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University of Southampton

Faculty of Environmental and Life Sciences

School of Psychology

Developing Culturally Responsive Educational Psychology Practice for Parents of Black African Autistic Children

by

Claire Cooper, BSc, MSc

Thesis for the degree of Doctorate in Educational Psychology

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University of Southampton

Abstract

Faculty of Environmental and Life Sciences

School of Psychology

Doctor of Educational Psychology

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Claire Cooper

Educational Psychologists (EPs) are privileged to work with autistic children, young people and their families. As a demographically homogenous white workforce working within an increasingly multicultural country, EPs will regularly work with parents and families of autistic children from different cultural backgrounds to their own. This thesis explored the way EP practice can be developed to be more culturally responsive when working with black African parents of autistic children.

This thesis details two separate but related studies; the first is a systematic literature review which aimed to synthesise the existing research about 'The experiences of black African parents of autistic children in the UK'. Eleven studies were included in this review and thematically synthesized. Five themes were developed describing the unique intersectional experiences of identifying as black African and being a parent to an autistic child. The findings demonstrated the influences of faith, religion, and cultural values on experiences of parenting, with an absence of universal language around autism impacting the ways parents understood and communicated about autism. Parents described challenges interacting with professionals and accessing support and their concerns for their child navigating systems as being both black and autistic.

The second study was a qualitative interview study of 11 EPs and two black African parents working and living across two London local authorities. The study aimed to investigate the interactions between EPs and black African parents when working together around autistic children. Five themes were developed using reflexive thematic analysis. The themes described EPs current practice and the systems they work within as barriers to changing practice. Additionally, parents described their positive and negative experiences working with professionals during their child's early years. Parents and EPs spoke about power, trust, and safety within this study, highlighting the essentiality of reducing power imbalances so that parents can feel safe during their work with EPs.

The findings of this thesis should be used to develop EP's cultural awareness about the experiences black African parents of autistic children may have, and to develop culturally responsive practice.

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P1: And so I think, but if you've been a parent like you know you've had other children etcetera or you've got experience of, for example, the autism in your family, then you might be a bit more take it with a pinch of salt and just be like I know my kid and that's fine.

I: Yeah.

P1: But I think, yeah, at the beginning. So as I am now, I'm like, OK, well, this is a report and that's fine. You saw XXX for half an hour. This is the first time he saw you.

I: Yeah.

P1: So I'm able to put it into perspective for myself now, but initially it was, but I I'll be honest with you, the way the EP was with us and the way she wrote the report, I was, yeah, it wasn't anything that made me sort of upset, I'll be honest.

I: I'm really glad you had such a positive experience.

P1: Yeah.

I: That's amazing. And did the EP come to your home?

P1: Yes, so there was a home visit.

I: And what was that like having a home visit done?

P1: Yeah, there was a home visit and oh, by then it was OK because we'd had like few speech and language and therapists coming in and I think, yeah...So it wasn't sort of anything that was new..yeah... So we had all the toys set up just like we wanted.....And there was, yeah, it was all just....Yeah, I wasn't fussed about that.

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Definitions and Abbreviations

EP ..... Educational Psychologist

EPS ..... Educational Psychology Service

EHCP ..... Education Health and Care Plan

LA ..... Local Authority

Black African ..... An ethnicity label which can be used by people with ancestral origins in Africa.

Chapter 1 Thesis Introduction

1.1 Context for Research

The overarching motivation for my thesis project was to understand further and develop educational psychology practice to better meet the needs of families of autistic children from diverse cultural backgrounds. This thesis contributes part of my educational psychology doctorate, alongside hundreds of placement days across three demographically distinct and diverse local authorities, two of which were in London. Throughout my time on placement, I have worked with parents of autistic children and young people at various ages and developmental stages and have had the privilege of being given an insight into their stories and journeys of parenting. I noticed that sometimes it felt as though there was a disconnect between my conceptualisation of autism and theirs. One poignant example of this was a consultation with a parent of an autistic child who had recently started school. The parent was from a different cultural background to mine (known due to them describing it within our conversation); the meeting felt like it had progressed well, and we had agreed on clear targets and next steps for all involved. Towards the end of the meeting, the parent asked me: "*When will my child get better?*". It was at this point I realised that no matter how well I felt I had managed the meeting, our understandings of autism were very different. I had not taken the time to reflect on what autism might mean to them and had assumed that we held the same understanding of autism.

My experiences and opportunities whilst on placement have developed my passion for working in a culturally *responsive* way; this refers to a dynamic and active process to ensure my practice best meets the needs of the families I work with, recognising the different belief systems they may hold to my own and what this means for my practice. The intention of this work is not to change parents' beliefs but instead to adapt my practice so that parents can be equal partners in the decision-making for their child, a vital principle of the Special Educational Needs Code of Practice (SEND COP; Department for Education; 2015). The awareness of the need for adaptations in practice is reflected through guidelines for practice shared by various professional bodies that Educational Psychologists must abide by. A fundamental principle in the British Psychological Society Code of Ethics and Conduct (BPS; 2021a)

is the need for *respect*, "to value dignity…with sensitivity to the dynamics of perceived authority or influence over people…members should consider communities and shared values within them". Additionally, the Health Care Professions Council (HCPC; 2023, p9) recognises:

> *"the impact of culture, equality and diversity on practice and practise in a non-discriminatory and inclusive manner…to respond appropriately to the needs of all groups and individuals in practice recognising this can be affected by…cultural differences.. to recognise the potential impact of their own values, beliefs and personal biases,…to ensure all service users and carers are treated with dignity and respect."*

A recent Association of Educational Psychologists survey (AEP; 2021) of approximately 900 members highlighted the UK educational psychologist workforce as a majority white (86%) female (86%) profession. With increases in multiculturalism in the UK and increases in autism diagnosis rates, educational psychologists are frequently working with parents from different cultural backgrounds to their own who may hold differing belief systems towards various special educational needs. Educational psychologists in the UK undertake rigorous doctoral-level training before practising, however, Phiri et al.'s (2023) research highlights the Western-centric nature of many psychology curriculums taught. A lack of instruction and information about alternative approaches and worldviews enhances the potential for educational psychologists in the UK to misinterpret and misunderstand the belief systems and attitudes parents from diverse cultural backgrounds may hold regarding special educational needs.

Within this research I have chosen to explore the experiences of black African parents of autistic children. Although as a white British woman this is not a cultural background I identify with, my proximity to this community (through my personal relationship with my partner, friends and local community, living in a London borough with a high population of black African residents) has motivated me to understand their experiences better and to support the development of educational psychology practice. In the second year of my doctoral training, I attended a clinical psychology doctorate thesis presentation at the postgraduate research conference at my university by Dr Melanie Osafo, who researched

black parents' experiences in accessing perinatal mental health services. At the end of the presentation, Dr Osafo stated, "It *shouldn't just be marginalised groups researching marginalised groups*." which has fuelled me whilst completing this research.

This thesis consists of two separate but related chapters/studies. Chapter two of this thesis reports on a systematic literature review (SLR) conducted to synthesise existing research into "The experiences of black African parents of autistic children in the UK". This SLR was the first to investigate the intersectional experiences of participants who 1) identify as black African, 2) are parents to autistic children, and 3) live in the United Kingdom. There is a growing body of existing research which has focused on the experiences of parenting autistic children in Africa, but limited research acknowledges the experiences of black African parents who have either relocated to the UK or were born here and hold this identity. This SLR synthesised parents' experiences from various African countries spanning the entire African continent. The intention of this research was not to amalgamate the range of cultural backgrounds that participants across the included studies held into one singular experience. Instead, the aim was to provide a synthesis of some of the commonalities in experiences parents shared across the papers to inform the reader of some of the experiences black African parents of autistic children in the UK may experience.

Chapter three documents an empirical research study into educational psychologists' practice when working with black African parents of autistic children in their early years, and black African parents of autistic children's experiences of professional involvement during their child's early years. By investigating both sides of these interactions, I intended to be able to 'co-produce' recommendations for EP practice development. My empirical paper sought to develop knowledge to answer two research questions: 1) How do EPs currently consider the needs of black African parents of autistic children, and what barriers do EPs encounter in their practice? 2) How do black African parents of autistic children experience working with professionals in their child's early years?

1.2 Research Paradigm and Reflexivity

This thesis aligns with a social constructionist paradigm, adopting an interpretive approach to understanding the experiences of participants shared within the research.

Social constructionism is considered at the ‘subjectivist’ end of the continuum between positivist and subjectivist research (Taylor, 2018), with the nature of reality and knowledge as subjective to the person experiencing them. Interpretivism and social constructionism are research terms often used interchangeably; however, it is essential to note that social constructivism is distinct from interpretivism due to its focus on the importance of language and human interaction as mediating meaning (University of South Australia (n.d.). In addition, this research also reflects the interactions of power, both interpersonally and systemically.

This research also draws upon on the axiology of social justice research which involves participation from within the community to achieve the research aims. It is defined by Cohen-Miller and Boivin (2022; p.4) as "the purposeful commitment and advocacy to address systemic and systematic issues of equality and inclusion in particular for marginalised and oppressed peoples". Both Schulze et al., (2017) and Garcia-Vazques et al., (2020; p.210) described how well-positioned Educational Psychologists are to promote social justice through their work with families, professionals, children, and young people. Specifically, they argue that Educational Psychologists can “enact social justice through culturally responsive professional practice and advocacy” Garcia-Vazques et al. (2020; p. 210).

Throughout my research, I have drawn on the fundamental tenets of Critical Race Theory, which acknowledges the interactions between society, power and race. Critical Race Theory suggests there can be a racial bias, consciously or unconsciously, within services and institutions in the Western world towards 'whiteness' holding this power (as a social concept, not necessarily focused on white people). Aydarova (2019) described how social justice research often focuses on the voices and experiences of marginalised groups, which, despite being extremely important in developing broader knowledge in this area, frequently disregards the actions of those holding positions of power. Accordingly, in addition to the experiences of black African Parents of autistic children, EPs’ experiences of their practice and knowledge were gathered. EPs are positioned as holding invisible and visible power sources due to their potential to create, maintain, or break systems of inequality and injustice through their practice. This approach was referred to by Aydarova (2019) as 'studying up'; by seeking to combine the experiences shared by participants across the systematic literature review

and the empirical paper, it is hoped that more positive change can occur due to these research findings.

Epistemologically, I identify with the social constructionist belief that the context and social world shape the reality the person is situated within, including the language spoken and the culture the person's world is shaped by. To explore this, knowledge within this research was developed and constructed through my interactions as the researcher with participants who shared their experiences. This was done through interviews using a dialogic qualitative methodology. Although I brought a topic guide for questions to the interviews, I was flexible in my approach to allow the participants to guide me where they wanted to go throughout the conversation, using my guide as a gentle anchor and prompt. Through my experience as a trainee EP, I developed my enquiry skills used within consultations with children and their families. I drew upon these skills when interviewing the parents; I checked my understanding by summarising and reflecting back to the parent, and where I had misunderstood, I was pleased to be corrected. It was important that during the interviews, participants felt comfortable sharing their 'authentic truth' with me. I knew the potential for the participants to be exposed to social desirability bias. Qualitative research methods such as interviews are considered to be susceptible to this type of bias (Bispo, 2022), and there was a potential that participants may answer in a way based on what they thought I wanted to hear.

I am aware that my positioning as a white British female trainee educational psychologist may have been both a facilitator and a barrier to the participants' ease when talking to me which would have been experienced differently for each group. For parent participants, I can speculate that my positioning as a 'professional' and as the 'researcher', in combination with my visible race differences, may have acted as a barrier for them to share their authentic truth with me. An example of this was when one parent shared their experience of working with a black EP; I felt a shift in the conversation as they became careful with how they worded their experiences, as it felt as though they did not want to offend me. Additionally, I felt relief when one parent felt comfortable pushing back on something I had asked her; it was validating for me as a researcher that I had created a comfortable virtual space to go against what I had presented. It was also important to me that during these parent conversations that I was clear that I did not share the experiences that the participants had; when

introducing myself, I told them my reasoning for the research and how (in addition to my visible race differences) I did not have an autistic child. This meant that knowledge was constructed with these participants through me learning about their experiences in conjunction with the findings of my systematic literature review.

In contrast, my positioning as a white British female trainee EP felt like a facilitating factor for my interviews with the EPs. Having worked alongside them daily, there were many 'shared' experiences between myself and the participants. This meant that it was necessary to acknowledge my 'researcher subjectivity' during the analysis stage for this data set and its influence on how my themes were generated. I was also aware of the differential power dynamics at play within these interviews; I was coming to the EPs as qualified experts and myself as a trainee; however, I held the 'power' during sensitive topics in which EPs might not have wanted to share gaps in their knowledge, practice, or experiences. In addition to ensuring confidentiality within the reports, I kept a reflexive diary across all interviews to help ensure that I was aware of my own experiences and how my reality compared to the participant's. This piece of research was ideal for the use of reflexive thematic analysis.

1.3 Ethical Considerations

At all stages of this thesis, the process needed to be conducted according to the University's and the professional ethical guidelines I was working within. To ensure the research adhered to the University's expectations, four amendments to the initial ethics application and documentation were made across the two years to reflect changes to the initial plans for recruitment. All decisions made throughout this research were made with the support and guidance of my thesis supervisors during regular supervision meetings.

From a research ethics perspective, the research must adhere to the BPS Code of Human Research Ethics (2021b). All participants in this study were required to give informed consent in two ways: by signing a consent form and sending it back to me to be stored securely, and the second was through verbal consent at the beginning of the interviews. All data gathered within the research process was anonymised, and care was taken to ensure that all transcripts were unidentifiable. A unique ethical challenge within this research was ensuring participants could identify themselves within the

research findings; however, they could not easily identify colleagues (for EPs) based on information divulged within the interview. All participants were given clear information about the date they could withdraw from the research process; no participants requested to do this. Due to the nature of the research, which investigated potentially sensitive topics, it was paramount that all participants were protected from harm; I was prepared to use supervision to navigate any difficult conversations that might arise during the interviews, ensuring the ethical handling of sensitive issues.

My conduct and interactions with participants within this research process needed to adhere to professional ethical guidelines, namely the BPS Code of Ethics and Conduct (2021a) and the HCPC Standards of Proficiency (2023). As this research involved working with participants from a different cultural background to my own and potentially from a different linguistic background, it was important to ensure ethical considerations were taken to ensure my practice within this research treated all participants respectfully. Study documentation was in lay terms, with the option for parents to have access to professionally translated versions in their preferred language. It was important to me that translated documents were readily available for parents to ensure parents who needed the translations could fully understand and consent to all aspects of the research instead of the translations being presented as an optional extra, which may have been a deterrent for the parents' consideration of participation. I also planned for a professional interpreter service to be available to join parent interviews. I have received previous training about working with interpreters whilst on placement, and I was confident that I could implement these skills into my research. Using the 'inclusion panel' whilst planning my interview guides ensured that the questions asked within my research were inoffensive and appropriate, including the views of a black African parent, parents of autistic children and a black African EP.

1.4 Language and Terminology

The importance of using appropriate language and terminology within this thesis was not taken lightly. Following conversations with friends and family about their language preferences, as well as through the analysis of contemporary discussions online, I have chosen to use the following language: 'black' and 'white'. These are used throughout this thesis as racial labels, representing a social construct and associating a group of people based on either ancestry or physical characteristics (University of

Bristol, 2023). I recognise the case for capitalising these labels; a capital B in 'Black' can be used to recognise the importance of "black power"; however, the capitalisation of ‘White’ can be used by white supremacists to signify their view of importance over black people (Ellis, 2022). Ellis (2022, p.18) described how these words hold power, but that they are social constructs, and a choice not to capitalise them emphasises a "sense of hope for a future where the importance of these constructs diminishes". I will, therefore, only capitalise these words if at the beginning of a sentence or where grammatically appropriate.

Black is a heterogenous label used to self-ascribe by people from an extensive range of ethnicities and races, and whilst there may be some shared beliefs amongst a cultural group, the lived experiences of each black person will vary immeasurably. This research has focused on the experiences of black African parents and EPs working with this population. This term is used due to its classification within the England and Wales government census. The use of this label was chosen as opposed to 'African' because many people who are African and of white European descent will hold different experiences of being labelled as African (BBC News, 2023), away from the intersectional experiences of being seen by others as black. Additionally, white and black African people may hold different cultural values; although it was not in the scope of this research to explore this.

Throughout this research, the use of identity-first versus person-first language to describe autism has been considered. Research by Kenny et al. (2015) found that in a UK sample, autistic adults and family members preferred the term 'autistic' (identity-first), while professionals preferred the term 'person with autism' (person-first). Similarly, a mixed methods investigation by Keating et al., (2022) explored the terminology preferences of 654 English-Speaking autistic adults across Australia, Canada, Ireland, New Zealand, UK and USA, and showed that there was an overall preference for identity-first language. At the present time, there is very little research into the language preferences of those from non-English speaking countries more generally, including African countries. Examples of where it does exist, is research by Buijsman et al., (2022) and De Laet et al., (2023) who both found that autistic Dutch participants and parents of autistic children in their respective studies showed a majority preference for person-first language. More research needs to be conducted into the terminology preferences of those from non-English speaking countries

including variation across African countries. It is important to note that parent participants within my empirical paper were not explicitly asked for their language preference, however where I am directly quoting a parent I have mirrored the parent's language verbatim out of respect for their language preferences. Throughout the main body of the research, I have used the term 'autistic child' to reflect the preferences of black African parents of autistic children who have been asked about their language preferences within their child's reports across my work on placement across the two local authorities.

1.5 Dissemination Plan

Both research papers within this thesis were written according to author guidelines for two academic journals. I intend to submit the systematic literature review to *Disability and Society* and the empirical paper to the *International Journal of Inclusive Education*. In addition to submitting to academic journals, the research will be presented to various audiences. Before submitting this thesis, an overview of the systematic literature review and the empirical paper has been shared with both the second local authority and the Autism Community Research Network @ Southampton (ACORNS); my research supervisors are the co-directors of this network of professionals and students who present findings of participatory and collaborative research about the experiences of autistic children, young people and adults. In addition, the research will be shared in a poster presentation at the Educational Psychologist Autism Special Interest Group and at the university's postgraduate psychology conference. In addition to this, I hope to present these research findings at the British Psychological Society Psychology of Education Conference. It has felt important to share these findings as widely as possible so that if even one EP adapts their practice with black African parents of autistic children, more positive interactions can be had, and better outcomes for the young person can be seen.

Chapter 2 The Experiences of Black African Parents of Autistic Children in the United Kingdom.

2.1 Introduction

Parenting a child is a complex biological and social process involving bi-directional relationships between members of at least two generations and is mediated by the child's characteristics, as well as the cultural experiences of the parent and child (Bradley, 2002). Globally, parenting shares three universal aims: 1) securing their child's safety and health, 2) making sure their child is prepared to be productive members of their society, and 3) conveying culturally embedded values across generations (American Psychological Association, 2024). Parenting plays a major role in the life course trajectory of a child, influencing developmental areas, including relationships, self-regulation and physical health (Sanders & Turner, 2018).

The bidirectional nature of parenting describes not only the influence that parents can have on their child but also the influence of the child on their parents; for example, research conducted by Coplan et al., (2009) highlighted the influence of a child's emotional regulation skills on maternal parenting styles. For those whose children develop differently, such as autistic children, parents can experience parenthood differently from those raising non-autistic children (Greenlee et al., 2023). Raising an autistic child can lead to different parenting aims than those with typically developing children, for example, research by Roquette Viana et al., (2021) found caregivers of autistic children developed a "new perspective on parenting", related to changes within their understanding of their role and the outcomes of their role as parents.

Autistic children experience strengths and areas of difficulties associated with (not limited to) communication and interaction, emotional regulation, sensory sensitivities and intense interests, which can require a diverse range of support needs (National Autistic Society, n.d.). The existing research into parenting an autistic child demonstrates the influence of having an autistic child on parenting experiences.

Parenting autistic children and meeting their support needs can often be associated with significantly higher levels of 'parenting stress' than parents of non-autistic children (Sacca, Cavallini & Cavallini, 2019). Rios et al., (2022) described parenting stress as feelings of being unable to cope with parenting demands, separate to other types of stress that some parents can experience such as financial stress or difficult life events and may be experienced because parental support systems are inadequate. Consistently, Galpin et al (2017) found that existing formal support systems for families of autistic children often do not meet the parent's or children's needs, contributing to higher levels of parenting stress (Galpin et al., 2017). Moreover, Myers et al., (2009) found that stress was experienced by the majority of parents of autistic children in their study, aged between 2 and 21 and was associated with challenging behaviour and increased care demands on parents. Accessing appropriate support through services for their child was difficult, and parents reported a negative impact on their personal well-being, work and marital relationships. However, it is important to note that parents also report many positive and rewarding aspects of parenting autistic children. Parents in Myers et al.'s (2009) study described many positive effects their child had on their life; their child had facilitated a new awareness and understanding of disabilities, and many parents were proud of their child's uniqueness and achievements. They described how their spiritual life was affected positively, and for some, having an autistic child had a positive effect on their other children.

Importantly, a lack of reporting of participants' ethnicity and racial information can be found in autism research more widely, which can lead to a potential for a bias towards white parents' experiences of parenting autistic children. This may have negative implications for recommendations for adequate support and service provision to meet the needs of parents and children from diverse backgrounds; Pierce et al., (2014) detail how across three major journals publishing research about autism, participant ethnicity or race was unreported. Steinbrenner et al., (2022) also highlight their findings of a large-scale review about reporting the way participant ethnicity and race was reported; only 25% of 1013 articles reported any data about this. Where it was reported, 64.8% of participants were white, and 7.7% were black. It is, therefore,

imperative to look deeper into the intersectional experiences parents of autistic children can have.

Further, it is essential to recognise that experiences of parenting are heavily influenced by the cultural norms parents are situated within; attitudes to parenting, parenting knowledge and childrearing practices are intertwined, comprising of 1) parents' own experiences during childhood, 2) the societal and cultural expectations learned from others, and 3) their child's characteristics (Breiner et al., 2016). Parents receive guidance and advice from family, wider society and community members about how to support their child's development, and therefore parenting expectations and patterns can be heavily influenced by others outside of the parent-child relationship.

An example of cultural influence on parenting can be found within the family traditions of African cultures. Although African cultures are heterogeneous and encompass wide variations in language, faith and cultural practices, including parenting and family traditions, there are some shared practices. Mawusi (2013) described how parenting in African cultures follows common values and practices, including extended family systems, knowledge sharing through folktales, and cultural rites of passage. African cultures are considered collectivist cultures, with the African philosophical framework of Ubunto encompassing the idea of the importance of interconnectedness between people, translated as "I am because of who we all are" (Mugumbate & Nyanguru, 2013). Collectivist cultures rely on members of society following shared expectations to work towards shared goals, meaning those who cannot conform to the expected behaviours cannot contribute to the societal goals and may experience stigmatisation (Papadopoulos et al., 2013).

Experiences of raising an autistic child in high-income areas of the world are well-documented. However, they have been studied much less frequently in low-income countries (Cardon & Marshall, 2020), such as various African countries. Where researchers have conducted investigations into the caregiver experience in African countries, challenges with diagnosis and care of autistic children, a lack of accessibility services to meet family needs, and a lack of local knowledge about autism have been

reported (Cardon & Marshall, 2020). To better understand the cultural and contextual factors that influence the help-seeking behaviours of caregivers of autistic children across the globe, not just the high-income areas, de Leeuw et al., (2020) conducted a systematic review and broader literature research of more than 800 existing studies and papers about caregivers' journeys from initial identification, help-seeking and then access to diagnosis. The findings of de Leeuw et al.,'s (2020) research were presented within a four interrelated-level conceptual framework. Within this framework, parental recognition of their child's needs was influenced by cultural norms of typical behaviour and caregiver awareness of their child's health status. If the needs were not recognised, parents would not be able to interpret their needs as the potential for being autistic. Additionally, parents' interpretation of their child's needs was often influenced by the cultural beliefs and associated stigma towards disability, religion, parents' mental health and their knowledge of typical child development. Further, parental reporting of their child's needs was influenced by the availability, accessibility, acceptability and affordability of seeking support. Parents would then choose between seeking mainstream medical support, or traditional religious-based support (or both). For parents who sought medical support, this was influenced by their literacy and language skills, which enabled them to communicate and complete paperwork and their own experiences of interactions with the professional. Research by Aderinto et al., (2023) described how the societal and cultural factors of stigma and discrimination were seen to have a significant impact on families and caregivers of autistic children and adults in Africa, particularly relating to the emotional and financial burden they experience. It is therefore reasonable to infer that black African parents of autistic children are navigating a dual challenge of raising an autistic child, alongside negative cultural attitudes towards autism, and an absence of professional and societal support for them and their child.

Globally, little research has been conducted into the transcultural experiences of black African parents raising an autistic child outside of Africa. As cultural worlds merge and attempt to maintain their own identities within societies that may hold differing values and norms, this can create a conflict between parenting and societal expectations and norms (Harkness & Super, 2002). Moreover, African parents raising

autistic children in the UK who identify as black will be required to navigate services and systems that are fraught with systemic and institutional racism, where indeed, “outright racism still exists” (Sewell et al., 2021). Beginning in 2020, the black British Voices Project (BBVP; Semple, Dyke & Monrose, 2023) investigated the views of over 10,000 black Britons about their lives in the United Kingdom. The findings of the study suggested systemic racism "remains an obstacle in every sector we studied... with racial prejudice and insensitivity in the UK". In total, 41% of participants identified racism as the most significant barrier to young black people's educational achievements. Moreover, 90% of participants responded negatively regarding their trust in the British Education System to support the needs and aspirations of black students, highlighting severe distrust in the systems in place to support black children and young people.

Alarming figures of disparity begin before black children are born; black babies are over two times more likely to be stillborn than white babies, and black parents are 43% more likely to have a miscarriage than white parents in the UK (The Sands and Tommy's Joint Policy Unit, 2023). In early education, implicit racial biases are seen to exist among early educators; Gilham et al., (2016) investigated how preschool teachers would anticipate displays of challenging behaviour from the children by measuring the frequency and duration of time the teachers gazed at the children. Teachers in this study gazed the most at boys and black children, with the most significant interaction found for teachers gazing at black boys, suggesting they anticipated challenging behaviour most frequently from this group of children. These findings suggest that black parents and children can hold unique parenting concerns compared to white parents and children.

The unique parenting experiences of black African parents of autistic children must be better understood, as the black African population in the United Kingdom is the fastest growing and largest population of people who identify as black (GOV.UK, 2022). Across the United Kingdom, diversity in ethnicity and culture is rapidly increasing; according to the 2021 census (GOV.UK, 2023), in England and Wales, 2.5% of the overall population identified as black African, equating to almost 1.5 million people,

while 58% of the black African population lives in London (GOV.UK, 2022). Moreover, autism diagnoses are increasing, with the highest rates in children being identified in black children (2.1%; Roman-Urrestarazu et al., 2021). Between 2005 and 2011, a 102% increase in diagnoses of autism was seen, specifically in black African children in the UK (Strand & Lindsay, 2012). These figures highlight the increasing number of black African families in the UK who have an autistic child, requiring them to navigate potentially unfamiliar systems and engage with professionals from cultural backgrounds different to their own. This must be better understood to ensure equity of resource access and appropriate support for these parents and children. This review of the literature, therefore, aims to synthesise the existing literature to describe the experiences of black African parents of autistic children in the UK.

2.2 Methodology

2.2.1 Search Strategy

A systematic search was conducted using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) approach (Page et al., 2021; see figure 1). Initial scoping searches were conducted between August and September 2023 to familiarise the author with existing research in this field and to identify a gap in the literature to be addressed. This gap was identified to be a review of the experiences of black African parents of autistic children, specifically those living in the United Kingdom. A review protocol was created following the Sample, Phenomenon of Interest, Design, Evaluation, and Research type guide (SPIDER; Cooke et al., 2012; see Table 1 for review protocol and search syntax). This style of review protocol was chosen in place of the more frequently used PICO as it is described as better suited to qualitative research (Cooke et al., 2012); this was due to the concept of an ‘Evaluation’ aligning more appropriately than ‘Outcomes’ in PICO when thinking about parental experiences.

The initial literature searches were conducted in October 2023 across four electronic databases. These were PsycInfo, ‘ERIC’, Scopus and Web of Science. The first two were chosen due to their subject foci being Psychology and Education, whilst

the latter two were chosen due to their content diversity, meaning they had the potential to include items from various subject disciplines relevant to the search.

Table 1: Review Protocol and Search Syntax

Letter	Section	Search Terms
S	Sample: Black African: • Mothers, fathers (Including step-parents and adoptive parents) • Carers	"South Africa*" OR "North African" OR "East African" OR "West African" OR "black African" OR "African" OR ghan* OR somali* OR ugan* OR niger* OR ethiopia* OR Congo* OR tanzan* OR Kenya* OR Sudan* OR Algeria* OR morocc* OR angola* OR ghana* OR mozambi* OR madagasc* OR ivor* OR cameroon* OR mali* OR burkin* OR malawi* OR zambia* OR chad* OR rwanda* OR benin* OR burundi* OR tunisi* OR sudan* OR togo* OR "sierra leon" OR libya* OR liberia* OR eritrea* OR gambia* OR namibia* OR “BAME” OR “BME” OR black OR immigrant OR culture OR acculturation AND parent* OR mothe* OR father* OR caregive*OR people OR person OR famil*
PI	Phenomenon of interest: • Autism in children • Children with additional needs	autis* OR disabl* OR difficul* OR impair* OR asc OR asd OR asperg* OR “autism spectrum disorder” OR “autism spectrum” OR “autistic disorder” AND

		child* OR yout* OR "young person" OR adolesc* OR “PRE-SCHOOL” OR “School-age”
D	Design: • Published (peer-reviewed) literature • Grey literature	
E	Evaluation: Experiences of parenting their child in the United Kingdom	"United Kingdom" OR "Great Britain" OR Britain OR UK OR England OR Ireland OR Scotland OR Wales OR London
R	Research Type: • Qualitative research • Quantitative research investigating experiences • Mixed methods research • Grey literature: unpublished and published academic theses.	

