before, you think for the next day, you plan for every journey you're going out away... It's just those small things we just have to think. Because if you don't have those things it's going to be, it can be a hard day for him and it ends up being a hard day for me when we are out. You have to be forward thinking (KM).

Parents pre-empt situations to minimise any disruptions to routine that negatively impacts their child's behaviours and by effect, parents' emotional and psychological wellbeing, similar to previous research (Hastings and Brown, 2002; Estes et al., 2013) which recognises that behaviours of concern are a source of stress for parents. In this current study, fathers discussed the emotional strain of dealing with their child's mood and behaviours '*obviously just autism on the whole just impacts on a daily basis, dealing with, I don't know, the tantrums and the attention and the frustration with little man as well [...] that can be hard*' (MF). Fathers recognise that parenting an autistic child '*does take a toll on the emotions, because you have these feelings that goes up and down*' (MM) indicating the complex emotional and psychological vacillations.

Fathers' multiple status as double disadvantage

Fathers' experiences in the wider contexts illustrate the tension between individuals and health, education systems, which perpetuates inequality that result from multiple axes of systemic oppression. Black fathers' experiences give further insight to how multiple social statuses might be experienced simultaneously. In wider social and systemic contexts, power is located across multiple dimensions of dominion that intersect such as race, class, gender (Dill, 1983) and operating within different domains of social organisation, for instance, structural, cultural, disciplinary, and

interpersonal (Collins, 1998). The main intersection fathers commented on is race and gender, which illustrates Black men's emasculation in social and structural contexts in contrast to the varying levels of privilege and assurance they experience in their homes. Fathers experience apprehension and feel *'very self-conscious going running in a really rural area...I feel anxious as a black man that I might be stopped...especially post George Floyd'* (JH). Black men's insecurity and alertness to danger in social settings highlight their vulnerability and helplessness to existing prescribed racial hierarchies (Hooks, 2000) and socially accepted spaces for Black men to inhabit. The concept of geo-social class means that rural areas are associated with class privilege (Schultz, 2022) not often associated with Black people, and heighten their awareness of their difference *'you are aware that you are a minority...it puts you on guard'* (MM).

In this study, Black men's powerlessness is depicted complexly across intersecting social categories, positions and social domains which encapsulates the interrelationship between historical, political, material, social inequality and stigma (Cole, 2009). General suspicion held towards Black men *'like being followed around the supermarket by a security guard'* (JH), and *'where every time I leave my house, I'm getting stopped by the police... Like before, I get stopped in my car for no reason, most of the time'* (LLF), highlight their precarious position in wider society where Black fathers recognise that *'it's a challenge being a Black man in the UK'* (KM) as they concurrently experience oppression, and enforcing racial hierarchies (Hooks, 2000). In social contexts, their race and gender function in the structural bases of domination and subordination (Chepp and Collins, 2013). In this study, Black men's experiences are inextricably and directly linked to their race as men from the dominant group do not experience such oppression, but rather show ways that social categories structure individual and social life. For example, a participant who *'look[s] White but [he's] mixed has been with a friend, he's Black...he doesn't smoke weed, but then we've been stopped by police, I've had weed on me, searched briefly, they never found anything, but then the way how they searched my friend was completely different to the way how they searched me'*, (MF). This implicitly illustrates the position of power and solidarity the police have towards a man who *'look[s] White'* and who can *'blend in'* (MF), yet immediately assigning blame and criminal status to a Black man, who in reality, *'does not smoke weed'* and demonstrates racist behaviours that indicate institutional racism (Home Office, 2019). Experiences of racism and micro-aggressions are pervasive in wider contexts, such as *'white women crossing [to] the other side of the road'* (LLF) which communicate negative and derogatory messages to Black men as violent and dangerous that highlight the hostility Black men in this study experience daily. These illustrations are a microcosm of racial and gender inequalities that Black men experience in social contexts.

Society's perceptions of *'them [Black men] and us'* (MF) appear to shape the nature and functioning of *'management meetings'* (MF) within institutions, as such, societal attitudes based on race and gender implicitly drive adverse institutional and professional approaches to Black men in White spaces. For instance, the laws and rules enforced on the public, specifically racial profiling through stop and search and targeting Black men to follow them in supermarkets are negative actions that contribute to a hostile environment, perpetuate racial hierarchies, and maintain social conflict and division. While these experiences do not have a direct relation to these

men's role as fathers of children on the autism spectrum, these broader experiences seem to influence how these men interact with professionals and organisations, and also what skills and knowledge they think is important for their autistic children to navigate the British society as Black men.

Individuals versus employment and education systems

Black men's experiences depict a reciprocal complex and multifaceted relationship between social and institutional settings. In institutional settings, particularly in employment, Black fathers remain alert to micro-aggressions and covert racism as they are denied employment and feel that *'not everyone really want to give you work. Not everyone actually trust you'* (AJ). This feeling was shared despite being qualified for the role. AJ shares an experience he had at a job interview *'it's a phrase that she used sense, which says "you really don't belong here...really, this is not the place for you in this university"*. Such experiences highlight the inhibition, hostility and rejection Black men experience in structural contexts. Where Black men are employed, they are aware of the sense of distrust employers have towards them so one participant recognise *'if you're in a workplace, document everything, stuff you do, so that's because we are the least likely people to be believed... But if you have evidence, yeah, they'll budge. If it's just word of mouth, no, they won't believe you'* (KM), which demonstrates a constant status of presumed guilty Black men encounter that shape their experiences in structural contexts. Since most of these men saw their role as a provider as an important element of their role as fathers and husbands, they found it stressful when their multiple identities were threatened in work contexts and more widely in social settings.

However, fathers noted that their class mediated against existing stereotypes or empowered them to challenge racism and micro-aggressions in society and within structural settings. Fathers in professional roles challenge and resist racism by *'knowing how to speak and being able to stand up for yourself in places where you think you're being mistreated'* (KM), confront existing policies and *'know when to push back... know how to appeal and when to make them accountable'* (FA). For example, a father from journalist background with his mixed-race children stated *'when I had the boys there was a sense of like, well, please stop me because boy, the BBC will have a big thing to talk about, you know, sort of like, you know, middle class black dad, works in so and so, works for so and so, stopped, harassed...how would you like me to do a report on the way you basically profiled me'* (JH). Such examples indicate social, cultural and economic capital acquired through one's class status. Fathers with low social and economic capital counteracted racism with more hard work *'when the indigenous are doing 50%, try to do 75%... and be content with that'* (HP) and another father stating *'I still work more and even though sometimes I deserve a raise and then I don't get it, still, I don't still take that too hard... even when we experience it [racism] everyday in our workplace, ...we live it as a normal life and we don't complain'* (AJ). This description of high effort coping (Jelsma et al., 2022) to moderate against racial discrimination and economic mobility appears to be a self-protective measure against the effects of racism, which indicates the prevalence of this theory across age groups within the Black community in Western contexts, not just in adolescence or in the US, as Jelsma et al. (2022) suggest in their study. This way of proving their worth, of course

reduces the time that they can spend with their children and the family responsibilities that they can take.

Fathers' experiences of racism can create anxiety and powerlessness '*it is not something that I dwell on*' (MM) and influence their fathering styles. Their awareness of how society perceived them increases their level of discipline towards their sons in public spaces, '*if they're in a shop with me, the first thing is [I tell them] you look with your eyes, not with your hands*' (JH). This advice is a protective measure against society's judgment and presumption of criminal behaviour towards Black males. Similarly, a father believes that their son's autism diagnosis is a '*blessing*', because '*I don't see him getting involved with gangs etc., given the autism*' (MM) which can safeguard and mitigate against gang exposure/involvement and its associated risks '*stabbing and all that*' (MM).

The relationship between parents, autistic children and the school context is dynamic and multifaceted. Fathers identify the conflict between autism characteristics and existing policies within the education system that can hinder their child's progress or heighten tensions with education professionals:

... I mean that's my biggest fear is this like, you know, at what point... he's already had run-ins with teachers before, you know, at primary school, and it's like at what point are the teachers just going to see him as the naughty kid or kick him out of the class because he's being too disruptive (JH).

This father also recognises the challenges of having a disability in a school setting, '*I'm putting a lot of my experience when I went to school, I guess, on him because my school was all boys, it was strict, and dyslexia never existed*' which increases his trepidation and influences his fathering styles. Fathers' focus on their child's behaviour implies the triple disadvantage of multiple statuses Black autistic boys experience in schools, which makes them more predisposed to stricter sanctions where their discipline stems from negative pre-conceived ideas about Black boys (Ashong and Perepa, 2023; Owusu-Bempah and Howitt, 2000; Gillborn, 2015). Conversely, lack of autism training in schools lead to decisions whereby fathers reported their children were often placed with other '*disruptive*' children and were kept away from other children of their ability because of the teachers' assumptions about the abilities of pupils on the autism spectrum. A father explains that one of the reasons for the existing disparity in Black children's educational attainment is due to teacher's low expectations of child's competence because of the intersection of race, gender and disability:

sometimes there might be a bias in the system... there's low expectation as well... sometimes when people are not expecting that much from you, you fall through. So, for reading, for instance, he used to read quite a lot at home but then at school they had very simple texts for him to read, which, you know, they probably thought he couldn't read... (FA).

Race, gender and disability intersect to contribute to Black autistic children's educational disparity (Guldborg et al., 2021). Lower expectation for racial and ethnic groups, different expectations based on gender and limited access to appropriate educational resources and accommodations of autistic children highlight the potential

biases educational professionals can have towards minoritised groups (Cogburn et al., 2011; Varner & Mandara, 2013). School policy and systems are another dimension of existing tensions between school and parents that influence their autistic children's educational experience. Based on his child's experience of school exclusion a father felt, *'sometimes within organisations, they have the organisation's best interest at heart so the schools, for instance, they're more concerned about the school's reputation and Ofsted rather than sometimes the child's education'* (FA). Parents and teachers' competing interests create tension and reflect educational policies framed on the premise of cost effectiveness, reputation, Ofsted grading and based on neuro-normative explanations than the needs of autistic students.