There was no limit on publication date; in total, 3628 papers were identified across the databases. Following the database searches, the same search terms were used in Google Scholar to see if further papers may be identified. Four additional doctoral theses were included. In addition to searching the electronic databases and websites, the author contacted an Educational Psychologist via social media who had previously led a workshop about their thesis and received a copy of their unpublished empirical study. The free version of Rayyan AI software (Ouzzani et al., 2016) was used

to identify and remove duplicates (n= 1389) manually; once removed, 2239 papers remained to be screened.

2.2.2 Inclusion and exclusion criteria

The inclusion and exclusion criteria were used whilst screening titles and abstracts of the remaining 2239 papers. Inter-rater reliability of the screening tool was assessed by the author and a colleague using the criteria to assess the same 30 titles. A 100% inter-rater agreement rate was obtained, and following some minor feedback on the wording, the inclusion/exclusion criteria was finalised (see table 2).

Table 2: Inclusion and Exclusion Criteria

Include	Exclude
Participants described as: • black OR African OR black African OR black and from: Algeria/n, Angola/n, Benin/ois, Botswana/n, Burkina Faso/Burkinabe, Burundi/an, Cape Verde/ans, Cameroon/ian, Chad/ians, Comoros/Comorian, Congo/lese, Ivory Coast/Ivorian, Djibouti/an, Egypt/ian, Guinea/n, Eritrea/n, Eswatini/Swazi, Ethiopia/n, Gabon/ese, Gambia/n, Ghana/ian, Kenya/n, Lesotho/Mosotho, Liberia/n, Libya/n, Madagasca/r/n, Malawi/an, Mali/an, Mauritiana/n, Mauritius/Mauritians, Morrocc/o/an, Mozambique/Mozambican, Namibia/n, Niger, Nigeria/n, Rwanda/n, Senegal/ese, Seychelles/Seychellois, Sierra Leone/an, Somali/a, South African (if identified as black), Sudan/ese, South Sudan/ese, Tanzania/n, Togo/lese, Tunisia/n, Uganda/n, Zambia/n, Zimbabwe/an	• No demographic data about participants is given • Participants are described as anything other than ‘black African’ (see inclusion) • Studies where participants are labelled as ‘black British’, with no elaboration • Participants not related to an autistic child • Participants not based/living in the United Kingdom.

• Participants who are dual heritage, with one or more from the list above. • Participants related to autistic children (with and without a diagnosis). • Participants who are carers.	
• Experiences of parenting/being related to autistic children • Experiences in the United Kingdom • Retrospective reflections about the experiences of autistic children during childhood	• Studies investigating the prevalence of autism • Studies exploring experiences of parenting autistic children outside of the UK
• Qualitative methods • Quantitative methods specifically looking at experiences of parenting • Mixed Methods research	• Quantitative methods not looking into experiences of parenting
• Experiences • Thoughts • Feelings • Reflections	• Papers not adhering to inclusion.
• Peer-Reviewed Journal Articles • Doctoral theses • Dissertations • Systematic/ Literature reviews • Meta-Syntheses • Conference proceedings • Unpublished theses	• Blog posts • Meta-analyses • Clinical trials • Opinion pieces

2.3 Results

Rayyan AI (Ouzzani et al., 2016) was used to screen the 2239 identified papers. The program enabled the author to view the titles and abstracts easily to decide whether to include the entry and attempt to retrieve it. Although the software has the

capabilities for AI to aid the screening process, the free subscription required the author to screen each paper using the screening tool manually. After screening by title and abstract, 59 potentially eligible papers remained. 49 papers were available online or through institutional journal subscriptions, and 10 authors were contacted directly to request access. Out of these 10 authors, one author stated the original study requested was no longer available and shared a copy of their unpublished study, which was eligible for this review and was then included. Seven papers were unobtainable due to the authors not responding to the correspondence. 52 papers were then screened again using the screening tool to ensure they fully met the inclusion criteria. In total, ten papers were obtained in the searches completed in October 2023. The searches were rerun in January and April 2024 to ensure any papers that had been published between the initial search and the end of the report-writing process were included. Study titles and abstracts were screened. In January, one additional paper was identified on Google Scholar, and the total number of studies included in this review was 11 (see Figure 1).

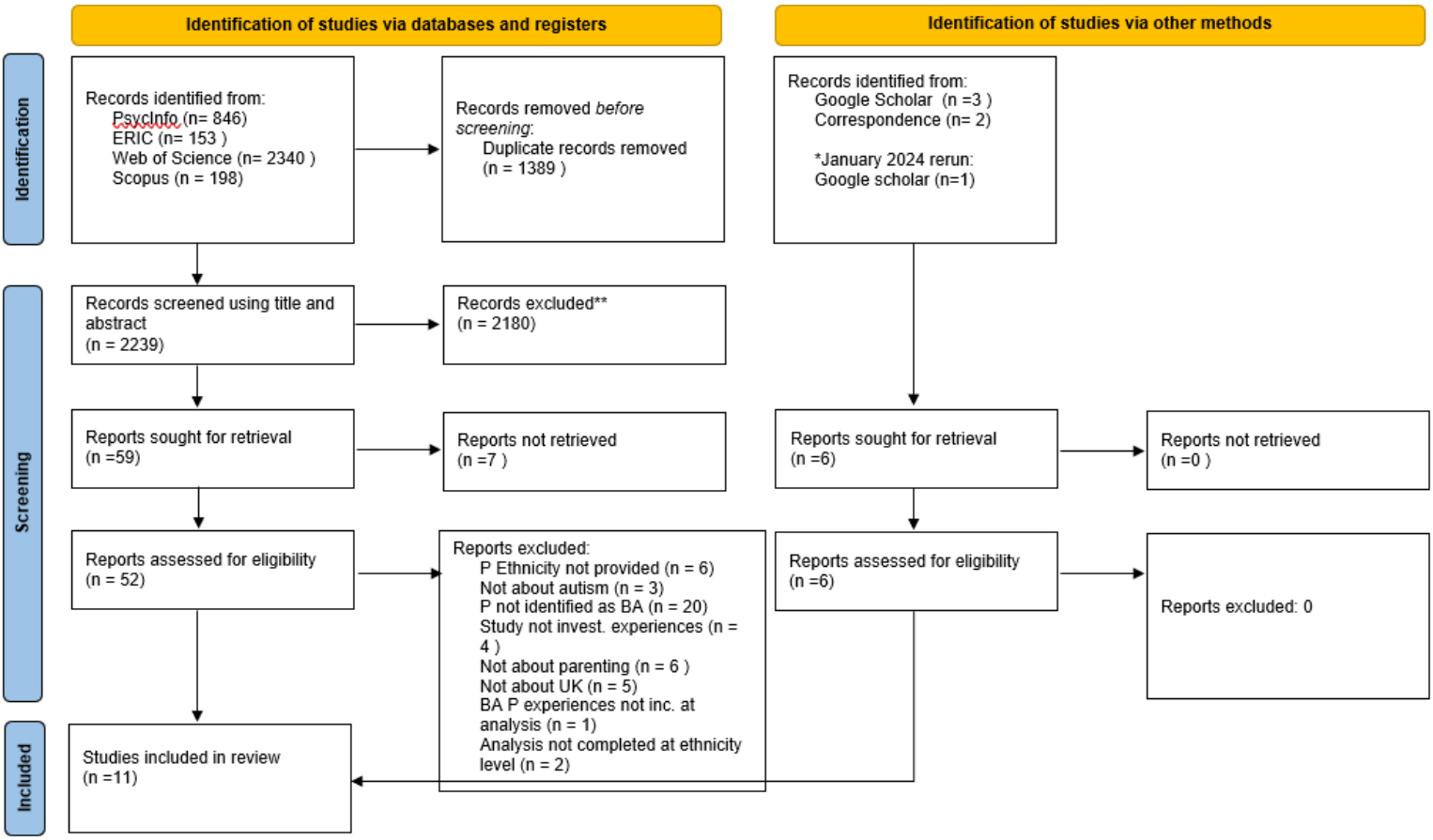


Figure 1: Systematic search strategy using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) approach (Page et al., 2021).

2.3.1 Quality Assessment

Once papers were identified to be included in the current review, each study was assessed using the Critical Appraisal Skills Programme (CASP; 2018) checklist for qualitative studies (see appendix A). The CASP checklists are split into three sections: 1) Are the results valid? 2) What are the results? 3) Will the results help locally?. The CASP requires each question to be answered with a 'yes', 'no' or 'can't tell'; in practice, the latter two options overlapped considerably and therefore the responses in this paper were adapted to also include 'Partly' to reflect where further detail could have been added. All papers included in this review used appropriate methodologies to investigate the aims. Seven papers received a score of 'Partly' for whether the methodologies addressed the research issue; this was due to there being no record of

whether an interpreter was offered to the parents to communicate in a preferred language, which may have excluded many potential participants from taking part in the study.

2.3.2 Overview of Studies

A descriptive summary of the eleven studies is provided (see table 3). These studies were published between 2015 and 2023.

2.3.2.1 Study Characteristics

As per the inclusion criteria, all studies focused on parent's experiences in the United Kingdom, using qualitative designs. Five studies also included participants who did not meet the inclusion criteria; during the data extraction phase only the responses for participants identified as black African were used within this analysis. Six studies explored the experiences of black African parents of autistic children living in London boroughs, one study explored experiences in Wales, and one study explored experiences of parents living in Scotland. Eleven studies outlined interview methods for data collection, six were analysed using thematic analysis, and three used interpretative phenomenological analysis. One study used a method called Data Explication (Hycner, 1999).

Selman et al., (2018) built upon the data obtained by Fox et al., (2016), to add a third analysis stage. The two studies share many of the same research team members. The original data sets were analysed using thematic analysis in the initial study; many of these themes generated in Fox et al., (2016)'s study were associated with the concept of stigma; Selman et al., (2018) built upon the previously conducted thematic analysis and added a stage of analysis, appraising the existing data using Link and Phelan's (2001) model of stigma. This model was used as an interpretative lens to describe and organise the data (Selman et al., 2018). Both studies reported and included different verbatim quotes from the original data (which was not accessed as part of this review) and therefore each study has been used as a separate entry into this review despite being data from the same sample.

2.3.2.2 Participant Characteristics

Studies included the experiences of 99 participants (counting the participants who appeared in two studies once), who were all described as either being 'black African', or as being from an African country, with Fox et al., (2016) and Selman et al., (2018) sharing the same participants. In total, participants from seventeen different African countries were included across the eleven studies. These countries span the width of the African continent covering all major regions. Ashong and Perepa (2023) did not differentiate their participant' demography into this level of detail, instead detailing whether participants were black African or Afro-Caribbean. Across the 11 studies, 39 participants were described as being Somali; this was due to two studies sharing the same data set (Fox et al., 2016; Selman et al., 2018) and another paper (Hussein et al., 2019) being solely about Somali parents' experiences (Fox et al., 2016; Hussein et al., 2019; Selman et al., 2018). Across the studies, 57 participants were married or in a relationship, 26 were either divorced, separated, single or widowed. Two studies did not provide this information for their participants (Oumar, 2021; Robbin, 2020). Where this information was reported, participants described as being from a range of faiths; 39 participants identified as Christian, nine Muslim, two Catholic and one Jehovah Witness. 75 participants identified as mothers, 24 as fathers. For a summary of participant labels, heritage/cultural background details and parenting role, please see appendix L.

Two studies included participants who were also professionals working alongside parents; Nair (2015) included a range of roles contributing to a stakeholder sample including specialist teachers, speech and language therapists and Ethnic Minority Achievement Service (EMAS) advisors, whilst Robbin (202) included social workers and social work educators.

Table 3: Systematic Literature Review Data Extraction Table

Study Characteristics						Participant Characteristics					
Study	**Study type**	**Published**	**General study focus**	**Data collection and Analysis method**	**Additional study information**	**Total participants in the study (N)**	**Number of Black African participants by country (n)**	**P's excluded**	**Relationship status**	**Religion /faith**	**Mother: Father**	**Number of autistic children and age range**
Ashong and Perepa (2023)	Journal article	University of Birmingham	Across UK- Experiences of black fathers of autistic children.	Interviews- Thematic analysis (Braun and Clarke, 2006)		11	(n) = 7, 7 - Details of country not provided	Afro-Caribbean fathers	Married - 5 Divorced - 1 Widowed - 1	Christian - 6 Not provided - 1	Fathers - 7	7 (5-25 years)
Fox, Aabe, Turner, Redwood and Raj (2016)	Journal article	Journal of Autism and Developmental Disorders	Bristol - Understanding the experiences of Somali families of autistic children and what support is needed by local services.	Interviews - Inductive Thematic analysis (Braun and Clarke, 2006)	Shared same data set as Selman et al., (2018).	15	(n)= 15, 15- Somalia	N/A	Married - 11 Separated - 4	N/A	Mothers - 12 Fathers - 3	17 (4-14 years)
Hussein, Pellicano and Crane (2019)	Journal article	Autism	London- Understanding and awareness of autism in Somali parents in the UK.	Interviews- Thematic Analysis (Braun and Clarke, 2020)		32	(n)= 16, 16- Somalia	N/A	Married- 6 Divorced - 8 Single - 2	N/A	Mothers -15 Fathers - 1	16 (6-15 years)

Lemboye (2023)	DEdChPsy Thesis	University of East London	London- Experiences of black African mothers raising autistic children in UK	Interviews- Interpretative Phenomenological Analysis	6	(n)= 6, 2- Nigerian 2- Ghanaian 1- Ugandan 1- Rwandan	N/A	Married- 5 Single – 1	Christian – 4 Muslim – 1 Catholic (Not practicing) - 1	Mothers - 6	6 (6-7 years)
Munroe, Hammond and Cole (2016)	Journal article	Disability and Society	South London- Experiences of African immigrant mothers in the UK with an autistic child who also has a learning disability.	Interviews- Interpretative Phenomenological Analysis	6	(n)= 6, 1- Sierra Leone, 1- Ethiopia, 2- Nigeria, 2- Uganda	N/A	N/A	Christian - 4 Jehovah Witness - 1 Muslim- 1	Mothers - 6	6 (7-13 years)
Nair (2015)	PhD thesis	Cardiff Metropolitan University	One LA in Wales- Experiences and perceptions of parents of autistic children from BME backgrounds, related to the support they receive for their child's education.	Interviews- Thematic Analysis (Braun and Clarke, 2006)	13	(n)= 3, 2- Ghana, 1- Sudan	Stakeholder study sample Participants not from black African background	Married - 3 (2 participants married together)	Muslim - 2 Christian - 1	Mothers - 2 Fathers - 1	2 (4-5 years)

Nweke (2019)	PhD thesis	University of Kent	Majority of participants live in South East London, remainder live in other parts of UK. Experiences of parents and siblings of autistic children, with a focus on intersectional experiences.	Interviews- Interpretative Phenomenological Analysis	37	(n)= 30 (from 20 families), Somalia -2 Nigeria -15 Ghana - 3 Congo - 1 Zimbabwe - 2 Uganda - 1 Cameroon- 1 Gambia - 1 Ghana - 3 Kenya- 2 Liberia- 2	Siblings of autistic children	Married - 24 (9 married together) Couple not married - 2 (in a couple together) Single - 4 Divorced - 2	Christian - 24 Muslim - 5 Catholic - 1	Mothers - 19 Fathers - 11	23 (6-18 years)
Oumar (2021)	DEdPsych Thesis	Unpublished - direct correspondence with author	Inner London local authority - Exploring understanding of autism within East African Immigrant Parents, and experiences of support including EP involvement.	Interviews - Thematic Analysis (Braun and Clarke, 2020)	8	(n) = 8, Somalia - 3, Eritrea -3 Rwanda - 1 Sudan -1	N/A	N/A	N/A	Mothers - 7 Father- 1	8 (4-15 years)

Robbin (2020)	PhD Thesis	University of Strathclyde	Scotland- Exploration of views of Social Work Educators, students, social workers and black African mothers of autistic children in Scotland	Interviews - Data Explication (Hycner, 1999)		4	(n) = 4, Democratic Republic of Congo- 1 Ghana- 1 South Africa - 1 Tanzania - 1	Social Workers Social Work Educators Social work students	N/A	N/A	Mothers - 4	5 (5-7 years)
Seach (2021)	DEd Thesis	Institute of Education, UCL	One London borough- Experiences of parents of autistic children from one school, using a transcultural lens.	Interview and Reflexive Journal - Reflexive Thematic Analysis (2020)		11	(n) = 4, Somalia - 3 Sierra Leone - 1	Parents not from African backgroun ds.	Married - 1 Separated -1 Divorced - 2	N/A	Mothers - 4	4 (6-7 years)
Selman et al., (2018)	Journal Article	Ethnicity & Health	Bristol- Experiences of stigma amongst Somali parents of autistic children.	Interviews - Thematic Analysis (Braun and Clarke, 2006), using Link and Phelam (2001) Model of Stigma	Additional analysis on data reported by Fox, Aabe, Turner, Redwood and Raj (2016)	15	(n) = 15, 15- Somalia	N/A	Married - 11 Separated - 4	N/A	Mothers - 12 Fathers - 3	16 (4-14 years)

2.3.3 Analysis of Themes

A thematic synthesis was conducted to create an aggregation of the experiences shared by parents across the 11 studies, following Thomas and Harden's (2008) guidelines for a three-stage analysis: 1) coding findings, 2) developing descriptive themes, and 3) developing analytical themes. This approach to analysis was chosen as it is a systematic method of collating qualitative data from multiple sources to produce a summary.

Following an initial period of familiarisation with each study to understand the context of the research, the synthesis process focused specifically on each study's findings section. The study authors' interpretation of the quotes was not included in this analysis; only the verbatim quotes shared within the qualitative papers were coded and analysed. As per the guidelines for thematic synthesis, the first stage of the analysis refers to the coding of the data. Each of the direct quotes shared within the studies was coded, line by line, to build a bank of codes. Initially, 474 quotes were lifted from the included studies, with 122 describing experiences that were relevant to the review question. The coding process was conducted by hand, with the author considering what each line of verbatim quotes meant concerning the study question. Many of the experiences shared within the included studies were parents' experiences of parenting an autistic child, but not with particular relevance to the uniqueness of being a black African parent, and so only the codes relevant to the review aims were included within the synthesis.

The relevance of each quote was assessed by considering the wider context in which the quote had been shared and checking if the quotes aligned with the review aim i.e., to describe the experiences of the participants parenting their child. An example of a quote that was included was the "*guilt phase"* described by Aisha, a Nigerian mother in Lemboye's (2023, p.62) study. In the same quote, Aisha asked "*Did I do something wrong? Did I hurt someone who put evil eye on me while I was pregnant?"* A shortened version of the quote was therefore included due to Aisha speaking about her culture's belief about the potential for autism to be caused by, or a result of, external forces such as the 'evil eye' was a form of punishment, which may not be a universal experience of parenting autistic children from other cultures. An example of a quote that was not

included within the review comes from the Sudanese mother named Alia in Oumar's study (2021, p.48), who shared: "*After the assessment and stuff you begin a process of accepting and then I started doing a lot more kind of research to understand the diagnosis and to understand how to support my daughter, and what things are available like in terms of toys and, and equipment and stuff that I can use to help her to develop*". This quote was not included within the review due to the universal nature of parents of autistic children completing their own research to support their child's development. This quote was not about the parent's experience of being a black African parent, simply about being a parent to an autistic child, which is likely to be shared by parents globally, regardless of cultural background.

The next stage referred to the development of descriptive themes (see Table 4 for details of which descriptive theme was identified in each study). The codes within the code bank were then grouped based on shared semantics. This was an iterative process, and the descriptive themes were revisited several times to ensure they encapsulated the shared meaning of the codes. The author sought to minimise their influence and interpretation of the theme names by ensuring they remained 'close' to the text within the studies. The third stage of the review referred to the development of analytic themes (see appendix B for details of each code label and how the analytic labels were developed), which required the author to 'go beyond' the data and apply their own interpretation of the descriptive themes in relation to answering the review question. The breadth of the research question exploring 'experiences' allowed for themes to be developed a posteriori, as opposed to having specific foci guiding the themes. The development of theme names was revisited throughout the write-up of the review to ensure they were analytical and related to the review question.

Table 4: Descriptive themes included in each systematic literature review study

	Ashong and Perepa (2023)	Fox, Aabe, Turner, Redwood and Raj (2016)	Hussein, Pellicano and Crane (2019)	Lemboye (2023)	Munroe, Hammond and Cole (2016)	Nair (2015)	Nweke (2019)	Oumar (2021)	Robbin (2020)	Seach (2021)	Selman (2018)
No word for autism in the home language.		Y	Y				Y	Y			Y
Differences of understanding between the parent and community		Y	Y	Y	Y						
Confusion around what autism is, and its cause.		Y	Y	Y	Y			Y			
Initial challenges with accepting their child is autistic.	Y			Y	Y	Y		Y	Y	Y	
Experiences of social isolation and stigma from other community members		Y	Y	Y	Y	Y	Y	Y			Y
African cultural and traditional family values impacting parenting	Y	Y		Y	Y	Y	Y		Y		

Faith supporting parents to accept their child's needs		Y	Y	Y	Y		Y			Y	Y
Religion provides tangible support for parents		Y	Y	Y	Y		Y				
Limited awareness about services and support available		Y		Y				Y			
Difficulty physically accessing the support		Y		Y				Y	Y		
Difficult interactions with professionals				Y			Y				
Parent support groups being a helpful resource for parents	Y	Y	Y	Y				Y			Y
Parents concerned with how their black child would be treated in a white-majority environment	Y			Y		Y	Y		Y		

Five analytical themes were developed from the descriptive themes (see appendix B) to describe 'The experiences of black African parents of autistic children in the United Kingdom'. These themes were:

1. An absence of shared language around autism impacted parents' own understanding of autism and the way they could communicate with their community about their child's needs.
2. Traditional cultural and community views about disability and parenting could lead to feelings of judgment and stigma.
3. Faith and religion were frequently used as a facilitator for acceptance and as a coping strategy for daily life
4. Parents accessing support outside of their community often worked within confusing systems and felt unsupported accessing them.
5. Parents of black autistic children held concerns about the way their child could be treated by others due to being black and autistic.

2.4 Findings

2.4.1 An absence of shared language around autism impacted parents' own understanding of autism and the way they could communicate with their community about their child's needs

This theme encapsulates the idea that the absence of shared language and understanding of autism impacted parents' own understanding of their child's needs and their ability to explain their child's needs to other members of their community. There was a sense of confusion around autism as a whole, including its cause, and some parents also shared beliefs that autism was externally driven and caused by curses.

Consistently, there is no word to describe autism in Somali (Fox et al., 2016; Selman et al., 2018; Hussein et al., 2019; Nweke, 2019; Oumar; 2021), and one parent in Nweke's (2019, p.192) study shared how they were unable to receive a diagnosis from their child's doctor because "*he didn't know what it was called in French"* (Ms Mulumba, Congolese Mother). An absence of clear language to describe autism led to

difficulties with community acceptance of their child's strengths and support needs as it was difficult to conceptualise due to the lack of visible physical features associated with autism. One parent in Fox et al., (2016, p.308, PPT6: Somali Mother) described how "*they've never come across a child that looks so normal as my son, but yet is different and it's the way he is*". The lack of physical features related to autism also made it difficult for others to understand it as a disability, and that "*if you see someone in a wheelchair…you cannot convince them that this person is able…if they don't see it, this person is mad*" (Munroe et al., 2016, p811, Sanaa: African Mother). Some parents described initially thinking that in their communities in Africa autism "*doesn't exist*", due to the belief that autism is caused by a lack of vitamin D, exposure to sunlight or the MMR vaccine (Hussein et al., 2019, p.1413: Somali parent; Lemboye, 2023, p.94, Sanyu: Ugandan Mother).

Cultural differences in expected developmental milestones between parents' African home countries made it difficult for parents to recognise developmental differences; "*back home kids can talk at any time…boys take longer to do everything"* (Lemboye, 2023, p.82, Saynu: Ugandan Mother). One parent in Fox et al.'s (2016) study described their confusion about the importance of eye contact, an important diagnostic feature for autism but not regarded as an important communication milestone in Somali culture. Parents in both Fox et al., (2016) and Oumar's (2021) studies shared how they were told by members of their community that it was normal for their child not to speak until after five years of age. The dismissal of the potential for their child to be autistic impacted parents' motivations and recognition for the need for more support (Fox et al., 2016; Oumar, 2021; Lemboye, 2023).

Parents included in this review revealed that they knew little about autism before it being raised by professionals, or friends and family. One parent in Lemboye's (2023, p.87, Afia: Ghanaian Mother) study described how "*If I did not give birth to my child…I would not even look for it*", whilst another in Oumar (2021, p.44, Liya: Eritrean Mother) described "*I didn't know about this illness, I had never heard of autism before*". Both these parents had immigrated to the UK, highlighting the limited awareness of autism in their home-country. Comparing their child to other children's development was a way for parents to recognise developmental differences, and they were often unaware of where to go or who to talk to when they noticed these differences leading to the parent

feeling "*miserable*" because they didn't know what to do (Oumar, 2021, p.44, Winta: Eritrean Mother). Once parents recognised the potential for their child to be autistic, parents across the studies reported feeling a sense of denial and refusal to accept their situation (Nair, 2015; Lemboye, 2023). Other parents who decided to seek support were often met with difficulties accessing assessments for their child; extremely long waiting lists made the process more challenging and confusing for parents (Lemboye, 2023).

After enduring the waitlists for assessment and receiving their child's diagnosis, parents frequently described an initial reluctance to accept the assessment outcomes (Robbin, 2020; Ashong & Perepa, 2023; Lemboye, 2023). One parent in Lemboye's (2023, p.88, Afia: Ghanaian Mother) study described this reluctance as being exacerbated by a lack of medicine, they thought "*they were going to give him medicine so that everything would go…I didn't want to hear…I was very sad".* Parents outlined grief for their unmet expectations and the loss of a child they hoped for (Ashong & Perepa, 2023; Munroe et al., 2016; Oumar, 2021). One parent in Seach's (2021, p.87, Nadifa: Somali Mother) study described how they *"sometimes see a neurotypical child around {child's name} and think "this would've been {child's name} if he was normal" and I don't think you ever let that go*".

2.4.2 Traditional cultural and community views about disability and parenting can lead to feelings of judgment and stigma

This theme refers to the differences between the views that parents often felt towards their children and the contradiction with the views that the wider community often held about autism or disability more generally. Community views were often built on traditional and cultural family values, which could sometimes lead parents to feel a sense of judgement related to their parenting, and stigma related to their child having additional needs.

Direct conflicts between potentially challenging behaviours of autism and societal expectations in the UK (Fox et al., 2016) meant parents were worried about what others would say about their parenting, or how they may react if their child displayed challenging behaviour in public, such as threatening to call the police (Fox et al., 2016).

Parents revealed that as some autistic children can find understanding instructions difficult, other adults from their community may interpret their child's behaviours as opposing these cultural values, suggesting the parent has not provided high-quality parenting. This in turn was internalised as a failure in parenting, as "*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 parent's fault* (Hussein et al., 2019, p.1412, Somali Parent). One parent shared that they were accused of spoiling their child and making it up as an excuse for his behaviour (Lemboye, 2023). Another parent from Munroe et al.'s (2016, p.809, Ife: African Mother) study described how people would start "*tagging you…that maybe you are a bad parent*".

Within many African cultures, traditional values drive societal expectations of parents and family dynamics. Parents in Nweke's study (2019) described how traditional African cultural values are often aligned with the child being born to take care of their parents. Only two papers included direct experiences about fatherhood; here, African cultural values of fatherhood were seen to be key concepts the parents relied upon when sharing their experiences. Gendered roles are commonplace in typical African cultural expectations: "*The African father goes out, makes the money, and then the mother is at home taking care of the kids*" (Ashong & Perepa, 2023, p.13, JF: African Father). Fathers in this study outlined how these ingrained cultural expectations made shifting their own narratives around parenting difficult if they were required to take on more caring responsibilities than other fathers in their communities typically would.

In Munroe et al.'s (2016, p.807, Nyah: African Mother) study, mothers described feeling exhausted as the primary caregiver for their child and "*you don't rest your mind*", whilst another described how "*autism is the most difficult for all your life…my life I give up.. that's it…everything*" (p.808, Ayana: African Mother). Another parent within the same study described how difficult dealing with other mums can be: "*You can see how judgemental they are, how they're like so uncomfortable*" (p.809, Sanaa: African Mother). One parent in Lemboye's (2023, p.62, Aisha: Nigerian Mother) study described the "*guilt phase*" they went through due to others' judgements and blame. Mothers reported that they frequently experienced higher amounts of blame from their communities for their child's needs than fathers due to a belief in the spiritual roots of autism as a punishment for the mother's behaviour (Lemboye, 2023; Nair, 2015).

Parents in Hussein et al.'s (2019, p.1414, Somali parent) study described the belief that autism is caused by a jinn (evil spirit) and that "*the strange noises, voices that don't belong to him [her son] that can be explained by the presence of a jinn*".

Additional examples of the internalisation of blame of having an autistic child comes from the influences of having another child, and the breakdown of relationships and marriages. Mothers in both Nweke's (2019) and Munroe's (2016) studies described how having an autistic child influenced their decision to have another child due to the intention to exonerate themselves from internalised guilt and self-blame by having a non-autistic child. One parent described their relief at their youngest child talking "*I can have this one who is good, he is okay, for me I was so relieved*" (Munroe et al., (2016, p.810, Mabinti: African Mother)). In four of the studies, parents described how their child's needs directly impacted their relationships, leading to breakdowns in marriage and partnerships, which was particularly challenging for some African parents. One parent in Nweke's (2019, p.247, Ms Dibango: Cameroonian Mother) study said that "*being African, you have the pressure of the in-laws saying no you need to get another wife to give you a child without…to give you a normal child*". Another parent in Nweke's (2019, p. 245, Ms Mulumba: Congolese Mother) study described how a relationship breakdown could bring additional shame, stigma and embarrassment to the family due to needing to repay the traditional African cultural custom of "*bride price"*. Disagreements between parents related to an understanding of their child's needs were often reasons cited for the ending of a relationship (Fox et al., 2016). Fathers who attempted to downplay or reassure a mother's initial thoughts about their child's development often led to conflict and disagreements if the mother did not feel supported (Oumar, 2021).