Supporting fathers

Fathers' first- and second-generation status and economic migration indicates minimal support from their immediate and extended family in the UK, which suggests various economic pressures, isolation and challenging work-life balance can strain family relationships. External pressures in addition to the parenting challenges associated with their autistic child's health, social care and educational needs can lead to added stress and financial strain on the family's wellbeing.

Fathers identified sources of support that would be useful for them. Culturally specific support networks such as online support groups for Black father *'having parent groups probably, you know, people that are black'* (FA) and accessing resources such as *'counselling, for men especially, is a big thing, it's a very big taboo, and I don't know how to talk about my feelings'* (MF) and culturally focused community programs *'where these things were run mainly by, like, black people, whether it's Caribbean, Afro-Caribbean, African, I think parents might be a bit more willing, because everybody understands the culture, the way children are raised and things like that'* (MF) as potential ways to support Black fathers. Fathers' race, cultural and ethnic background inform their outlook and fathering styles *'because we are different... there's an ecosystem that is different for us men of colour, which we ought to take into consideration'* (MM). Fathers highlighted their race as predominantly shaping the nature and quality of support they require in the UK, where the dominant culture is different to fathers' culture, therefore existing support might not be applicable to Black fathers. Additionally, respite and activities that are focused for fathers to engage with their autistic children were mentioned as resources that can alleviate the stressors and foster positive relationships within the family dynamic.

Conclusion

This study made a first step in the context of UK autism research by including Black father's experience of autism. This study's primary goal was to raise awareness of Black fathers' roles and involvement in their autistic child's life – challenging and shifting the common view of Black fathers as uninvolved, detached, and absent. This research reveals that unlike the stereotypical view, some Black fathers consider the importance of parents working together, sharing responsibilities and care for their family and their autistic children specifically. However, not all fathers are able to fulfil what they consider as a father's role because of their marginalised experiences due to racial and gendered stereotypes and their economic status. This research highlights how the intersection of race, class, gender and autism shape the fathering experiences of Black men. Fathers in this research felt that because of their different experiences from the dominant racial group, it is important that culturally specific father support services and respite need to be developed for Black fathers living in the UK.

Future research

This is small-scale research where participants were recruited using a convenience and snowball sampling. Therefore, it is possible that this study only represents a specific group of fathers who showed interest in the study are involved and engaged in their autistic children's development. The methods for participant recruitment limited the sample to parents with access to resources such as the internet and who were more likely to be part of a network of autism advocacy and support groups, and parents who are English speaking and literate. Recruiting fathers through others means and involving fathers who do not speak English could have provided a different set of results. Future research can investigate these factors as well as exploring reasons that lead to some Black fathers' non-involvement in their autistic children's lives, to give a more holistic picture of various factors that shape fathers' experiences of their autistic children.

This study showed the psychological effects of racial stigma fathers have experienced; it is important to examine the impact of counselling for Black fathers focusing on racial stigma. Research could also explore how employing personnel from Black and ethnic minority communities who can incorporate their knowledge and personal experience of intersectionality in counselling sessions would impact the experiences of Black fathers.

Future research can also investigate ways to improve relationships between the police and young Black males and by extension, examine the impact of anti-racist and disability training for police groups and patrollers in urban and rural areas.

Recommendations for professional bodies and institutions

- Health professionals and clinicians attending to autistic children or children on the path to an autism diagnosis should be aware that mothers and fathers need information and support and to signpost both parents to existing support services as mothers and fathers may have different needs.

- Health and educational professionals can offer flexible appointment times (outside working hours) and modes (Zoom, telephone) for fathers who do not have autonomy to adapt their schedules. This is to include fathers in decision making processes and updates about their child's wellbeing, health, and educational development overtime.
- Employers should consider reasonable adjustments to fathers' work patterns and communicate with fathers about existing policies on paid emergency leave.
- There is a need to include ethnicity and autism training for teachers and police as professional development to promote a holistic approach to supporting Black young males on the autism spectrum. It is essential for educators, educational and police institutions to be aware of potential biases, promote equity and provide individualised support to autistic children and young people based on their needs rather than preconceived notions related to race, gender and disability.
- Educational policies and practices should be designed to reduce racial and disability gaps and ensure that all students have an equal opportunity to succeed.
- Local, regional and national network for Black fathers specifically for informal support and solidarity to share life experiences as a Black man and father of an autistic child should be created.

References

- Alareeki, A., Shipton, L. and Lashewicz, B. (2022). "They're either afraid or ignorant": Experiences of stigma and blame among fathers raising autistic children. *Research in Autism Spectrum Disorders*, 96, p.101999.
- American Psychiatric Association, (2013). *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed. Washington, DC, American Psychiatric Association.
- Ashong, E., and Perepa, P. (2023). Black Christian women's experiences of their children's autism in faith and community contexts, Manuscript submitted for publication.
- Berg, B.L. (2001). *Qualitative research methods for the social sciences*, 4th Edition, Boston. MA: Allyn & Bacon.
- Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), pp.77-101.
- Bright, J.A. and Williams, C. (1996). Child rearing and education in urban environments: Black fathers' perspectives. *Urban Education*, 31(3), pp.245-260.
- Burrell, A., Ives, J. and Unwin, G. (2017). The experiences of fathers who have offspring with autism spectrum disorder. *Journal of autism and developmental disorders*, 47, pp.1135-1147.
- Burgess, A. and Goldman, R. (2021). *Lockdown fathers: The untold story*. London: Fatherhood Institute.
- Cazenave, N.A. (1979). Middle-income Black fathers: An analysis of the provider role. *Family Coordinator*, 28 (4), pp.583-593.
- Cheuk, S. and Lashewicz, B. (2016). How are they doing? Listening as fathers of children with autism spectrum disorder compare themselves to fathers of children who are typically developing. *Autism*, 20(3), pp.343-352.
- Coates, E.E. and Phares, V. (2014). Predictors of paternal involvement among non-residential, Black fathers from low-income neighborhoods. *Psychology of Men & Masculinity*, 15(2), p.138.
- Cogburn, C.D., Chavous, T.M. and Griffin, T.M. (2011). School-based racial and gender discrimination among African American adolescents: Exploring gender variation in frequency and implications for adjustment. *Race and social problems*, 3 (1), pp.25-37.
- Cole, E.R. (2009). Intersectionality and research in psychology. *American psychologist*, 64(3), p.170-180.

- Collins, P.H. (1998). It's all in the family: Intersections of gender, race, and nation. *Hypatia*, 13(3), pp.62-82.
- Chepp, V., Collins, P.H. (2013). Intersectionality, In K, Celis, J. Kantola, G. Waylen, and L. Weldon (Eds.) *The Oxford Handbook of Gender and Politics*, Oxford: Oxford Press, p.57-87.
- Crane, L., Chester, J.W., Goddard, L., Henry, L.A. and Hill, E., (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, 20(2), pp.153-162.
- Crenshaw, K., (1991). Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. In K. Bartlett and R. Kennedy (Eds.) 1st Edition, *Feminist legal theories* (pp. 23-51). New York: Routledge.
- Creswell, J.W., Klassen, A.C., Plano Clark, V.L. and Smith, K.C. (2011). Best practices for mixed methods research in the health sciences. *Bethesda (Maryland): National Institutes of Health*.
- Dill, B.T. (1983). Race, class, and gender: Prospects for an all-inclusive sisterhood. *Feminist Studies*, 9(1), pp.131-150.
- Estes A., Olson E., Sullivan K., Greenson J., Winter J., Dawson G., and Munson, J. (2013) Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain and Development*, 35(2), 133–138.
- Fox, F., Aabe, N., Turner, K., Redwood, S. and Rai, D. (2017). "It was like walking without knowing where I was going": a qualitative study of autism in a UK Somali migrant community. *Journal of Autism and Developmental Disorders*, 47(2), pp.305-315.
- Gemegah, E., (2022). *An intersectional approach to Black parents' experiences of autism in the UK*, Doctoral thesis, Warwick: University of Warwick.
- Gillborn, D. (2015). Intersectionality, critical race theory, and the primacy of racism: Race, class, gender, and disability in education. *Qualitative inquiry*, 21(3), pp.277-287.
- Guishard-Pine, J.A. (2002). *Beyond father absence: An investigation into black fathering and child outcomes in Britain*. Doctoral thesis, London: University College London
- Guldborg, K., Wallace, S., Bradley, R., Perepa, P., Ellis, L. and MacLeod, A. (2021). Investigation of the causes and implications of exclusion for autistic children and young people.
- Hannon, M.D., Blanchard, R. and Storlie, C.A. (2019). Microaggression experiences of fathers with children with autism spectrum disorder. *The Family Journal*, 27(2), pp.199-208.

- Hannon, M.D., White, E.E. and Nadrich, T. (2018). Influence of autism on fathering style among Black American fathers: a narrative inquiry. *Journal of Family Therapy*, 40(2), pp.224-246.
- Hannon, M.D. and Hannon, L.V. (2017). Fathers' orientation to their children's autism diagnosis: A grounded theory study. *Journal of Autism and Developmental Disorders*, 47(7), pp.2265-2274.
- Hannon, M.D., Johnson, K.F., Christian, N.A. and Hannon, L.V. (2017). Black and Latino fathers of students with autism: Culturally responsive support. *Journal of School Counselling*, 15(10), pp.1-31.
- Hannon, M.D. (2017). Black American fathers, their children with autism, and the utility of school-based family counselling: A narrative inquiry. *International Journal of School-Based Family Counselling*, 8, pp.1-16.
- Hastings R. P. & Brown T. (2002) Behavior problems of children with autism, parental self-efficacy, and mental health. *American Journal on Mental Retardation*, 107 (3), pp.222–232.
- Home Office. (2019). *Police Powers and Procedures, England and Wales, Year Ending 31 March 2019*. London: Home Office.
- Hooks, B. (2000). *Feminist theory: From margin to center*, 2nd edition, London: Pluto Press.
- Jelsma, E., Chen, S. and Varner, F. (2022). Working harder than others to prove yourself: high-effort coping as a buffer between teacher-perpetrated racial discrimination and mental health among Black American adolescents. *Journal of Youth and Adolescence*, 51(4), pp.694-707.
- McAdoo, H.P. and McAdoo, J.L. (1997). The dynamics of African American fathers' family roles. *Michigan Family Review*, 3(1), pp. 7-15
- McLaughlin, J., Goodley, D., Clavering, E. and Fisher, P. (2008). Families raising disabled children. *Enabling Care and Social Justice*. Basingstoke: Palgrave Macmillan
- Mahalingam, R. (2007). Essentialism in cultural narratives: A social-marginality perspective in A. Fuligni (Ed.) *Contesting stereotypes and creating identities: Social categories, social identities, and educational participation*, New York: Russel Sage Foundation, pp.42-65.
- Moh, T.A. and Magiati, I. (2012). Factors associated with parental stress and satisfaction during the process of diagnosis of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 6(1), pp.293-303.
- Munroe, K., Hammond, L. and Cole, S. (2016). The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed with an autism spectrum