Adults in positions of 'cultural power' (such as parents of non-autistic children) were seen as more judgemental than children, "*the children don't have a problem…they're sweet. But the adults, that's the problem*" (Selman et al., 2018, p.788, PPT15: Somali Mother). Privacy concerns around others from the same homeland talking about their child's needs led to shame, embarrassment and stigma (Lemboye, 2023; Munroe et al., 2016). Pressure for their child to meet other community members' expectations was the greatest source of stress for some parents, leading to self-isolation and internal conflicts around their parenting, and feelings of guilt for limiting

their child's exposure to experiences (Munroe et al., 2016; Lemboye, 2023). External pressures from the community also led to parents alienating themselves to avoid the judgements and shame from others (Lemboye, 2023). One example of specific judgements passed by other community members shared was how, specifically in the Somali population, parents were often labelled by their child's needs, for example "*if you're missing an ear, you would be called one ear girl, that's just normal*" (Hussein et al., 2019, p.1413, Somali Parent).

Despite the potential for judgements and comments to be made by others in the community, other parents reported that the African community was a source of support through the sharing of responsibilities. African cultures are deemed to be collectivist cultures; "*what I'm used to back home where your problem is everybody's problem*" (Nair, 2015, p.139, Fante: African Mother). One parent described how despite living in the UK, "*we have an inbred African culture within us…we are raised by a community not by a parent, but in Scotland you are raised by a parent*" (Robbin, 2020, p.321, Chibuye: Tanzanian Mother). Learning more about autism enabled parents to begin to accept the diagnosis (Fox et al., 2016; Munroe et al., 2016), and to distance themselves from the traditional African beliefs around witchcraft and spirituality they previously held (Munroe et al., 2016). One parent within Munroe et al.'s (2016, p.810, African Mother) study said "*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 stand by yourself*". Parents also distanced themselves away from the stigma cast by others about the parents being to blame for their child's differences (Lemboye, 2023; Selman et al., 2018). Another parent in Munroe et al., (2016, p.813, African Mother) described how "*the mentality here [UK] has really exposed me…that's why I don't mix up with [African people] because my way of life is different from my country's culture…most of the things they do, I can't even bear it*".

2.4.3 Faith and religion were frequently used as a facilitator for acceptance and a coping strategy for daily life

This theme encompasses how parents relied on their faith and religion to facilitate an acceptance of their child's strengths and needs and as tangible sources of support

that parents could draw upon during particular moments of stress. Parents across five papers referenced their religion as a coping mechanism for their daily stresses, enabling them to better manage the familial and societal challenges they experienced (Fox et al., 2016; Hussein et al., 2018; Lemboye, 2023; Munroe et al., 2016; Nweke, 2019). Parents within this review spoke about the importance of their child learning about their faith "*I tell my boys everyday it is important to keep your salahs [prayers]"* (Hussein et al., 2019, p.1414, Somali Parent).

Some parents believed their lives were predetermined by Allah or God which enabled them to accept and embrace their child's needs, due to their respect for their faith, which was seen to absolve the parent from the potential for internal guilt (Lemboye, 2023; Fox et al., 2016, Hussein et al., 2019, Selman et al., 2018). One parent in Hussein et al., (2019, p.1413, Somali Parent) described how "*Allah says what I give you, you must be happy with*", For some parents, trust and gratitude in Allah's plan for the future was a source of comfort (Fox et al., 2016). When some parents spoke about their faith, they believed that their lives were controlled by Allah or God, with "*it's what Allah already wrote* " (Fox et al., 2016, p.310, Somali Father), and that "*everything's got a plan*" (Lemboye, 2023, p.61, Aisha: Nigerian Mother). Faith facilitated an acceptance of their child's needs as one parent mentioned "*I have nothing to be ashamed of because Allah has made them this way*" (Hussein et al., 2019, p.1413, Somali Parent). Another parent in Munroe et al., (2016, p.811, African Mother) recounted how they described autistic people as "*special people, they are specially made by God*". For some parents, although they had accepted their child's autism, they continued to use their faith to help them to process this, and described how they would question their God and ask Him "*why was I given this child*?" (Seach, 2021, p.83, Hibaq: Somali/Kenyan Mother), and ask God "*why…it wouldn't have cost you anything to give me a child without autism*" (Munroe et al., 2016, p.811, African Mother).

Religion brought with it a distinct place for worship; for one parent, this place was a somewhere to physically and mentally retreat from the challenges in their own lives giving them "*peace, calm and hope…it gives me a sense of belonging and understanding*" (Nweke, 2019, p.308, Mrs Yeobah: Ghanaian Mother). For parents who attended a physical place of worship with their families, spiritual leaders were identified as being key facilitators in providing support and acceptance for their child; spiritual

leaders showing unconditional love for autistic children helped the parents to feel accepted and encouraged others to also accept their child, with one parent describing how their pastor has said "*it is for special needs children and adults*" (Nweke, 2019, p.300, Ms Dimka: Nigerian Mother). Another parent in Nweke's (2019, p.300, Ms Akinloye: Nigerian Mother) study talked about the support they had received from their Imam, "*even before our diagnosis…our little boy is very close to our Imam…he likes him, he treats him like a grandchild…its not like we have gone out to seek the advice…he comes out to us*". Other members of the congregation who also have autistic children were seen to be key sources of support for two parents in Lemboye's (2023, p.81, Amma: Ghanaian Mother) study; "*we have one lady at church…She also [has] a special boy like us…she advise us a lot",* whilst another said "*when we go to Church…they have set a place that another girl…is autistic…Both of them go inside to play with toys*" (p.86, Afia: Ghanaian Mother).

Conversely, one parent felt as though their place of worship, with a high African population, was not able to adapt and meet the needs of their child. This led to the parents becoming distanced from their place of worship and religious community and led to a sense of betrayal for the parents as the church had disproved ideas they had once held about their faith. They described church as "*the worst place and that came as a shock to me…we stopped going and maybe pray at home…its just soul destroying*" (Munroe et al., 2016, p.813, African Mother). Two Parents in Nweke's (2019) study described how they no longer attended church with their children because "*the church community don't offer help…I expect the church to be more caring and sympathetic and make room for disabled people, but that is not what you get*"(p.301, Mrs Adisa: Nigerian Mother) whilst the other described how they have to:

> "*make sure he does not stand on the alter when the pastor stands…it will look as if you have done something very terrible…when everyone is quiet, it's at that time he wants to sing". (p.301, Mrs Bankole: Nigerian Mother)*

Faith and religion also brought some parents the hope that God would 'cure' their child, potentially as a barrier to full acceptance of their child's needs. One parent in Nweke's (2019, p.313, Mrs Okoye, Nigerian Mother) paper told the researcher "*Do I believe God could cure autism? Yes! Yes! Yes! Yes!*", whilst another in this study described their "*prayer requests to ministers…the greatest prayer you pray is the picture*

in your heart…you pray on that picture every day" (p.310, Mr Ibori: Nigerian Father). One parent said "*I am hoping Allah will help, one day he will get better*" (Fox et al., 2016, p.310, PPT5: Somali Mother). Additionally, some parents described the relief that came after prayer: "*after praying about something there is a relief*" (Nweke, 2019, p.297, Mrs Akinloye: Nigerian Mother), "*we pray for him every day, that one day God will help him"* (Munroe et al., 2016, p.811, African Mother). One parent mentioned that they held pluralistic beliefs about their child's diagnosis; "*prayers are important but so is medical help*" (Hussein et al., 2019, p.1414, Somali Parent). Faith was seen to be a consistently available tool for parents; "*people can only help so much and then they go to their homes…so really only God, yeah you need supernatural help*" (Munroe et al., 2016, p.811, African Mother).

2.4.4 Parents accessing support outside of their community were often working within confusing systems, and felt unsupported accessing them

This theme refers to the experiences that parents shared when accessing support services provided by local authorities. Parents often did not know what support was actually available and were unfamiliar with formal and informal processes. When parents sought support, they frequently found these services difficult to access due to bureaucratic processes and language barriers, and also experienced difficult interactions with professionals in these services. Conversely, parent support groups were found to be a source of support that was beneficial due to a shared understanding of experiences.

Attitudes to the support available from social services varied. There was a sense of mistrust affecting parents' willingness to engage with social services, particularly around fears of their child being removed from the family, and "*the fear at the back of your mind is that they're watching you and they will take away from you"* (Fox et al., 2016, p.312, PPT14: Somali Mother). There was a preference to pay for services among members of their community instead of seeking support from social services; this was due to not knowing what support was available, and trusting their community more than local authority representatives (Oumar, 2021). After receiving their child's autism diagnosis, many parents did not know where to start when seeking support due to a lack

of familiarity with the system; one parent described this as "*exhausting…it wasn't so straight forward*" (Lemboye, 2023, p.64, Aisha: Nigerian Mother). This was exacerbated for parents whom English was not their first language; One parent in Hussein et al., (2019, p.1414, Somali Parent) described how not speaking the language "*mean[s] that families would lose out on crucial support*", whilst another described how "*I never had the opportunity to learn and understand the language, so there is a barrier of not understanding how this whole system works*" (Fox et al., (2016, p.311, PPT1: Somali Mother). This was added to by another parent who shared how "*I can speak English, I'm educated, but some of the services I still can't access it*" *(Robbin, 2020, p.317, Justine: Ghanaian Mother)*. This parent also described their frustration with the amount of paperwork being required; "i*t was more just 'paperwork' and they didn't have anyone who was going to do the work*" (Robbin, 2020, p.316, Justine: Ghanaian Mother). Additional barriers included professionals in local authorities being uncontactable, not "*answering phones or nobody answering the email"* (Oumar, 2021, p.51, Ali: Somali Father).

Some described experiences of professionals that "*look down on them*" and making assumptions about their family without asking (Robbin, 2020, p.335, Emmi: South African Mother). Parents were often uncertain about professionals' roles, particularly during the period between initial suggestions about developmental differences and the child's assessments, where the purpose of the meeting was not always clear (Fox et al., 2016). Others felt that professionals were "*shoved*" at them, with little explanation about how the professional would provide support or their role (Robbin, 2020, p.315, Justine: Ghanian Mother).

Some parents felt discriminated against whilst interacting with some professionals, and spoke about feeling like they had to work harder to receive support due to being black and having English as an additional language. For example, they described not being understood on the phone due to their accent and "*they will keep asking you to repeat yourself*" (Nweke, 2019, p.210, Ms Muluma: Congolese Mother). One parent described how they" *felt patronised at some point…you said I know best but then you're giving me this option, and its like if I refuse to take it…I'm going to be a bad parent…I don't want to assume that it has anything to do with my race or my child but you can't help it"* (Lemboye, 2023, p.84, Sanyu: Ugandan Mother).

Parents questioned whether white parents of autistic children encountered similar hurdles and barriers (Lemboye, 2023, p.91). Three parents across two studies described the need to "*fight*" for their child to receive support (Lemboye, 2023, p.84, Sanyu: Ugandan Mother; Nweke, 2019; p.214, Mrs Achebe: Nigeran Mother, p.215, Mrs Adisa: Nigerian Mother). A lack of diverse cultural representation in the services accessed by parents was described by one parent in Lemboye's (2023, p.72, Keza: Rwandan Mother) study as exacerbating the stigma that some professionals may have towards working with black parents and autistic children, leading to parents needing to "*fight so many battles before they even come to the point of having to advocate for their child"*.

More informal support services such as parent support groups were recognised as being a helpful source to learn from other parents (Ashong & Perepa, 2023, Fox et al., 2016; Hussein et al., 2019; Lemboye, 2023; Nair, 2015; Oumar, 2023; Selman et al., 2018). Talking to other parents in similar situations helped parents to feel "*less alone*" (Lemboye, 2023; p.25, Sanyu: Ugandan Mother). Culturally inclusive groups were highlighted as particularly beneficial due to a shared cultural understanding and language between the facilitators and attendees (Lemboye, 2023; Oumar, 2021; Ashong & Perepa, 2023).

2.4.5 Parents of black autistic children held concerns about the way their child could be treated by others due to being black and autistic – the "double barrier"

This final theme refers to the unique experiences, worries, and concerns parents of black autistic children hold that they felt were unlikely to be shared by parents of white children. These concerns were often focused on their child navigating systems and spaces independently from their parents, and within which parents may be unable to protect them. Parents reflected on their own experiences of being black at school and held concerns for their children experiencing a 'double barrier'.

Parents shared their views of their child being both black and autistic and the unique concerns they held related to this; one parent described how "*we have all these types of racism going around, very subtle but they are around…so you'll think if that*

happens to a (hand quotations) 'normal child', how about my child who has their limitations"? (Lemboye, 2023, p.84, Sanyu: Ugandan Mother). One parent in Nweke's (2019, p.236, Ms Kakooza: Ugandan Mother) study described their concerns about how their child was perceived by others when "*they look at her strangely, her size, the colour of her skin*". One father in Ashong and Perepa's (2023, p.18, FA: African Father) study described their perception of a *"bias in the system…there's low expectations*" related to their son's teacher's expectations of his reading ability. Further, a parent in Lemboye's (2023, p.80, Amma: Ghanaian Mother) study described their concerns with their race impacting the way their child was cared for by professionals "*that because I am a black, the way they take care of my son is not enough*"[1]. Another parent echoed their concerns about their child's intersectionality of being autistic and black, describing how their child's needs, coupled with their ethnicity, were viewed as a 'double barrier' to their education; "*first, he is black , then he's the only one in his class with autism*" (Robbin, 2020, p.337, Emmi: South African Mother).

2.5 Discussion

This systematic review sought to describe and collate the research outlining the experiences of black African parents of autistic children in the United Kingdom and has included the experiences of 99 participants shared across 11 studies. The findings of the review highlight that the absence of a shared language to describe autism in some African cultures impacts the parental and community understanding of autism. In turn, this lack of language and understanding can further impact parents' motivations to seek help from both community and professional services. Where parents sought support from professional services, they were often required to work within challenging and confusing systems and were frequently not supported with accessing them. These findings demonstrate the potential for parents to be exposed to traditional cultural and community views, which can lead to feelings of judgment and stigma. For other parents, faith and religion were seen to be a catalyst for acceptance, and they relied upon them as a coping tool for the daily stress associated with raising an autistic child. Unique to being a parent to a black autistic child, parents also held concerns for the "double

[1] This quote was copied verbatim from the presented quote within Lemboye's study (2023).

barrier" of their child being both black and autistic and the implications for how they would be treated and supported whilst in school.

The findings reported within this review of parental recognition, identification, and help-seeking align closely with the de Leeuw et al.'s (2020) conceptual framework introduced in the introduction. Specifically, the framework outlines how the experiences of being parents of autistic children are heavily influenced by the community and cultural values in which they are surrounded. This review also documents the impact and influence of community views about disability and parenting as critical moments of fallen identities or being let down by their communities. Parents' descriptions of distancing themselves from traditional cultural views towards disability suggested they were going through a process of grief and/or cognitive dissonance (Festinger, 1957), where they were required to resolve the conflict between their communities' beliefs about autism and their feelings towards their child. Some parents in this review, perhaps those that more successfully navigated this conflict, were encouraged to learn more about autism, advocate for their child, and empower other parents through support groups.

Faith and religion were identified as key facilitators for the acceptance of their child's needs and the parents' situation; this is consistent with the findings of Denney and Aten (2020), who described religion as a coping process that is readily accessible during times of distress and can be a cornerstone of resilience for families of autistic children (Kéri, 2023). Parents' descriptions of the influential power of faith leaders over their congregation and the community's acceptance of their child's needs demonstrate their potential role in facilitating acceptance within their wider community. Research led by Heward-Mills et al., (2018) investigated the role of faith leaders in influencing health behaviour in black African Christians in two churches in Leeds. The findings demonstrate the social influence faith leaders can have by serving as role models to facilitate behaviour change. Faith leaders therefore should be supported with this responsibility of the influence they can have over their community's experience, and more should be done to ensure faith leaders are informed about the support available so they can signpost others to support where needed.

Parents in this study also described the confusion they experienced working within unfamiliar systems and the lack of support they received when accessing the systems.

Dowling and Dolan (2001, p23) described similar findings from Beresford (1994), who suggested this existed 30 years ago: "black and single parents were the least likely to receive respite care, despite often having the greatest needs". More recently, the social care system in England has been described as "unfair, complex and confusing" (Curry, Hemmings, Oung & Keeble, 2019). For parents for whom English is not their first language, this can be an additional barrier to accessing support (NSPCC, 2014).

Although a less dominant theme, some parents held concerns for their child navigating systems and services independently, specifically related to their dual status (double barrier) of being black and autistic. Parents in this study described different treatment and expectations from others; this finding is consistent with previous research by Gershenson et al., (2015) who found non-black teachers of black students had significantly lower expectations than black teachers. This difference in expectations was described by Gilham et al., (2016) as an implicit racial bias existing within educators. Combined with findings by Zagona et al. (2017), who found that teachers can have low expectations for learners with additional needs, this review highlights the imperativeness of professionals working with black autistic children to have high expectations for their school achievement.

As stated above, this review is the first to synthesise the existing research to document the experiences of black African parents of autistic children living in the UK. However, previous research has investigated the experiences of parents of autistic children from other cultural backgrounds in other Westernised countries. A recent review by Papoudi et al. (2020) included 32 articles documenting the experiences and perceptions of parents of culturally diverse autistic children in the USA and the UK. Studies in the Papoudi et al. (2020) review included parents from 12 minoritised cultural backgrounds living in countries where they were not part of the cultural majority. Their review found similar findings to the current study, including the way that family understanding of autism is impacted by a lack of accurate knowledge, experiences of social stigma and isolation, and difficulties of access to service due to interactions with professionals. A key finding mirrored within the current review was the importance of culturally sensitive social support interventions. Papoudi et al.'s (2020) review also highlighted that there are some universal experiences shared by parents from a range of minoritised cultural backgrounds when parenting autistic children.

Within the current review, a key finding was that there can be considerable differences in the expected milestones for childhood development between cultures, which can influence parental recognition of the potential for developmental differences such as autism. Research by Genovesi et al. (2023) directly compared the perspectives of UK-based British and Egyptian/Sudanese communities about different developmental milestones and how these differences were interpreted. They found that British parents more frequently referred to developmental milestones in terms of age expectations and judged a child's development in comparison to other children more frequently than Egyptian/Sudanese parents. Genovesi et al.'s (2023) study highlights how minoritised cultural groups may recognise a child's development as different from the majority culture. This pattern is echoed in research by Ratto et al. (2016), who compared the perceptions of autism between Latina mothers and white mothers of autistic children in the USA. Their findings demonstrated that Latina mothers demonstrated significantly less awareness of developmental milestones and of typical traits of autism. This suggests that parents from minoritised cultural groups can have a different awareness of developmental trajectories than white British parents in the UK and may recognise developmental differences in different ways to white British parents.

One way in which parents from minoritised cultures may seek support once they have recognised their child's developmental differences is from within their community. Findings within the current review highlight parents' preferences for seeking community support instead of professional services operated by the local authority. This echoes research by Dyches et al. (2004) who found that reliance on organisational support was seen to vary according to the amount of family support available and the parent's familiarity with the majority culture. The current review suggested that some parents found systems unfamiliar and challenging to navigate. Therefore, there may be a difference in accessing services for parents from minority cultures who were born in the United Kingdom versus those who have immigrated to the UK. Speaking English was also seen within the current review as a critical determinant for ease of access to support; this is supported by research conducted by St Amant et al. (2017), who found a relationship between English proficiency levels and uptake of support from professional services.

Where parents did seek support from professional services within the current review, some spoke of experiences of discrimination from the professionals they worked with. Chowbey et al. (2015) described how parents from minoritised backgrounds in England can have a different engagement experience in their child's education and services. This can be due to language differences, visible race differences and cultural understanding. Parents who are part of a majority culture are more likely to see their race and culture represented within professional workforces. They, therefore, are less likely to experience discrimination based on this. Black African parents in Lawrence's (2014) study described their concerns about professional competency to meet the cultural needs of their children, whilst parents in Nnalue and Mahmud (2024) described their experiences of discrimination based on the way their verbal communication related to their English proficiency and pronunciation was received by professionals. This study's parents recognised unequal power when working with professionals. They did not feel like they had achieved a true sense of partnership with professionals and, therefore, lacked trust in their ability to meet their child's needs.

A final key finding from the current review was how parents described the way judgment and stigma from the wider community led to an internalisation of feelings of guilt. More traditional communities tend to align the cause of autism with religious interpretations and as though autism is a punishment due to their sins committed in a previous life, for example, Indian families in the USA (Gabel, 2004), Puerto Rican parents in the USA (Rogers-Adkinson et al., 2003), and South Asian community in the UK (Dobson & Upadhyaya, 2002). Guilt is a common theme described by parents of autistic children, particularly mothers (Marcinechova et al., 2023) and was seen to be a result of other's judgements and stigma within the community. In other minoritised cultures, such as Chinese culture, traditional Chinese values towards parenting are centred on the judgements of parents for their child's behaviour and success (Su et al., 2019). In comparison, parents from majority cultures may be less likely to internalise their child's autism because of their actions and instead be more likely to attribute it to genetic causes (Azad et al., 2023). For example, white parents are more likely to attribute autism to genetic causes than those from minoritised groups (Azad et al., 2023). Research by Lawrence (2014) also describes how parents felt that white communities were more accepting of disability and autism more generally, and as such, white

parents of autistic children may be less exposed to the judgements of other parents as a cause for their child's autism.

2.5.1 Strengths and Limitations of Papers in This Study

The papers in this review included parents' experiences from 17 African countries, spanning all regions of the continent. Agyemang (2005) described how ‘black African’ refers to people with ancestral origins from sub-Saharan countries, whilst those with ancestral origins from more Northern African countries may feel their cultures are influenced more heavily by Arabic cultures and, therefore may not use this terminology to describe their culture, such as Somali people. Within this review, 39 parents were identified as Somali. Oumar’s (2021) paper identified Somali parents as ‘East African’; this distinction is important as it may reflect the unique cultural influences these parents may have.

This review highlights the importance of language when talking about autism. Eight empirical papers specified participants needed to be interviewed in English; expecting participants to speak in English poses a risk that the participant’s true thoughts and feelings may be lost in translation. Many African languages use metaphors to convey a message more deeply than words (Harries, 2019). The expectation of participants to speak English also means participants are more likely to have been in the United Kingdom for longer periods or educated to a level of competence in the English language that allows them to convey their message. A strength of Fox et al., (2016) data collection and Selman et al., (2018) was using a co-researcher. This interpreter was a co-researcher involved in the study's design and acted as a ‘cultural insider’; including someone with a background similar to that of the participants can help to understand cultural information on a deeper level than the words being said (Tillman, 2002). Lemboye (2023) also used a co-researcher; they were someone who had the lived experience of being a black African mother to an autistic child. Lemboye (2023) trained them in key areas of research so that they could help shape the research and have their voice heard. This is a strength of Lemboye’s research, as the study was co-developed by two black African mothers of autistic children. This study was extremely culturally

sensitive as both the researcher and co-researcher were able to provide an insider perspective.

2.5.2 Strengths and Limitations of the Review

This is the first systematic review conducted to collate the existing literature in this field and look at the experiences of this population. Due to the author's cultural location, one strength of the review was regular conversations with community members about the study findings as they emerged.

This review sought to understand parents' experiences in the United Kingdom, however, no papers were included where participants lived in Northern Ireland. Most of the participants in this study lived in London or other major cities, so there was a lack of inclusion of participants living outside of cities. Black people who live in more rural areas of the United Kingdom can experience issues of race and engagement with services differently from those in more diverse cities (Parker, 2020). A further limitation of this review is that the literature search did not obtain papers detailing the experiences of participants who identified as dual heritage, who may experience interactions with systems and services differently (Brook, n.d.). A limitation of this review was that it was not within this project's scope to provide a synthesis of experiences by country which may have demonstrated specific patterns of experience related to parents from each country.

The nature of conducting a systematic review meant many papers were excluded within the screening process that may have contributed valuable insights into black African parent's experiences due to the authors identifying the participants as 'black' or grouping black parents with other ethnic groups. The study included only papers where participants were identified as 'black African', or from an African country. An additional limitation of the review process was due to the scope of this review, only papers that were published in English were considered.

Only the results from the study elements looking at parent experiences are included in the synthesis as part of this systematic literature review. However, these studies also include valuable information about the experiences of social workers and key personnel in education and support organisations.

2.5.3 Generalisability of Findings

This was a review of qualitative studies which are not usually expected to be generalisable (Leung, 2015). This review specifically looked at the experiences of black African parents, however, it does not intend to speak for the experiences of all black African parents of autistic children, and there will be many parents for whom the findings of this review are not true. The views included in this review are from parents who have willingly engaged in psychological research, creating potential bias within shared experiences. As highlighted in this review, many parents mistrust services and systems around them, and as such, the extent to which the views shared within these studies accurately depict participants' truths may vary. Mistrust in systems stems from historical events and can be reinforced by discrimination in the modern day (Scharff et al., 2010), and as such, the experiences in this review cannot be generalised.

Existing literature suggests parents of autistic children from different cultural groups may understand autism differently. The social construction of disability (Skinner & Weisner, 2007) highlights how a society's understanding of disability can be influenced by various historical, cultural and socio-political factors, suggesting the conceptualisation of disability, and therefore autism, varies greatly across cultures. Parent's interactions with services can vary across cultures; research by Theara and Abbott (2015) describes how South Asian parents of autistic children generally highly respect medical advice, whilst parents within this review appeared to hold a 'pluralistic view' about more traditional beliefs about autism, whilst adopting medical knowledge as a sense of empowerment to step away from negative societal views about their child. Kleinman (1980) describes how pluralistic views can shape service engagement, with people holding multiple 'truths' about medical diagnoses. Although this review's findings are not generalisable, they add to the foundations for an awareness of the cultural differences between interpretations of autism that parents in the United Kingdom may have.

2.5.4 Implications of the Review

This review has implications for professionals in a range of services supporting black African parents of autistic children across many stages of the child's life. Professionals must be aware of cultural differences in beliefs around the cause and

impact of autism on both the child's life and the caregiver systems around the child. It is also essential that professionals are mindful of their language use when working with families from African countries; this review has highlighted that many languages do not include a word for autism; thus professionals need to identify the understanding that parents may have and work together to ensure both parties share an understanding. This review highlights the importance of having greater representation of black African people in professional roles across all systems and institutions; the more diversity in the workforce serving local areas, the more effective the support can be. Additionally, parents in this review described their appreciation for culturally specific parent support groups, which should be implemented as a priority. The groups should be facilitated by a community member, informed with knowledge to reduce stigmatising views and support parents to access appropriate support within the community.

Chapter 3 To be respectful of the privilege that we've been given to hear people's stories": Developing Culturally Responsive Educational Psychology Practice for Black African Parents of Autistic Children

3.1 Introduction

Throughout their child's early years, families of autistic children may engage with services provided and facilitated by the Local Authority (LA) they reside within, including Educational Psychology Services (EPSs), to enable their child to receive appropriate educational provisions. Educational Psychologists (EPs) work on the frontline of facilitating this support, often engaging with parents at the beginning of their journey into accessing educational provisions for their child. Positive experiences with professionals, including EPs, during a child's early years can lead to high-quality support and positive learning and development outcomes (NICHD, 2021). Bronfenbrenner's Ecological Systems theory (1986) is a widely-used framework that can help to identify and understand how children can be impacted by many people and factors within their particular context (see Figure 2). The theory is often used within Educational Psychology to describe the systemic influences on the child and the interrelationships between each system level.

Framing an autistic child at the centre of the model, the microsystem around the child includes the parent and close family members, who will hold their own views and understanding of autism. As demonstrated by this model, parental views and experiences directly influence the child, as does the child on the parent. As a crucial component within the child's Mesosystem, the EP acts as a critical link between the family and access to other services. The Mesosystem includes influences from local politics, demonstrated by the EPS within the LA. The model also emphasizes the importance of shifting socio-historical circumstances over time by positioning the layers of influence on a child's development within a chronosystem. This study seeks to

understand the interrelationship between EPs in the mesosystem and parents in the microsystem around autistic children.

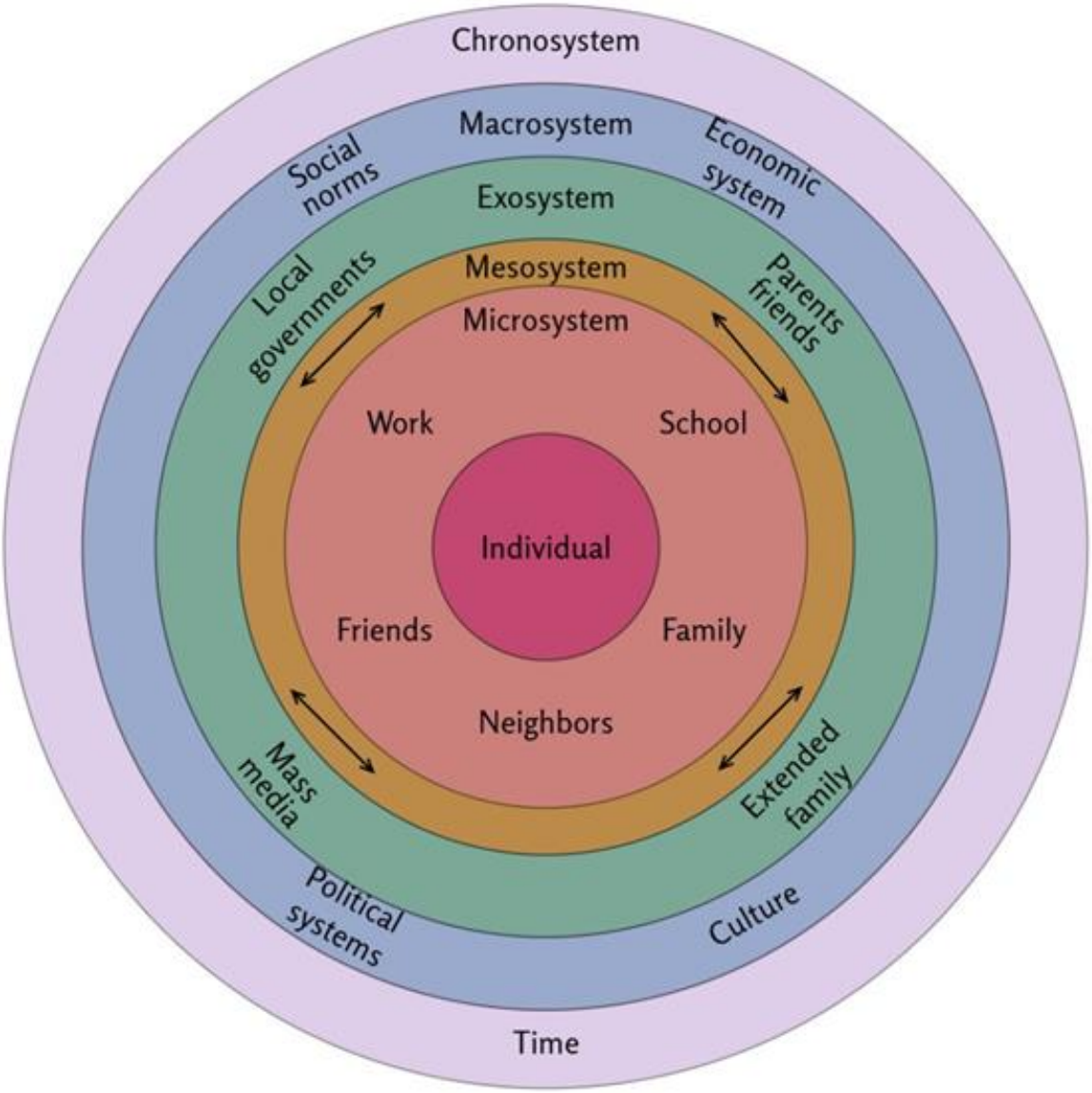


Figure 2: Bronfenbrenner's Ecological Systems Theory. (SimplyPsychology.Org (2024, January 17). https://www.simplypsychology.org/bronfenbrenner.html

The demographics of families accessing EP involvement for their autistic child are evolving; the UK is increasingly multicultural, with six million people reporting a

nationality of a different country in June 2021 (Sturge, 2022). 80% of the most ethnically diverse local authorities within the UK were within London, with 40.2% of London residents identifying as belonging to non-white ethnic groups (Office for National Statistics, 2020). London has the highest percentage of people identifying as 'black', at 13.5% of the city's population, compared to 4% nationally (GOV.UK, 2022). Parallel to this, rates of autism diagnoses have steeply increased in recent decades. Russell et al. (2022) outlined a 787% increase in diagnoses between 1998 and 2018, with reasons provided for this including raised awareness of autism diagnoses in girls and diagnosis in adulthood. O'Nions et al. (2023) estimated that between 0.77% and 2.12% of the UK population may also be undiagnosed with autism. Within school populations, there are ethnic and racial disproportionalities in rates of autism, with black children being 26% more likely to be diagnosed with autism than white children (Roman-Urrestarazu et al., 2021). Consistently, Perepa et al. (2023) reported on the over-representation of black African children diagnosed with autism (3.8% of the whole school population, but 4.7% of the autistic population) compared to other ethnic backgrounds. These figures combined highlight the growing number of black African parents seeking support for their autistic child.

This research has focused on the experiences of black African parents of autistic children in their early years, until the end of the reception year at school. Research by Hosozawa et al. (2020) investigated the factors that led to an autism diagnosis in early childhood versus adolescence. They found children who received an earlier diagnosis compared to during adolescence were more likely to have co-occurring additional learning needs and display difficulties with their social communication and emotional regulation skills, suggesting parents of autistic children diagnosed in their younger years may experience parenting their child differently to those diagnosed later in their life. Appropriate accommodations and support within educational settings to meet the child's needs in the early years is seen to have a positive effect on interpersonal skills and cognitive development (Clark et al., 2018), emphasising the importance of exploring the way EPs work with parents of autistic children in the early years.

A recent study into the demographic makeup of the UK EP workforce conducted by the Association for Educational Psychologists (AEP; 2021) found 86% of the 894 participants identified as 'White', a figure which is higher than the UK population of

81.7% from the 2021 census (GOV.UK, 2022). This suggests EPs working within London LAs in particular, will frequently be working with families with a cultural background different from their own. However, despite the growing awareness of the need for culturally responsive practice, many professionals do not feel equipped to appropriately navigate conversations around culture with parents from different backgrounds (Papoudi, 2020). Variations in culture bring variation in belief systems (Bornstein, 2012), and to fully serve diverse communities, EPs must be aware of the different belief systems that parents (who are framed as the 'experts in their child') *may* hold.

There is a growing awareness of the need to develop the profession's overall cultural competence and how educational psychologists work with minoritised cultures. Governing bodies to which EP's practice must adhere, such as the BPS Code of Ethics and Conduct and HCPC Standards of Practice, consistently emphasise the importance of addressing culture in EP's practice. Although there is little existing research in the UK to provide an understanding of *how* to practice culturally responsive with children and young people from minoritised cultures, recent examples of EP doctoral research into this field are increasing the body of literature. Anderson (2018) investigated how EPs perceived their competence to work cross-culturally, finding areas of perceived strength in awareness of assessment bias and the potential effects of poverty; however, lower perceived competency in theories of racial identity development and opportunities to engage with the community. This research also found that the more aware EPs were of the gaps in their knowledge, the more they recognised areas for development in their practice.

Research by Ratheram and Kelly (2021) sought to understand the influences on EP's practice with minoritised cultural and linguistic communities in the UK. They found that various factors influenced practice, including the policies, practices and systems across the education setting, EPS and the local authority within which the EPS was located. Both Anderson (2018) and Ratheram and Kelly (2021) highlighted that an EP's self-awareness of cultural competency is vital for them to work more successfully with individuals from minoritised cultures. Research by Sakata (2021) sought to develop a framework for EPs to reflect on how their practice is considered culturally responsive to the individuals they are working with. Within their research, they considered creating a

safe and inclusive environment as critical along with being empathetic to culturally diverse populations' experiences. Addressing language barriers for linguistically diverse populations was an additional area of practice recognised as necessary Sakata (2021).

Research by Krause (2018) sought to investigate the experiences of plurilingual EPs working with ethnic minority clients using languages other than English. Krause (2018) identified that plurilingual EPs may make a unique contribution to the profession by providing insight into children's and young people's linguistic knowledge and skills that cannot be assessed only by EPs working in English. Additionally, Krause (2018) found that plurilingual EPs can often work in ways that demonstrate a higher empathy for children, young people and their families. However, they also identified that the delivery of EP services in languages other than English can pose a threat to EPs' professional identity and can lead to ethical considerations.

Very little research currently exists looking specifically into the experiences of EPs working with parents of autistic children from minoritised cultures. Research by Allen-Biddell and Bond (2022) investigated the experiences of EPs working with autistic, gender-diverse young people. As part of this, EPs described how they also worked with parents of young people to help facilitate communication between parents and their children. To do this, EPs sought to avoid positioning themselves as 'expert' and instead drew on their skills to co-construct knowledge and understanding with the CYP drawing on their expertise. EPs described the unique complexity of supporting CYP at this particular intersectional identity as a challenge, describing it as looking at the young person as "two separate issues, trying to merge them" (Allen-Biddell and Bond, 2022, p.80, participant 5). EPs described how an accepting and collaborative approach was helpful for them to build positive relationships with children and young people. Another finding was the role EPs played in developing school staff knowledge and attitudes. EPs also described their need for evidence-based practice to give them the confidence to support this group of children and young people.

Research by Rupasinha (2014) investigated how EPs who conduct diagnostic assessments for autism consider other cultural factors. A key element of autism assessments involves information-gathering consultations with adults who know the young person best. Rupasinha (2014) found that EPs' approaches to the consideration

of culture during these consultations were rarely systemic and instead drew upon the EPs' knowledge base and opportunities within their local context, contributing to their professional experiences. This finding further provided support for the need for better evidence-based practice guidance when working with autistic young people with an intersectional identity.

In addition to belief systems, the understanding of, and attitudes towards autism may also be influenced by the language used to describe it in the parents' native language. For example, within the Somali language, there is no word to describe autism, and the vocabulary that is used is heavily associated with negative perceptions, which reinforces stigma (Hussein, Pellicano and Crane, 2018). Additionally, Bakare et al. (2009) suggested that professionals supporting autistic children and their families in Nigeria have the potential to reinforce stigmatising beliefs, including about the aetiology of autism, where 27% of professionals believed autism had a natural cause, 14% believed the cause was preternatural (beyond natural), and 27% believed autism had a supernatural cause, associated with faith and religion. Thus, the role of professionals in supporting families of autistic children from diverse cultural backgrounds is crucial to explore further. Within this research, culture is defined using the Tsui et al., (2014; p 239;) definition as the:

> ... total of the learned behaviours of a group of people who share patterns of values, beliefs, languages, ritual and customs, behaviours and interactions, cognitive constructs, and affective understanding through process of socialisation in the community and society.

The combination of increased awareness and diagnoses of autism in the UK for black African families means EPs must be able to meet the needs of these families, who may hold different expectations and understanding of autism. The motivation for this research is, therefore, to explore how EPs can better meet the needs of black African parents of autistic children by answering the following research questions:

1. How do EPs currently consider the needs of black African parents of autistic children, and what barriers do EPs encounter in their practice?
2. How do black African parents of autistic children experience working with professionals in their early years?

3.2 Methodology

3.2.1 Design

This qualitative, interpretive study was conducted using individual interviews with parents and EPs.

3.2.2 Ethical considerations

Ethical approval was received from the University of Southampton (ERGO Reference 76799; see appendix C.1) in April 2023 (see appendices D.1, D.2, E.1, E.2, F.1 and F.2 for ethics documents, including Participant Information Sheets and consent forms). All consequent actions taken as part of this project adhered to both University research guidelines and the British Psychological Society's Code of Human Research ethics guidelines (2021). Participants provided written consent before being interviewed and could withdraw their responses (through deletion of the audio recording by the researcher) up to four weeks after the interview date.

Parent study documentation, including recruitment posters (see appendix H.1), were professionally translated into the five most spoken languages from African countries in the first outer London local authority where participants were recruited. This was also where the lead researcher was on a trainee EP placement during the initial ethics application. The languages were Twi, Ga, Hausa, Somali and Yoruba. The translations, including the study advert and participant information sheet, were available from the beginning of the recruitment process. Parents and carers were also offered access to an interpreter for their chosen language during the study interviews; no participants asked for this, so all interviews were conducted in English.

In addition to the University of Southampton's ethics process, one of the local authorities in which data were collected required separate ethics approval. Accordingly, the ethics committee requested the lead researcher to meet with the research team of a recent project in the LA looking at autism in the Somali community. This meeting aimed to discuss some of the challenges the previous research team had encountered with their research and to provide more context for the current researcher when discussing autism within the black African community. Local authority ethics approval was

received after this meeting on the 11th December 2023 (RGF Reference CERGF292; see appendix C.2).

3.2.3 Recruitment and Sampling of Participants

3.2.3.1 Educational Psychologists

EPs from two inner London local authorities volunteered to participate in the study after being informed about the project while the researcher was on placement in their second and third years of EP training. The researcher shared the study documentation (see appendices D.2, E.2 and H.2) with the services via email and presented a summary of the research at 'Whole Service Days' to inform potential participants about the study. A reminder email was sent again two weeks after sharing the initial study details. After sharing the study advert with EP colleagues, potential participants then contacted the researcher to express their interest, and mutually convenient times for the interviews were arranged.

In total, 11 EPs were recruited, with six in one LA and five working in the second. EPs were required to have some experience working with families from black African cultural backgrounds and supporting autistic children in their early years. Three third-year trainees from the first LA were included in the sample due to the nature of completing casework independently from their supervisor; no trainees participated in the second LA. All EP participants self-identified as white women throughout the interviews.

3.2.3.2 Parents

In the first LA, parents and carers were informed about the study by sharing the study advert with a local autism specialist primary school and a local autism advisory service (see Appendix H.1). Additionally, the researcher attended two early years parent coffee mornings organised by the autism advisory service. The coffee mornings were attended by parents and carers of autistic children from a diverse range of ethnic backgrounds from across the LA. During the first meeting, the researcher presented the study with a summary of the topics for discussion during the interviews and the purpose of the participants' potential involvement. The researcher spent an hour talking with attendees, broadly about the rationale for the research and specifically about the

parents' experiences. Staff working with the autism service introduced black African parents to the researcher, where parents were able to ask more questions if interested in participating. Potential participants were provided with a physical copy of the study advert with the researcher's contact details and were asked to contact the researcher if they were interested in participating. During the second meeting, the researcher built on relationships formed with parents in the previous meeting and offered to take the parents' contact details if they were interested in participating.

Parents' and carers' eligibility for this study required them to:

- Identify as being from a black-African cultural background
- Have an autistic child, including both those with and without a formal diagnosis
- Have had previous experience of EP involvement for their autistic child during their child's early years.

Due to differences in available support provision in the second LA, SENCOs, whom the lead researcher worked closely with as the link EP, shared the study adverts with members of their school who had children in their early years who met the study criteria.

Once parents had shown potential interest in participating by emailing the researcher, they were sent a copy of the study documentation (see appendices D.1 and E.1). In total, two parents were recruited, one in each LA. As per the inclusion requirements, both parents confirmed at the interview that they identified as black African, with one parent describing themselves as Somali and the other as Nigerian.

3.2.4 Methods

The data were gathered through semi-structured interviews (see appendices G.1 and G.2), which were co-developed with a panel of 'experts by experience'. This panel included white autistic adults/parents and parents of autistic children (known to the researcher through a mutual research interest group), an EP from a black African cultural background (known through the researcher's taught university sessions), and a black African parent (known to the researcher personally). All panel members reviewed copies of the initially proposed interview schedules and were invited to provide

feedback about the appropriateness of the questions, and whether there were any experiences the researcher had not included that were important to the panel. One autistic adult responded with a request to change the questions from EP 'support' to EP 'involvement', to reflect on the nature of professional involvement not always providing support, and a recommendation about moving away from the idea of parents' "concerns" with their child's development (see appendix J for comments). At the end of each interview, participants were provided with their respective debrief ethics documents (see appendices D.1 and D.2).

3.2.4.1 Educational Psychologist Interviews

EPs were given the choice to be interviewed either online or in person within the Educational Psychology Service office. Two EPs from the first LA chose for their interviews to be conducted in person; the remaining interviews were conducted online. EP interview questions (see appendix G.1) were oriented around the various potential stages of involvement an Educational Psychologist may typically have in supporting families with autistic children in their early years, including initial consultations, statutory work and transition support to primary school. Information was also gathered about the EPs' professional experiences related to their understanding of black African parents of autistic children's experiences and the EPs' experiences of training and learning about different cultures to their own.

Interviews for EPs lasted for approximately 60 minutes, and participants were reimbursed for their time with a £10 coffee shop voucher. EP participants were also able to use their involvement as part of their Continuing Professional Development (CPD) evidence for their bi-annual Health Care and Professions Council (HCPC) re-registration, which was confirmed in a phone call by the researcher. This is due to the participants contributing to the ongoing development of practice by adhering to the Health Care Professions Council (2023) proficiency standards.

3.2.4.2 Parent Interviews

Parents' interview questions (see appendix G.2) were derived from the researcher's previous experiences working with culturally diverse families and were intended to develop the researcher's understanding of the participants' journeys of receiving involvement from EPs, and other early years support services. In particular,

the questions were designed to encourage reflection on whether the cultural background of the parent and family was acknowledged during EP interactions with families. The participants' understanding and personal meaning of autism were also discussed. All Interviews were conducted online to ensure researcher and participant safety by avoiding the risk of lone working and lasted for a duration of approximately 75 minutes. Before beginning the online interviews, the researcher confirmed with the parents that they were in a private room where they were comfortable to speak freely. Parent and carer participants were reimbursed for their time with a £20 digital shopping voucher, which had previously been detailed in the study advert.

3.2.5 Data storage and transcription

In-person and online interviews were recorded using Microsoft Teams, with the recording being made using the researcher's University Teams account to ensure secure storage on the University cloud system. The transcription feature on the Teams meeting was used to produce a copy of the automated transcripts. The researcher then edited for errors by listening to the original recording and amending the errors, anonymising the transcripts, and removing identifiable information (see appendices K.1 and K.2).

3.2.6 Data Analysis

Braun and Clarke's (2022) reflexive thematic analysis (RTA) process was used as a guide for analysis. This analysis process was chosen because it is considered a flexible and systematic interpretative analysis approach, with a key feature being the researcher's active role in knowledge production (Byrne, 2021). With the researcher being a trainee EP immersed within the research context and actively working with black African families of autistic children contemporaneously to the research process, RTA enabled the researcher's interpretive analysis and interpretations of patterns of meaning.

The six-phase analysis process was conducted independently across the parent and EP transcription sets to identify themes within the two distinct groups. The datasets were analysed separately due to different questions being asked within the interview. The analysis process began after all interviews were conducted. The first stage of RTA,

familiarisation, began during the initial editing of each transcript. This process also included listening to the audio recordings and following along with the transcription to ensure clarity and accuracy. During the familiarisation stage, the researcher kept a reflective diary, noting key reflective points made by the participants but also their experiences during the analysis. The second phase of analysis, coding, was completed using NVivo. Each transcript was coded line by line, and any relevant data to the research questions was given a code label. Each transcript was coded twice iteratively to ensure the code labels accurately reflected the coded data. The third phase involved generating initial themes. This was done by each of the codes being grouped based on the initial research question they appeared to answer. This list of codes was then grouped into clusters based on a shared meaning. Within each cluster, initial themes were identified, initially arriving at over 20 themes.

Phase four involved reviewing the initial themes, which included renaming and merging the initial themes until five themes were developed. During phase five, the theme names and details were refined by the author attempting to describe the themes to another person, which led to edits being made to the wording of the themes. The themes were edited to ensure they were interpretative and related to the research questions. Phase six involved the write-up of the findings. During this phase, the findings section felt too long by the researcher and their supervisor team, so phase four was returned and subsequent phases were revisited (see appendix I for the iterations to the theme names and sub themes) to lead to four themes being developed. After further feedback from the supervisor team, it was felt that there was insufficient reporting of the parent experiences and that a centrally identified link between three subthemes could be a standalone theme. As such, phase four was returned to for a final time, and the subsequent phases were revisited to lead to five total themes. Out of these five themes, themes one, two and three are based solely on data analysed within the EP interviews, whilst theme four is based on data analysed solely from parent interviews. Theme five encapsulates data from across both parent and EP interviews (for clarity around this, please see appendix I and the keys provided for details around the data contributing to each theme). Braun and Clarke's (2022; p269) 15-point checklist for good thematic reflexive thematic analysis was followed and regularly reviewed.

3.3 Findings

Following analysis, five major themes were identified, with 13 sub-themes (see Figure 2 for a thematic map). These themes were: 1) EPs are aware of the need to build trust with families in the way they discuss and report on culture, 2) EPs work within systems that influence their practice, 3) EPs recognise the importance of continuing to learn about other cultures to their own, 4) Parents have a range of experiences working with professionals and accessing services and support and 5) Power dynamics can impact a parent's sense of safety when working with professionals.

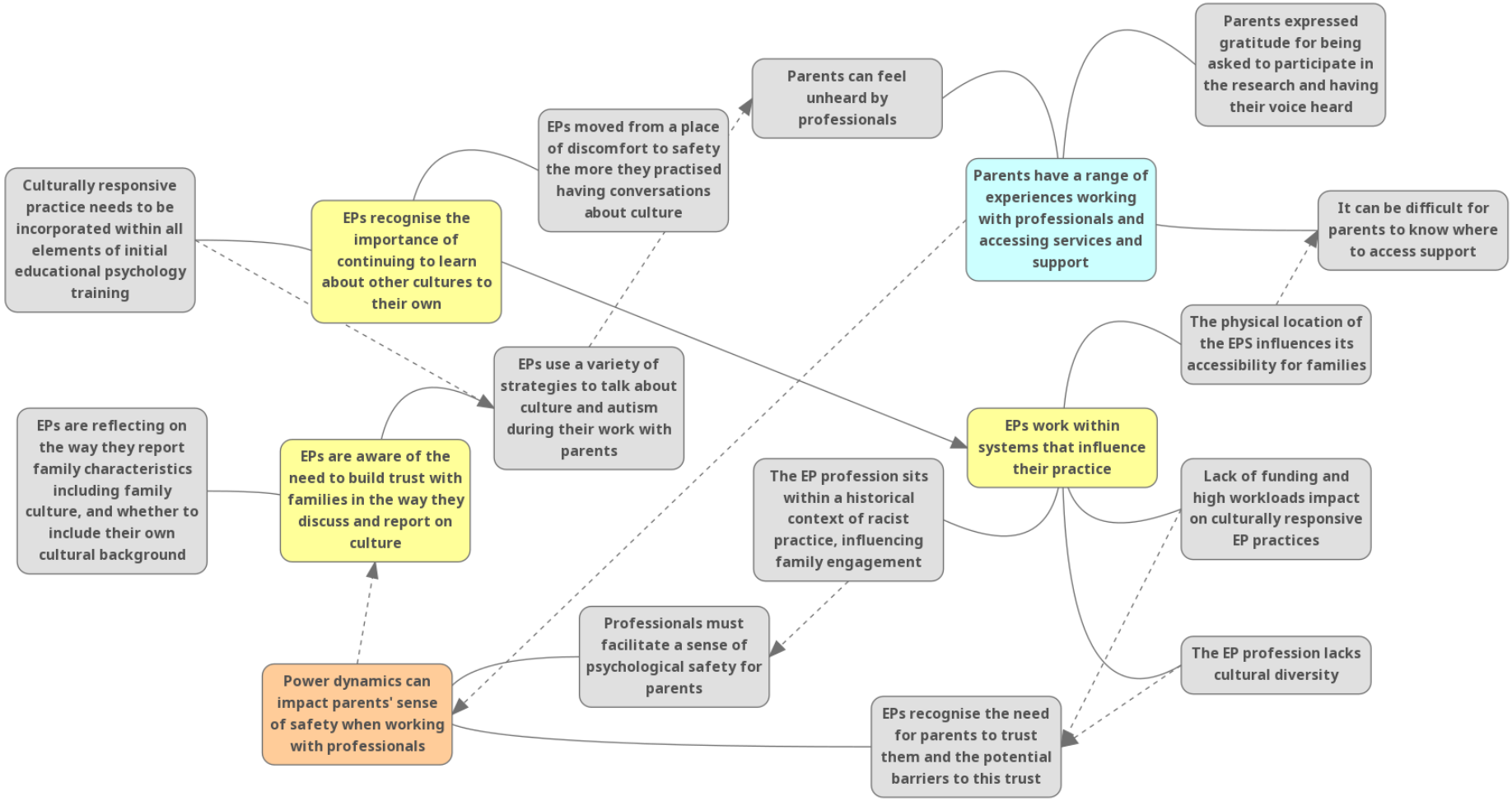


Figure 3: Thematic map of all developed themes and subthemes through the RTA process. (Dashed lines indicate links between themes and subthemes)

3.3.1 Theme 1: EPs are aware of the need to build trust with families in the way they discuss and report on culture

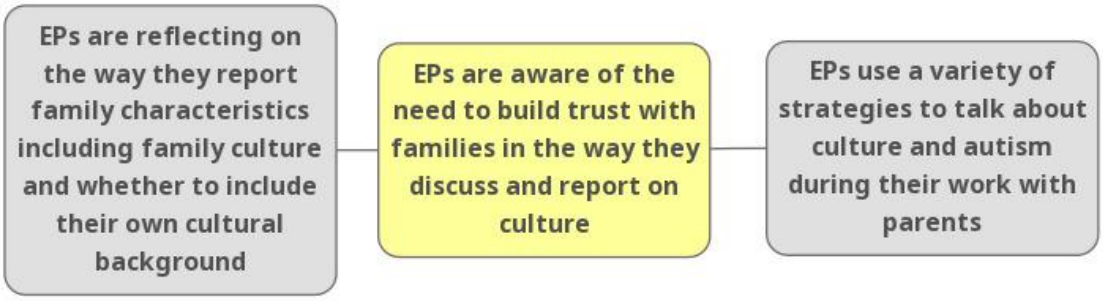


Figure 4: Thematic map for theme 1, including sub themes

3.3.1.1 EPs use a variety of strategies to talk about culture and autism during their work with parents

This theme reflects the practical approaches EPs take to develop their understanding of the child and family whilst working with black African parents by respecting differences in attitudes, views, and experiences. EPs use a variety of strategies to talk about culture and autism during their work with parents

During conversations about culture, EPs described it was important to avoid "*unintentionally making assumptions about people's culture or what's important to them... (EP11).* EP10 described how they "*try and take a curious stance...ask questions acknowledging that I don't know... I'm asking questions to help me better understand but acknowledge maybe the limitations of my knowledge"*.

Practical questions such as asking about the child's strengths and needs in different contexts enabled EPs to learn more and celebrate the child's and family's cultural identity:

"...thinking about them in different contexts of like, what are they like in their Quran school... what they're like outside of school and that's their identity and who they are and celebrating... it sometimes feels like within consultation we're talking about that

child in school…their life is so much bigger than this and actually acknowledging all the aspects of them is really important." (EP6)

EPs reflected that they could hold a different understanding of autism than black African parents did, describing it as "*It's [autism] not a universal truth.. like bodies are bodies…essentially in the lungs, work the same whatever side of the world you're on" (EP7).* EPs described how parents could hold pluralistic belief systems which were important for EPs to be aware of, and how they "*might rely on a whole range of different belief systems at the same time"(EP1).*

3.3.1.2 EPs are reflecting on the way they report family characteristics including family culture, and whether to include their own cultural background

EP1 described how they "*would always put the language and ethnicity of the child, whether its white British or whatever other language background they're from".* One EP echoed the idea that all cultures should be written in reports:

"…really, if we feel it's important to comment on culture at all, then I think we should be commenting on every culture…shouldn't be left to be a kind of presumption that if they don't comment, that means the person is White British, or if you don't comment, you're making a guess by someone's name." (EP10)

EPs held mixed views towards whether it was important to include their own cultural backgrounds within the reports. One EP described how they felt it was important to include this information as it helped to frame the personal constructs they had brought to the child's situation:

" I definitely think it is relevant…thinking of it from like kind of a…positionality statement and thinking of others reading your report … people read my name….Think she's gotta be a white girl…there should be an acknowledgement of who you are….Because realistically, a report is just like your perspective on a situation…" (EP6)

Another EP compared the production of a report to a piece of qualitative research, to justify how they came to their psychological formulation within the report:

"We *usually present our position within qualitative research…it is interesting that we don't necessarily do that in our reports…it provides a rationale of kind of why this is*

your psychological formulation of a child and the perspective you're coming from…" (EP5)

EP11 described how within their reports, *"…: I have my picture on them…so there's certain things you can see…"* Contrastingly, one EP described how they felt uncomfortable with describing their cultural background within a report, *"if I give out my label of my culture and my ethnicity…people might perceive me in a certain way and put me in the box and don't think I can relate…" (EP4).*

3.3.2 Theme 2: EPs work within systems that influence their practice

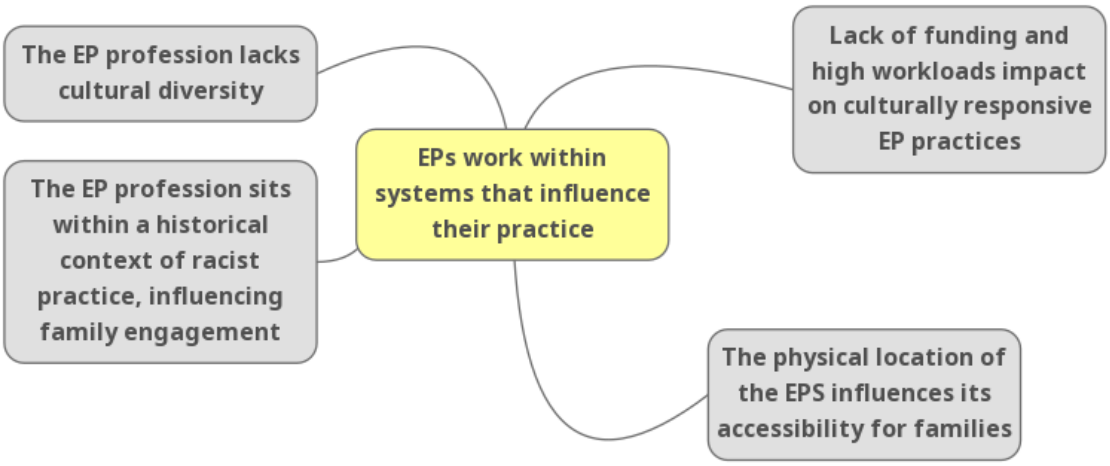


Figure 5: Thematic map for theme 2, including sub-themes.

This theme acknowledges the systems around the EP that shape their practice. The first subtheme refers to the homogeneity of demographics within the EP profession. This theme encompasses the high workloads EPs are working within, the impact on their practice, and the accessibility of their service to the families they support. This theme encapsulates the historical context in which the EP profession sits within the historically racist practice the profession and wider services are associated with.