disorder: an interpretive phenomenological analysis. *Disability & Society*, 31(6), pp.798-819.

Nye, F.I. (1976). *Role structure and analysis of the family*, New York: Sage

Oppenheim D., Dolev S., Koren-Karie N., Sher-Censor E., Yirmiya N. & Saloman S. (2007) Parental resolution of the child's diagnosis and the parent-child relationship. In: D. Oppenheim and D. Goldsmith (Eds.) *Attachment Theory in Clinical Work with Children: Bridging the Gap Between Research and Practice*, New York: Guilford Press. pp. 109–36.

Pleck, J.H. (2010). Fatherhood and masculinity. In M. E. Lamb (Ed.) *The role of the father in child development*, Chichester: John Wiley and Sons, pp.27-57.

Posey-Maddox, L. (2017). Schooling in suburbia: the intersections of race, class, gender, and place in black fathers' engagement and family–school relationships. *Gender and Education*, 29(5), pp.577-593.

Office for National Statistics. (2020). Coronavirus and how people spent their time under lockdown, Available at <https://www.ons.gov.uk/economy/nationalaccounts/satelliteaccounts/bulletins/coronavirusandhowpeoplespenttheirtimeunderrestrictions/28marchto26april2020/pdf>
Accessed 30th August 2023

Potter, C.A. (2016). “I received a leaflet and that is all”: Father experiences of a diagnosis of autism. *British Journal of Learning Disabilities*, 45(2), pp.95-105.

Owusu-Bempah, J. and Howitt, D. (2000). *Psychology beyond Western perspectives*. Leicester: BPS Books

Rafferty, D., Tidman, L. and Ekas, N. (2020) Parenting experiences of fathers of children with autism spectrum disorder with or without intellectual disability, *Journal of Intellectual Disability Research*, 64 (6), pp.463-474

Reynolds, R.E., Howard, T.C. and Jones, T.K. (2015). Is this what educators really want? Transforming the discourse on Black fathers and their participation in schools. *Race Ethnicity and Education*, 18(1), pp.89-107.

Reynolds, T. (2009). Exploring the absent/present dilemma: Black fathers, family relationships, and social capital in Britain. *The Annals of the American Academy of Political and Social Science*, 624(1), pp.12-28.

Reynolds, T. (2001). Caribbean fathers in family lives in Britain. In H. Goulbourne and M Chamberlain (Eds.) *Caribbean Families in Britain and the Trans-Atlantic World*, London: MacMillan Education Ltd, pp.133-153.

Schultz, N. (2022). Did the Pandemic teach us something new about Class? *COVID-19: Cultural Change and Institutional Adaptations*, London: Routledge.

Slade, G., (2014). *Diverse perspectives: The challenges for families affected by autism from black, Asian and Minority Ethnic communities. London: The National Autistic Society.*

Selman, E. L., Fox, F., Aabe, N., Turner, K., Rai, D. and Redwood, S. (2018). 'You are labelled by your children's disability'—a community-based, participatory study of stigma among Somali parents of children with autism living in the United Kingdom. *Ethnicity & health, 23(7)*, pp.781-796.

Seymour, M., Giallo, R. and Wood, C.E. (2017). The psychological and physical health of fathers of children with Autism Spectrum Disorder compared to fathers of children with long-term disabilities and fathers of children without disabilities. *Research in Developmental Disabilities, 69*, pp.8-17.

Stoetzler, M. and Yuval-Davis, N. (2002). Standpoint theory, situated knowledge and the situated imagination. *Feminist theory, 3(3)*, pp.315-333.

Towers, C. and Swift, P. (2006). *Recognising Fathers: Understanding the Issues Faced by Fathers of Children with a Learning Disability.* London: Foundation for People with Learning Disabilities.

Varner, F. and Mandara, J. (2013). Discrimination concerns and expectations as explanations for gendered socialization in African American families. *Child development, 84(3)*, pp.875-890.

Williams, R., Hewison, A., Wagstaff, C. and Randall, D. (2012). 'Walk with your head high': African and African-Caribbean fatherhood, children's mental well-being and social capital. *Ethnicity & health, 17(1-2)*, pp.89-103.