3.3.2.1 The EP profession lacks cultural diversity

One EP described the lack of diversity within the profession as a *"huge issue"* (EP 11). EPs reflected on the homogeneity of the EP demographic; *"Oh, you're a white woman, you got blonde hair.. I said no, it's brown…They went, oh well, you're still fitting" (EP7).*

One EP described the systemic barriers to being accepted into the initial doctoral training and the impact this may have on the families they serve:

"I've lived a privileged life…I could get on the course, and the course itself is very middle-class white…That's a systemic issue that comes down to then working with black families… it would just be better…If they were looking at a similar picture when they were being supported" (EP6)

A lack of diversity in the EP profession meant there was a lack of diversity within EP teams, which one EP described as impacting the way the team can reach the community they serve: "*I worked closely with a colleague who was Congolese and she had an amazing ability…to reach the community in ways that I would never be able to" (EP2).* The lack of diversity in the profession meant there was often a lack of people to challenge and think of different ways to approach cases based on their own knowledge:

> *"I think the real issue with like having these conversations…we're maybe not challenged or we don't think of things in a way that we maybe would if people had different backgrounds…" (EP6).*

3.3.2.2 Lack of funding and high workloads impact on culturally responsive EP practices

EPs work within a wider team that sits within the LA. One EP reflected that the EPS feels like it is different to other services within an LA, as a "*strange kind of offshoot*" (EP7). High EPS workloads impacted EP practice as EPs described how they "*don't feel like I get enough time to really stop, think and reflect…about the cultural aspects…"* (EP4). Another EP described how "*the more time you've got the more you can do…partly because of the pressure we're all under to get too many reports written in time*" (EP2). EP1 described the need to be "*realistic about what we can offer*", related to the time pressures of other work requirements. One EP reflected on a shift they had noticed around anti-racist practice being something that everyone in the team was aware of, with policies making it more official:

> *"I think in the UK there's just been… in the last few kinds of 5-10 years…a big kind of thing about…. anti-racist practice…I think I think it's become something that everyone was aware of and now I think we're at the point where either in private*

practice or public service, you've actually got policies written... It's become more official." (EP5)

3.3.2.3 The physical location of the EPS influences its accessibility for families

EPs reflected on the physical location of their services and the impact this had on accessibility for parents as "*There's various bits of research that say if you base psychologists in community places like religious places like mosques or a church...that can be really accessible..." (EP11*). Building relationships with the community was important to enable parents to feel safe:

"...There is room to be able to do more kind of community-based work.... providing kind of coffee mornings, I would love to do kind of more of those sorts of things to actually make sure that our services are accessible to everyone and not making parents feel like ...the first time they hear about psychologists is when they've been referred to us...knowing that it allows them to kind of access us in a kind of a safe way and on their own terms." (EP5)

Relatedly, one EP reflected on the nature of the EPS being commissioned by schools, instead of by families, as a barrier for access to parents and "*is not putting families first" (EP11)*.

3.3.2.4 The EP profession sits within a historical context of racist practice, influencing family engagement

EPs were acutely aware of the context of historical racism within the EP profession and within wider services as a "theme all the way through" (EP1). One EP described the historical racism in wider services designed to support local communities:

" Like the George Floyd thing... I think the Stephen Lawrence thing was the first kind of name where I can say I remember a big shift kind of in terms of how newspapers would report things...people could say actually, no, there's a lot of racism running through organizations..."(EP9)

For one EP, as they continued to learn more about the historical context of the EP profession, they were able to understand some of the challenges black parents had experienced when working with them in the past:

"...people have been concerned about what I was going to do, but I always thought that was about the job title....You're gonna mess with the head...but I hadn't really understood why some parents were so reluctant to think about special school and suddenly it made a lot of sense that things did happen historically... And the whole thing was just was like a.... penny dropping, really... I've just never understood why there was that reluctance where other cultural groups maybe didn't have that reluctance, and maybe even fighting for it..." (EP3)

3.3.3 Theme 3: EPs recognise the importance of continuing to learn about other cultures to their own

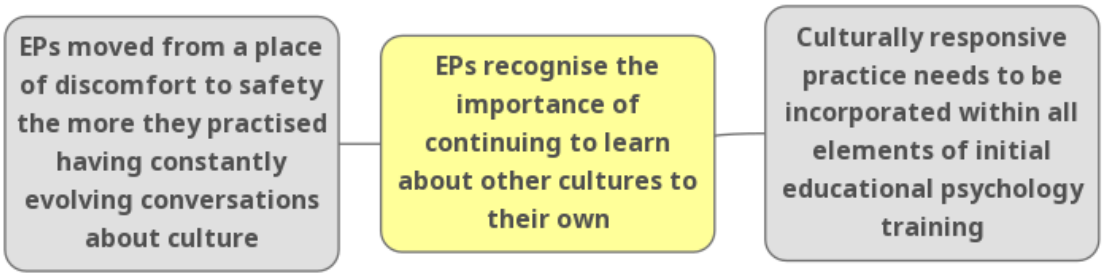


Figure 6: Thematic map for theme 3, including sub-themes.

This theme encapsulates EP's recognition that culture and society are constantly evolving, and therefore they have a responsibility to ensure they continue learning about community cultures whom they serve. EPs reflected that they do this through both formal and informal conversations, in training or reflective spaces such as supervision. This theme also encompasses the subtheme that the initial EP training course does not consistently prepare EPs to work with families from different cultures.

3.3.3.1 EPs moved from a place of discomfort to safety the more they practised having constantly evolving conversations about culture

Talking about culture with other people was seen to elicit a mixture of emotions. One EP described how the conversations felt unnatural to them, which added to the discomfort they experienced around the potential for saying the wrong thing, "*There's a bit of anxiety and worry of, you know...saying the wrong things and not being sensitive." (EP5).* One EP described how their fear of discussing culture with parents stemmed from a "*wish not to cause offence and not to play to different stereotypes..." (EP1).*

For one EP, talking about culture frequently enabled it to become a normalised conversation topic: " *We talk about culture all the time…feels really kind of safe and interesting and important*" (EP11). One EP described the shift in normalising these conversations: *"Five years ago, I probably would be a bit hesitant…a bit uncomfortable… not that I'm, you know, an expert or anything, but it feels that I feel kind of OK talking about it now…*" (EP8)

One EP emphasised the importance of talking about race and culture as part of a collective team, enabling them to reflect on their practice honestly: "*its all very well me saying I'm really reflective, I'm really culturally responsive you know, and we need to be able to hear from other people, but we all need to be brave enough to be sharing those thoughts" (EP3).* Supervision spaces appeared to be described as a 'safe place' for some EPs, who would use this time to be "*thinking about it quite carefully and in supervision… It would be about reflecting on or thinking about why this created a feeling.. putting that into my supervision…" (EP8).* One EP highlighted how understanding cultures and their influences never feels fully completed:

> "*… I think culture is one that feels quite fluid. …its about rolling tasks…it is a constant ongoing process because there are so many different communities and views are changing all the time as well…It's always gonna be a work in progress" (EP1)*

3.3.3.2 Culturally responsive practice needs to be incorporated within all elements of initial educational psychology training

EP's experiences of their university training differed across the sample. One EP described how learning about culture within their training had felt "*tokenistic in terms of let's quickly think about you know the equality, diversity, inclusion aspects of a particular problem scenario and then we think about it… there isn't enough of that transition from kind of reflection into practice" (EP4).* Another EP echoed this, that "*culturally responsive practice is part of all EP training programmes…not only as specific sessions but I think if you silo it up as something separate to mainstream practice … is what you're teaching culturally responsive?" (EP11).* The same EP reflected on how their experience of training EPs within their academic work had shifted a "*focus on decolonial approaches…by both critiquing kind of mainstream ways of*

thinking and psychology and also bringing in new alternative ways of doing psychology…" (EP11).

3.3.4 Theme 4: Parents have a range of experiences working with professionals and accessing services and support

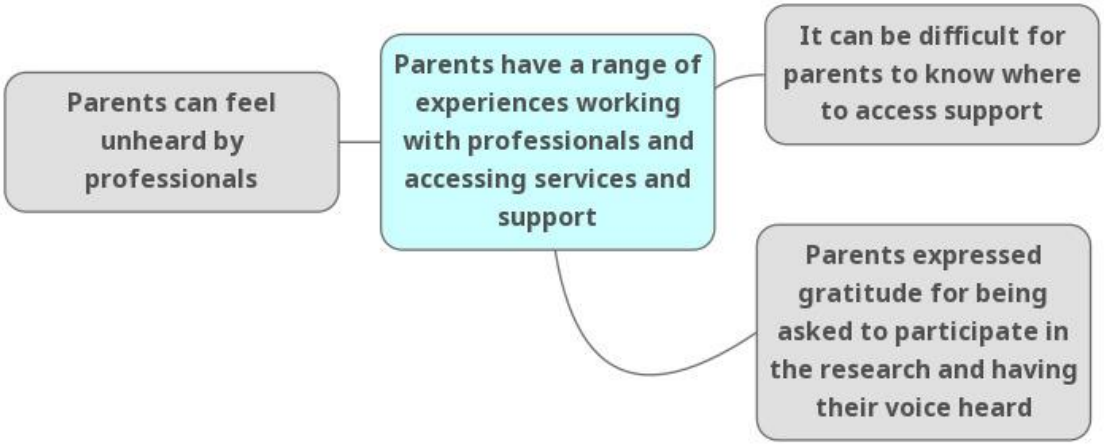


Figure 7: Thematic map for theme 4, including sub-themes.

This theme describes the spectrum of experiences parents shared about working with professionals, including parents not always feeling understood and heard by professionals. It also includes suggestions for things that can be done to build a sense of safety and facilitate parents feeling understood by the professionals working with them and their children.

3.3.4.1 Parents can feel unheard by professionals

P2 shared how, with their first interactions with a psychologist, "*I think the first year I was talking to myself*". P1 described how they felt unheard and dismissed when voicing their concerns to the early health visitor and were told, "*no, no, that's fine.".* P1 reflected on her journey of being a first-time mum with an autistic child; "*he was my first….So I had no idea… I didn't really know anything…".* This led to her reflecting on how this shaped how she listened to felt by professionals*: "I get that they have to sort of balance out our first-time parent. How much experience do you have.. but at the same time, if a parent I think has worked up the courage to say something, then maybe it's worth listening."*

P1 reflected that speaking English "*definitely helps…I've had group interactions where an interpreter is involved…Sometimes things can get lost in translation… what they're saying in Somali and then what's being translated…something is being lost here…".* P1 described how they felt the EP role was to be "*a listening ear… most of the time it's just being listened to so that you can get all your fears out and then being told, you know, we can connect you with other families…".*

3.3.4.2 It can be difficult for parents to know where to access support

Both parents described how they felt they had a lack of knowledge about the support available for their child and their family. This reflection was particularly important for parents with a young autistic child, at the beginning of their journey:

> *"If you're at the beginning of the process…it can be overwhelming, you kind of just don't know where to go next… especially if you're going through some sort of crisis with your child and you just don't have the capacity to do any of that leg work yourself…it can be overwhelming" (P1)*

Parent 2 described how they would have liked to know the support available to "*have the right to select…if I wanna access support I can do so".* Parent 1 shared that it would have been helpful for professionals to make referrals for parents, as opposed to the onus being on them to make the referral:

> *P1: "… we got our report through… it's just like so this is your report and then you could go to a couple of these organizations….there's not really much sort of support in terms of maybe connecting you to other families or connecting you to some sort of local support directly… sometimes just being able to say I can put that through for you…so they'll get in touch with you kind of thing… So then that's one less form for you to worry about" (P1)*

3.3.4.3 Parents expressed gratitude for being asked to participate in the research and having their voice heard

Both parents expressed gratitude about being asked to participate in the research. One parent described how they "*believe the topic is so important in supporting*

families…thank you so much for the opportunity to participate" (P1)[2]. The other parent described the way they felt listened to and that their voice was becoming heard:

"It's been lovely to speak with you too, and thank you for this, because it's actually is I've, I feel honoured and I feel like my community is being heard…. So thank you a lot cause I've not had this, and it feels good to actually say these things and know that you're not judging me…that as a person of colour, I can actually speak on behalf of other people of colour and have that published because it matters….It is nice to actually have a voice and actually see it being put in black and white and actually being published…It feels good, it feels really good" (P2)

3.3.5 Theme 5: Power dynamics can impact parent's sense of safety when working with professionals

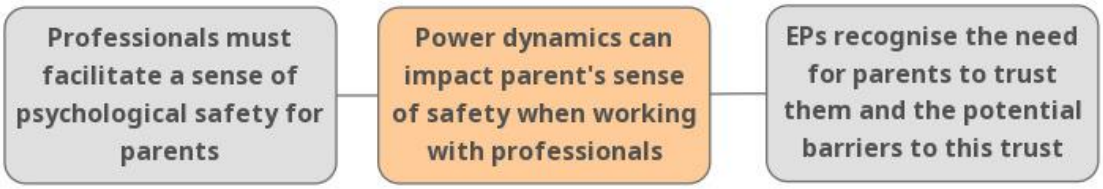


Figure 8: Thematic map for theme 5, including sub-themes.

This theme straddles both parent and EP datasets and refers to the perceived power dynamics of professionals holding power and parents feeling unsafe. EPs described being aware of the importance of parents trusting them, whilst parents shared the negative psychological impact of professional involvement.

3.3.5.1 EPs recognise the need for parents to trust them and the potential barriers to this trust

EPs described the importance of parents trusting them:

"*I was a trusted person that the mother could speak to and that understood home and helped her and understand how to how to communicate….with her older son" (EP1).*

[2] This information was provided in email correspondence post-interview, not within the interview itself.

EPs attempted to build this trust with parents by explaining their role to them:

"I don't know why I think the title sounds maybe a bit grander....So to sort of normalize that I just say a little bit about what we do actually, what the role of an EP (is)*..." (EP9).*

EPs were also aware of the importance of:

"Recognizing the power of being EP and....How we need to use that power for good... to be respectful of the privilege that we've been given to hear people's stories" (EP6).

EPs described how visible race differences between themselves and parents may be perceived as a barrier for black African parents to feel safe to share their experiences:

"*I am a white individual .... I do wonder what are the barriers, in terms of kind of race, occur in interactions and whether and that whether that has an impact on... a parent from a different cultural background to feel comfortable with me, to share their experiences..." (EP5).*

Another participant described their view that black parents may feel more comfortable sharing with their experiences with a black EP:

EP6: I mean, I think one big barrier is the fact that... being a middle class white woman may make other families not feel as comfortable ...Like I might not be able to make people feel as safe or understand their context in the way that a black EP would...

In addition to visible characteristics, EPs reflected on other invisible barriers to some parents feeling comfortable to share their experiences as "*they have real struggles which I will never really understand because of the privileges that I have" (EP4).*

3.3.5.2 Professionals must facilitate a sense of psychological safety for parents

P1 described how "*the whole process when it came to interacting with the professionals...I think I was always a bit anxious because you never really know what's gonna happen...".* P2 described how parents, in general, lacked a sense of safety when working with professionals, which in turn impacted their comfort to ask for help:

"... a general sense of safety...I think that's what a lot of parents are lacking right now....That's that thing of being feeling safe, like, OK, we've established my child needs help, now do I feel safe enough to ask for this... But when you think about it... in hindsight... are you saying that I'm...I can't look after my children. Am I a bad mum?" (P2)

P1 described their experience of feeling understood by a black EP who 'got' some things that an EP who was not black might not have:

> *"... the EP that we had.... She was black, so I don't know if that made a difference... I think maybe she just sort of got some things...I don't know if the interaction or the questions would have been different ..., but I think it is worth mentioning" (P1)*

Additionally, parent 2 described having a lack of trust in the systems designed to support them and their family, particularly in being coerced into applying for a special school place for their child. They reflected that this may have been due to being black:

> *"Apparently the school does a thing where they try and push the parents into putting kids in a special needs school after a certain age, and they say that, oh, the child's needs [are] becoming too much and we can't handle it... sadly enough its been 2 BAME parents...I don't wanna now have that, that anxiety...oh they're gonna do this to me..." (P2)*

3.4 Discussion

The aim of the current study was to better understand the interactions that occur between black African parents of autistic children and professionals (EPs) working with black African autistic children and their families. EPs play a crucial role as intermediaries between families of autistic children and additional services and support. In culturally diverse local authorities, EPs often work with families from various cultural backgrounds, including black African families. Given that the majority of the EP workforce identifies as 'white', it becomes crucial to learn from the positive and negative experiences of black African parents so that EPs can adapt their practice to lead to better outcomes for black African autistic children in the UK.

The findings highlighted that EPs were aware of the potential for mistrust from parents towards the services and professionals and were reflective of their conversations about culture with parents. EPs described barriers to working in culturally responsive ways, including high workloads leading to a lack of time to reflect on their practice and physical barriers such as a lack of cultural diversity within EP teams and the physical location of the EPS services. EPs recognised the importance of learning about cultures other than their own. Having regular opportunities to do this made them feel more confident in having conversations about culture. Parents described a range of experiences working with professionals and their access to support, including feeling misheard by professionals and a lack of psychological safety. Parent's descriptions of feeling grateful for being asked to participate in this research highlight the need for the inclusion of black voices in research into practice supporting autistic children and young people.

These findings add to a growing body of literature on the importance of developing culturally responsive practice within psychology, exemplifying how current practice does not consistently meet the needs of black African families.

3.4.1 Interactions in the Mesosystem

EPs are a critical link between parents and access to further support, theoretically situated within Bronfenbrenner's (1986) mesosystem. One of the findings was the relationship between power dynamics, trust and psychological safety. EPs were aware of the power they can hold, and parents did not trust professionals and did not always feel psychologically safe when working with professionals. Greaves (2022) described how communication difficulties between 'minority ethnic' communities and professionals can lead to challenges forming mutually trusting relationships. While working with families, EPs work within delicate social dynamics involving the potential for power imbalances. Using French and Raven's (1965) bases of power theory, EPs could be considered to hold two types of power: 1) legitimate power, and 2) expert power (both of which stem from their professional role within the education system hierarchy), and 3) referent power (which occurs when families can identify with the EP in some way). EPs are practitioner psychologists and must adhere to the Health Care Professions Council (2023, p.9) standards of proficiency, which outline the need to "recognise the power imbalance....understand the dynamics of power relationships".

EPs were aware of the actual and perceived power they could hold, and parents described feeling concerned about what could happen with this power, which left them feeling unsafe to ask for help and feeling anxious about their involvement.

One parent spoke about the positive impact of a black EP on their experience. Research conducted by Lawrence (2014) supports this finding; they found that some parents within their study held a concern that white professionals held specific cultural stereotyping and specific harmful ideologies about black children, impacting parents' engagement with professionals. Ajewole (2023) described how EPs from all backgrounds can successfully and meaningfully engage with black families with the appropriate skills and values and following sound ethical guidance. This further supports the present research since the findings can help inform training and guidance for EP practice.

3.4.2 Wider Systemic Influences

While the main focus of the research was within the mesosystem regarding interactions between parents and EPs, wider influences will inevitably impact experiences, which are recognised through the Exosystem and (next) the Macrosystem and Chronosystem. Some of the systemic barriers that EPs experienced were universal across the two boroughs. All EPs were employed, at least part-time, within EPS' that were positioned within the LA, meaning that service priorities were shaped by the local government. A recent report by Atfield et al. (2023) sought to understand the EP and Principal EP workforce experiences regarding the range of services delivered, the demand for work, and the barriers and drivers to staying in the workforce. EPs within this study outlined how their support to schools and education settings was funded by one of four funding mechanisms by the local authority, with each local authority using a different funding model. These were: 1) free consultations funded by the local authority, 2) fully or partially traded services where schools bought packages of support through either time or activity allocations, 3) statutory only, where the local authority commissioned EPs to only deliver EHCP assessments, and 4) referred to specially funded projects through central government schemes, which the LA funded directly or indirectly. Within the current study, both LAs operated as fully traded services, meaning EPs within this study were working in both statutory and traded capacities. The variety of

ways the different EPS' operate highlight how the LA influences the ways EPs can practice.

EPs are working within a chronosystem which accounts for the context of time in which they are practicing. As described within the findings, EP practice sits within a context of historically racist practice; Ajewole (2023, p2) outlines educational psychology's history as being "fraught with racism, oppression, coloniality and a preoccupation with individual differences (e.g. eugenics and psychometric testing) which all directly negatively impacted black people". Research by Stunk and Andrezejewski (2023, p.58) describes:

> *"the contemporary complicity of the [educational psychology] field in sustaining anti-black racism, through the omission of both the racist beginnings of the field…and the omission of the lives and experiences of Black individuals…in terms of representation in research, and the omission of anti-black racism as a topic of concern for the field"*.

Stunk and Andrezejewski (2023) also described how the 'institution' of educational psychology was built upon concepts of white supremacy; the initial educational psychologists (scientists and researchers) were exclusively white, developing various methodologies for race science. Many of these people were in favour of eugenics, holding a positivist psychology approach that race was a biological genetic factor that governed intelligence. In the contemporary EP world, much of the research findings produced by the initial 'EPs' have gone on to form the foundations of current education training practice "as if they were ideologically neutral" (p.61). This also aligns with the finding in the current study about how initial educational psychology training does not consistently teach about how to practice in anti-racist ways.

Parents in the current study highlighted the value of being asked to participate and described how they felt their community's voice was not usually heard. Research by Kumar and DeCuir-Gunby (2022) sought to investigate the extent to which articles published in a major Educational Psychology journal published research about race-related issues. They found 31 (3.2%) of all articles published between 1963-2022 met the inclusion criteria, 12 of these appearing as special issues focused solely on race and ethnicity. Positioning this research as a special topic segregated from mainstream educational psychology research highlights the failure to include the perspectives and

experiences of black people within educational psychology practice and the way that contemporary EP practice (as an institution) continues to reinforce racist practice. This mirrors a finding within the current study, about how culturally responsive practice is often taught as individual topic sessions at university, instead of a way of universal practice. It does not become a ubiquitous type of practice by siloing sessions about this into individual topics.

EPs within this study spoke about their experiences on their initial training courses, with a combination of experiences shared by participants who completed the previous Masters degree training requirement, and those who completed the three year Doctorate. All EP participants were currently practising in London local authorities but had undertaken their training at a range of training providers across the UK. Within these conversations, it emerged that initial training courses did not appear to consistently prepare EPs to have the confidence to engage in conversations about culture and to reflect on their own cultural identity and biases. A large part of the learning on the EP Doctorate comes from experiences on placement, and as such there is the potential that trainees undertaking placements in very culturally diverse areas may have opportunities to develop their skills working with a variety of cultures away from university, somewhat filling gaps in taught university approaches. In contrast, Macdonald (2015) describes how the experience of being a psychologist in rural areas can be vastly different to others in the profession working in busy, built-up cities due to the systems they are working within, the availability of services, and the multiple interpersonal relationships that psychologists may have with members of their community. Rural areas of the UK tend to have much lower levels of cultural diversity than more built-up cities, meaning children and families from global-majority cultural backgrounds can often experience marginalisation and discrimination due to their race and ethnicity, compared to those from the same background living in more diverse areas (De Lima, 2008). As such, more thought needs to be given to those who undertake training and placements in areas with fewer opportunities for these learning moments to develop their practice, to ensure the EPs can appropriately and effectively support children and families from diverse backgrounds in less diverse areas.

3.4.3 Continuing to Develop Culturally Responsive Practice

EPs generally perceived themselves to be competent to work with black African autistic children and their families related to their knowledge of the appropriateness of types of assessment. However, they also spoke about their lack of knowledge about cultural experiences that were not theirs and a lack of opportunities to engage with the local community. These findings align with Anderson (2018), who found that EPs typically perceived themselves as competent with knowledge of assessment bias and socio-economic effects such as poverty, whilst EPs also reported lower competence areas around theoretical knowledge of racial and ethnic identity development. Sue et al. (1992) outlined that two fundamental characteristics related to effective service provision for diverse cultural groups involve the practitioner being aware of their own cultural assumptions and biases, in addition to understanding the experiences of people from diverse cultures. EPs within the current study spoke about their awareness of biases and assumptions. However, this highlights that more needs to be done for EPs to understand the experiences of people from diverse cultures.

One way EPs could develop this understanding was through discussions with other EPs where they could learn from each other, particularly as discussed within this research, where EPs described the importance of working in culturally diverse teams. This finding aligns with Broadwell's (1969) Four Stages of Competence model, describing how learners (in this case, EPs) move from a place of unconscious incompetence (ignorance) to conscious incompetence (awareness). This is followed by conscious competence (learning), ultimately arriving at unconscious competence (mastery). The model suggests that the more these conversations stretch the competence of EPs, the more EPs will be able to master these skills and work in a culturally responsive way.

3.4.4 Strengths and Limitations

Like all research, this study is not one without associated strengths and limitations. A major strength of this research is that the data was collected across two diverse London LAs. Additional research should consider extending this to explore EPs' experiences outside of London's LAs, with considerably less cultural diversity. Another

strength is that this research felt meaningful for the participants. Parent participants shared how they valued their participation, and EP participants shared their appreciation outside of the recorded interviews about how it had given them a space to reflect and identify the gaps in their knowledge bases, which they were then able to go and act on by reading more and having reflective conversations.

A key limitation is the participant sample, with only two parents recruited. One explanation for this may be the researcher being white, which may have acted as a barrier to participation due to potential mistrust in the study's purpose. Previous successful research into black African parents' experiences of having an autistic child has included the use of a co-researcher (Lemboye, 2023; Fox et al., 2016), who was someone from the community who provided cultural brokerage. Future research should consider adopting this approach. Further, the EP participant sample is race and gender homogenous; all participants self-identified as white women. Although the onus should not be on black people to research black experiences, a heterogeneous sample may yield different responses. A further limitation of this study is that it did not capture the views of young black African autistic children and their perspectives of involvement from EPs. Future research should seek to prioritise an exploration into their views to ensure that EPs directly working with this population of young people are gathered and practice is developed in response to feedback.

3.4.5 Implications and Recommendations

The findings highlight a lack of trust black African parents have when working with professionals to receive support for their autistic child and awareness from the EPs that building such trust is central to providing effective support. It is imperative that more needs to be done to support the development of this trust. Recommendations to do this include:

- Enabling better engagement with the local community that the EPS serve through the physical location of the service, such as being based within a community building which is easily accessible.
- EPs being encouraged to report on culture within written reports consistently.
- Building a more diverse EP workforce, so that parents are more likely to see their own cultural representation.

- Creating additional opportunities for parents to meet with EPs outside formal consultations, such as coffee or open mornings.
- Using appropriate interpreters so parents can express themselves accurately and be understood.

An additional implication of this research is the limited resources and skills reported by the EPs, impacting their comfort and confidence in having these conversations. Recommendations to facilitate this include:

- Providing specific time for EPs to engage in reflections about their practice.
- Ensuring inclusive and structured training to teach EPs the skills, values and knowledge to practice in a culturally responsive way.
- Conducting an audit into how EPs are taught about culture during their initial training courses. An example is the Decolonising SOAS Learning and Teaching Toolkit (Decolonising SOAS Working Group; 2018).
- Conducting an audit into EP's own cultural competence and awareness, for example using Sakata's (2021) self-reflective framework for EPs to develop CRP.