Appendices

Appendix 1 – Interview guide

Understanding Black fathers' experiences of autism their child's autism

In the process of recounting their experiences that makes them distressed, they can seek help from their General Practitioner (GP) or one of the helplines listed below:
Samaritans 0330 094 5717

Campaign Against Living Miserably (CALM) – for men 0800 58 58 58

Themes	Key questions and prompts
Participant info/ Family structure and dynamic	Tell me about you and your family.
Autism – prior and post diagnosis	<p>At what age was your child diagnosed with autism?</p> <p>How did the diagnosis come about – parent seeking, suggested by other professionals (school, health etc)?</p> <p>How does autism influence your day-to-day experiences? Job, Home, friendship group, community. Etc</p>
Fathers' perception and definition of fatherhood	<p>What is your role as a father in your family?</p> <p>What does it mean to be a 'good dad'?</p> <p>What aspects of fatherhood do you enjoy most?</p> <p>Sensitive question: Tell me about your expectations of fatherhood.</p>

<p>Practicalities of fatherhood – engagement/involvement</p>	<p>What is the most important thing you do with and for your child? Prompts:</p> <ul style="list-style-type: none"> • Making decisions • Arranging or proactively involved in child's personal care, needs and development • Arranging child's activities outside the home • Education/interacting with teachers/ homework • Attending health visits/ interacting with health professionals <p>What aspects of fathering your child do you need support with?</p> <p>Where do you get your support? When you need help, do you seek support?</p>
<p>Engagement barriers and facilitators</p>	<p>What things would you say help or prevent your involvement in your child's life? Prompts.</p> <ul style="list-style-type: none"> • Child's needs • Skills and competency • Finances • Institutional barriers (work – policy, start and finish hours, employer's behaviour) • Cultural perceptions of domestic roles (own upbringing) • Religious beliefs and values
<p>Experience of being a Black man in the UK</p>	<p>Tell me about your experience as a Black man in the UK.</p>

Appendix 2

Table 2: Themes derived from interviews with Black fathers of autistic children.

Themes	Key quotes
Family structure and dynamic	<p>But as in terms of helping my boys, like I say, mum does a lot of the work and I just support, you know. The best I can do really, you know, just sort of like support them and try and just keep them entertained (JH, 8) [working from home] so I've been able to support my partner. I would take him to school in the morning and my partner would pick him up (JH, 7)</p> <p>Traditional male duties like DIY, taking the bins out. I cook. I do a lot actually. I cook, I clean, I do my own laundry, (LLF, 3)</p> <p>we're really involved with his school that he was at. He's now moving to a more specialised school which we think's better for him. So, we went to view that and spoke to the teachers and stuff and we agreed together that it would be a better placement for him there. And we think he can improve a lot more there with a lot more attention (LLF, 5)</p> <p>obviously just autism on the whole just impacts on a daily basis, dealing with, I don't know, the tantrums and the attention and the frustration with little man as well, because that's one thing that I've noticed, where he can't talk, he gets frustrated a lot, and when he gets frustrated he lashes out and throws things and things like that, so yeah, that can be hard. (MF, 3)</p> <p>I think having little man has been a big strain on the relationship. I think it takes a lot of time away from us. Obviously, she gets frustrated, I get frustrated and we kind of take it out on each other. (MF, 7)</p> <p>we need to give him the moral support, which we do, yeah, because if he wants to go the cinema, we take him to cinema, if he wants to go for a walk, we take him for a walk. Yeah, there will always be somebody there to do that with him. If he wants to eat, we make sure we serve him, he will eat, and eat well (HP, 4)</p> <p>And I would say to his sister from time to time, "Your brother is going to need you, your brother is going to need you (MM, 2)</p>
Impact of autism	<p>So there's a psychological level to it where there is a thinking all the time, this is something that is always on your mind. Two – you are thinking about how you can improve or give the child...improve the life chances of the child, or give him a chance to be the best that he would want to be (MM, 1)</p>

	<p>stressful and time-consuming (JF, 7)</p> <p>trying to make our day as predictable as possible, so, you know, predictability and having a routine works. we try and make him aware as much as possible of what's going on just so, yeah, he can know what to expect and if there's anything that has the potential to cause a meltdown that way, we'll have, yeah, pre-empted it. (FA, 1)</p>
<p>Cultural influence vs journey to knowledge</p>	<p>where I came from I think most kids with autism were just seen as probably spiritually problematic kids, you know? I came from a more traditional and spiritual family kind of so I didn't really understand too much about it (JF, 1)</p> <p>I was like, "No". I was in denial. And we thought it was just a delayed speech...But then I was like, you know what, just have to accept it and find ways how to deal with the situation, find ways how to make his life better and our family life better and try to accept it. (KM, 1)</p> <p>we got a diagnosis that we actually started researching what does this actually mean? And then over the years it's, still been a learning curve, what does this mean? How does that actually affect us? Does that impact him? What are the things that we need to be aware of just so that we can provide the right support? And yeah, what is determined in terms of schooling, how it's in, you know, government support in terms of, yeah, just a network that we need to have around and what are the resources that he needs to be accessing. So...it's been a steep learning curve and, yeah, we've just learnt as we've gone along really. (FA, 5)</p> <p>I had to be the one to be there to take care he's a male child. Where I'm from, it is a father that trains the boy to be a man. And now when I have a child with disability, I think that's a full-time responsibility to be the one to train him up the way he should be. While also not trying to create and to train up a weak man, I still am, I'm also very cautious of his disability and the nature of his disability and the fact that maybe the way I might talk to him might actually affect the way he thinks or might make him have a crisis or so (AJ, 2)</p>
<p>Fatherhood as a multidimensional role</p>	<p>Just being the provider, the leader... to be an advocate for my child (MM, 9)</p> <p>be there to be that person that can kind of guide, so yeah, they turn to as a dictionary/ as a Google.</p>