Appendix A CASP Quality Assessment Checklist

	Section A) Are the results valid?						Section B) What are the results?			Section C) Will the results help locally?
	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between the researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research? (1 Not Very -5 Extremely)
Ashong and Perepa (2023)	YES	YES	YES	YES	PARTLY	PARTLY	YES-	YES	PARTLY	4
Fox, Aabe, Turner, Redwood and Raj (2016)	YES	YES	YES	YES	YES	YES	YES	YES	YES	4
Hussein, Pellicano and	YES	YES	YES	YES	PARTLY	PARTLY	YES	YES	YES	4

Crane (2019)										
Lemboye (2023)	YES	YES	YES	YES	YES	YES	YES	YES	YES	5
Munroe, Hammond and Cole (2016)	YES	YES	YES	YES	PARTLY	NO	YES	YES	YES	4
Nair (2015)	YES	YES	YES	YES	PARTLY	PARTLY	YES	YES	YES	3
Nweke (2019)	YES	YES	YES	YES	PARTLY	YES	YES	YES	YES	5
Oumar (2021)	YES	YES	YES	YES	YES	YES	YES	YES	YES	4
Robbin (2020)	YES	YES	YES	YES	PARTLY	PARTLY	YES	YES	YES	3
Seach (2021)	PARTLY	YES	YES	YES	PARTLY	YES	YES	YES	PARTLY	4
Selman et al., (2018)	YES	YES	YES	YES	YES	YES	YES	YES	YES	4

Appendix B Thematic Synthesis: Analytical Themes from Codes

Analytic Theme	Descriptive Themes	Code label	Number of quotes within code
1. An absence of shared language around autism impacted parent's own understanding of autism and the way they could communicate with their community about their child's needs.			
	No word for autism in home language		
		No word in Somali	5
		Dr did not know the word for autism.	1
	Differences in understanding between the parent and community		
		Autism not seen in parent's home country	2
		The child is described as 'crazy'	4
	Confusion around what autism is and it's cause.		
		Autism doesn't look like a disability	2

		Differences in cultural development milestones	4
	Initial challenges with accepting their child is autistic		
		Lack of parent knowledge	3
		Refusal to consider possibility of autism	2
		Difficulty accepting diagnosis	7
2. Traditional cultural and community views about disability and parenting can lead to feelings of judgement and stigma.			
	Experiences of Social Isolation and stigma from community members		
		Worried about what others would say about parenting	6
		Adults are highly judgmental, children are accepting	1
		Concerns about others in the community knowing about their child's needs	2
		Preference to not go out to avoid other's comments	1
		Hurtful nicknames	1

	African cultural and traditional values impacting parenting		
		African children are expected to look after their parents	2
		Gendered parenting roles	6
		Child being autistic due to mother's wrongdoings	2
		Decision to have another child due to autistic child	2
		Breakdown of parental relationship	2
		Sense of community as a key part of African culture	2
		Learning about autism led to distancing from traditional beliefs	7
3. Faith and religion were frequently used as a facilitator for acceptance and a coping strategy for daily life.			
	Faith supporting parents to accept their child's needs		
		Important to pass down faith and religion to child	1
		Lives predetermined by God/Allah and	6

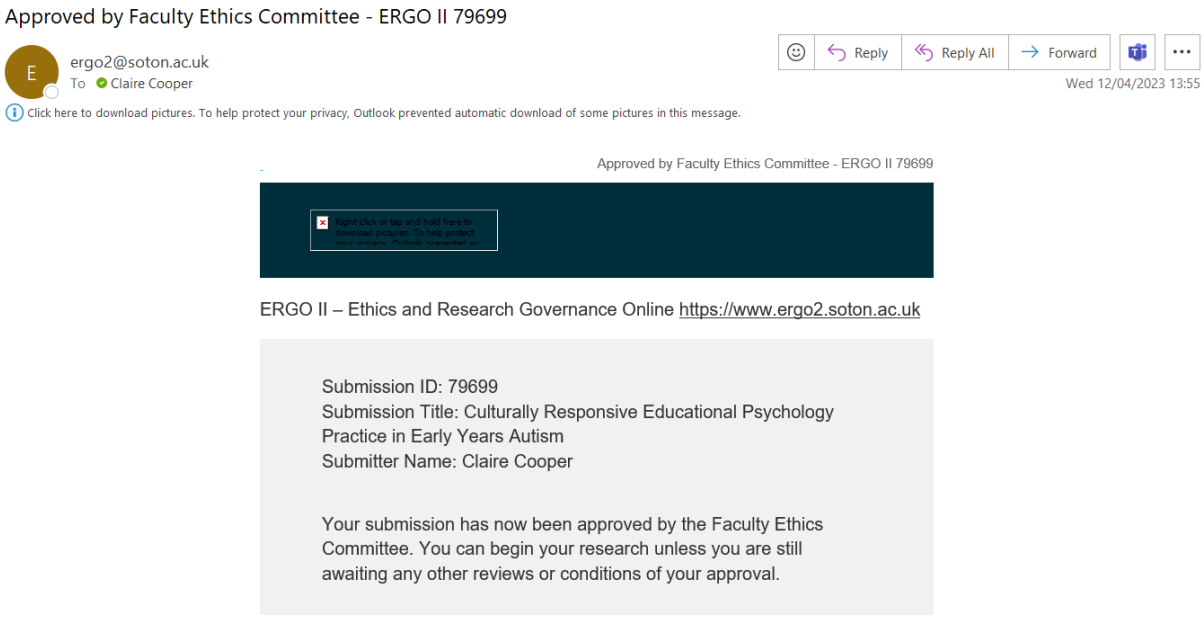
		therefore must be accepted	
		Prayer for a cure for child's autism	7
		Continuing to ask God/Allah, "why"?	2
	Religion provides tangible support for parents		
		Place of belonging for all	2
		Religious leaders being important sources of support	2
		Other community members with autistic children being sources of support	2
		Lack of flexibility at place of worship led to parents disengaging	3
4. Parents accessing support outside of their community were often working within confusing systems, and felt unsupported accessing them.			
	Parents had limited awareness of services and support available		
		Varying attitudes towards social services	2

		Not knowing where to start when seeking support	2
	Parents found it difficult to access support		4
		English as an Additional Language was a barrier to access	4
		Large amounts of paperwork frustrating	1
		Phone calls/emails not responded to by professionals	1
	Difficult interactions with professionals		
		Lack of clarity about the professional's role	2
		Parents working harder to receive support due to being black	2
		Parents having to 'fight' for support	2
		Lack of diverse cultural representation from professionals	1
	Parent support groups as helpful support		
		Parent support groups as informal spaces helpful	6

		Culture specific support groups particularly useful	4
5. Parents of black autistic children held concerns about the way their child could be treated by others due to being black and autistic- the “double barrier”			
	Parents of black autistic children held concerns about the way their child could be treated by others due to being black and autistic- the “double barrier”		
		Being black AND autistic as a unique and particularly difficult challenge	2
		Concerns around how their child is perceived by others due to their race	1
		Concerns about low expectations from professionals due to racial biases	1

Appendix C Ethics Approval

C.1 Southampton University Approval



Approved by Faculty Ethics Committee - ERGO II 79699

E ergo2@soton.ac.uk
To Claire Cooper

Reply | Reply All | Forward

Wed 12/04/2023 13:55

Click here to download pictures. To help protect your privacy, Outlook prevented automatic download of some pictures in this message.

Approved by Faculty Ethics Committee - ERGO II 79699

Right-click or tap and hold here to download pictures. To help protect

ERGO II – Ethics and Research Governance Online https://www.ergo2.soton.ac.uk

Submission ID: 79699
Submission Title: Culturally Responsive Educational Psychology Practice in Early Years Autism
Submitter Name: Claire Cooper

Your submission has now been approved by the Faculty Ethics Committee. You can begin your research unless you are still awaiting any other reviews or conditions of your approval.

C.2 LA2 Council Research Approval

13 December 2023

Reference: CERGF292
RGF Application Approval

Dear Claire

Research Title: Culturally Responsive Practice in Early Years Autism in Black African families

This is to confirm that your research proposal has been approved by the Research Governance Framework Panel.

Upon completion can you please submit a copy of your report or an extract from your conclusion to the above postal or email address. We may then publish details of your research on the National Social Care Research Register or equivalent.

Please do not hesitate to contact me should you need any further assistance.

I wish you well in your research study.

Yours sincerely,

RGF Co-Ordinator

Appendix D Debrief Forms

D.1 Parent

Debriefing Form - Parents

Study Title: Culturally Responsive Practice in Early Years Autism

Ethics/ERGO number:79699

Researcher(s): Claire Cooper

University email(s): cc21g15@soton.ac.uk

Version and date: Version 1, 31.03.23

Thank you for taking part in our research project. Your contribution is very valuable and greatly appreciated.

Purpose of the study

The aim of this research was to explore the experiences of parents and close family members of autistic children from Black-African cultural backgrounds working with Educational Psychologists. Your participation contributed to developing an understanding of how Educational Psychologists can adapt their practice to be more culturally responsive.

Confidentiality

The results of this study will not include your name or any other identifying characteristics.

Study results

If you would like to receive a copy of the final report when it is completed, please let us know by using the contact details provided on this form.

Further reading

If you would like to learn more about this area of research, you can refer to the following resources:

https://documents.manchester.ac.uk/display.aspx?DocID=62182 (Page 28-30 in particular)

Further information

If you have any concerns or questions about this study, please contact the researcher Claire Cooper at cc21g15@soton.ac.uk, or Dr Hanna Kovshoff at h.kovshoff@soton.ac.uk who will do their best to help.

If you remain unhappy or would like to make a formal complaint, please contact the Head of Research Integrity and Governance, University of Southampton, by emailing: rgoinfo@soton.ac.uk, or calling: + 44 2380 595058. Please quote the Ethics/ERGO number which can be found at the top of this form. Please note that if you participated in an anonymous survey, by making a complaint, you might be no longer anonymous.

Thank you again for your participation in this research.

If you would like to receive a copy of the final report, please leave your email address here:

_____

D.2 EPs

Study Title: Culturally Responsive Practice in Early Years Autism

Ethics/ERGO number:79699

Researcher(s): Claire Cooper

University email(s): cc21g15@soton.ac.uk

Version and date: Version 1, 31.03.23

Thank you for taking part in our research project. Your contribution is very valuable and greatly appreciated.

Purpose of the study

The aim of this research was to explore the experiences of culturally responsive practice in Early Years Autism support from the perspectives of both Educational Psychologists (EPs) and caregivers of autistic children. Your participation contributed to developing an understanding of how EPs adapt their practice to support children and their families from Black-African cultural backgrounds and will be used to develop a framework for future practice for EP's across the United Kingdom.

Confidentiality

The results of this study will not include your name or any other identifying characteristics.

Study results

If you would like to receive a copy of the final report when it is completed, please let us know by using the contact details provided on this form.

Further support

If taking part in this study has caused you discomfort or distress, you can contact the following people for support:

LA PEP:

SENDIASS:

Further reading

If you would like to learn more about this area of research, you can refer to the following resources:

Lawrence, Z. (2014). Black African parents' experiences of an educational psychology service. *Educational Psychology in Practice*, *30*(3), 238–254. https://doi.org/10.1080/02667363.2014.919249

Durand, T. M. (2010). Celebrating diversity in early care and education settings: Moving beyond the Margins. *Early Child Development and Care*, *180*(7), 835–848. https://doi.org/10.1080/03004430802466226

Sakata, E. (2021). *How can educational psychologists develop culturally responsive practice?: A delphi study* (thesis).

Further information

If you have any concerns or questions about this study, please contact the researcher Claire Cooper at cc21g15@soton.ac.uk, or Dr Hanna Kovshoff at h.kovshoff@soton.ac.uk, who will do their best to help.

If you remain unhappy or would like to make a formal complaint, please contact the Head of Research Integrity and Governance, University of Southampton, by emailing: rgoinfo@soton.ac.uk, or calling: + 44 2380 595058. Please quote the Ethics/ERGO number which can be found at the top of this form. Please note that if you participated in an anonymous survey, by making a complaint, you might be no longer anonymous.

Thank you again for your participation in this research.

If you would like to receive a copy of the final report, please leave your email address here:

_____

Appendix E Participant Information Sheet

E.1 Participant Information Sheet- Parents

PIS Version 1 Dated 31.03.23

Participant Information Sheet - Parents

Study Title: Culturally Responsive Practice in Early Years Autism

Researcher: Claire Cooper

ERGO number: 79699

You are invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or if you would like more information before you decide to take part in this research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This research is being conducted as part of a thesis requirement for the qualification for a Doctorate in Educational Psychology. My name is Claire Cooper and I am a trainee Educational Psychologist. I am completing this research as I am very interested in supporting the Educational Psychology profession to develop in a Culturally Responsive way. Throughout my career I have enjoyed working closely with families and caregivers, in particular supporting families towards the start of their journey in learning about their child's strengths. I will be asking you questions about your experience of working with professionals supporting you and your child and asking for examples of practice you have felt was particularly respectful to your culture and understanding of important values to you. My interest in exploring the experiences of Black-African parents and caregivers stems from being part of a mixed-race family, with Black-African family members.

Why have I been asked to participate?

You are an expert in your experience of being a parent/close family member to an autistic child from a Black-African cultural background. In respect of this, I am seeking your views and experiences to construct with me a framework for future practice for Educational Psychologists to use when supporting families and autistic children from Black-African backgrounds in their Early Years.

What will happen to me if I take part?

If you agree to take part in this study, you will be asked to join an online conversation with me (Claire Cooper) where we will discuss your experiences. If you have requested for an interpreter to be present, they will also be in the meeting. The interview will follow a semi-structured interview format, where we will loosely follow questions that have arisen from my previous experience, and existing research. The interview will last approximately 30 minutes. The interview will be recorded using Microsoft software, which will then be transcribed to be used for analysis as part of the project.

Are there any benefits to my taking part?

Although there are no direct benefits to yourself by taking part in this study, you will be contributing to the development of Educational Psychology Practice, intending to improve services received for future families. As compensation for taking part in this study, I will offer a £20 gift card for every parent or caregiver as a thank you for participating in the study.

Are there any risks involved?

Your involvement in this study will not involve any physical risks, however, discussions around sensitive and personal issues may lead to the possibility of psychological discomfort. If this is to arise, you are welcome to leave our conversation at any time, and either rejoin when you feel able to, or terminate the interview.

What data will be collected?

Personal information will be collected within this study; your name will be collected whilst signing the consent form which will be saved on the secure university cloud system (if a paper copy is signed, the document will be scanned in and saved in the secure cloud system, and the paper copy will be shredded). Within the report, your name will be removed and a unique identifier will be assigned to you to ensure your responses are anonymised. Any identifiable information provided by you within our conversation will be carefully edited/anonymised.

Transcripts of the interviews will be saved in a password-protected word document; only the research team will have access to this document. The documents will be saved on the secure university cloud system.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people must keep your information, as a research participant, strictly confidential.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

What happens if I change my mind?

You have the right to change your mind and withdraw without giving a reason and without your participant rights being affected until 4 weeks after your interview date. The date of analysis will be confirmed with you before signing the consent form.

What will happen to the results of the research?

Your details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

The results of the research will be written up into a final report which will be submitted as part of the researcher's doctorate qualification. This report may then be published. If you would like to receive a copy of the final report, you will be able to provide your email address for the report to be sent at the end of our conversation.

The anonymised transcripts of the interviews will be made available within the University of Southampton's data repository, (PURE) where the data will be held for a minimum of 10 years. Access to this repository will be monitored and controlled by the research supervisors, Dr Hanna Kovshoff and Professor Sarah Parsons. This data will be stored to enable future researchers to use the experiences shared by you within the research to inform and support future research.

Where can I get more information?

If you have any further questions, please do not hesitate to contact:

- Claire Cooper – Researcher – cc21g15@soton.ac.uk
- Dr Hanna Kovshoff – Supervisor – h.kovshoff@soton.ac.uk
- Professor Sarah Parsons – Supervisor- s.j.parsons@soton.ac.uk

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in the research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear about what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you.

Thank you for taking the time to read this document, and for considering participating in this study. If you do have any questions, please do not hesitate to reach out.

E.2 Participant Information Sheet – EPs

PIS Version 2 Dated 14.04.23

Participant Information Sheet- Educational Psychologists

Study Title: Culturally Responsive Practice in Early Years Autism

Researcher: Claire Cooper

ERGO number: 79699

You are invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or if you would like more information before you decide to take part in this research. You may like to discuss it with others, but it is up to you to decide whether to participate. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This research is being conducted as part of a thesis requirement for the qualification for a Doctorate in Educational Psychology. My name is Claire Cooper and I am a trainee Educational Psychologist. I am completing this research as I am very interested in supporting the Educational Psychology profession to develop in a Culturally Responsive way. Throughout my career, I have enjoyed working closely with families and caregivers, in particular supporting families towards the start of their journey in learning about their child's strengths. I will be asking you questions about your experience of working with autistic children and families from Black-African cultural backgrounds. I will be asking for examples of practice you have felt was particularly respectful to culture and understanding of important values to you. My interest in exploring the experiences of Black-African parents and caregivers stems from being part of a mixed-race family, with Black-African family members.

Why have I been asked to participate?

As part of my second year of training, I have been on placement in your Local Authority where I have been very interested in the conversations, and spaces held for developments within culturally responsive practice. I am asking for your participation to contribute to an understanding of the current experiences of Educational Psychologists working with children in their early years, and their families from Black-African cultural backgrounds.

What will happen to me if I take part?

If you agree to participate in this study, I will require you to take part in one interview, lasting approximately 30 minutes. The interview can take place online, or in person, depending on what is convenient and comfortable for you. During the interview, we will discuss your previous experiences working with autistic children and their families from Black-African cultural backgrounds, supporting them through their transitions into educational settings. The interview will follow an interview topic guide, with questions that have been checked by a 'panel of experts including educational psychologists. Interviews taking place in person will be audio-recorded using a university-provided Dictaphone, or recorded on a Microsoft teams call with the camera off, whilst interviews being conducted online will be recorded on Microsoft teams, and will be transcribed and anonymised.

Are there any benefits to my taking part?

Participation in this study can contribute to your record of Continuing Professional Development (CPD). Further to this, you will be contributing to the development of the Educational Psychology practice field. As a token of appreciation for taking part in the interview, you will receive a £10 Costa Coffee gift card.

Are there any risks involved?

It is not anticipated that there will be any significant associated risks with participating in this study. If any psychological discomfort arises, you can pause the interview, and either resume after a short (15-minute break) or terminate the interview.

What data will be collected?

Personal information will be collected within this study; your name will be collected whilst signing the consent form which will be saved on the secure university cloud system (if a paper copy is signed, the document will be scanned in and saved in the secure cloud system, and the paper copy will be shredded). Within the report, your name will be removed and a unique identifier will be assigned to you to ensure your responses are anonymised. During the interview, we will be discussing your previous experiences and therefore information about your current role in the service will be gathered. Your role may be referenced throughout the report if relevant to the themes identified during the analysis.

Transcripts of the interviews will be saved in a password-protected word document; only the research team will have access to this document. The documents will be saved on the secure university cloud system.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people must keep your information, as a research participant, strictly confidential.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form (if the interview is taking place in person, this will be a paper copy, if taking place online this will be a digital copy) to show you have agreed to take part and have had an opportunity to ask any questions you may have.

What happens if I change my mind?

You have the right to change your mind and withdraw until the date of analysis without giving a reason and without your participant rights being affected. The date of analysis will be confirmed with you before signing the consent form, and will be 4 weeks after this interview date.

What will happen to the results of the research?

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent. The results will be written up as part of the completion of the researcher's submission for their doctoral thesis. The thesis will be written with the intention to be published in a research journal. If you would like to receive a copy of the research, you can provide your contact email address for it to be sent to.

After completion of the report, the anonymised transcript data will be deposited in the Institutional Research Repository (PURE). Access to the data will be authorised by the supervisory team if appropriate for future research.

Where can I get more information?

If you have any further questions, please do not hesitate to contact:

- Claire Cooper – Researcher – cc21g15@soton.ac.uk
- Dr Hanna Kovshoff – Supervisor – h.kovshoff@soton.ac.uk
- Professor Sarah Parsons – Supervisor- s.j.parsons@soton.ac.uk

What happens if there is a problem?

If you have a concern about any aspect of this study, you are welcome to speak to the researchers who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in the research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear about what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you.

Thank you for taking the time to read this document, and for considering participating in this study. If you do have any questions, please do not hesitate to reach out.

Appendix F Consent Forms

F.1 Parents Consent Form

Parent consent form Version 1 31.03.23

CONSENT FORM- Parents and Caregivers

Study title: Working with Black-African Families with Autistic Children in their Early Years: Culturally Responsive Practice Framework

Researcher name: Claire Cooper

ERGO number:79699

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (31.03.23*/version 1*) and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I agree to take part in the interview for the purposes set out in the participation information sheet and understand that these will be recorded using audio notes.	
I understand my participation is voluntary and I may withdraw my data until 4 weeks after this interview (date _____) for any reason without my participation rights being affected.	
I understand I will be required to take part in one interview.	
I understand that I may be quoted directly in reports of the research but that I will not be directly identified (e.g. that my name will not be used)	
I understand that if I requested an interpreter, they will also be present in the interview.	

Name of participant (print name)……

Signature of participant……

Date…….. ……

Name of researcher (print name)……

Signature of researcher ……

Date……

F.2 EPs Consent Form

EP Consent form Version 1 31.03.23

CONSENT FORM – Educational Psychologists

Study title: Culturally Responsive Practice in Early Years Autism

Researcher name: Claire Cooper

ERGO number: 79699

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (*31.03.23 /version no.1*) and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw until the point of data analysis _____ (date confirmed in interview) or any reason without my participation rights being affected.	
I understand that I may be quoted directly in reports of the research but that I will not be directly identified (e.g. that my name will not be used).	
I understand that taking part in the study involves audio recording which will be transcribed and then destroyed for the purposes set out in the participation information sheet.	
I understand that the personal information collected about me such as my name, role and location of employment will not be shared beyond the study team.	
I agree to take part in the interview for the purposes set out in the participation information sheet and understand that this will be recorded using audio notes.	
I give permission for the anonymised transcripts produced from the audio recordings to be deposited to the PURE repository as described in the	

participant information sheet so it can be used for future research and learning in the field of Educational Psychology practice.	
I agree that I have had an opportunity to ask any questions about this research prior to signing this consent form.	

Please turn this page over to consent to take part in this study.

Name of participant (print name)……

Signature of participant……

Date…….. ……

Name of researcher (print name)……

Signature of researcher ……

Date……..

Appendix G Interview Schedules

G.1 EP interview schedule

	Focus / purpose	Indicative questions
1	Rapport building Experience of being an EP	Can I start by asking for how long you have been an EP? Can you explain in what ways you are currently involved in supporting children and their families in their early years? For how long have you worked for this local authority? [if relevant, where were you before?] Did you have any experience with supporting children and their families from African backgrounds during your training? If relevant: - Experience as an independent practice?
	EP Training	How did your training course support you to have discussions about culture?
3	'African' understanding of Autism	My research focuses on Black African families in the early years. What experiences have you had so far in supporting children and families from this cultural background?

		Based on those experiences, how did families think about and understand autism? In what ways were they the same or different from other families you were supporting? In what ways did they talk about or mention African traditions as influencing their views or experiences (if at all)? Did that raise any questions or issues for you in terms of your own understanding? If so, in what ways?
4	Scenario- Receiving a referral for a 4 year old child, who has a diagnosis of autism. Child was born in London, both parents from Ghana, arriving in the UK 5 years ago. You are visiting the child in their nursery setting to support a transition plan to assess their needs and produce strategies to support their transition to primary school.	What is the first thing you would do when you receive a referral for your involvement?
4	Consultation with parents	How do you plan consultations with parents? How do you ask parents about their cultural background? How do you structure your consultation questions? Do you follow a framework?
5	Observations of the child	Describe some of the things you may look out for in an observation What might you note down?

		What environmental factors might you acknowledge?
6	Direct work	What assessment tools would you be likely to use?
7	Report writing	To what extent is the child's culture acknowledged within your reports? Do you mention it? If so how? If not why? To what extent do you feel your own cultural identity is included in your reports? How do you approach writing recommendations in your reports in relation to the child's culture?
8	Traded vs Statutory work	Are there differences in your approach when working in a statutory vs traded capacity?
9	Conversations around culture	How does the prevalence of Black African families in your LA affect the LA's motivation to support these families? How have conversations about culture changed during your time as an EP? Are there any pivotal moments you can reflect on that have instigated cited this change? What were conversations about culture like prior to this event? What are the benefits and challenges about conversations around culture? What is the impact of these conversations on your practice?
10	Barriers to work	Are there barriers you have experienced to working with families from black-African backgrounds?

		what important moments/experiences have stayed with you/ shaped your practice? How did these experiences make you feel? What helped you through them? What did you learn? What could alleviate or remove the barriers?
11	Internal Emotions	How does it feel to acknowledge someone's culture? Talk me through the feelings of supporting families from different cultures. What helps you with this work? What helps you to manage these feelings?
12	Responsibility for being culturally responsive	Does the responsibility for being culturally responsive lie within the EP or the employer, or both? As a practising EP, where do you get your information about different cultures? What do you feel services should be doing to promote CRP?
13	Define Culturally Responsive Practice	Thank you so much for your time in talking that through today. As a final question, and reflecting on our discussion today, what keywords for CRP would you want to include in a definition {Prompt: What would it not look like?}

G.2 Parent interview schedule

	Focus/purpose	Questions
1	Introductions	Let's start with introductions. My name is Claire, and I am a trainee Educational Psychologist. As I mentioned in the information sheet about this study, I am part of a mixed black African family and I am really interested in understanding more about how professionals can better support Black African families in a way that respects and celebrates their culture. Please can you tell me a little about yourselves and your child? I would love to know more about your child, what kind of things do they like doing? Prompts: - age, are they in school? What shows do they like?
2	EP and other professionals' involvement history	What involvement have you had with any early years support services? What involvement have you had with an educational psychology service? Have you had involvement with any other professionals? For example, teachers, doctors etc?
3	Involvement	When did you first become aware of differences in your child's development? If a professional mentioned X's differences – how did other people describe or try to explain these differences?

		Please could you talk me through the timeline of professional involvement? [if needed] when was the word 'autism' first used to describe the difficulties your child was experiencing?
4	Understanding about Autism	What does the word 'autism' mean to you?
5	Consultation	Thinking back to your first meeting with an EP, can you explain what that was like for you? Do you remember what kinds of questions they asked you? Was there anything that surprised you? Did you feel there were questions that should have been asked but were not? How did you feel during the consultation? Were your child's strengths or needs discussed? If so, how? Was any reference made to your heritage? If so what was said and how was it said?
6	Assessment	Are you aware of how your child's needs were assessed by an EP? How was this explained to you? Was any reference made to your culture? If so what was said and how was it said?

7	Written record	Did you receive a written record of the EPs involvement? How was this given to you? How did the report describe your child's strengths and needs? Did you have an opportunity to discuss the report with anyone? How did you feel when reading the report? Was any reference made to your culture? If so what was said and how was it said?
8	Target setting	How involved were you in target-setting discussions for your child? what did target setting consist of? How did the EP explain the process? What was your role? How able did you feel to contribute, agree or disagree? How did the EP explain what happens next? Was any reference made to your culture? If so what was said and how was it said?
9	Post-EP involvement	After the EPs involvement, did your understanding of your child's needs change in any way? Is there anyone else whom you feel has made a difference to your understanding?

10	Informing others	What would you like EPs and other professionals to know about how they can support children with Autism who come from diverse cultural groups? What unique understandings would you like the EP to be aware/knowledgeable about prior to meeting you? What types of questions should be included to address cultural factors? How would the process differ for you to know the positive change had occurred?
11	Interview reflections	Share my own reflections/surprises that arose during the interview.

Appendix H Recruitment Posters

H.1 Parents Recruitment Poster

University of Southampton

Educational Psychologist (EP) Practice in Early Years Autism

Ethics approval number: 79699

What is the aim of the study?

This study aims to explore the experiences of parents and caregivers of autistic children from Black-African who have received involvement from Educational Psychologists.

The findings of this study will be combined with findings from interviews with Educational Psychologists to create guidelines for more inclusive practice.

Researcher: Claire Cooper,
Trainee Educational Psychologist

Who can take part?
(all 3 must apply)

Parents or Caregivers :

1. who identify as being from a Black-African Cultural Background
2. Have a child who is either diagnosed with autism, or receives support for autism
3. Have had an EP involved in their child's support

What are the benefits of participating?

As a token of appreciation, you will receive a £20 digital Love2Shop giftcard upon completion of the interview.

What will I be asked to do?

You will be asked to meet online with me for a conversation for 60-75 minutes.

If you would like an interpreter to support you, please let me know.

If you are interested in participating or have any questions, please contact me at: cc21g15@soton.ac.uk

H.2 EPs Recruitment Poster

University of Southampton

Culturally Responsive Educational Psychologist Practice in Early Years Autism

Ethics approval number: 79699

What is the aim of the study?

As part of my doctoral thesis study, this research will explore Educational Psychologists' experiences supporting Black African families with autism in the Early Years. Findings from these interviews will be analysed, alongside the experiences of parents and carers, to produce a framework of CRP for future practice.

Researcher: Claire Cooper,
Trainee Educational Psychologist

Who can take part?

Any Trainee or Qualified Educational Psychologist working for a Local Authority Educational Psychology Service

What will I be asked to do?

You will be asked to meet with me, either online or in person, for a 40-60 minute interview.

What will be the benefits of my participation?

As a token of thanks, you will receive a £10 Costa Coffee gift card upon completion of the interview.

Participation in this study can be used towards your CPD log.

Your contribution will also help to shape recommendations for future Educational Psychology practice.