teaching them about God, spirituality and all of that. Also, you know, morally, teaching them about right and wrong and that, and also, you know, someone who is on the spectrum also teaching him how to manage his emotions, how to be more socially aware as well. You know, what he might think is acceptable, might not be acceptable, you know, how to visualise the world and, you know, respond to other people (FA, 3)

the best thing that you can give your child is time... the more time that you spend with your children, the more valuable lessons they're going to learn from you and then if you want to raise them to become a better person than you, then the best way is being around them a lot and influencing them. (LLF, 3)

you have to know the areas that you're needed in the family. You know, so and then those areas have to be blocked first. So, you have to sort those out first. I have to make sure that this is what is expected of me. If it is to put the bins out before I leave the house. I know very well that this is what they need. I'll make sure those things are provided before I travel so, I just want them to be comfortable. I want them to have all the things that they need especially, what they need to eat. Yeah, so I try to consider them and then put them in my plans. (UO, 4-5)

to make sure the family is safe, the family has peace at home... (HP, 2)
Sometimes he just plays with things that he's not supposed to play with and they could really, really hurt him... So you just have to give him so much attention that he needs (JF, 2)

you want to be your child's friend, but you also have to understand that you have to discipline them as well. (LLF, 3)

sometimes doing chess or before I used to take them for bike rides... go-karting...they did climbing... I used to go for runs with them, so I'll go for a run and I'll run sort of behind them and they would cycle with their bikes... they love their Xbox and their games, and I used to play it a lot... But every now and again I sort of play computer games with the boys. (JH, 8-9)

So by then, whatever comes out of it, because you are being a good father, you are being able to supervise their level of school attendance, you are being able to supervise their homework at home, you will make sure...you might not be able to help them but you make sure any homework, anything

	<p>work that is given to them, they are able to do it. How to know they are doing it is going to PTA meetings, where the teachers will tell you this and that, and you can also take it away from there. So you work in collaboration with the school. (HP, 3)</p> <p>It's just watching, yeah, watching the children grow into their own person because, you know, we've got three kids and they've all got three different personalities, they've all got, you know, things they like and dislike, so I think it's just watching them grow into three distinct personalities and being able to kind of support them to explore what they like and who they want to be really (FA, 4)</p>
Expectations of fatherhood	<p>I had that sort of fantasy of, you know, them being men and me just looking at them and thinking, "Okay, I did alright," you know. And if they buy me a pint out of it, I've done a good job. it's weird because you have these sorts of ideas of your kids going off to university and stuff like that, or at least just getting a job and just basically being sort of independent...but it's like it's one of those things where I just... don't know. It's like the canvas is kind of open, you know. It's not written. Nothing is written. You don't know, and that's a really sort of uneasy uncertainty is the best way to put it. at the moment it's an open book because I don't know (JH, 2)</p> <p>I probably naively assumed my child will just be the way all the other children are that I've grown up around, you know what I mean? Like, I assume my child will crawl, walk, talk, go to school, go to college, on into the world. So, that was an assumption that I made that obviously I found out wasn't going to be as straightforward as that (LLF, 4)</p> <p>I actually didn't expect parenting to be this tough because I grew up in a home where the mum always does everything. The father just makes the money, goes out, fathers make the money, and then the mum is like at home taking care of the kids. (JF, 4)</p> <p>I wanted to be a caring, a loving father who has time, a father who understands and who spends time, yeah, spending time with them. They've [fatherhood expectations] changed in a better way because trying to accommodate his autism and knowing what he needs and trying to find things which will help him, like his sleeping. (KM, 5)</p>

Supporting fathers	<p>if there was certain programmes where these things were run mainly by, like, black people, whether it's Caribbean, Afro-Caribbean, African, I think parents might be a bit more willing, because everybody understands the culture, the way children are raised and things like that (MF, 7).</p> <p>But I think there's not a lot of activities for dads and autistic children... maybe there should be some stuff for dads, go and do some boys stuff, I'm sure there must be some dads out there that are struggling with their autistic daughters, and they won't even know. (MF, 8)</p> <p>Learning about autism, how to navigate this because I think it's in its early stages trying to understand it. If there are other dads who have autistic children, who have been through, who have been where I am or where, who have more experience, yes, I would like to know how to deal with every situation as it grows, as it develops. Yeah, when you're dealing with an autistic child like this, there's a long, lots of things which I need to learn.</p> <p>having like a sort of father support group would help so that you can talk about things of how to deal with certain things within an autistic child, how to help yourself mentally as well. I think we also need to take care of ourselves as well (KM, 5)</p> <p>so I actually started seeing a counsellor. And I think counselling, for men especially, is a big thing, it's a very big taboo, and I don't know how to talk about my feelings. I think for guys, just in general, as much as you can do the programmes, but I think just talking, just talking, having a space where dads can talk to someone, because it's not easy sometimes, especially having children with autism... you can just be free, open, and let it all out, which I think would help a lot of dads. But that's education, and I do think it is a big taboo for the community. (MF, 8)</p> <p>growing up with the passages, like, "Honour your mother and father," yeah, just the general teachings within faith, and I can only say that as a Christian... But for me, it has helped me just, yeah, growing up, having that grounding, having that foundation, growing up around a lot of role models. That's another thing that I've found really helps, because my church is quite big as well, so I've had a lot of role models doing various types of things, both male and female, so....Yeah, that's another thing. And community as well. (MF, 9)</p> <p>And in a way it's exactly what my mum did for me, you know, because I was diagnosed with dyslexia and, to be honest with you, my mum pretty much</p>
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	<p>threw everything she had at it. In one way I guess it paid off because I was able to get to where I am now, where I can do the same thing for my children. (JH, 4)</p> <p>I don't think I've got much support really. I don't think so, no. (KM, 6)</p> <p>we are actually taught that a man actually handles his problem by himself or just with his family so it's something I'm used to, I unconsciously do it. For you to be a man you have to be able to provide, you have to be able to just do something, and when you go around asking it becomes... you're seen as not a real man, yes, they [the community] will say, "You not be a real man". Okay, so you just have to learn how to provide and then keep your problems to yourself sometimes. (JF, 7)</p>
Individual vs systems	<p>I know it's going to be expensive because, you know, I am in a position to pay for things and to help (JH, 4)</p> <p>... I mean that's my biggest fear is this like, you know, at what point... he's already had run-ins with teachers before, you know, at primary school, and it's like at what point, yeah, at what point are the teachers just going to see him as the naughty kid or kick him out the class because he's being too disruptive, you know. (JH, 5)</p> <p>I had to change my hours at work so on a Thursday and Friday, I have to leave early, and that way, yeah, she can go to work and do what she needs to do. (MF, 3)</p> <p>work is the biggest interference. my bosses can be quite flexible, but again, there's time when they can't be, and I get that, from just the working business point of view. But obviously that can't work, you need two incomes to run a household... if I could afford to work part time, and spend more time with him, I would love that, but obviously that's not going to happen. (MF, 10)</p>
Experiences as a Black man in the UK	<p>feel very self-conscious going running, [in a really rural area] you know, as a black man running, "I feel that people are wondering why, judging me," ... "I feel anxious going out as a black man that I might be stopped," (JH, 17)</p> <p>Just stuff like being followed around the supermarket by a security guard... But that's more when I was growing up... when I was younger, in my teens,</p>

early 20s, there was a lot of those sort of microaggressions. Women, white women crossing the road, the other side of the road, stuff like that. And it's like, oh okay. I'm not going to hurt you, but if that makes you feel safe, then that's fine by me. (LLF, 8)

knowing how to speak and being able to stand up for yourself in places where you think you're being mistreated. Just being able to stand up for yourself and to make sure you report or document things because you have to document whatever you, if you're in a workplace, document everything, stuff you do, so that's because we are the least likely people to be believed. But if you have evidence, yeah, they'll budge. If it's just word of mouth, no, they won't believe you. (KM, 7)

you walk into a particular restaurant and you're looking around and you're the only one that looks like this in this restaurant, and then you have a sense that you have this... I don't know if it's within me, but be, like, "Really, what are you doing here in this place?" And so when I do this, what I do, I combat that with holding my head up high and walk in, "I am here." Another thing that is my mantra is that I was not...I was placed in a place like this, not to blend in, but to stand out, I need to stand out, stand out in terms of my integrity, stand out in terms of my research work, stand out in terms of how I deal with people, because above all, I'm a Christian and I'm not asked to do anything but to love my enemies (MM, 8)

the psychological aspect, and the social aspect, you are aware that you are different, you are aware that you are a minority, there is no missing, there is no doubting that you are in a majority Caucasian country. So first of all there is an awareness of that. Secondly, it puts you on your guard, because I'm looking around, so, "What do you mean? Talk to me. What am I sensing here?" So, being a black man in the UK is not easy. It's not easy. It's not, as we still know, the idea of racism still works a lot. Not everyone really want to give you work. Not everyone actually trust you. I still work more and sometimes even though sometimes I deserve a raise and then I don't get it, still, I don't still take that too hard (AJ, 8)

I think I've lived a privileged life compared to a lot of black males, young black males coming up so I can't really complain. (LLF, 7)

I'm an immigrant and I feel there are some problems I have to avoid at all cost. I try my very best to do that (AJ, 8)

sometimes there might be a bias in the system... Because sometimes there's low expectation as well... sometimes when people are not expecting that much from you, you fall through (FA, 7). So, for reading, for instance, he used to read quite a lot at home but then at school they had very simple texts for him to read, which, you know, they probably thought he couldn't read... But then during the pandemic, because he was at home, I actually bought loads of books. And now, yeah, he's one of the top readers in the class. (FA, 6)

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