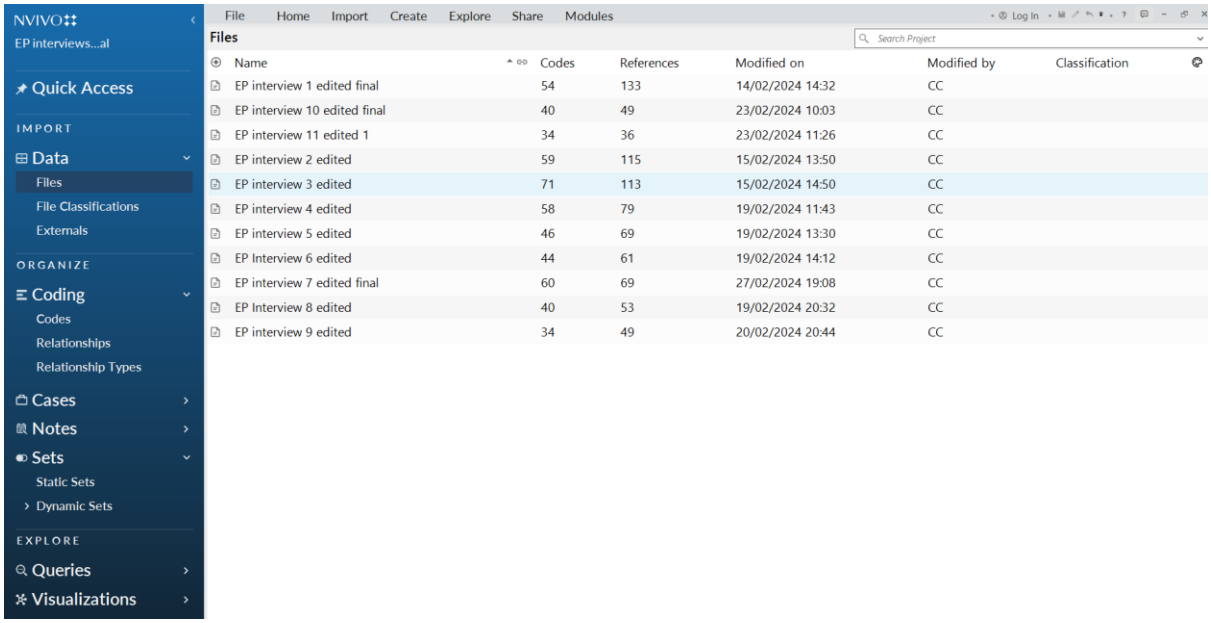
If you are interested in participating or have any questions, please contact me at:

cc21g15@soton.ac.uk

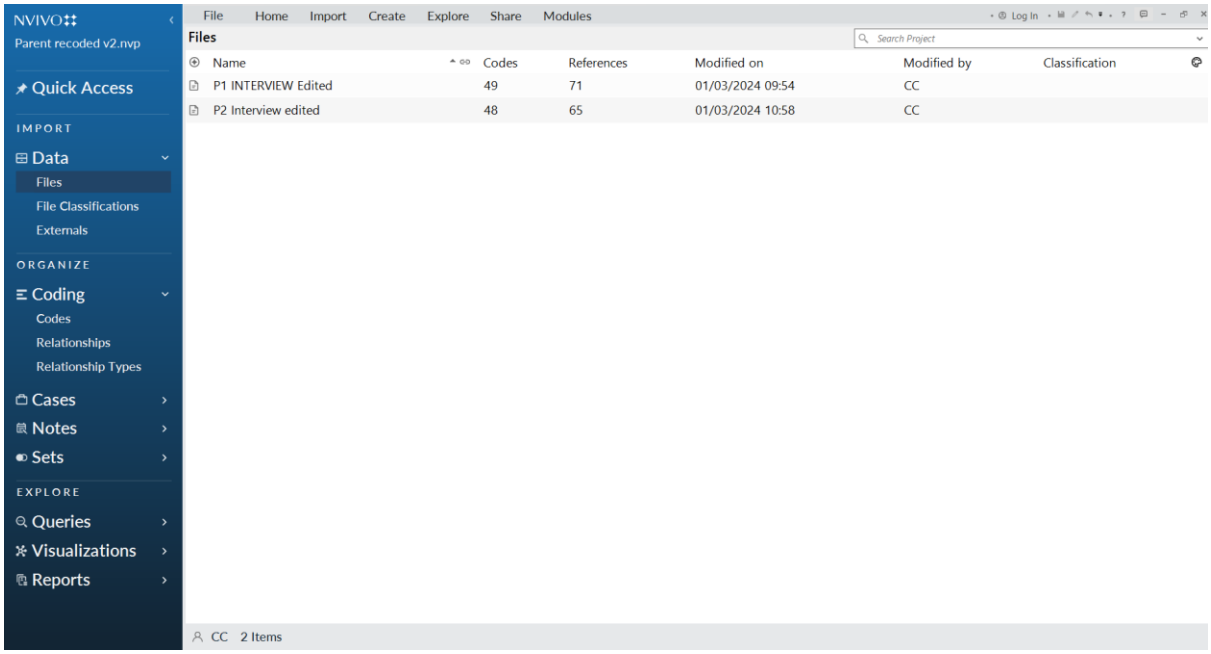
Appendix I Thematic Analysis process

Phase 2: Coding

Screenshot from NVivo for codes from EP interviews



Screenshot from NVivo for codes from Parent interviews:



Screenshot of some of the EP Codes exported to Excel:

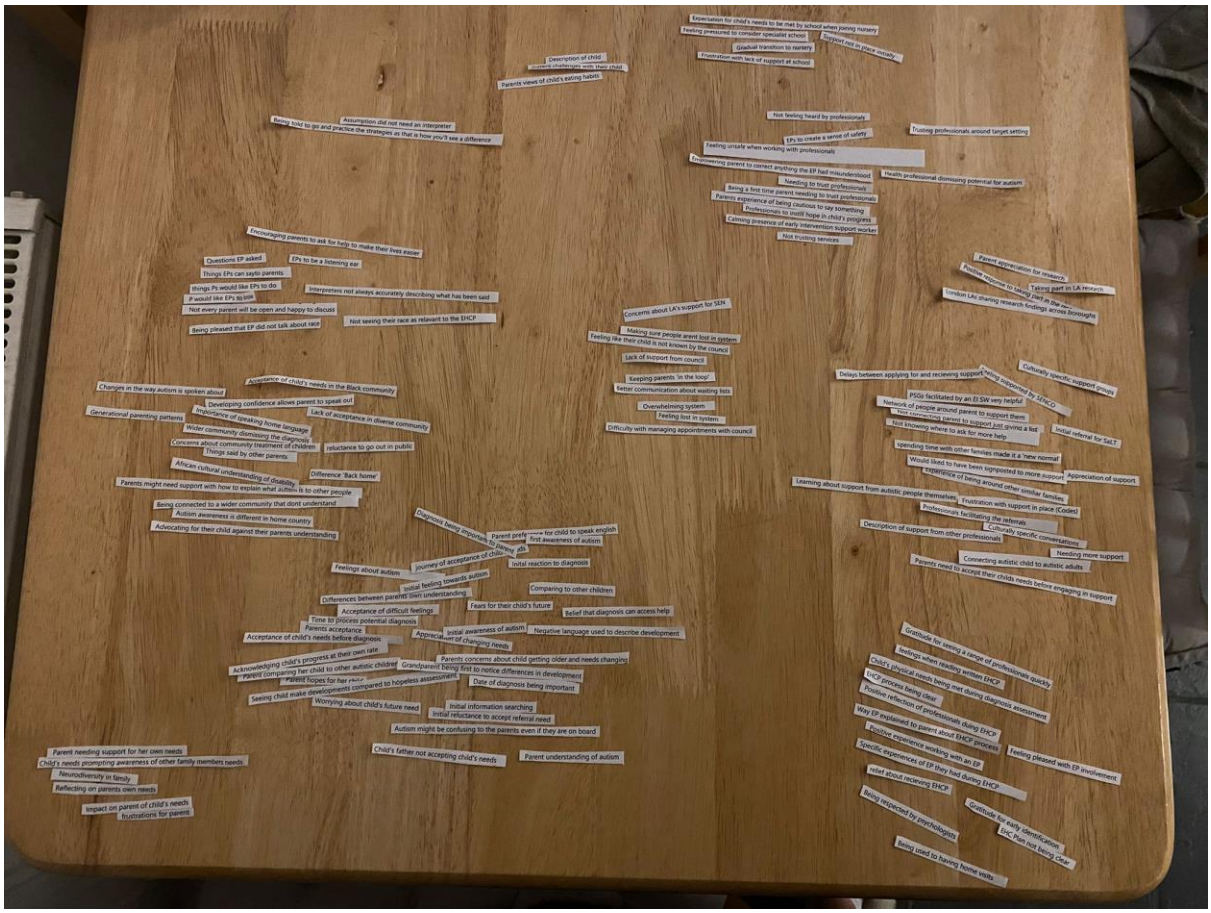
Name	Files	References
2020 as a pivotal year	1	1
A range of experience working with Black Afri	5	8
Accountability within services	1	1
Additional trainings and seminar	1	1
African psychology lecture	1	1
Aiming to be respectful	1	1
Antiracist practice training as a space to come	1	1
Applying learning from conversation spaces to	2	3
Appreciation for diversity in London	1	1
Ask about the diagnosis process	1	1
Asking questions about different contexts	1	1
assessments not culturally linked	1	1
Assessments with autistic children	3	5
Autism not being a universal truth	1	1
autism support different to other needs	1	1
Avoid assumptions	2	6
Avoid making assumptions that parents would	1	1
avoiding some observational assessments	1	1
Aware of own intersectionality, but do not refe	2	2
Awareness of historically racist EP practice	1	1
Awareness of own privieldge as a barrier to uc	1	2
Awareness of power dynamics	4	5
background information included in report	1	1
Barriers to access for parents	2	3
Being an agent of hope following initial reacti	1	1
Being aware of stereotypes	2	5
being based in community places	1	1
being based in schools as families can access t	1	1
being compassionate and offering an alternat	1	1
Being conscious of respecting faith and cultur	1	1
Being data driven when talking about culture	1	2
Being flexibile in approach to working with co	1	3
being part of system around child and family	1	1
Being unsure how to discuss culture	1	1

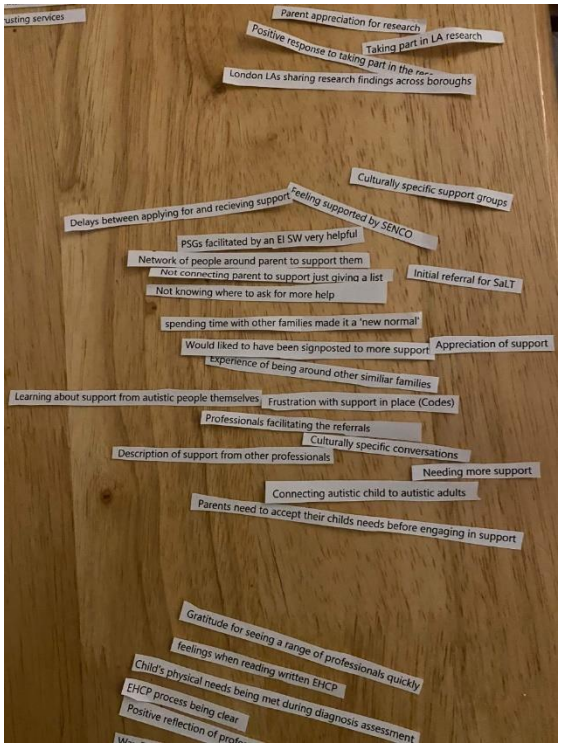
Screenshot of some of the parent codes exported to Excel:

Name	Files	References
Acceptance of child's needs before diagnosis	1	1
Acceptance of child's needs in the Black community	1	3
Acceptance of difficult feelings	1	1
Acknowledging child's progress at their own rate	1	2
Advocating for their child against their parents unde	1	1
African cultural understanding of disability	1	1
Appreciation of changing needs	1	1
Appreciation of support	1	1
Assumption did not need an interpreter	1	1
Autism awareness is different in home country	1	1
Autism might be confusing to the parents even if the	1	1
Being a first time parent needing to trust professiona	1	2
Being connected to a wider community that dont un	1	1
Being pleased that EP did not talk about race	1	1
Being told to go and practice the strategies as that is	1	1
Belief that diagnosis can access help	1	3
Calming presence of early intervention support work	1	1
Changes in the way autism is spoken about	1	1
Child's father not accepting child's needs	1	1
Child's needs prompting awareness of other family n	1	3
Comparing to other children	1	1
Concerns about community treatment of children	1	1
Connecting autistic child to autistic adults	1	1
current challenges with their child	1	1
Date of diagnosis being important	1	1
Description of child	1	4
Developing confidence allows parent to speak out	1	1
Diagnosis being important to parent	1	1
Difference 'Back home'	1	1
Differences between parents own understanding	1	1
Empowering parent to correct anything the EP had n	1	1
Encouraging parents to ask for help to make their liv	1	1
EPs to be a listening ear	1	1
EPs to create a sense of safety	1	2

Phase 3: Initial theme generation:

Code labels printed from Excel and manually grouped into 9 initial clusters of shared meaning.





Initial codes were then revised within their allocated clusters.

Screen shot from word to demonstrate movement from initial codes and the revision of code labels:

Initial code cluster 1	Revised codes	Revised code pt2	Revised Codes PT3
A range of experience working with Black African families Aiming to be respectful Ask about the diagnosis process Asking questions about different contexts assessments not culturally linked Assessments with autistic children Avoid making assumptions that parents would want to talk about their culture avoiding some observational assessments Aware of own intersectionality, but do not refer in reports Awareness of own privilege as a barrier to understanding parents experiences Awareness of power dynamics background information included in the report Being an agent of hope following initial reactions being part of system around child and family bigger meetings mean parents specific views can get lost	<u>Consultation</u> • Ask about the diagnosis process* • Asking questions about different contexts* • Avoid making assumptions that parents would want to talk about their culture* • Awareness of own privieldge as a barrier to udnerstanding parents experiences* • Awareness of power dynamics* • Building trust with parent* • Celebrating diversity in language * • Explaining role to parent** • Explicitly talking about race where it is relevant • Making sure both parents have an opportunity to share • Meeting parents where they are in their journey - Supporting plurality • Producing a visual record of meeting • questions around differences	<u>Building trust with parents</u> • Building trust with parent* • Explaining role to parent** • Awareness of power dynamics • Empowering parents • EPs being white as a barrier for parents to feel safe • Producing a visual record of meeting • Making sure both parents have an opportunity to share • taking time to check parents give informed consent • <u>Talking to parents to elicit an understanding of their culture</u>	*Avoiding making assumptions that parents want to talk about culture.* *Asking questions about different contexts the child is in.* *Parents can hold pluralistic views, eg. Accepting diagnosis and holding faith about child no longer being autistic.* Making sure both parents have an opportunity to share.

List of revised EP codes chosen due to specific focus around EP interactions with black African parents.

Code Label	*Number of quotes associated*
Avoiding making assumptions that parents want to talk about culture.	*5*
A lack of time and opportunity to pause and think about the work being done.	*5*
Asking questions about different contexts the child is in.	*4*
Awareness of black parent's experiences of racism.	*2*
Awareness of contemporary institutional racism.	*3*
EP's awareness of the history of the profession.	*4*
EP's views of including their own identity within their reports.	*5*
EPSs are different to other LA services	*3*
Fear of mistake making and causing offence when talking about culture	*4*
Importance of being honest with cultural competency	*2*

Importance of community psychology approaches	*3*
Importance of cultural diversity within EPS teams.	*4*
Importance of formal spaces to continue learning (EG. Structured trainings)	*3*
Importance of including the child's cultural background in reports.	*6*
Importance of informal spaces for continuing learning (EG. Supervision spaces)	*3*
Influences of visible race differences as a barrier to trust for parents	*2*
Lack of diversity within the profession	*5*
Moving from fear to confidence with practice when talking about culture	*3*
Needing to acknowledge all cultures in reports, including white British.	*3*
Parent's experience of autism is not a universal experience.	*6*
Parents can hold pluralistic views.	*2*
perceived power imbalances between EP and parent	*3*
Policy makes culturally responsive practice a priority.	*3*

Recognised the need to build trust with parents	*5*
Tokenistic way in which initial training courses teach how to practice in culturally responsive ways.	*4*

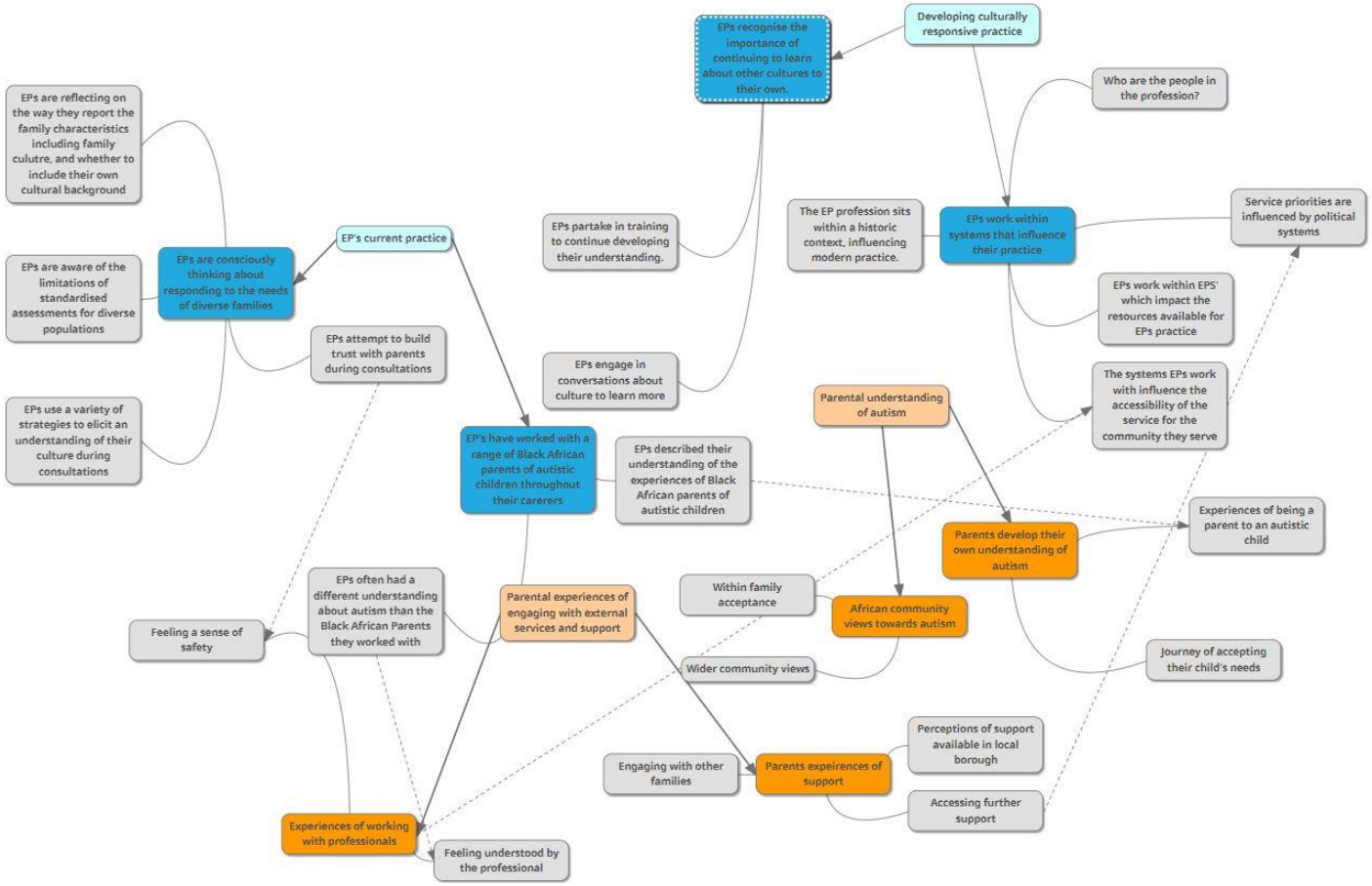
List of revised Parent data codes chosen due to specific focus on interactions with professionals.

Code label	*Number of quotes associated*
Impact of being a first time parent on interactions with professionals	*2*
Appropriate use and offering of an interpreter.	*1*
Confusion around support available.	*2*
Initial concerns being dismissed by professionals.	*2*
Lack of being connected to other families by professionals.	*1*
Lack of perceived safety to ask for help from professionals.	*1*
Lack of trust in systems to support them.	*1*
Not being listened to by professionals.	*2*
Parents felt like this was an important topic to be researched.	*2*
Professional involvement causing anxiety for parents.	*2*

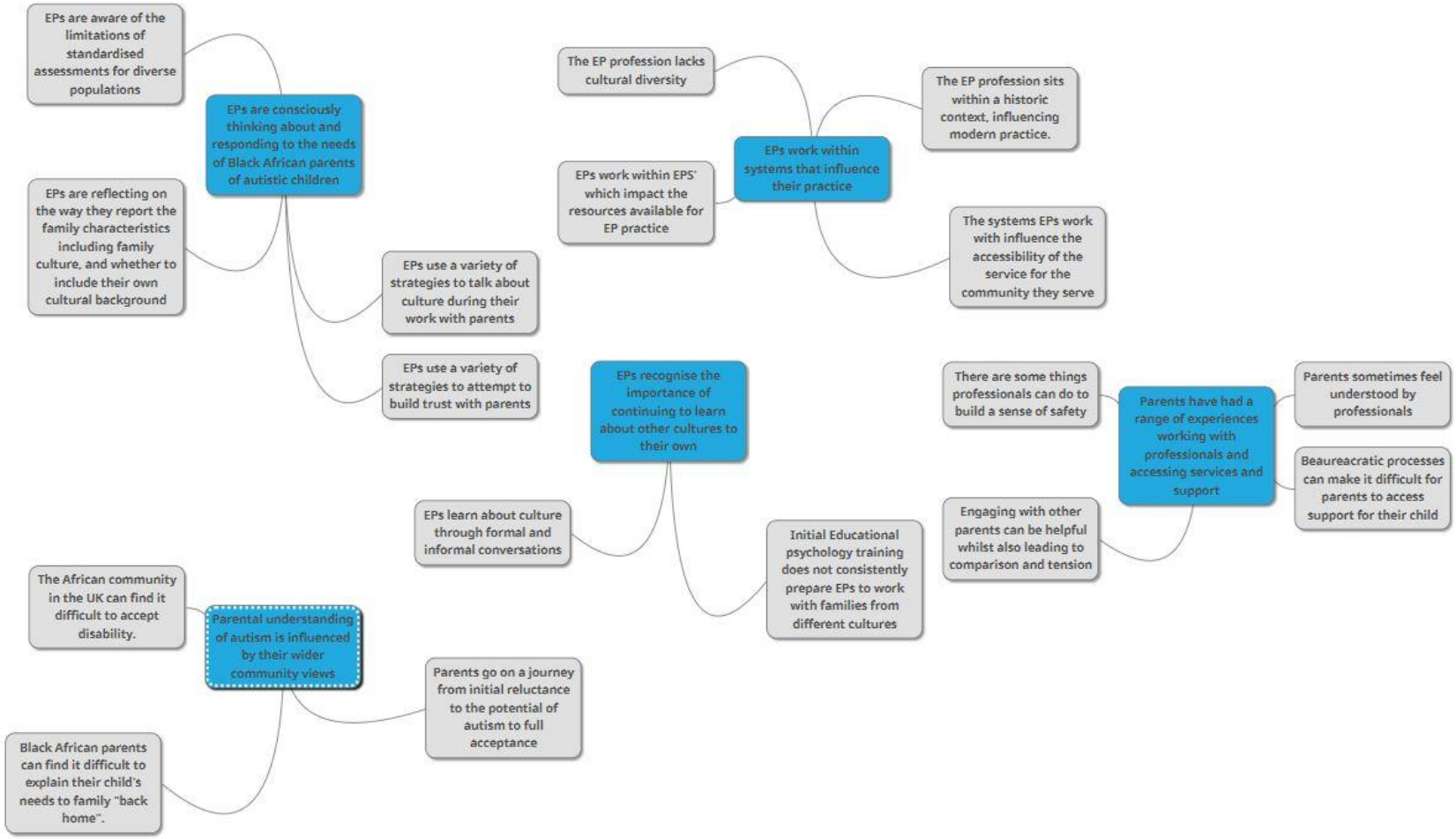
Too much paperwork, would like professionals to make referrals for them.	*1*

Phase 4: Reviewing initial themes:

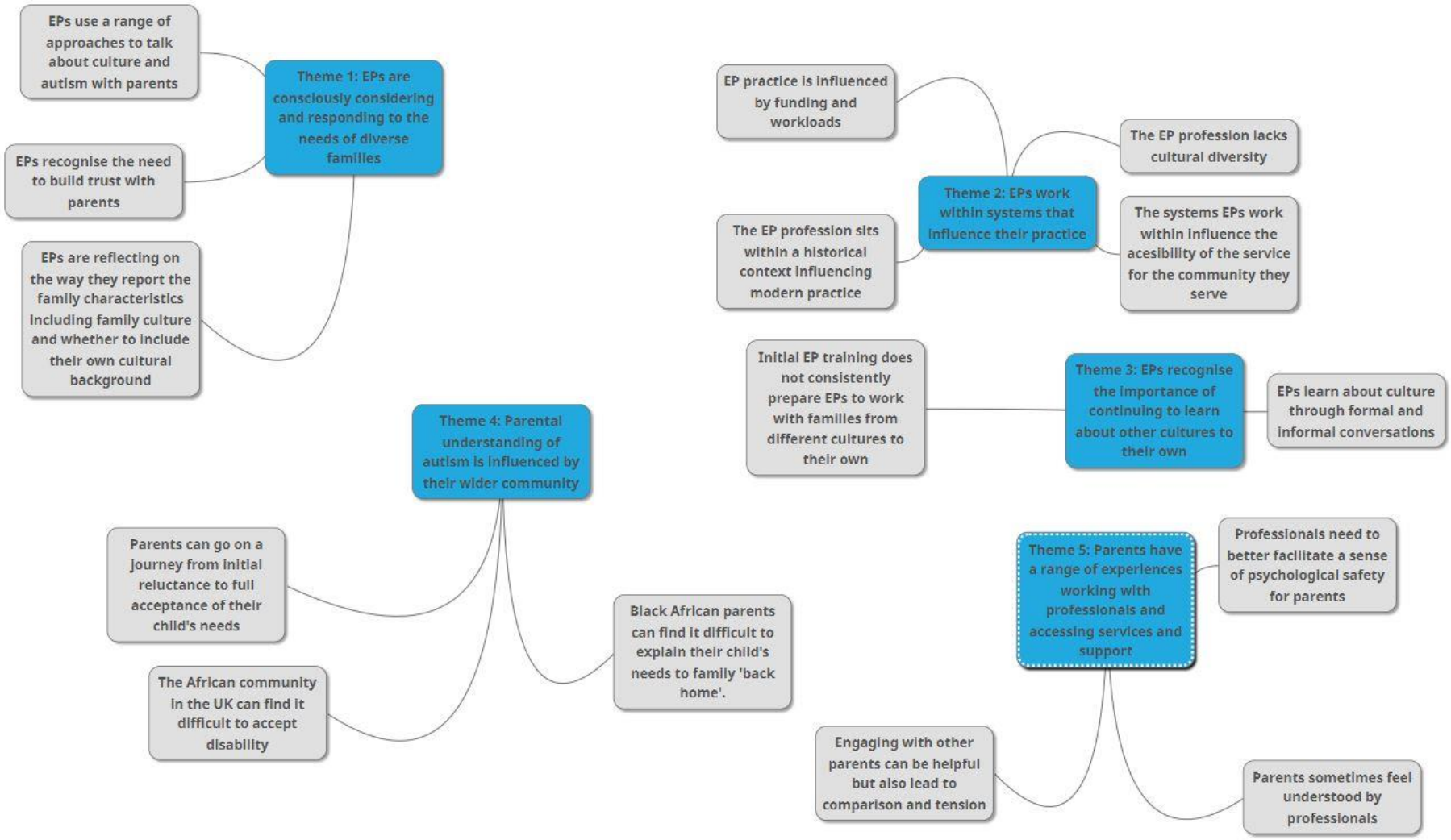
First iteration: 05.03.24 (Light blue boxes related to wider EP themes, dark blue boxes related to initial EP themes, light orange related to wider parent themes, dark orange related to initial parent themes, Grey initial sub themes)



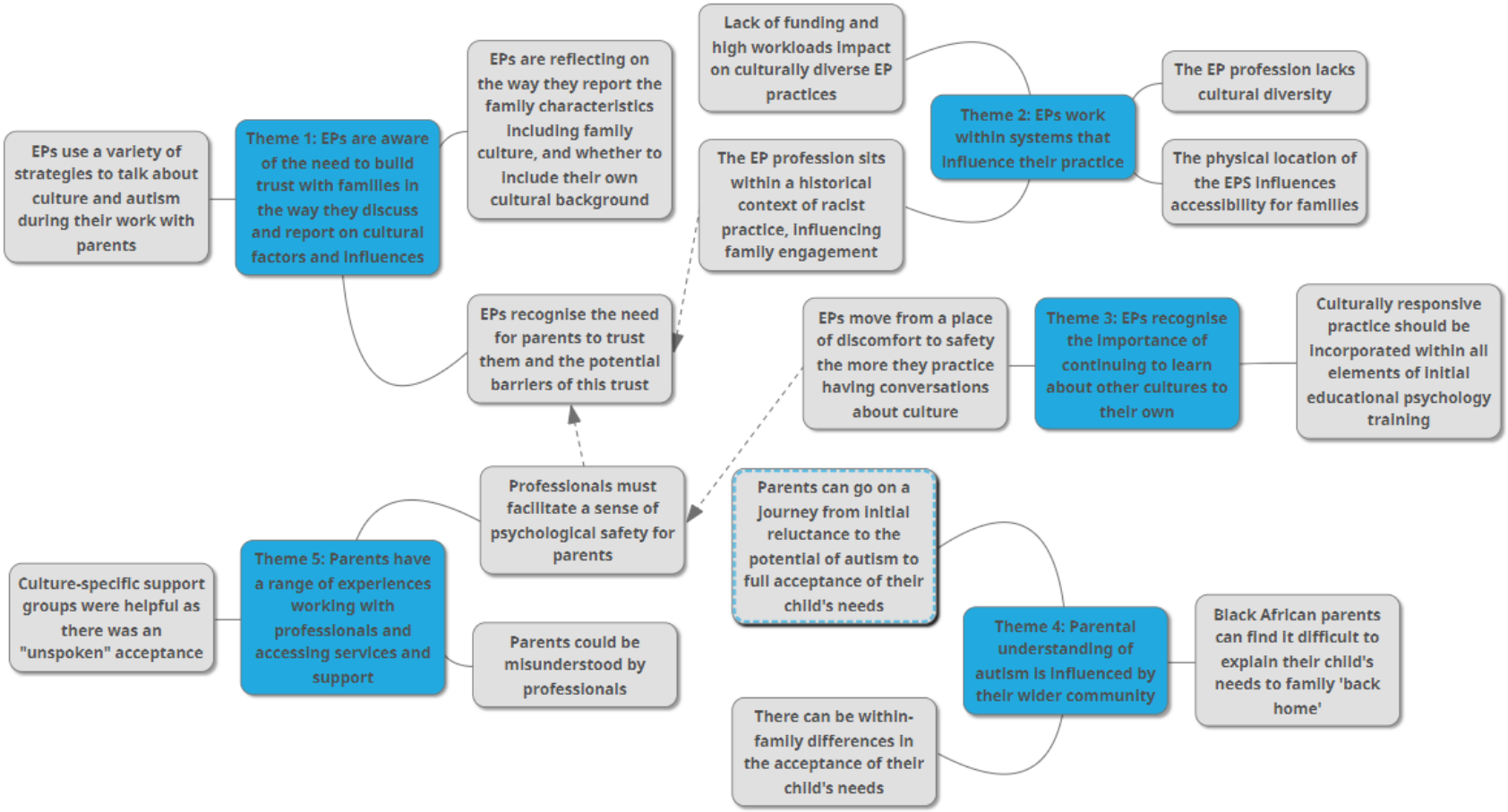
Second iteration: 06.03.24 (Blue boxes related to initial themes, grey boxes related to subthemes).



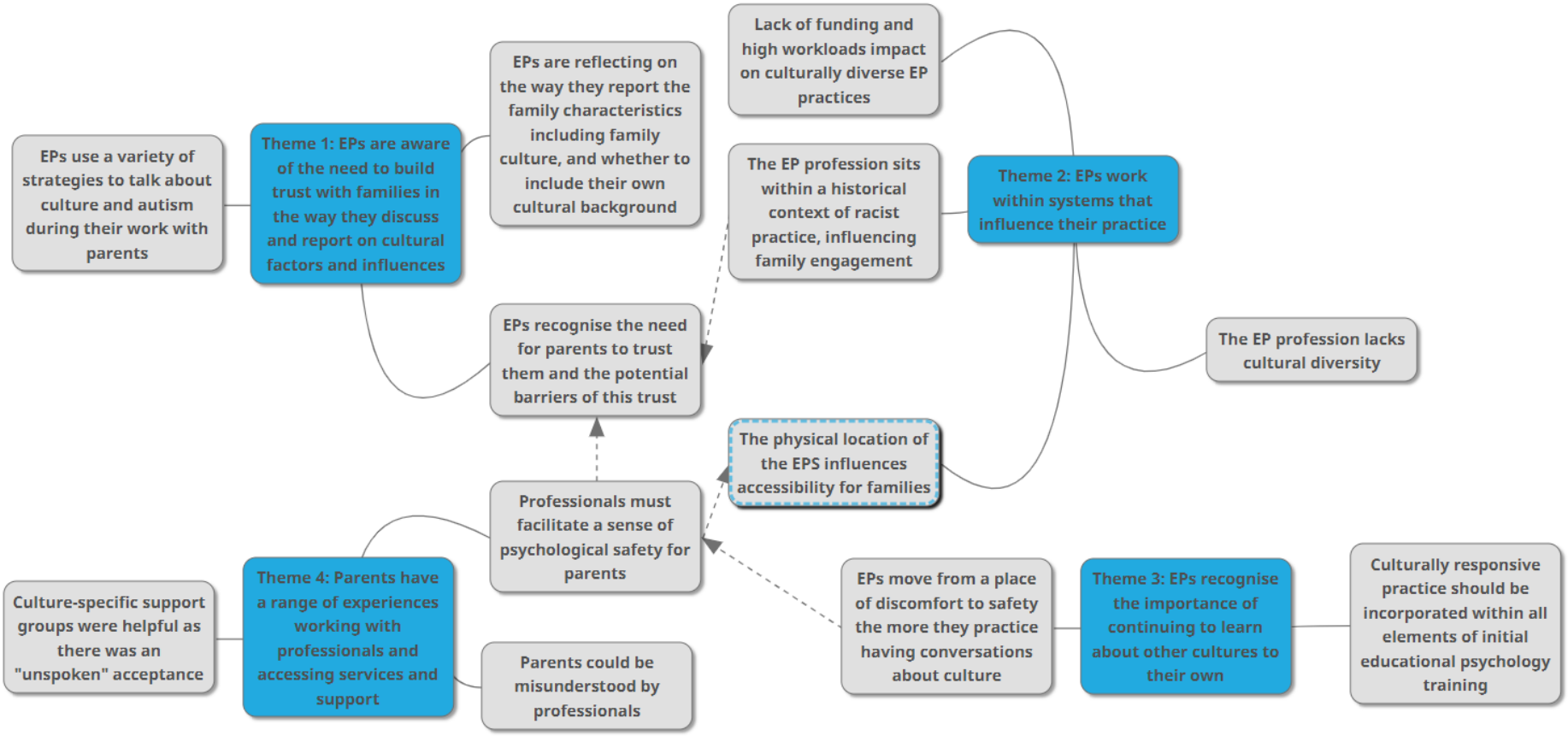
Third iteration: 19.04.24: (Blue boxes related to themes, grey related to subthemes)


EPs use a range of approaches to talk about culture and autism with parents
Theme 1: EPs are consciously considering and responding to the needs of diverse families
EPs recognise the need to build trust with parents
EPs are reflecting on the way they report the family characteristics including family culture and whether to include their own cultural background
EP practice is influenced by funding and workloads
The EP profession lacks cultural diversity
Theme 2: EPs work within systems that influence their practice
The EP profession sits within a historical context influencing modern practice
The systems EPs work within influence the acesibility of the service for the community they serve
Initial EP training does not consistently prepare EPs to work with families from different cultures to their own
Theme 3: EPs recognise the importance of continuing to learn about other cultures to their own
EPs learn about culture through formal and informal conversations
Theme 4: Parental understanding of autism is influenced by their wider community
Parents can go on a journey from initial reluctance to full acceptance of their child's needs
Black African parents can find it difficult to explain their child's needs to family 'back home'.
The African community in the UK can find it difficult to accept disability
Theme 5: Parents have a range of experiences working with professionals and accessing services and support
Professionals need to better facilitate a sense of psychological safety for parents
Engaging with other parents can be helpful but also lead to comparison and tension
Parents sometimes feel understood by professionals

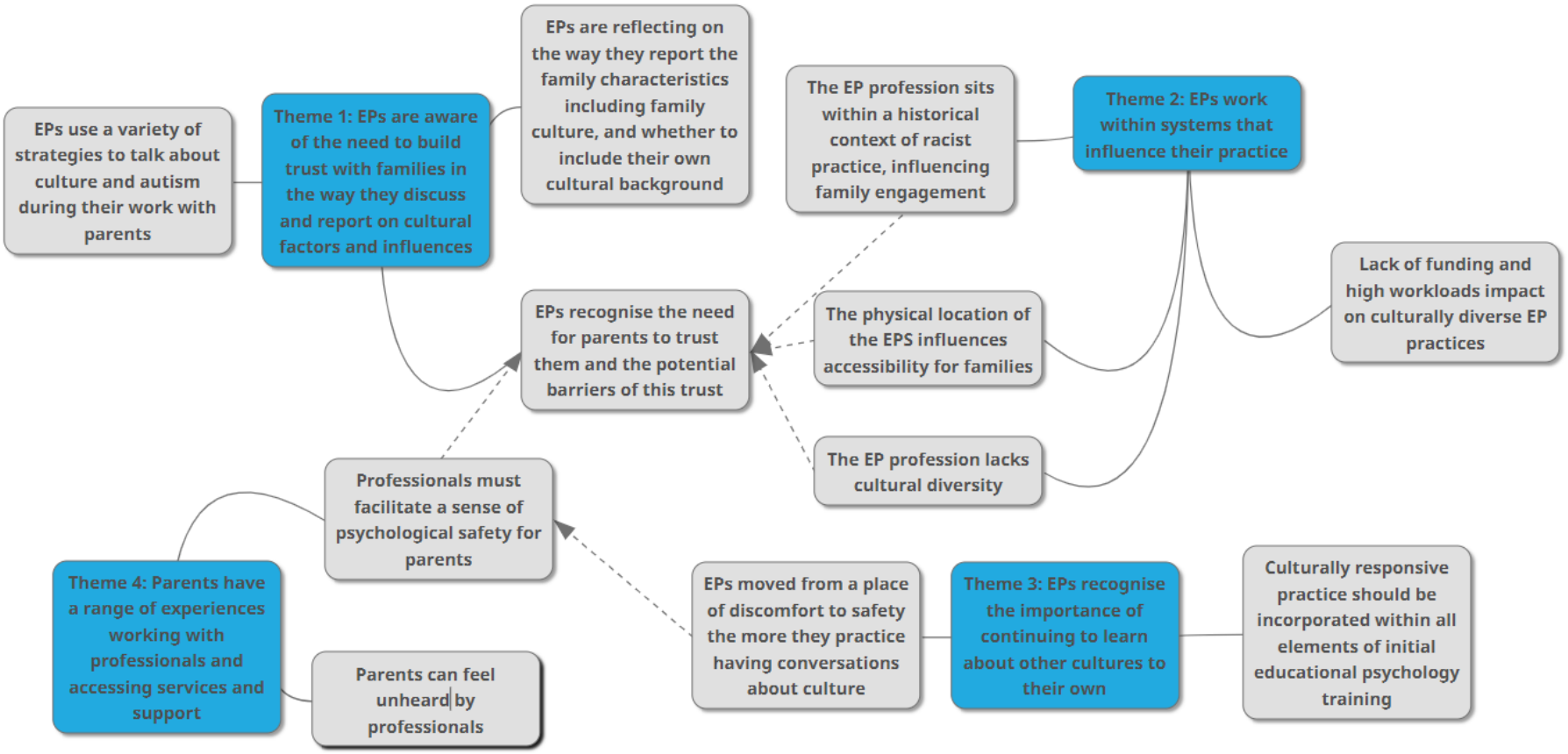
Fourth iteration: 22.04.24 : (Blue boxes related to themes, grey boxes related to subthemes)


EPs use a variety of strategies to talk about culture and autism during their work with parents
Theme 1: EPs are aware of the need to build trust with families in the way they discuss and report on cultural factors and influences
EPs are reflecting on the way they report the family characteristics including family culture, and whether to include their own cultural background
EPs recognise the need for parents to trust them and the potential barriers of this trust
Lack of funding and high workloads impact on culturally diverse EP practices
The EP profession sits within a historical context of racist practice, influencing family engagement
Theme 2: EPs work within systems that influence their practice
The EP profession lacks cultural diversity
The physical location of the EPS influences accessibility for families
EPs move from a place of discomfort to safety the more they practice having conversations about culture
Theme 3: EPs recognise the importance of continuing to learn about other cultures to their own
Culturally responsive practice should be incorporated within all elements of initial educational psychology training
Professionals must facilitate a sense of psychological safety for parents
Culture-specific support groups were helpful as there was an "unspoken" acceptance
Theme 5: Parents have a range of experiences working with professionals and accessing services and support
Parents could be misunderstood by professionals
Parents can go on a journey from initial reluctance to the potential of autism to full acceptance of their child's needs
Theme 4: Parental understanding of autism is influenced by their wider community
Black African parents can find it difficult to explain their child's needs to family 'back home'
There can be within-family differences in the acceptance of their child's needs

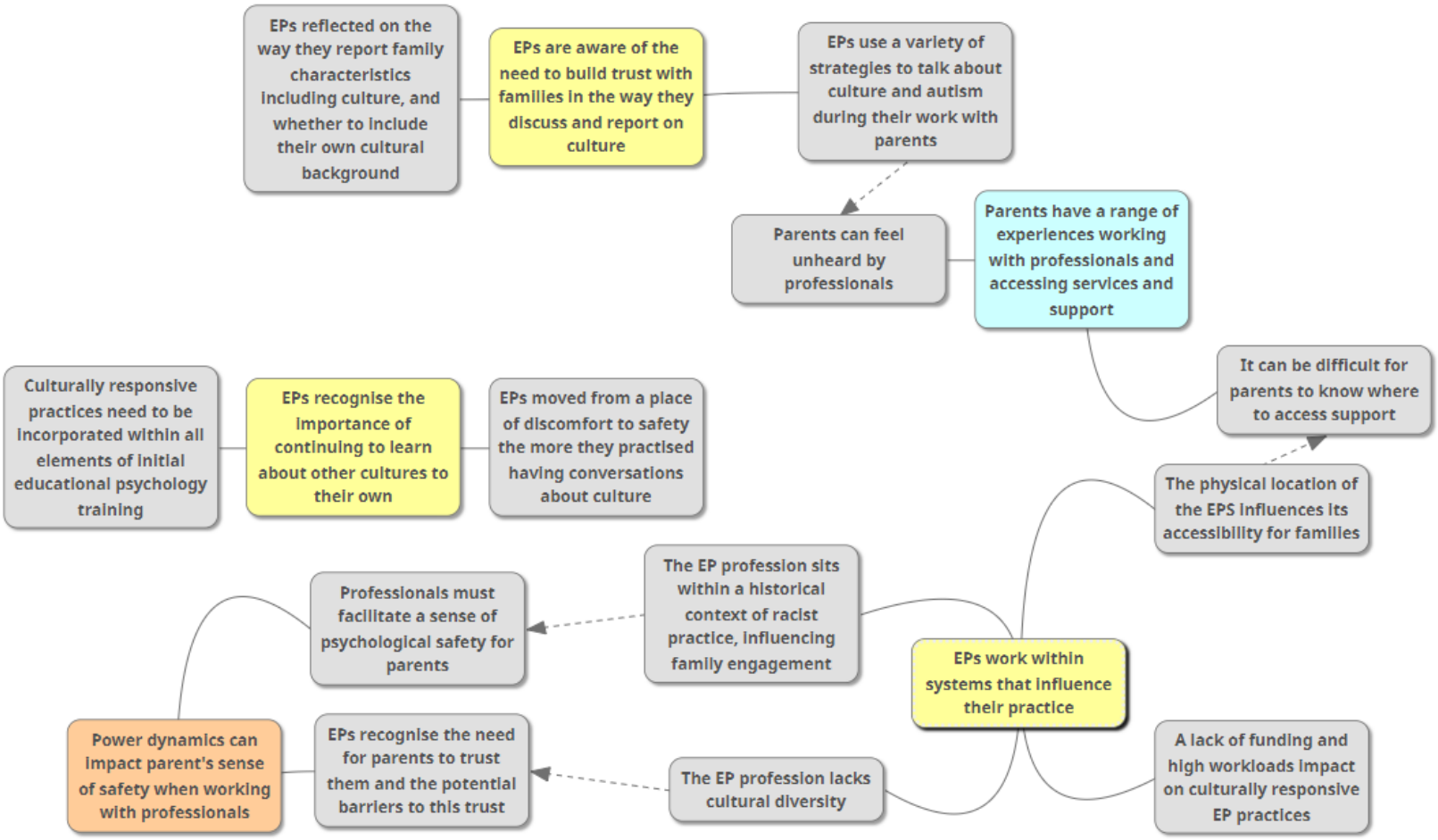
Fifth Iteration: 22.04.24: (Blue boxes relate to themes, grey relate to subthemes)



Sixth iteration: 28.04.24: (Blue boxes relate to themes, grey boxes relate to subthemes)



Seventh iteration: 18.05.24 (Yellow boxes relate to EP themes, light blue boxes relate to parent themes, orange box relates to a combined parent and EP theme, grey relates to subthemes)


EPs reflected on the way they report family characteristics including culture, and whether to include their own cultural background
EPs are aware of the need to build trust with families in the way they discuss and report on culture
EPs use a variety of strategies to talk about culture and autism during their work with parents
Parents can feel unheard by professionals
Parents have a range of experiences working with professionals and accessing services and support
It can be difficult for parents to know where to access support
The physical location of the EPS influences its accessibility for families
Culturally responsive practices need to be incorporated within all elements of initial educational psychology training
EPs recognise the importance of continuing to learn about other cultures to their own
EPs moved from a place of discomfort to safety the more they practised having conversations about culture
Professionals must facilitate a sense of psychological safety for parents
The EP profession sits within a historical context of racist practice, influencing family engagement
EPs work within systems that influence their practice
Power dynamics can impact parent's sense of safety when working with professionals
EPs recognise the need for parents to trust them and the potential barriers to this trust
The EP profession lacks cultural diversity
A lack of funding and high workloads impact on culturally responsive EP practices

EP codes contributing to each theme, and links between themes:

Code Label	*Contributes to theme:*	*Also contributes to__ and reason why:*
Avoiding making assumptions that parents want to talk about culture.	*Theme 1*	*Theme 4* (Parents not feeling listened to)*
A lack of time and opportunity to pause and think about the work being done.	*Theme 2*	*Theme 5 (Lack of time impacts the power dynamics and parent's sense of safety)*
Asking questions about different contexts the child is in.	*Theme 1*	*Theme 4 (Parents not feeling listened to)*
Awareness of black parent's experiences of racism.	*Theme 3*	*Theme 5 (Lack of time impacts the power dyanmics and parents sense of safety)*
Awareness of contemporary institutional racism.	*Theme 3*	*Theme 5 (as above)*
EP's awareness of the history of the profession.	*Theme 3*	*Theme 5 (as above)*
EP's views of including their own identity within their reports.	*Theme 1*	

EPSs are different to other LA services	*Theme 2*	
Fear of mistake making and causing offence when talking about culture	*Theme 1*	*Theme 5- importance of building trust with parents*
Importance of being honest with cultural competency	*Theme 3*	
Importance of community psychology approaches	*Theme 2*	*Theme 4- Parents don't know where to access support*
Importance of cultural diversity within EPS teams.	*Theme 2*	*Theme 2- lack of cultural diversity in team impacts way for EPs to learn from each other and be challenged*
Importance of formal spaces to continue learning (EG. Structured trainings)	*Theme 3*	*Theme 2- these spaces need to be accommodated within work allocations*
Importance of including the child's cultural background in reports.	*Theme 1*	
Importance of informal spaces for continuing learning (EG. Supervision spaces)	*Theme 3*	

Influences of visible race differences as a barrier to trust for parents	*Theme 2*	
Lack of diversity within the profession	*Theme 2*	*Theme 5- visible race differences can be a barrier to trust*
Moving from fear to confidence with practice when talking about culture	*Theme 3*	*Theme 2- Need time in allocation to be able to practice*
Needing to acknowledge all cultures in reports, including white British.	*Theme 1*	
Parent's experience of autism is not a universal experience.	*Theme 1*	*Theme 3- EPs need to continue to learn about different cultures*
Parents can hold pluralistic views.	*Theme 1*	
perceived power imbalances between EP and parent	*Theme 5*	
Policy makes culturally responsive practice a priority.	*Theme 2*	*Theme 3- EPs need to continue to learn and develop their practice*
Recognised the need to build trust with parents	*Theme 5*	*Theme 2- lack of funding and the EP profession*

		lacking diversity as a barrier to this trust
Tokenistic way in which initial training courses teach how to practice in culturally responsive ways.	*Theme 3*	

Parent participant codes and links between themes:

Code label		
Impact of being a first time parent on interactions with professionals	*Theme 4*	
Appropriate use and offering of an interpreter.	*Theme 4*	
Confusion around support available.	*Theme 4*	*Theme 2- lack of accessibility can make it difficult for parents to know where to look for support*
Initial concerns being dismissed by professionals.	*Theme 4*	

Lack of being connected to other families by professionals.	*Theme 4*	*Theme 5- Professionals need to do more to facilitate this sense of safety*
Lack of perceived safety to ask for help from professionals.	*Theme 5*	*Theme 2- Parents don't always feel safe due to historical and contemporary instutuional racism*
Lack of trust in systems to support them.	*Theme 5*	*Theme 2- Parents don't 'see themselves' in the EP profession* *Theme 1- Parents don't trust the systems around them*
Not being listened to by professionals.	*Theme 4*	*Theme 1- Professionals don't use the appropriate strategies to talk about culture and autism*
Parents felt like this was an important topic to be researched.	*Theme 4*	
Professional involvement causing anxiety for parents.	*Theme 5*	*Theme 2- Historically racist profession causing trauma for black parents*
Too much paperwork, would like professionals to make referrals for them.	*Theme 4*	*Theme 2- this would facilitate trust in systems.*

Appendix J Feedback from panel from ‘Experts by Experience’

Email from an autistic adult and parent of autistic child:

Basically, it's non-problematic to me as an autistic parent of autistic children. So well done!

I have two thoughts:

1. Perhaps the second question should be about involvement rather than support as some involvement will not be supportive even if that is the professional's intention.
2. I paused at the word 'concerns'. I'm not sure I was concerned. I think I began to observe differences in how they were developing compared to most other children. Some might be uncomfortable with 'concerns' because it can feel as if it implies something is 'wrong' with their child.

Appendix K Example Transcripts

K.1 Excerpt from P1 Transcript

P1: And so I think, but if you've been a parent like you know you've had other children etcetera or you've got experience of, for example, the autism in your family, then you might be a bit more take it with a pinch of salt and just be like I know my kid and that's fine.

I: Yeah.

P1: But I think, yeah, at the beginning. So as I am now, I'm like, OK, well, this is a report and that's fine. You saw XXX for half an hour. This is the first time he saw you.

I: Yeah.

P1: So I'm able to put it into perspective for myself now, but initially it was, but I I'll be honest with you, the way the EP was with us and the way she wrote the report, I was, yeah, it wasn't anything that made me sort of upset, I'll be honest.

I: I'm really glad you had such a positive experience.

P1: Yeah.

I: That's amazing. And did the EP come to your home?

P1: Yes, so there was a home visit.

I: And what was that like having a home visit done?

P1: Yeah, there was a home visit and oh, by then it was OK because we'd had like few speech and language and therapists coming in and I think, yeah...So it wasn't sort of anything that was new..yeah... So we had all the toys set up just like we wanted.....And there was, yeah, it was all just....Yeah, I wasn't fussed about that.

I: Yeah.

P1: That felt strange.

I: And if you think that, then to your first home visit, how did that feel having a professional come into your home and yeah.

P1: Yeah, that felt strange. So yeah, that felt strange because again, that was when the whole autism was being talked about and the whole like, although they couldn't say exactly, I don't think they said Ohh he is autistic but they like you know our you know he has delays and the child with a disability and then you know all that's when we're talking about all these things and the different assessments and yeah that felt very overwhelming and scary and I think I got a bit tearful to be honest with you.

I: Professionals coming into your home and being within your safe space, talking about scary things when you're at the beginning of the journey. And yeah, that's completely understandable.

P1: Yeah.

I: Yeah. And so the thinking then about within the EHP, there's the targets and kind of goals for working towards how involved were you in the target setting and the discussions around those put your child?

P1: And I'll be honest, I wasn't really they. They said Ohh, these are the targets. But I didn't think by then also I at that time I didn't really know much about targets.

I: Umm yeah.

P1: I'll be honest with you, I was just thinking, well, you know where he, you know, what's sort of a milestone he should be at or whatever. So then OK, let's work towards that. It wasn't, whereas now I could say Ohh I don't think he's ready for this or we're past this. But at the time it was umm, OK, well, you know what you're doing. So then let's just take it as it seemed that nothing seemed sort of outer because it was mostly about helping him with the communication and being able to interact with peers, which all seems sort of age-appropriate to me.

I: Yeah.

P1: But obviously, with a developmental delay and stuff now, I know there are some things that aren't always necessarily going happen at the same time as other children. So, at the time, it just seems like these are targets that you are manageable to work towards, yeah.

K.2 Excerpt from EP 11 Transcript

something really important to families… it's a small samples size but actually I was wrong, and they were like "I'm not talking about being Islamic I'm talking about my kids…and so those situations are where I probably got it wrong and I felt embarrassed. So yeah I think it depends on the situation. I think its not a reason not to ask…

I: earlier you mentioned about getting it right, what does getting it right mean to you?

E11: Its about not unintentionally making assumptions about peoples culture or what's important to them. Because we know so little from a referral, find out the parents are from Ghana but what do you actually know? Know they've lived in a different country. If you kind of think about intersectionality and how all those different intersectional characteristics that we all hold come together, then you can only find out what's important, what's influencing people by talking about it.

I: yeah that's so interesting, when you receive a referral form, you only learn a small amount of information, it doesn't tell you about the intersectional layers that they bring to those consultations.

E11: I think where we made progress…when we talk about culture, but I think when we talk about culture we mean race…I think other intersectional factors we don't consider as much, and I think It will be really interesting in the next few years to see if that narrative changes, I think gender for example that's going to be talked about more. And the fact that most families we work with are living in poverty, the impact of this on parents mental health and the child's development. So there are many layers.

I: that's really interesting, I will be interesting to see where it goes. And so then thinking about more kind of systemic levels now, nationally and locally, what are some of the barriers you've experienced to working with people from different backgrounds to your own, so kind of barriers to access for families to come and work with you?

E11: Well we very rarely offer a service directly to the family, I think the whole system of our like being commissioned by schools in itself is not putting families first. I think we are child psychologists, but in reality we are school psychologies, and occasionally get to do family work, and this massive issue about schools being the gatekeeper to our work, and you know there's lots of issues about who our schools prioritise… you know if you've got a black kid and they get labelled as naughty than autistic and you know, who comes our way and who doesn't? I think it's a huge issue that we don't…families aren't able to access our services directly.

I: That's such an interesting point. Like who are we working for?

E11: We have the child as our client, but yeah, I think we should be in a community building across the borough, where families can access us directly. I think that's the only way of making us accessible to families. And we have this huge issue about the demographics of our profession and I think…I don't think everyone who is an EP needs to be from a minorities group, but I think if we aren't, we need to think about actively involving people with lived experience in our work…and certainly in the boroughs I've worked in, we don't do anything through lived experience. I think we should at the very least have kind of advocates that we work with, who help to bridge the gaps between professionals and different community groups. I mean, my interested is in participatory research. My dream would be that um we have experts by experience that were helping the discussions about how our EPS or all EPS' are run, like who do we work with, how that's decided, the sort of work we do. Do we think standardised cognitive assessments are valid? If so, in what situations…like really making meaning full decisions, especially in the autism world. All the autism research is based on stuff that a load of academics in America think is relevant, like relevant to autistic people like its… at what point am I going to ask someone whose autism what they want the research to be because I don't know…in terms of systemic issues about accessing services it's the same principles. Let's actually ask autistic people what they want.

I: I wonder how often that is done in kind of services nationally.

E11: Nothing, never.

I: So if I were to ask you what more can they do?

E11: I think to be in the communities more, not just being in the town hall or civic centre. It has to be community based, being based in schools is good cause most families access schools. There's various bits of research that say if you base psychologists in community places like religious places like mosques or a church, how that can be really accessible. I don't know how that would work logistically, but really thinking about community psychology. I think its really important that culturally responsive practice is part of all EP training programmes…not only as specific sessions but I think if you silo it up as something separate to mainstream practice … you really need to be thinking is what you're teaching culturally responsive. And that is both critiquing kind of mainstream ways of thinking and psychology and also bringing in new alternative ways of of doing psychology, kind of doing both of those things whether that's in initial training, or in CPD.

I: so kind of embedded in everything that's done, not just kind of ticking the box.

E11: Exactly, I think looking at who is coming into the profession, and the barriers to who is becoming an EP is really important.

Appendix L Additional Participant Information from Included Studies in Literature Review

Ashong and Perepa (2023):

Participant Label	Heritage/Cultural description	Parent
AJ	African	Father
JF	African	Father
BO	African	Father
FA	African	Father
HP	African	Father
KM	African	Father
HD	African	Father

Fox, Aabe, Turner, Redwood and Raj (2016) and Selman et al., (2018):

Participant Label	Heritage/Cultural description	Parent
PPT1	Somali	Mother
PPT2	Somali	Father
PPT3	Somali	Mother
PPT4	Somali	Father
PPT5	Somali	Mother
PPT6	Somali	Mother
PPT7	Somali	Mother
PPT8	Somali	Father
PPT9	Somali	Mother
PPT10	Somali	Mother

PPT11	Somali	Mother
PPT12	Somali	Mother
PPT13	Somali	Mother
PPT14	Somali	Mother
PPT15	Somali	Mother

Hussein, Pellicano and Crane (2019):

Participant Label	Heritage/Cultural Description	Parent
PPT1	Somali	Father
PPT2	Somali	Mother
PPT3	Somali	Mother
PPT4	Somali	Mother
PPT5	Somali	Mother
PPT6	Somali	Mother
PPT7	Somali	Mother
PPT8	Somali	Mother
PPT9	Somali	Mother
PPT10	Somali	Mother
PPT11	Somali	Mother
PPT12	Somali	Mother
PPT13	Somali	Mother
PPT14	Somali	Mother
PPT15	Somali	Mother
PPT16	Somali	Mother

Lemboye (2023):

Participant Label	Heritage/Cultural Description	Parent
Aisha	Nigerian	Mother
Keza	Rwandan	Mother
Tiwa	Nigerian	Mother
Amma	Ghanaian	Mother
Sanyu	Ugandan	Mother
Afia	Ghanaian	Mother

Munroe, Hammond and Cole (2016):

Participant Label	Heritage/Cultural Description	Parent
Mabinti	African	Mother
Ayana	African	Mother
Fumni	African	Mother
Ife	African	Mother
Sanaa	African	Mother
Nyah	African	Mother

Nair (2015):

Participant Label	Heritage/Cultural Description	Parent
Fante	African	Mother
Shara	African	Mother
Adeo	African	Father

Nweke (2019):

Participant Label	Heritage/Cultural Description	Parent
Mr Egal	Somali	Father
Mrs Egal	Somali	Mother
Mr Adisa	Nigerian	Father
Mrs Adisa	Nigerian	Mother
Mrs Okeke	Nigerian	Mother
Ms Mulumba	Congolese	Mother
Mrs Okoye	Nigerian	Mother
Mrs Matonga	Zimbabwean	Mother
Mr Matonga	Zimbabwean	Father
Mrs Kakooza	Ugandan	Mother
Mrs Dibango	Cameroon	Mother
Ms Kama	Gambian	Mother
Mr Yeobah	Ghanaian	Father
Mrs Yeobah	Ghanaian	Mother
Ms Dimka	Nigerian	Mother
Mr Kimani	Kenyan	Father
Mrs Kimani	Kenyan	Mother
Mr Akinloye	Nigerian	Father
Mrs Akinloye	Nigerian	Mother
Mr Ibori	Nigerian	Father
Mr Kromah	Liberian	Father
Mrs Kromah	Liberian	Father
Mrs Bankole	Nigerian	Father
Mr Bankole	Nigerian	Father
Mr Achebe	Nigerian	Father
Mrs Achebe	Nigerian	Mother
Mr Aguda	Nigerian	Father
Mrs Aguda	Nigerian	Mother

Ms Mensah	Ghanaian	Mother
Mrs Diya	Nigerian	Mother

Oumar (2021):

Participant Label	Heritage/Cultural Description	Parent
Fatima	Somali	Mother
Amira	Somalia	Mother
Liya	Eritrean	Mother
Ali	Somali	Father
Winta	Eritrean	Mother
Neza	Rwandan	Mother
Faven	Eritrean	Mother
Alia	Sudanese	Mother

Robbin (2020):

Participant Label	Heritage/Cultural Description	Parent
Annabelle	Democratic Republic of Congo	Mother
Justine	Ghanaian	Mother
Emmi	South African	Mother
Chibuye	Tanzanian	Mother

Seach (2021):

Participant Label	Heritage/Cultural Description	Parent
Sahra	Somali	Mother

Fatou	Sierra Leone	Mother
Hibaq	Somali/Kenyan	Mother
Nadifa	Somali	Mother

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